Experiences of Dementia in a UK Bangladeshi Community: An Exploratory Study

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Mohammad Nazmul Hussain

University of Salford

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GLOSSARY

Abul-Tabul: (Sylheti) Talking nonsense

Bhul pori zay: (Sylheti) Forgetful

Bhuta: (Also *Bhoot*; Sylheti): a supernatural creature, particularly the spirit of a deceased person. Associated beliefs vary by region and community but tend to refer to souls prevented from moving on (to transmigration, non-being, nirvana, or heaven or hell, according to Hindu religion).

Boyar (Sylheti) means air (also called *kharap batash*).

Fagol/Pagol/Pagal:(Sylheti; Bengali;Urdu) Crazy/Insane

Fani fora/ Pani Pora: (Sylheti) Holy water. A spiritual healer often recites some verses of their religious scripture then blows on the water.

F*awrilai:* (Sylhet)I forget

Ferot: (Sylheti) Evil spirit or ghost

Foo-faa: (Sylheti) Blowing on a person by reciting a supplication

Fawri gesi: (Sylheti) I have forgotten

Jinn: (Arabic) Supernatural creature from pre-Islamic Arabian religious systems, co-opted by Islamic mythology and theology. This term is used both for any supernatural creature and also to refer to a specific type of magical creature; often mentioned together with devils (*shayāṭīn*). These are frequently blamed for misfortune, possession, and diseases.

Kabiraz: (Bengali) (Also *Kabiraj* or *Kobiraj*) is a folk healer. It is an occupational title found in persons of the Eastern Indian subcontinent. In olden days, people traditionally practising Ayurveda were generally called *kabi/kobi* in eastern India including Bangladesh.

Kharap Batash: (Bengali) Bad air; used in Bangla for possession by supernatural agencies.

Mulla-Molovi: (Sylheti; Urdu) Islamic Scholars, Imams

Mono thakey na: (Sylheti) Can’t remember

Matat Dush: (Sylheti) Mad, Crazy

Mata Kharap: (Bengali) Crazy

Nobodong: (Sylheti) Nonsense

Tabiz: (Bengali) Amulet (also *Tawiz*); locket or chain treated as a good luck charm and offering protection from *nazar* or black magic. Worn by practitioners of religions including Islam for protection from evil powers.

Suta Fora: (Sylheti) Blowing on a fibre after reciting any supplication

Sriti-bhula: (Bengali) Memory loss, forgetfulness

Upri (Sylheti) is possession by supernatural forces e.g. *jinn*, *bhuta*, black magic.'Upri Bemar' is a sickness caused by these possessions.

Challan (Hindi;Sylheti) is a form of black magic

Saram/Shorom (Bengali; Urdu; Sylheti) means shame

Thesis Abstract:

This thesis explores the experiences of people with dementia and their caregivers and gathers the views of service providers / stakeholders to make recommendations to improve provision for the dementia support needs of the UK Bangladeshi community. Previous research highlights that Bangladeshis have poor health outcomes in the UK and a higher risk of developing type 2 diabetes and heart disease; these are significant risk factors for vascular dementia development in old age. Although we have knowledge about risk factors, less is known about experiences of living with dementia and the associated support needs. Existing research has explored the knowledge and help-seeking behaviour of the Bangladeshi community towards dementia from the caregivers' perspective. However, no study has captured the direct experiences of people within the Bangladeshi community with the condition, despite previous studies emphasising the importance of including the views and experiences of people with dementia in research.

This qualitative research was accomplished in three distinct phases using semi-structured interviews with a total of 25 participants, who were recruited from community settings. The first and second phases explored the experiences of people with dementia and their family caregivers; The third phase of this study examined stakeholders' / service providers' views. Interviews were recorded digitally, transcribed verbatim, and thematically analysed.

The study revealed that participants with dementia and their caregivers have ‘alternative’ knowledge about dementia, and they do not necessarily understand dementia in a westernised scientific/bio-medical context. Misconceptions about dementia, and belief in various myths, can lead them to go to spiritual healers, or practice homemade remedies, rather than going to their GPs, which often delays their dementia diagnosis. The thesis highlights that there is stigma attached to dementia in the Bangladeshi community. Consequently, many participants with dementia have concealed their condition from the broader community because of a sense of shame and from a fear that others may consider them mad. This research also found that despite having high motivation to care for their relatives with dementia, many caregivers have difficulties providing adequate care due to their work and other commitments.

The findings of this thesis lead to the conclusion that there needs to be culturally appropriate health and social care provision for people living with dementia and those who provide care and support. Raising awareness of dementia, dispelling myths, and removing the stigma surrounding dementia from the Bangladeshi community is essential. This thesis concludes with policy and practice recommendations to improve the support available to people living with dementia and their carers in the Bangladeshi community that could be applicable to other minority communities.

Chapter 1: Introduction to the Thesis

1.0 Introduction

This research aims to explore the experiences of people with dementia from the Bangladeshi community to better understand their support needs. Chapter 1 offers the readers some background information about dementia and an introduction to the thesis. First, I present an outline of the prevalence of dementia globally, nationally, and among the BAME and UK South Asian communities, along with the Bangladeshi community's health outcomes and dementia risk factors. Second, I explain the research rationale and personal motivation for this PhD study on dementia. Third, I present the conceptualisation of dementia and highlight the Government's policy context towards dementia in the BAME communities, including Bangladeshis. Then, I justify why I have written a chapter on the conceptual framework for understanding stigma. Fourth, I highlight different theoretical perspectives on dementia, and then explain why this thesis has used the psycho-social approach to understand the lived experiences of people with dementia. Fifth, the rationale for the research site where this research has taken place, and the research aims and objectives, are mentioned. Finally, I present my insider/outsider positionality and reflexivity briefly. The chapter ends with a brief outline of the thesis.

1.1 Background

Dementia is a growing global health care challenge (McGeown et al., 2019; Prince et al., 2014). As the population ages worldwide, the prevalence of dementia also increases. Someone in the world develops dementia every three seconds, and almost 10 million new cases of dementia are added each year worldwide (ADI, 2020). There are over 55 million people worldwide living with dementia, and this number may almost double every 20 years, reaching 78 million in 2030 and 139 million in 2050 (ADI, 2020). The total estimated worldwide cost of dementia was US$ 818 billion in

2015, and US $1.3 trillion in 2020, which is expected to rise to US$ 2.8 trillion by 2050 (ADI, 2020).

Dementia is one of the top five underlying causes of death in the UK, with 1 in 3 deaths in over 65s attributed to dementia (Prince et al., 2014). It is estimated that approximately 850,000 people in the UK are living with dementia, at a cost of £26 billion per year (DoH, 2015). By 2050, this number is predicted to rise to two million (Prince et al., 2014). As the population ages, the economic cost associated with dementia is expected to rise significantly whereas annual spending on dementia is projected to reach £35 billion in 2026 (Prince et al., 2014). Mr. David Cameron, the former Prime Minister of the UK, named the national dementia strategy as a Prime Minister's Challenge (DoH, 2015). There are around 540,000 caregivers of people with dementia in England, and it is estimated that one in three people care for a person with dementia at some point in their lifetime (Parkin & Baker, 2021). Half of these are employed, and it is thought that some 66,000 people have already cut their working hours to care for a family member, while 50,000 people have left work altogether (Parkin & Baker, 2021).

Fourteen percent of the UK population (8 million people) are from Black-Asian-Minority Ethnic (BAME) backgrounds, which is around the same as the total population of Scotland and Wales combined (ONS, 2012). Researchers estimate that there are currently 25,000 people from the UK BAME communities living with dementia, a figure which is predicted to increase to 1,720,000 by 2051 (Parveen et al., 2017). This number would be a sevenfold increase in 40 years compared to the two-fold increase predicted in the majority population (Parveen et al., 2019; Parveen & Oyebode, 2018). Despite the growing prevalence of dementia among minority ethnic people, evidence suggests such groups remain underrepresented in specialist dementia services (Cooper et al., 2018). Vascular dementia is the most common form of dementia amongst minority ethnic communities in the UK (mainly South Asian and Black Caribbean), affecting 22% of those living with dementia. Lawrence et al. (2011) assert that older adults are vulnerable to high blood pressure, heart disease, stroke, and diabetes - all dementia risk factors and things which are more common in the South

Asian community. Therefore, due to the higher prevalence of risk factors such as diabetes, hypertension, and cardiovascular disease, the risks of vascular dementia are high in these communities (Moriarty, Sharif & Robinson 2011). Young-onset dementia (affecting those under the age of 65) is also more common amongst minority ethnic groups, accounting for 6% of the BAME population living with dementia compared to 2% of the White British population with dementia (Knapp et al., 2007; Parveen, 2017).

South Asian communities (mainly from India, Bangladesh, and Pakistan) form the largest minority ethnic group in the UK, accounting for 5% of the population, or approximately 3.3 million people (ONS, 2016; Atcha, 2018). Most migration from India and Pakistan to the UK happened after India and Pakistan attained independence from the British Empire in 1947. Over a third of ethnic minority individuals living in Great Britain are UK-born (Herat-Gunaratne et al., 2019). The migrants came at that stage from many different locations and their reasons for arriving were related to industrial labour shortages (Herat-Gunaratne et al., 2019). According to the 2011 Census Report, the UK South Asian population increased from 3.9% of the total population in 2001 to 5.3% in 2011 and will continue to grow (Mukadam et al., 2011). The number of people with dementia in the UK South Asian population is expected to increase significantly as the population ages, dramatically impacting the lives of older people and their families (Hossain & Khan, 2020). Herat-Gunaratne et al. (2019) argue that Pakistani and Bangladeshi communities experience exceptionally high inequalities within the UK compared with other minority populations and the wider population generally (Harding & Balarajan, 2001).

Large-scale migration from Bangladesh to Great Britain occurred during the liberation war of 1971 (Spencer, 2002; Herat-Gunaratne, 2019). Despite the long-established presence of people of Bangladeshi origin in the UK, they have inferior health outcomes (Higgins, 2017, p.29). Research suggests that in the last two decades, Pakistani and Bangladeshi women in England and Wales have had persistently higher levels of poor health (measured by limiting long-term illness) than White women (Higgins, 2017, p.29). Modood et al. (1997) found that Bangladeshi and Pakistani men report the highest rates of long-standing illnesses among all ethnic minority groups.

Bangladeshis have a higher risk of developing type 2 diabetes and heart diseases, both of which are important indicators for the development of vascular dementia in old age (Higgins, 2017, p.29). Despite the rapid growth in the number of aging Bangladeshi people living in the UK, little research has been conducted to understand the lived experience of people with dementia among this minority ethnic group.

This thesis explores the experience of people with dementia and their family caregivers. The study also reports the views of service providers / stakeholders to make recommendations that might improve and influence responses to the dementia support needs of the Bangladeshi community.

1.2. Research Rationale

Although the UK Bangladeshi community has the highest rates of illnesses in the UK of any ethnic group (Census Data 2001 and 2011; Higgins, 2017), very little research has sought to understand the experiences of people with dementia among this minority ethnic group. Previous research has highlighted aspects of caregivers' knowledge of dementia in the Bangladeshi Community in England; however, scholars in the field have ignored the voices of people who have been diagnosed with dementia. For example, Hossain (2017) aimed to understand the knowledge and attitudes of people with the condition. However, he failed to capture the voice of the people living with the syndrome. Similarly, recruiting 53 English/Bengali speaking South Asian adults, Mukadam et al. (2015) attempted to explore the barriers and challenges encountered by South Asians accessing dementia services and people's attitudes towards this. However, their entire sample comprises adults that have not been diagnosed with dementia. Therefore, the voices of the people living with the condition have remained unheard. Despite an increasing recognition amongst researchers that people with dementia should be included in the research as active participants (Beuscher & Grando, 2009; Dewing, 2007; Nygård, 2006), people with the condition within the Bangladeshi community are left under-researched. In addition, previous research has not conclusively explored misconceptions about dementia among British Bangladeshis. However, it is evident that British South Asians, in common with other

BAME Communities, have alternative knowledge and hold different beliefs about dementia (Ahmed & Eagle, 2018; Parveen et al*.,* 2018; Mukadam et al*.,* 2015).

Existing literature has revealed that people with dementia from the BAME communities are heavily stigmatised. Stigma not only affects self-esteem and may cause distress but affects social inclusion and can delay the diagnosis of dementia (Mukadam et al*.,* 2015; Mukadam & Livingston, 2012; Mackenzie, 2006; Ahmed et al*.,* 2017). However, little is known if dementia is stigmatised within the Bangladeshi community specifically.Although the ultimate aim of this thesis was to explore the lived experience of dementia including dementia care and support for individuals from Bangladeshi communities; this research used stigma as a conceptual framework to understand these experiences.

1.3. Motivation to do a PhD about Dementia

A few years ago, one of my uncles passed away because of dementia, and another uncle is living with this condition. My parents have high blood pressure and have had minor strokes, which are risk factors of vascular dementia. I was afraid that I might develop it in the future because of my genetic history. Therefore, I obtained some dementia training from the Alzheimer's Society and eventually became a dementia champion. Later on, I studied some MOOC programmes of the University of Tasmania, Australia, on understanding dementia and how to prevent it. These courses further motivated me to undertake a PhD project on dementia study.

I am a Bangladeshi by birth and have worked as a Minister of Religion in the UK for two decades and delivered over a thousand sermons on Fridays and other Muslim religious sermons. My personal history has enabled me to create good bonds, a bridging network, and link households with the Bangladeshi community. To complete my master's dissertation from Loughborough University, I undertook a Muslim chaplaincy and spiritual care project and worked for 60 hours on placement in Greater Manchester hospitals. That fieldwork steered me to help and support older people and to learn more about aging. Through conversations with many of my elders who regularly visit the mosque, I heard stories where they shared their struggles with their memory problems. They often forget to pray, ask the same questions repeatedly, and face difficulties maintaining their social lives. My experiences working with South Asian communities, especially with Bangladeshis, and my family history with dementia led to my interest in conducting qualitative research to learn more about people with dementia and to understand their support needs.

1.4. What is Dementia?

Dementia is an umbrella term to describe many symptoms caused by neurological conditions associated with changes or damage to an individual's brain (WHO, 2017). The term 'dementia,' otherwise known as 'major neuro-cognitive disorder,' is not a specific disease, rather a group of symptoms caused by disease (ADI, 2021). There are many underlying conditions that cause the symptoms of dementia through changes that happen in the brain and the ultimate loss of neurons, i.e., nerve cells (ADI, 2021). These syndromes are usually of a chronic or progressive nature, leading to worsening in cognitive functions beyond what might be expected from the usual consequences of biological aging (WHO, 2021). Dementia affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected, and it is commonly accompanied and occasionally preceded by changes in mood, emotional control, behaviour, or motivation (WHO, 2021). It affects each person differently, depending upon the underlying causes, other health conditions, and the person's cognitive functioning before becoming ill (WHO, 2021).

There are over 200 subtypes and causes of dementia, but the four most common are Alzheimer's disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies (Parkin & Baker, 2021: Dementia UK, 2018). Alzheimer's disease is the most common type, caused by the build-up of beta-amyloid proteins in the brain, which form tangles and amyloid plaques (ADI, 2021, p.26). It is a progressive disease in that its symptoms slowly worsen over time as the brain becomes more damaged, and the symptoms gradually become severe enough to disrupt everyday activities (ADI, 2021, p.26). Alzheimer’s disease accounts for between 60 and 80 percent of cases of dementia.

Vascular dementia is the second most common type of dementia, and occurs when the brain is deprived of vital nutrients and oxygen from the blood flowing through the brain (ADI, 2021, p.26). It also happens after one stroke in a strategic brain area or a series of small strokes (ADI, 2021, p.26). One’s history of heart attack, irregular or unusually rapid heartbeat (atrial fibrillation), hardened arteries that restrict blood flow (atherosclerosis), high blood pressure, diabetes, high cholesterol, obesity, and smoking can also contribute to vascular dementia (ADI, 2021, p.26).

Dementia with Lewy bodies is the third most common category of dementia, generating over 15% of the cases in the UK; it is caused by abnormal proteins that appear in the brain’s nerve cells, thus impairing its functioning (ADI, 2016). Lewy body dementia can present with many symptoms, including problems with memory, moving, sleeping, and thinking (ADI, 2016).

Frontotemporal dementia is the fourth most common type of dementia and is relatively rare (AR UK, 2013). Frontotemporal lobe dementia (FTD) is believed to be caused by damage to or shrinkage of primarily the brain’s frontal lobes. It has its own set of symptoms; however, there are cases when most forms of dementia overlap. Each type of dementia is concerned with specific brain cell damage which affects a particular area of the brain (AR UK, 2013). Early signs of frontotemporal dementia are usually changing in speech, personality, behaviour, impulse control, and coordination. Frontotemporal dementia tends to occur at a younger age (ADI, 2021).

Young-onset dementia, accounting for approximately 3% of cases, may be caused by any of the above-described diseases, including Alzheimer’s, vascular, Lewy bodies, or frontotemporal dementia. The only difference is that it occurs in people under 65 (ADI, 2021). Most people with a diagnosis have mixed dementia, a condition in which a person has more than one type of dementia, such as Alzheimer’s disease and vascular dementia or Alzheimer’s disease and dementia with Lewy bodies (Alzheimer’s Society, 2018).

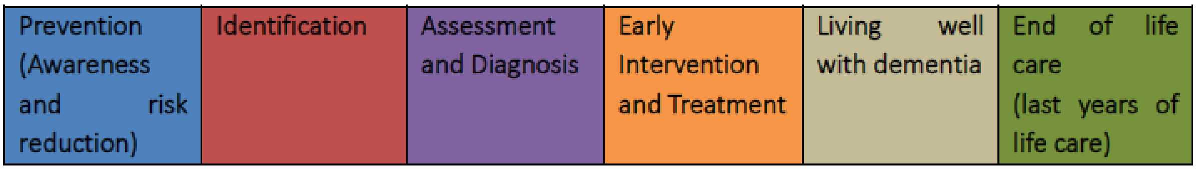
1.5. Policy Context

Dementia and its care services have historically occupied a low position on the political agenda, with little government policy regarding caring for people with dementia (Innes, 2009). The Government first developed a 'National Dementia Strategy (NDS) in 2009 (DoH, 2009). The strategy delineated three key aims to advance the quality of life for people with dementia and their caregivers in England:

- Raising awareness of dementia and removing the stigma that surrounds the condition
- Improving diagnosis rates for people with dementia
- Increasing the range of services for people with dementia and their carers (Parkin & Baker, 2021).

The strategy outlines how a person with dementia should experience services and how different services should connect. It can be summarised as broadly having six stages: prevention, identification, assessment and diagnosis, early intervention and treatment, living well with dementia, and end-of-life care (Ahmed et al., 2017, p.12; Lim et al., 2014).

Table1: *The six stages of the Dementia Care Pathway established by the National Institute for Health and Care Excellence (NICE).*



Prevention (Awareness and risk reduction)	Identification	Assessment and Diagnosis	Early Intervention and Treatment	Living well with dementia	End of life care (last years of life care)

Although the National Dementia Strategy was formed to address all needs, it does not explicitly address issues of dementia in the context of BAME communities, ethnicity, religion, or race (Regan, 2016, p.703). Many services are not perceived as culturally appropriate or as delivering 'culturally competent practice' (La Fontaine et al., 2007; Regan et al., 2013). For instance, the NHS's organisational culture operates within a cultural framework of Western society, where a female touching a male in a simple exchange, such as a handshake, is considered culturally appropriate. In contrast, this means of communication may be deemed inappropriate in a South Asian cultural setting (Regan et al., 2013).

In 2010, the Equality Act 2010 was introduced, which clearly stated that it is illegal for public bodies to discriminate (either directly and indirectly), harass, or victimise people on the grounds of their age, disability, gender reassignment, marriage or civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. However, it is evident that people from BAME backgrounds still underutilise dementia services (Mukadam et al., 2015). This inequality of service use is thought to lead to poorer dementia outcomes among BAME groups. It has led to the UK policy of ensuring that services are culturally targeted and appropriate and suggesting the creation of special memory services for BAME groups (Mukadam et al., 2015).

There are some positive political moves noticeable from 2012. For instance, in March 2012, then Prime Minister David Cameron launched an action plan to fight dementia, recognising dementia as one of the significant challenges faced by the aging population of the UK (Alzheimer’s Society, 2012, p.5). In 2013, dementia was a topic of conversation at a summit of the G8 countries (Alzheimer’s Society, 2012, p.5).

In May 2013, all Party Parliamentary Group on Dementia (APPG) investigated the experiences of people from BAME communities with dementia and found that dementia services are too few and far between, and many people struggle with too little support from the NHS or Local Government. The Parliamentary Group also indicated an urgent need to increase awareness of dementia among BAME communities and that service providers must be sensitive to cultural stereotypes (*Ibid*, p.5). BAME communities are often not seeking out services as there is a general concern that dementia services are not culturally friendly (*Ibid*, p.31). This is the only report about UK policy to address dementia in an ethnic minority context. This report highlights many problems that BAME communities face, including the paucity of data on the "incidences of dementia in different ethnic groups" (*Ibid*, p.5), cultural issues such as language (*Ibid*, p.25), and stigma (*Ibid*, p.26), along with many barriers to access to services (*Ibid*, p.31). However, APPG’s (2013) focus was on culture only, whereas religion was not considered explicitly within this report. Although there is a reference to "myths and misconceptions about dementia" (APPG on Dementia, 2013, p.27) where "*Jinns*" are alluded to in the Black Caribbean population, this is not discussed in depth, nor is adequate consideration given to the importance of religious beliefs and their impact on dementia care access.

The Prime Minister's Challenge on Dementia (2015) focused on delivering change in three key areas:

- Creating dementia-friendly communities that understand how to help – including improving awareness among the public; and the establishment of recognised dementia-friendly communities, led by the Alzheimer's Society.
- Driving Improvements in health and care – including better diagnosis; improving care in hospitals; improving standards in care homes; more information for patients and families; and more support for carers.
- Better research – including increased funding for research into care, cause, and cure, with a commitment to more than double funding for dementia research to over £66 million by 2015 (DoH, 2015; Parkin & Baker, 2021).

Then the Prime Minister, David Cameron, set the following two principal objectives for the Challenge on Dementia 2020:

- By 2020, England to be the best country in the world for dementia care and support and people with dementia, their carers, and families to live; and
- The best place in the world to research dementia and other neurodegenerative diseases.

The Government's vision is to create a society by 2020 where –'*every person with dementia, their families and carers - whatever their background, geographical location, age, gender, sexual orientation, ability or ethnicity – receive high quality companionate and competent care'* (DoH, 2015, p.29).

Despite the formal interest, there is a large discrepancy between policy and dementia service use by BAME communities. Mukadam et al. (2015) call for the UK's policy to ensure culturally appropriate services to maximise dementia outcomes among the BAME communities and suggest special memory services for BAME groups.

Greater Manchester Combined Authority set out a local Dementia Strategic Plan, 'Dementia United', on 27 January 2017. This implementation plan has its 5-year vision statement - *'making Greater Manchester the best place to live in the world for people living with dementia and their carers.'* Dementia was highlighted as one of the first devolution priorities. Dementia United sets out its Work Plan Development 2018/2019. One of the objectives is to increase diagnosis and support for BAME communities that find dementia services hard to access (Dementia United, 16 March 2018). However, 'Dementia United' also did not provide a detailed strategy for raising awareness of dementia in the Bangladeshi community, especially removing the stigma and cultural myths and ensuring equal service use.

1.6. Understanding of dementia: Theoretical perspectives

1.6.1. History of the condition

Dementia was not recognised as a disease until the 1980s, as people believed it was a normal part of aging (Fox, 1989). The medicalisation of dementia and developments in the care of people with the condition began in 1980 (Innes 2009, p.45). It is almost 100 years since Alois Alzheimer first described the disease that bears his name, though the importance of his observations was not fully appreciated for nearly 60 years (Whalley & Breintner, 2002). In 1907, German neuroscientist Alois Alzheimer first identified the relationship between brain lacerations in one of his patients and her ‘abnormal behaviours’ (Holstein, 1997; Swerdlow, 2007). Upon this discovery, the newly named Alzheimer’s disease was considered a rare brain condition in younger adults (Holstein, 1997; Chaufan et al., 2012). The same symptoms in older people were viewed as inevitable senility and a normal part of the aging process (Bond, 1992). It was not until the mid-1970s that the neurological damage associated with Alzheimer’s and what was then known as senile dementia were found to be almost identical, and dementia as a disease in older adults was identified (Katzman, 1976). Thus, dementia as a neuropsychiatric disorder replaced the idea of senility as a normal part of aging (Downs et al., 2006). Within this bio-medical approach, dementia is viewed as an abnormal, pathological condition to be controlled within the bio-medical sphere, and the lived experience of those with dementia is seen as a direct result of the damage to the brain (Sabat, 2008; Innes, 2009).

1.6.2. Bio-Medical Understanding of Dementia

The bio-medical model of dementia study has been dominant for the last 100 years (Whalley & Breintner, 2002). This approach has made a considerable contribution to the study of the disease (Holstein, 1997). As a result of medical science, researchers are now closer than ever to establishing the specific organic changes in the brain associated with the disease and have identified several modifiable and non-modifiable risk factors (Brodaty et al., 2011; AR UK, 2018a) as well as strategies for prevention (Frankish and Horton 2017). Bio-medical research has also contributed to developing diagnostic tools and treatment options (Hutchings et al., 2010; Martorana et al., 2010). Medical interventions can be helpful if dementia is diagnosed early, enabling treatment to begin, which has been shown in some people to slow the disease’s progress (Douglas, 2016). Prince et al. (2011) suggest that seeking help early enables healthcare professionals to address any concerns people with dementia and their family members may have about the disease and support they can access.

However, despite the advancement of the bio-medical approach to understanding dementia, it has some limitations as well. For instance, Innes (2009) argued that the current understanding of dementia as a disease reflects that the emphasis remains on the individual rather than on social or political factors (Innes, 2009). The bio-medical views, with a focus on symptoms and the control of the ‘disease’, are inadequate for preparing professionals to best support people living with dementia (Kitwood and Bredin, 1992a; Gilmore and Brannelly, 2010). Kitwood (1989) also argued that this prioritised neuropathological symptom disregards the social environment of the person presenting with dementia-like symptoms and failed to acknowledge the consequences of a diagnostic label on the individual. The bio-medical model was criticised for seeing people living with dementia primarily as ‘patients’ and for neglecting the social and psychological context of individual experiences (Samsi & Manthrope (2020). As dementia progresses, an individual's communication ability is likely to become compromised, and there may be a corresponding decline in social activities or social functioning (Sommerlad et al., 2017).

In addition, neuropathology alone is insufficient to account for the cognitive limitations and behavioural symptoms associated with dementia (Sabat, 2008; Innes, 2009). A further criticism of bio-medical understandings of dementia is that they negatively position the individuals with the condition by reframing them in the context of their diagnosis rather than as a unique person (Kitwood, 1997a; Innes, 2009). There remains a clear emphasis within bio-medical models upon loss of independence, inevitable loss of function, and, ultimately, death. Therefore, an individual with dementia is apparent predominantly as a patient, a passive 'victim,' and a 'sufferer' (Downs et al., 2006), or worse, as an 'empty shell' (Bryden 2005, p.156), 'the living dead' (Beuniak, 2011), or a person that no longer exists (Cahill, 2018).

Downs et al. (2006) argued that dementia becomes more common with age. Most instances of dementia occur amongst older members of society; therefore, the study of dementia often appears inevitably bound up with gerontology. From the 1950s onwards, researchers began to consider the impact of social and economic factors on aging and the recognition of ageism as a social problem (Downs et al., 2006).

1.6.3. Psycho-Social Understanding of Dementia

Dementia not only affects the individual diagnosed with the condition: it will affect their whole society, including their immediate family members and their caregivers, one way or another (Innes, 2009, p.73). Innes (2009) argues that the most significant contribution of social psychology to the field of dementia was placing the person with dementia at the centre of both academic and practical endeavours. The introduction of person-centred approaches (Kitwood, 1995) led to placing the person with dementia at the focus of research and service development, meaning that there has been a shift toward understanding the condition in terms of the psychological and social factors which directly affect an individual's experience thereof and the healthcare attention they receive. Kitwood (1997) highlights the potential others have to influence the lived experiences of dementia, in either a negative (malignant social psychology) or positive way, according to how they interact with the person who has dementia. While there is no doubt that the person-centred approach is now an accepted and widely used model within academia and practice, it is not clear to what extent it has influenced the understanding of dementia among the general public. Kitwood (1995) points out the importance of implementing dementia and dementia services based on a person's lived experience with the condition, the negative and positive interactions they experience, and its impacts. Social-psychological approaches to dementia study provide an opportunity to refocus on the personhood or self of everyone with dementia and provide the theoretical basis for person-centred approaches to dementia care (Kitwood, 1997; Sabat and Harre, 1992).

During the past three decades, social scientists have been instrumental in unpicking the dominant views about dementia based on a unidimensional (bio-medical) approach and challenging the prevailing public narrative of dementia as an illness or disease (Harding and Palfrey, 1997; Innes, 2009; Sabat, 2008). The psycho-social understandings of dementia were developed as a reaction against the dominance of the bio-medical paradigm and its failure to fully explain the complex factors contributing to an individual’s experience of dementia (Taft et al., 1997; Sabat, 2008; Behuniak, 2010). Kitwood (1993a; 1997a), for example, highlights the limitations of the bio-medical model and identifies the need for a more holistic understanding of the condition, calling to the reader’s attention the psycho-social factors which have a part to play in an individual’s experience of dementia and the presentation of their symptoms. Additional research suggests that the behaviour associated with dementia is affected by at least four interconnecting factors: damage to the brain caused by the disease process, an individual’s reaction to that damage, the way others treat the individual, and the response of the person living with dementia to the way others treat them (Sabat, 2008, pp.70-71).

Kitwood (1993a, p.541) sets out a simple equation of SD (Senile Dementia) as something which might be understood as arising from a complex interaction between five factors: SD = P + B + H + NI + SP. Within this equation, the 1st factor ‘P’ refers to an individual’s personality and, more specifically, their ability to cope with loss and change and their openness to helping others. The 2nd factor ‘B’ signifies an individual’s biography, i.e., past experiences. The 3rd factor ‘H’ refers to physical health status, including the acuity of the sense. The 4th factor ‘NI’ refers to the neurological impairment. Finally, ‘SP’ is the social psychology in relation to their social environment with particular reference to interactions with others, as these interactions have the potential to uphold or diminish an individual’s sense of safety, value, and personal being (Kitwood, 1993a, p.541). Brooker (2003) has expanded further on this with her VIP model. This approach acknowledges the biological, psychological, and social factors that impact people’s experience of dementia. The framework offers an alternative way of understanding dementia. It highlights the role that interaction with others can have in influencing the experience of dementia, thus bringing the individual with dementia to the forefront of the discussion (Kitwood 1997a). In so doing, the importance of providing good quality care and support to people living with dementia becomes imperative in improving well-being for those living with the condition (Brooker and Duce, 2000; Phinney, 2008; May et al., 2009). This challenges the traditional culture of physically orientated dementia care (that focuses primarily on the physical body) and emphasises the need for a more holistic and person-centred alternative (May et al., 2009; Innes, 2012). This thesis uses psycho-social approaches by exploring the experiences of people with dementia to understand their dementia support needs.

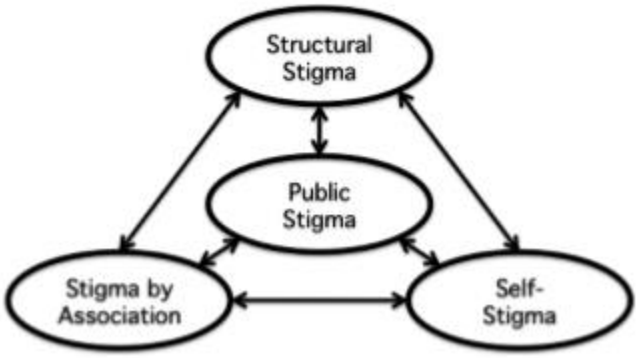
1.7. Understanding Stigma: Justification of Conceptual Framework

The research highlights that dementia is considered a highly stigmatised condition, leading to significant adverse effects on the health and well-being of people with dementia and people supporting someone living with dementia (Kim et al., 2019). Notably, the stigma of dementia is a severe problem in many BAME communities (Parveen, 2017). Some of these ethnic minority communities, including South Asian people, consider dementia taboo (Ahmed & Eagle, 2018; Ahmed et al., 2017). People with dementia and mental health issues are devalued, rejected, shamed, and excluded based on a socially discredited health condition (Livingstone, 2020). Research shows many underlying factors associated with stigma about dementia, including labelling, stereotypes, lack of knowledge/awareness, misperceptions, myths, and the internalisation of stigma and shame (Livingston, 2020) (see details in Chapter 2).

My conceptual framework on stigma has guided me to develop appropriate strategies to recruit research participants, collect data, and analyse them effectively. Maxwell (2005, p.33) defines a “conceptual framework”- as a system of ideas, assumptions, expectations, beliefs, and theories that support and inform research (Maxwell, 2005, p. 33). Grant & Osanloo (2014) suggested that the underlying assumptions and concepts of the researcher would influence the phrasing of the research questions, the choice of strategies used to collect data to answer the research questions, and, ultimately, the interpretation of the research findings.

By adopting Pryor & Reader’s (2011) conceptual model of stigma, this thesis will explore whether the participants with dementia and their caregiver from a Bangladeshi community experience any of the four aspects of stigma: self, social, and structural stigma and stigma by association. Self-stigma occurs when individuals perceive that other people may not like them (Link, 1987). Consequently, they have low self-esteem and avoid seeking opportunities to improve their lives (Corrigan et al., 2011, p.18). Social stigma (also called 'Public stigma') refers to the negative attitudes held by members of the public about people with devalued characteristics (Corrigan, 2005). Structural stigma refers to how communal ideologies and institutions spread or aggravate a stigmatised status (Corrigan & Lam, 2007). Others often devalue the friends and family members or caregivers of people who are stigmatised because of their connection with them which is known as ‘stigma by association’ (Neuberg et al., 1994).

Figure1: Four kinds of stigma based on Pryor & Reader (2011), in Boss et al. (2013, p.2).



The operationalising of this conceptual framework on stigma as it pertains to my thesis's data collection and analysis is presented in Sub-section 2.9: (p.56).

1.8. Why the Bangladeshi community?

Previous literature has mainly focused on the South Asian and BAME community in general, or had a specific focus on the UK Indian or Pakistani community (see Table 2: the characteristics of sources of evidence, p.34). These studies have mostly South Asian communities together historically when in fact there are significant socio-demographic differences between British Indians, Pakistanis and Bangladeshis. Research shows that there is a large discrepancy between the UK Bangladeshis, Indians, Pakistanis, and White British communities in regards to their social and economic circumstances, lifestyles, anthropometric measures, and diseases. (Bhopal et al.;1999).

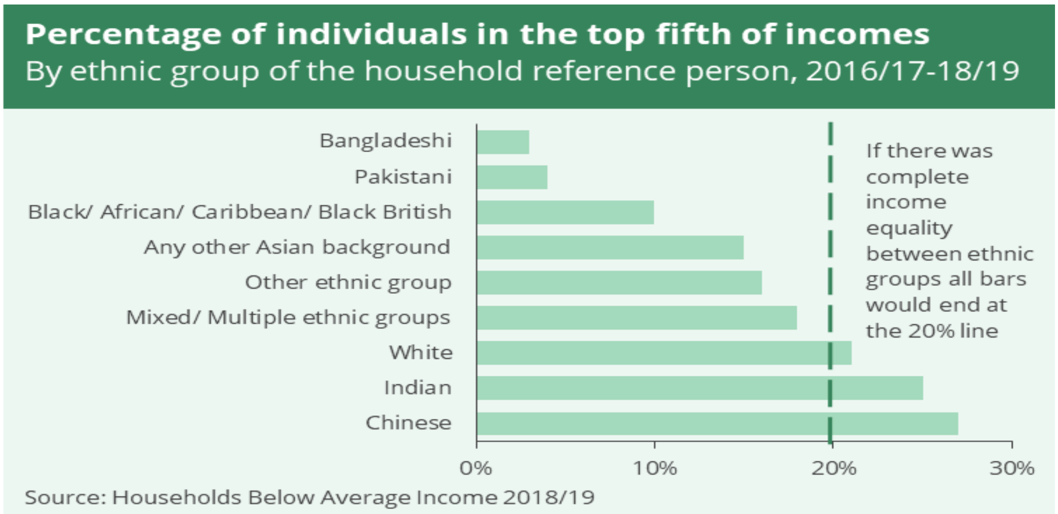
The Bangladeshi community arrived in the UK (Peach, 1996) slightly later than the Indian and Pakistani communities. In the early 1950s, the UK government experienced a labour shortage in the manufacturing industries and, therefore, openly encouraged migration from the former colonies of UK to fill the jobs vacuum (Tackey et al, 2006). The initial steady flow of Indian and Pakistani migration started in the 1950s, whereas the Bangladeshi people migrated following the damage caused by the 1971 liberation war (Blackburn et al., 1997). Due to the first Commonwealth Immigration Act in 1962, South Asian single males had opportunities to bring their wives to join them; Indian Sikhs and Hindus were the first to bring their families, beginning in the 1960s (Dale et al., 2002). Pakistani Muslims were more reluctant to expose their families to British morality and did not begin large-scale family reunification until the 1970s. However, Bangladeshi migration peaked around 1980s, when many Bangladeshis who settled earlier brought their wives and children), ten years behind the Pakistanis and around 20 years behind the Indians. (Peach, 1996). Settlers from Bangladesh often filled manual jobs, particularly in steel mills and the textile industry (Kalra, 2000). Due to poor English skills, many could not progress in their employment or interact with the broader population (Dale et al., 2002). On the other hand, many Indian migrants were well educated and entrepreneurial (Kalra, 2000).

According to 2011 data, Indians in the UK are far more likely to work in higher-skilled professional jobs than Bangladeshis and Pakistanis. For example, 27% of Indian men in higher managerial and professional occupations compared with 8% of Bangladeshi and 11% of Pakistani men in such professional jobs (Census Data, 2011; https://commonslibrary.parliament.uk/income-inequality-by-ethnic-group/). In addition, 13% of Indian women were in higher managerial professions whereas 5% of Pakistani and 4% of Bangladeshi women were in similar jobs (Ibid). The following four figures (Figures 2, 3, 4, and 5) illustrate the socio-economic discrepancy between Bangladeshi, Indian, Pakistani, and other BAME groups compared to the British Whites.

Figure2: Median household income by ethnic group (https://commonslibrary.parliament.uk/income-inequality-by-ethnic-group/).

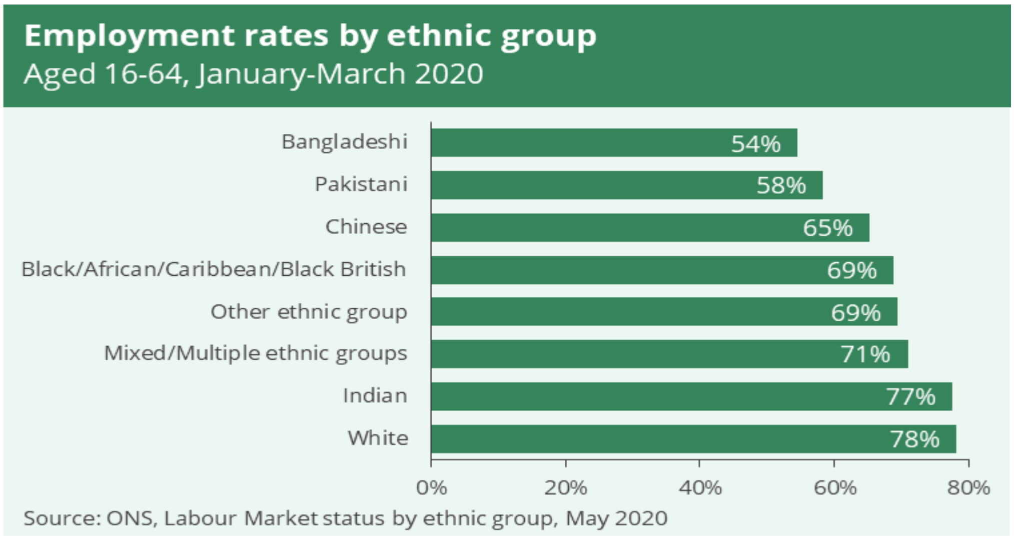
Source: House of Commons Library analysis of DWP, Households Below Average Income survey data, 2018/19

The above chart shows the median weekly household income in the three years 2016/17 to 2018/19, when people from the Pakistani and Bangladeshi ethnic groups had the lowest median incomes, while people from White and Indian ethnic groups had the highest (House of Commons Library, August 2018, p34). Figure 3: Income distribution and the discrepancy among the Bangladeshi and other south Asian groups: (https://commonslibrary.parliament.uk/income-inequality-by-ethnic-group/)

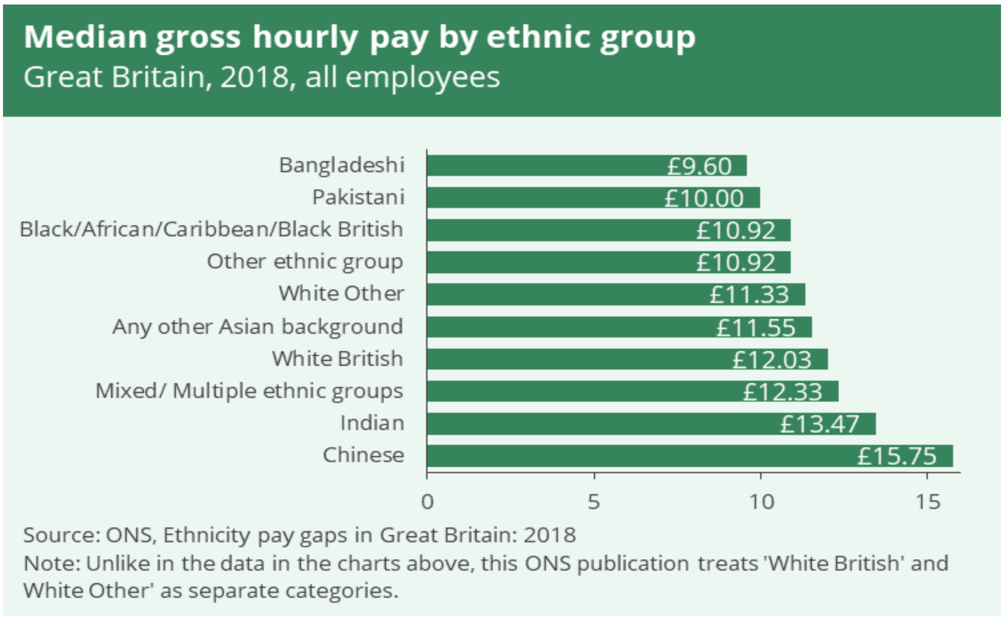


The above chart shows that in the income distribution, only 3% of people from the Bangladeshi ethnic group and 4% of those from the Pakistani ethnic group lived in households that were in the top fifth by income, whereas this applied to 27% of people from the Chinese ethnic group, 25% of people from the Indian ethnic group, and 21% of people from a White ethnic group. Figure4: Employment rates and the Bangladeshi community:

(https://commonslibrary.parliament.uk/income-inequality-by-ethnic-group/)



Data from ONS show that employment rates followed a similar pattern to median incomes: people from Bangladeshi (54%) and Pakistani (58%) ethnic groups had the lowest rates, while people from Indian (77%) and White (78%) ethnic groups had the highest. These employment gaps begin to explain income inequality between ethnic groups Figure5: Median gross hourly pay and the Bangladeshi community:(https://commonslibrary.parliament.uk/income-inequality-by-ethnic-group/)



Source: ONS, Ethnicity pay gaps in Great Britain: 2018
Note: Unlike in the data in the charts above, this ONS publication treats 'White British' and White Other' as separate categories.

Statistics presented above show that around 57% of women from Bangladeshi and Pakistani ethnic groups were economically inactive, compared to 26% from Black and Indian ethnic groups and 22% from the White ethnic group (ONS, March 2020). In 2018, people from Bangladeshi (£9.60), Pakistani (£10.00), Black £10.92), and Other (£10.92) ethnic groups had the lowest average pay, and people from Chinese (£15.75) and Indian (£13.47) ethnic groups had the highest.

The above five figures indicate that although historically Bangladeshis, Indians, and Pakistanis are grouped as South Asian communities, they have significant socio-demographic differences. A substantial income inequality exists between these three ethnic groups; the Bangladeshi and Pakistani people are around twice as likely to be in the bottom fifth of incomes than average and have the lowest median household incomes. At the same time, significant health inequality exists between these three groups. Research shows that UK Bangladeshis are at greater risk of heart disease (Patel & Bhopal, 2004). Type 2 diabetes shows a markedly higher incidence for Bangladeshi immigrants than 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 significant indicators for developing dementia (Bruce et al., 2001; Peila et al., 2002; Stewart & Liolitsa, 1999). In addition, in England, Bangladeshi communities have been shown to have the lowest education rates, the highest smoking rates, the poorest socio-economic conditions, the worst health rankings, the most risk factors associated with underdiagnosis, and the poorest access to healthcare services and support (Garbin, 2005; HSCIC, 2006; ONS, 2002). As the Bangladeshi community is unique regarding their socio-economic disadvantage and poor health outcome, it is necessary to research this community with a specific focus. Therefore, this study will explore the lived experiences of people with dementia from a UK Bangladeshi community that will significantly impact understanding of the support needs of this minority ethnic group.

1.9. Research Aims and Objectives

1.9.1. Aim:

This thesis aims to explore the experiences of people with dementia among the UK Bangladeshi community to better understand their support needs.

1.9.2. Objectives:

This study addresses the following objectives to meet the research aim:

1. To explore the understanding of dementia for people diagnosed with dementia and their caregivers from a UK Bangladeshi community.
2. To explore the experiences of people with dementia among a UK Bangladeshi community, to ascertain their views about the support provided, and identify any gaps.
3. To explore whether or not dementia is stigmatised in a UK Bangladeshi community and how the stigma may impact the lives of people with the condition.
4. To explore the views of stakeholders / service providers about the support provided for a UK Bangladeshi community and determine if there are any gaps.

1.10. Researcher’s Positionality and Reflexivity

1.10.1. Positionality

Foote and Bartell (2011, p.46) suggest that researchers' positionality and personal experiences may influence the research process and their interpretation of outcomes. The term positionality refers to an individual’s worldview and the position they adopt in research and its social and political context (Foote & Bartell 2011, Savin-Baden & Major, 2013; Rowe, 2014). It acknowledges and recognises that researchers are part of the social world they are researching and that existing social actors have already interpreted this world (Holmes, 2020). Kanuha, (2000) put forth the view that being an insider increases validity via understanding and closeness with the participants in the research study.My ethnicity and religious background gave me the privilege of insight into the perceptions and understanding of the verbal and body language of the research participants that other researchers might not have (Gilgun and Abrams, 2002; Labaree, 2002). I undertook my undergraduate study in Bangladesh (1998), where Bangla literature was one of the compulsory modules. I can communicate with others in Bengali, Sylheti (dialect), and English fluently. My insider role facilitated interviewees to interact freely and encouraged them to share their problems as the participants and I shared culture, religion, and a common language (Gibson and Abrams, 2003; Anderson and Jack, 1991).

I acknowledge that I am not a neurologist by profession, whereas dementia is a neurological disorder. However, this research is not designed to seek the bio-medical approach to understanding dementia. Instead, I chose to generate knowledge about my research topic through psycho-social approaches, suitable for me considering my position in society and my educational background.

1.10.2 Reflexivity

Mason (2002, p.7) suggests that qualitative research should involve critical self-scrutiny by the researcher or active reflexivity. The author has explained further that a researcher cannot be neutral, objective, or detached from the knowledge and evidence they are creating. Therefore, throughout this thesis, I have critically assessed and questioned my role in the research process. I have reflected upon how I may have affected the research participants, my interpretations, and my understandings of the findings. I always carried a reflective diary to record my field notes and memos concisely during and after each interview.

I agree with Braun and Clarke (2013), who argue that “bias as a concept does not apply as a valid critique of qualitative research” (p.328). The authors suggest the researcher’s humanness and subjectivity can be utilised as a research tool by being reflexive. I have striven to engage with and share my reflexivity during the research process. Reflexivity helped me reflect upon my actions and values during the study, particularly to prepare and write up the data and to assess the opinions and views of others (Seale, 2012). (Details of my research reflexivity are provided in Chapter 3; Sub-section 3.5: Researcher’s Insider/Outsider Positionality and Reflexivity, p.115).

1.11. Thesis Structure

This doctoral thesis is divided into eight chapters.

Chapter 1 presents the introduction to this whole thesis.

Sub-section 1.1 shows the research background, where the researcher has demonstrated dementia’s prevalence globally, nationally among the BAME communities and UK South Asian population. It also presents the health outcome of the Bangladeshi community, their dementia risks, and an initial indication of the challenges that UK Bangladeshis and BAME communities face in accessing dementia and health care services. 1.2 discusses the rationale of this study. 1.3. explains why I decided to do a PhD about Dementia. 1.4. presents a conceptualisation of dementia. 1.5. highlights the Government’s policy context towards dementia in the BAME communities, including Bangladeshis. 1.6. highlights different theoretical perspectives on dementia, then justifies why this thesis used the psycho-social approach to understand the lived experiences of people with dementia. 1.7. presents the justification for writing a conceptual understanding of the stigma framework, though this research study is about dementia. 1.8. gives the rationale for the research site where this research has taken place. This sub-section also demonstrates how the UK Bangladeshi community is different from other south Asian communities 1.9. shows the overall aims and objectives of this study. 1.10. presents the researcher's personal motivation for the study, insider/outsider positionality, and reflexivity briefly. Again, this reflexivity is illustrated broadly in Chapter 3: Research Methodology and Design (see sub-section 3.5. Researcher's Insider/Outsider Positionality and Reflexivity, p.110). Finally, 1.10. presents the thesis outline in brief.

Chapter 2 presents a scoping review of the existing literature to evaluate existing studies on the experiences of South Asian individuals and families with dementia, their dementia diagnosis process, their experiences with dementia services uses, and their engagement with health and social care services, with particular attention to the UK Bangladeshi community. This chapter presents first the rationale for the Scoping Review and its aims and objectives including the research questions that will guide the literature search. Second, the search strategy adopted to identify relevant studies is mentioned; it includes protocols of this review, eligibility criteria, information sources (i.e., the search engines & database used), and search terms & keywords. Third, the study selection process and data charting procedures are illustrated with a PRISMA diagram. Then it presents a Synthesis (collating, summarising and reporting the results with critical appraisal and detailed focus of the study. It also explains the limitations and knowledge gaps of the existing literature. This chapter also develops the conceptual understanding of stigma adopted for this study, drawn from Goffman (1963), and Link & Phelan (2001). First, the definition of stigma, its historical origin, and typologies of stigma are illustrated broadly in sub-section 2.9. (A Conceptual Framework for the Study of Understanding Stigma attached to Dementia, p.56). Second, an explanation of the understanding of stigma in dementia is offered based on certain cultural perspectives.

Chapter 3 presents the methodology and research design of this study. This chapter first discusses the ontological perspective and epistemological position of this study, which lead the researcher to choose the correct research strategy to achieve the overall aim and objective of the study (Walliman, 2016, p.12). Second, it demonstrates the rationale for using a qualitative approach and the research strategy used in this study, in conjunction with the data collection, management, and analysis methods and techniques. The ethical considerations for this study are highlighted as they are central to social research (Morris, 2015, p.17; Thomas & O'Kane, 1998). Finally, a detailed step-by-step thematic analysis process is explained, based on Braun and Clarke (2006).

Chapter 4 presents the findings from participants with dementia from the Bangladeshi community. Participants with the condition have various views of dementia; therefore, they have tried in different ways to solve their problems. However, almost all the participants said they had never heard the word dementia until they were diagnosed, suggesting that participants with dementia do not understand dementia in its scientific, bio-medical context. Many participants went to spiritual healers in Bangladesh and the UK, considering their condition to involve possession by supernatural entities. The data also highlighted that some so-called spiritual healers in the UK have no formal medical or therapeutic qualifications and, in some cases, exploits the families of people with dementia equating their conditions with spiritual possession. At least 4 people with dementia reported that they often tried to hide their condition from others and did not like to disclose them to anyone apart from close family members. They feared that the community would start gossiping about them in a way that might destroy their wider family’s reputations. They reduced their social contact with people and avoided gatherings for fear that other people might label them as mad, which might jeopardise their family honour. Two participants with the condition had reduced contact with their extended family or broader community to keep the information private from others. They were also afraid that if someone knew they had dementia, they might spread the news of that individual’s problem throughout the community. Eventually, they became socially isolated. One individual with dementia was concerned that if the members of his extended family and the broader community knew of his condition, it would pose a severe threat to his daughter’s marriage prospects, which is a clear sign of courtesy stigma or stigma by association. Participants have also identified some gaps in GP and hospital services. One participant reported that he went to the doctor many times and explained his problem to his GP, but his GP did not respond to him. The participant felt he was not diagnosed promptly due to his GP's negligence. Some participants commented that their GPs' services are not as good as they were in the past. They also commented that some GPs are too busy and did not want to give a patient enough time to talk. In addition, respondents relayed it was sometimes difficult to obtain a doctor's appointment.

Three participants reported that they did not speak English and could not communicate with their doctors properly. Although there are interpreters available, some participants feared that interpreters may miss important points. Participants believed that family members knew their health situation better, and therefore, they could explain better than formal interpreters. However, family members or relatives were not allowed to interpret for them in hospital, so the participants with dementia seemed unhappy with the interpreters' services.

Chapter 5 explores the findings from the family caregivers of people with dementia from the Bangladeshi community. Most of the carers have reported that there are various misconceptions and myths about dementia among the Bangladeshi people. Caregivers tended to expressed that dementia services are not culturally appropriate or religiously sensitive for the Bangladeshi community. Several participants have reported that healthcare service providers often do not understand all ethnic groups' specific needs. They take generic approaches, and people feel this is destructive to their lives, so they are better off without their services.

Family caregivers have shown a strong sense of family obligation to provide care for their loved ones with dementia at home. Findings from this thesis demonstrate that several family caregivers did not have the time to cope with their care duties due to work and other commitments despite their sincere willingness and motivation to care.

Chapter 6 examines the perspectives of the stakeholders and service providers regarding the knowledge and help-seeking attitudes of people with dementia from the Bangladeshi community and the challenges they face in accessing health and care services. All stakeholders' / service providers' data revealed that their service users from the Bangladeshi community do not understand dementia from a Western/scientific perspective. However, these service users, i.e. people with dementia, have some sort of understanding about dementia even though they did not at first have any word for it in Bangla. Almost all stakeholders / service providers suggest that many Bangladeshi patients and clients are not familiar with navigating systems. They do not know when to ask, who to ask, or where to ask for dementia help.

Chapter 7 offers an overall discussion of the findings from all three phases of the research study (i.e., interviews with people with dementia, their caregivers, and stakeholders) and how they link to the literature review. Data analysis from all three participant groups highlights that people with dementia among the Bangladeshi community are heavily stigmatised. People living with dementia have symptoms that are deemed 'not normal' (after Goffman, 1963) and this gives rise to being viewed as 'different' and subject to ridicule. This indicates there is significant level of societal stigma existing among the service users as reported by the stakeholders / service providers. In turn, a person with the condition feels guilty and ashamed. They often become socially isolated from fear that other people may judge them mentally ill. This is similar to Pryor & Reader (2011), in that all 3 participant groups suggest that they see all 4 aspects of stigma comprising self-stigma, social (public) stigma, structural stigma and the stigma by association attached to the UK Bangladeshi community.

Chapter 8 is concerned with the conclusions and recommendations drawn from the complete thesis and the original contribution made by the research, and recommends areas for further study.

Chapter 2: Scoping Review of the Literature

2.0. Introduction

This chapter presents a scoping review of the existing literature on exploring the understanding of dementia and the experiences of people with dementia from the UK South Asian communities, with special reference to the Bangladeshi community. Scoping reviews are defined as a process of mapping the existing literature or evidence base to identify trends and summarize research findings (Munn et a. 2018). The justification of this approach to literature review is provided below (in sub-section 2.1; p.27).

This review has targeted identification and analysis of the existing literature focused on the South Asian community, along with that specific to the Bangladeshi community, as geographically, Bangladesh is among the South Asian countries (Rahman et al., 2014). In the ancient past, it was an integral part of India (Rahman et al., 2014). In 1947, when British colonial rule ended, the province of Bengal (within India) was partitioned into East Bengal and West Bengal. East Bengal was renamed again as East Pakistan in 1947, and later became an independent country in 1971, called Bangladesh (Rahman et al., 2014).

This chapter describes first the rationale for the Scoping Review and its aims and objectives, including the research questions that will guide the literature search. Second, I will discuss the search strategy that I adopted to identify relevant studies which includes protocols of this review, eligibility criteria, information sources (i.e., the search engines & database I used), and search terms & keywords. Third I will illustrate the study selection process and data charting procedures with a PRISMA diagram. Then I will present a synthesis (collating, summarising, and reporting) of the results of the study. It also explains the limitations and knowledge gaps of the existing literature. Finally, this chapter will conclude with a discussion and conclusion.

2.1. Rationale for the Scoping Review:

This research used a scoping review as my research questions are exploratory, and the goal of this study is to map the current literature from a broad perspective. (Wanga et al. 2019). Scoping studies aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as standalone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before (Mays et al. 2001, p.194). Arksey and O'Malley (2005, p10) identified at least the following common reasons why a scoping study might be undertaken:

1. To examine the extent, range and nature of research activity. It is a useful way of mapping fields of study where it is difficult to visualise the range of material that might be available.
2. To summarise and disseminate research findings.
3. To identify research gaps in the existing literature.

Armstrong et al. (2011, pp. 147-150) argued that compared with a systematic review, a scoping review answers broader research questions; does not regard study quality as the initial priority; and synthesizes findings more qualitatively than quantitatively. This explicit approach increases the reliability of the findings and responds to any suggestion that the study lacks methodological rigour (Mays et al. 2001).

2.2. Aims of the Review:

The aim of this literature review was to identify papers which would help in understanding the experiences of people with dementia from a UK Bangladeshi community. A broad approach was adopted to capture as much relevant literature as possible, which was then refined using screening procedures. This review aims to address the following questions:

- What is known from the existing literature about the lived experiences of people with dementia among the UK Bangladeshi community?
- What does this research tell us about the knowledge, believes and help seeking attitudes of people with dementia and their family carers among this community?
- What is the state of research on understanding the support needs of people with dementia in UK Bangladeshi community? What are the key issues and challenges attached to accessing dementia services?
- Is dementia stigmatised in the UK Bangladeshi community?
- What are the gaps in research that could inform future intervention and policy?

2.3. Protocol

The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA ScR) guidelines-2022 guided the approach and structure of this review. (see Figure 6: PRISMA-ScR flow diagram of literature search, p.34; see the guidelines of PRISMA-ScR,2022 in appendix19, p.347). This review is not registered.

2.4. Search Strategy

Implementing a clear search strategy in formulating a literature review supports transparency of the process and reliability of the conclusions and facts drawn from it (Morse & Richards, 2002). It allows the researcher to choose papers relevant to the given topic carefully and to plan how the research is to be conducted (Morse & Richards, 2002). To reach the review goal, the researcher has applied the following search strategies.

2.4.1. Eligibility Criteria

The search strategy aimed to find all peer-reviewed journal articles, book chapters, unpublished PhD theses, and reports from charitable organisations that address the understandings of British South Asian people with dementia, their experiences, and their cultural expectations of care. Some of the papers published in the period 2001-2005 are very much relevant to my research aims and crucial for this research. On the other hand, the latest paper published on this topic was 2020. I have limited my search span from 2001 until 2020. The search also included methodologically diverse studies using qualitative, and mixed-method approach. The studies retrieved using search terms (see sub-section 2.4.3, p.33) and were manually evaluated using inclusion criteria to decide on the composition of relevant research articles on dementia, focusing on the South Asian experience. The following inclusion criteria guided the search:

- Studies that cover UK South Asian communities including Bangladeshi, Indian, Pakistani, Sri Lankan, Nepalese, Bhutanese, Maldivian, and Afghan communities
- Studies that follow all empirical research designs and methodologies i.e. quantitative, qualitative, and mixed methods
- Studies including south Asian people with dementia as well as those focused-on family carers and health care professionals working with people with dementia
- Studies that explore the knowledge, understanding, attitudes, or experience of dementia from the perspective of people with dementia, their family caregivers' experiences, and healthcare professionals' experience of dementia diagnosis and experience of using dementia services, and engagement with dementia services
- Studies published in the English and Bangla languages only.
- Studies conducted from 2001 until 2020

2.4.2. Information Sources

I used the following advanced searching and filtering tools: The Cumulative Index of Nursing and Allied Health Literature (CINAHL), Database of the National Library of Medicine (MEDLINE) (1950-), ProQuest, PubMed Central, Web of Science, PsycINFO (1806), British Library Electronic Thesis Library (British Library Ethos), and

PsycEXTRA. Additional internet searches were conducted for ‘grey literature. (Details are given in Appendix 1, p.252). Final searches were conducted on 30/11/2020.

2.4.3. Search Terms and Keywords

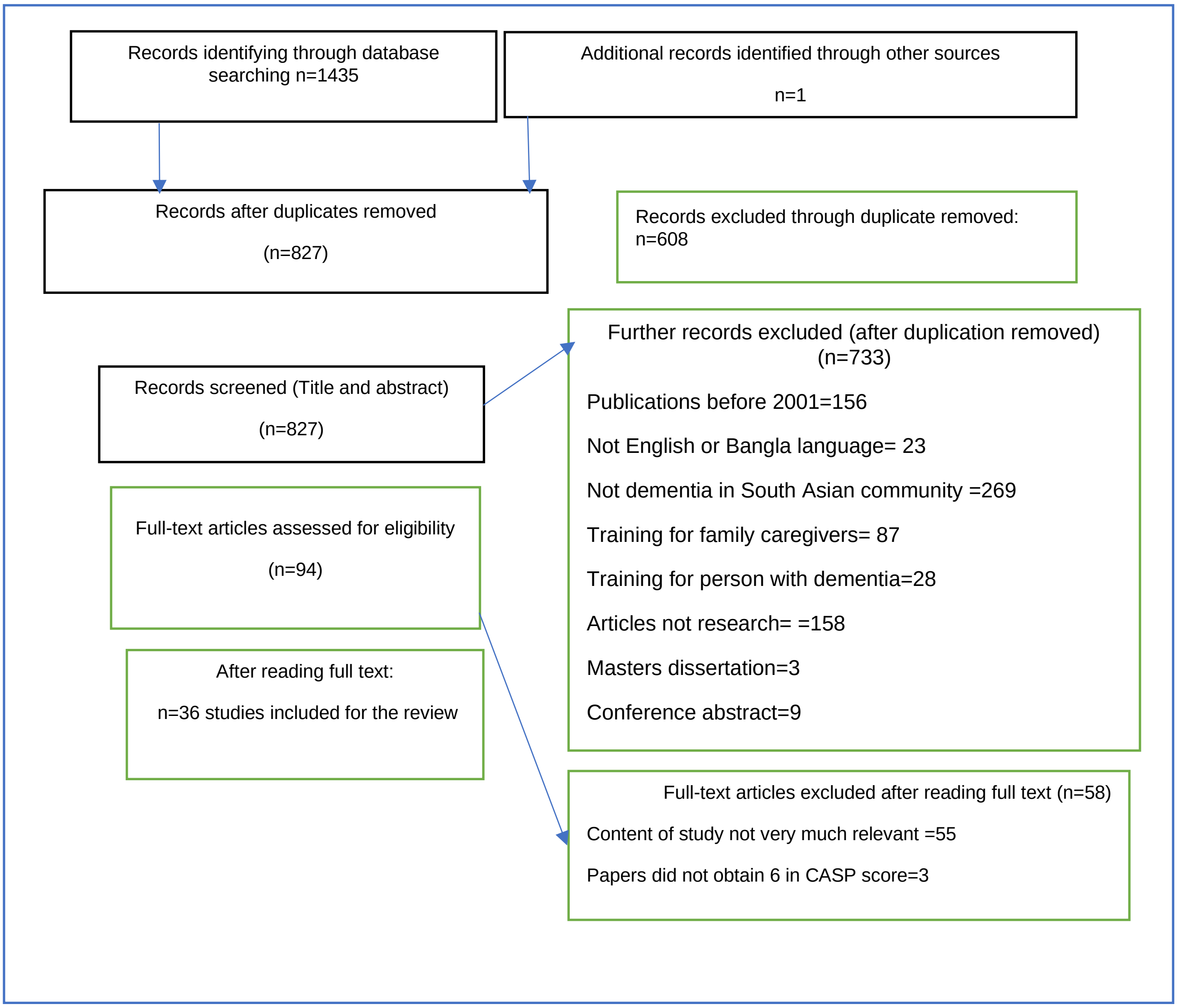
This literature search focused to identify documents about ‘understanding the knowledge, beliefs, health-seeking attitudes of people with dementia among the South Asian communities in the UK.

2.5. Charting the Data

2.5.1. Data Screening

Following the search strategy, and limiting the results with strict inclusion criteria, 1435 papers were found initially. While selecting sources of evidence, duplicates were removed, and records were screened and removed if they did not meet eligibility criteria. After removing duplicates, 827 papers were remained. Then reading titles, abstracts, and introductions, 94 papers were eligible for full-text screening. One article was identified from hand searches and reference lists. After reading full text and using a quality appraisal (according to the Critical Appraisal Skills Programme CASP guidelines), a total of 36 articles were included in this scoping review. Electronic search results were managed using referencing software Mendeley and Microsoft Excel. Titles and abstracts of all citations were first screened. Those that were not related to dementia and South Asians or that had been conducted outside the UK were discarded. The full texts of all potential eligible papers were assessed against the inclusion criteria. Where the full text of the papers was not available, the researcher contacted the authors to request the papers. Studies that met the review criteria were charted using a data extraction sheet. Content was then charted and sorted by publication type and study focus (see Table 2; Characteristics of sources of evidences, p.36).

Figure 6: *PRISMA-ScR flow diagram of literature search is demonstrated in the following page):*



The next step was to appraise the qualities of the studies selected for the review. Crowe et al. (2011) advocate that any qualitative, quantitative, or mixed-method research should be appraised for internal validity by using a standardised approach to rate the quality of individual studies. To adopt a consistent approach to appraising the qualitative, quantitative, and mixed-method studies, the researcher used the Critical Appraisal Skills Programme, CASP (2006). The appraisal aimed to check the suitability of data collection methods, appropriateness of analysis methods with regards to the study topic and context, how accurate the analysis was, and the accuracy and the applicability of results from the study (Long et al., 2002). This appraisal tool consists of the following 10 questions:

1. Was there a clear aim of this research?
2. Is the methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in the way that addressed the research issue?
6. Has the relationship between the researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

(A summary of CASP scores given to each paper included in the literature review is provided in Appendix3; p.266.)

Every question had one of the three options to choose; i.e., Yes, No, Can't tell. The researcher has scored 1 to answer “yes” and 0 to assign a paper to the other two categories. 36 papers obtained 6 or more, therefore they were included in the scoping review (details in Appendix3; p.266). A summary of research included in the scoping review is presented in Appendix 2; p.259.

2.5.3. Characteristics of sources of evidence with the details of study focus:

Characteristics of research included in the scoping review are organised by publication type, methods, design, community focus and emerging themes. Thirty-six studies met the eligibility criteria. The earliest pertinent published study was in 2001, whereas 19 of these works were published in the period 2015-2020; 28 of them were published in last ten years (2011-2020). The majority were cross-sectional. Qualitative approaches were the most common method, with a mixture of semi-structured interviews and focus group approaches used. Three papers included people with dementia in the study with very small numbers of participants e.g. 1, 2 and 4. Three studies explicitly focused on dementia in the UK Bangladeshi community. However, these studies that are explicitly about the Bangladeshi community did not include people with the condition in the research.

Table2: *The following table details the characteristics of sources of evidences:*

Publication Type		Study Focus			
		Community Focus		Emerged themes	
				Themes	Studies
Peer-reviewed journals	31	Studies explicitly focused on the UK Bangladeshi Community	Hussain& Khan (2020); Herat-Gunaratne et al. (2019); Hossain (2017);	**Theme1:** The Attitudes of UK South Asians towards Dementia service usage	Kenning et al. (2017); Hossain (2017); Hailstone et al. (2017); Giebel et al. (2016); Regan (2016); Mukadam et al. (2015); Regan (2013); Victor et al. (2012); Lawrence et al. (2008); Adamson & Donovan (2005);
Unpublished Thesis	4	Studies explicitly focused on the UK Indian community	Jutlla (2015); Uppal et al. (2014); La Fontaine (2007);		
URL Monograph (of University of Salford)	1	Studies explicitly focused on the UK Pakistani community	Giebel et al. (2015)	**Theme2:** Knowledge/ understanding/ perceptions of Dementia among the UK's South Asians	Hussain& Khan (2020); Giebel et al. (2019); Hossain et al. (2018); Atcha (2018); Hossain (2017); Mukadam et al. (2015); Ahmed et al. (2017);; Yong & Manthorpe (2016); Giebel et al. (2015); Mukadam et al. (2015); Mukadam et al.(11); La Fontaine (2007); Purandare et al. (2007); Mackenzie (2006); Bowes & Wilkinson (2003) ; Adamson (2001)
Total Papers	36	Studies focused on the UK South Asian communities In general,	Giebel et al. (2019);; Hossain et al. (2018); Atcha (2018); Blakemore et al. (2018); Hailstone et al. (2017); Giebel et al. (2016); Regan (2016); Yong & Manthorpe (2016); Mukadam et al. (2015); Mukadam et al. (2015b); Regan (2013); Parveen et al. (2011); Purandare et al. (2007); Mackenzie (2006); Turner et al. (2005); Bowes & Wilkinson (2003)		
Methodology		Studies focused on the UK BAME communities in general	Baghirathan et al. (2018); Kenning et al. (2017); Parveen et al. (2017); Ahmed et al. (2017); Khan & Tadros (2014); Victor et al. (2012); Mukadam & Livingston (2012); Bhattacharyya et al. (2012); Lawrence et al.	**Theme3:** Beliefs about Dementia among the UK's South Asians	Hussain& Khan (2020);; Regan (2016); Khan & Tadros (2014); Turner et al. (2005);

			(2011); Mukadam et al. (11); Lawrence et al. (2008); Adamson & Donovan (2005); Adamson (2001)		
Qualitative	34			**Theme4:** Stigma	Atcha (2018); Ahmed et al. (2017); Mukadam & Livingston (2012); Mukadam et al. (11);
Quantitative	0				
Mixed Methods	2				
Design					
Cross-sectional	27				
Longitudinal	1			**Theme5:** Cultural Expectations and Caregivers' Burdens	Herat-Gunaratne et al. (2019); Jutlla (2015); Parveen et al. (2011);
Reviews of literature	8				
Total papers=36					
				Theme6: Experiences of Dementia Service Users: Gaps in Services	Herat-Gunaratne et al. (2019); Blakemore et al. (2018); Baghirathan et al. (2018); Kenning et al. (2017); Ahmed et al. (2017); Bhattacharyya et al. (2012); Lawrence et al. (2011);

2.6. Synthesis:

There are many ways in which research evidence can be brought together to give an overall picture of current knowledge (Pope et al. 2007). This research used a thematic synthesis approach to identify and combine the relevant framework information from relevant studies for this qualitative research and trailed the following form of three stages:

- The free line-by-line coding of the findings of primary studies
- The organisation of these 'free codes' into related areas to construct 'descriptive' themes
- The development of 'analytical' themes

The use of line-by-line coding enable the researcher to undertake the translation of concepts from one study to another (Britten et al.2002). I have also examined all the text with a given code applied to check the consistency of interpretation and to see whether additional levels of coding were needed.

Analysis of the studies discussed above gave rise to the following five themes:

The attitudes of UK South Asians towards dementia service usage knowledge of dementia among the UK's South Asians (addressed in 16papers); beliefs about dementia among the UK's South Asians (addressed in 4 papers); stigma and concealment (addressed in 4); cultural expectations to care (addressed in 3 papers); and experiences of dementia service users (addressed in 7 papers). Three papers, including Hossain & Khan (2020), Herat-Gunaratne (2019), and Hossain (2017), have a specific focus on understanding dementia amongst the UK Bangladeshi community and their dementia support needs specifically. Besides these, the following three papers, Mukadam et al. (2015), Atcha (2018), and Victor et al. (2012), also include a sizeable number of participants from the Bangladeshi community in the research presented.

2.7. Findings of the Scoping Review:

Findings from this scoping review will be presented below in the following 5 themes:

- Dementia Service Usage: The Attitudes of UK South Asian Communities
- The knowledge of dementia among the UK's South Asians
- The Belief about dementia among the UK's South Asians
- Cultural Expectations and the Caregivers' Burdens;
- The Experiences of Dementia Service Users: Gaps in Services.

I have presented a Conceptual Framework for the Study of Understanding Stigma attached to Dementia in subsection 2.9. (p.56),

2.7.1. Dementia Service Usage: The Attitudes of UK South Asians

Research suggests that by 2051, there will be a sevenfold increase in the prevalence of dementia in the minority ethnic communities, compared to a two-fold increase among the White British population (Wohland et al., 2010; Griffiths et al., 2018). The All-Party Parliamentary Group on Dementia (2013) highlighted the need to develop appropriate services and improve access to high-quality services for people with dementia amongst these communities. Their report also emphasises the need for service providers to avoid the stereotypes and assumptions that minority ethnic families ‘care for their own’ and do not require outside help (Parveen et al., 2017). In addition, one of the core aspects of government policy was indicated to be developing initiatives to improve public understanding, awareness, and attitudes towards dementia, improve timely diagnosis, improve services for people living with dementia, and remove the stigma attached (National Dementia Strategy 2009; DoH, 2015; Alzheimer’s Disease International, 2012). However, despite such policies, a growing body of literature has recognised that people from the BAME backgrounds are underrepresented in service usage (Moriarty et al., 2011, Mukadam et al., 2011;

Cooper et al., 2012). They also present later to dementia specialist care than their White British counterparts (Mukadam et al., 2015; Hailstone et al., 2017; Ahmed et al., 2017). Bhattacharyya et al. (2012) and Turner et al. (2012) argue that despite South Asians having a greater risk of developing dementia, they have poorer access to dementia-related services. In Parveen et al. (2017), the vast majority (over 70%) of research participants from all groups (including South Asians) reported that sufficient information was not available in their community; most did not know how to access social services for support and were not aware of specific services. Purandare et al. (2007) argue that this inequality in access to dementia services by the South Asian community remains a concern for policymakers because of the implications for poorer outcomes in dementia treatment amongst minority ethnic groups.

There is evidence to suggest that dementia diagnosis usually happens among South Asians after an acute medical problem or hospital admission (Zaidi et al., 2018, p.5). Interviewing 37 first- and second-generation South Asian adults in the UK, Hailstone et al. (2017) noticed that thirty of them had a minimal understanding of dementia, which affected their willingness to seek healthcare services. The strongest predictor of desire to seek help was apparent social pressure from significant others regarding help seeking (Hailstone et al., 2017.). Analysing 2,511,681 individuals' data from The Health Improvement Network database between 2007 and 2015, Pham et al. (2018) report that people with a South Asian background living in the UK were less likely to receive a dementia diagnosis compared with the White majority population. The All-Party Parliamentary Group's (APPG) report (2013) also highlighted that ethnic minority groups have a low diagnostic or referral rate as the assessment may be too Eurocentric to enable a culturally appropriate diagnosis. Hailstone et al. (2016) suggest that many people from the UK South Asian communities seek help with memory problems due to social pressures from significant others, who have their own beliefs about dementia. Similarly, Lawrence et al. (2008) have reported that UK South Asian caregivers tend to have traditional ideologies. This puts the person with dementia's needs above their own; consequently, caregivers consider that seeking professional help is a form of failure at their caregiving responsibilities (Lawrence et al., 2008). In contrast, Hossain (2017) claims that the family caregivers of Bangladeshi people with dementia view dementia as a medical condition rather than merely considering it part of the normal aging process. Therefore (according to Hussain), the carers benefit from effective interactions with service providers, which helps them prepare themselves for dementia care.

Katbamna et al. (2001) argue that a lack of culturally sensitive dementia services, and health professionals' prejudices against the South Asian community, may make it hard to obtain referrals to secondary services or recommendations to another specialist. Therefore, people often feel the available healthcare services are inappropriate, failing to meet their cultural and faith needs. Consequently, families of people with the condition are reluctant to use the services and instead cope without support (Katbamna et al., 2001; Atcha, 2018).

2.7.2. Knowledge of dementia among the UK's South Asians

Dementia is a complex and challenging condition that can be experienced differently depending on one's age, class, gender, other health conditions, life experiences, and many other social differences (Innes, 2009; Kitwood, 1997). Dementia means different things to different people depending on their social context (McParland et al., 2017). Research has suggested that South Asian people have a lack of knowledge about dementia that often prevents them from seeking dementia help and early diagnosis (Mukadam et al., 2015; Mackenzie, 2006*;* Giebel, 2016; Regan, 2016). Much current literature highlights that many people from the South Asian communities did not hear of the term dementia until they or a relative was diagnosed with it (Hossain & Khan, 2020; Ahmed & Eagle, 2018; Ahmed et al., 2017; Parveen et al., 2018; Mukadam et al., 2015; Jutla, 2013). People who live with dementia and their families often have a presumption that nothing can be done to help them, because of a lack of information about available services or how to access them (Bowes and Wilkinson, 2003; Lawrence et al., 2006; Livingston et al., 2002). Purandare (2007) has concluded that older Indian people have significantly less 'basic knowledge' about dementia. Similarly, conducting a series of focus group interviews with 28 Sikh participants, Uppal (2014) found that this group have poor knowledge of dementia, and they place greater emphasis on physical illnesses than on conditions such as dementia. Likewise, interviewing 96 South Asians aged 58-85 years in a community-based setting, Turner et al. (2005) highlight that South Asian people have less specific knowledge and understanding of the various symptoms, causes, and treatments of dementia. In addition, the knowledge of these communities about dementia is more limited than their counterpart White British communities in the UK (Turner et al., 2005). McClearly et al. (2013) have found that dementia diagnosis usually happens among the South Asian communities after an acute medical problem or hospital admission or due to another health concern taking priority, suggesting a need for increased awareness of dementia signs in the South Asian communities. Zaidi et al. (2018) state that some South Asians believe there is no 'cure' for dementia; thus, people live a better life without a diagnosis. Therefore, the beliefs, attitudes, and awareness about dementia among the public are very significant, as patients' and caregivers' perceptions of symptoms could help in treatment-seeking behaviour and pathways to care, and may also reduce the burden and stress on the caregivers (Zaidi et al., 2018, p.1).

Parveen et al. (2017) have noticed that when participants with dementia of South Asian origin do not find a word to express dementia, then they refer to it as 'memory problems' and they commonly note 'memory loss' and being 'forgetful' as symptoms of dementia. Botsford and Dening, (2014) state that there is no word for dementia in the Urdu, Gujarati, Bangladeshi, Hindi, and Punjabi languages. Likewise, Hossain et al. (2017) have found that there is no synonymous word for 'dementia' in Bangla. However, Bangladeshi people often use several Bengali terms to understand dementia, e.g., *'smoroksoktithakena'* means 'memory loss,' which they use to mean short-term memory loss (Hossain, 2017, p.84). They also use the term '*smoronsoktiharano*,' meaning 'lost memory,' which is generally used for someone who has completely and permanently lost their memory (Hossain, 2017, p.84). Those who are unable temporarily to remember something but who regain their memories later are called '*Mon Bhula*' in the Bangla idiom (Hossain, 2017).

Through interviewing 53 English or Bengali speaking adults (aged 18-83), Mukadam et al. (2015) have found that South Asians and Bangladeshis have little awareness of dementia and other chronic degenerative brain conditions. The eighteen interviewees said that the characteristics of dementia are regarded as part of aging, or a nonpathological deviation from typical aging. Giebel (2016, p.1), suggests that a rather significant proportion of older adults without any consultation with their GPs consider memory problems to be something that is inevitable in old age.

2.7.3. Beliefs about dementia among the UK's South Asians

In Giebel et al. (2015), thirty out of thirty-three older Indian adult participants reported that memory problems are "given by God,". In a mixed-method study, Giebel et al. (2016) noticed differences in the perceptions of South Asians who do and do not consult a general practitioner (GP) about dementia. Using the Bart's Explanatory Model Inventory for Dementia (BEMI-D) among 33 English-, Gujarati-, or Urdu-speaking older South Asians aged 65 or above with memory problems, they identified that those who do not consult a GP are significantly more likely to consider memory problems to be given by God, taking the view that medical intervention is therefore inappropriate. Likewise, by in-depth semi-structured interviews with a large sample (n=53), Mukadam et al. (2015, p.4) show that some of their participants believe that memory problems may be due to spiritual wrongdoing (Mukadam et al., 2015, p.4). It is also noticeable that the majority (60%, 32 persons) of those in that study were from the Bangladeshi community, and 74% were Muslims (Mukadam et al., 2015, p.4). Investigating the importance of understanding a person's religious community, Regan (2016) found that attitudes and beliefs about dementia could serve as barriers to accessing healthcare; in particular, understanding dementia within a religious context can delay help seeking. Regan (2016) also suggests that it is crucial to understand more about the religious context in which people comprehend dementia and for healthcare providers to engage with local communities and religious leaders to work with them to increase support.

A segment of the literature suggests that people in South Asian communities often consider dementia a mental health problem (Moriarty, 2015; Ahmed et al., 2017; Hossain, 2017, p.99; Mukadam et al., 2015, p.7). Atcha (2018, p.167) mentions that almost all of her research participants have reported that the concept of dementia is unfamiliar to South Asians; therefore, a person living with dementia is commonly referred to as having gone "*Pagal*" (insane) or "mad." Moreover, Atcha (2018) explores the finding that many participants view dementia as a *jinn* (spirit) possession, and an individual with dementia is “possessed,” “taken over,” or controlled by external forces. Brar (2012) suggests that many South Asian communities use religion and possession by supernatural powers to explain mental illness or blame the individual with the mental illness. Similarly, McClelland et al. (2014) argue that many people from the Bangladeshi and South Asian population believe that various supernatural forces like *Jinn*, *Bhuta*, or spirits may cause mental illness. In contrast, Atcha (2018) argues that though there is a common perception among many South Asians that individuals with dementia are controlled by external forces like *Jinn*, *Bhuta*, or black magic, they have no control over their behaviour (Atcha, 2018).

2.7.4. Cultural Expectations and the Caregivers’ Burdens

The family remains central in providing care and support for South Asian older people (Victor et al., 2012). From semi-structured interviews with 20 Bangladeshi and Pakistani women and men aged 50 years and over, Victor et al. (2012) found that all participants expressed a clear expectation that their children would care for them in their old age. Similarly, Hossain (2017) found belief in ‘familyism’ was a significant barrier to access to dementia services, particularly for those representing the wider Bangladeshi community's husbands, wives, children, and grandchildren. In a recent study, Herat-Gunaratne et al. (2019) reports a conversation with one of their participants who said that there is an expectation now from parents that their children could have been entirely selfish or absorbed in the Western way of life, as parents have chosen to raise them in this country, but they (parents) made a conscious decision not to do that, and they invested all their life savings in children. Therefore, now it is over to the children to pay the favour back.

Adamson & Donovan (2005) report that living with and caring for ill husbands is a core teaching and established practice in Hinduism. Similarly, Qadir et al. (2013) reveal that Pakistani Muslim family carers fear retribution from Allah for not providing care. Research shows that policymakers have assumed that South Asian families have an extensive extended network of family members who 'look after their own’ (All-Party

Parliamentary Group on Dementia, 2013). However, Parveen et al. (2017; 2014) argue that a strong stigma is attached to dementia amongst the South Asian communities, meaning that people conceal it from the wider family, and thus wider family networks are not supportive. In some cases, they feel the stress caused by family members to have triggered dementia. Parveen and Oyebode (2018, p.3) explain further that this may be due to health care professionals making assumptions about families' looking after their own and not requiring services or feeling they may offend by even mentioning services. Similarly, Herat-Gunaratne et al. (2019) cited in Parveen and Oyebode, 2018), pointed out that previous assumptions that minority ethnic communities require less health care services due to their cultural values are now being challenged. However, although many minority ethnic carers feel culturally obliged to provide care, this does not mean that they feel eager or well prepared to do so. In addition, interviewees' narratives describe a high carer’s burden that is only partly alleviated by support from formal and informal networks, and employment roles and relationships are sacrificed due to the primacy of the duty to care (Herat-Gunaratne, et al., 2019).

2.7.5. Experiences of Dementia Service Users: Gaps in Services

Parveen et al. (2017) indicate that some BAME families report that health care professionals are not offering them adequate support. Participants in that study perceived a lack of awareness and cultural sensitivity from services, particularly GPs (Parveen et al., 2017). Many perceived that their GPs lacked dementia knowledge and were too busy to provide people with care and support (Parveen et al., 2017). All participants felt GPs require more training as first contact points (Parveen et al., 2017). They also suggest that more support groups should be set up for carers, and services should be based on the community's cultural needs and provide language support (Parveen et al., 2017). Furthermore, services should seek to maintain high standards of confidentiality when employing translators (Parveen et al., 2017). Unlike Adamson (2001), Atcha (2013) states that it appears that the services often do not meet these people’s needs. The lack of linguistically or culturally appropriate services can result in further delays or underuse of dementia services. A segment of the literature (including Giebel, 2016; Regan, 2016; Seabrook & Milne, 2004) has explored that dementia health and care services are not providing culturally informed or religiously appropriate services, due to lack of knowledge among service providers and managers about the lifestyles, health, and religious and cultural needs of BAME and South Asian Communities. Interviewing 11 caregivers and conducting four case studies with South Asian people with dementia in Scotland, Bowes and Wilkinson (2003) have explored overwhelmingly negative experiences of dementia and relevant services. From the interviews with health professionals, the authors advocate for a need to develop and promote culturally sensitive services. Similarly, Jutlla (2015) calls for culturally appropriate services and person-centred dementia care. Likewise, interviewing 9 South Asians aged 67-87 years (5 male and 4 female), Lawrence et al. (2011) suggest that the development of culturally sensitive approaches to care should promote roles, relationships, and activities that the patient values.

BAME carers provide proportionately more care than White British carers do, and this increases their risk of ill health, loss of paid employment, and social exclusion (Carers UK, 2011). Pakistani and Bangladeshi carers experience higher isolation and additional barriers, including cultural barriers, stereotypes, and language issues, which can increase their chances of poorer health, poverty, and social exclusion (Carers UK, 2011).

Most south Asian people feel that care homes are not suitable for their requirements (Mohammed, 2017, p.21). It is embedded in the South Asian Community to take care of family members for longer than in the general population; usually this is what most people with dementia want to be done for as long as possible (p.21). In South Asian families, although the son or husband may be the registered carer, in most cases, the daughters-in-law are the hidden carers. However, at a particular stage in the dementia condition, caring responsibilities may put too much of a strain on the family carer(s); it is then that people with dementia are usually admitted to a care home (Mohammed, 2017, p.21).

From a systematic review, Katbamna et al. (2001) conclude that health professionals' prejudices against the South Asian community may make it hard to obtain referrals to secondary services or recommendations to another specialist. People often feel the available healthcare services are inappropriate, failing to meet their cultural and faith needs. Hence, families are reluctant to use the available services and try to manage without support (Katbamna et al., 2001).

In a qualitative meta-synthesis, reviewing twenty-eight studies, Kenning et al. (2017) report that dementia diagnosis amongst the BAME communities is problematic because of the diagnostic tools and skills of primary care staff and due in part to cultural beliefs.

Testing the Mini-Mental State Examination (MMSE) in a population of South Asians, including Gujarati and Pakistani participants, Rait et al. (2000) state that there are no definitive guidelines for interpreting questionnaires of the MMSE. The authors find high levels of sensitivity and specificity for the MMSE, but with a lower cut-off score for identifying mild dementia in the South Asian group. Findings indicate that the Gujarati version of the MMSE may be effective at identifying dementia, where the diagnosis is precise and symptoms are moderate to severe. However, it may be less useful in identifying dementia where symptoms are mild or diagnosis is uncertain.

To explain the role of an Asian link nurse for Punjabi-speaking people of Asian origin in a dementia service in Wolverhampton, Kaur et al. (2010) report success in providing appropriate and culturally sensitive service information regarding healthcare professionals, voluntary services, and South Asian people with dementia. Similarly, Seabrooke and Milne (2009) discuss the Dementia Collaborative Project in North West Kent. They report an increase in referrals to a specialist clinic for memory assessments, some of which were for South Asian patients, and an increase in health professionals’ knowledge of memory problems in South Asians.

Echoing Giebel et al. (2015), Atcha (2018) argues for a global and national appeal to enhance similar dementia services for minority groups, including the South Asian population, to guarantee access to services and offer the same potential health benefits for everyone. The UK government has recommended particular memory services for ethnic groups to ensure ethnically targeted and appropriate services. Research highlights that it is difficult for people with dementia or carers who cannot speak English fluently to communicate with health professionals, go through a proper diagnosis, understand the service availability, and access the memory clinic or other adequate and appropriate support (Botsford & Dening, 2015). It is also very challenging and distressing for them to be admitted to hospital (Botsford & Dening, 2015). Likewise, several stakeholders in Ahmed et al. (2017) suggest that language barriers, cultural factors, and stigma surrounding dementia could prevent people from BAME communities from coming forward and accessing services.

2.8. Discussion of the Other Literature:

The scoping review has provided valuable insights to help advance the research questions (see p.29-46). During this review, I also found links to other papers that provide a deeper understanding of the Bangladeshi community's beliefs and cultural understanding about dementia and the roots of such beliefs. As these papers are not directly about dementia in the UK Bangladeshi community, I did not include them in the scoping review literature list. However, I will discuss the findings of these papers (through a traditional literature review) in this section to have a more profound knowledge of the beliefs of the above minority group.

Existing literature suggest that the Bangladeshi and South Asian communities have little knowledge and understanding of dementia. Many of them have incorrect beliefs and wrong perceptions about dementia, such as dementia being madness or possession by supernatural entities, or that it is a punishment from God for people's past sins. Consequently, a person with the condition may be socially isolated and avoid seeking necessary help from the fear that other people may not like them.

Previous research has found that many of South Asian origin, including the Bangladeshi community, seek spiritual healing rather than modern bio-medical treatments because they believe in supernatural forces (Rozario, 2009; Dein et al., 2008, p.37; Hussain & Cochrane, 2004). Dein et al. (2008, p.37) suggest that many people of South Asian heritage are persistent in their demand for traditional healers to resolve treatment issues associated with spirit possession and the evil eye. In a study of Muslims living in Leicester, 80% believed in *Jinn,* 74% in the evil eye, and 65% in black magic, with a majority believing that *Jinn* and the evil eye could cause mental illness (Khalifa et al.*,* 2011). Similarly, interviewing 40 Bangladeshis living in East London, researchers found that mental illness was commonly attributed to *Jinn* possession, particularly among the older and less educated individuals who would rather go to traditional healers instead of mental health professionals (Dein et al., 2008).

Rozario (2009, p.179) has reported that Bangladeshi Muslim families often categorise all illnesses into two types: either '*Daktari*' (Bio-medical) in nature, or *'Upri'* caused by *Jinns* or spirits*,* where medical doctors can treat medical problems and the Imams or other spiritual practitioners can generally treat '*Upri*' issues. In some cases, the Bangladeshi families navigated between medical and religious healing, considering remaining an excellent Muslim to mean accepting whatever Allah decided for them (Rozario, 2009*,* p177). Likewise, Hussain & Cochrane (2004) found that religious or spiritual healers, who offer culture-specific approaches to mental illness and treatment, are an established therapy element within the Asian communities.

It is common among the Bangladeshi community to consult several types of healers simultaneously, such as *Hakim* (a folk healer who uses traditional medicine from trees), *Kabiraz (*a *Jinn* exorcism and black magic specialist)*,* and *Mullahs* (Imams) (Dein et al., 2008, p.42). In rural Bangladesh, '*Upri*' also refers to *'Bhuta* (i.e., evil spirit or ghost), or '*Kharap Batash*' (bad air) (Dein et al., 2008*,* p.179). It is held that illness caused by *'Bhut'*/'*Upri*' or '*Kharap Batash*' cannot be cured by medical doctors but must be dealt with by traditional folk healers or Imams (religious leaders) (Dein et al., 2008*,* p.179). This sort of cultural belief may on the one hand increase the demand for spiritual healers. On the other hand, people with dementia may not want to go to seek the most scientific medical treatments or services for dementia.

Dein et al. (2008) suggest that spirit possession and its close link with mental illnesses are believed in all major religions, including Hinduism, Buddhism, Judaism, and Islam. Khalifa and Hardie (2005) argue that there is a widely accepted belief amongst Muslims that *Jinn* can cause physical and mental harm (Khalifa & Hardie, 2005), and when they possess any individual, they control the person (Dein, 1997; Littlewood, 2004). Some Muslims also believe in black magic and the evil eye (Khalifa et al., 2011). On the other hand, Padayachee et al. (2014) argue that belief in possession by '*Bhuta*' (a ghost or an earth-bound spirit) is an integral part of Hindu faith, which is all about the journey of a soul and its '*karma"* (Padayachee et al., 2014, p.4; Betty, 2005). *'Karma'* refers to the law of moral causality necessary to control imperfection (Padayachee et al., 2014, p.4). Research suggests that the Indian subcontinent has approximately 5000 years of history and cultural heritage, whereby Hindu culture has a significant influence all over South Asia (Chandra, 2007). Although Bangladesh has existed as an independent country only since 1971, historically, it was part of India in the ancient past (Kalra, 2000). In 1947, when British colonial rule ended, the province of Bengal (of India) was partitioned into East Bengal and West Bengal.

East Bengal was renamed again in 1947 and later became an independent country in 1971 called Bangladesh (Chandra, 2007). From 2800 BC to 1900 BC, the period is called the Indus Valley Civilization Period (Chandra, 2017), where evidence suggests that many people believed in some major gods and goddesses (Chandra, 2007). The Vedic Period (c. 1750-500 BCE) is named for the oldest scriptures in Hinduism, composed during this period (Chandra, 2007). Buddhism flourished from the 3rd century as the Mauryan emperors extended their influence in Bengal (Chandra, 2007). However, in 321 BC, Chandra Gupta Morjo established the Gupta dynasty in India (in Northern Bengal) in the period of Ashak (269-232 BC), when Bogra Mahasthan-Ghar and the Pundra Nagar of modern-day Bangladesh were their capitals (Chandra, 2007). The Gupta Kings re-established Hinduism in India from the early 4th to the late 6th century BCE. In the 8th–12th century era, the Pala dynasty was established under 'Chandra' in the east. By the end of the 11th century, the Senas, a very strong fanatical group of Hindus, had gained control of a powerful part of Bengal and revived conventional Hinduism (Chandra, 2007). Muslims ruled the whole of India during the Mughal Empire (16th–18th centuries), while in Eastern Bengal and much of the northern part of the Indian subcontinent, Islam became the religion of the majority (Chandra, 2007). Now, in contemporary Bangladesh, over 90% of the total population is Muslim (Bangladesh Bureau of Statistics, 2004). Research highlights that despite the enormous majority of Muslims in Bangladesh, because of their minimal general education and lack of Islamic knowledge, a group of Muslims in Bangladesh follow this Hindu culture and believe in *Bhuta (*Deinin et al.*,* (2008). Some Muslim groups fervently believe in miracles and supernatural entities that are heavily influenced by Hindu traditions such as '*puja,'* 'the veneration of Hindu gods' e.g. '*Lakshmi',* and the use of drama and dancing, which are all elements in local Hindu rites (Dein et al*.,* 2008, p.35). Because of this, people with dementia may go to spiritual healers and religious leaders expecting that any miracle can happen for them and they will be cured soon, which can prevent them from seeking bio-medical treatment.

Padela et al. (2012) suggest that religion is the central resource for healing in South Asian communities. Abu-Ras et al. (2008) comment that traditional spiritual leaders or *Imams* are often seen as indirect agents of God's will and facilitators of the healing process. Dein et al. (2008, p.44) have found that the members of the Bangladeshi community often consult Imams as they consider their problems to be related to *jinn*, and many people will go to the doctor or a psychiatrist based on an Imam's advice. People follow the Imam's advice, even though these Imams lack knowledge and expertise within this area (Ciftci et al., 2012). Many participants in Atcha's (2018) study have commented that religion overrides every other type of treatment. It is apparent that Imams are a preferred source for advice as shown; hence, people will go to religious scholars/Imams rather than a bio-medical doctor. The Imam (religious preacher) is seen as an authority figure within the South Asian community (Atcha, 2018). However, Abu-Ras et al. (2008) argue that because of the authoritative power the Imams possess, the Imam can play a beneficial role in changing perceptions and could challenge the stigma within the South Asian community.

Cliftci et al. (2013, p.26) mention that although religious leaders are often the first-line mental health care providers to Muslims, they are not trained to be a referral agent into conventional medicine, which usually leaves the patient receiving inadequate psychiatric assessments or treatments (Budman, Lipson, & Meleis, 1992). Similarly, Dein et al. (2008, p.41) mention that some of their participants reported that a clear majority of Imams do not have the correct knowledge of Islam; therefore, they often give people wrong advice, and charge money for religious services that are unacceptable to charge for in Islam. At an Imams' meeting in the East London Mosque in 2003, some local Imams commented that members of the local Bangladeshi community frequently sought help from traditional healers at often massive cost to themselves (Dein et al., 2008*,* p.43). Rozario (2009) highlights that most of the Imams were trained in *madrasah* (Islamic colleges) in Bangladesh and had little Western-standard education and little or no understanding of genetic disorders in bio-medical terms (Rozario, 2009, p.183).

Amri and Bemak (2012) state that under the Asians' religious beliefs, a person with mental illness is perceived as "crazy" or having lost faith in God. Interviewing Sikh, Hindu, and Muslim participants, Lauber and Rossler (2007) found that they believe mental illnesses are caused by God, black magic, and the evil eye (*nazar*), which is jealousy from another person or spirits. Similarly, interviewing 40 Bangladeshis from East London, Dein et al*.* (2008) found that many Bangladeshis believe mental illness can be generally attributed to *Jinn* possession*.* The beliefs regarding spirit possession and its associations with mental illnesses are not only found in Islam; rather, they are held in all dominant religions, including Hinduism (Halliburton, 2005), Buddhism (Gaw, 1998), and Judaism (Greenberg & Witztum, 2001).

Many South Asians believe that magic or witchcraft cause mental illness (Ton & Lim, 2006, p.39). India is known as one of the birthplaces of magic (Templeman, 2002). Witchcraft has a long history recorded in an ancient Hindu scripture, the 'Atharva Vedas', in the second millennium BCE (Templeman, 2002). Belief in witchcraft is a prevalent occurrence in many South Asian communities. For instance, the Indian National Crime Records Bureau reported that 2,097 people were murdered from 2000 to 2012 in the name of witch-hunting (Schaffer, 2014). Witchcraft may be defined as the deliberate use of magic or enchantment, typically harming another (Padayachee & Laher, 2014, p.4; Ally & Laher, 2008). The conceptual framework adopted by this study has been illustrated comprehensively in this chapter and will also guide the researcher in the data analysis.

The literature review has also highlighted some socio-cultural factors that may prevent them from accessing dementia health and care services. For instance, stigma is one of the critical factors for many South Asian communities that may negatively impact people with dementia in these communities and delay their help seeking. Religion and spirituality may often fuel stigma about dementia; therefore, it is essential to understand their impacts and influences in the context of dementia.

Research suggests a similarity between the impact of dementia and the consequences of mental illnesses in the South Asian and Bangladeshi communities. For example, the previous studies have highlighted that Bangladeshis are less likely to interact with their general practitioners about their mental health issues and, therefore, are more likely to be disadvantaged in obtaining appropriate healthcare (Uddin, 2017). Brar (2012) argues that culture, family honour, and religion usually dominate decision making; therefore, mental illnesses remain within the family. Otherwise, if this were known to the community, their family would face scrutiny; and they would be worried as other people might think of their family negatively (Uddin, 2017). Notably, South Asian communities are very close-knit, and most people are related to or know each other. So, this may lead to fear or embarrassment about being the subject of gossip or damaged pride at asking for help with caring for a family member with dementia (Uddin, 2017). There is a tendency for the close family to reduce the amount of contact the person might have with the extended family or broader community to protect the wider family's reputation, and party and wedding invitations, for instance, may be declined (Uddin, 2017). A similar consequence has been reported by a series of previous papers (Atcha, 2018; Ahmed et al., 2017; Parveen et al., 2017). For example, Atcha (2018) argues that stigmatisation of dementia in the South Asian community is a serious problem that results in families becoming fearful of receiving a diagnosis of dementia because they are afraid to disclose it in the community.

According to Moses (2014), acknowledging a mental illness can endanger an individual's marriage prospects, especially for women, maintaining internalised stigma. Likewise, Tabassum et al. (2000) have looked at attitudes towards mental health issues among Pakistani families and identified that none of the participants would consider a spouse with a mental illness. Similarly, Van-Brakel and Miranda-Galarza (2014) have reported that families examine the potential bride or groom and their families for any unwanted characteristics, such as mental illness. Thus, this

inhibits women from pursuing help from therapists, to avoid the negative consequences, which then causes distress to their well-being (Ciftci et al., 2012).
On the other hand, a similar trend has been reported in the previous literature concerning people with dementia. In South Asian communities, it is common for the families of the bride and groom to look into each other's backgrounds to ensure their child is marrying into a good family. Consequently, any marriage prospects may also be damaged because of the perception that dementia is incurable and can be passed on through the generations via genes, which is a severe threat to marriage proposals in a community where arranged marriages are common (Mohammad, 2010).

Kishore et al. (2011) state that mental illness is viewed as a taboo subject that can disrupt one's *izzat* (honour) in the South Asian community; therefore, labels are avoided to prevent negative consequences. Likewise, Ahmed et al. (2017) suggest that in many South Asian and BAME communities, dementia is considered a taboo subject. Regarding mental health, label avoidance is expected within the South Asian community along with repression of stigmatising features to uphold a perfect image to the public (Chaudhry, 2016). Similarly, beliefs and views on dementia cause South Asian people with dementia and their family members to conceal dementia in the community and make them unwilling to disclose the illness to others (Atcha, 2018).

Amri and Bemak (2012) explain that cultures from Bangladesh and Pakistan perceive mental health problems as shameful and involving loss of face. The association between mental illness and the feeling of shame can act as a deterrent to treatment to avoid being socially excluded (Uddin, 2017). Similarly, Parveen et al. (2017) say that South Asian participants in their research discussed the "embarrassment" associated with the forgetfulness of the person living with dementia. In addition, these minority ethnic groups also addressed the shame and guilt associated with dementia, perceiving the condition as "damaging to self-respect." However, it is not clear whether these emotional representations also extended to family members. (Details on stigma and concealment are given in subsection 2.6.6.4. (Factors Associated with Dementia Stigma: Consequences of Stigma; p.63) and 2.9.6.5. (Dementia Stigma among the South Asian communities, p.66).

The literature review provides the wider context of hearing the voices of people living with dementia and the absence within this growing ‘movement’ of representatives from the Bangladeshi community. Evidence suggests that people with dementia from this minority ethnic group have never had the chance to participate in any dementia research; therefore, their voices remain unheard. Involvement enables people with dementia to assist in identifying research priorities and the nature of the study to be undertaken, influence the direction and conduct of research, have their voices heard, and in so doing, contribute towards the quality, relevance, and ethical conduct of research (Gove et al., 2018). Murphy et al. (2015) put forth the view that those wanting to be more actively involved in research, groups, and forums have been integral in allowing people with dementia to express their views, aid in developing services, and ultimately challenge attitudes towards dementia.

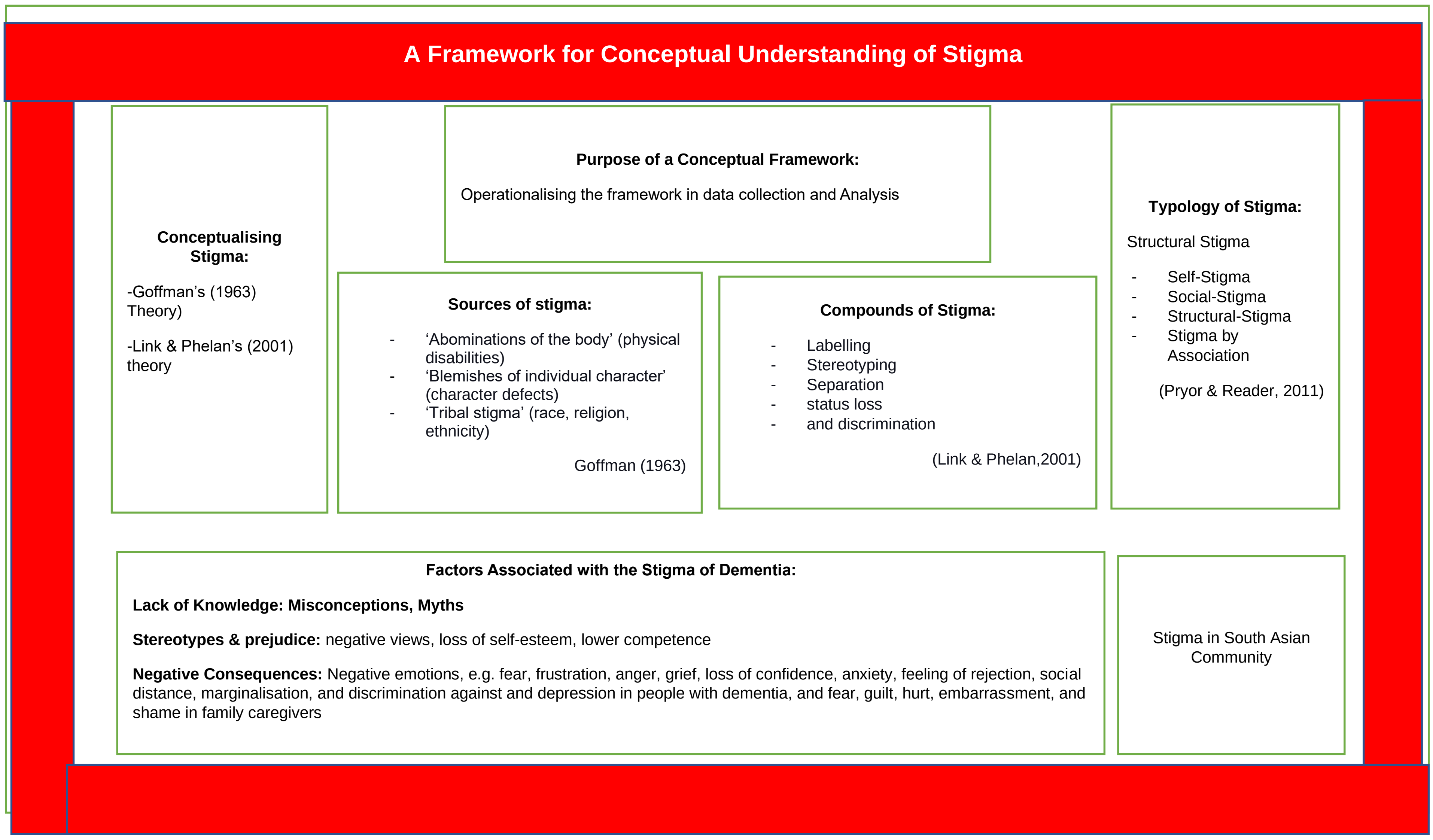
2.9. A Conceptual Framework for the Study of Understanding Stigma attached to Dementia

This section discusses the development of a conceptual framework used in this study to explore whether or not dementia is stigmatised in the Bangladeshi community. Much previous literature suggests that stigma is a serious and common problem for people with dementia in the UK’s South Asian communities in general (Herat-Gunaratne, 2019; Atcha, 2018; Parveen et al., 2017). However, we know little if dementia is stigmatised in the UK Bangladeshi community. Therefore, it is worth exploring the phenomenon of stigma of dementia in this minority ethnic group and how it impacts on peoples’ social lives, help seeking, diagnosis, and access to dementia services.

The figure on the next page provides a comprehensive conceptual framework summarising the various aspects of stigma related to dementia. The framework guides us to the following four analytical questions:

a. Are there core components of stigma, i.e., labelling, stereotyping, separation, status loss, and discrimination, that happen in the Bangladeshi community because of dementia?
b. Do people with dementia experience any of these four types of stigma, i.e., individual, societal, or institutional stigma?
c. What do we know about the stigma of dementia in South Asian communities?

Figure7**:** *An overview of a conceptual understanding of stigma about dementia is presented below (in the next page):*



A Framework for Conceptual Understanding of Stigma

Conceptualising Stigma:

-Goffman's (1963) Theory)

-Link & Phelan's (2001) theory

Purpose of a Conceptual Framework:

Operationalising the framework in data collection and Analysis

Sources of stigma:

- 'Abominations of the body' (physical disabilities)
- 'Blemishes of individual character' (character defects)
- 'Tribal stigma' (race, religion, ethnicity)

Goffman (1963)

Compounds of Stigma:

- Labelling
- Stereotyping
- Separation
- status loss
- and discrimination

(Link & Phelan,2001)

Typology of Stigma:

Structural Stigma

- Self-Stigma
- Social-Stigma
- Structural-Stigma
- Stigma by Association

(Pryor & Reader, 2011)

Factors Associated with the Stigma of Dementia:

Lack of Knowledge: Misconceptions, Myths

Stereotypes & prejudice: negative views, loss of self-esteem, lower competence

Negative Consequences: Negative emotions, e.g. fear, frustration, anger, grief, loss of confidence, anxiety, feeling of rejection, social distance, marginalisation, and discrimination against and depression in people with dementia, and fear, guilt, hurt, embarrassment, and shame in family caregivers

Stigma in South Asian Community

2.9.1. The purpose of using a Conceptual Framework for this thesis

This conceptual framework guided me throughout this research journey, including participant recruitment, data collection, and analysis. My reading for the literature review has driven me to develop a conceptual framework to study understanding of "stigma" before data collection, as there is evidence to suggest that dementia is considered a highly stigmatised condition (Kim et al., 2019). Particularly, the stigma of dementia is a severe problem in many black and minority ethnic communities (Parveen, 2017) (see details in Chapter 2; sub-section 2.9.6.5. Dementia Stigma among the South Asian communities; p.84). Liehr & Smith (1999) suggest that a conceptual framework presents an integrated approach to a problem under study. It is linked with the concepts, empirical research, and essential theories used in promoting and systematising the knowledge espoused by the researcher (Peshkin, 1993). It assists the researcher in identifying and constructing their worldview on the phenomenon to be investigated (Grant & Osanloo, 2014). Therefore, it guides a researcher's choice of research design and data analysis plan. The conceptual framework also shows the kind of data to be accumulated for a particular study (Lester, 2005). Figure 6 illustrates an overview of the chapter and highlights a conceptual understanding of stigma as investigated in this thesis.

2.9.2. Conceptualisation of Stigma

"Stigma is not a self-evident phenomenon but, like all concepts, has a history" (Tyler & Slater, 2018). It is a Greek word that metaphorically describes shame or taboo, where a person is reduced from 'normal' to someone who is a person with whom something is wrong (Innes, 2009, p.73). Initially, it referred to the brand or scar burned or cut into the body, indicating that the person who bore this was a slave, a criminal, or a traitor - therefore, such a blemished, ritually polluted person needed to be avoided, especially in public places (Goffman, 1963, p.11). However, stigma is not merely a physical mark in today's society but an attribute that results in widespread social disapproval. It is a discrediting social phenomenon named ‘spoiled identity’ in Goffman’s terms. Erving Goffman explained that the term ‘stigma’ refers to a profoundly discrediting attribute (Goffman, 1963, p.13). In other words, any quality that an individual may possess, if it negates someone socially, then this is stigma; “the stigmatised individual will be disqualified from full social acceptance” (Goffman, 1963, p.9). In further elaborating on the stigma definition, Goffman suggests a discrepancy between a person’s virtual identity and actual social identity (Goffman, 1963, p.13). However, the World Health Organisation describes stigma as a mark of shame, disgrace, or disapproval, which results in someone being rejected, discriminated against, and excluded from taking part in different areas of society (WHO, 2001, p.16).

Link and Phelan (2001) redefine stigma as the co-occurrence of its components, i.e., labelling, stereotyping, separation, status loss, and discrimination. Link & Phelan’s (2001) conceptualisation of stigma suggests that it exists when several interrelated components converge. The components include:

1. Noting and labelling human differences occurs
2. Dominant cultural beliefs link labelled persons to undesirable characteristics (negative stereotypes)
3. Labelled persons are categorised to achieve separation of “us” from “them”
4. Stigmatised persons lose status and experience discrimination, leading to unequal outcomes (Link & Phelan, 2001).

Jorm & Oh (2009, p.183) list components of stigma as ‘personal stigma,’ stigma perceived in others, internalised self-stigma, perceptions of mental disorders as due to weakness, reluctance to disclose to others, perceived dangerousness, desire for social control, and goodwill.

In British history, stigma was initially linked with Christianity (Mackenzie, 2006, p.233; Whitehead et al., 2001), then slavery (Goffman, 1963), and, latterly, poverty (Spicker, 1984). In the 16th and 17th centuries, the stigmatised poor were identified by the compulsory wearing of a badge of shame (Spicker, 1984). Link & Phelan (2001, p.363) state that the concept of stigma has applied to scores of circumstances ranging from urinary incontinence (Sheldon & Caldwell 1994) and exotic dancing (Lewis, 1998) to leprosy (Opala & Boillot, 1996), cancer (Fife & Wright, 2000), and mental illness (Angermeyer & Matschinger 1994, Corrigan & Penn, 1999, Phelan et al., 2000).

According to Goffman, stigmatisation arises when there is a discrepancy between the virtual social identity and individuals' actual attributes (Goffman, 1963). Stigma in his theory is developed and maintained through the process of social interaction: Goffman looks at when a particular group or community establishes how to live and what is classified as normal behaviour through social interactions, referring to this as a "virtual social identity" (Goffman, 1963). Goffman (1963) notes that there are three types of people in a community. First, those who bear the stigma of anything and have thus spoiled their social identity; because of this, Goffman categorises them as 'stigmatised' or 'deviant.' Secondly, those who do not carry any stigma are called normal (Goffman, 1963, p.15). Those among the normal whose situation has made them intimately aware of the secret life of the stigmatised individuals and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the society, are called 'wise' (Goffman, 1963, p.41). Goffman remarked that, by definition, the person with a stigma is not quite human (Goffman, 1963, p.15), so they will be stereotyped and discriminated against by society and disqualified from enjoying equal opportunities. In the context of dementia, people with the condition might be considered deviant or stigmatised, people whose identity needs to be managed during their social interactions with the normal (who do not have dementia). However, the central part of Goffman's stigma theory is that it is not the fault of the stigmatised; instead, it is the unjust actions of the society or some individuals therein who do the stigmatising through their social interactions. Goffman (1963) emphasises the importance of the social context when defining what is classed as a deviant condition. In addition, Goffman also acknowledges that structural power has a role to play when classifying individuals with mental illness as deviant. Goffman (1963) asserts that when people with a mental illness (a non-visible stigma) understand the social viewpoint (cultural understanding) of what it might be like to live with mental illness within a community, they and their family members will be afraid to disclose their disease or diagnosis to the community. This fear is rooted in fear of losing status (going from "normal" to "discredited" (Goffman, 1963, p.32); Goffman describes how “discretisation” (“othering”) by the individual’s society or community results in the individual forming a new identity (i.e., as a person with mental illness).

Echoing Parker and Aggleton (2003), Tyler & Slater (2018) claim that Goffman (1963) was mainly interested in micro-level interactions, especially how individuals present themselves to others during their social interactions and manage their spoiled identity. His stigma theory is very much individual-focused and micro-level-based. Still, social and political issues such as “how individuals, communities use stigma and the state to produce and reproduce social inequality – these questions are frequently missing” (Tyler & Slater, 2018, p.721). Goffman (1963) mainly emphasises the correction and management of the spoiled identity of stigmatised individuals. Kusow (2004) claims that Goffman’s theory of stigma is outdated as society has changed. In contrast, Link and Phelan (2001) argue that Goffman’s stigma concept is still relevant today.

Drawing from Goffman (1963) originally, but adding a broader concern for power operation in society, Link and Phelan (2001) have developed a “conceptualisation of stigma” and further indicate that for stigmatisation to occur, power must be exercised (Link & Phelan, 2001, p.363). Link & Phelan (2001) also stated that stigmatisation negatively impacts on access to social, economic, and political power. It allows the identification of difference, the construction of stereotypes, the separation of labelled individuals into diverse groups, and the complete execution of disapproval, rejection, exclusion, and discrimination (Link & Phelan, 2001, p.367). Labelling develops from a societal selection process to determine which differences matter in society (Link and Phelan, 2001). This labelling and stereotyping process creates social divisions such as ‘them’ and ‘us’ (Link & Phelan, 2001).

In considering the impact of labelling and stigma of mental health, Link & Phelan (2001) suggest that long before a person becomes mentally ill, they will have internalised ideas and beliefs related to what people think of mentally ill people. In general, these are negative (Link & Phelan, 2001). They also argue that when a person becomes mentally ill, these beliefs now link directly to how others may regard them; this translates into an expectation of rejection, impacting their ability to interact with others and increasing the chances of rejection (Atcha, 2018). In terms of dementia, it is closely linked to Sabat’s (2001) work on presentation and maintenance of self. People with dementia, or, indeed, those who may live with dementia in the future, are already very familiar with the negative discourse surrounding this ‘disease’ (Atcha, 2018).

Drawing on Bourdieu (1987; 1990), Link and Phelan (2001) develop further the concept of stigma power as they believe that stigma is a form of power that society uses to achieve the aims of stigmatisers, such as the exploitation, control, or exclusion of others. Link & Phelan argue that when people are interested in keeping other people down, in, or away, they use stigma as a resource (Link & Phelan, 2001). For example, people with dementia are often prevented by stigma from acknowledging their symptoms and seeking the assistance they need for the best possible quality of life. They feel embarrassed or incompetent (Rahman S., 2015, p.52). According to Link (2004), stigma is not a discrete event; instead, it is a process created by societal, economic, and political power. For instance, people with mental health issues may lose their right to vote. Das et al. (2001) and Corrigan et al. (2004) suggest that power rests in the state’s authority, which can stigmatise communities or groups. This power can lead people with dementia to social isolation, despite their care needs (Lion et al., 2015, p.226; Rahman, 2015, p52; Link and Phelan, 2001). Lion et al. (2015) suggest that stigma affects the person with dementia and their family, their friends, and health professionals (Lion et al., 2015, p.226).

Link et al. (2004) describe the multi-faceted aspects of stigma: the person with a condition is labelled, and negative stereotypical views are attributed to that person. Perceived separation – isolation from the elements of modern life – then occurs (“normal”/healthy people cognitively detach from people with a condition, viewing them as different: “them and us” (Link et al., 2004, p.149) – which informs the emotional reaction toward people with that condition. Individuals with a particular disorder are thus negatively labelled, experience a loss of community status, and are likely to experience an unequal outcome due to community-level stigma and institutional-level stigma. Institutional-level stigma (Link and Phelan, 2001) suggests that power plays a role in creating stigma.

Rothman (1971) emphasises that structural power can influence the stigmatisation of individuals with mental illness. The author suggests that, historically, treatment facilities for mental sickness tended to be in an isolated setting, away from other people, resulting in a stereotypical stigmatising view toward people with mental illness, implying that they pose a risk (Atcha, 2018). Many people perceive them as insignificant individuals who cannot benefit society. Das et al. (2001) and Corrigan et al. (2004) further argue, in relation to power resting in the state's authority, which can stigmatise particular communities or groups, that it is noticeable that the Immigration Act 2002 and the Equality Act 2010 (introduced to prevent discrimination against a person on the grounds of race or disability) have reduced the impact of the power to stigmatise individuals and their social identity.

Link and Phelan (2001) have begun to develop a supplementary account of how stigma functions as a form of power. Jessop (2009) identifies a need to develop a more prosperous and fuller understanding of stigma as a 'cultural and political economy.' Tyler & Slater (2018) argue that the conceptual understanding of stigma inherited from Goffman, along with the use of micro-sociological and psychological research methods in stigma research, often side-lines questions about where stigma is produced, by whom, and for what purposes. Parker and Aggleton (2006, p.17) comment that in Goffman's (1963) stigma theory, social and political questions are frequently missing, such as 'how individuals, communities and the state use stigma to produce and reproduce social inequality (Parker and Aggleton, 2006, p.17).

Goffman (1963) identifies the following three primary sources of stigma:

(1) 'Abominations of the body' (physical disabilities), e.g., people who are deaf, disabled, and blind; people with cross-eyes, harelip/cleft lip, and other physical deformities;

(2) 'Blemishes of individual character' (character defects), e.g., people with bipolar disorder, OCD, mental disorders, addiction, LGBT, suicide attempts, alcoholism, radical political behaviour/extremism; and

(3) 'Tribal stigma' (race, religion, ethnicity), e.g., Rohingya, etc. (Goffman, 1963, p.14). As my research participants are from one specific minority ethnic group, it is worth

exploring whether people with dementia or their caregivers face any societal stigma, racism, or discrimination due to their colour, race, or immigrant status.

2.9.3. Typology of Stigma

Link & Phelan (2001) suggest three types of discrimination grounded on stigma: institutional or structural, individual, and self-discriminatory. Structural discrimination can be seen in policy and structural practice, allocation of financial resources, such as research funding, and interpretation and administration of law (Link & Phelan, 2001). However, they did not include stigma by association in their model. In contrast, Pryor & Reader (2011) articulate a new conceptual model of stigma building on previous theories (Corrigan, 2004; Herek, 2007) and describe a scheme where there are four types of stigma, i.e., structural stigma, public stigma, stigma by association, and self-stigma (Boss et al., 2013, p.2). My thesis will explore these four aspects of stigma, drawing on Pryor & Reader (2011) as their model is more comprehensive than Link & Phelan’s model.

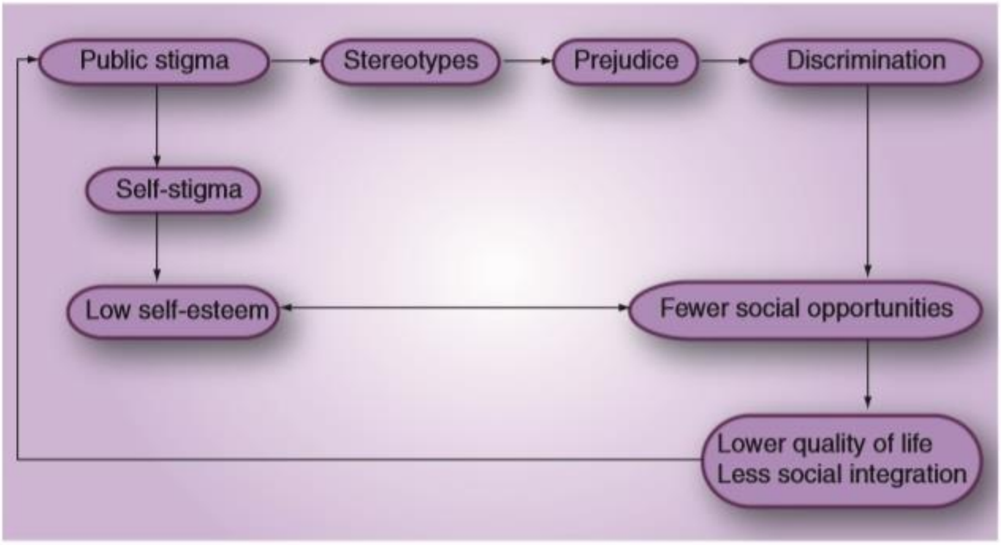
Structural stigma refers to how communal ideologies and institutions spread or aggravate a stigmatised status (Corrigan & Lam, 2007). Hatzenbuehler & Link (2014) define structural stigma as the societal-level condition, cultural norms, and institutional practices that constrain stigmatised populations' opportunities, resources, and well-being (Hatzenbuehler & Link 2014, p.2). Interpersonal discrimination occurs within the broader context of structural stigma, whereby it is more likely to happen in the context of high levels of structural stigma (Hatzenbuehler & Link 2014). It may contribute to or interact with interpersonal stigma and operate independently of interpersonal stigma (Link & Phelan, 2001; Livingston, 2013). Schulze (2007) claims that it is not only the ordinary public that produces stigma but also some medical professionals, who often share their stigmatised attitudes towards dementia. Mukadam & Livingston (2012, p.380) suggest that early dementia diagnosis would be more likely if all medical professionals were more willing to consider and make the diagnosis. However, many primary care professionals in the UK are reluctant to do so because of its stigma. Koch & Iliffe (2010) have found from a systematic literature review that stigma affects GPs' willingness to make a diagnosis. They assume that people with the condition or their family members would not want to hear a dementia diagnosis until the symptoms were so severe that it was inevitable (Koch & Iliffe, 2010). Hermann et al. (2014) highlights that health care providers and the public might hold stigmatising attitudes toward persons with dementia that may be particularly harsh when racial and minority ethnic groups are involved.

Social stigma/'Public stigma' refers to the negative attitudes held by members of the public about people with devalued characteristics (Corrigan, 2005). When an individual is publicly labelled with any stigma, e.g., mental health or dementia, it is called 'public stigma' and harms this person in many ways (Corrigan, 2004, p.616). It creates prejudice and discrimination that block an individual's access to employment, educational opportunities, health care, and housing (Corrigan et al., 2011, p.18). Public stigma occurs when the public endorses stereotyped behaviour about mental illness and acts based on these stereotypes (Corrigan et al., 2011, p.18). The origin of stigmatisation lies in people's cognitive representations regarding those who possess the stigmatised condition, which can trigger adverse emotional and behavioural reactions (Dijker & Koomen, 2003; Weiner et al. (1988).

Stigma by association is another type of stigma as having a stigmatised condition can negatively impact the person living with dementia and their family and friends. Others often devalue people associated with stigmatised individuals such as family, friends, or caregivers because of their connection with them (Neuberg et al., 1994). Goffman (1963) names this type of stigma courtesy stigma, related to lower self-esteem and psychological distress for stigmatised individuals (Mak & Kwok, 2010; Struening et al., 2001). People often try to hide their relationship with a stigmatised family member (Phelan et al., 1998) or encourage family members to conceal their condition. Stigma by association can also impact people other than family who have developed social connections to stigmatised persons, such as AIDS volunteers (Li, 2008).

Stigma does not always come from others; it often occurs because of a person's self-doubt. There is a famous Bangla song: "*boner bagh-e khayna, monerbagh-e khay*" (the tiger of the forest does not always eat you; it is the tiger of the mind who does (boner baghe khayna jeno moner baghe khay (nagg ponchomi) - YouTube, last watched 6 September 2022). Burgener et al. (2015) report that self-stigma impacts functioning and quality of life in persons with dementia. Research shows that higher levels of stigma are associated with higher anxiety, depression, and behavioural symptoms and lower self-esteem, social support, participation in activities, personal control, and physical health (Burgener et al., 2015). According to Link (1987), self-stigma occurs when individuals perceive that other people may not like them; consequently, they have low self-esteem and avoid seeking opportunities to improve their lives. Because of the self-stigma or psychiatric level of stigma, individuals may choose not to associate themselves with a mental health clinic or professionals (Corrigan et al., 2011, p.18). Therefore, the person with mental health issues may accept these notions and suffer diminished self-esteem, self-efficacy, and confidence in their future (Corrigan, 1998; Watson & River, 2005). The person who agrees with prejudice concurs with the stereotype 'that is right; I am weak and unable to care for myself'. Self-prejudice leads to an adverse emotional reaction; prominent among the symptoms of this are low self-esteem and low self-efficacy (Link et al., 2001). The effect on self-esteem is typically operationalised as diminished views about personal worth (Corrigan et al., 1999) and sufferers often experience shame. Low self-efficacy and demoralisation are associated with failing to pursue work or independent living opportunities (Link 1982; 1987). There is evidence to suggest a significant relationship between shame and avoiding treatment, as Leaf et al. (1986) present their findings that participants with psychiatric diagnoses were more likely to prevent services from being obtained if they believed family members would have an adverse reaction to these services. The perception of people with dementia as incomplete due to their memory problems could also mean that their personal preferences, including spirituality, could be ignored (Graham et al., 2003; Mukadam & Livingston, 2012).

Figure8: *The circle of social effect of stigma, based on Mukadam & Livingston (2012, p.380)*



The stigma associated with providing care for a relative with Alzheimer's disease is called *family stigma* (Herrmann et al., 2018; Werner, 2014). Providing unpaid care for a relative with dementia is associated with considerable emotional, financial, and health difficulties at the individual level (Alzheimer's Association, 2018). Research shows that family stigma is associated with significant negative consequences such as increased caregiver burden and depression (AboJabel & Werner, 2016).

2.9.4. Factors Associated with Dementia Stigma: Consequences of Stigma

McParland (2014) argues that our understanding of dementia and an individual's experiences of dementia are again complicated because of the stigma associated with mental illness and the process of diagnostic overshadowing that takes place when a diagnosis or label has been attached to the person. Dementia is still perceived as a highly stigmatised condition (Blay & Peluso, 2010), leading to significant negative effects on people with dementia and their carers (Livingston & Cooper, 2013; Werner et al., 2012). Stigma is also a significant barrier to people seeking information, help, advice, and support, as well as to putting plans in place (Alzheimer's Disease International, 2019; Parker et al., 2020; Werner et al., 2014). Goffman (1963) suggests that the stigma occurs when the anticipated attributes assigned to someone in any interaction are not fulfilled. Thus, a person with dementia or mental illness is reduced in our mind from a whole and a usual person to a tainted, discounted one (Goffman 1963, p.12). Following Goffman’s idea, Innes (2009, p.39) suggests that attitudes towards dementia can reflect negative views of old age and mental health stigma. Nevertheless, Goffman goes so far as to suggest that we view a person stigmatised as not quite human.

Stigma causes serious emotional, behavioural, and social problems for people with dementia, such as damaging self-esteem, feeling anxiety, and developing a sense of shame and fear of others’ judgment (Rahman, 2015). Family members and relatives of the individuals with these conditions also often face the consequences of stigma, such as embarrassment and anxiety. Their circle of friends and acquaintances appears to decrease (Lion et al*.,* 2015, p.226). People choose not to seek help for mental health problems in order to avoid negative labels (Ciftcy et al., 2013, p.18). According to Patrick, people labelled as having a ‘mental disorder’ have issues finding and keeping a job, renting an apartment, and keeping in touch with a health professional, and avoid seeking help in institutions that may be perceived as stigmatising (Patrick, 2011). Likewise, the stigma of dementia can also make people isolated and jobless.

Kitwood (1997, p.14) explains that people turn individuals with dementia into another species, not persons in the complete sense, to reduce their anxiety and fear. Reviewing existing literature on dementia, Nguyen, and Li (2018) also conclude that most studies confirm negative beliefs about people with dementia and explore stereotypes, prejudice, and discrimination against people with dementia (Nguyen and Li, 2018). In addition, commonly perceived stereotypes targeting this group include dangerousness, loss of self-esteem, lower competence, and greater tendency to morbid thoughts (Nguyen and Li, 2018).

Warner & Davidson (2008) suggest that people with dementia are not viewed as dangerous or morally responsible for their condition. Instead, they are considered kindlier and more sympathetic than those with other types of mental illnesses.

Deitrich et al. (2004) suggest that an individual’s experience of stigma is most usually in the form of social distance. Echoing the same, Warner & Davidson (2004) argue that in the case of other mental illnesses, the process of stigma is linked primarily to a view of the person as dangerous. However, in the case of dementia, the feeling of rejection experienced by participants towards people with dementia may be associated with the distancing, marginalisation, and discrimination that characterise stigma and its negative consequences.

Wadley & Hayley (2004) warn that while people with Alzheimer’s disease might not generate negative feelings of anger and fear, this does not mean they are free from stigma. These authors also point out that individuals are no less stigmatised because they are viewed compassionately. Instead, the stigma still has the power to facilitate exclusion and discrimination (Wadley & Hayley, 2004).

Warner (2005, p.374) has found that negative emotions such as fear and anger are triggered in response to mental disorders, leading to social distance. However, the author argues that personal experience or familiarity with mental illness promotes more positive emotions (Warner, 2005). Similarly, Link et al. (1999) report that they found a correlation between fear and a desire for social distance; therefore, the authors argue that the symptoms of mental illnesses represent “undesirable personal attributes” that people like to avoid. However, Warner & Davidson (2004, p.395) suggest that fear and rejection might be associated with distancing, marginalisation, and discrimination that characterise stigma and its negative consequences.

Crisp et al. (2000, p.6) explain that social distance has ensured that the public or health professionals do not fully understand the reality of the experiences of those with mental illnesses. They also suggest that stigmatising attitudes are just as prevalent among younger people who know someone with a mental illness, making them just as likely to hold negative opinions.

Exploring the impact of a career in dementia care on senior health professionals Walmsley & McCormack (2016) reviled that participants experienced a wide range of negative emotions in their daily lives, e.g., fear, frustration, anger, grief, loss of confidence, and depression in people with dementia, and fear, guilt, hurt, embarrassment, and shame in family caregivers. Anxiety, particularly as regards seeking help, was experienced by people with dementia and their family caregivers (Devlin et al., 2006). Similarly, Nguyen and Li (2018) found that there were adverse emotional reactions towards people with dementia who had attended in an awareness campaign about AD in Creuse, France.

Piver et al. (2013) and Werner et al. (2010) also report that ‘fear’ was the most frequent emotional reaction reported by their participants. Piver et al. (2013) also adds that the general public also associates the dementia label with ‘anxiety’ and ‘shame’.

Heinik (2008) and Gove et al. (2016) report that healthcare professionals often discriminate against people with dementia and their family caregivers, negatively impacting their help-seeking, service access, and timely diagnosis. The Alzheimer’s Society (2018) reports that people living with dementia often worry that their social lives will change after a diagnosis of dementia, as they feel that they may slowly lose their friends and face isolation because of public stigma.

2.9.5. Dementia Stigma among the South Asian communities

Stigma is a serious and common problem faced by people with dementia among the South Asian communities (Mackenzie, 2006*;* Giebel, 2016; Regan, 2016; Ahmed & Eagle, 2018). There is a higher level of stigma and a lower level of awareness of dementia amongst the many BAME ethnic groups (Ahmed & Eagle, 2018). It affects a person’s self-esteem, causes distress, affects social inclusion, and delays dementia diagnosis (p.377). Like Jolley et al. (2009) and La Fontaine et al. (2007), Atcha (2018) also argues that the negative connotations of the terms often used to refer to dementia - losing memory, possession by an evil spirit, unable to remember things - shape negative perceptions of dementia. Jolley et al. (2009) argued that this has resulted in people of South Asian origin correlating fear and shame with dementia and producing stigma, which prevents family members from seeking help or admitting publicly that someone in their family has dementia, to maintain community ties. Likewise, Kenning (2017) suggests that shame and stigma are among the most challenging barriers for many South Asian families, who commonly respond with denial, fear, and embarrassment when their elders show signs of dementia symptoms.

Mukadam and Livingston (2012, p.377) report that a dementia diagnosis brings enormous stigma, often due to various cultural beliefs/myths and because of the atypical behaviours that may result from cognitive impairment. Likewise, Parveen et al. (2017) have found that the underrepresentation of minority ethnic groups in dementia services may be due to cultural stigma attached to dementia, lack of knowledge of dementia, and little awareness of services. There is evidence to suggest that people living with dementia from minority ethnic groups face multiple jeopardies which involve the combination of the stigma associated with a dementia diagnosis, the stigma of a minority ethnic status, being perceived as a migrant, and also, for many, having a lower socio-economic class (Parveen et al., 2014). A study by Mackenzie (2006) with South Asian and Eastern European groups in the United Kingdom suggests more significant cultural stigma attaches to a diagnosis of dementia and, therefore, there are additional consequences of being diagnosed with dementia for those from minority ethnic backgrounds. Conducting semi-structured interviews with 12 representatives of BAME background people in Salford, focus groups with 6 representatives from BAME groups, and interviewing 30 key stakeholders, Ahmed et al. (2017) concludes as indicated above that some of the BAME communities consider dementia to be a ‘taboo’ subject. People’s lack of awareness usually leads to heightened fear and mythmaking (Ahmed et al., 2017). Likewise, Lawrence et al. (2008) argue that South Asian family carers might be more likely to conceptualise dementia as a natural aging process, possibly as an attitudinal response to the stigma associated with dementia. Ahmed et al. (2017) have found stigma and embarrassment surrounding dementia in many South Asian communities, including the Punjabi, Gujarati, and some of the Chinese diaspora in the UK. The authors also claim that dementia is considered in the above communities a ‘taboo’ subject, resulting in stigma and social isolation. In reaction, families often distance themselves from the person with dementia by hiding them or abandoning them out of fear of rejection from the wider community. It is also notable that when an individual develops dementia in these cultures, people think that there is something wrong with the whole family, preventing engagements and marriages (Ahmed et al., 2017). It needs to be explored further whether stigma is attached to dementia among the Bangladeshi community as it is in the Gujarati and Punjabi communities (Ahmed et al., 2017) or they are different as Hossain (2017, p.160) claims: “dementia was not considered a stigma at all among the participants”. However, it is noteworthy that historically, Bangladesh was part of India (until 1947) and part of Pakistan (1947-1971). There are huge similarities between Punjabis (of Pakistan), Gujaratis (of India and Pakistan), and Bangladeshis in lifestyle, food habits, culture, religion, etc., as a country of the Indian subcontinent.

Blakemore et al. (2018) state that stigma, fear, and mistrust of dementia services have been cited as possible explanations for the low rate of help seeking from formal services reported in South Asian and other minority ethnic groups. In addition, fear of a move to long-term care may also prevent BAME families or persons with dementia from seeking help from formal services (Blakemore et al., 2018). Dementia is often viewed with loss and shame, which leads to a reluctance to seek help, diagnosis, and services (Blakemore et al., 2018, p74). Likewise, interviewing 12 Sikh families, Jutlla (2015) identifies that dementia prompts social isolation for the South Asian families affected, resulting in delayed diagnosis. People with the condition often hide and avoid seeking medical attention because of the stigma associated with dementia (Jutla, 2015). From a qualitative meta-synthesis and reviewing 28 studies, Kenning (2017) has found that shame and disgrace are among the most challenging barriers for many Asian families, who commonly respond with denial, fear, and embarrassment when their elders exhibit dementia symptoms. Stigma exists surrounding diagnosis as well; hence, many people worry about receiving negative perceptions from professionals and are afraid of making the situation known to social care organisations (Ahmed et al., 2017, p19).

There are many myths and stereotyped ideas that have developed among the various South Asian communities. Rygan (2013) has reported that individuals from South Asian backgrounds and many other communities may believe that dementia and mental illness develop because of their past sins; therefore, they take the view that people with the condition are being punished in some way. Consequently, people with dementia may feel guilty about their illness and may not access dementia services (Ahmed et al., 2017). Although dementia is a degenerative neurological condition that often affects memory, judgment, and behaviour, many people classify it as a mental illness (Morgan et al., 2002). Mackenzie (2006) explores the idea that participants from South Asian communities in previous dementia research often tend to conceal mental illnesses from the wider community, on the basis that their family's reputation would be at stake. Mukadam et al. (2015, p.7) finds that many Bangladeshis and South Asians consider dementia a kind of mental illness. Thus, people with the condition often receive the stigma of 'madness.' Similarly, Ahmed et al. (2017) stated that South Asian communities usually recognise dementia as a mental health problem (Moriarty, 2015; Ahmed et al., 2017). Asian communities seem to attach a more significant stigma to mental illness than do their White British counterparts (Hussain & Cochrane, 2004). Ciftcy et al. (2013) report that individuals choose not to seek help for mental health problems to avoid negative labels (Ciftcy et al., 2013, p.18). Corrigan (2011) argues that people labelled as having a 'mental illness' have issues with finding and keeping their job, renting an apartment, and keeping in touch with a health professional, and thus avoid seeking help in institutions that may be perceived as stigmatising. Likewise, people with dementia may face many challenges if the stigma of mental health is attached to this (Mukadam & Livingston, 2012). During the early Middle Ages, dementia was considered an effect of an external force limiting free will (Bosco et al., 2019, p.6). Some religious groups still believe that dementia is associated with divine punishment such as God's wrath or the karmic penalty for past sins (Bosco et al., 2019, p.9; Mukanzie, 2006; Ahmed & Eagle, 2018). Koeing et al. (2012, p.8) argue that religion could sometimes be misunderstood or wrongly practised; therefore, it may often produce psycho-social damage. For instance, due to failure to live up to high religious standards, religion may be used to validate hate, violence, prejudice, and stigma (Koeing et al., 2012). Likewise, it may lead to anxiety, fear, and excessive guilt over minor infractions (and even self-mutilation in some cases) (Koeing et al., 2012). Multiple views around dementia are present in contemporary societies, following the values and beliefs shared by different cultures (Sweeting & Gilhooly, 1997). The meanings around dementia are interpreted, assimilated, or rejected by individuals in their socio-cultural context, such as their social location (e.g., gender, social class), their biography, and their level of self-awareness (Kontos & Martin, 2013; Bar-On, 2001). Meanings of dementia vary within the Bangladeshi community. For example, from semi-structured interviews with 53 English- or Bengali-speaking UK South Asians, Mukadam et al. (2015) report that 22 of them commented that societal pressure or public stigma prevents South Asians (including Bangladeshis) from seeking help for dementia (Mukadam et al., 2015, p.4).

Ten interviewees expressed their views that people in these communities believe that dementia is a kind of mental illness; therefore, people with dementia are stigmatised as “mad” individuals (Mukadam et al., 2015). Six participants commented that people with dementia are often stigmatised because of their cognitive decline (Mukadam et al., 2015). Two interviewees expressed the view that dementia is a dangerous illness (Mukadam et al., 2015). Another four persons expressed their view that Bangladeshi people expect that family should look after their own for as long as possible (Mukadam et al., 2015, p.4). Finally, the family of a person with dementia might feel that they would lose their social status if they sent their relatives or loved ones to social care services rather than fulfilling their obligations towards them (Mukadam et al., 2015, p.7).

Mukadam et al. (2011) report that their respondents gradually lost their social networks as people recognised their condition. Likewise, Parveen et al. (2017) explore the evidence that families withdraw from the wider community network when someone is diagnosed with dementia, and this is due to wanting to hide the diagnosis from others. In addition, people from South Asian communities are not interested in dementia until it personally affects them, and many do not discuss the condition due to the stigma in the wider community (Parveen et al., 2017).

Interviewing 11 Pakistani and 5 Indian carers, Mackenzie (2006) explores the idea that stigma results from religious and magical beliefs around the causes of dementia and results in concealment from their community and delays in help seeking. People with dementia among these communities are worried about breaking with traditional beliefs and concerned about what others may think about their condition. An individual with dementia symptoms, such as memory loss, may become stigmatised by a negative labelling process, which may affect the person’s social activities and interactions, leading to declining social status (Mackenzie, 2006). Turner et al. (2005) explore the notion that the stigma of caring for a person with dementia is rooted in a widespread belief in the South Asian communities that the condition is caused by tension between good and evil. Interviewing 96 South Asian participants aged 58-85 years old, Turner et al. (2005) highlight that participants believe that if someone does evil things, something terrible will occur to them or their grandchildren.

Family members of people living with dementia expressed their view that the community's beliefs and perceptions of dementia tend to be negative, resulting in stigmatisation that results in broader experiences of family members' shame and embarrassment about their relative’s dementia (Atcha, 2018). Consequently, families frequently avoid disclosing dementia and are described as going to great lengths to hide the dementia diagnosis, fearing that the family’s standing in the community might be affected. Families of people living with dementia tend to manage/contain their relatives at home, which the participants perceive as harming the well-being of all concerned. As a consequence of having a family member with dementia, the family experiences discrimination and may become alienated from the community, potentially losing their sense of belonging.

Exploring perceptions of dementia in British Indian, African and Caribbean, and Eastern and Central European communities in the United Kingdom, Parveen et al. (2014) have found that all groups discussed the ‘embarrassment’ associated with forgetfulness on the part of the person with dementia. In addition, the Indian group also mentioned the shame and guilt associated with dementia, perceiving the condition as ‘damaging to self-respect’.

2.10. Limitations of the Existing Research

Despite the increasing number of older people in the Bangladeshi community in England, little research has been conducted on understanding their lived experiences and knowledge about dementia. We know little about how their religious-cultural beliefs and practices may influence the formation of misconceptions about dementia in the Bangladeshi community that may prevent people with dementia from accessing dementia services. Although some studies have revealed, in general, the issues around dementia in the UK South Asian Community context, most participants have either Indian or Pakistani backgrounds; therefore, the Bangladeshi community remains under-researched (see Table 1: the characteristics of sources of evidence, p.53). Evidence suggests that UK Bangladeshis are different from Indians and many other BAME groups in regards to health and socioeconomic circumstances. For example, UK Bangladeshis are at higher risk of heart disease (Patel & Bhopal, 2004). Type 2 diabetes is markedly higher for Bangladeshi immigrants compared to both South Asian and other ethnic minority immigrant groups in the UK (Diabetes UK, 2010). The main risk factors of diabetes and heart disease have been identified as significant indicators for developing dementia (Bruce et al., 2001; Peila et al., 2002; Stewart & Liolitsa, 1999). In addition, in England, Bangladeshi communities have the lowest education rates, the highest smoking rates, the poorest socioeconomic conditions and the worst health, the most risk factors for underdiagnosis, and the poorest access to healthcare services and support (Garbin, 2005; HSCIC, 2006; ONS, 2002). (Details on how UK Bangladeshis are a single group, different from other south Asian communities, is illustrated in Chapter 1, section 1.8: Why the Bangladeshi community? p.32).

While previous research has identified some knowledge and attitudes of the Bangladeshi community in England about dementia from the caregivers' perspective, no research has tried to capture the direct experience of people with the condition among the UK Bangladeshis; therefore, the voice of these people remains unheard. For instance, Hossain (2017) sought to understand the knowledge and attitudes of people with dementia. However, his study confined itself to caregivers' understanding of dementia. He likewise failed to capture the voice of the people living with dementia (Hossain, 2017, p.23). Similarly, recruiting 53 English/Bengali speaking South Asian adults, Mukadam et al. (2015) attempted to probe the barriers and challenges South Asians encounter in accessing dementia services and people's attitudes towards this. However, their entire sample comprised adults that had not been diagnosed with dementia. Therefore, the voice of the people living with the condition was still not heard.

Despite an increasing recognition amongst researchers that people with dementia should be included in research as active participants, people with dementia within the Bangladeshi community have been left under-researched (Beuscher & Grando, 2009; Dewing, 2002, 2007; Hubbard, Downs & Tester, 2003; McKeown et al., 2001; Nygård, 2006; Reid et al., 2001; Clare, 2002; Pesonen et al., 2001, p.651). To make dementia health and social care services high-quality, effective, and efficient, people with dementia must be fully engaged with (Alzheimer's Society, 2022). The government also has clear guidance that patients and the public have the right to be involved, directly or through representatives, in the planning of the healthcare services commissioned by NHS bodies (Department of Health, 2013a). The Health and Social Care Act requires councils and Clinical Commissioning Groups to involve local people in preparing their plans for local health and social care services, called Joint Strategic Needs Assessments (Department of Health, 2013a). Although the National Institute for Health Research (NIHR) (2015) highlights the importance and the necessity of public and patient involvement in research, there is little to be found in the literature that includes people with dementia from the Bangladeshi community. Research has shown that the views of people with dementia are often ignored, as 38 percent of people with dementia do not have a choice about how they live their life, which means research evidence is not being implemented in practice (Alzheimer's Society, 2014). The Mental Capacity Act (MCA, 2005) states that a diagnosis of dementia does not necessarily mean that the person diagnosed cannot give or refuse consent (Department for Constitutional Affairs, 2007; Dewing, 2007; Nygård, 2006).

However, the views and lived experiences of people with dementia are an under-researched area among Bangladeshis and other BAME communities (Hossain, 2017, p.172). A failure to include people with the condition from the UK Bangladeshi community in research may put future researchers at risk of imposing their understandings onto the accounts of the people with dementia in this community. Although there is negative stigma and prejudice surrounding a dementia diagnosis, individuals with dementia have frequently been excluded from research under the false perception that they "cannot do it" (Cantley et al., 2005). However, Turner (2012) demonstrated that people with dementia could make valuable contributions to research. The author also suggests that if the researcher takes time to collect background information and set up preparatory sessions with people with the condition, they can identify both strengths and weaknesses of each individual and can therefore help support the person with dementia accordingly throughout the process (Turner (2012).

Higgins (2013) suggests that to better understand the care needs of people with dementia, it is essential to involve them in research as their experiences can allow the service providers to re-think their practices and provide better care. Kapp (1998) argues that asking someone with dementia to participate in a research study can make them feel recognised as capable. Hellstrom et al. (2007) argue that excluding people with dementia from taking part in research could reduce their dignity while including them could enhance it.

Hossain’s (2017) work is the only study focusing on understanding dementia in the Bangladeshi community in England. He suggests that the Bangladeshi community has the right attitudes towards dementia as every one of his participants believed that dementia was a medical condition such as a brain disease; thus, anyone could suffer from it (Hossain, 2017). The author has not found any misbeliefs or misconceptions that the UK Bangladeshis have about dementia. Instead, he expresses the view that Bangladeshis are different from other South Asian communities because religion and culture have a less negative influence on people of Bangladeshi origin in their understanding of dementia (Hossain, 2017, p.150).

Hossain (2017) further claims that Bangladeshi people trust their GPs and hospital doctors; value their advice; and believe health professionals have the authority to make any decision concerning the patient's well-being (Hossain, 2017, p.150; Khanom, 2009). However, the findings of this research are disputable. Most scholars have continuously warned that people from South Asian communities remain underrepresented in specialist dementia services (Baghirathan et al., 2018; Parveen et al., 2017; Mukadam et al., 2011; Tuerk & Sauer, 2015). They also present later to dementia specialist care than their indigenous counterparts (Mukadam et al., 2015; Hailstone et al., 2017; Ahmed et al., 2017). On the other hand, the majority of South Asian studies, including Mackenzie (2006), Giebel (2016), Regan (2016), and Mukadam et al. (2015), have suggested that South Asians have erroneous beliefs about dementia, which may keep them from diagnosis and treatment.

The existing literature has indicated that people with dementia from the BAME communities are heavily stigmatised. Stigma not only harms self-esteem and may cause distress but also affects social inclusion and can delay the diagnosis of dementia (Mukadam et al., 2015; Mukadam & Livingston, 2012; Mackenzie, 2006;

Ahmed et al., 2017). However, we know little as to whether or not dementia is stigmatised in the Bangladeshi community. Although Hossain (2017) claimed that his study did not find any evidence of stigma in the Bangladeshi community, it is noticeable that his study included only 6 caregivers in the research, which is a small sample size. Furthermore, it did not include people with dementia or any dementia service holders/professionals in the research.

2.11. Conclusion:

There are significant gaps worth noting from the literature review. Based on the work so far reviewed, the following knowledge gaps have been identified:

First, existing research has not conclusively explored the knowledge and beliefs of people with dementia among the UK Bangladeshi community.

Second, little is known about how stigma,cultural myths, and religious beliefs may prevent people of Bangladeshi origin from accessing dementia services, although we know quite a bit from the previous literature about these issues in relation to the South Asian community more generally.

Third, we know little about the lived experience of people with dementia from the Bangladeshi community; therefore, the voice of the people with the condition from the UK Bangladeshi community has remained unheard.

Chapter 3: Methodology and Research Design

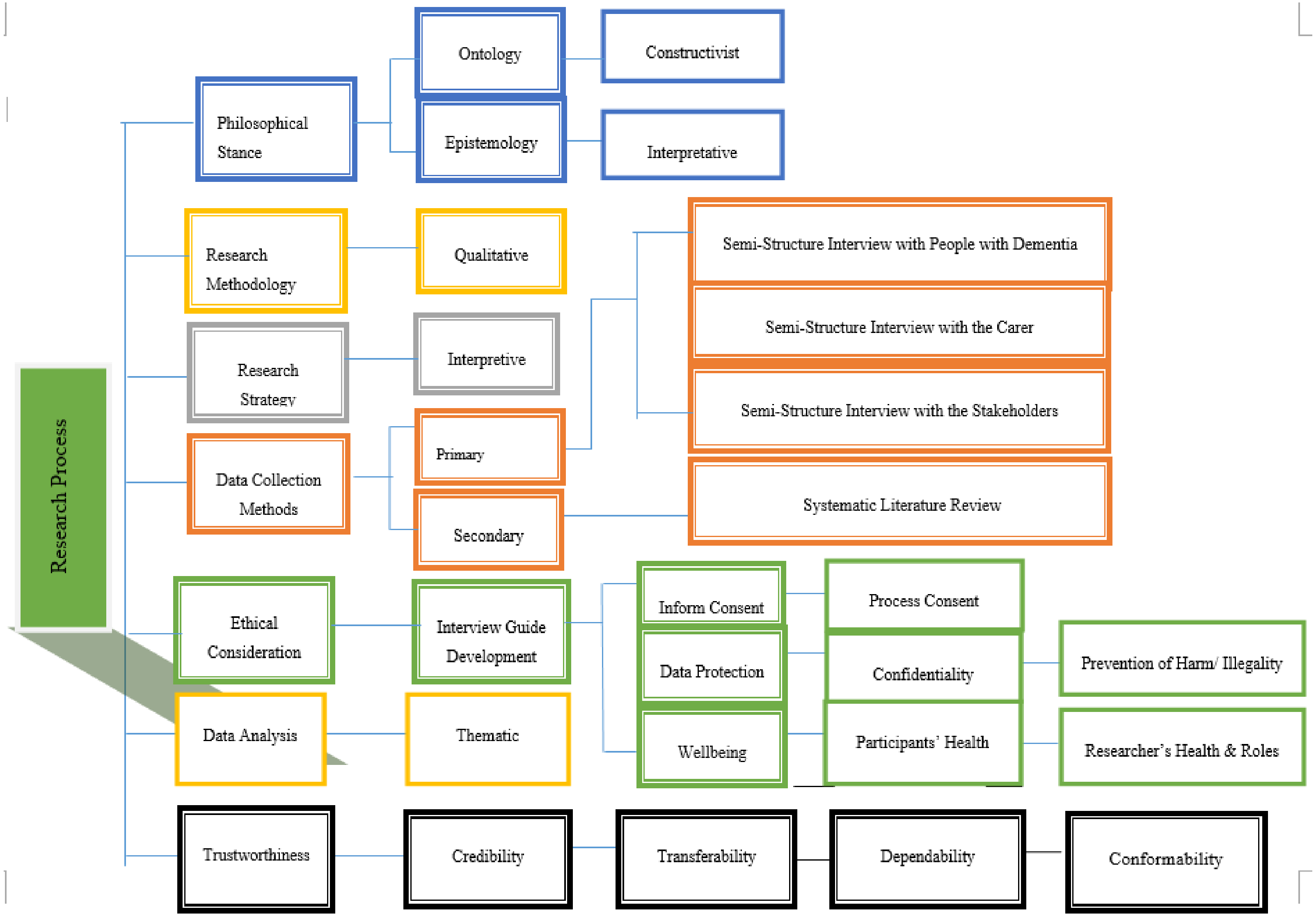
3.0. Introduction

The purpose of this chapter is to discuss the research methodology and design adopted for this study. Schwandt (2007, p.193) defines methodology 'a theory of how research inquiry should develop, along with the implementation of the philosophy, a statement about the validity and often preferred methods of data collection and analysis' (Bazeley, 2013, p.8). This section will first outline the philosophical stance, i.e., the ontological and epistemological position of this study, which led the researcher to choose the correct research strategy to achieve the overall aim and objectives of the study (Walliman, 2016, p.12). Second, it will demonstrate the rationale for using a qualitative approach and the research strategy used in this study, in conjunction with the data collection, management, and analysis methods and techniques. Furthermore, the ethical considerations underlined for this study will be highlighted as these are very significant in social research (Morris A., 2015, p.17; Thomas & O'Kane, 1998). Finally, a detailed step-by-step thematic analysis process will be explained based on Braun and Clarke's (2006) approach to thematic analysis, relevant to this study.

The diagram on the following page illustrates a summary of the research process undertaken in this study:

Figure 9*: S*ummary of the research process to be adopted in this study.

The ontological position of the researcher and the relevant epistemology are shown in blue. The research methodology is shown in yellow and the strategy to be used in grey. Data collection methods are shown in amber. Ethical considerations are shown in green, drawn from Dewing (2007). Finally, the trustworthiness (validity & reliability) is shown in black, based on Lincon & Guba (1985) and Shenton (2004).


Research Process
Philosophical Stance
Ontology
Constructivist
Epistemology
Interpretative
Research Methodology
Qualitative
Research Strategy
Interpretive
Data Collection Methods
Primary
Secondary
Semi-Structure Interview with People with Dementia
Semi-Structure Interview with the Carer
Semi-Structure Interview with the Stakeholders
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3.1. Research Approach (Epistemology; Ontology; and Methodology)

The core philosophical assumptions underpinning any research project influence the type of research and how that research is to be accomplished; therefore, it is essential to understand the research paradigm that incorporates the ontological, epistemological, and methodological perspective of a researcher (Grix, 2010). Guba and Lincoln (1994, p.105) define “paradigm a set of beliefs or worldview that informs a researcher from a distinct discipline about which phenomenon to study, how to conduct the research, and how to explain the research findings."

This research study has been informed by a constructivist interpretivist epistemological position and is grounded in the interpretivist approach of social constructivism. Justifications for ontological and epistemological stances are given below:

'Ontology' refers to the characteristics of the social world and the views individuals hold about the nature of social reality (Ormston et al., 2014), which might represent the question 'What exists that we might acquire knowledge of?' (Hay, 2002, p.61). 'Ontology' is derived from two Greek words: 'onto,' which means 'being' and 'logia,' is a science, a study, or a theory. The term then refers to the "science or study of being" (Hamza 2015, p.218). Ontology is a branch of philosophy relating to how we see the truth and the nature of the phenomenon, or entities, or social world that we want to investigate (Mason, 2018, p.4). Different versions of worldly things' nature, character, and essence may be different; however, an alternative ontological view might tell other stories. Therefore, a researcher needs to determine their ontological perspective (Mason, 2018). Bryman (2012, pp.32-3) classifies two opposing theoretical attitudes to social entities: constructionist and objective. The emerging ontological perspective of my research underpins the belief that reality is a process of mind, external social actor, subjective, multiple, and in a continuous state of revision that is understood through 'social constructions' (Mason, 2018, p.5). It relies upon the participant's views and experiences and on the background of the case study (Creswell, 2003). Savickas (1989) defines "constructivist" perspectives as the "meaning-making paradigm," (p.1).

Constructivism proposes that everyone mentally constructs the world of experience through cognitive processes (Rechard et al.,2003, p.375).

I wished to explore people's experiences and subjective views about dementia and their support needs in a UK Bangladeshi community; therefore, adopting a social constructivist paradigm was the best choice for my research. The constructivist approach acknowledges that knowledge is produced by exploring the social worlds of individuals and constructing meaning and interpretations from these individuals. Constructivism believes that social phenomena depend on social interaction and are constantly changing (Walliman, 2016, p.12). Social constructivists consider reality to be not a given nor defined *a priori*, but instead transformed and shaped by socially interacting individuals (Bosco et al., 2019). Spivey (1997) argues that constructivists assume an individual's mind is active in making and structuring knowledge. Constructivism attempts to find the meanings of human actions with the conceptual understanding of the researchers and participants (Guba & Lincoln, 1989; Schwandt, 2001).

Epistemology is "the process in which the investigator comes to know the truth and reality" (Antwi & Hamza, 2015, p.218). Epistemology considers how we can know about our world and what forms the basis of knowledge (Denscombe, 2014; Ormston et al., 2014). Mason (2018, p.7) defines epistemology as a theory of knowledge that concerns the principles and rules by which the researcher makes their mind up as to whether and how the social phenomenon can be known and how knowledge can be validated and revealed. The significant paradigms based on the underlying research epistemology are positivism, interpretivism, and critical realism (Mackenzie & Knipe, 2006). This research has used interpretivism (formulated by Wilson, 1970), which assumes that meaning is produced and exchanged through the interpretive process.
In addition, the study has to analyse the concepts presented and used in these processes (Flick, 2015, p.24). Interpretivism emphasises the sense people make of their own lives and experiences, whereas the researcher tries to find out and interpret people's meanings and interpretations (Mason, 2018, p.8). It adopts exploratory approaches that enable a researcher to understand an individual's underlying reasoning, beliefs, and motivations (Denzin & Lincoln, 2011). It concerns understanding human experiences by imposing knowledge and meaning as acts of

interpretation (Mackenzie & Knipe, 2006). Lather (2006) explains that interpretivism aims to generate knowledge relevant to the clinical context of related health disciplines (Lather, 2006) and facilitate the researcher to understand individual experiences, believing that reality is subjective and constructed by the individual. Schwandt (2001.p134) takes the view that "to understand the meaning, one must interpret words". Interpretivism refers to “an approach to studying social life with the assumption that the meaning of human action is inherent in that action” (Schwandt, 2001, p.134). It often provides a more detailed understanding of the situation and significantly facilitates a researcher to gather in-depth and insightful information from the participants (Kelin & Meyers, 1999). This research design has enabled the researcher to interpret the meaning of participants’ experiences and offer a comprehensive understanding of the experience of people with dementia amongst the Bangladeshi community with reference to understanding their support needs. This theoretical approach aims to uncover meaning so as to move towards a better understanding of the issues involved in the study and has informed every element of the research, from the initial decision about what should be researched to the research design, methods used, and conclusions drawn from the findings (Alvermann & Mallozzi, 2010).

Along with the interpretive approach, this research also used the ‘social constructivism’ paradigm, a school of thought founded on the belief that individuals’ reality is constructed over time in response to their own experiences and broader social factors; personal experiences are interpreted through a range of historical and sociocultural factors (Burr 2015). Social constructivism may be described broadly as an approach that recognises one or more of the following fundamental assumptions:

1. Knowledge is historically and culturally specific. Therefore, it is acknowledged that the way we understand the world is founded in culture and history. For example, understanding of dementia and the notion of dementia care is recognised as historically and culturally specific. It has changed over time and is different across cultures.
2. Knowledge is sustained by social processes and therefore is a construct between people or national groups.

3. This research is positioned within these assumptions since it assumes the social world is fashioned by social, cultural, political, economic and historical influences.
4. Knowledge and action are interlinked, and therefore different social constructions invite various human activities.
5. Constructions of the social world are thus bound up with power relationships that can influence the fair treatment of others. For example, within the Bangladeshi community, the construction of dementia and the culture of care (as shared fundamental beliefs developed by a group of care staff that influences the way that group works) will influence how individuals who live with dementia are treated (Burr 2015). Indeed, both the perception of dementia and shared beliefs about the appropriate ways to care for and support individuals living with the condition are socially constructed phenomena.

An interpretivist constructivist approach is the most appropriate for this study as a social reality is understood as an entity that is continuously being constructed and reconstructed, shaped through individuals' everyday actions, words, and beliefs (Denscombe 2014).

This study has used a qualitative research methodology to best answer the research question and fulfil the objectives set out above. Qualitative research provides an in-depth, socio-contextual, and detailed description and interpretation of the research topic (Holloway & Wheeler, 2010; Smith et al., 2011; Ormston et al., 2014). This methodology is advantageous to understand the perceptions and actions of people who live with health-related issues and deliver insights about people's attitudes, beliefs, motives, or behaviours (Wong, 2008). It enables the researcher to understand individuals' underlying reasoning, beliefs, and motivations (Denzin and Lincoln, 2011). Qualitative research approaches are a source of well-grounded, rich explanations and descriptions of procedures in the understandable local context (Bazely, 2013, p.4). Creswell (2003) defines qualitative research as distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting (Creswell, 2003, p. 15). Denzin & Lincoln (2011) argue that this method entails an exploratory approach that enables researchers to understand individuals' underlying reasoning, beliefs, and motivations. Miles and Huberman (1994) advocate, 'with qualitative data, one can preserve chronological flow, see the consequences of one event on another, and derive fruitful explanations precisely (Bazely, 2013, p.4).”

The qualitative research methodology is the most appropriate for this study, as this approach, with its emphasis on people's lived experiences, is fundamentally well suited to locating the meanings that people place on the events, process, and structures of their perceptions and assumptions (Muniri 2012, p.90). It also facilitates tools for researchers to understand various phenomena in their contexts (Ormston et al., 2014). Similarly, Creswell (2003) advocates the notion that this approach, emphasising people's experience, is fundamentally well suited to locating people's meanings in the events, processes, and structures of their perceptions and assumptions. The qualitative methodology in exploratory research uses open-ended questions and probing that allow the research participants to respond in their own words, rather than forcing them to choose from fixed responses, as quantitative methods do (Farrelly, 2013). As this study involves health-related issues that will be understood only by interpreting participants' views and experiences, qualitative methodology is the best choice for this research. Opdenakker (2006) advocated that qualitative interviews facilitate the researcher to communicate synchronously with the participants, which is advantageous in social cues. For example, the voice, intonation, and body language of the research participants can give the researcher much extra information that can be added to the verbal answer of the interviewee to a question.

3.2. Data collection Process:

This research study was compiled in three distinct phases. Participant Group One were some dementia service providers/stakeholders from one of the towns of the United Kingdom (n=5). Participants Group Two were some family caregivers from a Bangladeshi community (n=10). Participant Group Three are some people with dementia from the above community (n=10). I will present below the data collection method for all three-participant groups (together) in 3.2.1 (p.89) first. Then, sampling size (see p.90) and recruitment strategy (see p.92) for each participant group will be discussed in order.

3.2.1. Method:

This study used the qualitative interviewing method, as research has shown that collecting the subjective views of people living with dementia helps provide meaningful insights into the experiences of people with the condition (Samsi & Manthrope, 2020). This approach enables a researcher to understand how individuals construct the reality of their situation from the delicate personal framework of beliefs and values they have developed from exposure to events in their world (Easterby-Smith et al., 2004, p.86; Yin, 2009). Interviews are well suited to constructivist approaches, as epistemologically, a researcher views understanding social knowledge, especially contested or contentious knowledge, as requiring attention to nuance, complexity, contradiction, and depth (Mason, 2002, p.65). The interview provides an intimate and, hopefully, trusting space for these to emerge (as opposed to surveys, for example), but it is based on the (re)construction of experience, and understanding the epistemological implications of this is vital in analysing the interview data (Mason, 2002). There is a general acceptance that interviews do not simply yield statements of fact but represent reconstructed articulations of what people do/think (Watson & Meah, 2012, p.107). Kvale (1996, p.14) remarks that the qualitative research interview is a construction site for knowledge. An interview is an interchange of views between two persons conversing about a theme of mutual interest. Taber (1993) suggests tactics for checking 'validity' in the interview encounter, such as returning to a similar point in a different context later in the interview, seeking clarification, or paraphrasing what one feels a respondent is saying/arguing and seeking confirmation. However, I also recognise the dependence of the discussion on people's capacity to verbalise, remember, and conceptualise, as well as their willingness to share thoughts (Mason, 2002, p.64). While affording participants a chance to speak more freely than methods such as surveys or document analysis, I also hoped that they would provide interviewees and myself an enjoyable and thought-provoking experience.

There are different types of interviews, such as the structured, semi-structured, and unstructured (Wragg, 2011). This study used semi-structured interviews as this method involves comprehensive conversations between the researcher and interviewee, which have an overall purpose prompted by the research aims but strongly guided by the interviewees' perceptions, opinions, and experiences (Dickson et al., 2007; Bowers et al., 2007; Minichiello et al., 1995, 1999). Semi-structured interviews can uncover the interviewees' perspectives on a given topic, which allows the participants to speak freely (Patton, 1990, p.196). This approach encourages the researcher to engage with the data actively and begin identifying and analysing issues (Simons 2009; Mason, 2002). Marshall and Rossman (1999) state that semi-structured interviews could help the researcher understand the meaning people give to their activities. Sekaran (2003) also points out that in this type of conversation, the researcher can clarify doubts and ensure that respondents understand the questions and that the interviewer has understood the responses. Furthermore, in a semi-structured interview, the schedule's flexibility permits the researcher to collect data on unexpected dimensions of the topic (Cohen et al., 2000; Kvale, S. & Brinkmann, S. (2009). Easterby-Smith et al. (2004) assess the semi-structured interview as valid where the interviewer has a list of themes or questions to cover. Therefore, the semi-structured interview approach was appropriate for this thesis.

With Participant Group 1 (stakeholders and service providers) and Participant Group 3 (people with dementia), Interviews were undertaken face-to-face. However, interviews with the family caregivers of the people with dementia were taken via telephone and virtual platforms, due to the ongoing Covid-19 restrictions. Details of the pandemic effects are given in Sub-section 3.7. Covid-19 Impacts, (see p.122).

3.2.2. Sampling:

In the first phase of this study, I recruited dementia service providers/stakeholders (n=5) from one of the towns of North Manchester as the service providers and stakeholders have professional experiences and may also contribute by sharing their experiences regarding people with dementia amongst the Bangladeshi community.

In the second phase of this study, I recruited 10 family caregivers of people with dementia, as family members and caregivers can provide insights into peoples' experiences with dementia because they are associated with them through their relationship and have the opportunity to monitor their circumstances very carefully (Pratt et al., 2002).

During the third phase, I recruited 10 people with dementia from a UK Bangladeshi community of North West. A review of the existing literature emphasises that including the views and experiences of people living with dementia in research and broader decision-making is vital (Innes et al., 2021). Researchers have acknowledged 'hearing' the voices of people living with dementia to be of paramount importance in shaping and developing future research, policy, and care practice (Bethell et al., 2018; Gove et al., 2018; Miah et al., 2019).

I used purposive sampling (for all three participants groups), as purposive sampling involves identifying and selecting persons or groups who are exceptionally knowledgeable about or experienced with a phenomenon of interest (Cresswell and Clark, 2011). Patton, (2002) suggests that with purposive sampling, the researcher has access to key informants in the field who can help to identify information-rich cases. Quantitative researchers often use probabilistic or random sampling to ensure the generalisability of findings by minimizing the potential biases (Palinkas et al., 2013); however, qualitative researchers commonly use purposive sampling. This research did not aim for statistical generalisability; therefore, purposive sampling was adopted in this research.

Sandelowski (1996) suggests that samples in qualitative research tend to be small to support the depth of analysis that is fundamental to this mode of inquiry. A qualitative researcher needs to establish a stable, productive relationship with respondents and, through theoretical contemplation, address the research problem in depth (Crouch & McKenzie, 2006, p.1). According to Crouch & McKenzie (2006), 20 or less can be a fair number for qualitative research. This number will enable close researcher associations with the respondents and enhance the validity of fine-grained, in-depth inquiry in a naturalistic setting. Similarly, Sandelowski (1986) suggests that the sample size must be large enough to achieve data saturation yet small enough to allow in-depth analysis. This study recruited a total of 25 interviewees, including ten people with dementia, ten caregivers/care partners, and five stakeholders and staff from local dementia services. Considering the practicalities, this number was sufficient to reach the point of data saturation and answer my research questions.

3.2.3. Recruitment Strategies:

I had delineated a clear recruitment strategy before the interviews as an effective recruitment plan helps the researcher to obtain an appropriate sample in all research studies (Dickson-Swift et al., 2007). In Phase 1, I contacted the senior managers of seven organisations providing dementia services in my research area via email and telephone. Ultimately, five participants took part in the face-to-face semi-structured interviews, while two declined due to their busy schedules. I had collected their contact numbers from their organisations' websites and through my social network.

To recruit Participant Group Two (family caregivers), I first made some posters and leaflets and displayed them inside mosques, temples, and shops with the appropriate authority’s permission. I also advertised via WhatsApp, Facebook, and various social media through my contacts and requested that if someone is living with dementia or caring for someone with the condition they might participate in this research study. Moreover, I had many of the Imams’ and faith leaders’ phone numbers in my collection; some of the contact details I collected from others. Then, I requested by phone that these Imams and faith leaders help me recruit participants for my research as gatekeepers as they are well engaged with older people due to their job roles. I explained to the gatekeepers the nature of the study and how to brief potential participants about the research, I also gave them an information sheet with a more detailed description, contact details, and the study participants’ rights. As I have been an Imam for a long time in the research locale and due to my roles in the community, all the Imams and faith leaders tried to contact the family caregivers of people with dementia whom they knew and introduced them to me over the phone. Prospective participants completed a form that permitted me to contact them by telephone immediately (Appendix 17; p.307). I sent a participants' information sheet and consent form directly to some potential participants by email and post, inviting them to participate in this research study and share their experiences as caregivers. I also used the snowball sampling strategy, where some participants helped me in recruitment via reference and gatekeeping help.

In phase3, to recruit participants with dementia, I also displayed posters, advertised on social media, and sought gatekeepers' help as I did with Participant Group 2. (caregivers). I also used the snowball sampling strategy, similar to Phase 2 of this study. The majority of participants with dementia (n=7) were recruited through the referral of other family caregivers of people with the condition. Only one person with dementia was recruited from same household.

I drew up clear inclusion criteria for the participants with dementia and their family caregivers (Participants Group 2 and Group 3) who were eligible to participate in the research study. Table 4 provides these criteria:

Table 3*:* *Inclusion criteria for a person with dementia and their family caregiver (for Groups 2 and 3):*

Inclusion Criteria
Over 18 years of age
UK Bangladeshi living in my research area only
A family caregiver who has taken care of a person with dementia within the last 24 months
Family caregiver who has been directly involved in the day-to-day activities of the person with a dementia diagnosis given within the previous 24 months

Capacity to provide consent to be included in the study
Diagnosed with any type of dementia or the family caregiver of a person with any type of dementia
Male, female, transgender
People of any faith or no faith

3.3. Ethical Issues

This research involved participants with dementia who are considered vulnerable under the Mental Capacity Act (MCA 2005). Although the Act states that people with dementia should be considered able to provide informed consent, I took due care to ensure the study was carried out ethically (Cowdell, 2006). The process of gaining formal ethical approval acts as a valuable prompt to ensure a rigorous ethical approach to research; therefore, I followed the Social Research Association (SRA) Guidelines carefully throughout my research (http://the-sra.org.uk/research-ethics/ethics-guidelines/). These guidelines highlight the need to ensure the physical and psychological safety of both the participants and the researcher and confirm that appropriate processes are put into place to gain informed consent, protect participant anonymity and confidentiality, and store sensitive data. I also consulted methodology textbooks (e.g., Mason, 2002) and papers (e.g., Katz, 1992) for guidelines on ethical research and the BSA's Ethical Guidelines that demonstrate the relationships between the researcher and subjects with the view to avoiding harm, manipulation, or inadvertent deception (Maxey, 1999).

I obtained ethical approval from the University of Salford in June 2020. Then, I requested amendments to the approved design to accommodate changes due to Covid-19 in November 2020 and March 2021. (Details are provided in sub-section 3.7:

Covid-19 Impacts; p.122). The critical ethical considerations within the application for ethical approval were to:

1. Ensure the identity of the participants was kept confidential
2. Protect the safety, dignity, and welfare of each participant and ensure the researcher’s safety
3. Ensure that each interviewee had given informed consent to participate in the research (Bartlett and Martin, 2002; Sherratt et al., 2007; Heggestad et al., 2013).

During the data collection and writing of this thesis, I made every effort to protect the privacy and confidentiality of any personal information on my research participants, which is imperative in any social research (Sherratt et al., 2007). Researchers in the UK are governed by the General Data Protection Regulation (GDPR) 2018, which regulates how data is stored and processed. Therefore, the information collection, storage, and disposal follow the GDPR 2018 carefully. To keep the participants’ data secure and confidential by adhering to strict protocols during this research, I ensured that individuals remained anonymous when the data was written up, and any names and addresses were removed. Data stored electronically is saved onto an encrypted device in a password-protected computer at the University of Salford, with only the research team having access to it. I was clear that if I were to suspect any illegal activities or harm during the research process, then as part of my role as the researcher, implicit consequentiality, ethical reasoning, and personal values, I would break this confidentiality; however, I found nothing suspicious. Interviews were recorded using a Dictaphone with participants’ permission to protect confidentiality.

The recordings were transcribed, anonymised, and then uploaded to a secure password-protected drive. All participants were anonymised using a code known only to me. All collected data, such as interview recordings and transcripts, were kept anonymous and coded; hard paper copies of data, including consent forms, were stored in a locked cabinet within a locked room. The research team (my supervisors and I) had access to the data throughout the data collection process. It was stored according to data protection laws and University of Salford policy and held in a password-protected folder. All data transported on computer discs and USB memory sticks were anonymously identified only by a code and encrypted. All dissemination of the data had it written such in a way as to disguise the identity of the research participants involved. Data was not collected from any individual unless prior consent had been gained from the individual concerned. Participants were given assurance that their data will be used only for this study.

Participants were informed that the data will be kept for approximately two years after I obtain the award of the PhD. At this point, all data will be destroyed accordingly. Any decision is entirely voluntary; therefore, the participants have the right to withdraw from the study without prejudice. They were also informed that if any interviewee withdraws from the study, all their information and data collected will be destroyed, and their names will not remain in the study files. However, the cut-off point from the withdrawal is four weeks after the interview; after this deadline, the researcher is not bound to oblige any withdrawal request from any participant.

Throughout the study, I have adopted moral sensitivity to judge each situation morally and ethically (Heggestad et al., 2013 p.32), considering that any interview might cause psychological or physical harm. It was important that no detriment came to participants or any other individual during the data collection within 'the ethical principles of beneficence and non-maleficence' (Bartlett and Martin 2002, p.49) throughout data collection. So, to mitigate any potential risk, I spoke with the family caregivers of participants with dementia to identify any situation that was likely to occur. For example, if the family carer knew that their relative with dementia often became distressed when talking about their past, I did not attempt to speak to them about their life history.

Before the research, I visited individuals with dementia at their homes for them to become familiar and comfortable with my presence. I formed and maintained a high-quality professional relationship with the participants. I did not give out my mobile number, home number, or home email to any participant. The second phase of data collection was undertaken via telephone or online platform, and participants could take part from any convenient location. As interviews with people with dementia in the third phase of this research took place face-to-face when the government's Covid-19 restrictions were lifted and visiting people's houses was allowed; participants were given a choice of any convenient location they wanted. However, all participants with the condition preferred to take part in the research from their own houses. I ensured interviews took place in participants' prepared locations and a safe place, maintaining the research ethics of the University of Salford. I secured the welfare of all the participants, who could leave any time if they did not want to continue the interview. Each interviewee was treated with great respect. Considering participants' health conditions and well-being, I carried out the interviews during an appropriate time when the individuals living with the condition are usually in a good mood. Considering the current pandemic situation, I complied with the University of Salford’s Guidance and national government guidance at every phase of my research. I had clear plan that if any participant would become distressed during the interview, I would stop collecting data immediately and give them time to compose themselves. They had the right to withdraw from the meeting. However, there was no evidence that any participant became upset or wished to withdraw from the project during the data collection. The approach taken was in line with the Mental Capacity Act (UK Government, 2005) provisions designed to mitigate harm to participants. I ensured that my research process would not interfere with an individual's freedom or privacy in a significant way or be unduly invasive. Nobody was forced to take part in the interview if they did not show interest. (The detailed risk assessment is provided in Appendix 10, p.290).

Along with participant safeguards, I was also concerned about my own safety during the whole research process. I understand that the PhD research is a lonely journey that requires an ample amount of time spent in study. Therefore, I considered my health and well-being. I strictly followed the Lone Working Code of Practice, accordingly, designed by the University of Salford. No female participants were interviewed one-on-one, respecting Bangladeshi culture. My wife was always informed of where the interview would take place and my expected return time. I had a plan that if a participant disclosed that there was or would be a risk of serious harm to either themselves or someone else (including myself), then I would break confidentiality, speak to my supervisor, and report this information to the relevant authorities.

Obtaining informed consent is an integral part of any research project involving human participants (Agre & Rapkin, 2003). A person must have enough information about the research and have the power of free choice so that they can voluntarily consent or decline (Polit and Hungler, 1995; World Medical Association, 1964). Informed consent verifies that the person involved in the study understands the aims of the study, their role, the potential risks and benefits of their participation, and the projected outcomes of the research (Agre & Rapkin, 2003; van den Hoonaard, 2002). However, it is a process that becomes complex when it involves individuals living with dementia who may not be able to give their consent to participate in research in a way that can genuinely be considered to be ‘informed’ (Hellström et al., 2007; McKeown et al., 2010; Sherratt et al., 2007). Despite this, a growing body of research suggests that these individuals should be allowed to participate in a research study (Keys et al., 2014). However, the consent process must be tailored to the cognitive abilities of individuals with dementia (Heggestad et al., 2013). Prior to each phase of data collection, I was proactive to gain participants’ consent; therefore, I developed a participants’ information sheet and consent forms that delineate issues such as the purpose of the study, how the results will be presented, the confidentiality and anonymity procedures, data storage, and the participants' right to withdrawal from the interview if they want to. In all three research phases, participants were fully informed of the study and any attendant risks. I sent the information sheet, consent form, and interview guide to each of the potential interviewees via email/post and through gatekeepers and requested them to complete the consent forms and return them to me before the interview began. A person with dementia may consider the usual documents to be too lengthy, complicated, or even non-practical for them. Therefore, considering their cognitive issues, I made a dementia-friendly version of the PIS (participant information sheet), which is very brief and straightforward with key messages (see Appendix 12, p.299).I requested them to complete the consent forms before the interview began. Many of my research participants among the people with dementia and their care partners may be old and not speak English. So, considering their language barriers, I have designed Bangla versions of all interview-related documents, including an information sheet, consent form, and interview guide, and supplied them to each potential interviewee. I understand that it is obligatory to obtain participants' consent prior to data collection (https://www.gov.uk/service-manual/user-research/getting-users-consent-for research); therefore, I never attempted to collect any information from any participant without their written consent. I introduced myself first and said I was the researcher and that I would be collecting data for the study purpose only. Then, I explained to them what data would be collected, what would happen during the research, how I would use the results of the research, what the participants' rights would be, how they could complain, and how I would handle their data. Participants were asked to read my information sheet, and only if they willingly agreed to participate would they sign the consent forms. To ensure participants fully understood what would happen to them during the interview and the information sheet and consent form, I visited participants' houses several times. I talked to them and their family caregivers about their health and memory before the interview.I included them in my research study when it was confirmed that participants could talk and explain what they were being asked to do to participate in this research, and their conversation made sense.

Throughout all interviews with the participants with dementia, as suggested by the process consent procedure (Dewing, 2008b), I paid careful attention to the participants' body language to ensure they understood the research and willingly participated. If this had appeared not to be the case, I would have been prepared to discuss this with them and emphasise that they would have been able to leave the interview irrespective of having given written consent.

I used Dewing's (2007) continued consent process to interview people with dementia to answer specific research questions. Hellstrom et al. (2007) suggest that it is essential to consider a process for gaining their consent, which should be used each time the person takes part in the research, rather than just once (Hellstrom et al., 2007; Nygard, 2006; Dewing, 2002; Pratt and Wilkinson, 2001). The continuous consent process enables the researcher to review and re-establish initial informed consent moment by moment depending on the individuals' inclination to participate (Dewing 2002; 2007). As a result, participants were able to dip in and out of participation in the project as they wished. Their willingness (or not) to participate was judged continuously by listening to them and observing their body language. Family members were made aware that participants with dementia could withdraw from the research at any time if they wished to do so. I asked family members and caregivers before each virtual/telephone interview to ensure that the person living with dementia was capable of participating in an interview. I asked them what stage of dementia their relative was at, their cognitive abilities, or how well the person with the diagnosis functioned. To ensure participants' continued permission to participate in the study, I introduced myself and asked for the participant's agreement to interview before the beginning of each day. In addition, I sought verbal consent before engaging participants in an interview, which is the principle of best practice in research with people living with dementia (Dewing 2002; 2007). Permission to participate was continually renegotiated. For example, even though we agreed on a fixed time for an interview before I met a participant with dementia, I phoned them or asked if it was the best time to talk and whether I should go some other day. Following the ethical principles of avoiding harm or distress to participants (Bartlett and Martin 2002), interviews or conversations were suspended if a participant appeared to become upset or seemed as though they did not wish to take part.

Before recruitment of the person living with dementia occurred, I met their family caregivers and asked them to consider whether the person with dementia was happy to talk about their life and whether there was anything from their past that they might not wish to be reminded of. This understanding of the biography of the participant before meeting the person with dementia provided me with clues about how the person usually presents themselves when in a relative state of well-being (Dewing 2007). Hubbard et al. (2003) suggest that a pre-meeting may be helpful to get to know the person and to assess their abilities.

In Phase One of this research, I collected the contact details of some dementia support organisations from websites and other social contacts and contacted the managers or heads of the organisations over the phone or by email. I introduced my PhD topic, built some rapport with them, and then sent the Personal Information Sheet, Consent Form, and Interview Guide via email and requested that they return the Consent Form when they had signed it.

In the second phase of research, I emailed or posted an information sheet, consent form, and interview guide to each potential interviewee and requested them to complete the consent form and return it to me before the interviews began.

In the final phase of the data collection, I verbally explained the research to each person with dementia. I also kept a note listing appropriate words to be used; as Cowdell (2008, p.32) notes, trying to find the right words without being patronising can be very challenging. Ultimately, I established evidence to account for the methods I

used to indicate the person was giving consent. I critically reflected on the degree of consistency between facial expression or body language with how permission was granted for inclusion in the research and how it was usually given in day-to-day life.
Data collection was carried out respectfully with an approving atmosphere. Even though there were difficult subjects to discuss, attention was paid to supportive resources, such as access to dementia services and how they are living with it.

The interviews were intended to be conducted one-on-one, mainly, so that no one would interfere with individuals' voices being heard (Pesonen et al., 2011, p.655). However, if the study participants preferred joint interviews, they were planned according to their wishes. Some research suggests that joint interviews feel safer than an individual discussion with people with dementia, partly because family carers can provide support if needed, partly because those with dementia want an open and sincere interview with someone close to them participating (Pesonen et al., 2011, p.655). I had a clear plan as to how to ensure I valued the views and the perspectives of participants while also maintaining neutrality towards them. For example, If a disagreement were to take place between the person with dementia and the family caregivers, then I would allow both participants to express their point of view by asking questions when necessary or offering a neutral interpretation of the issue. This unbiased interpretation would lead to further development of the conversation with both study participants.

I kept evidence that consent had been continually monitored by maintaining an audit trail explaining what decisions were made and what actions taken (Cowdell, 2008). I also regularly assessed the person's choice to continue in the interview and revisited the initial consent and re-established it on every occasion or even within the same event (Butterworth, 2005; Dewing, 2007).

The participants were kept involved and updated by face-to-face contact. I have ensured that anything the person with dementia would want to be kept confidential will remain so. However, the families and carers were provided with necessary feedback, if the people with dementia agreed beforehand. All interactions with participants and their family members/caregivers were noted in field notes, and issues for further discussion were taken to supervisors. With research involving vulnerable people such as persons with dementia, many researchers often face ethical and practical challenges, including identifying potential participants, assessing mental capacity, and obtaining informed consent (Sherrat et al., 2007). Therefore, suitable preparation for interview guide development is vital for a researcher, and it underpins the interview process and influences the research stages (McIntosh & Morse, 2015). I developed an interview guide with topic questions before each phase of the research (see Appendix 13, p.300; Appendix 9, p.287 and Appendix 7, p.281; Table4; p.102).

Table 4: *The following table summarises the interview questions (mapping with my research questions and the conceptual framework of stigma):*

Participants with dementia were asked the following topic questions:

1. When and how did you realise something was going wrong with their memory? When and how were they diagnosed with dementia? Did you know what dementia was before you were diagnosed with it?

2.Have you noticed any societal reaction to dementia since your diagnosis. Did dementia in some way affect your social life?

3. Can you tell me your experiences with dementia. What were the key issues and challenges attached to accessing dementia services, and what kinds of support are lacking?

Interviews with the family caregivers: Topics guided the interview:

1. When and how did the person with dementia they care for come to have a diagnosis? Did they know what dementia was before this person was diagnosed?

2. Did the caregiver see any societal reaction to dementia since their relatives with the condition were diagnosed? Did dementia somehow affect their social life or the life of the person with dementia?

3. Participants were asked to discuss their lived experiences as family caregivers of a person with dementia. What are the key issues and challenges attached to accessing dementia services, and what kinds of support are they lacking?

Service providers/professionals were asked the following topics questions:

1. The stakeholder's/service provider's views about the knowledge and beliefs of people with dementia in this Bangladeshi Community.

2. Their views/experiences about service use by this community and engaging with services before/during/post-diagnosis compared with the homogenous British Whites.

3. Their views about the support provided and if there are any gaps.

4. Their perception of the stigma of dementia, and suggestions to overcome it.

5. If there is any barrier to access to dementia services for the people of the Bangladeshi community.

The Conceptual Framework of Stigma guided the following four analytical questions during all three sets of interviews:

1. Are there core components of stigma i.e., labelling, stereotyping, separation, status loss, and discrimination happens in the Bangladeshi community because of dementia?

2. Do people of dementia experience any of these four types of stigma i.e. individual, societal, and institutional reactions to dementia?

3. What do we know about the stigma of dementia in the South Asian communities

The interview guide was designed to give a range of considerations such as the likelihood of memory impairment, the participant's health issues, the researcher's health, covid-19 impacts, confidentiality, data protection, prevention of potential harm, finding the right timing for an interview, and ensuring the participants' well-being. This guide included some introductory statements to remind participants about the interview's general focus (Cridland et al*.,* 2016). Mapping with the research objectives, questions were asked of each interviewee. There were three different participant groups participated in this research study.

Participants with dementia were asked to explore their experiences with dementia, ascertain their views about the support provided, identify gaps, and explore whether or not dementia is stigmatised in this Bangladeshi community and how the stigma may impact their daily lives. Participants among the family carers of the people with dementia were interviewed to explore their understanding of dementia and their experiences of the caregiving journey for people diagnosed with dementia from this Bangladeshi community; explore their experiences with dementia; ascertain their views about the support provided, identify any gaps, and explore whether or not dementia is stigmatised in this Bangladeshi community; and how the stigma may impact the lives of people with the condition. Participants from the dementia stakeholders/service providers were interviewed to explore the views of stakeholders/service providers about the support provided and determine if there were any gaps. Participants were also asked for their views about the knowledge, beliefs, and help-seeking attitudes of their service users from a Bangladeshi community. They were requested to explain whether or not dementia is stigmatised in the Bangladeshi community and how the stigma may impact the lives of people with the condition.

In Phase 1, interviews were held face to face, maintaining Covid-19 restrictions. In Phase 2, I interviewed the family caregivers of people with dementia by telephone only, in consideration of the current Covid-19 impact. However, during the third phase of data collection, government social distancing restrictions were lifted; therefore, interviews were conducted face–to–face in participants' houses based on the university’s ethical guidance. Each interview lasted approximately 50-60 minutes. The interview location was chosen with careful thought after negotiating with the participants. Such considerations were a matter of convenience for interviewees but did also factor in recording quality issues. Herzog (2012) notes that a focus on interviewee comfort alone can depoliticize locational factors in interviews as spaces for the playing out of power inequalities between researcher and interviewee. Therefore, arranging locations involved subtle negotiations between my preference for meeting in public places for safety reasons and giving participants agency to determine the setting (Crang & Cook, 2007).

Participants were, as I have indicated, informed that if anyone wanted to withdraw from the study, their names would be removed from the research files, and all the information and data collected from them would be destroyed. Any decision is voluntary; therefore, participants had the right to withdraw from the study if they wanted to do so without giving a reason. However, the cut-off point from removing was one month after the interview, allowing me time in such circumstances to recruit new participants, analyse the data, and change my findings. However, nobody asked to withdraw or asked me to exclude their interview data from the research. I did develop Topic Guides to discuss with the participants during the interviews (see Appendix 7; p.281 and Appendix11; p.295).

With all three of my participant groups, I established good relationships and built rapport with the interviewees based on trust, warmth, and empathy (Bartkowiak, 2012). I anticipated the participants' needs, and maintained consistent contact, stayed visible, found a chance to chat, and took time to listen to their concerns. Rapport is the ability to communicate with others to create a climate of trust and understanding. It gives the power to value others' opinions and understand and accept others' feelings (Knight, 2009). Maintaining a good rapport between the researcher and participant helps generate rich data while also respecting researcher and participant (Guillemin & Heggen, 2009). Therefore, considerable attention was given to this, and great care was taken during the interview. Molden (2011) argues that without understanding and trust, people may be sceptical and suspicious. Therefore, to create a good rapport with my research participants, I was open-minded, flexible, reassuring, friendly, genuine, warm, sincere, empowering, respectful, sensitive, and empathetic towards the interviewees (Leach, 2005). I contacted my participants via phone at least once before the interview, and explained the purpose of my study, etc., honestly in order to ensure a good a first impression. I increased the inflow of conversation, relaxed my body language, increased eye contact, and improved listening and responsiveness (Leach, 2005; Elliott & Martin, 2013). When communicating with the participants, I was always an active listener during the ice-breaking session and in the interview through verbal cues ("hmmm", "yah", "right") and non-verbal encouragers such as eye contact, nodding, and leaning forward. The participants felt that I was interested in what they were trying to say or do and, in turn, this gave them courage. (Hull, 2007).

Before the interview, I asked each participant (for all three groups) for permission to record the interview, as this will record all conversations accurately. All interviews were transcribed verbatim. Verbatim transcription is time-consuming: for instance, for every hour of taped interview, 6 to 7 hours of transcription may be required (Britten 1995). However, it was practicable for my study, as I had only 25 interviews to transcribe. My transcription process focussed more on interpretation and generating meanings from the data and was not simply a clerical task (Cluett & Bluff, 2006).

The interviews were conducted in English or Bangla based on the participants' preferred language, and each meeting lasted around 50-60 minutes. I am fluent in Bangla and English; therefore, I translated and interpreted all the interview transcripts; however, if any participant used a word with no synonyms to English, I asked the participant to explain this further. If it is possible to describe, I have done so as Bangla is my first language. All the interview-related materials, including Participant Information Sheets, Consent forms, and Interview Guides, were provided in both languages.

In this study, research participants were volunteers; therefore, I was not obliged to reimburse the interviewees in any way. No travel expenses were involved in this study because participants were interviewed within their own locality. However, I was willing to pay a taxi fare if any participant claimed it.

I will disseminate the findings at local community events, such as mosques, temples, and the Alzheimer's Society. I will present my research findings at various conferences and publish this in relevant peer-reviewed journals.

3.4. Data Analysis

Data Analysis is ‘a process of reducing a large amount of collected data to make sense of them’ (Kawlich, 2015, p.97). It enables the researcher to convert raw data into a story (Lecompte & Schensul, 1999). It also provides the researcher guidance on interpreting large amounts of qualitative data and ensuring that the data are thoroughly analysed (Murphy et al., 1998). This thesis used thematic analysis, which is a widely used method for categorising, examining, and reporting themes in data (Braun and Clarke, 2006; Spencer et al., 2014). It is a valuable method to explore the viewpoints of different research participants, scrutinise the similarities and differences, and produce in-depth insights (Braun and Clark, 2006; King, 2004). Braun & Clarke (2006, p.78) define thematic analysis as 'a process of identifying patterns or themes within qualitative data that provides core skills that will be useful for conducting many other kinds of analysis' (Braun & Clarke, 2006, p.78). This type of analysis helps highlight the most significant patterns present within a body of data concerning the focus of a study (Joffe 2012). As an analysis method, it emphasises an understanding of respondents' subjective experiences through obtaining a complete description by allowing them to express their experiences freely and in their own words (Guest & MacQueen, 2012). This method offers the researcher many advantages as it is flexible and can summarise the salient points of an extensive dataset while facilitating a richness and depth within those findings (Braun and Clarke 2006). It enables the researcher to explain the dataset in rich detail and interpret different aspects of the research topic (Boyatzis, 1998). Moreover, the thematic analysis steps are easy to follow but rigorous enough to generate meaningful findings from the data (Braun & Clarke, 2006; King, 2004). This method offers a more accessible form of analysis and is easily grasped and can be learned relatively quickly, with a few directions and procedures (Braun & Clarke, 2006).

Clarke and Braun (2013) suggest that thematic analysis (TA) is appropriate from a theoretical perspective for four reasons:
(a) it works with a wide range of research questions, from those about people’s experiences or understandings to those about the representation and construction of particular phenomena in particular contexts.
(b) it can be used to analyse different types of data, from secondary sources such as media to transcripts of focus group conversations or interviews.
(c) it works with large or small datasets; and

(d) it can be applied to produce data-driven or theory-driven analyses (p.120).

Themes or patterns within data can be identified in one of two primary ways in thematic analysis: via an inductive approach (e.g., see Frith & Gleeson, 2004), or in a theoretical or deductive way (e.g., see Boyatzis, 1998; Hayes, 1997). Braun & Clarke (2006) suggest that any researcher doing TA must decide what form of TA they will use and understand why they are using this specific approach.All data analysis took an inductive approach as the themes identified by these techniques are strongly linked to the data themselves (Patton, 1990); no prescribed codes or themes were prepared before analysing the data. To create a preliminary list of ideas related to the data, I organised my data into significance groups and gave the initial codes to the data (Braun and Clark,2013). At first, it had a long list of codes (See appendix18). However, I have gradually brought similar codes under a set meaningfully; I gave a name to each set and wrote a consistent explanation for those names separately (See appenix18). Thus, I sought themes from these codes (Braun and Clarke, 2006). The themes identified explicitly address the research question, while the coding framework was flexible enough to allow themes to emerge naturally during data analysis (Joffe, 2012). Given the flexibility and ease of organising large data volumes, I decided that TA was the most suitable method for data analysis.

All data were transcribed verbatim. I read all of them to “get a feel” for what seemed to be the main issues emerging from the data. I ensured that I had transcribed what the participants had said. For instance, if the participant’s quotes are used, the researcher has put the verbatim quote, then explained it, if necessary, in square brackets afterwards. My data analysis adopted Braun & Clarke’s (2020) six steps of data analysis procedures, as follows:

1. Data familiarisation and writing familiarisation notes.
2. Systematic data coding.
3. Generating initial themes from coded and collated data.
4. Developing and reviewing themes.
5. Refining, defining, and naming themes.
6. Writing the report.

As part of familiarising myself with the data, I transcribed all of the interviews. I conducted all the interviews with the participants, which already made me familiar with the data. I made reflective notes on each interview, noting my initial thoughts and comments in the right-hand margin. In preparing the transcription, I recorded all verbal utterances verbatim. I also included some non-verbal data if I felt they would help provide a ‘truer’ account of the conversation. This process helped me gain a better grasp of the data and begin understanding and interpreting it. For the transcribed data, I made sure I read the transcript while listening to the recordings, which enabled me to check the transcription for accuracy and ensured I became more familiar with the data. Once all of the data had been transcribed, I read through the entire dataset twice more to become accustomed to it and begin the interpretative process. I repeatedly read the transcripts to work closely with the text, highlighted information of interest, and made notes in the left-hand margin.

I have used a thorough, inclusive, and comprehensive coding process to extract themes from the data. I have highlighted the relevant paragraph/lines or phrases in yellow, mapping with my research questions, and put the code in a comment box (See Appendix 18, p.308). I paid equal attention to all interview data. I scrolled through and looked for the key messages; I avoided having too many sub-codes that I do not need. Using the 'interview' as a frame, I paid full attention to my research questions, though I have some data within these interviews that do not concern my issues directly; they nonetheless tell us of something important. I drew some tables with the codes in one column and examples of the quotes aligning to these codes in the next column. I frequently revisited the themes and accordingly reorganised the overarching themes from this collection of interviews. Initial codes considered to be similar were reduced and merged to generate new codes. I repeated this exercise until the generated codes specifically and meaningfully reflected the interview data

This research phase also followed Braun and Clarke's (2006) criteria for performing proper thematic analysis by using a 15-point checklist that offers a clear and usable framework for undertaking thematic analysis (see below):

Consistency and validity were obtained by sharing the anonymised data with my supervisory team. The codes were categorised into themes and sub-themes by writing them down on post-it notes. These were organised and re-organised until key themes accurately represented the data. To obtain reliability, I shared the thematic mapping with my supervision team and revised it for clarity. Regarding searching for themes, Braun and Clarke (2006) posit that this phase involves sorting the different codes into potential themes and collating all of the relevant coded data extracts within the identified themes. I labelled each code with a short description and then organised them into theme piles. Finally, I developed tables, where I had the codes in one column and examples of the quotes that fit under these codes in the next column. Potential themes were reviewed and merged by re-reading specific information from the transcripts from which the codes and themes had been derived. All relevant extracts for each theme were organised logically (see Appendix 18, p.295). I made sure that themes are internally coherent, consistent, and distinctive. Then, I had a detailed discussion with my supervisors about the coding process; they have done a sense check with me. I reviewed potential themes and merged them by re-reading specific information from the transcripts from which codes and themes had been generated. I paid particular attention to whether the themes sat together meaningfully and whether there was a clear and identifiable distinction between the themes (Braun and Clarke, 2006). As part of this process, I read each of the themes to ensure a coherent pattern. I removed specific data extracts and either applied them to another theme or discarded them from the analysis. Once I was satisfied that I had developed a thematic map, I re-read the data set to ascertain whether the themes sat well with the rest of the data and to code any additional data within themes that were missed in earlier coding stages. I also provided my supervisors with a list of the codes and themes to enhance the rigour of my analysis. I had developed a set of themes that sat together well and provided an overall story of the data. As part of naming and defining the themes, I created sub-themes to provide a structure to the large and complex themes. The themes included in the final analysis were clarified and described at this stage, explaining what each theme told us and how this related to the research topic while using quotes from the interview transcripts to support this. In thematic analysis, the researcher is expected to go beyond words in an attempt to explain the underlying meanings of data and to correctly tell the story of what the data means, to make sense of the information truly, and to accurately represent participants' stories (Glaser, 1965;

Braun and Clark, 2006). Finally, I reframed my story around the themes, pieced all this together, and wrote a report in the manner of telling a story.

Table5: *Braun and Clarke's (2006) criteria for performing proper thematic analysis using a 15-point checklist:*

Transcription	**1.**	**The data was transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.**
Coding	2.	Each data item was given equal attention in the coding process.
	3.	Themes were not be generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive and comprehensive.
	4.	All relevant extracts for all each theme were collated.
	5.	Themes were checked against each other and back to the original data set.
	6.	I ensured themes are internally coherent, consistent, and distinctive.
Analysis	7.	Data was analysed rather than just paraphrased or described.
	8.	I ensured that analysis and data match each other – the extracts illustrate the analytic claims.

	9.	Analysis tells a convincing and well-organised story about the data and topic.
	10.	A good balance between analytic narrative and illustrative extracts was provided.
Overall	11.	Enough time was allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once over lightly.
Written report	12.	The assumptions about the thematic analysis was clearly explicated.
	13.	I have ensured that there is a good fit between what I claim I do, and what I show I have done – i.e., described method and reported analysis are consistent.
	14.	I have ensured that the language and concepts that will be used in the report are consistent with the epistemological position of the analysis.
	15.	I was positioned as *active* in the research process; themes do not just 'emerge'.

Research with a qualitative element is sometimes criticised for lacking scientific rigour (Noble and Smith 2015). However, by using a systematic approach to data collection and analysis, it is possible to find out about the lived experience of individuals in a reliable and rigorous (albeit subjective and relative) way (Hanson, 2008; Ormston et al., 2014). To attain rigour and trustworthiness in quantitative research, the positivist school seeks to satisfy specific criteria to ensure accurate analysis. For example, they provide Internal Validity, External Validity, Reliability, Generalisability, and Objectivity (Guba and Lincoln, 1994; Ali et al., 2012, p.30). Reliability and Validity are crucial requirements (Morse et al., 2002) that increase transparency and decrease opportunities to insert researcher bias in qualitative research (Singh, 2014). Spencer et al. (2003, p. 65) define reliability as whether another researcher investigating the same issue or working with the same data set would derive the same findings. Reliability indicates the consistency, stability, and repeatability of the informant's accounts and the researcher’s skills to truthfully collect and record information (Selltiz et al., 1976, p.182). However, validity in qualitative research shows consistency and trustworthiness about activities and events related to the phenomenon, as signified by the inquiry results explored in the study (Golafshani, 2003).

On the other hand, social constructivists have developed different criteria and frameworks (Patton, 2005; Putton, 1999; Flick, 2008; Silverman, 2001). Many of them use the terms credibility, trustworthiness, truth, value, applicability, consistency, conformability, etc., instead of validity and reliability, for evaluating the scientific merit of qualitative research (Glaser and Strauss, 1967; Leininger, 1991; Lincoln & Guba, 1985). Guba and Lincoln (1985) constructed the following four criteria: credibility, transferability, dependability, and conformability (Lincoln and Guba, 1985; Shenton, 2004). Credibility in qualitative research means that the researcher has expressed an accurate picture of the phenomenon under study (Shenton, 2003). Transferability means the researcher has shown adequate detail of their fieldwork during the research (Shenton, 2003). Meeting the dependability criterion is difficult in qualitative work, although researchers should strive to enable a future investigator to repeat the study (Shenton, 2003). However, to reach confirmability, researchers must take steps to show that their findings emerge from the data and not their predispositions (Shenton, 2003).

Despite this, there remains no consensus regarding how rigour may be judged within a qualitative approach (Rolfe 2006). Therefore, Noble and Smith (2015) have developed a strategy by which researchers using qualitative methods might ensure credibility and rigour. This strategy highlights the importance of acknowledging personal bias (see also Braun and Clarke, 2006) and bias in sampling, which may influence the findings. Detailed record keeping, demonstrating a clear decision trail and thought processes during the data analysis, representing all aspects of the data, and including rich verbatim quotes is also imperative, as is engaging with other researchers and participants to validate findings (Nobel & Smith, 2015, p.2). Within this study, this strategy was followed as far as was possible. Further analysis of how this strategy was applied during the research process is offered within the discussion of this thesis (Nobel & Smith, 2015, p.191).

This study has ensured the following provisions to attain trustworthiness, drawing on Guba's (1985) four criteria.

Table 6: *Provisions of Trustworthiness based on Guba (1985); Shenton (2004); Putton (1999), Silverman (2001); Khayyat (2017).*

Qualitative Criterion	Provision to be made by the researcher
Credibility : **(Internal Validity)**	1. Adoption of appropriate well recognised research methods for gathering high-quality data that will be carefully analysed. 2. Development of early familiarity with the culture of participating individuals. 3. Iterative questioning in data collection dialogues. 4. Debriefing sessions between researcher and superiors. 5. Peer scrutiny of the project. 6. Use of "reflective commentary". 7. Description of background, qualifications, and experience of the researcher. 8. Member checks on data collected and interpretations/theories formed. 9. Thick description of the phenomenon under scrutiny. 10. Examination of previous research to frame findings.
Transferability: **(External Validity/Generalisability)**	1. Provision of background data to establish the context of the study and detailed description of the phenomenon in question to allow comparisons to be made. 2. The number of individuals taking part in the study and where they are based. 3. Any restrictions on the type of people who contributed to the data. 4. The number of participants involved in the fieldwork. 5. The data collection methods that were employed. 6. The amount and length of the data collection sessions. 7. The period over which the data was collected.
Dependability: **(Reliability)**	1. In-depth methodological description to allow the study to be repeated.

Confirmability: **(Objectivity)**	1. Admission of researcher’s beliefs and assumptions. 2. Use of diagrams to demonstrate “audit trail”. 3. Recognition of shortcomings in methods of the study and their potential effects. 4. In-depth methodological description to allow the integrity of research results to be scrutinised.

3.5. Researcher’s Insider/Outsider Positionality and Reflexivity

This section reflects on my positionality and reflexivity in relation to this study. According to Kim (1994), a researcher's positionality and biography directly affect research fieldwork. Reflexivity is considered an integral aspect of qualitative research. It involves making researchers understand how the process of doing research shapes its outcomes; therefore, researchers need to appraise their research methods critically and engage in methodological reflexivity (Hardy et al., 2003). From the onset of this study, I have contemplated how and where I would be positioned within this research investigation. "Positionality refers to how others position the individual identity and affiliations they may have. This can have a bearing on whether the researcher acquires the position of an 'outsider' or an 'insider'" (Sanghera and Thapar-Bjorkert, 2008, p.553). Tinker and Armstrong assert that researchers are always both insiders and outsiders in every research setting and are likely to oscillate between these positions as they move in and out of similarity and difference, both within and between interviews. (Tinker and Armstrong, 2008, p.54). Liamputtong writes that the insider and outsider status, as I have suggested, may shift at a particular moment of one’s fieldwork, and this may mean that one needs to reconsider one’s research process repeatedly (Liamputtong, 2010, p.133). It has been documented that the intentions of some minority ethnic researchers and how their findings are utilised has been considered with suspicion by participants from the same race and ethnic groups and cultural affiliation as the researcher (Kusow, 2003; Tillman, 2006).

I was born in Bangladesh; I have worked as a Muslim cleric in the UK for the past two decades and delivered over a thousand sermons. My own past has enabled me to form good links within the Bangladeshi community in my research area. To complete my Master's at Loughborough University, I undertook a Muslim chaplaincy and spiritual care project and worked for 60 hours on placement in hospitals in Greater Manchester. That pointed me towards helping and supporting older people and learning more about aging. Through conversations with many of the elderly who regularly visit the mosque, I heard stories about their struggles with their memory problems. They often forget to pray, ask the same questions repeatedly, and face difficulties in their social lives. My experiences working with South Asians, especially with the Bangladeshis, led to my interest in qualitative research to learn more about people with dementia and to understand their support needs. A few years ago, one of my uncles succumbed to dementia. My father was also diagnosed with vascular dementia. I was afraid that I might develop such a condition in the future because of my genetics. Therefore, I obtained some dementia training from the Alzheimer’s Society and eventually became a dementia champion. Later, I studied some MOOC programmes from the University of Tasmania, Australia, on dementia and how to prevent it. These courses further motivated me towards this research project on dementia. After all this, I incorporate additional information from the literature review, which initially set out to understand the support needs of people with dementia in the UK Bangladeshi community.

Before beginning my data collection, I assumed that recruiting participants from among the people with dementia and their family caregivers would be perhaps the most challenging part. However, my ethnicity and religious background gave me the privilege of insights into their perceptions and understanding of the verbal and body language of the research participants that other researchers might not have (Gilgun and Abrams, 2002; Labaree, 2002). Carter and Bolden (2012) state "the significance of the researcher obtaining "insider" or "outsider" status varies depending on the topic of discussion and participants' perceptions of the researcher" (p.264). Stanfield (1998) argues the researcher's autobiography, culture, and historical context is of great significance as this determines what the researcher is and does and does not see, in addition to their ability to analyse data and disseminate knowledge adequately.

Stanfield notes that people of colour, women, and others traditionally outside the domain of research authority have argued that only those researchers emerging from the lifeworlds of their "subjects" can be adequate interpreters of such experiences. (Stanfield, 1998, p.335). Plummer (2011) writes of "tensions over the differences across cultures and languages we are born into which are the limiting horizons of our thinking and practices" (p.209). I was born in the Sylhet Division of Bangladesh, the homeland of around 90% of the UK Bangladeshi community (Hossain, 2017).

I underwent my undergraduate study in Bangladesh (1998), where Bangla literature was one of the compulsory modules. I can communicate with others in Bengali, Sylheti (dialect), and English fluently. My insider role facilitated interviewees to interact freely and encouraged them to share problems as the participants and the researcher shared culture, religion, and a common language (Gibson and Abrams, 2003; Anderson and Jack, 1991). Being an insider increases validity via understanding and closeness with participants in the research study (Kanuha, 2000).

I acknowledge that I am not a bio-medical doctor by profession, whereas dementia is a neurological disorder; therefore, some participants may have considered me an outsider. Merriam et al. (2001) write that previously it was assumed a researcher was predominantly either an insider or an outsider, each of which resulted in corresponding advantages and disadvantages. However, now there is recognition that the boundaries between these two positions are not clearly delineated, and there are complexities within either status. Merriam et al. (2001) note that it has commonly been assumed that being an insider means easy access, the ability to ask more meaningful questions and read non-verbal cues and, most importantly, project a more genuine, authentic understanding of the culture under study. On the other hand, insiders have been accused of being inherently biased and too close to the culture to be curious enough to raise provocative questions. The insider's strengths become the outsider's weaknesses and vice versa. The outsider's advantage lies in curiosity at the unfamiliar, the ability to ask taboo questions, and being seen as non-aligned with subgroups, thus often getting at more information. (Merriam et al., 2001, p.411).

Conducting semi-structured interviews, I realised that most family caregivers/care partners from the Bangladeshi community are women; therefore, I tried to recruit more women participants purposefully in the second phase of data collection. Out of ten interviewees (carers), five of them were women. I have cautiously undertaken cross-gender interviews as gender is an essential factor within the particular socio-cultural context, where segregation by gender is the norm. (Pini, 2005; Jarviluoma, Moisala and Vilkko, 2003). I talked to the male family members of a female participant first before speaking to a female participant. Among the seven participants, two were male, and three of them were women over 60 years old, such that it was simple to talk to them. However, two female carers were young (married, 30-year-old) women. I spoke to one woman's mother first, and she passed the phone to her daughter for an interview with me.

Ryan et al., (2011) paper focusing on the insider/outsider status of peer and academic researchers in researching British Muslim communities highlights an insider peer researcher’s experience. He was employed because of his location within a specific religious and ethnic community and found that participants regularly positioned him as an outsider because of his physical appearance and dress. Far from being recognised and accepted as an insider, he frequently had to tell participants he was, in fact, 'one of them.' (Ryan, 2011, p. 55-56). The authors above note one advantage of being outsider researchers was "people tended to assume that we knew little or nothing about their culture, attitudes, religion, lifestyles, family structures… rather than assuming any shared understanding, they tended to explain things to us in detail" (Ryan et al. (2011, p.57). I suggest that despite careful planning regarding researcher positionality, the participants, the researcher, and the research process itself will determine where the researcher, and indeed the researched, are placed in each study. Throughout the research process, I maintained clear and firm boundaries with the participants, and I only engaged with them in a research capacity.

Egharevba (2001), a first-generation British-born Nigerian woman, writes that she dressed conservatively when meeting research participants who were women of South Asian heritage and all, except one, practising Muslims. She ensured her arms and legs were covered with clothing that was not too revealing, fitting, or tight. To illustrate my respect towards the participants' religious and socio-cultural beliefs, facilitate the research engagement, and reduce some visible barriers, I also took care in my dress code when meeting the participants. For instance, I did not wear any T-shirts, sleeveless shirts, short trousers, or clothing such that my arms and legs were exposed.

Quraishi (2008) draws attention to the dilemma he experienced as a British Muslim researcher greeting Muslim male participants detained at some prisons in England. Due to the prison environment and researcher boundaries, he could not exhibit some of the customary physical greetings between Muslim men, i.e., firm handshaking, kissing the cheeks, hugging, et cetera. Instead, he would place his right "outstretched palm to them and wave by way of 'salaam'" (Quraishi, 2008*,* p. 462). He then incorporated this into a more heartfelt and sincere greeting by "folding the arm inwards to rest on the heart" (Quraishi, 2008*,* p.462). The experience I read about may have indicated I was an outsider in my acceptance of what may be considered cultural norms regarding greetings. However, I was mindful of my personal space being encroached on without my consent, and I wished to have clearly defined professional boundaries yet offer them a welcoming gesture. Due to my insider awareness, I was attentive to the fact that some Muslim men will not shake hands with a female researcher due to their religious beliefs, which is also documented by Al-Makhamreh and Lewando-Hundt (2008). As suggested by Tillman (2006), I cogitated upon the extent of my own "cultural knowledge, cross-race and same-race perspectives, and insider/outsider issues related to the research process" (p. 269). During the interviews, I was mindful of the research relationships: gender, ethnicity, power, language, education, socioeconomic status, regional and language inflection, employment, religiosity, age, appearance, culture, and subculture variations. I suggest that, to some degree, the participants would have noticed this too. Spoken and unspoken negotiations took place for both parties to facilitate developing a mutually meaningful research experience. I verbalised to each participant that there were no correct or incorrect answers to the questions. It was made explicit to them that they were under no obligation to answer any question they might feel uncomfortable with, and I welcomed any questions regarding the research study and interview process.

One could argue that my biography and close relationship with the interviewees could influence my subjectivity or cultural bias during participants' responses and influence my interpretation of the collected data as qualitative research depends on the researcher's experience and judgment (Seale, 2012). Irvine, Roberts, and Bradbury-Jones (2008) acknowledge that researcher intimacy may result in complacency, and overfamiliarity may result in loss of objectivity and a disregard of specific nuances. However, they argue that insider researchers can immerse themselves in the original data and, if bilingual or multilingual, can mediate between linguistically diverse datasets; this may provide insight and clarity to the interpretive process. (Irvine, Roberts and Bradbury-Jones, 2008, p.44). Nevertheless, to avoid my subjective influence on the participants, I took many careful steps in my approach. For instance, I formed my research design cautiously and recruited participants from different age groups and both genders. My views correspond with Kusow's assertion: We must not see insider/outsider identities as predetermined roles, but rather as a result of the nature of the research topic under investigation, the status characteristics and biographical particularities of both the researcher and the participant(s), and the local conditions in which the fieldwork takes place. (Kusow, 2003, p. 598).

In my opinion, regardless of whether researchers are insiders or outsiders, they must remain focussed upon their role and responsibilities as researchers without entering into advice-giving positions. Otherwise, this could contribute to a significant power imbalance and reduced egalitarian dynamic in the relationship, with the possibility of the researcher being positioned in a superior and expert status. I was always a good listener and asked the participants questions so that my body language would not influence their responses. I checked all of the University of Salford's ethical guidelines accordingly to make sure my research was rigorous. I recorded all of the interviews, transcribed them verbatim, and included all of the results. I followed my interview guide but did not force interviewees into a limited set of answers; instead, they could freely provide information.

Due to the research topic, the persons being researched, and my interest, throughout this research I reflected upon how I might have affected the research participants, my interpretations, and my understanding of the findings. I am aware that the participants impacted me, and I suggest that the converse will have occurred. Alvesson and Skoldberg (2009) in referring to reflexivity write that "there is no one-way street between the researcher and the object of study; rather, the two affect each other mutually and continually in the course of the research process" (p. 79). Mason (2002, p.7) writes that qualitative research should involve critical self-scrutiny by the researcher, or active reflexivity. This is based on the belief that the researcher cannot be neutral or objective, or detached, from the knowledge and evidence they are generating. I concur with Braun and Clarke's (2013, p.328) argument that researcher "bias as a concept does not apply as a valid critique of qualitative research". The authors suggest the researcher's humanness and subjectivity can be utilised as a research tool by being reflexive. I have endeavoured to engage with and share my reflexivity throughout the research process.

3.6. Strengths

My background and experiences enabled me to relate to my research participants and build rapport with them, key to gaining access to the research samples. My positionality and multi-linguistic skills facilitated my collecting, translating, transcribing, interpreting, and analysing the data from the research participants directly, all of which have been invaluable in limiting translation difficulties and improving the quality of the transcribed data (Temple and Young, 2004). I can speak English, Bangla, and Sylheti dialects smoothly, and I was born in the Sylhet division, where most UK Bangladeshi immigrants came from, which has facilitated accessible communication. I understand the phrases and idioms of the Sylheti dialect the participants used. It could be challenging for other Bangladeshi researchers if unfamiliar with the Sylheti language and culture. For instance, many words the participants with dementia and their carers used will not be found in the Bangla dictionary, such as "*upri*," "*boyar*," "*ferot*," "*nobodong*," "*fawrilai*" etc. However, my strength could also be a potential limitation because participants might not tell me something; they would explain better to a researcher they consider an outsider.

3.7. Covid-19 Impacts:

This research was initially designed before the Covid-19 pandemic. After I applied for ethical approval, pandemic restrictions were enforced by the government of the UK, which impacted my research study. 23 March the PM announced the first lockdown in the UK, ordering people to “stay at home,” then 16 April lockdown was extended for ‘at least’ three weeks. However, I obtained ethical approval from the University of Salford on 2 June 2020, whereas on 23 June the PM said the UK’s “national hibernation” was coming to an end – he announced a relaxing of restrictions and the 2m social distancing rule. After the restrictions were eased, then I started face-to-face data collection from the stakeholders and service providers. By mid-July, I had finished my first phase of data collection. However, I was advised by my supervisors not to start recruiting participants in Group 2 (carers), or Group 3 (people with dementia) face-to-face until the university allowed me to do so. The government imposed stricter restrictions (Tier 3) in Greater Manchester in 20 October 2020, whereby visiting people's homes was very much restricted. Furthermore, the government implemented a second national lockdown for Covid-19 from 5 November. Therefore, to start the second phase of data collection in compliance with government guidance, I applied for a further ethics amendment, seeking to conduct online and telephone interviews. The ethics committee approved the amendment request on 5 November 2020 (please see Appendix 4b (p.270), Amended Ethics Approval 5.11.2020, p.257). In Phase 2 of the data collection, the family members who provided care for the persons with the condition were interviewed remotely via telephone and virtual platforms. On 6 January 2021, England entered its third national lockdown. In February 2021, I applied for a further ethics amendment in line with the pandemic guidance at the time, which was approved on 12 March 2021 (see Appendix4c, p.272). Although the University of Salford Ethics Committee had allowed me to collect data remotely if possible, by this time, the government had proclaimed that the Covid-19 restrictions would soon be eased, and visiting people's houses while maintaining safeguards would be allowed. Therefore, I waited a couple of weeks to conduct face-to-face interviews with people with dementia.

3.8. Conclusion

This chapter has presented my research methodology and its design, with its justification. It adopts an ontological position based on the assumption that reality is understood through understanding an individual's subjective world. Therefore, this thesis was constructed from the social constructivist perspective. Furthermore, an understanding of the lived experiences of people with dementia and their caregivers and the stakeholders'/service providers' subjective views can be enhanced by adopting an interpretivist epistemology. To meet the overall aims of the study, a qualitative approach was used to provide insight into the research topic.

Moreover, the data collection techniques, and the ethical issues of the research, including participants' welfare, researcher's safeguards, professional conduct, etc. have been illustrated in detail. The researcher has explained how this research's credibility, transferability, dependability, and conformability will be achieved to ensure its rigour and trustworthiness. Finally, the thematic analysis procedure and its justification have been explained.

Chapter 4: Findings from Participants with Dementia

4.0. Introduction

This chapter presents the findings from the Participants with dementia from a UK Bangladeshi community. After describing participants' demographic information, I first explore the knowledge and beliefs of people with dementia from this community. Second, I describe the experiences of GP services on the part of the people who have been diagnosed with the condition. I also highlight participants' cultural attitudes towards dementia, including the influence of spiritual healers on people with dementia and the societal reaction towards dementia, including stigma, self-isolation, and hiding the illness. Thirdly, I explore whether participants perceived the dementia health and social care services provided as culturally appropriate to the Bangladeshi people or identified gaps in services. I also explain their cultural norms and expectations of care. Finally, I have captured the recommendations and suggestions of people with dementia from the Bangladeshi community to raise awareness about dementia and remove the stigma attached to it.

All of the participants were allocated pseudonyms to protect their identities. I have included the data which is directly related to the research focus and excluded data that was superfluous and not directly related to the study. I have highlighted the participants' quotations in *italic* text. My commentary illustrates the patterns and themes that emerged from the data and connects the narratives more cohesively. I have attempted to balance the participants' voices and my vocalization to connect their words into a chain of meaning. Text placed within quotation marks within my commentary represents the words spoken by the participants.

Stakeholders were asked about their views on diagnosis, barriers to accessing services, and any knowledge they had of policies or initiatives designed specially to address the needs of the Bangladeshi community. Participants were asked the following topic questions:

a. When and how did you realise that something is going wrong with your memory? When and how you were diagnosed with dementia? Did you know what dementia was before you were diagnosed with it? Can you tell me more about what you understand by dementia?
b. Did you notice any societal reaction to dementia since you were diagnosed? Did dementia somehow affect your social life? Can you tell me more about it?
c. Can you tell me your experiences with dementia? What are the key issues and challenges attached to access dementia services, and what kinds of support are lacking?
d. Can you tell me your experiences with the help and treatment you have received?

I followed a conceptual understanding of stigma during my data collection and analysis, taking account of the different dimensions of stigma identified in the literature (as discussed in Chapter 2 sub-section 2.9, (A Conceptual Framework for the Study of Understanding Stigma attached to Dementia, p.56). Mapping from my research questions, the following themes have emerged from my analysis of the participants' data:

Theme1: Knowledge and Beliefs

Theme2: Experiences of Use of GPs and Hospital Services by the People with Dementia: Gaps

Theme3: Experiences of Use of Care Services by the People with Dementia: Cultural Attitudes and Expectations of Care

Theme4: Raising Awareness

4.1: Participant Demographics

Ten people with dementia from a Bangladeshi community in North Manchester participated in this research study. The age range of the participants was 60-85 years. All participants were born in Bangladesh and Muslims by faith. Six were male and four were female. Five were the relatives of family caregivers interviewed earlier as research participants in the second phase of this research. Four participants were recruited through gatekeepers including Imams, one interpreter, and one dementia worker. One participant was recruited via the help of a family carer. All these people with the condition had capacity to consent for themselves, willingly participated in the research, verbally consented, and signed the consent form. I had informal discussions with the carers before the meeting that enabled me to better understand these participants' health conditions. I ensured that participants fully understood what would happen to them during the interview and the information sheet and consent form. So, I visited the participants' houses and talked with them and their family caregivers about their health and memory before the interview. I included them in my research study when it was confirmed that participants could talk and answer my questions and that their conversation made sense. The following table provides an overview of all the participants, including their gender and religion. However, I have once again anonymised my data by using a unique number for each participant.

Table 7: *Demographics of the participants:*

ID	**Gender**	**Age range of the PwD**	**Length of time since diagnosis**	**Relationship between PwD and Carers**
PWD1	M	75-80	15 years	Child
PWD2	M	75-80	7 years	Spouse
PWD3	F	65-70	3 years	Child
PWD4	M	55-60	15 years	Wife and children
PWD5	M	60-65	3 years	Wife and children

ID	Gender	Age range of the PwD	Length of time since diagnosis	Relationship between PwD and Carers
PWD6	F	80-85	5 years	Child
PWD7	M	80-85	6 years	Wife and children
PWD8	F	80-85	15 years	Children and daughter-in-law
PWD9	F	80-85	2 months	Child
PWD 1	M	60-65	2 Years	Wife and children

4.2. Themes & Sub-themes from the data

4.2.1. Theme1: Knowledge and Help-Seeking Behaviour

Participants were asked whether they had any previous knowledge about dementia. Almost all participants (n=9) said they never heard the word dementia until they were diagnosed. However, they had realised that they have some problems in their memory. One woman with dementia said:

"I never heard the word dementia before. I was a bit forgetful. I had type 2 diabetes and kidney problems for a long time. Last Ramadan, I went to my local hospital to check my kidney. Eventually, doctors tested my memory and made a CT scan of my brain, and then reported to me that I had got the early stage of dementia." (PWD9)
Similarly, another participant (PWD10) also expressed that he knew nothing about dementia before. He went to his GP to discuss his physical illness, but the doctor referred him to a local hospital; he was diagnosed with dementia from there. Explaining how his dementia diagnosis took place, the participant said:

“I have type 2 diabetes, depression, hypertension, and [an] osteoarthritis problem for a couple of years, and had a crush injury to my hand. One day I went to my GP to discuss my osteoarthritis problem. However, he referred me to the [x] Hospital. They referred me further to the [y] Hospital for more tests. Then in August 2017, [y] Hospital had done my CT scan and many other tests. Then I was told that I had developed Vascular Dementia with the possibility of superimposing to Alzheimer’s. I still do not know what dementia is (PWD10).

Analysis of the data from the above two interviews indicates that many participants do not understand dementia in the western/scientific bio-medical context, as they had never heard the word dementia, and there is not a synonymous word for it in Bangla. It is clear that they did not know that they have a condition called dementia even though they did feel they had something wrong with them, but they do not have word for it. Consequently, they did not go to doctors first for dementia diagnosis. Rather, their dementia was identified when another health condition was being reviewed.

4.2.2. Misconceptions and Myths

Three people with the condition believed that they had *"upri bemar"* (possession by supernatural entities). Two of these participants with the condition believed that they had some *jinn* within them, whereas another interviewee reported that some people did *"challan"* (black magic) on them due to jealousy. All three participants went to many spiritual healers in Bangladesh and in the UK. One participant was asked whether he thought dementia was an *"upri bemar"* or bio-medical disease. Then the participant replied:

*"To be honest, it is "*upri bemar*", nothing [to do] with bio-medical problem. But I go to doctor just because of the pressure of my wife and children. However, I know that no medicine will work on me, as it is upri* (PWD5).’’

However, one participant disliked going to any spiritual healers. Although he takes medicine, he believes that only Allah can cure him; nobody else can do it. He stated:

*"I never go to any spiritual healers. '*ita talti-balti' *[they often deceive and lie].* fu-fa ze, ita nobodong *[blowing and various forms of spiritual healings] are just a joke. Nobody can cure you except Allah. '*Allahar fu oi boro fu*' [Allah's treatment is the best]. Only we need to ask Allah for help."* (PWD1)

Another participant reported that her relatives advised her to go to the spiritual healers; however, some family members, including her son, who works in the NHS, suggested she not go to them. She said if she had not had these people in her family, she might have listened to other people and gone to the spiritual healers.

"Many of our extended family members suggested I go to any spiritual healers as I thought I might have some upri *problem. However, my son works for NHS, and some of our relatives are nurses who explained that this is not '*upri*' [supernatural interventions]. Therefore, I did not go to that line. Otherwise, I might go to them* (PWD9).''

One participant (PWD4) told a childhood story that was relevant to his dementia and said that when he was a student in Class Five, about ten years old, he used a *kuta* (bamboo stick) to pick a *katal* (jack-fruit) from the garden in Bangladesh. Suddenly, a *katal* (with a weight of 7 to 8 kilos) fell on his head, and he became senseless. His parent went to many spiritual healers and *kabiraj* (folk healers) but did not go to any doctor. Regretting his past, this person with dementia reported:

*My grandmother thought, "*amar batash lagse*" [an evil jinni possessed me]; therefore, they called a spiritual healer to treat me. A few hours later, I got my sense back. My family people thought I am OK, and this* jinni *has gone now. They did not take me to any medical doctor. When I came to the UK, doctors made a CT scan of my head and asked me was I ever injured in my head. I told the detailed story. Then the doctor confirmed to me that some cells from my memory had been damaged. I have developed schizophrenia, and then a few years later, I was diagnosed with dementia.* (PWD4).''

This quote highlights further that many Bangladeshis believe in different cultural myths and superstitions and they also have misconceptions about dementia and mental health problems. This participant felt that if his parents had taken him to any hospital instead of spiritual healers, then doctors could have treated him earlier, so that he might not have dementia and schizophrenia today.

Interview data revealed that some participants considered their memory problem to be due to dementia, but other behavioural symptoms, such as mood changes or being aggressive, urinating/soiling in the bed or on the floor, were "*upri*" (the possessions of *Jinn* and many other supernatural forces). Therefore, when the health condition of a person with dementia (PWD5) deteriorated, and he used to urinate or soil himself often on the floor or in bed, his family members took him to a spiritual healer. The participant reported:

"Around 6/7 years ago, I went to a spiritual healer in Birmingham who was an Indian Gujarati Imam. My dementia had suddenly worsened. I could not control my urine or toilet at that time. My children bought a new house, and I used to get scared when we moved into this new house. Therefore, my wife and children thought I had Jinn *with me. So they took me to Birmingham to this imam to see me. He had blown on me, gave "*pani pora*" and "*suta pora*””* (PWD4).

I prompted him again - “can you tell me more, what did this spiritual healer say?” This interviewee replied:

"He drew some lines and told us that just above my bedroom, and in the loft, some Jiins *are living there. These* Jinns *caused me to do excessive toilets and urine. He also said that this is nothing with dementia; but an* upri *problem. The healer also advocated that if we sell our house and move to different houses, the Jinn will move to the new house. So, we decided not to sell the house, rather we paid four thousand pounds to this healer for* Jinn *exorcisms. However, the healer could not solve this problem* (PWD4).’’

The above quotes indicate that this participant with dementia and his family members believe dementia is a supernatural intervention. They think that person’s memory problem is dementia and other dementia symptoms are due to supernatural intervention. Although this participant knew that he had memory problems due to his history and the dementia diagnosis, he still visited spiritual healers due to the misconceptions about dementia. The data also highlight that some folk healers in the UK do not have any qualification relating to dementia but take large amounts of money from the people with dementia in the name of *jinn* removal.

Some persons with dementia believe dementia has no any medical treatment. Only Allah can cure them. One participant commented:

"I am now an old man. In old age, people develop diabetes and lose memory. Did you not know in Bangladesh, older people have many health problems?" (PWD1)
The above participant was prompted further and asked whether he takes his doctor's medicine regularly; to which he commented:

"ita difa-tali dewa *[taking medicine in old age is just a formality]. It is useless.* Ekhon shesh khali shomoy *[Now it is time to die].* Ekhon Allah-er dactory oi boro dactori *[Now Allah's treatment is the best treatment].* Allah chara keu ita bala korto parto nay *[Nobody can cure it except Allah]* (PWD1)''.

The above participant does not view dementia as a bio-medical problem. He thinks only Allah can cure the dementia that usually occurs in old age.

4.2.3. Stigma Surrounding Dementia

This phase of study found that most participants, after their dementia diagnosis, tended to hide this information and stayed away from the public view, which suggests that self-stigma is a serious problem among the participants. Four participants reported that they tried to keep information private from the community. They were concerned that if someone knew they had dementia, they might spread the news of an individual's problem throughout the community, which would affect their family '*izzat*' (honour), which indicates that there is self-stigma existing in the Bangladeshi community. One participant said:

*"I tell my friends and extended family members that I cannot remember things or forget recent events. However, I do not tell them that I have dementia; people will not understand what dementia is, and they may judge me. People are not educated. People might say- "*e beti pagol oigese*" [she has gone mad]; then the whole community may gossip about my family and me," which may damage my family's* 'izzat' *[honour]* (PWD3)''.

It is noticeable that the above participant used the words 'forgetfulness' and 'memory problem' when she had to explain her situation to her extended family members and friends, but she purposefully avoided the term 'dementia' from fear that other people might misunderstand what dementia was and label her as a mad person because of their lack of knowledge about dementia. It also indicates that there might be a correlation between beliefs that dementia might be a reflection of supernatural causes and the social standing of people with the symptoms of dementia.

Many participants have reduced contact with their extended families or broader community from fear that if other people knew their condition, they might start gossiping in the community and that might harm the wider family's reputation. Some participants even avoided telephone contact out of anxiety that other people might know about their situation, which is "*shorom*" (shameful). Consequently, many participants became socially isolated. For example, one participant reported in part of a more extended discussion of his social isolation:

"Since [the] last ten years, I never went out to spend time with friends. Most of the time, I am lonely at home. No one comes to visit me apart from my close family members (PWD4).''

Another person with the condition said:

"I don't go anywhere. I do not even go to the mosque now to pray the daily prayer apart from Fridays. I don't go to any parties or social events. I don't like people. I don't even like to talk to anyone over the phone (PWD10)''.

This participant was prompted further why he did not like that; he then replied:

*"Sometimes, I don't feel good as I have depression as well. I get annoyed easily, and my mood changes. I shout to everyone, even my daughters and wife. If I do not behave with others appropriately, other people will take it seriously. Not only that, people might say: "*e beta pagol oi gese*” [this guy has become mad], and then I might be the talk of the town. It might affect my daughters' marriage as well. So, better I stay at home.”* (PWD10)

This recently diagnosed person with dementia has reduced his social contact with people, and he avoids gatherings, including going to the five daily prayers. The participant was afraid that other people might label him as mad, which might jeopardise his family honour, affect his daughters' marriage proposals, etc. The above quote indicates that this participant with dementia was concerned that he would be stigmatised by the members of his extended family and the broader community, which posed a severe threat to his family’s marriage prospects. Interview data have highlighted that participants with dementia had gradually become socially isolated after their diagnosis. Their fear and shame around social interaction and often depression may lead them to social withdrawal.

One woman with dementia was asked if her children could not look after her due to their business or job, would she think about going to any care home? She replied:
*"*Na-re-shuna-re- *[No way]."*

When she was prompted again: "Why not?" then she mentioned:

*"*Manush-e Kita Khoibo?*"- [what people are going to say?]. How could we show our face to the community? It is not our culture to send older people to the care home. However, my children will also not feel good to send their mum to a care home.”* (PWD3)

The above quotation suggests that this participant with dementia felt '*shorom*' (ashamed) to live in a care home for two reasons. First, other people might know that she has dementia. Second, caring for old parents is a duty upon children according to Bangladeshi culture. Therefore, if her children could not care for her at home then it will be a major assault on their family reputation; this suggests that sending older adults to a care home is a matter of stigma in the Bangladeshi community.

4.2.4. Theme2: Experiences of Use of GPs and Hospital Services by the PwD: Gaps

The findings from this study indicate that there are some gaps between services and people's expectations of them. One person with dementia reported late referral by her GP to the memory services and discussed its implications for her late diagnosis:

"I went to the doctor many times and explained my problem. My GP did not respond to me. After I had visited him many times, then the doctor referred me to a memory clinic. Then I knew that I had some memory problem. However, it was a very late diagnosis. If my GP could refer me to the memory services earlier, I could [be] diagnose[d] earlier and live well (PWD2)''.

From this interview, it is understood that some GPs' late referral to memory clinics can often delay the diagnosis of people with dementia.

Two participants reported that GPs or doctors only responded to them when they called them. Most of the time, doctors gave them repeat prescriptions to collect medicine from the chemist. However, their health condition changes, and dementia progresses. Therefore, it is essential to see a doctor. Nevertheless, obtaining an appointment to visit a doctor is very challenging task. One person with the condition stated:

"My son takes me to the doctor. However, for a long time, I did not see my GP, because they give a repeated prescription, and my son gets the medicine from the chemist for me (PWD2)''.

This interviewee expressed that if they never contacted a doctor, they might have only repeat prescriptions. It might be impossible to consult with a doctor, despite the conditions of people with dementia needing to be reviewed with the progression of their dementia. The above interview data analysis highlights that people with dementia should be prioritised for quick service. However, participants with dementia have reported that they are not receiving any special service from the doctors.

4.2.5. Language Barriers

Three participants reported that they do not speak English, therefore cannot communicate with their doctors properly. Although interpreters are available, they felt that these interpreters might not accurately translate whatever they said to their doctors. Sometimes doctors gave too much information in one go when they used interpreters. Therefore, participants have suggested that their family members know their health situation better; consequently, they can explain better than any interpreters can. One woman with dementia said:

“I don’t speak English. I cannot communicate with doctors. It is a big problem. I cannot say my problems correctly, how my children can express. However, in the hospital, family members aren’t allowed to translate for me. Therefore, I do not know what to ask or which problem needs addressing. An interpreter only translates what I say.” (PWD3).

Another woman with a diagnosis was concerned that interpreters might not translate appropriately. She also faced a further barrier in communicating with the interpreters who speak in a different dialect of Bangla. She stated:

“I have got a language issue. However, doctors in the hospital do not allow any of our family members to translate for me. However, the interpreter they book sometimes talks in the Dhaka dialect, where I understand the only Sylheti dialect. Sometimes interpreters also cannot accurately translate what I wanted to say. One day my son stayed with me by request, and one interpreter was translating for me. Then my son told me - mum, this interpreter made wrong interpretation (PWD9)’’.

One male participant was not happy that a third person would explain his situation to the doctor. He preferred his daughter to be allowed to interpret for him, as he stated:

“My daughter could go to the GP with me. However, in the hospital, family members are not allowed to interpret. Nevertheless, I do not feel comfortable communicating with the doctors via another third person I do not know before… I would be happy if my daughter could come with me and explain my situation to the doctors during my hospital appointments (PWD10)’’.

The above three interviews indicate that the language barrier is an obstacle, which affects participants with dementia seeking to communicate with doctors or seek help. These participants recommended that their family members must be allowed to interpret for them as they could interpret better than any other interpreter could, and they would feel more comfortable. However, hospital staff did not permit any family members to interpret.

4.2.6. Theme3: Experiences of Use of Care Services: Cultural expectations and Norms of Care

Participants reported that they expect only their children and close family members to provide care. Because of their cultural expectations of the care, many participants did not accept help from care services. For example, one person with the condition was asked whether he used any care services. Then the interviewee replied:

“No. Because, my wife cares for me enough. I don’t need anybody else’s care (PWD1)’’.

Another male participant was asked if he would be happy if someone else took care of him or helped him. This person responded:

“No. because nobody can take care of me how my wife does. Because she is my wife.” (PDW2)

Explaining the cultural expectations and norms, one participant stated:

"In our culture, people like to stay in the family and children look after their parents in their old age. That is why they [have] children. Therefore, it is a big shame and discredit on any family if they cannot look after their parents." (PWD3)

Participants with dementia were mainly cared for by their family members. However, one person with the condition lived in a care home for a couple of weeks. Then, he left the care home after two weeks, as he did not like the services. When he was prompted to share some of his experiences about the care home, he then replied:

"*Terrible experience. It was not clean. I felt bad smell everywhere. They did not clean me properly. They give mixed staff. When I see women, I did not want their any services. I stopped eating there. Then my family took me home back.* (PWD4).

This interview data suggests that even though this one participant considered living in a care home, thereby going against his cultural norms, he could not stay there long specifically because the environment was not clean enough. Staff allocated to personal care also lack understanding of Bangladeshi culture.

Another female participant expressed the view that there will be a need for Muslim care homes in the future where culturally and religiously friendly services are guaranteed as the Bangladeshi population is aging. She stated:

"As population are aging, and our girls are going to the colleges and universities, and they are working full time instead of just being housewives, therefore the care home service needs will be increased as well. I think if Muslim families or Bangladeshi Muslims run any Muslim care home and provide prayer facilities, halal foods, and culturally appropriate care services, they may start using care home services. But I think it will take some time. People are still not ready to stay away from the family and children and live in a care home (PWD3)''.

Participants were asked to share their experiences of dementia care services use. One person with dementia reported:

“A long time ago, some carers used to come but they do not come now. We stopped using their services… they were male and female both mixed… I did not like their services as they did not clean me properly. I used to feel shame and embarrassed when a woman used to take me to the toilet. I never felt comfortable. I told them not to come (PWD4).’’

This interview data indicates that staff who deliver personal care at home and care homes need more training and development to run these services more professionally and understand different cultural needs. My data suggests that even though one participant wanted to live in a care home, breaking cultural norms, he had to leave that home as he found the environment was not clean enough. Staff allocated to personal care also lack understanding of Bangladeshi culture. Cultural expectations of care are also a significant factor that leads many participants not to accept care service help.

4.2.7. Theme4: Raising Awareness about Dementia

Participants were asked how awareness about dementia could be raised amongst people living with dementia amongst the Bangladeshi community.

One person with dementia (PWD9) then gave the following suggestions:

“I think mosque council can arrange events where people with dementia and their carers will share their lived experiences about dementia and its services. All mosques’ chairpersons, Imams, and community leaders, and Bengali councillors will be present. Then these events need to be broadcast on different community TV channels and social media. Then one Friday in every mosque Imams should give their Friday sermon about dementia (PWD9).’’

Similarly, another participant advocated:

“Leaflets (written in Bangla) can be distributed in every house where people 40 years and above live. Imams can give some Friday sermons about dementia. Professionals

and community leaders may arrange some talk shows in the various Bangladeshi community Television channels, like Bangla TV, Channel S, ATN Bangla, that Bangla speaking adults watch mostly." (PWD3)

One participant suggested that the government should improve people's literacy rates and then give some training about dementia. He said:

"We need to think first about improving [the] literacy and numeracy rate amongst the Bangladeshi community adults. Then people need to be taught what dementia is and what the challenges are. Now people ... lack awareness about dementia. Therefore, education and training are vital (PWD10).''

This quote indicates that it might possibly be that many Bangladeshi older adults do not understand dementia in the western/scientific bio-medical context due to the low literacy rate. Therefore, this participant advocated improving the literacy rate of the UK older Bangladeshis.

4.8. Discussion

Participants were asked whether they had any previous knowledge about dementia. Respondents tended to express that they had never heard the word dementia until they were diagnosed. However, they realised that they had some problems with their memory. Several participants with dementia went to their local GP to discuss their physical illness, but the GPs referred them to their local hospital. Eventually, they were diagnosed with dementia. Findings also indicate that participants have some knowledge, or at least alternative views, of dementia as they live with the condition and have tried different ways to live with the symptoms. However, interview data suggest that participants with dementia do not understand the condition in its scientific bio-medical context, as many of them had never heard the word dementia until they were diagnosed.

This thesis revealed that many participants with dementia went to many spiritual healers in Bangladesh and the UK, considering their condition to involve possession by supernatural entities. Data also highlighted that a few participants believed that their condition is a '*upri bemar*,' i.e., possession by supernatural forces or '*chalan*' (a form of black magic by others due to jealousy). Notably, data suggest that some participants' understanding of dementia differs from that of their children. This interview data also highlighted that all UK Bangladeshi are not a single group; instead, there is a clear generation gap between older adults who migrated from Bangladesh and second-generation people born and brought up in the UK. This thesis also identifies that several so-called spiritual healers conned several persons with dementia and their family caregivers in the UK. For example, one spiritual healer drew some lines on a piece of paper to manipulate a person with dementia and their family and explained to them that above the bedroom of the person with dementia and in the loft, some *Jiins* are living. These *Jinns* caused the person with dementia to produce excessive stools and urine. The spiritual healer also said that this is nothing to do with dementia; but a *upri* problem. The healer also advised them that if they sold their house and moved to a different house, the *Jinn* would move to the new one. So, it was better not to move house; instead, it was better to pay the healer some money for *Jinn's* exorcism. Although this family was in some financial difficulties, taking the deal, they borrowed some money from somewhere and paid £4000 to the spiritual healer, but he could not solve the problem. This interview data also highlighted that some spiritual healers in the UK have no formal qualifications relating to dementia but take large amounts of money from people with dementia in the name of *jinn* removal and con them. Data also identified that many participants with dementia went to spiritual healers when they developed dementia symptoms with the advice or influence of their extended family members. These findings echo the report of APPG on Dementia (2013, p.27), where there was a reference to "myths and misconceptions about dementia" where "*Jinns*" are alluded to about the Black Caribbean population. However, this was not discussed in depth, nor was adequate consideration given to the influences of religious beliefs and their impact on access to dementia care and support. This thesis seeks a deeper understanding of the effect of a UK Bangladeshi community's religious and cultural beliefs about dementia and how they influence people's help-seeking behaviour and access to services. The participants with dementia suggest that the Bangladeshi ethnic group might be a unique community among the South Asian communities regarding their beliefs in supernatural intervention and associating dementia with possession by *jinn/bhuta*. The experiences participants shared with me also echoes Hussain (2017, p.151), who claims that the Bangladeshi community is unique because of its religious and cultural identity. He also added that there is a wide diversity of different denominations within the religion of Islam, as some Muslim countries are less religious than others. Some practices strictly follow the Quran and Hadiths (the sayings of the Prophet Muhammad, PBUH), and some do not (p.151). This claim is also supported by Parveen et al. (2011). They state that British Bangladeshis are more religious than British Pakistanis, whereas Pakistanis are more Westernised than Bangladeshis in the UK (Hussain, 2017, p.151).

Findings suggest that many participants with dementia often tried to hide their condition from others and did not like to disclose it to anyone apart from close family members. They feared the community would start gossiping about them in a way that may destroy their wider family's reputation. They have reduced their social contact with people and avoid gatherings out of fear that other people might label them as mad, which might jeopardise their family honour. This indicates that dementia is stigmatised in the Bangladeshi community. Participants with dementia were worried about social stigma; therefore, they had reduced contact with their extended family or broader community to keep information private from others. Data also suggests that several participants became socially isolated because of their self-stigma. They feared that if someone knew they had dementia, they might spread the news of an individual's problem throughout the community. Eventually, they became socially isolated, indicating that public stigma exists in the Bangladeshi community. Findings suggest that a few participants have not spent time with their friends for years. Some of them stopped going to the mosque to pray the daily prayers and did not go to parties or social events as they were afraid of people and even afraid to talk to anyone over the phone. An individual with dementia was also concerned that if the members of his extended family and the broader community knew his condition, it would pose a severe threat to his daughter's marriage prospects, which is a clear sign of courtesy stigma or stigma by association.

Some participants expounded that family members only should provide care; therefore, participants did not access healthcare for dementia. One interviewee suggested that the care home environment should be cleaner and more culturally friendly. They also recommended more staff training and development. A few individuals indicated that there would be a need for Muslim care homes in the future as the population is aging.

Participants identified that there are some gaps in GP and hospital services. For example, findings suggest that several participants were not diagnosed promptly due to their GP's negligence. They also added that if their GPs could have referred them to the memory services earlier, they would have been diagnosed earlier and lived better. Some participants commented that their GPs' services could have been better in the past, and some GPs are too busy and do not want to give a patient enough time to talk, and it was sometimes difficult to obtain a doctor's appointment.

This thesis suggests that many participants need to speak English and communicate with their doctors properly. While interpreters are available, some participants fear that interpreters may miss important points. Therefore, participants believe that family members know their health situation better and can explain better than other interpreters. However, NHS doctors in hospitals do not allow family members to interpret for the patients, so the participants with dementia are unhappy with the interpreters' services. A detailed overall discussion will be presented in Chapter 7, linking with previous studies.

Chapter 5: Findings from the Family Caregivers of Persons with Dementia

5.0. Introduction

This chapter presents the analysis and findings from Participant Group Two of this research, derived through interviews with the family caregivers of people with dementia from a Bangladeshi community. Participants answered the following topic questions:

a. When and how did the person with dementia you care for come to have a diagnosis? Did you know what dementia was before this person was diagnosed? Can you tell me more about what you understand by dementia?
b. Did you see any societal reaction to dementia since the person you cared for was diagnosed? Did dementia somehow affect your social life or the life of a person with dementia? Can you tell us more about it?
c. Can you tell us your experiences as a family caregiver of a person with dementia? What are the key issues and challenges attached to access dementia services, and what kinds of support are they lacking?
d. Can you tell me your experiences with the help and treatment the person you cared for has received?

Mapping from my research questions, the following themes emerged from my analysis of the participants' data:

Theme1: Knowledge and Beliefs
Theme2: Cultural attitudes of the Bangladeshi community towards dementia
Theme3: Experiences of Service Usage: Gaps in Services
Theme4: Raising Awareness of Dementia

After presenting participants' demographic information, this chapter will discuss the themes and sub-themes derived from the data. Sub-section 5.2.1. presents the knowledge and beliefs about dementia on the part of the participants. 5.2.2. discusses the cultural attitudes of the Bangladeshi community towards dementia. 5.2.2.1. presents the myths regarding supernatural interventions in the above community. 5.2.2.2. presents the consequences of stigma, including shame concealment and social isolation. 5.2.3. illustrates the norms and cultural expectations to care. 5.2.4. is experiences of service usage gaps. 5.2.5. reports participants' recommendations on raising awareness about dementia and supporting people with the diagnosis in this community. Further, linking with the previous literature, overall findings will be presented in the discussion chapter (Chapter 7, p.193-211).

5.1: Participants' Demographics

Ten caregivers from eight different families from a Northwest Bangladeshi community participated in this research. The age range of the participants was 27-65 years. All these participants were born in Bangladesh and Muslims by faith. Five were male, and five were female. The age range of those in receipt of the care they provided was 70-94. The following table provides an overview of all participants, including their gender, relationships with a person with dementia, how long ago the persons with the condition were diagnosed, and carer's employment status. I have anonymised my data by using a unique number for each participant.

Table 8: *Demographics of the participants from the family caregivers of people with dementia*

ID	Gender	Relation with the PwD	Age of the PwD	Diagnosed since	Employment Status
DCG1	M	Child-Parent	84	4 years	In Paid Employment
DCG2	F	Child-	78	5 years	In Paid

ID	Gender	Relation with the PwD	Age of the PwD	Diagnosed since	Employment Status
		Parent			Employment
DCG3	F	Child-Parent	83	6 years	In Paid Employment
DCG4	F	Spouse	85	2 years	Not in Paid Employment
DCG5	M	Child-Parent	94	8 years	In Paid Employment
DCG6	M	Child-Parent	81	3 years	Not in Paid Employment
DCG7	F	Spouse	80	6 years	Not in Paid Employment
DCG8	M	Child-Parent	90	2 years	In Paid Employment
DCG9	F	Spouse	78	5years	Not in Paid Employment
DCG10	M	Child-Parent	80	16 Years	In Paid Employment

5.2. Themes & Sub-themes from the data

5.2.1. Knowledge and Beliefs about Dementia

This section first explores participants' knowledge and beliefs about dementia. There are cross-cutting issues in my broad themes that relate to cultural beliefs and norms that I have chosen to discuss here under the sub-theme: “Cultural Attitudes, Norms and Expectations.”

Participants were asked if they had previous knowledge of dementia before their loved ones were diagnosed. Almost all family carers who participated in this research reported that they had no prior knowledge about dementia from a bio-medical perspective. Many of them even were not familiar with the word dementia until their loved ones received the diagnosis. One caregiver said:

"To be honest, in Bangladesh, we never heard the word dementia. Even in the UK, I only knew about it since my husband was diagnosed (DCG7).’’

In contrast, data analysis suggests that participants realised there was something wrong with their loved ones when they developed dementia. Therefore, they wanted it to be fixed or have a 'resolution' for it even though they not have any word for it. Due to the misconceptions or various cultural myths, many participants used homemade remedies or went to the folk healers at home and abroad (as will be discussed in the next section). One caregiver said:

“Some people are confused with mental health. They believe the individuals who have dementia are crazy, or their brain is not functioning. People think as a mental problem instead of a physical, i.e., a neurological problem, because of their ignorance” (DCG10).

So, it is clear that many participants’ understandings of dementia are very basic, and they do not necessarily understand what dementia is from a westernised scientific/bio-medical viewpoint. However, they feel that they have some problem even though they do not have a word for it. Three participants said that they were not aware of available dementia services, which indicates that some Bangladeshi families may not be familiar with navigating the system, which would be a further barrier.

This thesis has revealed that participants had misconceptions about dementia. These misconceptions can be linked to their cultural and religious beliefs. Therefore, in the following section, I will present a detailed analysis demonstrating how cultural perspectives affect people in the Bangladeshi community in their dementia help-seeking.

5.2.2. Cultural Attitudes towards Dementia: Myths

5.2.2.1. Supernatural Interventions

Due to cultural and religious beliefs, many participants considered dementia a supernatural intervention rather than a neurological disorder. For example, one family caregiver said:

"You may know that we Bangladeshi see the spiritual side first. When this spiritual treatment finishes, then we see the medical side. Sometimes these spiritual lines come to you automatically." (DCG6).

Another participant reported:

"Everyone in my family said we should call Mulla/Molovi *[i.e., Imams and spiritual healers] to give him a "*foo*" [blowing on any patient after reciting some verses of the Quran or any supplication]. We did many different treatments in the line of spiritual therapy. When none of these treatments was working, we told our GP everything in detail about our father. Later, we understood from his GP that he has Dementia."* (DCG5)

From the above two participants' personal experiences, it is clear how cultural attitudes influenced their help-seeking behaviour. The above quotes also suggest that there is an influence of spiritual healers in the UK amongst the Bangladeshi community. Hence, family caregivers went to different folk healers and Imams (also known as spiritual healers) instead of bio-medical doctors.

Describing the influence of spiritual healers, another caregiver (DCG10) explained:

"From our childhood, we see people in Bangladesh have a common tendency to go to a spiritual healer, Imams or Kabiraj *(Folk Healers), etc., besides bio-medical treatment. People with low income or less educated people living in rural areas go to them first, instead of medical treatment. In contrast, any mental health problem, the neurological disorder will be labelled as* Jinn's *possession.*

This participant also added that he heard his extended family members and other Bangladeshi community people to say:

*"*tain re Jinn-e dhori laise*" [Jinn possesses him/her] "*Tainre Shaitaney asor kori laise*"[Satan or evil has attacked him]; "*Jar-fuk dew" *[Blow on them (by some spiritual healers)], etc."; This is a huge business, and those so-called healers or* kabiraj *often earn an ample amount of money with conning people by the name of* jinn *expulsion* (DCG10).''

Many participants reported that some Imams and spiritual healers did not have training in counselling or basic knowledge of dementia. However, they encouraged people with dementia to use their treatment and not go to medical doctors. They never corrected any misconceptions of people, perhaps due to their lack of knowledge of dementia, although many people trusted them. For example, one participant reported that he had met Imams (who are spiritual healers too) who had no basic understanding of dementia themselves but tried to heal by their methods for years, an approach that may cause a delay in people's dementia diagnosis (DCG6). When this carer (DCG6) and his mother came back from Bangladesh, his mother's health condition had not improved. Then, his mother questioned whether the *Tabiz* she had (from a spiritual healer of Bangladesh) was the correct one for her issues, (a *Tabiz* or *Tawiz* is an amulet or locket worn for good luck and protection, which is very common in South

Asia). Later, she showed this *tabiz* to one of their local Bangladeshi spiritual healers who told them:

"This is a dangerous tabiz *which will harm you. Someone made "*Chalan*" [black magic] on you for jealousy. Put this* tabiz *into hot water; then all bad reaction will be removed."*

DCG6 said that his mother and their family trusted this healer and followed all his advice. Later, this healer gave her another *tabiz*; however, they could not see any improvement in her. Then they went to Blackburn to a Bangladeshi Imam. DCG6 said in regret:

"We trusted them so blindly; we never realised the importance of showing my mum any medical doctor. When we did not see any change in my mum's health condition, we went to some other Imams (not Bangladeshi). We went to Blackburn, an old Pakistani Imam. He also gave another Tabiz*"* (DCG6)

From this carer's report, it is clear that some participants trusted Imams and spiritual healers blindly though these imams did not know about dementia.

Participants reported that many people have links with different *Kabiraj* and spiritual healers abroad and when people with dementia or their families from the UK visit Bangladesh, they advise them to go to some *Kabiraj* and healers to solve their problems. These Bangladeshi relatives often call for their friends and family members who live in the UK to contact these *Kabiraj*. One interviewee mentioned:

"When we went to Bangladesh with our father, we found that many people do not know what dementia is, and they thought my father has gone mad. Some people made excessive fun of my father, which hurt us significantly. People used to advise us to go to different Kobiraj*, or Mullah [spiritual healers]."* (DCG1)

It is noticeable that even though the participant did not ask anyone to give him any advice, some people automatically went to him to offer free advice. Hence, it is clear that there is an apparent influence on the families of people with dementia from their other Bangladeshi relatives and neighbours.

One woman (DCG9) who cares for her husband reported that her mother had dementia before coming to the UK. They never diagnosed her because they were not familiar with the word dementia and did not know what to do if someone developed this condition. However, she can see all symptoms of dementia in her mother, like her husband's symptoms. During the interview she burst into tears and said:

"People used to think my mum had gone mad. They used to make cruel jokes and fun of her. I saw my mum often cried when she could not tolerate these jokes and humiliation. Later, she died in Bangladesh. Now when I care for my husband, I miss my mum, and I wish if I had some knowledge of dementia back then, I could serve my mum lovingly and stop others from making cruel jokes or making fun of her" (DCG9)

The above quote suggests participants' relatives had no word for dementia and also did not understand what dementia is in the western/scientific context. Therefore, they often mistreat people, considering them to be mad people. This also suggests that there is social stigma existing in Bangladesh which has some negative impact here as well, in the UK Bangladeshi community. Another participant noticed in Bangladesh that when someone repeats his/her conversation a few times, people call them "*Pagal hoi geche*," i.e., this person has gone mad. Similar attitudes and beliefs were reported by my participants, where people understand dementia as madness.

Some participants travelled to Bangladesh to visit "*kobiraj*" (folk healers). For example, one family caregiver (DCG6) shared a long story that shows how his mother Jamila (pseudonym) went to different *Kabiraj* here in the UK and Bangladesh many times, but nothing worked for her. She further reported that she was conned out of thousands of pounds by many so-called spiritual healers. This participant (DCG6) also reported:

"My mother went to Bangladesh to get some alternative treatment from some Kabiraj *[A* kabiraj *is someone who does spiritual healing and eliminates the possession of* Jinn *and* Bhuta *etc.]. You know Bangladeshi culture, don't you?"*

In 'X'ganj (A place in Bangladesh), two of my grandson in-laws advocated for my mother to get some Tabiz. *My mother had received them. We never thought my mother had any bio-medical problem. We believed that this is a* upri bemar *[supernatural intervention, i.e., the possession of* Jinn*]. This* Kabiraj, *who gave* tabiz, *convinced us* *that my mum has* upri*, not* dactori bemar *[medical illness]. You know what happens in Bangladesh, don't you? Nothing is impossible."* (DCG6)

This participant reported that some spiritual healers convinced them that they had problems because supernatural forces possessed them. They also insisted that this person could get better only with their folk healing treatment. They advised them not to go to the doctor at all. Some of my participants often blindly trust them without knowing that some of these so-called miracle makers are money takers.

Another family caregiver commented:

"I will never go to Bangladesh with my mother again. It is not enjoyable. I think ordinary people and many doctors in Bangladesh may not know what dementia is or how to treat them. If I went to Bangladesh, I would not give my mum any dementia treatment. Now I understand most of these so call kabiraj *and spiritual healers could [de]fraud us.*" (DCG6)

This caregiver expressed frustration about when he and his family visited Bangladesh, and some spiritual healers conned them. First, they were convinced by the promises given by the healers that their folk healings would cure their mother. However, ultimately, they were very disappointed when nothing they tried worked.

5.2.2.2. Stigma: Shame Concealment and Social Isolation

This study has revealed that family caregivers do not feel embarrassed or ashamed about caring for their relatives with dementia. However, they often hide dementia from the broader community due to the fear that other people may not like them, which suggests that people with dementia in this community are stigmatised. Many family carers indicated that their relative with dementia became socially isolated because of the social stigma. Some participants reported that dementia was a taboo subject in the Bangladeshi community. Family caregivers also felt that due to the behavioural and psychological symptoms of dementia, people with dementia become socially isolated, thinking that maybe other people do not like them. It affects their self-esteem. For instance, one caregiver (DCG5) reported:

"People try to hide if their family member has got dementia. In our community, dementia is a taboo subject. Some people consider dementia as madness, and it could ruin family honour and reputation; therefore, people try to conceal it. Brother, what can I say about other people when people in my own family went to imams and spiritual healers rather than a Doctor?" (DCG5)

Another family carer stated:

"Dementia is a taboo subject. There is a considerable stigma attached to it. Neighbours and our community people used to think she has gone mad. They did not consider my mum as an average person any more. Some people advised as to go to Mulla and kabiraj *for* tabiz*."* (DCG6)

This participant highlighted that people often understand dementia as a mental health problem. Another person stated:

"There is a massive stigma on this. Not only dementia, with any illness, but people of this community also make stigma on it. For example, if any child is disabled, we hide this from others. However, our family is different." (DCG10)

This participant felt that the Bangladeshi community heavily stigmatises many illnesses, including dementia.

One carer commented that he did not feel shame in looking after his father. However, he gets embarrassed when his father shows atypical behaviours in public. He said:

"Some people think it is embarrassing and shameful, and there is stigma, but we do not feel this. Sometimes when my father speaks out of line in social interaction, we feel bad and embarrassed. But those who know he has dementia do not mind him behaving like this." (DCG1)

Some people worry and hesitate if their loved one who has dementia behaves differently; as others may say something judgmental about them.

A female carer reported that when her husband does not understand the mosque's ethos and talks to people excessively, people misunderstand him. Some people have come to their house to suggest she not send her husband to the mosque.

"He had developed some behavioural syndrome; therefore, sometimes he used to behave with people rudely or got angry for no reason. Therefore, people used to come to our house and complained against him. Some people used to suggest we not send him to the mosque, which is because people do not know about dementia, and people are stigmatised.” (DCG9)

This interview data indicated that there is some social stigma about dementia that might make a person with dementia socially isolated. One participant stated:

"He does not want to go to the mosque. He does not like any social gatherings. The mosque is just next door to our house. When he was well, he could go to the mosque regularly. Now, he does not want to go. He likes to be alone. Last year before the pandemic, there was a marriage ceremony of his brothers' daughter. We all went there. We requested him so much. However, he did not go there. He said, you go, I don't like to go anywhere.” (DCG7)

This interviewee highlighted that his father with dementia became socially isolated, considering other people might not like him, which may worsen his dementia.

A family carer has found that her husband has excluded himself from all social engagement types and fears that others will not like him. Another family carer described:

"My father was a very social person. He used to always pray in the mosque and meet with other people. He used to love visiting neighbours, going shopping, meet his friends regularly. However, now he does not like any form of social gathering.” (DCG2)

All participants (n=10) mentioned that religion was vital to them. Even though people are ill or have memory problems, to the point that they cannot remember how to pray or speak, they are still keen to perform prayers. They try to fast in the month of Ramadan and accomplish the pilgrimage in whatever way they can. However, as prayer is communal worship and many Bangladeshi people do not know about dementia, people with dementia are often misunderstood or judged by others, which may create societal reactions or contribute to stigma. One female carer stated:

"My husband wanted to go to the mosque regularly. However, when he used to go to the mosque, some people would misunderstand him because of some of his atypical behaviour and advised him not to go to the mosque and better to pray at home. However, my husband would reply: 'I bought the house next to the mosque to pray regularly. Now please don't prevent me from going there. If I die, I want to die in the mosque (DCG9).''

Participants were asked about their feelings in relation to care home provision. In reply to this question, a majority, n=8 participants, answered negatively. Cultural expectations, stigma, lack of trust, and lack of culturally appropriate services were significant obstacles that prevent people from sending their loved ones into care homes. One carer stated:

"Sending an old English person is not a matter of stigma in their culture. But in Muslim culture, this is a big shame and stigma attaches to it. If you want to raise awareness about it and advocate people to send older adults into a care home, you will face many challenges and criticism. People may think you want to take all parents and loved ones out of home and put them in to care home. People will not accept it. Because of the stigma, I know some people who left their well-paid job to look after their parents to avoid societal pressure." (DCG10)

It is clear from the above participant's report that some caregivers from the Bangladeshi community left their well-paid jobs to look after their parents or older relatives to avoid shame and disgrace, which suggests that social stigma and self-stigma (Pryor & Reader, 2011) are a serious problem in this community.

5.2.3. Norms and Cultural Expectations to care

Findings from the family caregivers indicate that looking after one’s own parents and/or older adults is an established cultural norm and practice for these participants. Sending older people into a care home is perceived as shameful as participants believe that parents have many rights over their children, and one of their rights is that they need to be looked after in their old age just as they looked after their children when they were young. According to their faith, if they can make their parents happy by serving them in their old age, they will go to paradise in the hereafter. Therefore, they are motivated to sacrifice their jobs and comforts to look after their parents. One carer mentioned:

"I will never send my dad to a care home as long as I am alive… I know I could earn a lot of money, buy my own house, and do the job I wanted. But my parents' comfort was my main priority. I will always look after my mum and dad, even though I had to lose my job.” (DCG8)

Another carer also replied in the same tone when he was asked whether he will send his mother to a care home if they are too busy to take care of her:

"No, Never, brother. Until my last breath, I will look after my mother. I already left my job to care for my mum full time. Please make dua *[supplication to God]; I will take care of my mother all my life.”* (DCG6)

The researcher wanted to determine if this is because they dislike the available care home services or any other reason. Then, one carer confirmed:

"If you ask me this question, I will say no matter how fantastic care home services are, I won't send my mum or dad to a care home. They are my parents. They gave us birth and looked after us when we needed their help. Now they are old. We need to provide them with some things back. This is their right. I can't sleep one night, leaving my parent in a care home.” (DCG8)

Similarly, another family caregiver commented:

"We would not have sent my father to a care home as long as we were alive. Even if the government offered us £500 a week to send him to a care home, we would not have done it.

No one in the Bangladeshi community would send their elderly parents to care homes. Everyone wants to look after their parents themselves even, if they have to sacrifice their lives, because this is our culture. We are Muslims, and our Quran, the book of God, and our beloved prophets taught us to serve our parents because it is their right on their children." (DCG5)

A female carer mentioned:

"My whole life, my husband looked after us and gave us food. Now he is ill, so he deserves our help. A wife means a lifelong friend. I am pleased with whatever I am doing for him. Please pray for me if Allah enables me to fulfil my duty and look after my husband appropriately." (DCG7)

One family carer reported why she cannot trust care home services. She said:

"I knew one person who had dementia had been in the care home; however, he was neglected and did not receive adequate care; eventually, he was taken out of care homes and returned home. I know another patient in the [same] hospital as my dad. He was physically more substantial than my dad, had no physical problems but did not like to eat anything. He was just a patient in the same ward. Later, his family sent him to a care home. After sending him to care home, his physical and mental health deteriorated. He was then taken back to hospital, then sadly, he died in hospital. If I compare my dad with him, my father was more ill than him. I know that people change when they get dementia; however, this man was very calm. I believe if he were looked after at home and not sent to a care home, he would've been better off (DCG2)."

This quote indicates that some people with dementia and their family carers from the Bangladeshi community do not trust the care home services. They also believe that their family can provide better care than a care home.

Despite willingness and motivation to care for the parents and loved ones, several participants reported that it was hard for them to care for people with dementia because of their business and other commitments. Participants were asked to share their experiences and the difficulties they face in caring for persons with dementia. Some family caregivers have reported that it affects their daily routine very much, and often they have to spend sleepless nights and have faced many difficult times throughout their care-giving journey. One carer stated:

"What can I say? Sometimes I used to cry because it was very hard. I work in a restaurant, and I come home late. Dad used to stay awake all night; he used to open the door and leave the house in the middle of the night. He used to ask questions all the time. Many nights my mother and I used to stay awake all night taking care of him. My mother was also ill, but she did a lot for him that we cannot forget." (DCG5)

Similarly, another woman carer said:

"Whenever I get some chance, particularly during the daytime when my son is at home, I sleep for a few hours. I have lots of sleep distraction." (DCG9)

One carer mentioned his mother's daily struggle:

"I cannot explain in words the burden and difficulties in being a caregiver. My mother is always by my dad's side. She cleans him, comforts him when he is angry, she stays awake all night keeping him company." (DCG1)

Another caregiver reported a similar care burden:

"My mum always looks after my dad, we sometimes rest and sleep, but my mother doesn't sleep even at night if my father is awake. My dad sometimes soils his clothes and gets to the bathroom first, [after] which my mum spends hours cleaning his clothes and rooms. My mother is diabetic, but because she cares for my father, she does not sleep well or look after herself properly." (DCG2)

Some family carers have reported that although doctors warn some women or older carers to look after their health, do regular exercise, and lead healthy lives, these family caregivers often ignore this advice and sacrifice their own comfort to look after their loved ones. One woman stated:

"Once, my daughter, son, and I went to the hospital with my husband. The doctor told my children that they should take care of their mother now. She is working hard excessively. She might be ill very soon if she continues like this. She needs some rest now. If she gets disabled, then who is going to look after her?" (DCG4)

These interview data suggest that due to maintaining cultural expectations and avoiding shame and embarrassment, carers are ‘getting by’ caring for people with dementia no matter how hard it is. They consider caring for older adults to be their moral duty, cultural norm, and religious obligation. However, data also indicate that the caregivers' experience many difficulties that are often challenging to cope with, suggesting they may not be fully managing. The family caregivers are forced to cope with situations to avoid societal stigma. One participant explained that he does not see any rapid change coming soon among the Bangladeshi community regarding care home use. However, it is wise to think about how these services can be culturally appropriate and fight against the stigma. He said:

"Well, not a quick change. I think it will take time. However, when our children are old, their children might consider sending them into a care home because they are born and brought up here, and their perception will be different from ours. Men, and women, everybody will work. For example, if a daughter-in-law works full-time, who will look after mother-in-law? Therefore, in their generation, they will be bound to use care home services. So, it is wise to think about how these services can be culturally appropriate and fight against the stigma.” (DCG10)

Findings of this phase of this research show that the women participants who took part in this study did most of the care jobs and all the household work compared to men. Especially, the wives of the persons with dementia and their daughters-in-law (or sometimes their daughters) had to provide care for the older adults. In many families, women work, therefore, they do not have enough time to give persons with dementia better care. One carer said:

"A while ago, I saw a dementia patient outside our local college because he was lost. He couldn't remember the way home, but a college student recognised him and took him home. One of my friends’ mother was lost after going out alone, and the police found her. Women carers are the ones who provide most of the care. I believe men should help out more or take care of homes as women need rest and a break.” (DCG1)

One carer explained that even though they were a big family, only his mother had to look after his father; nobody else could see them. From the analysis, it was clear that it is wrong to assume “they look after their own, so they don’t need help.” For example, the carer said:

"We are six brothers and two sisters. All of us live in our own houses; therefore, we cannot care for my dad all the time. My wife sometimes comes when she can. Everybody is busy with their own family and lives… My mum and dad lived alone for one year. I came again with my wife and children for my parents' love. When I see my other brothers and their wives do not care, I regret it, and sometimes I think I should leave the house again. However, it is a tough decision to make.” (DCG8)

Although Bangladeshi family carers care for their older adults, often risking their own lives by adapting their lifestyles, some underlying negative issues are present that need to be overcome. For example, interview data analysis suggest that caregivers asked for help when they could no longer cope by themselves or when the hospital doctors recommended and referred them to social workers for help. Therefore, most people with dementia and their carers did not use dementia services earlier, nor were they diagnosed on time.

5.2.4. Experiences of Service Usage: Gaps

Participant Group 2 have identified many gaps in the dementia service provision. Many carers had little awareness about the available services, so they could not navigate the health and care systems. At the same time, several interviewees, due to late referral by their GPs to memory services, highlighted that people with the condition receive their diagnosis at a later point in the progression of the condition.

One male carer (DCG5) reported:

"My mother was diagnosed with dementia at a very late stage. She used to see hallucinations, even a couple of years before she had been diagnosed.” (DCG5)

Another female carer reported her experience of her father's diagnosis:

"One day, my dad went to the marketplace, but suddenly he lost the way to return home. Eventually, he went far away. Fortunately, one of the Bangladeshi community members asked him, "Why are you here with lots of shopping? How can I help you?" Then this good gentleman took him home. …Then we talked to our GP. Thus, he was diagnosed with dementia." (DCG2)

The above two quotes indicate that some people from the Bangladeshi community were diagnosed with dementia so late that they are already in the last stage of dementia, as some family caregivers had no clue what to do about the condition. However, when the person with dementia developed behavioural symptoms of dementia and the situation worsened, they discussed this with their GPs, and they were diagnosed.

Most participants (n=8) reported delaying visiting the doctor; however, some of them blamed their GPs for not referring their relatives to the memory services; therefore, they think their loved ones were diagnosed late. For instance, DCG10 stated:

"…There was a delay in receiving diagnosis of my mother, due to other measures explored before visiting the doctor. She was diagnosed with dementia 15 years ago when she was around 65 years old. First, we struggled a lot with our GP. They even disagreed with diagnosing her. They did not refer her to memory services on his initiative. Instead, we had to convince and requested him to send her for a memory test. Another thing is that there is not a fixed doctor for her in the surgery. Different ones saw my mum at different times." (DCG10)

He also added that when he was concerned about his mother, he asked one of his friends for advice as the GP was not doing much for them, so what could they do? His friend explained that his mother might have dementia, so they should have her diagnosed as soon as possible. Then they requested to speak with their GP and convinced him after a lengthy discussion.

In this interview, it is noticeable that a few GPs appear to have been negligent about the early diagnosis of dementia. If this participant's friend had not recommended and the carer had not forced the GP, his mother's diagnosis would have been further delayed.

Another family carer (DCG1) reported about his father:

"My dad was diagnosed with dementia in 2000. He was diagnosed very late because many doctors didn't have full knowledge about dementia; therefore, it takes 10-15 years to identify if someone has dementia." (DCG1)

This interview analysis has revealed that experiences of dementia diagnosis vary, and some people are diagnosed very late; that suggests more awareness raising targeting Bangladeshi and other South Asian communities is required to avoid the delays in seeking advice and help that come about via going to faith healers and hiding within the family. Some doctors might need to give more thought to referring people for diagnosis earlier.

This research has identified many gaps in dementia health and care services, as most participants have reported that services are not culturally appropriate. Participants were asked to discuss their experiences with the hospital services. Three participants explored the notion that they did not receive culturally appropriate services from the hospital. For instance, one carer said:

"*The food provided is not as tasty as the food they cook at home. That is why I used to take food from home when my father was in the hospital. Although they provided halal food, It was not cooked or processed how we (Bengali people) eat. My father wanted a male nurse to look after him. He was very embarrassed when he saw that some female nurses came to him and took him to the toilet. It was a big shame for my father as a Muslim when he realised that a woman would see his private parts (DCG2).*
Another carer said:

"When we took our dad to the hospital, the Doctor said my dad was not passing urine. Two nurses came to check him, but my dad refused to let them check him. I knew my dad would behave like this with the nurses. If a male nurse treated him, he would not have the same problems." (DCG3)

Another family caregiver shared a similar experience:

"My father is a religious man who prays five times a day. Suppose a woman comes to take care of him, like bathed him, assisted him in using the toilet, or feeding him; he

will not tolerate this. Sometimes my dad used to ask why nurses are not wearing headscarves. He used to tell my mum: 'if a lady nurse touches me, my wudu *[ablution for prayer] will break, you know. He was also concerned about food and whether it was halal."* (DCG8)

The above three participants reported that hospitals failed to meet people's cultural norms by not providing gender-specific services. Data analysis has revealed that Muslim people think it is against their religious and cultural ethos if any person of the opposite gender touches them for any reason. Therefore, it is needful that hospitals and all care services should provide culturally appropriate gender-specific services.

Participants were asked to share their experiences of their care service usage. Some caregivers have reported that they struggled greatly to receive care services because of the language barrier. They recommend same language-speaking carers as essential for the people of the Bangladeshi community. One participant reported:

"We had lots of problems with the first carer, because of the language issue, who could not communicate with my mum or my wife. Now they are OK with the current carers, who are Sylheti Bengali. So, if people with the same language had served, then it would be easy to communicate." (DCG10)

Another participant commented that there is a communication barrier that negatively impacts on the family caregiver and the person with the condition. She stated:

"They [carers] ask if they [person with dementia] have taken medication and then write a statement and go. My father and my wife could not communicate with them because of the language barrier. If they just come for the sake of their job and sign the attendance paper and leave, it is not called caring, and nobody deserves this type of care." (DCG2)

This participant also added that a same language-speaking carer could serve them better because they could communicate better with them. In addition, the participant also felt the caregivers must be well trained. They should not think that attending to the duty is their routine job; rather, they should be caring and thoughtful and show empathy towards people with dementia.

One participant reported a perceived development need in care workers, that they should show more empathy towards people with dementia when they serve them (DCG4). She also added:

"First, they sent one male carer; however, he was not good with hygiene and cleanliness. He also not had any compassion or empathy for my husband. My husband complained that he got in pain when this caring person held him. So, we asked for a different carer, and they sent one from the hospital. They were mixed, both male and female. So, we didn't like their services." (DCG4)

The above quote suggests that this participant felt that there is a need for better staff training. The family carers also advocated that the care services staff should recognise and respect the cultural values and religious beliefs of people with dementia. In this regard, participants felt that some well-trained Bangladeshi carers could be better for them, as they would understand more about their culture and communicate better with the persons with dementia and their carers. However, when they do not find professional caregivers who speak their language, they prioritise professionalism over the same culture. For instance, this family carer was happy with the English carer because she could do her job well.

Another interviewee mentioned that they were not very happy with the care services received, therefore they stopped using this service, and the family members perform the tasks by themselves. The carer said:

"Although a carer would come to our home, my father would not go to the toilet. He would go after the carer left. Besides, there was no specific time the carer would come; it was random times. My mum would end up doing all the caring, including changing nappies and cleaning him. Therefore, we stopped using this service, and occasionally my brother and sister would help my mum." (DCG2)

One carer expressed that they do not trust that any care services will be good for her father. They think nobody can care for an elder as family members will do.

"To be honest, whatever service we provide for our dad, a care home staff will not do this. They will provide primary care as a duty or job. For example, when my father was

in the hospital, he did not like the service. We cannot trust their service because of how we feel for our father; they will not show the same feelings." (DCG2)

One participant reported a good example and expressed that she was delighted with some English carers who were very professional about their job. She said:

"They are mainly English. They are good. First, we change three-four carers who are not acceptable, and my dad did not like them at all. They were of Jamaican and Pakistani origin. We did not like their services at all. Our current carer is a fantastic woman. When her father died, she started this job as our dad's caregiver. She used to consider my dad as her dad. We used to record her services on our mobile. However, we never found anything to complain about against her. She used to miss my dad even after his death." (DCG3)

One carer felt that her father did not want anybody's services, he only wanted her mother to look after him and be with him. She stated:

"When the carers used to come, my father could not tolerate them. He used to dislike them. The truth was my father wanted my mother to take care of him. If he did not see my mum for a while, he would keep asking where she is and why she is not coming today? My father used to think my mother has left, and she will not come back." (DCG10)

One participant reported that any Asian carers could provide more culturally appropriate services for his mother.

"First, carers who used to serve my mum were of South Asian origin. Now some English carers are coming. In my experience, these South Asian carers served better than the English ones. We wanted to change the time. I thought they should come a bit later to help if my mum needs the toilet. They feed her and go. So when my mum needs them desperately, they are not here. Therefore, we do not feel we need their help any more. We must do everything." (DCG8)

Similarly, other participants also expressed their views that south Asian carers might be better for them.

"Well, there was a Pakistani lady. She was very much experienced, and she did an excellent job. However, she left this company, then an English carer came. There was a language barrier. When I was not there, communication was a problem. If a Bengali carer could care for my mum, maybe it would be better." (DCG2)

Participants were asked via prompts if they knew a care service in their locality run by Asian Muslims who claim that their services are culturally appropriate and provide Muslim male carers for males and females for females. The carer replied:

"Yes, I know them. We went to that care service first, which gave two male careers. But they don't clean properly, and we don't like their services at all. They need more training and development. Now, those who are coming are very professional. We appreciate their services. If Asian carers could provide better services, we would go to them. My mum also gets ill. Changing nappies regularly and take all of his care is very difficult for my mum—that's why we got these English carers." (DCG8)

Interview data have thus revealed that participants perceive care services as culturally inappropriate: Bangladeshis would appreciate carers who are both better trained and appropriately segregated by gender to enable compliance with Muslim culture.

5.2.5. Raising Awareness of Dementia

Participants were asked who they thought could help raise awareness about dementia in the Bangladeshi community in the research area. Almost all family caregivers (n=7) felt that Bangladeshi community leaders might play various roles aiming to raise awareness about dementia in the Bangladeshi community. For example, they can campaign through multiple print and electronic media, social media, and community events, and educate people about dementia. One informant proposed:

"I think we need to do a lot to raise awareness of dementia in the Bangladeshi community. We can arrange some talk shows on our Asian TV channels like Bangla

TV, YouTube channels, and other social media. We can also bring in people with dementia in these talk shows to talk about their experiences so that when people see their faces and listen to their struggles, they would be aware of this illness.” (DCG1)

Another participant proposed that Bangladeshi community leaders raise their voices in community events, electronic and print media, and other social platforms. As the informant remarked:

"We do not see any activity happening in our town among the Bangladeshi community as dementia is still a hidden subject. People are not aware of that. If community leaders were aware of dementia, they could discuss it on social media and community events. We see the physical injuries, but we do not realise the pain of mental illness. We all need to work together as a community.” (DCG10)

The family caregiver emphasised that community leaders should talk on all social platforms about dementia, its symptoms, and how to live with dementia and remove the stigma.

Family caregivers have emphasised that it is essential to raise awareness about dementia in the mosque congregation and make the mosques dementia-friendly.
One carer said:

"My father would raise his voice to say hi to someone he knows when he needs to be silent in the mosque, which causes us embarrassment as people don't understand why he is behaving like this. Even if a few people know about his dementia, not everyone is aware; therefore, they get annoyed at his behaviour. If our Imams talked about dementia in their sermons, people would understand it more and not show frustration towards dementia. There are already chairs provided for people who cannot stand and pray, so if we offered Dementia-friendly spaces and signage, it would benefit everyone.” (DCG1)

This interviewee suggested allocating some spaces in the mosque for people with dementia, can be beneficial for the people with dementia. The informant highlighted the significant role the Imams and religious leaders have to play as Imams have a high rank in society, and community people always go to them and listen to them. One caregiver suggested:

"Imams and religious leaders could educate the community by saying that dementia is just an illness, and ... stigma are not allowed in Islam; visiting ill people and serving them is rewardable." (DCG10)

Similarly, another participant suggested:

"Mosques can play huge roles. They can run some sessions on understanding dementia, [how to] live with it better, or prevent it if possible. If Imams were trained and had some knowledge about it, they could talk about it in their Friday sermons as many older people come to the mosque. Women could listen from home as most mosques have indoor mikes or mosque radios. They would not get socially isolated or much depressed. Maybe people would get proper knowledge about dementia. Imams' speeches should significantly impact removing stigma and misconception about dementia and easing many people's lives." (DCG6)

This participant emphasised training Imams first and requesting them to talk about dementia in their Friday sermons. They might also run some dementia awareness sessions for their congregations. Simultaneously, the mosque management committee could facilitate some dementia cafés or luncheon clubs for people with dementia to be socially engaged and save themselves from the social isolation that is a severe risk factor of dementia. One carer advocated that the mosque should recruit volunteers from their fellow worshippers to assist people with dementia when they go to the mosque. She explained:

"*Bangladeshi community needs to do a lot more for people with dementia. Some people or voluntary organisations could work in mosques to offer dementia patients support to return home from the mosque. Many people have no understanding of dementia; therefore, my younger brother does not like to go to the mosque with my father. If my dad went to the mosque on his own, he would forget the way back home. Often, people used to see him lost and bring him home. If there were any training for the congregation, they would have been more useful.*" (DCG2)

Another participant provided the following suggestions:

"I think our mosque management committee should come forward and take some initiative for these people so that they can have a cup of tea together and socialise. Mosques can run tea parties, dementia cafés, or luncheon clubs there for them. Look, in some families where the husband died, and the wife has dementia or wife died, and husband is diagnosed with dementia if they do not have children or their children work full time, then where should they go? They must stay at home isolated, which is not good for them. If the mosque provides them some support, provides information, talks to them nicely, it will help them." (DCG10)

Participants emphasised making all mosques dementia-friendly so that people will be more aware of dementia. People with dementia will go to the mosque, pray together, and socialise.

5.3. Discussion:

Data analysis from the family caregivers of people with dementia revealed that the participants had little knowledge about dementia. There was a sense of expression of family carers who participated in this research that they had no previous knowledge about dementia. They were also unfamiliar with the word dementia until their loved one's diagnosis. This thesis found that people with dementia and their family caregivers struggled to navigate the healthcare system as they did not know what to do or where to go with these conditions. Thus, people went to their GPs and other services late, which delayed their dementia diagnosis. Several caregivers also reported that they often asked the GP, but their loved ones were not referred to memory services. Therefore, they claimed their loved ones' late diagnosis was due to their GP's negligence. Data analysis also indicates that participants did notice something 'wrong' with their loved ones. Therefore, they wanted whatever it was to be fixed or have a 'resolution,' even though they did not have the word 'dementia' to describe the problem.

Findings from the family caregivers of people with dementia suggest that many caregivers have various misconceptions about dementia due to their cultural and religious beliefs. Some family caregivers went to different folk healers and Imams (also known as spiritual healers) here in the UK. At the same time, several family caregivers reported that they went to Bangladesh to visit some *Kobiraj* (folk healers) but did not go to any bio-medical doctors. Findings suggest that dementia diagnosis could be delayed due to these beliefs and cultural practices of jinn extortion. Data also revealed that many spiritual healers do not have training in counseling or basic knowledge of dementia. They also encouraged people with dementia to seek treatment and not go to medical doctors. Many respondents tended to explain that their extended family members told them to go to Imams and spiritual healers first. Therefore, they went to spiritual healers to exorcise *jinn* as they thought *Jjnns* possessed their loved ones. This research also suggests that some so-called healers or *kabiraj* often earn ample amounts of money by conning people in the name of *jinn* expulsion. It also indicates that not all Bangladeshi are the same regarding who goes to these healers.

This research has explored societal stigma, self-stigma, and courtesy stigma attached to dementia in this community. Consequently, people often hide dementia out of fear that other people from the community may judge them. Many family carers stated that their relative with dementia became socially isolated because of the social stigma. Family caregivers also felt that due to the behavioural and psychological symptoms of dementia, people with the condition become socially isolated, thinking that maybe other people do not like them. This study has explored the issue that receiving care home services or sending one's elders to a care home is a subject of stigma in the Bangladeshi community, and removing the stigma is challenging. Cultural expectations, stigma, lack of trust, and lack of culturally appropriate services are significant obstacles that prevent people from sending their loved ones to care homes. Some participants reported that GPs were resistant to caregivers' repeated requests for diagnosis and assistance. This indicates that there might be institutional racism in health care services that may delay diagnosis or access to services.

This study has found some gaps in dementia health and care services. For example, family caregivers have reported that dementia health and care services are not culturally appropriate. For example, participants feel it is against their religious and cultural ethos if any (unrelated) person of the opposite sex ever touches them. Some participants reported a need for better staff training. The family carers also advocated that the care services staff recognise and respect the cultural values and religious beliefs of people with dementia. In this regard, participants would prefer some well-trained Bangladeshi carers who could be better for them, as they understand more about their culture and communicate better with the persons with dementia and their carers.

Most participants felt caring for elders to be their moral duty, religious obligation, and precious task; therefore, they did not want to send their loved ones to care homes. Some participants have left their well-paid jobs to look after their loved ones. They also said they would never send their mums or dads to a care home as long as they live. They also added that they could earn money and do the job they wanted, but their parents' comfort was the main priority. Some caregivers have expressed that no matter how fantastic care home services are, they will not send their parents to a care home because they are their parents who gave them birth and looked after them when they needed their help. The caregivers also expressed that they want to look after their parents, even if they must sacrifice their lives because it is their culture. The main reason they identified is that they are Muslims, and their Quran, the book of God, and their beloved prophets taught them to serve their parents because it is their right to receive that from their children. Family caregivers have the religious-cultural motivation to care for their family members, hold their families' values in the highest esteem, and sacrifice their comforts for their family's sake. This finding echoes Parveen (2011, p.128), who found that British South Asian caregivers had significantly higher levels of familism than White British caregivers. *Familism* is defined as ‘’the strong identification and attachment of individuals with their families (nuclear and extended) and intense feelings of loyalty, reciprocity, and solidarity among members of the same family" (Sabogal et al.,1987). These findings also support Hossain's thesis (2017, p.152), which found that British Bangladeshi family caregivers were more willing to provide family care than British Indian and Pakistani carers.

In contrast, data also indicate that some caregivers have experienced many difficulties that are often challenging to cope with. However, they were bound to give care because of their social norms and religious obligations, even though they lacked an understanding of dementia in the broader community and suffered from the lack of availability of culturally appropriate services. Therefore, some participants believed that when people cannot manage their elders well, sending them to a care home for better help and support for their loved ones is good. Participants have provided suggestions for raising awareness about dementia and improving health and care services, which will be presented in Chapter 8 (my conclusions and recommendations chapter). A detailed discussion will be provided in Chapter 7, mapping with existing literature.

Chapter 6: Findings from the service providers and stakeholders

6.0. Introduction

This chapter illustrates the findings derived from the qualitative interviews with the dementia service providers and stakeholders of a UK Bangladeshi community as answers to the following questions:

a. What is the knowledge and beliefs of people living with dementia in the UK's Bangladeshi community?
b. How do Bangladeshi individuals and families experience life with dementia? What are the key issues and challenges attached to accessing dementia services, and what kinds of support are they lacking?
c. Is dementia stigmatised in the Bangladeshi community?
d. What is the understanding of stakeholders/service providers about the dementia support needs among this community?

Stakeholders were asked first what services they provide for people with dementia and their roles in these organisations. They were questioned regarding whether people from the Bangladeshi community are diagnosed early and have access to dementia services on time. They were also asked to express their views if they see any barriers to the above community accessing dementia services or feel there is any gap in service provision. Mapping from my research questions, five interlinked topics emerged. These were:

a. Knowledge of Dementia and Help-Seeking Behaviour
b. Misconceptions and Myths about Dementia
c. Dementia Stigma
d. Cultural Expectations of Care
e. Gaps in Service Provision.

After presenting participants' demographic information, this chapter will discuss the themes and sub-themes derived from the data. Sub-section 6.2.1. presents the knowledge of dementia and help-seeking behaviour of the service users among the Bangladeshi community, 6.2.2 discusses misconceptions and myths about dementia, 6.2.3. presents how dementia is stigmatised in this community, 6.2.4. illustrates their cultural expectations of caring, and 6.2.5 presents what the gaps in service provision are. However, linking with the previous literature, overall findings will be presented in the discussion chapter (Chapter 7, p193-211).

6.1. Participant Demographics

Five dementia service providers/stakeholders from my research area participated in this phase of the study. The age range of the participants was 40-65 years. Four of these participants were Muslims, and one service provider was Hindu by faith. Three participants were British Bangladeshi, one was British Pakistani, and another was of British African origin. All of them were male. Table 6 provides an overview of all participants of Group 1.

Table 9: *Participants' Characteristics (Stakeholders/service providers)*

Participants ID	Age Range	Service	Ethnicities	Religion
SPASHI1	40-45	NHS Health Professional	British Bangladeshi	Hindu
SPASHI2	60-65	Dementia service provider - Charitable OIrganisation Head	British Pakistani	Muslim
SPASHI3	40-45	One of the senior mangers of an umbrella organisation for 33 Mosques and Inter Faith Forum	British Bangladeshi	Muslim
SPASHI4	40-45	A senior manager of a dementia care service provider	Afro-Caribbean	Muslim
SPASHI5	55-60	A dementia champion trainer/ Faith Organisation Head	British Bangladeshi	Muslim

6.2. Themes & Sub-themes from the data

6.2.1. Knowledge of Dementia and Help-Seeking Behaviour

All stakeholders/service providers suggested that their service users from the Bangladeshi community understand that they have something wrong with them because of dementia although they did not have any word for it. Therefore, they wanted it to be fixed or have a 'resolution' for it, suggesting they understand dementia partially and have some idea of what dementia is. However, participants also emphasised that these people do not necessarily understand dementia in a westernised scientific/bio-medical context. For instance, an NHS health professional mentioned:

People often think it is just about forgetfulness. Their behaviour and cognition are often misunderstood. Dementia is a neurodegenerative condition, but people don't understand it most of the time. They think they are all psychotic. So, they mixed up with whether it's a psychosis, psychotic, or neurodegenerative condition. (SPASHI1)

Another participant reported:

*"Our Bangladeshi service users usually go to the doctor or ask for help very late or just in a crisis point in all mental health diseases, whether dementia, schizophrenia, depression, postnatal, or any other mental illness. People do not go to the doctor first; instead, they try to use their home remedies in most cases; and when they struggle a lot and think they need to have it diagnosed, or if there is no other option for them, they will seek medical help." (*SPASHI3)

From the above two quotes it is clear that service users, i.e. people with dementia and their family caregivers from the Bangladeshi community, understand that there is something wrong with them, so they want to fix it in their own way. However, their understanding is limited and often not correct according to the westernised scientific/bio-medical perspective.

Almost all participants (n=4) reported that these service users of Bangladeshi and South Asian origin were not familiar with navigating systems, which would be a significant barrier to accessing services as they do not know when to ask, whom to ask, or where to ask for dementia help. One stakeholder illustrated with an example that not only do ordinary people struggle to navigate the system; even professional people also often get confused. For instance, Dr. X and his wife had developed dementia, and were keen to maintain their Hindu religious practices. They shared their experiences to a care home manager:

"Hi, I 'm a consultant and work for NHS whole life. My wife is a consultant too, who is a ‘y’. She was in the hospital five weeks ago, and we can't navigate care services to get her appropriate care. I'm shocked that we can't navigate the social care system and don't know what to do with it (SPASHI4).’’

Participants were asked to share examples of the help-seeking behaviour of the Bangladeshi community towards dementia. Almost all of them (n=4) reported that their service users from the Bangladeshi community access dementia services late. One stakeholder said:

"*There is a concern that people do not go to their GP or memory services on time, therefore their diagnosis [is] delayed* (SPASHI2).’’

6.2.2: Misconceptions and Myths about Dementia

Participants (n=5) also reported that there are various misconceptions and myths about dementia amongst many of the Bangladeshi people. For instance, one service provider stated:

*“When someone with dementia cannot remember things or lose their perception of power, they become frustrated or aggressive, that frustration is misunderstood as a “mental health” problem. Specially, when someone develops behavioural syndromes such as hallucinations, then many Bangladeshi presume that individuals with the condition became “*Pagol’ *[crazy].”*(SPASHI1)

The quotation above indicates that many people from the Bangladeshi community mistakenly believe that dementia is a mental health problem.
Almost all interviewees (n=4) reported that many Bangladeshi believe dementia is because of the possession of "*jinn-bhuta*" (spirits or unseen forces) or some other form of supernatural entity. Consequently, they go to spiritual healers for folk healing instead of dementia health and social care services.

One stakeholder reported that some Bangladeshi service users view that dementia and all mental health related conditions occur because of black magic. The participant stated:

"*Some people think that someone has done some form of black magic on them, which is making them feel that way, and they would go to a religious scholar, and they would get blessed water or Talismans to wear around the neck, and they would deal with that way*." (SPASHI3)

One participant commented that some people believe dementia and mental health problems only might be cured by God, where bio-medical treatment might not be useful. The stakeholder said:

"People think dementia is something given by God that cannot be medically supported. Because of such an assumption, people do not necessarily take any further action. Eventually, they will realise they have a memory problem, and when they learn, sometimes it will be too late." SPASHI2

One stakeholder has reported some Bangladeshi individuals with the condition among their service users believe that dementia could be some sort of punishment from God.

*"Some service users (who are Hindu by faith) from the Bangladeshi community believe that anything wrong happens because of their past sin. People think it is happening because of any spiritual influence or some actions of their past lives; they became mad." (*SPASHI1)

Such beliefs can be dangerous for persons with dementia: they might fuel social stigma. A person with the condition also might possess self-stigma through thinking that other people may not like them or treat them as bad.

One stakeholder expressed his view there are some Bangladeshis who believe dementia is a natural part of aging. One participant stated:

"People who reach 65/70, if they develop dementia, it's not diagnosed because people do not realise that it is a problem. They think this is a part of old age, which kicked in. People often think that people who reach the age of 70 'lose their marbles.' Thus, they start to act like children or forget things. Therefore, people do not see dementia as an issue. When they see they are seriously affected and challenging to manage, they will only go for help." (SPASHI3).

6.2.3. Dementia Stigma:

My analysis was guided by conceptualisations of stigma as set out in Chapter 2. This section therefore demonstrates the operationalisation of my conceptualisation of stigma. When discussing the response of others to dementia within the Bangladeshi community, almost all stakeholders reported that people with dementia among the Bangladeshi community are heavily stigmatised. One participant commented:
"When people have got dementia, they start losing their friends as other people avoid them considering that people with dementia are not in the right frame of mind, or became crazy." (SPASHI3)
Another participant said:

"People feel embarrassed. So, when people are embarrassed, they try to keep everything under the carpet. Could be socially isolated from the community. … They may stop coming to the mosque, or they may not frequently come to the mosque. The activities would change for that person." (SPASHI3)

These quotes suggest that people living with dementia have symptoms that are deemed 'not normal' (after Goffman, 1963) and that this gives rise to being viewed as 'different' and subject to ridicule. This indicates there is significant level of societal stigma existing among the service users, reported by the stakeholders/service providers. In turn, a person with the condition felt guilt and ashamed, which is constructed by other members of their society. They often become socially isolated from the fear that other people may judge them as mentally ill. The quote above also highlights that even those who used to go to the mosque five times a day stopped going because they felt embarrassed, considering others would laugh at them or judge them as crazy. Consequently, people become entirely isolated. So, it is clear that there is both self-stigma and public stigma attached to people with the condition, which drives them to conceal their condition or live in socially isolated fashion.

One participant has reported that because of the public stigma attached to dementia, the marriage prospects of a family member of person with the condition can be affected badly.

"*Suppose my father had Dementia, my daughter is 25 years old, and I am waiting for my daughter's good marriage proposal. I will worry; because the family coming to see my daughter will find out my father has Dementia or behaves differently. So, they can have a perception that this can gradually go to other members of my family, and everyone will be like this; thus, a good marriage proposal can deteriorate.*" (SPASHI2).

One stakeholder mentioned that people's self-stigma is worse than public stigma as people with dementia often feel nobody likes them even though others are respectful and sympathetic towards them. The participant said:

"I know a lady for years. Nobody knows that this woman had Dementia. When she passed away, it became publicly known. When I went to her funeral, I couldn't believe thousands of people turn up. I was amazed at the reception. But the fear from the family, I can tell. I mean, we discussed it. Probably just going to view how. They had this fear of what other people would think! But I think I haven't picked up any negative reaction from society or any bad commenting. However, people do indeed feel what

other people will think. Because of this fear, they will hide this and not disclose it publicly (SPASHI4)’’.

It is clear from this quote that self-stigma is a dangerous factor driving people with dementia from the Bangladeshi community to hide their condition or undergo social isolation.

6.2.4. Cultural expectation to Care

Participants reported some cultural expectations of the Bangladeshi service users. One service provider said:

“It is mandatory and a religious obligation to look after their parents and elder relatives within the Muslim culture. Sometimes a person with dementia does not even have to make a cup of tea because other family members are there to 'serve' them. It is a shame in Muslim culture if a family cannot look after their older relatives.” (SPASHI2)

Another participant expressed his view:

*“Family caregivers of a person with dementia might worry that their ‘*izzat*’ (reputations) might be damaged if they send their loved ones into any care home unless nobody is there to look after them. Even if children work full time, they still manage some time in rotation to look after their loved ones at home, even though they had no training how to care for an individual with dementia. Care homes will be their last choice when there is no one to look after them* (SPASHI4).’’

From the above quote, it is clear that there is enormous pressure within the community not to put people in a care home; rather, a family member should do it. However, it might possibly be hat a family member does not know how to cope with dementia care. Moreover, families also may not be able to provide full-time 24-hour support at home due to work and other commitments.

6.2.5: Gaps in Service Provision

Participants identified some gaps in dementia health and care services that are presented here under two sub-themes: Language Barrier and Lack of Culturally Appropriate Services:

6.2.5.1. Language Barrier

All participants (n=5) have reported that the language barrier is the most crucial obstacle in Bangladeshi and South Asian communities that prevents people from accessing dementia services and delays dementia diagnosis. Many people could not communicate with their GPs, who are the gateway to other services. For example, one participant (who is an NHS health professional) mentioned:

"Even not only delayed, but there is also a possibility of misdiagnosis. People get misdiagnosed because of the language barriers as what patients want to say; doctors may not understand. Sometimes, what doctor is trying to explain, a patient may not understand (SPASHI1).''

This stakeholder also added:

“Although there are interpretation services available in NHS services, they are not accessible. For instance, to book an interpreter, someone needs to wait for two/three months. It is not always possible to obtain an interpreter on time. Sometimes interpreters use a telephone line that can risk missing the correct information.” SPASHI1

6.2.5.2. Lack of Culturally Appropriate Services

Stakeholders were asked if they could find any gap in dementia services that should be improved in regards to the Bangladeshi community's needs. Almost all (n=4) reported a lack of services tailored to Bangladeshi and South Asian communities' needs and said that services are not culturally appropriate or religiously sensitive. The service providers need to understand the cultural expectations and requirements of people with dementia first. One health professional showed his frustration and said:

"I don't think we are even in the Western World... Our hospitals are not dementia-friendly; not every care home is dementia-friendly. So, every service is not even [catering to people's needs]". SPASHI 1

One stakeholder has commented that dementia training for service providers is not culturally sensitive and does not consider the different backgrounds of those with dementia. For instance, people's early memories will not necessarily be a setting in this country; it will be a setting somewhere else that does not always correspond to people's training in this country. Therefore, it needs to be tailored to the context of individuals.

"So, when you / when somebody from a Bangladeshi background will probably come to this country in the late 60s/early 60s/mid-60s and 70s. When they do have dementia, they are living a life in rural Bangladesh rather than here. So, when talking about cooking, if they're going back to their early 20s, cooking is not necessarily on a gas stove or oven fire. Unless you've trained, you won't be able to recognise it (SPASHI5)”.

Three participants commented that healthcare service providers often do not understand all ethnic groups' specific needs. One service provider stated:
“Care service providers take generic approaches for all, and people feel this is more destructive to their lives, so it is better for them to avoid it. There is a need for religious-friendly and cultural appropriated services.” SPASHI4

Several participants reported that care service staff lack understanding about the cultural needs of the BAME community. If they know the BAME community's needs, they can serve them better. For example, one participant said:

“All health-care staff must be trained on the religious and cultural sensitivities so that individual patients feel respected, valued, and enjoy going into a service where they know the cultural and religious needs will be met.” SPASHI1

Another stakeholder shared a story from his own experience that shows that some health professionals/staff do not know BAME communities’ cultural needs. The participant said:

“I had once been called into my local Hospital at the mental health unit, and the doctor was sectioning someone. I said, well, why are you sectioning them? He said I saw him he washed his body, water all over his body, and bang his head on the floor. In reality, this patient was doing his prayers because the doctor didn't understand that he was doing the prayers. He will section him, so you must represent the community you live in wherever you work (SPASHI3).’’

Almost all (n=4) participants reported that the care homes do not provide gender-specific services; therefore, Bangladeshi or South Asian people do not send their loved ones there. They advocate that all care providers need to provide services in a gender-specific way, and care organisations need to restructure themselves to have people who deliver services either through experience or by learning in other organisations. One participant stated:

"Whenever there is personal care involved, male should provide support to males and females for the female. Unfortunately, it is a fact that all (I am saying all, not most) of the other providers are not doing this. Even some English people will ask for this sometimes, and unfortunately, the system still hasn't picked up whenever we discuss it (SPASHI 4).’’

Almost all (n=4) participants reported that Bangladeshi people or other South Asians usually do not like to send their loved ones to a care home as they do not provide culturally appropriate services. They further advocate that all care providers need to ensure males serve males and females, females.

One stakeholder suggested:

"Every organisation should have trained staff who understand the BAME community. If they know the BAME community's needs, they can serve them better.” (SPASHI4)

One stakeholder has suggested that services will be improved if care staff are employed who are of Bangladeshi background or the same ethnic group as the people with dementia (SPASHI5).

Another interviewee perceived that the Bangladeshi community could benefit from a carer coming to the home and taking the dementia patient out for a couple of hours (SPASHI3).

6.2.5.3. Good Practices/Initiatives

Stakeholders and service providers were asked if they had identified examples of initiatives developed to address the needs of people living with dementia from the Bangladeshi community. Participants mentioned several positive initiatives from local CCGs directed toward helping BAME communities. For example, one stakeholder (SPASHI2) has reported that the local CCG is already aware of a lack of understanding in the BAME community about dementia. Therefore, they have funded a volunteer organisation and appointed a 'dementia link worker' to raise awareness among the BAME community. This link worker, a recruit during Covid, was also working with carers and providing them with the necessary information. So, for the CCG, raising awareness is new for this community.

"The CCG made a consultation with all communities, including the Bangladeshi community, and I was involved with this. We had to find out the challenges these South Asian people with dementia and their careers face and their cultural expectations and needs (SPASHI 2).’’

This participant also stated that the local memory service had appointed a clinical psychologist from a South Asian background who works on translating awareness-raising materials and developing short courses for Pakistani, Bangladeshi, and Indian communities to support them with their memory problems. They also have interpretation services available for those who cannot speak English. However, these findings suggest that the local CCG has started limited awareness-raising programmes for the Bangladeshi and BAME community towards dementia. However, they are not intensive enough as almost all participants reported that their service users from the Bangladeshi community had little understanding of dementia and struggled to navigate dementia services.

Stakeholders have reported some activities of their local faith centres directed towards the well-being of people with the condition. One interviewee, executive personnel of the local mosques' council (an umbrella organisation of 37 local mosques together), has mentioned that they have discussed several times how mosques could be dementia-friendly. They held meetings, and some Imams talked about dementia in their Friday sermons. They also added that three mosques now in their locality have become dementia-friendly, and they have specially trained officers who can look after the needs of people with dementia. The same person reported that the Interfaith Forum has a discussion meeting where all faith leaders come together every three months. One of the discussion meetings covered how best they can support people with dementia from all faiths and how different communities and faiths talk about dementia and support clients or customers, or parishioners, with dementia to come into the church or the mosque, and how best to support them. So, the raising of awareness has started.

Similarly, one participant confirmed that their mosque is dementia-friendly. If anybody comes to this mosque, they will be dealt with appropriately and sensitively. If any person with dementia behaves aggressively, other people will not mind because the mosque management has educated their congregation on coping with persons with dementia. The congregation is trained to deal with that situation. When someone cannot remember the Surah (Quran), they cannot remember how many Raka't (units of prayer) they have done, and so on, and then they come to the Imam for Islamic theological guidance. The Imam explains the rulings/Hadith on how to perform prayers and conduct themselves.

"*We provide training for our congregation on how to deal with people with dementia, where [there] are these support mechanisms around. We run several sessions on how* *to live and support people with dementia. We run training sessions for female careers who have people living with dementia and their families. So, we have run dedicated sessions for women (*SPASHI 5).''

Although the Bangladeshi population in my research area comprises mainly Muslims, a group of people from a Hindu background live there. One participant (SPASHI1) informed me that their local temple runs a luncheon club twice a week where Hindu people with dementia, those without dementia, and everyone of old age can enjoy 4 hours, two days a week.

Findings from the above two interviewees indicate that some faith organisations also started to work voluntarily to raise awareness amongst their fellow Bangladeshi community. However, these activities are limited only to one or two mosques. These research participants anonymously suggest that if all mosques/ faith centres come together to raise awareness of dementia, there will become a revolutionary change.

6.3. Stakeholders' Views:

Participants were asked to suggest how best we can raise awareness of dementia, remove stigma, and make services more inclusive. They were also asked for their ideas about how to create a dementia-friendly environment and improve people's social engagement. Almost all participants (n=4) suggested that the Clinical Commissioning Group (CCG) should appoint some dementia link workers who will work closely with the community, especially with the mosques and temples, and organise activities for the people with dementia and awareness training sessions. Also, if, for example, any organisation offers some weekly or monthly activities in any area where the Bangladeshi community is living nearby, they can advise the organisers to attract more Bangladeshi people. The link officer can then raise awareness amongst the Bangladeshi community that these things are happening in the local area. He needs to go into the community, raise awareness of dementia, and direct them to services to help. For example, he may say that *such and such* centre is running these classes and advise someone to participate if they can, or *this, this* help is available for someone on *this*.

The participant also argued that as with dementia services, memory services also need to redesign their services. They should put together Bangla-translated material and make online bilingual information available.
"All these services CCG or local authority do is just stage 1 [very basic]. These services need to be redesigned. For instance, now we got a few more Bangladeshi or Pakistani staff in our team. Those staff are still junior. They won't be involved much in how the services are designed (SPASHI 4).''

Participants were asked to express their view in the light of their service users' experiences and suggest on how to improve dementia diagnosis and other services. Some stakeholders/service providers found that their service users were not satisfied about their GPs services. One stakeholder suggested:

"*Health professionals have a major role to play to make people aware of dementia. GPs can obtain information from their patients' families as they often visit their houses and are directly connected with the patients. They can display posters in their surgeries to raise awareness of dementia and translate these posters into different languages (SPASHI2).*''

The participant also added that community nurses also have a major role in identifying their problems and needs. Participants were asked to suggest how to raise awareness of dementia in the Bangladeshi community; almost all stakeholders/service providers have suggested that mosques and faith centres could contribute to educating people and raising awareness about dementia. Imams and religious leaders can play a part to an enormous degree in educating people as they are very respected individuals in the community, and people listen to them whatever they say. They can talk about dementia and old age in their Friday sermons. One participant took the view that the mosque management committee could run some workshops with people or committee members of the mosque to look out for a dementia client or patient to support them when they come to the mosque, so they feel comfortable coming there (SPASHI5).

Another interviewee suggested that mosques and temples can organise specific shows in their places of worship. The mosque congregations can speak to the local authority and advise on what is available for people with dementia and raise any gaps or barriers as to why people do not access the services. One participant said:

"Imams and priests can run some informal sessions and raise awareness of dementia. They can talk about dementia in their Friday sermons, how they previously did it for mental health issues when we used to go to them. Imams are OK with this. There is no problem with the Imams whatsoever in any area. They will do the same for dementia, I believe. People listen to whatever they say." (SPASHI 2)

All stakeholders have suggested that Mosques should run dementia cafés for the Bangladeshi people. One participant suggested, giving examples from his locality:

" One café will not be enough because people live in different places. We can't expect someone living in our locality, for example, to go to a Mosque in another locality Because of travelling. They [are] already down with the stigma for them to go and meet new people. That's not going to happen. We need at least three mosques in three different areas to provide these services." (SPASHI3)

Three participants have expressed the view that several mosques could open luncheon clubs. Family members can bring loved ones into a culturally friendly atmosphere where they know they will be looked after and have a nice hot meal and be able to socialise.

"Within our community, that aspect is missing. We need to get these people together. We need to put on activities for them, so they know that they can relate to people. We don't want all the mosques to do it. If we've got two/three mosques in different areas, who would do this, then that would be sufficient/enough for people to come out and to join." *(*SPASHI 3)

A few participants were concerned that some mosque management committees might not agree to start a luncheon club or any other activities for people with dementia in the mosques because they have no funding; On the other hand, some might argue, saying a mosque is a place of worship and there should not be other activities in the mosques apart from worship (SPASHI5).

Many stakeholders emphasised the need to involve community leaders and run community events to raise awareness of dementia. One service provider suggested: *"Whenever Bangladeshi leaders organise any community event, they can give a small stall for dementia awareness, or they can invite somebody who will talk [for] five minutes about dementia. Community leaders or faith leaders or media personnel can arrange some talk show about dementia on community TV channels."* (SPASHI4) Almost all stakeholders (n=4) felt that community leaders can play significant roles in raising awareness, supporting people with dementia, removing stigma, and creating dementia-friendly neighbourhoods*.* They can educate people on dementia, its symptoms and signs, its risk factors, and how to cope with it.

6.4. Discussion

Data analysis of stakeholders/service providers suggests that their service users from the Bangladeshi community understood that something was wrong. However, they did not know any word for it. Therefore, they wanted a remedy for it, suggesting they understand dementia partially and have some idea of what dementia is. However, these people do not necessarily understand dementia in a scientific/bio-medical context. Several participants said that their service users, the people with dementia from the Bangladeshi community, often think dementia is just about forgetfulness; their behaviour and cognition are often misunderstood, and they think they are all psychotic. In addition, many Bangladeshi service users usually go to the doctor late or ask for help at a crisis point in any mental health issue, be it dementia, schizophrenia, depression, postnatal issues, or any other mental illness. People do not go to the doctor first; instead, they try to use home remedies in most cases; when they struggle excessively and think they need to have something diagnosed, or if there is no other option for them, only then will they seek medical help. Participants tended to express that the service users of Bangladeshi and other South Asian origin were unfamiliar with navigating systems, which would be a significant barrier to accessing services as they do not know how to get dementia help.

The findings from this research phase imply that in the Bangladeshi community, the underlying cultural factors, such as cultural beliefs, customs, and practices, result in associating dementia with spiritual causes. Participants have reported various misconceptions and myths about dementia among many Bangladeshi people. For example, when people with dementia cannot remember things or lose their powers, they become frustrated or aggressive. That frustration is misunderstood as a "mental health" problem. When someone develops behavioural symptoms such as hallucinations, many Bangladeshi presume that individuals with the condition become "*Pagol"* [crazy]." Almost all interviewees reported that many Bangladeshis believe dementia is due to the possession of "*jinn-bhuta*" (spirits or unseen forces) or some other form of a supernatural entity. Consequently, they go to spiritual healers for folk healing instead of dementia health and social care services. Some service users from the community believe that someone has done some form of black magic to them, making them feel that way. They go to a religious scholar, get blessed water or talismans to wear around the neck, and deal with the condition.

Almost all stakeholders reported that people with dementia in the Bangladeshi community are heavily stigmatised. When their service users from the Bangladeshi community have dementia, they start losing their friends as other people avoid them, considering that people with dementia are not in the right frame of mind or have become crazy. There is a sense of expression by many stakeholders feel that these service users feel embarrassed; therefore, they try to sweep everything under the carpet and eventually become socially isolated from the community. Many participants with dementia who used to come to the mosque frequently before their dementia diagnosis has stopped attending. These suggest that people with dementia have symptoms deemed 'not normal' (after Goffman, 1963) and that this gives rise to being viewed as 'different' and subject to ridicule. It indicates a significant societal stigma among the service users, reported by the stakeholders/service providers. In turn, persons with the condition felt guilt and ashamed concerning what other members of their society might think about them. They often become socially isolated, fearing that other people may judge them as mentally ill. Findings also highlight that even those who used to go to the mosque five times a day stopped going because they felt embarrassed, considering others would laugh at them or see them as crazy. Consequently, people often become isolated. So, it is clear that self-stigma and public stigma are attached to people with the condition, which drives them to conceal their condition or live in a socially isolated fashion. On the other hand, another stakeholder (SPASHI4) reported that he had attended the funeral prayers of a lady with dementia, where thousands of people turned up. That lady's family feared what other people would think; that is why they used to hide the condition from others. However, the stakeholder did not notice any adverse societal reaction or nasty comments about her. This massive gathering and people's love for her indicate that self-stigma is a dangerous factor driving people with dementia from the Bangladeshi community to hide their condition or social isolation. It indicates that people's self-stigma is worse than the actual public stigma, as people with dementia often feel that nobody likes them even though others are respectful and sympathetic towards them. Some participants felt that there is enormous pressure within the community not to put people in a care home; instead, a family member should do the caring, which proves that there are various myths and stigmata regarding care home service users. They thought that family caregivers of a person with dementia might worry that their '*izzat*' (reputations) might be damaged if they send their loved ones to any care home unless nobody is there to look after them. Care homes will be their last resort.

Participants identified some gaps in dementia health and care services. First, all participants have reported that the language barrier is the most crucial obstacle in the Bangladeshi community that prevents people from accessing dementia services and delays dementia diagnosis. Many of their service users could not communicate with their GPs, who are the gateway to other services. What patients want to say, doctors may not understand; what the doctor is trying to explain, a patient may not understand. This stakeholder also highlighted from his professional experience that although interpretation services are available in the NHS, it is not always possible to obtain an interpreter on time. To book an interpreter, someone must wait for two/three months. Moreover, sometimes interpreters use a telephone line that can risk missing the correct information.

Second, almost all (n=4) reported a lack of services tailored to Bangladeshi and South Asian communities' needs and said that services are not culturally appropriate or religiously sensitive. The service providers often do not understand the cultural expectations and requirements of Bangladeshi and South Asian people with dementia. Three participants commented that healthcare service providers often do not understand all ethnic groups' specific needs. For example, one stakeholder (SPASHI4) mentioned that care service providers take generic approaches for all, and people feel this is more destructive to their lives; therefore, they do not use these services. Another interviewee (SPASHI1) commented that hospital environments are not dementia-friendly, and only some care homes are dementia-friendly. So, not every service is even catering to people's needs. One stakeholder (SPASHI5) claimed that dementia training by service providers is not often culturally sensitive and does not consider the different backgrounds of those with dementia. For instance, he noticed that people's early memories would not necessarily be a setting in this country. He argued that many people from a Bangladeshi background who have developed dementia came to this country in the 60s and 70s. When they do have dementia, they are recalling a life in rural Bangladesh rather than here. So, when talking about cooking, for example, if they are going back to their early 20s, cooking is not necessarily on a gas stove or oven fire. Unless they are trained, professionals will not be able to recognise this. This stakeholder's interview suggests that dementia training needs to be tailored to the context of individuals. SPASHI1 advocated that all healthcare staff must be trained on religious and cultural sensitivity so that individual patients feel respected and valued, and enjoy going into a service where they know their cultural and religious needs will be met. SPASHI3 shared a story from his experience that shows that some health professionals/staff do not know BAME communities' cultural needs. SPASHI4 reported that the care homes do not provide gender-specific services; therefore, Bangladeshi or South Asian people do not send their loved ones there. He advocated that all care providers need to provide gender-specific services, and care organisations need to restructure themselves to have people who deliver services through experience or by learning in other organisations.

From the stakeholders'/service providers' interviews, we know that some good initiatives have been taken by the local CCGs, mosques councils, and some of the volunteer organisations. One stakeholder (SPASHI5) confirmed that they made their mosque dementia friendly and provided training for their congregation on dealing with people with dementia; where [there] are these support mechanisms around. Their mosque runs several sessions on how to live and support people with dementia. They also run training sessions for female careers who have people living with dementia and their family. Another stakeholder (SPASHI1) reported that a Hindu temple in their locality has a luncheon club twice a week where Hindu people with dementia, those without dementia, and everyone in old age can enjoy four hours, two days a week. One stakeholder (SPASHI2) has reported that some volunteer organisations provide information and support for the people with dementia, though predominantly English-speaking or British White people make use of their support. A care home manager (SPASHI4) said that they have appointed Bangla- and Urdu-speaking staff and provided gender-specific and culturally appropriate care services for South Asian people in the research area for some years. One participant (SPASHI2) reported that they run some dementia awareness sessions / talk shows with some prominent leaders from the Bangladeshi community on ‘Probash Bangla TV.’ However, due to the Covid-19 pandemic, community involvement and face-to-face training or awareness programmes were impossible to deliver according to plan. However, they did plan to do more through virtual platforms.

Chapter 7: Overall Discussion

7.0. Introduction

This research has sought an understanding of the lived experiences of people with dementia and their family caregivers, and the perspectives of service providers/stakeholders, to make recommendations that might improve and influence the dementia support needs of the UK Bangladeshi community. Drawing on an interpretive approach has enabled an exploration of the understanding, knowledge, beliefs, and sociocultural issues of the people with dementia and their caregivers in a UK Bangladeshi community. Chapters 4 (p.124-142) and 5 (p.143-171) analysed the findings regarding how the participants with dementia and their caregivers access dementia services, the consequences of living with dementia, and community health service provision. Chapter 6 (p.172-192) examined the view of the service providers/stakeholders to identify the dementia support needs of this minority ethnic group. This chapter discusses the findings from that analysis in the context of existing knowledge, drawing on scoping review of literature (presented in Chapter 2; p.29-81).

7.1. Alternative Knowledge and Misconceptions about Dementia

In discussions of the lived experiences of people with dementia, all three participant groups of this doctoral research have touched on the idea that most of the participants with dementia understand they have something wrong with them because of dementia, although they do not have any word for it. Therefore, they want it to be fixed or have a ‘resolution,’ suggesting they understand dementia as an illness that needs control or even cure. In addition, this implies that participants have some idea of what dementia is. However, they do not necessarily understand dementia in a westernised scientific/bio-medical context. Participants with dementia and their caregivers have mentioned no synonym for dementia in Bangla. In referring to the dementia of their relatives, some caregivers and a few participants with dementia used the words “*mono thakena*” (can’t remember anything), “*bhul pori zay”* (forgets things), “*smriti shokti harai geche*” (lost memory). This suggests that they understand memory loss as the only symptom of dementia. However, this is only a partial comprehension according to westernised scientific and bio-medical discourses.

Dementia is not just about memory loss but an umbrella term for various symptoms, including declines in various abilities (Alzheimer’s Research UK, 2013). Dementia symptoms are likely to include memory loss, confusion, inappropriate behaviour, getting lost, communication problems, difficulty finding the right words, faulty reasoning, sleep disturbance, hallucinations, fainting, and agitation (Alzheimer’s Society, 2014). This finding is consistent with Hussain (2017) and Atcha (2018). They found it to be commonly the case that many participants never heard the word dementia until someone in their family was diagnosed with it. However, this study slightly contradicts previous research that suggested South Asian communities, including the Bangladeshi population, lack knowledge about dementia (Hossain, 2017; Mukadam et al., 2015; Mackenzie, 2006*;* Giebel, 2016; Regan, 2016). Rather this thesis suggests that they have an alternative way of understanding dementia even though they do not have a word for it.

Data analysis from stakeholders and service providers suggests some of the people with the condition and their family caregivers from the Bangladeshi community are not familiar with navigating systems. They do not know when to ask, who to ask, or where to ask for dementia help. The other two participant groups of this research echoed the same. For example, many participants with dementia and their caregivers mentioned not being aware of the available dementia services; this lack of awareness implies difficulty accessing/navigating dementia health and care services. Consequently, they went to their GPs and other services late, which delayed their dementia diagnosis. Stakeholders/service providers also explored the notion that some persons with dementia and their family caregivers did not consider memory problems to be a medical problem. Therefore, they did not go to their GPs for any consultation about this concern. However, whenever they went to them for another physical illness, they were diagnosed with dementia, which indicates that they did not know what dementia is. Previous literature has identified that some BAME communities are more reluctant to access dementia services, partly due to not knowing ‘how the system works’

(Hossain & Khan, 2020). Some family carers of person with dementia also have complained that their GPs did not respond to their insistent requests for help, which delayed people's dementia diagnosis.

Hussain (2017) claims that the family caregivers of Bangladeshi people with dementia view dementia as a medical condition. Therefore, (according to Hussain) the carers benefitted from effective interactions with service providers, which helped them prepare themselves for dementia care. This thesis also partially agrees with Hussain's claim. For example, the data analysis highlighted that dementia is understood by most of the participants with the condition and their family caregivers as a memory problem that needs to be fixed. This indicates that they feel that they have a medical illness that needs control or cure. However, this thesis has also explored the finding that several participants with the condition and their family caregivers believe dementia is not a bio-medical problem. Therefore, they have gone to spiritual healers instead of doctors, following their cultural myths. More detailed discussions about this issue, i.e., participants' beliefs and help-seeking attitudes, will be provided in the next section ("Religious-Cultural Understandings of Dementia: Influence of Spiritual Healers"). The dementia service providers and stakeholders also explained their professional experiences with serving the Bangladeshi community for a long time; this enhanced the findings from the participants with dementia and their caregivers.

Under the Equality Act 2010, dementia is categorized as a disability, and people with dementia and their caregivers belonging to groups with protected characteristics such as age, disability, race, religion, or belief should not be excluded from accessing activities, services, and support (DoH, 2010). However, a series of previous studies, including Parveen & Oyebode (2018, p.3); Giebel (2015); and Mukadam et al. (2015), have suggested that people with dementia from the BAME communities are underrepresented within dementia services. Zaidi et al. (2018, p.5), Atcha (2018), and Parveen et al. (2017) have found that a diagnosis usually takes place among South Asians after a critical medical condition or hospital admissions. Uppal et al. (2014, p.400) write that research suggests people with dementia from BAME communities are less likely to contact dementia services in the UK, less likely to receive a diagnosis, and, if they do, more likely to receive it at a later stage than their White counterparts. Echoing the existing literature, these combined findings from the interviews with the service providers, family caregivers, and people with dementia in this research have suggested that people from the Bangladeshi community gain access to dementia services late. It is possible that due to their misconceptions and alternative way of understanding dementia, grounded in cultural and religious beliefs, people with dementia and their caregivers from the Bangladeshi community are underrepresented in dementia services.

7.2. Religious-Cultural Understandings of Dementia: Influence of Spiritual Healers

This thesis has identified that many participants have misconceptions about dementia and that these misconceptions occur due to their religious and cultural beliefs. For example, three people with dementia and two caregivers have mentioned dementia as a possession of supernatural entities, such as *Jinn*, *bhuta,* and *"challan"* (black magic), etc., that they call "*upri."* For example, one person with dementia (PWD5) emphasised that he has an absolute belief that he has a "*upri*" problem - not any bio-medical disease. However, he went to the doctor merely because of family pressure. Many carers in this research have reported that their family members and neighbours advised them to go to Imams or spiritual healers to expel *Jinn* or obtain homemade remedies out of the belief that supernatural entities cause dementia. (*Jinn* are, in Arab mythology, magical spirits who are devils, and "*Bhūta"* (*bhūt* in modern Indic languages) means a "supernatural being," a ghost or spirit, more often than not evil and a source of anxiety for individuals and communities (Chandra, 2015).) Several family caregivers reported influences on the people with the conditions from their family members who live in Bangladesh, who advise their loved ones in the UK to go to the spiritual healers in Bangladesh, even though these spiritual healers do not know much about dementia. Some participants have reported that when people with dementia or their families from the UK visit Bangladesh, they advise them to go to some *Kabiraj* (a title of honour) and spiritual healers to solve their problems. These Bangladeshi relatives often call for their friends and family members in the UK to contact these *Kabiraj*. A series of previous studies, including Rozario (2009, p179), Dein et al. (2008), and Ciftci et al. (2013), have revealed how the UK Bangladeshi community uses spiritual healing alongside medical treatment. For example, Rozario (2009, p179) states that Bangladeshi Muslim families often categorise all illnesses into two types, either '*Daktari*' (bio-medical) in nature or *'Upri'* caused by *Jinns* or *spirits.* They also take the view that medical doctors should treat medical problems, and the Imams or other spiritual practitioners can generally treat '*Upri*' issues (Rozario, 2009, p.179). The current study has revealed that, believing dementia symptoms to be supernatural interventions, at least three participants with dementia and their caregivers went to various spiritual healers in Bangladesh and the UK instead of seeking bio-medical treatment. When nothing worked, then they went to the doctors. Therefore, participants have reported that their dementia diagnosis was late. This finding is also consistent with other South Asian studies. For example, Atcha (2018) has suggested that in the Bangladeshi, Indian, and Pakistani communities, the underlying cultural aspects, including their beliefs, customs, and practices, link dementia with spiritual causes. This suggests that the South Asian community comprehends and treats persons with dementia differently – and, in turn, individuals with the condition behave atypically compared to other community members or hide their state from the extended family and broader community.

Similarly, Parveen et al. (2017) and Johl et al. (2014) state that many BAME communities utilise religion and spirituality as a form of coping more than is the case in the UK White British population. However, Regan et al. (2013) report that religion could delay access to dementia health and care services in Indian and South Asian communities. Their families may favour using community support and faith to assist in coping rather than using health services (Regan et al., 2013).

Previous literature suggests that faith-based, religious, and spiritual healing have positive benefits. For example, Uppal et al. (2014, p.401) indicate that religion has often been used as a source of comfort and security and may provide a framework to help people adjust to a difficult situation. Similarly, Parveen et al. (2012) argue that a growing body of evidence outside the field of dementia suggests that religious faith can positively benefit coping and living well with dementia. Likewise, Gonclaves et al. (2015) also indicate that religious or spiritually based therapy could significantly reduce stress, anxiety, and depression in individuals who perceive religion to be an essential aspect of their life. However, there has been little focus on developing services and support packages mapping with the religious and spiritual needs of minority ethnic carers.

However, Bhattacharyya et al. (2013) argue that although religion helps in positive coping, it is likely to have hampered access to dementia services for specific minority communities compared to the majority. In this doctoral research study, some people with dementia and caregivers have discussed their negative and bitter experiences from their journeys to religious and spiritual treatments that were devastating and are an alarming sign for the Bangladeshi community. Participants shared their experiences that some miracle makers (i.e., spiritual healers) were money takers doing cruel business with the families of persons with dementia by *jinn* exorcism or spiritual therapy and earned ample amounts of money conning them. It was also reported by some participants with dementia and family caregivers that the religion-based healings they received were very expensive but useless for them.

Previous studies have reported similar accounts of the confidence tricks on the part of spiritual healers in the Bangladeshi community (Dein et al., 2008; Rozario, 2009; Cliftci et al., 2013). In 2003, in an Imams' meeting arranged by a local Bangladeshi health education group in collaboration with the East London Mosque, some local Imams described their observations about the attitudes of some spiritual healers. A local Imam decried that members of the local Bangladeshi community frequently sought help from traditional healers, often at massive cost to themselves, in the mistaken belief that their problems occur because of *jinn* possession or black magic (Dein et al., 2008, p.43). In this research study, many participants also experienced that most Imams and spiritual healers did not have training on counselling or basic knowledge about dementia. These findings echo those of Dein et al. (2008, p.41), who highlight that some of their participants have reported that it is clear some Imams do not have proper knowledge of Islam. Therefore, they often give people wrong advice, and charge money for religious services, which is unacceptable in mainstream Islam. Rozario (2009, p.187) suggests that most Imams and spiritual healers were educated in madrasas (Islamic colleges) in Bangladesh. They studied only Arabic and religious studies and had little Western-style education. Therefore, it was not surprising that they had little or no understanding of bio-medical terms. Similarly, Cliftci et al. (2013, p.26) mention that although religious leaders are often the first-line mental health care providers to Muslim communities, they are not trained to refer someone into conventional medicine, which usually leaves the patient receiving inadequate psychiatric assessments or treatments. However, given the potential value of religious coping mechanisms, Parveen & Oyebode (2018) suggest that health and social care professionals might find it beneficial to consult with religious leaders about what they need to know to support families in their communities who are affected by dementia.

7.3. Impact of Stigma: Bangladeshi community

Previous research suggests that the stigma of dementia is a severe problem in many black and minority ethnic communities (Parveen, 2017) (see details in Chapter 2). Therefore, the researcher used a conceptual framework for understanding stigma. A conceptual framework assists the researcher in identifying and constructing their worldview on the phenomenon to be investigated (Grant & Osanloo, 2014). Also, it guides a researcher's choice of research design and data analysis plan. The conceptual framework also shows the data accumulated for a particular study (Lester, 2005). I used this conceptual framework throughout this research journey, including participant recruitment, data collection, and analysis.

By adopting Pryor & Reader's (2011) conceptual model of stigma, I designed my topic questions and interview guides before the data collection to explore if the participants with dementia and their caregivers from the Bangladeshi community experience any of these four aspects of stigma: self, social, and structural stigma and stigma by association. All these four types of stigma were experienced by many caregivers and persons with the condition and are presented below under four sub-themes.

7.3.1. Self-stigma

Link (1987) suggests that self-stigma occurs when individuals negatively perceive that others may not like them; consequently, they have low self-esteem and avoid seeking opportunities to improve their lives. Because of the self-stigma or psychiatric level of stigma, individuals may choose not to associate themselves with a mental health clinic or professionals (Corrigan et al., 2011, p.18). In this study, most participants with dementia and their caregivers have reported that participants with dementia have separated themselves from their extended family members and the wider Bangladeshi community. I prompted them further as to their reasons for being isolated. They then replied that individuals with dementia and their family carers tried to hide these conditions from others because they felt "*shorom*" (shame) about it, suggesting that there is self-stigma attached to dementia among these research participants. Burgener et al. (2015) reports that self-stigma impacts functioning and quality of life in persons with dementia. Research shows that higher levels of stigma are associated with higher anxiety, depression, and behavioural symptoms and lower self-esteem, social support, participation in activities, personal control, and physical health (Burgener et al., 2015). Therefore, the person with mental health issues may accept these notions and suffer diminished self-esteem, self-efficacy, and confidence in their future (Corrigan, 1998; Watson & River, 2005). Warner & Davidson (2004, p.395) suggest that fear and rejection might be associated with the distancing, marginalisation, and discrimination that characterise stigma and its negative consequences. Anxiety, particularly around seeking help, was experienced by people with dementia and their family caregivers (Devlin et al., 2006).

Similarly, Nguyen and Li (2018) report that they found adverse emotional reactions towards people with dementia. Piver et al. (2013) and Werner et al. (2010) also report that 'fear' was the most frequent emotional reaction reported by the participants. Piver et al. (2013) also add that the public associates the dementia label with 'anxiety' and 'shame.' Self-prejudice leads to an adverse emotional reaction; prominent among these symptoms are low self-esteem and low self-efficacy (Link et al., 2001). The effect on self-esteem is typically operationalised as diminished views about personal worth (Corrigan et al., 1999) and sufferers often experience shame. Low self-efficacy and demoralisation are associated with failing to pursue work or independent living opportunities (Link, 1982; 1987). Evidence suggests a significant relationship between shame and avoiding treatment. For instance, Leaf et al. (1986) shows that participants with psychiatric diagnoses are more likely to avoid services if they believe family members would have an adverse reaction to these services. The perception of people with dementia as incomplete due to their memory problems could also mean that their personal preferences, including spirituality, could be ignored (Graham et al., 2003; Mukadam & Livingston, 2012). Stigma causes serious emotional, behavioural, and social problems for people with dementia, such as damaging self-esteem, feeling anxiety, and developing a sense of shame and fear of others' judgment (Rahman, 2015). People choose not to seek help for mental health problems to avoid negative labels (Ciftcy et al., 2013, p.18). According to Patrick, people labelled as having a 'mental disorder' have issues finding and keeping a job, renting an apartment, and keeping in touch with a health professional, and avoid seeking help in institutions that may be perceived as stigmatising (Patrick, 2011). Likewise, the stigma of dementia can also make people isolated as well as jobless. This current research suggests that sending someone's parent to a care home is against the Bangladeshi cultural norm and a matter of stigma; therefore, one family carer (DCG6) left his job to look after his mother.

7.3.2. Social (Public) stigma

'Public stigma' refers to the negative attitudes held by members of the public about people with devalued characteristics (Corrigan, 2005). It creates prejudice and discrimination that block an individual's access to employment, educational opportunities, health care, and housing (Corrigan et al., 2011, p.18). Stigmatisation originates in people's cognitive representations of those who possess the stigmatised condition, triggering adverse emotional and behavioural reactions (Dijker & Koomen, 2003; Weiner et al., (1988). Data analysis of all 3-participant groups suggests that public stigma has caused tension for many participants with dementia and their caregivers. Almost all stakeholders / service providers have reported that their service users from the Bangladeshi community are heavily stigmatised.

Similarly, most people with dementia and their family caregivers have expressed that if other people from the Bangladeshi community or their extended family members knew that someone in these families had dementia, they might start gossiping about them, which might destroy their wider family's reputation. Eventually, many became socially isolated because people might label them mad. Some participants in the second and third phases of this research have reported that even those with dementia who used to go to the mosque five times a day stopped going there because they felt people would laugh at them or they would be embarrassed. My findings echo those of Atcha (2018), who explores the view that this withdrawal often occurs when people face negative stereotyping and feel more slowly than other community members think they are. Atcha (2018) also explains that the concept of stigma as outlined by Goffman (1963) suggests that when a society stigmatises individuals, they believe in disgraceful or less human qualities or consider they are not accepted, which may cause people with dementia to reduce or even stop all social interactions. In addition, such fear of stereotypical levels of madness or prejudice, social isolation, and withdrawal indicate that participants with dementia are concerned that other people may consider them deviant or not "normal" like themselves (Atcha, 2018). Therefore, participants with dementia have tried to avoid social interactions, and this deviant identity is called stigma according to Goffman's (1963) theory.

Several participants in Mukadam et al.'s study (2015, p.6) reported many stigmas attached to dementia in the BAME communities, classified as a type of mental illness. Similarly, Mohammad (2017) also reveals that many participants with dementia from the South Asian community reduce contact with their extended families or broader community to keep information private from the others. However, Innes (2009) argues that the stigma of dementia is something shared across all populations, not just ethnic minorities. It is a common challenge for all; she suggests that attitudes towards dementia in all minority ethnic groups, in general, can be seen to reflect negative views of old age and the stigma surrounding mental health (Innes, 2009, p.39).

Bows and Wilkinson (2003, p.387) suggest that similarities between South Asian communities and non-South Asians include stress on carers, increasing isolation, problematic diagnostic practices, lack of knowledge, and demand for support services.

Nevertheless, Parveen & Oyebode (2018, p.2) argue that the negative impact of caregiving for persons with dementia is more significant for minority ethnic carers. They are more likely to experience multiple jeopardy due to combinations such as the stigma of dementia, being perceived as a migrant, racism, and lower socioeconomic status (Parveen & Oyebode, 2018). Some interviewees in all three phases of this study reported that dementia is taboo in the Bangladeshi community. These finding echoes those of Ahmed et al. (2017) that suggest that among Punjabi (Pakistani), Gujarati (Indian), Chinese, and some African communities such as the people of Nigeria, Cameroon, and the Central African Republic, dementia is considered a ‘taboo’ subject. The Alzheimer’s Society (2018) reports that people living with dementia often worry that their social lives will change after a diagnosis of dementia, as they feel that they may slowly lose their friends and face isolation because of public stigma.

In contrast, this thesis contradicts Hussain’s (2017) claim that there was no evidence of stigma amongst England’s Bangladeshi community. In all three participant groups of this thesis, most interviewees reported many components of stigma in the Bangladeshi community. One of the key objectives of this doctoral thesis was to understand better whether there is such a stigma in the Bangladeshi community. Therefore, the researcher developed a conceptual framework on understanding stigma before the study that guided his participant recruitment, data collection, and analysis. The researcher also included the people with dementia in the research, who reported they were impacted by public stigma, self-stigma, and stigma by association.

Previous researchers did not prioritise hearing the voices of the UK Bangladeshi people living with dementia. Moreover, this researcher was from the Sylhet division, and most UK Bangladeshis originate from that area. Because of his positionality and role in the community as an Imam, he was considered an insider, which was advantageous for him to build rapport with the participants adequately and dig out more information about stigma.

7.3.3. Structural Stigma

Structural stigma refers to how communal ideologies and institutions spread or aggravate a stigmatised status (Corrigan & Lam, 2007). Hatzenbuehler & Link (2014) define structural stigma as the societal-level condition, cultural norms, and institutional practices constraining stigmatised populations' opportunities, resources, and well-being (Hatzenbuehler & Link 2014, p.2). Interpersonal discrimination occurs within the broader context of structural stigma, whereby it is more likely to happen in the context of high levels of structural stigma (Hatzenbuehler & Link, 2014). Schulze (2007) claims that not only does the ordinary public produce stigma, but so also do some medical professionals, who often share their stigmatising attitudes towards dementia. Some family carers of the persons with the condition blamed their GPs for not diagnosing them earlier or referring them to the memory clinic in a timely fashion. Some persons living with dementia also reported being referred late to the memory clinic by their GPs. Therefore, their dementia diagnosis was delayed (DCG4, DCG5, DCG7); this could indicate that it is worth investigating whether there is any institutional racism or structural stigma amongst health professionals. Two participants with dementia also commented that their GPs' services are not as good as they were in the past. They also added that some GPs were too busy and did not want to give patients enough time to talk.

In a previous study, Ahmed et al. (2017) explores the notion that many people were not diagnosed and treated but were unwilling to challenge the GP's decision. Similarly, Parveen et al. (2017) stated that some minority ethnic families reported that health care professionals were not offering them the available support. Furthermore, Parveen & Oyebode (2018, p.3) explained that this might be due to healthcare professionals making assumptions about families' looking after their own and not requiring services or feeling that they might offend by mentioning services. A similar concern is reported in Blakey et al. (2016), who suggest a need for healthcare services to work with third sector organisations to enable better service provision for minority ethnic communities. Mukadam & Livingston (2012, p.380) suggest that early dementia diagnosis would be more likely if all medical professionals were more willing to consider and make the diagnosis. However, many primary care professionals in the UK are reluctant to do this because of its stigma. Koch & Iliffe (2010) have found from a systematic literature review that stigma affects GPs' willingness to make a diagnosis. They assume that people with the condition or their family members would not want to hear a dementia diagnosis until the symptoms were so severe that it was inevitable (Koch & Iliffe, 2010). Hermann et al. (2014) highlight that health care providers and the public might hold stigmatising attitudes toward persons with dementia that may be particularly harsh among racial and minority ethnic groups.

7.3.4. Stigma by Association

Stigma can negatively affect the person living with dementia and their family and friends (Bilkhu, 2016; Bowes & Wilkinson, 2003). Family members and relatives of the individuals with these conditions also often face the consequences of stigma, such as embarrassment and anxiety, and their circle of friends and acquaintances appears to decrease (Lion et al*.*, 2015, p.226). Goffman (1963) names this type of stigma ‘courtesy stigma’, related to lower self-esteem and psychological distress with stigmatised individuals (Mak & Kwok, 2010; Struening et al., 2001). People often try to hide their relationship with a stigmatised family member (Phelan et al*.*, 1998) or encourage family members to conceal their condition. This thesis found that dementia was an obstacle to arranging marriages for the children of participants with dementia. Therefore, families kept this secret as people with dementia and their caregivers were being stigmatised by members of the wider community, which posed a severe threat to their marriage prospects. Some participants with dementia reported that they reduced contact with people and even avoided telephone conversations because if people knew that they had dementia, it might jeopardise their daughters’ marriage proposals. One stakeholder also echoed similar concerns in Phase One of this research study, and a similar finding was revealed by Mohammad (2017).

7.4. Gaps in services

All three participant groups of this research were asked to discuss the process of obtaining a diagnosis of dementia and gaining access to appropriate treatment and support. Hence, participants with dementia and their caregivers have reported gaps in health and social care services. This study revealed the language barrier as a severe problem for some individuals with dementia seeking to access the services. Some participants with dementia reported that it was difficult for them to communicate with health professionals to conduct a diagnosis as they cannot speak English fluently. It was also challenging to understand service availability and access the memory clinics and dementia health and care support due to their language barrier. Although there are interpreters available, several participants with dementia reported that they were concerned over the accuracy and completeness of their interpretations, as the interpreters they used had limited English proficiency. Therefore, they had anxiety over the possibility of missing out on important information. In a previous study on the experience of interpreter access and language-discordant clinical encounters in Australian healthcare, a mixed-method qualitative study found that patients with low English proficiency were at risk of being less informed of care processes and receiving an excessive volume of information from their doctors in a shorter period when an interpreter is present (White et al., 2018). Participants expressed the view that their family members know their health situation better; they can explain better than other interpreters. All the stakeholders and service providers also reported similar findings about language barriers. One service provider (also an NHS doctor/SPASHI1) commented that people are misdiagnosed because of language barriers: doctors may not understand what patients want to say. Sometimes, the patient may not understand what a doctor is trying to explain. It is not always possible to obtain an interpreter on time. Sometimes interpreters use a telephone line, which can risk missing the correct information.

In this study, some participants with dementia and their caregivers have suggested that hospital staff do not always understand the cultural needs of patients. Some family caregivers reported that their male relatives (with dementia) have refused to accept female nurses / hospital staff services because they feel that it is against their religious and cultural norms if any person of the opposite gender touches them for any reason; therefore, it seems that gender- and religion-specific services are essential for people from the Bangladeshi community. Participant Group 1 of this research echoed similar findings. Some stakeholders / service providers suggested that dementia health care services were not tailored to Bangladeshis’ and South Asian communities' cultural needs. All stakeholders emphasised the need to increase the knowledge of Bangladeshi culture and community needs among staff / service provider organisations. One NHS health professional expressed the feeling that it is unbelievable that dementia services are so poor He also added that it does not seem that we live in the Western world; even if every hospital is dementia-friendly, not every care home is dementia-friendly. This finding is consistent with the existing literature. For example, describing the hospital environment, participants in Waller and Masterson (2015) report that staying in hospitals is a frightening and confusing experience for people with dementia: unfamiliar surroundings, noise, and very busy places.

Several participants with dementia in this research suggest that the care homes' services are not culturally appropriate and not to a good standard. For example, one participant with dementia (PWD4) has described his care home lived experience and said it was terrible as the care home premises were not clean enough. It was also not culturally appropriate as a woman used to look after him, which he did not like as a Muslim male. He stopped eating there; that is why their family took him back home. Another woman with dementia (PWD3) was asked whether if her children could not look after her due to their business or job, would she mind going to any care home? She replied that she would never go to a care home because other Bangladeshi people would speak ill about their family and they would be embarrassed to show their face *to the community.* In their previous studies, Giebel (2016), Regan (2016), and Seabrook & Milne (2004) have reported similarly that dementia health and care services are not culturally informed or religiously appropriate. This is perhaps because service providers lack knowledge about the lifestyles, health, and religious and cultural needs of the BAME and South Asian Communities. Likewise, Mohammed (2017, p.21) has suggested that many South Asian people feel that care homes are not suitable for their requirements (Mohammed, 2017, p.21). It is embedded in the South Asian communities to take care of family members for longer than it is in the broader population - for as long as possible (Mohammed, 2017, p.21).

7.5. Cultural Expectations of Care

All stakeholders / service providers in the first phase of this study reported that older people in the Bangladeshi culture usually expect their family members, including children and spouses, to look after them, as they view it as an obligation. To explain these cultural expectations, one stakeholder commented that older adults in this community sometimes do not even make a cup of tea because other family members are there to 'serve' them. The third phase of this study has also supported stakeholders' claims. Some of the participants with dementia have mentioned that Bangladeshi people have children in the hope that their children will take care of them when they get old. They follow what their children/carers tell them to do. Almost all participants with dementia reported that their children or other close relatives had provided care for them. Participants' accounts of family obligations regarding care are replicated in other South Asian and minority ethnic communities (Herat-Gunaratne et al*.*, 2020; Lawrence et al., 2008; Victor et al., 2012). In a recent study, Herat-Gunaratne et al*.* (2020) also found a similar result, reporting that some Bangladeshi caregivers have said that there is an expectation from their parents with dementia that children should now look after them; otherwise, these children might be marked as selfish or engrossed in the Western way of life, ignoring the fact that the parent has chosen to raise them in this country, and that they invested all of their life savings in having children (Herat-Gunaratne et al*.*, 2020). Among Participant Group 2 of this research, all family caregivers have shown high motivation to care for their relatives with dementia. They felt that doing so was an obligation and part of their duty to care for their elders. This finding is also consistent with what is found in many South Asian and BAME communities. For example, Lawrence et al. (2008) and Parveen & Oyebode (2018, p.3) have written that South Asian and Black Caribbean carers of people with dementia hold a more traditional caregiver ideology than White British carers, viewing caring as natural, expected, and virtuous.

Regarding the cultural expectation to care, it is noteworthy that family caregivers among the Bangladeshi community (who have participated in this research) did not feel any stigma attached to looking after their parents or loved ones living with dementia. In contrast, evidence suggests a stigma associated with providing care for a relative with Alzheimer's disease elsewhere in the world, which is called '*family stigma'* (Herrmann et al., 2018; Werner, 2014). Providing unpaid care for a relative with dementia is associated with considerable emotional, financial, and health difficulties at the individual level (Alzheimer's Association, 2018). Research shows that family stigma is associated with significant negative consequences such as increased caregiver burden and depression (AboJabel & Werner, 2016). However, like Hossain (2017), no such family stigma was reported by any caregiver in this research.

However, in this present study, some carers have admitted that although they tried hard to cope with people with dementia, they might not manage the caring fully because of their business and other commitments and the lack of appropriate training regarding dementia. For example, one family caregiver (DCG5) commented that he used *to cry because it was very hard as he used to return home late at night from restaurant work, but his father used to stay awake all night; used to open the door and leave the house in the middle of the night. Therefore, he could not sleep properly.* Another carer (DCG8) expressed his anger that though they were a big family with six brothers and two sisters, and all of them were married too, only he and his wife cared for his father in rotation, whereas everybody else was busy with their own family and lives. The carer and his wife also left him for one year (DCG8). Another carer (DCG1) saw a person with dementia being lost and walking outside his local college, and the police took her home. The above three incidents indicate that not all carers might fully manage the caring duty because of their business and other commitments or lack of appropriate training.

Several family caregivers also mentioned that they were forced to cope with this because of their social norms and religious obligations, even though they have many limitations. This finding is consistent with Parveen et al. (2017). They report evidence suggesting that some family carers cannot deliver the appropriate services that their relatives with dementia require. This research study also echoes the findings of Parveen & Oyebode (2018, p.2) that the assumption should not be made that persons with dementia from the BAME communities do not require health care services merely because of their cultural norms and values.

Some caregivers have suggested that although male carers said that they would care for their elders by any means, women do most of the care jobs and all household work. The wives of the persons with dementia and their daughters-in-law (or sometimes their daughters) must provide elders with care. In many families, women also work; therefore, it is impossible to give persons with dementia better care due to time limitations. Therefore, some participants strongly recommend that the Bangladeshi community use care services. However, participants with dementia and the caregivers emphasised that these external care service providers should know about Bangladeshi culture, and dementia care services should be culturally appropriate.

7.6. Conclusion

The discussion above has highlighted that the participants had alternative knowledge and lack awareness about dementia. They did not understand dementia in the western/scientific bio-medical context; therefore, they did not access dementia services in a timely fashion. A number of participants also complained that their GPs did not make timely referrals, which delayed their dementia diagnosis. They also had various cultural beliefs that affected their health-seeking attitudes and delayed or even in many cases prevented access to dementia services. Participants often went to spiritual healers instead of bio-medical doctors, considering dementia to be possession by supernatural forces. Several participants reported that they went to these healers because of family pressure from relatives in Bangladesh, and because of stigma associated with dementia.

Applying a conceptual framework to understanding stigma and analysing interviewees' data, this thesis explored the perspective that participants with dementia are stigmatised. Because of shame and the fear that other people might say bad things about them, many participants with dementia became socially isolated, which has worsened their dementia symptoms. Mapping onto Pryor & Reader's (2011) conceptual model of stigma, this thesis suggests that participants with dementia and their caregivers from the Bangladeshi community experience all four aspects of stigma comprising public stigma, self-stigma, structural stigma, and stigma by association.

By analysing qualitative data, this thesis suggests that there are gaps in health and care service provision. Participants felt the health and social care services were not culturally appropriate, and healthcare staff needed to understand cultural issues with care. This doctoral study suggests that the language barrier was a severe problem for some participants with dementia seeking to access the relevant services. It was difficult for many of them to communicate with health professionals for diagnosis, as they could not speak English fluently. It was also challenging to understand service availability and access the memory clinics and dementia health and care support due to their language barrier. Although there were interpreters available, several participants with dementia reported that they were concerned over the accuracy and completeness of interpretations. Therefore, they had anxiety over the possibility of missing important information. Participants expressed the view that their family members know their health situation better; they can explain better than other interpreters can.

The data analysis revealed that family caregivers showed a strong sense of family obligation, religious belief, and interpersonal motives for caring for their loved ones with dementia at home. However, some caregivers admitted that although they have tried hard to cope with caring for people with dementia, they might not manage to give sufficient care because of their work and other commitments and the lack of appropriate training regarding dementia. Key recommendations for policy and practice will be demonstrated in the next chapter (Chapter 8: Conclusions and Recommendations; p.201-218).

Chapter 8: Conclusions and Recommendations

8.1. Conclusion

This doctoral research has explored the lived experience of people with dementia and their family caregivers and gathered the views of service providers / stakeholders to make recommendations that might improve/influence the dementia support provided to the UK Bangladeshi community. It was undertaken with three different participant groups, drawing on an interpretive approach. The thesis used semi-structured interviews with ten participants with dementia, ten family caregivers of persons with the condition, and five dementia service providers / stakeholders. First, this thesis presented the knowledge, beliefs and lived experiences of people with dementia from a UK Bangladeshi community from the perspective of participants with the condition (Chapter4, p124-142) and their family caregivers (chapter5). Then, the perspectives of the stakeholders and service providers are presented regarding the knowledge, belief, and help-seeking attitudes of people with dementia from a UK Bangladeshi community and the challenges people with the condition face in accessing health and care services (detailed findings in Chapter 6; p.172-192). Based on my literature review, it transpires that there has been no research conducted to explore the lived experiences of people with dementia among the UK Bangladeshi community apart from the current study. It is of paramount importance to hear the voice of people with the condition. Hence, this thesis is the first study in the UK Bangladeshi community to have involved people with dementia in the research to explore their lived experiences.

My review of the existing literature inspired me to understand better if people with dementia from the above community are experiencing the stigma of dementia; hence, I developed a conceptual framework to make sense of stigma in the context of this study. A conceptual framework frames theoretical perspective, research design, data collection, analysis, and theoretical engagement and argument development. Therefore, I used my conceptual framework for understanding stigma as the principal guidance for my data collection, participant recruitment, and data analysis, implying both empirical and theoretical advancements (details are presented in Chapter 2, subsection 2.9: A Conceptual Framework for the Study of Understanding Stigma attached to Dementia, p.56). Mapping with this framework, I have recruited participants using snowball sampling and with reference to gatekeepers, keeping in mind that if participants are stigmatised, they might not agree to participate in the research merely from reading a leaflet or social media advertisements. During interviews, I asked participants with dementia and their family caregivers questions if there was any societal reaction since they were diagnosed with dementia or if it impacted their social inclusion. I was keen to hear if the participants reported multiple 'stigma' such as social withdrawal, shame, stereotypes, and prejudices about dementia. In my coding and theme finding, I was also searching for any aspect of stigma based on Pryor and Reader's (2011) schema. Then, I positioned my results concerning stigma in relation to the existing literature and discussed them critically in Chapter 8 (p.212-230). Based on participants' experiences about dementia-related stigma and their suggestions, I wrote recommendations/implications for policy and practice, with a particular focus on how to raise awareness about dementia, dispel myths, and remove the stigma attached to dementia. Thus, my conceptual framework guided my data analysis, findings, discussions, and conclusion about the overall results.

This chapter summarises the findings mapped against the research objectives, synthesises the unique contributions to knowledge, methodology and practice, and identifies this research study's key limitations and strengths. My recommendations for possible future research, along with implications for policy and practice, are made explicit to improve/influence the support available for the UK Bangladeshi community based on the unmet needs identified in my thesis. Finally, a concluding remark on the whole of my research completes this chapter.

Objectives

The research objectives of this study were:

1. To explore the understanding of dementia for people diagnosed with dementia and their caregivers from a UK Bangladeshi community.

2. To explore the experiences of people with dementia among a Bangladeshi community, to ascertain their views about the support provided, and to identify any gaps.
3. To explore whether or not dementia is stigmatised in a Bangladeshi community and how the stigma may impact the lives of people with the condition.
4. To explore the views of stakeholders' / service providers about the support provided and determine if there are any gaps.

In addressing Objective 1, this thesis has explored the notion that participants with dementia and their caregivers did not necessarily understand dementia in a scientific/bio-medical context. However, most of the participants with the condition realised that they had memory problems and other difficulties, although they did not have any word for it. Therefore, they want it to be fixed or have a ‘resolution’ for it, suggesting they understand dementia partially and have some idea of what dementia is.

Participants with dementia and their caregivers have mentioned there is no a synonymous word for dementia in Bangla. In referring to the dementia of their relatives, some caregivers and a few participants with dementia used the words “*mono thakena*” (can’t remember anything), “*bhul pori zay”* (forgets things), “*smriti shokti harai geche*” (lost memory). It suggests that they understand memory loss as the only symptom of dementia, which is incorrect according to westernised scientific and bio-medical discourses.

These findings are consistent with the broader academic literature on the South Asian and wider BAME communities concerning accessing services (Hossain, 2017; Atcha, 2018; Baghirathan et al., 2018). This thesis also echoes the previous literature about the language used to describe dementia (Parveen et al., 2017; Mukadam et al., 2011; 2015; Ahmed et al., 2017) and suggests no synonyms for ‘dementia’ in the Bangla language. Instead, it is explained with numerous phases, such as ‘madness,’ an act of God, forgetfulness, or natural memory loss due to old age (Hussain & Khan, 2020; Parveen & Oyebode, 2018).

This thesis suggests that participants have various misconceptions about dementia. There was a tendency for participants with the condition and several carers to link dementia to other illnesses and supernatural forces. Similar to Rozario (2009, p.179), this research found that Bangladeshi Muslim families often categorise all diseases into two types. They view such things as either '*Daktari*' (Bio-medical) in nature or '*Upri*', caused by *Jinns* or spirits, meaning that they take the view that medical doctors should treat medical problems and 'Upri' issues can generally be treated by Imams or other spiritual practitioners. Some participants with dementia went to spiritual healers in Bangladesh and in the different cities of the UK instead of to bio-medical doctors. Participants' religious-cultural beliefs and attitudes towards dementia might lead them to have different views and thoughts about dementia. The various understandings of dementia tend to influence access to healthcare services by the Bangladeshi community. My respondents tended not to seek medical support until the later stages of the condition. This attitude may be due to diverse understandings that constitute barriers to accessing appropriate support for people with the disease. Therefore, a great deal of work needs to be done in the UK Bangladeshi community to promote understanding of dementia and outline the risks of going to spiritual healers. At the same time, this finding suggests that awareness of the available dementia services and barriers to accessing services by this minority ethnic group ought to be raised among the dementia service provider organisations, including health and social care and older people's services.

This study has revealed that participants with dementia and their caregivers often went to their GPs and other services after symptoms had progressed, which delayed their dementia diagnosis. This study also found that when participants with dementia went to their GPs for a physical illness, it was then that they were diagnosed with dementia. However, caregivers and participants with dementia reported that they had never heard the word dementia until their relative was diagnosed with the condition. This thesis has also found that the research participants struggled to navigate health and care services as they did not know when to ask, who to ask, or where to ask for help with dementia. A diagnosis usually takes place after a critical medical condition or hospital admission. It is noteworthy that under the Equality Act 2010, dementia is categorized as a disability, and people with dementia and their caregivers thereby belong to groups with protected characteristics such as age, disability, race, religion, or belief that should not be excluded from accessing activities, services, and support (Department of Health, 2010). However, despite the Equality Act, this thesis suggests that the sample of Bangladeshi respondents tended to not avail themselves of services as often as the British White people. Data analysis also suggests that there might be discrimination in the provision of health services that breaches the Equality Act 2010. (See Chapter 6; sub-section 6.2.4. Experiences of Service Usage: Gaps; p.179).

In addressing Objective 2 it became evident that there are gaps in health and care service provision. Participants felt the health and social care services were not culturally appropriate, and healthcare staff needed to understand cultural issues with care. A culturally suitable approach is required to ensure effective management of dementia in the UK Bangladeshi community. Participants also suggested that GPs' referrals to memory services and dementia diagnosis should be timely and avoid discrimination against the Bangladeshi community.

This doctoral study suggests that the language barrier was a severe problem for participants with dementia seeking to access the relevant services. It was difficult for many of them to communicate with health professionals for diagnosis, as they could not speak English fluently. It was also challenging to understand service availability and access the memory clinics and dementia health and care support due to the language barrier. Several participants with dementia reported that they were concerned over the accuracy and completeness of interpretations, as they felt that the interpreters they used had limited English proficiency. Therefore, they had anxiety over the possibility of missing important information. Participants expressed that their family members could explain better than some interpreters could. My interviews with stakeholders and service providers tended to echo these issues.

Participants with dementia in this study tended to relay that their children or daughters-in-law took care of them and, therefore, they did not want anybody else to look after them. Most family caregivers in my sample expressed high motivation to care for their relatives with dementia. They felt that it was an obligation to care for their elders in reciprocity for their care received in earlier years. However, some family caregivers relayed the pressures they felt balancing care responsibilities on the one hand and other commitments on the other.

Moreover, they did not have any training on coping with people with the condition. This finding suggests that although these carers think they are dealing successfully with their relatives with dementia, they might not manage appropriately. Several caregivers reported that they faced difficulties providing good care despite willingness to do so, due to their work and other commitments; that indicates that not every carer is coping well with their care duties. Several carers mentioned that they tended to cry when they returned home from work at night but could not sleep for almost the entire night because of their care duties. Therefore, it is wrong to assume that Bangladeshi people do not need care service help because their children care for them.

In addressing Objective 3, this research suggests that the participants with dementia were stigmatised. Mapping onto Pryor & Reader's (2011) conceptual model of stigma, this thesis suggests that participants with dementia and their caregivers from the Bangladeshi community experienced all four aspects of stigma: public stigma, self-stigma, structural stigma, and stigma by association. For example, most of the participants with dementia were worried that other people might judge them as mentally ill. Even those individuals with dementia who used to go to the mosques five times a day stopped going because they felt people would laugh at them or label them mad, which suggests a public stigma attached to dementia amongst the Bangladeshi community.

Many participants with dementia became socially isolated from fear that others might not like them or might gossip about them, which may harm their family reputation; this indicates that there is self-stigma among the participants as these withdrawals, fears, and prejudices are compounds of stigma (Link & Phelan, 2001). Several participants with dementia have reported in this thesis that they have reduced contact with people and even avoided telephone conversations because if people knew that they had dementia, it might jeopardise their daughters' marriage prospects. This suggests there might be stigma by association within the UK Bangladeshi community.

This research study found that some participants with dementia were not happy with the dementia health and care services, as they were not diagnosed on time despite repeatedly reporting their condition to their GPs, but they were unwilling to challenge the GP’s decision. Referrals to the memory clinic by their GPs were delayed; therefore, their dementia diagnosis was also delayed. Some participants commented that their GPs’ services are not as good as they were in the past. They also complained that some GPs were too busy and did not give patients enough time to talk.

In addressing Objective 4, Stakeholders / service providers have reported that their service users among the people with dementia from the Bangladeshi community have a competing understanding of what dementia is, how its symptoms can be recognised and explained, and how individuals, families, and care providers respond to these. In common with Participant Groups 2 and 3, almost all stakeholders reported that their Bangladeshi clients with dementia faced adverse societal reactions because of dementia, which suggests that people with dementia amongst the Bangladeshi community are heavily stigmatised. Stakeholders / service providers also have found some similar gaps in services that echo the findings reported by people with dementia and their family caregivers in this research study.

8.2. Key Messages and the Research Contributions

This thesis offers the following two main contributions.

8.2.1. Contributions to Knowledge

This thesis is the first and thus far only study in the UK to have explicitly focused on Bangladeshi people living with dementia by including persons with the condition directly in dementia research and gathering their experiences. This doctoral research offers a unique insight into the lived experiences of people with dementia among a Bangladeshi community in the UK acknowledging the socio-cultural issues that affect access to dementia health and care services. This study has contributed to the academic discourse about the experiences of people with dementia and the implication this new knowledge has for developing support and care provision. The research has sought to listen to the voices of the person living with dementia, which is a central part of this research. The voices of those living with dementia are so often lost in favour of proxy accounts (Gove et al., 2018). Previous studies have not included people with dementia from the Bangladeshi community, despite growing acknowledgment that people with dementia should be included in the research as active participants (Beuscher & Grando, 2009; Dewing, 2002, 2007; McKeown et al., 2010). Previous research has not explicitly focused on the lived experiences of people with dementia from the Bangladeshi community specifically. Therefore, the views and lived experiences of people with dementia are an under-researched area among Bangladeshis and other BAME communities (Hossain, 2017, p.172). Turner (2012) demonstrates that people with dementia could make valued contributions to research. The author also suggests that if the researcher takes time to collect background information and set up preparation sessions with people with dementia, it can help support the person with dementia accordingly throughout the process (Turner (2012). Higgins (2013) suggests that to better understand the care needs of people with dementia, it is essential to involve them in research as their experiences can allow the service providers to re-think their practices and provide better care. Kapp (1998) argues that asking someone with dementia to participate in a research study can make them feel recognised as capable. Similarly, Hellstrom et al. (2007) argue that excluding people with dementia from taking part in research could reduce their dignity while including them could enhance it.

Data analysis suggests that the participants with dementia were heavily stigmatised. Following Pryor & Reader's (2011) conceptual model of stigma, this thesis suggests that participants with dementia and their caregivers from the UK Bangladeshi community experienced all four aspects of stigma comprising public stigma, self-stigma, structural stigma, and stigma by association. The thesis found that many participants with dementia became socially isolated due to anxiety that other people might judge them as mentally ill. Participants with dementia often tried to hide their condition from others for fear that the community would start gossiping about them, which might destroy their wider family's reputation. Such fear of stereotypical levels of madness or prejudice, social isolation, and withdrawal indicates the stigma attached to dementia among the UK Bangladeshi community. Although Hussain (2017) claimed there was no stigma of dementia in the Bangladeshi community due to their religious morals, my findings suggest otherwise. Nevertheless, it is consistent with other South Asian literature about stigma and dementia where stigma was present (Atcha, 2018; Ahmed et al., 2017; Parveen & Orboyde, 2018; Mukadam et al., 2011; 2015). (Details are discussed in Chapter 7; p182-199).

Findings from this thesis demonstrate that several family caregivers did not have the time to cope with their care duties due to work and other commitments despite their sincere willingness and motivation to care. Therefore, consistent with previous South Asian studies (including Parveen & Oyebode, 2018), this study contradicts the myth that Bangladeshis, along with other south Asians, look after their elders and might not need care services.

Many participants with dementia have reported that they visited Bangladesh and many parts of the UK to find spiritual healing or *jinn* exorcisms instead of bio-medical treatments. This research study also found an influence of spiritual healers among the Bangladeshi community that often delays help-seeking on the part of the persons with the condition. It suggests how significant it is for policymakers to engage religious scholars/Imams in dementia awareness-raising campaigns and train them about dementia as local leaders who can influence thinking.

This study identified that some participants with dementia and their caregivers felt that the interpretation services they used were not accurate. Several participants also expressed their view that their children/family members could explain better than the interpreters. Data analysis also highlighted that participants with dementia were not comfortable that a third person from the Bangladeshi community would know that they have dementia, which they consider a shame (see chapter4, subsection 4.2.5 (Language Barriers; p.135). Moreover, a few participants have suggested that booking an interpreter is time-consuming and their work is often inaccurate. It is also not always possible to obtain an interpreter on time. In a previous study, Bailey et al. (2018) also raised concerns about some South Asian women's language barriers when booking GP appointments. The authors highlighted that language and literacy might hinder building confidential and ongoing professional relationships with primary care professionals (Bailey et al., 2018).

These thesis findings were reached using an interpretive approach, this emphasising the sense people make of their own lives and experiences and how they frame and understand dementia. A researcher using an interpretive research design tries to find out and interpret people's meanings and interpretations (Mason, 2018, p.8). This research framework has facilitated a more holistic understanding of the subject (i.e., the lived experiences of people with dementia and their caregivers; and the views of stakeholders/service providers) through direct interaction with them. This research has made a unique contribution to knowledge that may help practitioners and policymakers to know about experiences of dementia and hear the voices of the unheard from the Bangladeshi community.

8.2.2. Contributions to Practice

This research has made the following contributions to practice:
First, participants in this research have discussed the importance of more comprehensive societal/community responses to undertake dementia-friendly initiatives that are culturally appropriate.

Participants emphasised that the Bangladeshi community leaders could campaign through social media and other platforms about dementia, arrange some community events, and deliver talk shows on various Bangla television channels and community radio about how to live with dementia and remove its stigma. Women's organisations can develop training sessions and events for women in any community centre. Imams/Faith Leaders may talk about dementia and the importance of removing stigma based on Islamic jurisprudence and theological perspective during their weekly/Friday Sermons (details are presented in this chapter 8; sub-section, 8.4; p.223).

Second, this thesis revealed that some participants with dementia were not happy about the health and care services they received, as there is a gap between the services and the expectations of the participants with dementia (see Chapter 4; sub-section 4.2.4; p.134). Data analysis highlighted that some participants with dementia were not diagnosed on time despite repeatedly reporting their condition to their GPs, but were unwilling to challenge the GP’s decision. They were referred late to the memory clinic by their GPs; therefore, their dementia diagnosis was also late. They also commented that some GPs were too busy and did not give patients enough time to talk. A few participants commented that their GPs’ services were not as good as they had been before. Some participants reported that GPs or other doctors only responded to them when they called them. Participants in this study reported mixed feelings about their dealings with GPs; however, GPs offer access to many other services, and, as such, they are vital to enabling better experiences. Therefore, I suggest a need to develop improved ways to spot dementia and give referrals from GPs in the early stages of the disease.

8.3. Limitations

My research included 25 participants from one community in one geographical area (See Chapter 3, sub-section 3.2.2: Sampling, p.86). Therefore, the sample size is limited, and the generalisability of my findings could be questioned. The aim of this research was to explore the lived experiences of people with dementia from the Bangladeshi community only, which was possible with this small size. As the study did not use a random sample and the sample size could not be taken to statistically represent people with dementia from all of the UK Bangladeshi population, one of the limitations of this study may be not possessing statistical generalisability. Nevertheless, my findings may match individuals with dementia amongst the Bangladeshi communities in other parts of the UK: many qualitative researchers suggest that specifics of qualitative research can be generalized to a different similar situation - the aim is for a theoretical generalisability rather than an empirical one (Creswell, 1998).

Another limitation is that due to the impact of Covid-19, it was impossible to fully execute the original plan to collect data and recruit participants that I made before the pandemic. Therefore, I had to adopt alternative strategies in my data collection and participant recruitment methods due to the impact of the pandemic on recruitment. For example, I undertook telephone interviews with the family caregivers (Participant Group Two) instead of the face-to-face interviews; therefore, I missed non-verbal communication. In addition, I aimed to build rapport with them quickly, which was not that easy without face-to-face interactions. However, recruiting participants was not a problem because of my positionality and community work experience.

8.4. Recommendations/Implications for Policy and Practice

8.4.1. Implications to Raise Awareness of Dementia, Remove Stigma, and Dispel the Myths:

This thesis revealed that there is an unequivocal need to make the Bangladeshi community dementia-friendly. Many participants with dementia and their caregivers believed in various myths, such as beliefs around supernatural interventions that often delay access to dementia services. Several participants with dementia and the caregivers in this study have reported that they went abroad or visited different spiritual healers instead of medical doctors. This thesis has sought a deeper understanding of the effect of religious and cultural beliefs of a UK Bangladeshi community about dementia and how they influence people’s help-seeking behaviour and access to services. The all-party parliamentary group on dementia (APPG, 2013, p.27) highlighted a reference to “myths and misconceptions about dementia” where “Jinns” are alluded to in the Black Caribbean population’s culture. However, this was not discussed in depth, nor was adequate consideration given to the impact of believing in such myths. Echoing Hussain (2017), this thesis also suggests that although the UK Bangladeshis may have some common beliefs, norms, and values with other South

Asians, or with other Muslim communities, Bangladeshis and others are not homogenous. Instead, the people with dementia and their caregivers from the Bangladeshi community should be considered a separate group. Findings from this thesis suggest that the misconceptions about dementia and beliefs in various myths, i.e., supernatural interventions, are the biggest pertinent challenge for the Bangladeshi community. Therefore, to combat these problems, i.e., to raise awareness about dementia, develop knowledge and understanding of dementia among the Bangladeshi community, and remove the stigma surrounding dementia, I recommend the policies below to implement:

(a). CCG should run a pilot project to increase awareness within the Bangladeshi community, educate people about dementia, remove the stigma and dispel the myths about dementia. These educational programmes and campaigns should target the UK Bangladeshi community, specifically through community events and talk-shows on community TV and radio channels. People with dementia and their caregivers could be involved in planning these events. To reach this objective efficiently, CCGs can commission any third-party organisation with some UK Bangladeshi experts who learned from their lived experiences as family caregivers of persons with dementia. ‘TIDE’ (Together in Dementia Every Day) can be a good example to be followed. It developed various training and awareness programmes, mapping the cultural needs of the UK South Asian communities, which was first commissioned by the Heywood Middleton and Rochdale clinical commissioning Group (HMR CCG) and Rochdale Borough Council (RBC) in 2018 (https://www.tide.uk.net/resources/south-asian-carer-resources/). ‘TIDE’ developed a project called ‘Dementia Dekh Bhal’ (To Care For Dementia’), having three overreaching aims. First, to develop and deliver a training package for professionals to provide more culturally competent care. Second, to develop a campaign to increase awareness within the community, general public, and public sector staff around BAME dementia. Third, to use the power of stories to change perceptions, including creating a suite of videos capturing the experiences of people with dementia and their carers (https://www.tide.uk.net/dementia-dekh-baal-evaluation-report/). They also developed a campaigning tool kit for BAME carers to get their voices heard (co-developed with the ten TIDE volunteers). For example, they brought a ‘Storytelling’ approach to the fore via three short films from three carers with different experiences (a homemaker, a working professional, and a carer with complex health needs). The campaigning has been initiated through community roadshows, radio work, and community engagement, resulting in carers signing up to be involved with TIDE for networking and personal development.

However, this research study shows that the Bangladeshi community is unique as several participants with dementia have a sense of understanding that the possessions of supernatural forces could cause dementia. Therefore, they often seek spiritual healing or *jinn* exorcisms instead of bio-medical treatments. Therefore, I suggest that a group of dedicated Imams/faith leaders happy to work for the community needs to be trained first on understanding dementia and deliver that knowledge during their weekly/Friday sermons. Gradually, they can invite other same-minded Imams to receive this training. They can arrange some seminars/symposiums locally, regionally, or nationally and discuss Islamic perspectives and the importance of receiving bio-medical treatments. They can also explain the myths around possession by supernatural forces and issue fatawa (Islamic stance/consensus) about how monopolising people and charging money is immoral, fraudulent, and against the Quranic law.

(b). CCGs should recruit some outreach workers with Bangladeshi backgrounds to raise awareness through campaigns. All information leaflets/booklets should be written in Bangla and English, so that people who understand Bangla only, can read the information directly. On the other hand, if they lack any literacy in Bangla <u>or</u> English, their children or other family members who understand English can explain the contents.

(c). GPs should display some Bangla and English posters in their surgeries and have some booklets available explaining dementia risk factors, how to prevent the condition, and how to live well with it. Essential contact details of relevant services could be included in this booklet to help encourage older adults from the Bangladeshi community to learn more about dementia and understand how to navigate the health and care system if someone is diagnosed with dementia.

(d). Women are the primary carers in the Bangladeshi community. Due to the cultural expectations around gender roles, it is not convenient for them to attend any training sessions with males; therefore, Women’s Organisations can develop training sessions and events for women in any community centre.

(e). Mosques can be used as significant venues for dementia awareness events, where more community members can be encouraged to attend. Imams/faith leaders could take advantage of their leadership roles to help spread messages about raising dementia awareness and the challenges faced by people with dementia and their family caregivers. Mosques’ / faith centres’ management committees could allocate some spaces in the mosque / faith centre for people with dementia, with a signpost indicating the dementia corner. They could recruit some volunteers from their fellow worshippers to assist people with dementia when they go there. Mosques/faith centres can run some workshops with people or committee members of the mosque for people with dementia when they come to the mosque, so they feel comfortable coming there.

(f). The faith leaders / Imams need to be more proactive to discourage stigma and taboo by addressing factors like the importance of honesty in Islam/religion, not to deceive or conceal - e.g., in the case of marriage and hiding dementia to increase the marriageability of children.

8.4.2. Implications to Improve Dementia Health and Care Services:

This thesis identified a necessity to raise awareness of the dementia support needs of the UK Bangladeshi community among GPs. For example, several participants with dementia were diagnosed late as their GPs did not refer them for a memory test in time. Late diagnosis and referral may lead to years of delay in obtaining the required services. Early communication with their GP and timely recognition of dementia symptoms may help people with the condition better understand their daily activities. This thesis also explored the idea that dementia health and care services are not culturally appropriate. Therefore, the following recommendations can be implemented:

(a). GPs require more training to understand the dementia support needs of the Bangladeshi community. They should be proactive in developing improved ways to spot dementia and make referrals in the condition’s early stages.

(b). Services should be gender-specific and culturally appropriate. A male should be cared for by another male, and a female should be cared for by a female. Food should be cooked how Bangladeshi people cook in their homes.

(c). Service providers might recruit more staff from the Bangladeshi community to be involved in care and support for their community members to build trust and rapport and early screening and detection.

(d). There is growing recognition of the importance of the active involvement of consumers and community members in health care (Sarrami-Foroushani et al., 2014). Representation of Bangladeshi community members on boards and committees relating to dementia might be one way to help address the needs of people with dementia from the Bangladeshi community. Employing health and social care workers of Bangladeshi origin would also promote accessibility of services.

(e). Education and training can help support caregivers of people with dementia as informal caregivers of people with dementia often struggle with several stressors. Providing care can negatively affect their mental and physical health (Teles et al., 2021). There is a need to provide education about dementia to the Bangladeshi community, as there is often a lack of insight from people living with dementia and their family caregivers. Family caregivers should be encouraged to take dementia training courses to deliver the best service to their relatives with dementia. The classes will also help them learn more about dementia and subsequent daily caregiving consequences.

(f). People with dementia and their family caregivers can benefit from online training and face-to-face education. Internet-based interventions can improve dementia and mental health outcomes for family caregivers of people with dementia (Egan et al., 2018). “iSupport” is an online self-help programme designed by the World Health Organization to provide education, skills training, and support to prevent or minimize mental and physical health problems and improve the quality of life of dementia caregivers (Egan et al., 2018).

(g). There is a need for staff training to approach people with dementia within the Bangladeshi community. Therefore, all health and social care service providers, including hospital, respite care, day care, and care home services staff, should increase their professional development about the socio-cultural beliefs and lifestyles of the Bangladeshi community and their attitudes towards dementia. Service providers must undertake cultural sensitivity training and allow family members, where appropriate, to interpret.

(h). Care service providers need to build trust between the Bangladeshi community and health and social care providers to raise the probability of services being taken up.

(i). Community centres can run dementia cafés culturally sensitively and engage with people with dementia through creative activities such as storytelling.

8.7. Recommendations for future research

Along the research journey, this study has highlighted the need for further research on other significant areas to attain a greater understanding of supporting people with dementia from the Bangladeshi community. Hence, I recommend that further research consider the following points of focus:

- To investigate how UK Bangladeshis' religious values, influence their experiences caring for people with dementia and how the family caregivers cope with their cultural expectations of care.

- To investigate to what extent spiritual healers are accountable for preventing/delaying the diagnosis of people with dementia from the UK Bangladeshi community.
- To explore the influence of gender on the experience of dementia care among members of the UK Bangladeshi community.
- To investigate the role of multiculturalism in determining an individual's experiences of dementia diagnosis, treatment, and care, which may influence inequalities in diagnosis.
- To understand the UK Bangladeshi community's cross-cultural conceptualisations of dementia and mental health.

8.8. Concluding remarks

This study has explored the lived experiences of people living with dementia and caregivers and other dementia stakeholders within the Bangladeshi community. This study has identified aspects of the knowledge, beliefs, and cultural attitudes towards dementia held by the people with the condition and their family caregivers from the Bangladeshi community. It has also highlighted the religious-cultural expectations of care for those with the condition. Findings from all three phases of this study have revealed that participants with dementia and their carers have ‘alternative knowledge’ about dementia. They do not understand dementia in a scientific bio-medical context.

This thesis suggests that participants have various misconceptions about dementia. They access dementia services late and usually go to the doctor only when a crisis point is reached. Many participants with the condition and several carers link dementia to other illnesses and supernatural forces. Due to their misconceptions about dementia, many participants in this research with dementia went to spiritual healers instead of bio-medical doctors, even though theses healers did not have a bio-medical understanding of dementia. These cultural understandings can lead to stigmatisation of persons with dementia and their family caregivers, which may influence the family not to seek medical help for fear of the diagnosis.

It is explicit from the data analysis that participants with dementia and their caregivers from the Bangladeshi community are stigmatised. They have experienced all four aspects of stigma comprising public stigma, self-stigma, structural stigma, and stigma by association.

It was suggested by many participants with dementia and their caregivers that health and social care services were not tailored to the Bangladeshi community's cultural needs. Hospital staff did not always understand the cultural needs of patients; therefore, many male participants with dementia refused to accept services from some female nurses and hospital staff. Participants felt it to be against their religious and cultural norms if any person of the opposite gender touched them for any reason. It was difficult for many participants with dementia to communicate with health professionals and obtain a diagnosis, as they could not speak English fluently. Due to the language barrier, it was also challenging to understand service availability and to access the memory clinic and dementia health and care support. The study highlights the importance of raising awareness of dementia in the Bangladeshi community, eliminating the possibility of fear and of concealing the dementia condition by removing its stigma. This thesis has also explored that many family caregivers found the situation challenging because of socio-cultural expectations placed on them by the wider Bangladeshi community with their care duties on top of work and other commitments, despite their sincere willingness and motivation to care. Nonetheless, a culturally appropriate approach is needed to effectively manage dementia and improve services for the UK Bangladeshi community.

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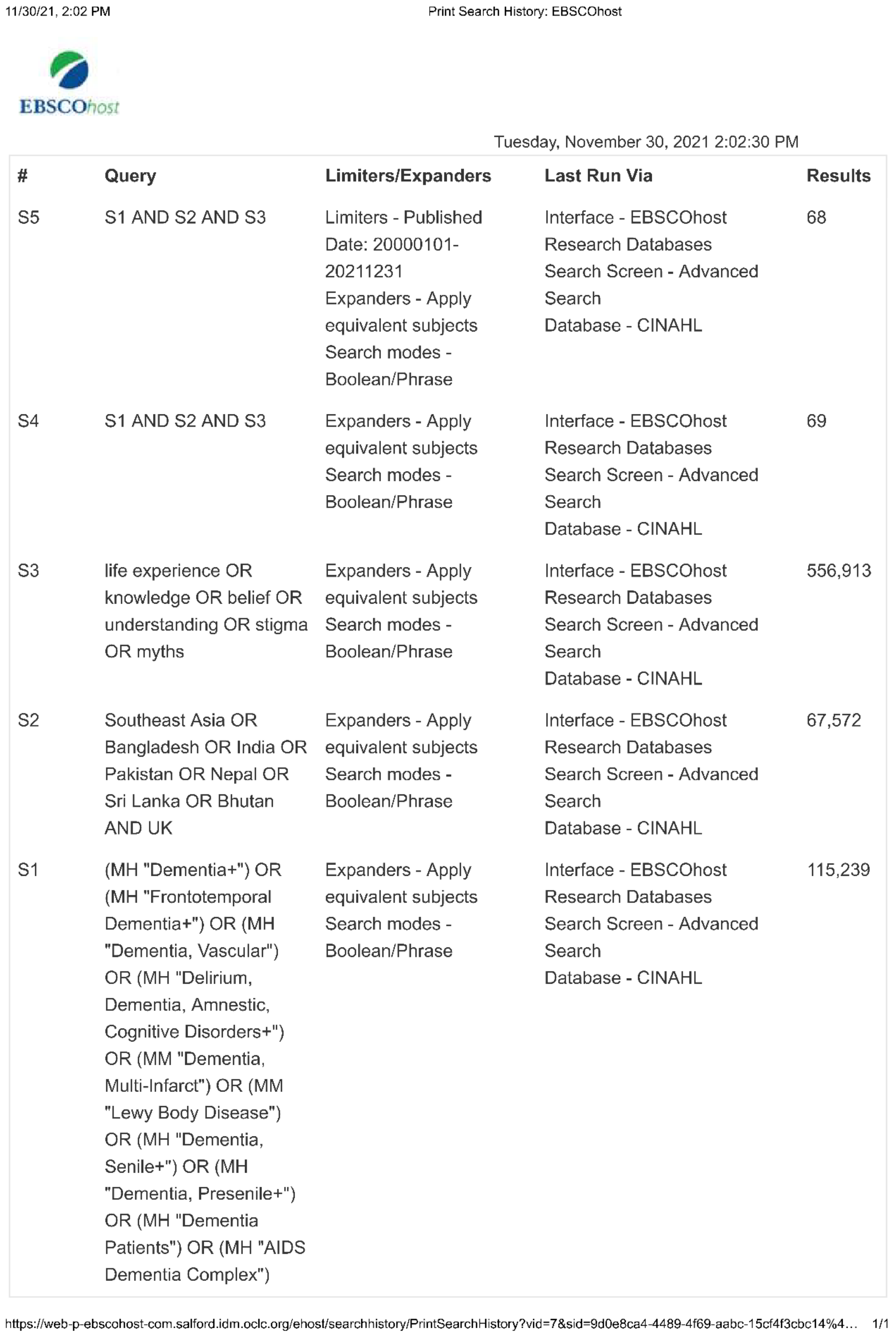
Appendices:

Appendix 1: Systematic Literature Searches



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Tuesday, November 30, 2021 2:02:30 PM

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S4	S1 AND S2 AND S3	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	69
S3	life experience OR knowledge OR belief OR understanding OR stigma OR myths	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	556,913
S2	Southeast Asia OR Bangladesh OR India OR Pakistan OR Nepal OR Sri Lanka OR Bhutan AND UK	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	67,572
S1	(MH "Dementia+") OR (MH "Frontotemporal Dementia+") OR (MH "Dementia, Vascular") OR (MH "Delirium, Dementia, Amnestic, Cognitive Disorders+") OR (MM "Dementia, Multi-Infarct") OR (MM "Lewy Body Disease") OR (MH "Dementia, Senile+") OR (MH "Dementia, Presenile+") OR (MH "Dementia Patients") OR (MH "AIDS Dementia Complex")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	115,239

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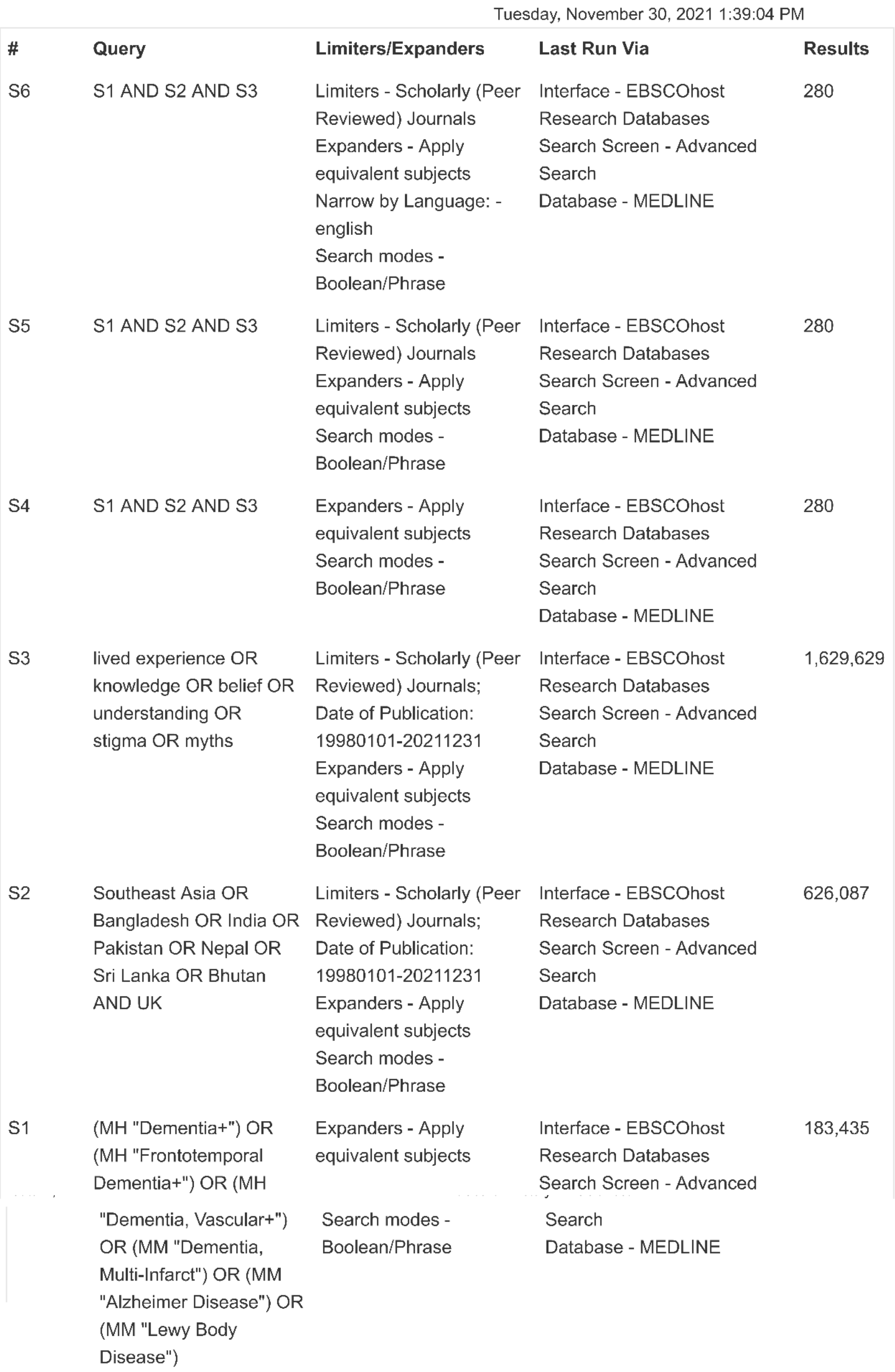

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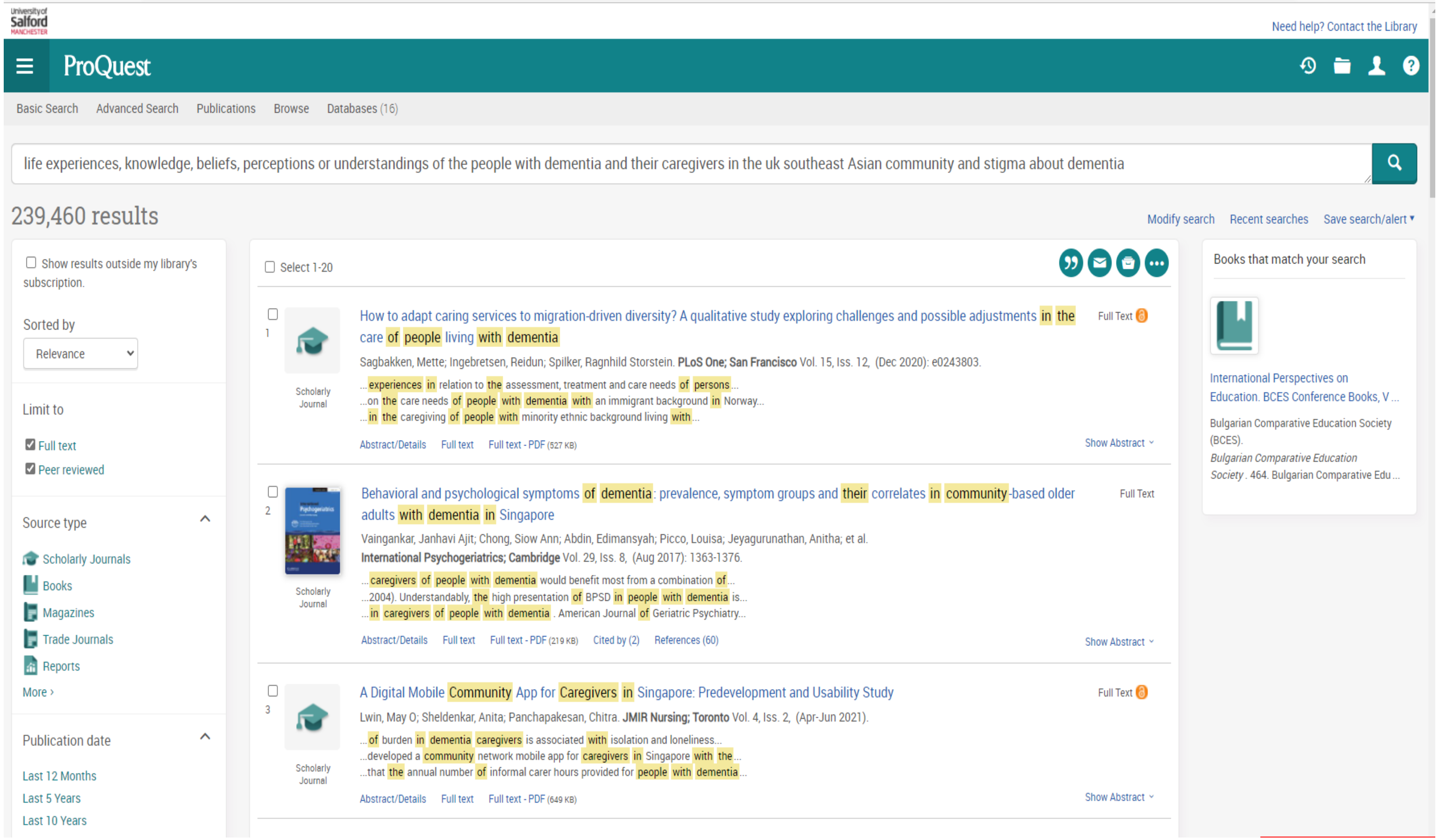
S5	S1 AND S2 AND S3	Limiters - Scholarly (Peer Reviewed) Journals Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	280
S4	S1 AND S2 AND S3	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	280
S3	lived experience OR knowledge OR belief OR understanding OR stigma OR myths	Limiters - Scholarly (Peer Reviewed) Journals; Date of Publication: 19980101-20211231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	1,629,629
S2	Southeast Asia OR Bangladesh OR India OR Pakistan OR Nepal OR Sri Lanka OR Bhutan AND UK	Limiters - Scholarly (Peer Reviewed) Journals; Date of Publication: 19980101-20211231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	626,087
S1	(MH "Dementia+") OR (MH "Frontotemporal Dementia+") OR (MH "Dementia, Vascular+") OR (MM "Dementia, Multi-Infarct") OR (MM "Alzheimer Disease") OR (MM "Lewy Body Disease")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	183,435



life experiences, knowledge, beliefs, perceptions or understandings of the people with dementia and their caregivers in the uk southeast Asian community and stigma about dementia

239,460 results

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☑ Full text

☑ Peer reviewed

☐ Select 1-20

☐ 1 How to adapt caring services to migration-driven diversity? A qualitative study exploring challenges and possible adjustments in the care of people living with dementia — Full Text

Sagbakken, Mette; Ingebretsen, Reidun; Spilker, Ragnhild Storstein. **PLoS One; San Francisco** Vol. 15, Iss. 12, (Dec 2020): e0243803.

...experiences in relation to the assessment, treatment and care needs of persons...
...on the care needs of people with dementia with an immigrant background in Norway...
...in the caregiving of people with minority ethnic background living with...

Scholarly Journal — Abstract/Details — Full text — Full text - PDF (527 KB) — Show Abstract ⌄

☐ 2 Behavioral and psychological symptoms of dementia: prevalence, symptom groups and their correlates in community-based older adults with dementia in Singapore — Full Text

Vaingankar, Janhavi Ajit; Chong, Siow Ann; Abdin, Edimansyah; Picco, Louisa; Jeyagurunathan, Anitha; et al.
International Psychogeriatrics; Cambridge Vol. 29, Iss. 8, (Aug 2017): 1363-1376.

...caregivers of people with dementia would benefit most from a combination of...
...2004). Understandably, the high presentation of BPSD in people with dementia is...
...in caregivers of people with dementia . American Journal of Geriatric Psychiatry...

Scholarly Journal — Abstract/Details — Full text — Full text - PDF (219 KB) — Cited by (2) — References (60) — Show Abstract ⌄

☐ 3 A Digital Mobile Community App for Caregivers in Singapore: Predevelopment and Usability Study — Full Text

Lwin, May O; Sheldenkar, Anita; Panchapakesan, Chitra. **JMIR Nursing; Toronto** Vol. 4, Iss. 2, (Apr-Jun 2021).

...of burden in dementia caregivers is associated with isolation and loneliness...
...developed a community network mobile app for caregivers in Singapore with the...
...that the annual number of informal carer hours provided for people with dementia...

Scholarly Journal — Abstract/Details — Full text — Full text - PDF (649 KB) — Show Abstract ⌄

Books that match your search

International Perspectives on Education. BCES Conference Books, V ...

Bulgarian Comparative Education Society (BCES).
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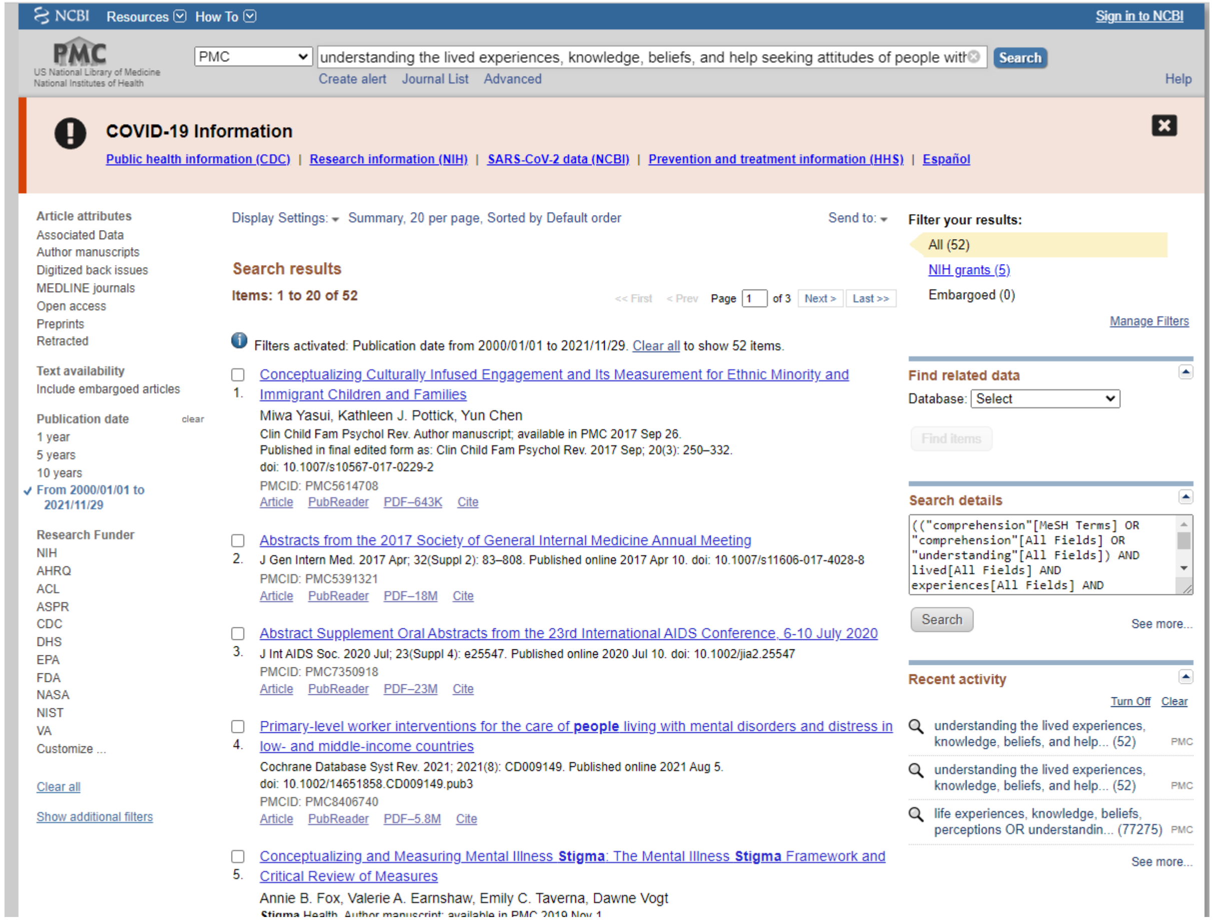

understanding the lived experiences, knowledge, beliefs, and help seeking attitudes of people wit

COVID-19 Information

Public health information (CDC) | Research information (NIH) | SARS-CoV-2 data (NCBI) | Prevention and treatment information (HHS) | Español

✓ From 2000/01/01 to 2021/11/29

Display Settings: Summary, 20 per page, Sorted by Default order

Search results

Items: 1 to 20 of 52

Page 1 of 3

Filters activated: Publication date from 2000/01/01 to 2021/11/29. Clear all to show 52 items.

☐ 1. Conceptualizing Culturally Infused Engagement and Its Measurement for Ethnic Minority and Immigrant Children and Families
Miwa Yasui, Kathleen J. Pottick, Yun Chen
Clin Child Fam Psychol Rev. Author manuscript; available in PMC 2017 Sep 26.
Published in final edited form as: Clin Child Fam Psychol Rev. 2017 Sep; 20(3): 250–332.
doi: 10.1007/s10567-017-0229-2
PMCID: PMC5614708
Article PubReader PDF–643K Cite

☐ 2. Abstracts from the 2017 Society of General Internal Medicine Annual Meeting
J Gen Intern Med. 2017 Apr; 32(Suppl 2): 83–808. Published online 2017 Apr 10. doi: 10.1007/s11606-017-4028-8
PMCID: PMC5391321
Article PubReader PDF–18M Cite

☐ 3. Abstract Supplement Oral Abstracts from the 23rd International AIDS Conference, 6-10 July 2020
J Int AIDS Soc. 2020 Jul; 23(Suppl 4): e25547. Published online 2020 Jul 10. doi: 10.1002/jia2.25547
PMCID: PMC7350918
Article PubReader PDF–23M Cite

☐ 4. Primary-level worker interventions for the care of **people** living with mental disorders and distress in low- and middle-income countries
Cochrane Database Syst Rev. 2021; 2021(8): CD009149. Published online 2021 Aug 5.
doi: 10.1002/14651858.CD009149.pub3
PMCID: PMC8406740
Article PubReader PDF–5.8M Cite

☐ 5. Conceptualizing and Measuring Mental Illness **Stigma**: The Mental Illness **Stigma** Framework and Critical Review of Measures
Annie B. Fox, Valerie A. Earnshaw, Emily C. Taverna, Dawne Vogt
Stigma Health. Author manuscript; available in PMC 2019 Nov 1

Filter your results:
- All (52)
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- Embargoed (0)

Find related data

Database: Select

Search details

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(("comprehension"[MeSH Terms] OR
"comprehension"[All Fields] OR
"understanding"[All Fields]) AND
lived[All Fields] AND
experiences[All Fields] AND
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Recent activity
- understanding the lived experiences, knowledge, beliefs, and help... (52) PMC
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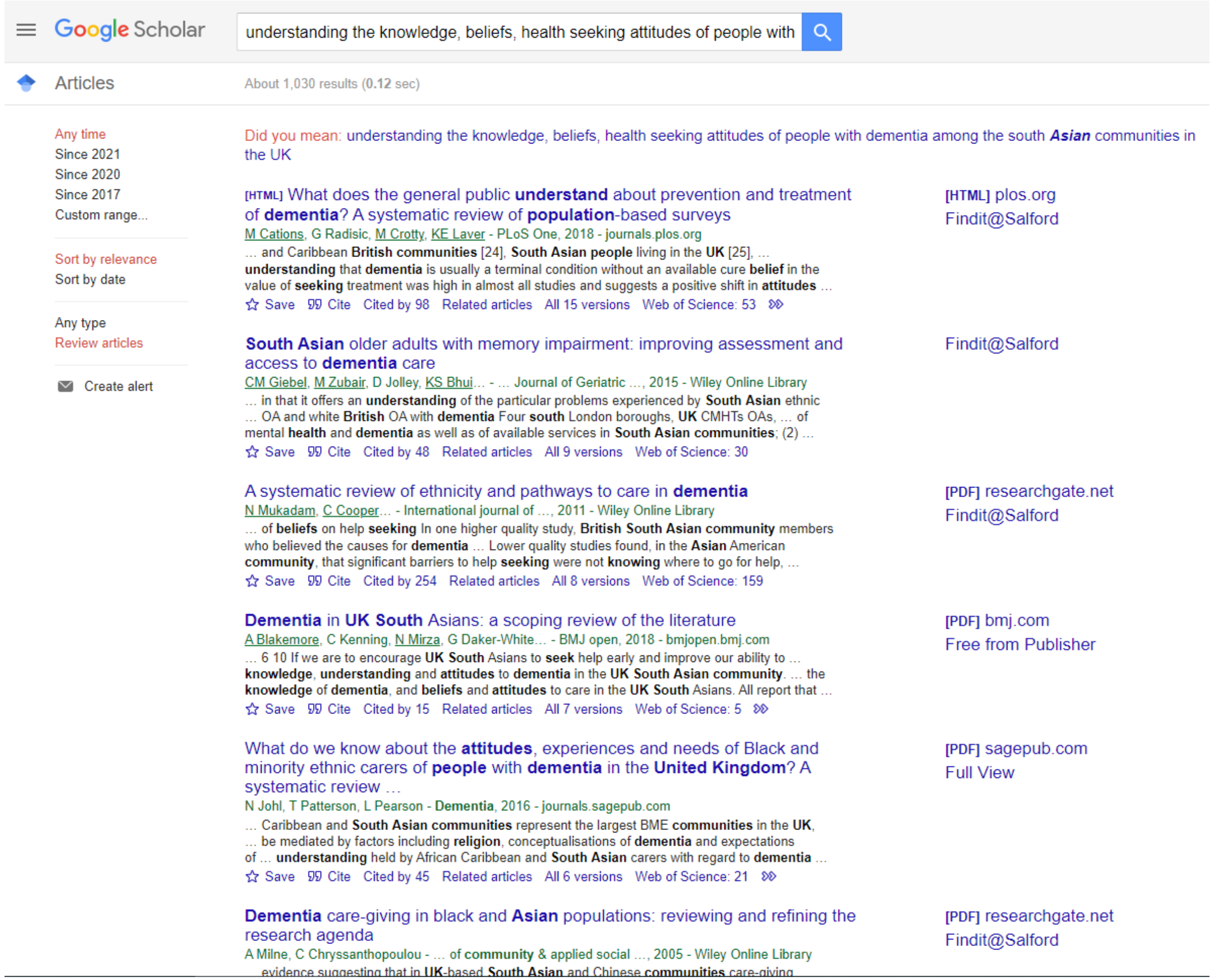
- life experiences, knowledge, beliefs, perceptions OR understandin... (77275) PMC



understanding the knowledge, beliefs, health seeking attitudes of people with

About 1,030 results (**0.12** sec)

Did you mean: understanding the knowledge, beliefs, health seeking attitudes of people with dementia among the south ***Asian*** communities in the UK

[HTML] What does the general public **understand** about prevention and treatment of **dementia**? A systematic review of **population**-based surveys

M Cations, G Radisic, M Crotty, KE Laver - PLoS One, 2018 - journals.plos.org

… and Caribbean **British communities** [24], **South Asian people** living in the **UK** [25], … **understanding** that **dementia** is usually a terminal condition without an available cure **belief** in the value of **seeking** treatment was high in almost all studies and suggests a positive shift in **attitudes** …

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[HTML] plos.org
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South Asian older adults with memory impairment: improving assessment and access to **dementia** care

CM Giebel, M Zubair, D Jolley, KS Bhui… - … Journal of Geriatric …, 2015 - Wiley Online Library

… in that it offers an **understanding** of the particular problems experienced by **South Asian** ethnic … OA and white **British** OA with **dementia** Four **south** London boroughs, **UK** CMHTs OAs, … of mental **health** and **dementia** as well as of available services in **South Asian communities**; (2) …

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A systematic review of ethnicity and pathways to care in **dementia**

N Mukadam, C Cooper… - International journal of …, 2011 - Wiley Online Library

… of **beliefs** on help **seeking** In one higher quality study, **British South Asian community** members who believed the causes for **dementia** … Lower quality studies found, in the **Asian** American **community**, that significant barriers to help **seeking** were not **knowing** where to go for help, …

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[PDF] researchgate.net
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Dementia in **UK South** Asians: a scoping review of the literature

A Blakemore, C Kenning, N Mirza, G Daker-White… - BMJ open, 2018 - bmjopen.bmj.com

… 6 10 If we are to encourage **UK South** Asians to **seek** help early and improve our ability to … **knowledge**, **understanding** and **attitudes** to **dementia** in the **UK South Asian community**. … the **knowledge** of **dementia**, and **beliefs** and **attitudes** to care in the **UK South** Asians. All report that …

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[PDF] bmj.com
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What do we know about the **attitudes**, experiences and needs of Black and minority ethnic carers of **people** with **dementia** in the **United Kingdom**? A systematic review …

N Johl, T Patterson, L Pearson - **Dementia**, 2016 - journals.sagepub.com

… Caribbean and **South Asian communities** represent the largest BME **communities** in the **UK**, … be mediated by factors including **religion**, conceptualisations of **dementia** and expectations of … **understanding** held by African Caribbean and **South Asian** carers with regard to **dementia** …

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Dementia care-giving in black and **Asian** populations: reviewing and refining the research agenda

A Milne, C Chryssanthopoulou - … of **community** & applied social …, 2005 - Wiley Online Library

… evidence suggesting that in **UK**-based **South Asian** and Chinese **communities** care-giving

[PDF] researchgate.net
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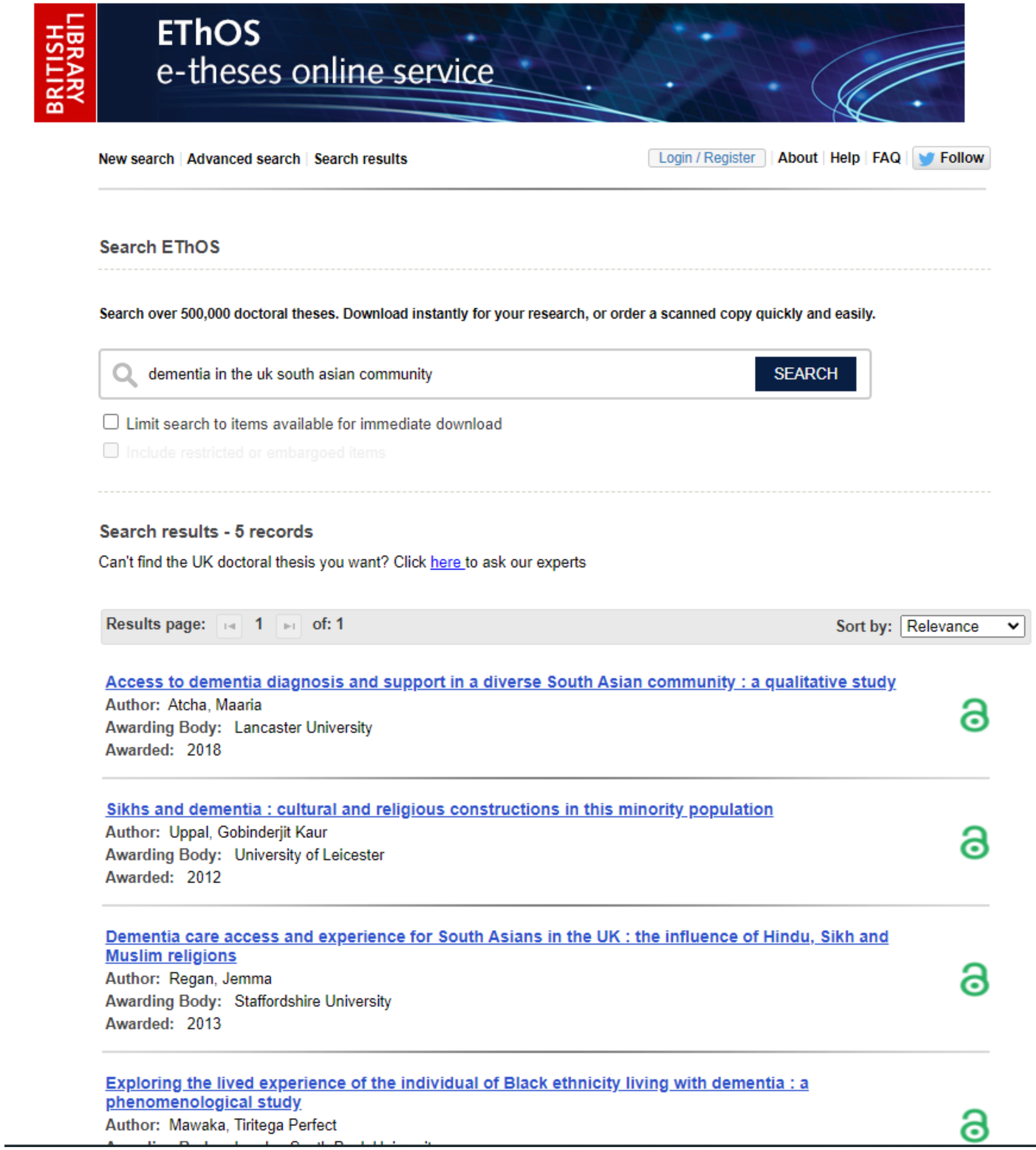

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Access to dementia diagnosis and support in a diverse South Asian community : a qualitative study
Author: Atcha, Maaria
Awarding Body: Lancaster University
Awarded: 2018

Sikhs and dementia : cultural and religious constructions in this minority population
Author: Uppal, Gobinderjit Kaur
Awarding Body: University of Leicester
Awarded: 2012

Dementia care access and experience for South Asians in the UK : the influence of Hindu, Sikh and Muslim religions
Author: Regan, Jemma
Awarding Body: Staffordshire University
Awarded: 2013

Exploring the lived experience of the individual of Black ethnicity living with dementia : a phenomenological study
Author: Mawaka, Tiritega Perfect

Appendix 2: A summary of research included in scoping review:

Reference	Date	Publication Type	Methodology	Design	Study Population	Sample Size	Study Focus
Hossain, M. Z., & Khan, H. T.	2020	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Focus group n=21 Bangladeshi aged 23-64 years (male 12 and female 9); Caregivers interviewed: n=6 Bangladeshi carers	27	This paper reports findings from a qualitative study that examined the barriers to health care service use in the Bangladeshi community living in the United Kingdom.
Giebel CM, Worden A, Challis D., Jolley D., Bhui KS, Lambat A., Kampanellou E., Purandare N.	2019	Peer-Reviewed Journal Article	Mixed-Methods	Cross sectional	N=72 younger and middle-aged adults (Group A); n= 88 older adults. The older age group consisted of 55 people with no subjective memory problems (Group B) and 33 with subjective memory problems (Group C).	160	This study aimed to explore in detail the perceptions of dementia (symptoms, causes, consequences, treatments) held by South Asians and to discern how these understandings vary by age and by the self-recognition of memory problems, as these influence help-seeking behaviour.
Herat-Gunaratne R., Cooper C., Mukadam N., Rapaport P., Leverton M., Higgs P., Samus Q., Burton A.	2019	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Semi-structured interviews with 10 Bangladeshi and Indian family carers of people living with dementia at home. Recruited participants from community settings in London and Bradford, UK.	10	This research explored the experiences of South Asian carers of people with dementia receiving health or social care in the United Kingdom.

Hossain, M., Crossland, J., & Stores, R. (2018).	2018	Peer Reviewed Journal Article	Qualitative	Systematic Review of the literature	A qualitative synthesis of primary studies was conducted using a meta-aggregation method guided by the Joanna Briggs Institute (JBI) approach.		The aim of this qualitative synthesis was to clearly identify the gaps in the literature and produce new insights regarding knowledge and understanding of the attitudes, perceptions, and beliefs of the South Asian community about dementia.
Atcha M. (2018),	2018	Unpublished PhD Thesis	Qualitative	Cross Sectional	Three focus groups with n=13 people involved in a community project; 2 interviews with people living with dementia and their family members; and 8 interviews with 9 dementia services healthcare professionals [HCPs].	23	This study aimed to identify the socio-cultural issues in accessing dementia services in the population living in Blackburn and Darwen in the North-West of England.
Blakemore A., Kenning C., Mirza N., Daker-White G., Panagioti M., Waheed W.(2018)	2018	Peer Reviewed Journal Article	Qualitative	Scoping Review of the literature			This is the first scoping review of the literature to identify priority areas for research to improve care for UK South Asians with dementia.
Baghirathan S., Cheston R., Hui R., Chacon A., Shears P. Currie K. (2018).	2018	Peer Reviewed Journal Article	Qualitative	Cross Sectional	interviews with 27 participants and 8 focus groups attended by 76 participants.	103	The aim of this study was to generate a grounded theory. The following questions guided the study: firstly, what experiences do people from three different BAME communities who provide care for people who are living with dementia in Bristol have of dementia-specific care? Secondly, why do they think people might be reluctant to access dementia care services?
Kenning C., Daker-White G., Blakemore A., Panagioti M. and Waheed W.	2017	Peer Reviewed Journal Article	Qualitative	Systematic Review of literature			The aim was to systematically review qualitative studies and to perform a meta-synthesis around barriers and facilitators to accessing dementia care in ethnic minorities.
Hossain M.Z.	2017	Unpublished PhD Thesis	Qualitative	Cross Sectional	Focus group n=21 Bangladeshi aged 23-64 years (male=12 and female=9); interviewed: n=6	27	This study aimed 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,

					Bangladeshi carers		
Parveen, S., Peltier, C., &Oyebode, J. R.	2017	Peer Reviewed Journal Article	Qualitative	Cross Sectional	The British Indian roadshow was attended by 62 people who were divided into six discussion groups	62	This scoping exercise makes use of Leventhal's Self-Regulation Model as a framework to explore perceptions of dementia and use of services among British Indian, African and Caribbean, and East and Central European communities
Hailstone, J., Mukadam, N., Owen, T., Cooper, C., & Livingston, G.	2017	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Focus groups; n=58 Mean age 60.; 59% female (n=34); 37 South Asian older adults.	58	This study aimed to devise and validate a theory of planned behaviour questionnaire to measure attitudes that predict medical help-seeking for UK-based South Asian people, to assess the effectiveness of future interventions promoting earlier help-seeking.
Ahmed, A, Wilding, MA, Haworth-Lomax, R and McCaughan, S.	2017	Monograph; Publisher: University of Salford	Qualitative	Cross Sectional	Semi-structured interviews with representatives from BME communities in Salford (n=12); Focus groups with representatives from BME communities in Salford (n=6); and Semi-structured interviews with key stakeholders (n=30)	48	The aims of the study were to improve access to dementia services for BAME communities in Salford, increase carer identification and registration, and raise awareness of the needs of Salford's diverse communities; to increase staff knowledge/develop evidence-based decision making relating to minority communities who may access dementia services/general health and social care related services in Salford.
Giebel C. , Challis D.,5, Worden A. , Jolley D., Bhui K.S., Lambat A., Purandare N.	2016	Peer Reviewed Journal Article	Mixed Methods	Cross Sectional	The newly developed Bart's Explanatory Model Inventory for Dementia (BEMI-D) was administered to 33 older South Asians aged 65 or above with memory problems. Chi-square and independent t-tests were used to investigate	33	This pilot study investigated how South Asians with self-defined memory problems, with and without GP consultation, construe the symptoms, causes, consequences and treatment of the condition.

					variations in perceptions, demographics, and medical characteristics between Groups 1 and 2.		
Regan J.L	2016	Peer Reviewed Journal Article	Qualitative	Cross Sectional	A qualitative case study of a male Muslim patient with young onset frontotemporal dementia	1	This study highlights the importance of recognising the motivations and experiences of a service user from an underrepresented cultural and religious demographic in relation to UK dementia health and social care services. Motivations for accessing health and social care services in the UK should not derive from 'desperation', but from an informed choice. Educating all services about dementia and dementia care – traditional and alternative – alongside the person with dementia and their carers is imperative.
Yong, BO. & Manthorpe, J.	2016	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Semi Structured Interviewed with migrant Indian Care workers	12	The aim of this study was to adapt the previously designed Barts Explanatory Model Inventory Checklist (BEMI-C), a tool designed to elicit perceptions of mental illness from people with different cultural backgrounds, for use with people with dementia in the South Asian population.
Giebel CM, Zubair M, Jolley D, Bhui KS, Purandare N, Worden A, Challis D.	2015	Peer Reviewed Journal Article	Qualitative	Cross Sectional	qualitative interviews; The emergent themes and perceptions were added to the BEMI-C through synthesis of the findings.	25	Investigation of motivations and experiences of accessing dementia-related health and social care services for a Muslim, Pakistani male with dementia.
Mukadam, N., Waugh, A., Cooper, C., & Livingston, G.	2015	Peer Reviewed Journal Article	Qualitative	Cross Sectional	53 English- or Bengali-speaking South Asian adults, aged 18-83.		This study sought to determine the barriers to timely help-seeking for dementia among people from South Asian backgrounds and what the features of an intervention to overcome them would be.
Mukadam N, Cooper C, Kherani N, Livingston G. A	2015	Peer Reviewed Journal Article	Qualitative	Systematic Review of the literature			The study aimed to systematically review the literature for interventions intended to increase the detection of dementia or suspected dementia or people presenting with memory complaints.

Jutlla, K.	2015	Unpublished PhD Thesis	Qualitative	Cross Sectional	12 Sikhs caring for a family member with dementia. 9 female, 3 males,		This doctoral study aimed to identify how migration experiences and personal histories influence experiences of caring for a person with dementia for Sikhs living in Wolverhampton.
Uppal G.K., Bonas S & Philpott H.	2014	Peer Reviewed Journal Article	Qualitative	Cross Sectional	28 Sikh participants aged over 18 years; Six focus groups in total: three consisting of 18–25-year-olds; two with 26–40-year-olds, and one with 41–55-year-old participants.		The aim of this study was to explore the understanding and perceptions of dementia amongst Sikhs living in the UK.
Khan, F., & Tadros, G.	2014	Peer Reviewed Journal Article	Qualitative	Systematic Review of the Literature	Interview with older Bangladeshi and Pakistani women and men aged 50 years and older	20	The aim of this research was to study the influence of cultural believes on the acceptance and accessibility of dementia services by patients from British Minority Ethnic (BME) groups. .
Regan, J.L.	2013	Unpublished PhD Thesis	Qualitative	Cross Sectional	Semi-structured interview: n=17 Formal observation n=6	23	This doctoral thesis Aimed to investigate of the influence of religion on access to - and experiences of - dementia care services, for South Asians from the Sikh, Hindu and Muslim communities in the West Midlands.
Victor C.R., Martin W. & Zubair M.	2012	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Semi-structured interviews with older Bangladeshi and Pakistani women and men aged 50 years and older	20	This study explores participants' understandings and experiences of care and support in the context of their family lives and social networks
Mukadam N., & Livingston G.	2012	Peer Reviewed Journal Article	Qualitative	Review of the literature			This research aims to suggest implications for reducing the stigma associated with dementia and recommend successful interventions involving a multifaceted approach that tackles self-stigma and public perceptions approaches and goals.
Bhattacharyya S., Benbow S.M., and Kar N.	2012	Peer Reviewed Journal Article	Qualitative	Systematic Review of the literature			This review analyses the magnitude of the problem, current service provision, and utilization of services by the Black and Minority Ethnic (BME) communities and

							suggests methods to improve services to these sections of the elderly.
Lawrence V, Samsi K, Banerjee S, Morgan C, Murray J.	2011	Peer Reviewed Journal Article	Qualitative	Cross Sectional	in-depth individual interviews were conducted with 11 Black Caribbean, 9 south Asian, and 10 White British older people with dementia.	30	This study examined the subjective reality of living with dementia from the perspective of people with dementia within the 3 largest ethnic groups in the United Kingdom.
Mukadam N., Cooper C., and Gill Livingston G.	2011	Peer Reviewed Journal Article	Qualitative	Systematic Review of the literature			This paper aimed to explore why people from minority ethnic (ME) groups with dementia present later to specialist diagnostic and therapeutic dementia services.
Parveen, S; Morrison, V; Robinson, C.A	2011	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Eight Bangladeshi, nine Indian, four Pakistani and nine White-British caregivers participated in five focus groups	30	This study aimed to establish an in-depth qualitative analysis of the convergence and divergence of the experiences of caregivers from four ethnic groups. Bangladeshi, Indian, Pakistani and White-British caregivers. Differences and similarities between motivations for role adoption, willingness to care, experience of role, adaptation to role, coping, use of and satisfaction with support were discussed.
Lawrence, V. Murray, J. Samsi, K. Banerjee, S.	2008	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Indepth individual interviews with 32 carers of people with dementia (10 Black Caribbean, 10 south Asian, 12 White British).	32	To explore the caregiving attitudes, experiences and needs of family carers of people with dementia from the three largest ethnic groups in the UK.
La Fontaine, J., Ahuja, J., Bradley, N.M., Philips, S and Oyebode, J.R.	2007	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Focus-group interviews with English-, Hindi- and Punjabi-speaking British South Asians, aged 17-61 years.	49	This paper is a report of a study to explore perceptions of ageing, dementia and ageing-associated mental health difficulties amongst British people of Punjabi Indian origin.
Purandare, N., Luthra, V., Swarbrick, C., & Burns, A.	2007	Peer Reviewed Journal Article	Quantitative	Cross Sectional	Dementia Knowledge Questionnaire (DKQ). One hundred and ninety-one DKQs from Indian and 55 DKQs from Caucasian (white UK/Irish/European) older people were included in the	246	The aim of this study was to examine knowledge of dementia in South Asian older people, as compared with Caucasian older people.

					analyses.		
Mackenzie, J.	2006	Peer Reviewed Journal Article	Qualitative	Some phase is Cross Sectional; and Some part is longitudinal	n=16 (76%) South Asian carers of people with dementia; n=11 Pakistani; n=5 Indian; n=4 Polish, n=1 Ukrainian.	21	In keeping with the philosophy of the National Service Framework, this research project set out to begin to: • identify the support needs of family carers from Eastern European and South Asian communities living in a northern England city; And subsequently to: • develop and deliver tailored 10-week support group programmes combined with advocacy support for carers.
Turner S., Christie A., & Haworth E.	2005	Peer Reviewed Journal Article	Qualitative	Cross Sectional	Semi-structured interviews; open-ended questions; N=96 South Asian and n=96 white older people, between the ages of 58 and 85 years	192	The study aimed to provide more information about the mental health needs of South Asian older people, and to contribute relevant information to the development of pathways to care for depression and dementia as required by the National Service Framework for Older People.
Adamson J., Donovan J.	2005	Peer Reviewed Journal Article	Qualitative	Cross Sectional	interviews with 21 African/Caribbean and 15 South Asian carers.	36	The paper attempts to consider the relationship between individual experiences, cultural factors and macro-social structures.
Bowes A, Wilkinson H.	2003	Peer Reviewed Journal Article	Qualitative	Cross Sectional	11 interviews with caregivers, 4 case studies of South Asian people with dementia	15	The aim of this paper was to examine some views and experiences of dementia among older South Asian people, as well as their families and carers, and to explore central issues of service support.
Adamson, J.	2001	Peer Reviewed Journal Article	Qualitative	Cross Sectional	n=30 carers, n=12 (40%) South Asian Carers of People with Dementia (Pakistani and Indian); 18 African/Caribbean	30	The objective of this study was to explore awareness, recognition and understanding of dementia symptoms in families of South Asian and African/Caribbean descent in the UK

Appendix 3: Summary of CASP scores given to each paper included in the literature review

N	Author + year of Publication	Clear Research Aim?	Appropriate Methodology?	Appropriate Research Design?	Appropriate Recruitment Strategy?	Data collection adequate?	Rapport built?	Ethical issues considered?	Data Analysis rigorous?	Findings Clear?	Peer-reviewed?	Total Score Obtained
1	Hossain & Khan (2020)	1	1	1	0	1	0	1	1	1	1	8
2	**Giebel et al. (2019)**	1	1	1	1	1	1	1	1	1	1	10
3	Herat-Gunaratne et al. (2019)	1	1	1	1	1	1	1	1	1	1	10
4	**Hossain,** et al. (2018)	1	1	1	0	0	0	0	1	1	1	6
5	Atcha, (2018)	1	1	1	1	1	1	1	1	1	0	9
6	Blakemore (2018)	1	1	1	0	0	0	0	1	1	1	6
8	Baghirathan et al.(2018)	1	1	1	1	1	1	1	1	1	1	10
9	Kenning et al. **(2017)**	**1**	**1**	**1**	**0**	**0**	**0**	**0**	**1**	**1**	**1**	**6**
10	Parveen et al. (2017)	1	1	1	1	1	1	1	1	1	1	10
11	Hossain (2017)	1	1	1	0	1	0	1	1	1	0	7
12	Hailstone et al.(2017)	1	1	1	1	1	1	1	1	1	0	9
13	Ahmed et al. (2017)	1	1	1	1	1	1	1	1	1	0	9
14	Giebel et al. (2016)	1	1	1	1	1	1	1	1	1	1	10
15	Regan (2016)	1	1	1	1	1	1	1	1	1	1	10

16	Yong et al. (2016)	1	1	1	1	1	1	1	1	1	1	10
17	Mukadam et al. (2015)	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**10**
18	Mukadam et al. (2015)	**1**	**1**	**1**	**0**	**0**	**0**	**0**	**1**	**1**	**1**	**6**
19	Jutlla (2015)	1	1	1	1	1	1	1	1	1	1	10
20	Uppal et al. (2014)	1	1	1	1	1	1	1	1	1	1	10
21	Khan & Tadros (2014)	1	1	1	0	0	0	0	1	1	1	6
22	Regan (2013)	1	1	1	1	1	1	1	1	1	0	9
23	Victor et al. (2012)	1	1	1	1	1	1	1	1	1	1	10
24	Mukadam & Livingston (2012)	1	1	1	0	0	0	0	1	1	1	6
25	Bhattacharyya (2012)	1	1	1	0	0	0	0	1	1	1	6
26	Lawrence et al. (2011)	1	1	1	1	1	1	1	1	1	1	10
27	Mukaddam et al. (2011)	1	1	1	0	0	0	0	1	1	1	6
28	Parveen et al. (2011)	1	1	1	1	1	1	1	1	1	1	10
29	Lawrence et al.(2008)	1	1	1	1	1	1	1	1	1	1	10
30	La Fontaine et al.(2007)	1	1	1	1	1	1	1	1	1	1	10
31	Purandare et al. (2007)	1	1	1	1	1	1	1	1	1	1	10
32	Mackenzie (2006)	1	1	1	1	1	1	1	1	1	1	10
33	Turner et al. (2005)	1	1	1	1	1	1	1	1	1	1	10
34	Adamson& Donovan (2005)	1	1	1	1	1	1	1	1	1	1	10

35	Bowes & Wilkinson (2003)	1	1	1	1	1	1	1	1	1	1	10
36	Adamson (2001)	1	1	1	1	1	1	1	1	1	1	10

Appendix 4: Ethical Approvals

4a

University of Salford MANCHESTER

Research, Enterprise and Engagement
Ethical Approval Panel

Doctoral & Research Support
Research and Knowledge Exchange,
Room 827, Maxwell Building,
University of Salford,
Manchester
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk

2 June 2020

Dear Mohammad,

RE: ETHICS APPLICATION–HSR1920-075 - Understanding the Support Needs of People with Dementia among the Bangladeshi Community in Oldham.

Based on the information you provided I am pleased to inform you that application HSR1920-075 has been approved.

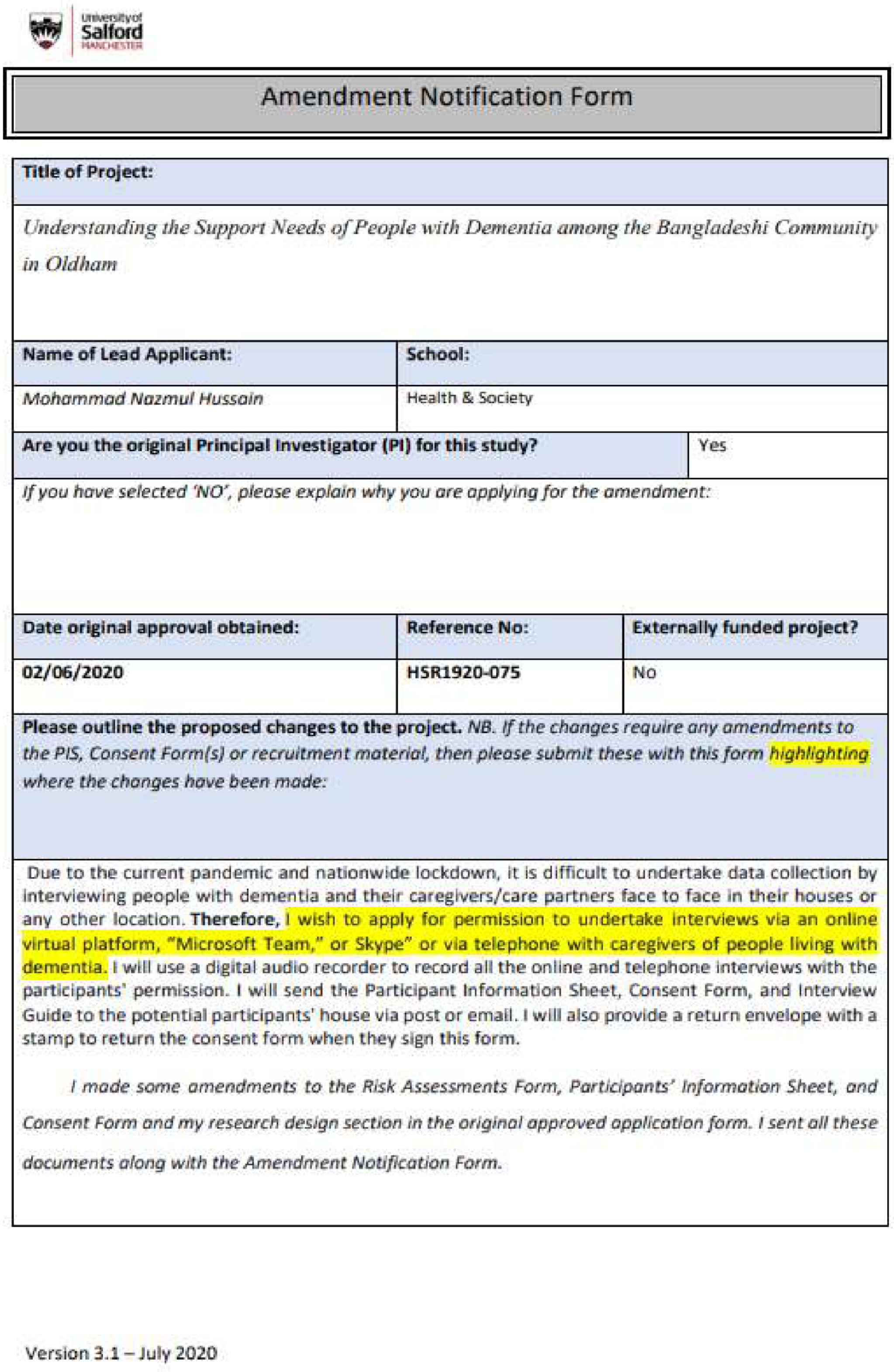
If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

K. Szczepura

Dr. Katy Szczepura
Deputy Chair of the Research Ethics Panel

4b

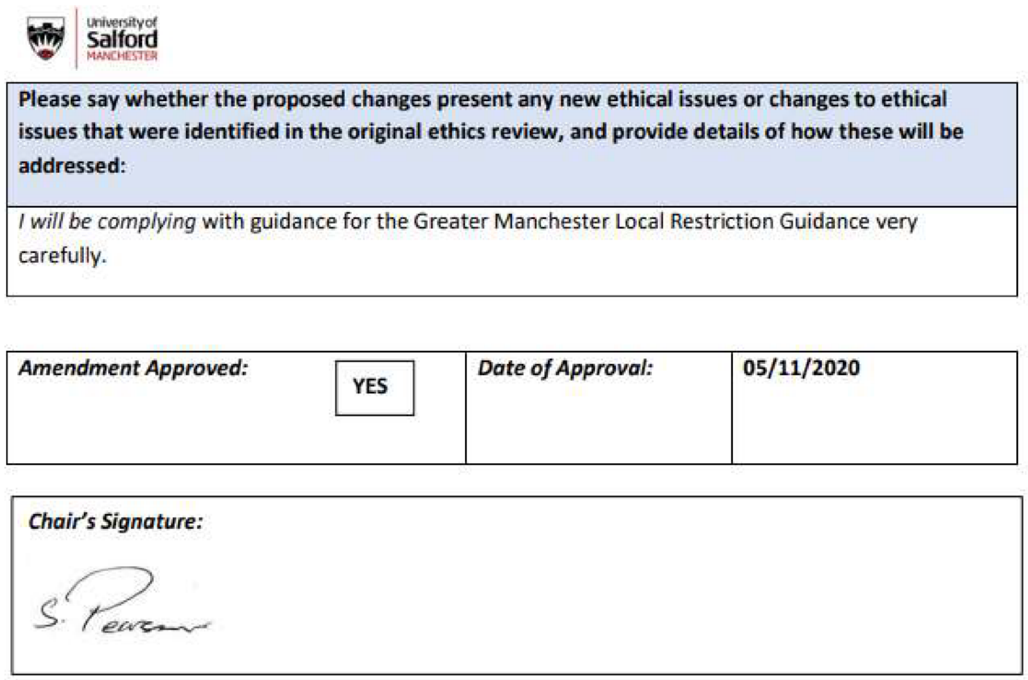


University of Salford MANCHESTER

Amendment Notification Form

Title of Project:		
Understanding the Support Needs of People with Dementia among the Bangladeshi Community in Oldham		
Name of Lead Applicant:	**School:**	
Mohammad Nazmul Hussain	Health & Society	
Are you the original Principal Investigator (PI) for this study?		Yes
If you have selected 'NO', please explain why you are applying for the amendment:		
Date original approval obtained:	**Reference No:**	**Externally funded project?**
02/06/2020	**HSR1920-075**	No
Please outline the proposed changes to the project. *NB. If the changes require any amendments to the PIS, Consent Form(s) or recruitment material, then please submit these with this form highlighting where the changes have been made:*		
Due to the current pandemic and nationwide lockdown, it is difficult to undertake data collection by interviewing people with dementia and their caregivers/care partners face to face in their houses or any other location. **Therefore,** I wish to apply for permission to undertake interviews via an online virtual platform, "Microsoft Team," or Skype" or via telephone with caregivers of people living with dementia. I will use a digital audio recorder to record all the online and telephone interviews with the participants' permission. I will send the Participant Information Sheet, Consent Form, and Interview Guide to the potential participants' house via post or email. I will also provide a return envelope with a stamp to return the consent form when they sign this form. *I made some amendments to the Risk Assessments Form, Participants' Information Sheet, and Consent Form and my research design section in the original approved application form. I sent all these documents along with the Amendment Notification Form.*		

Version 3.1 – July 2020



Please say whether the proposed changes present any new ethical issues or changes to ethical issues that were identified in the original ethics review, and provide details of how these will be addressed:

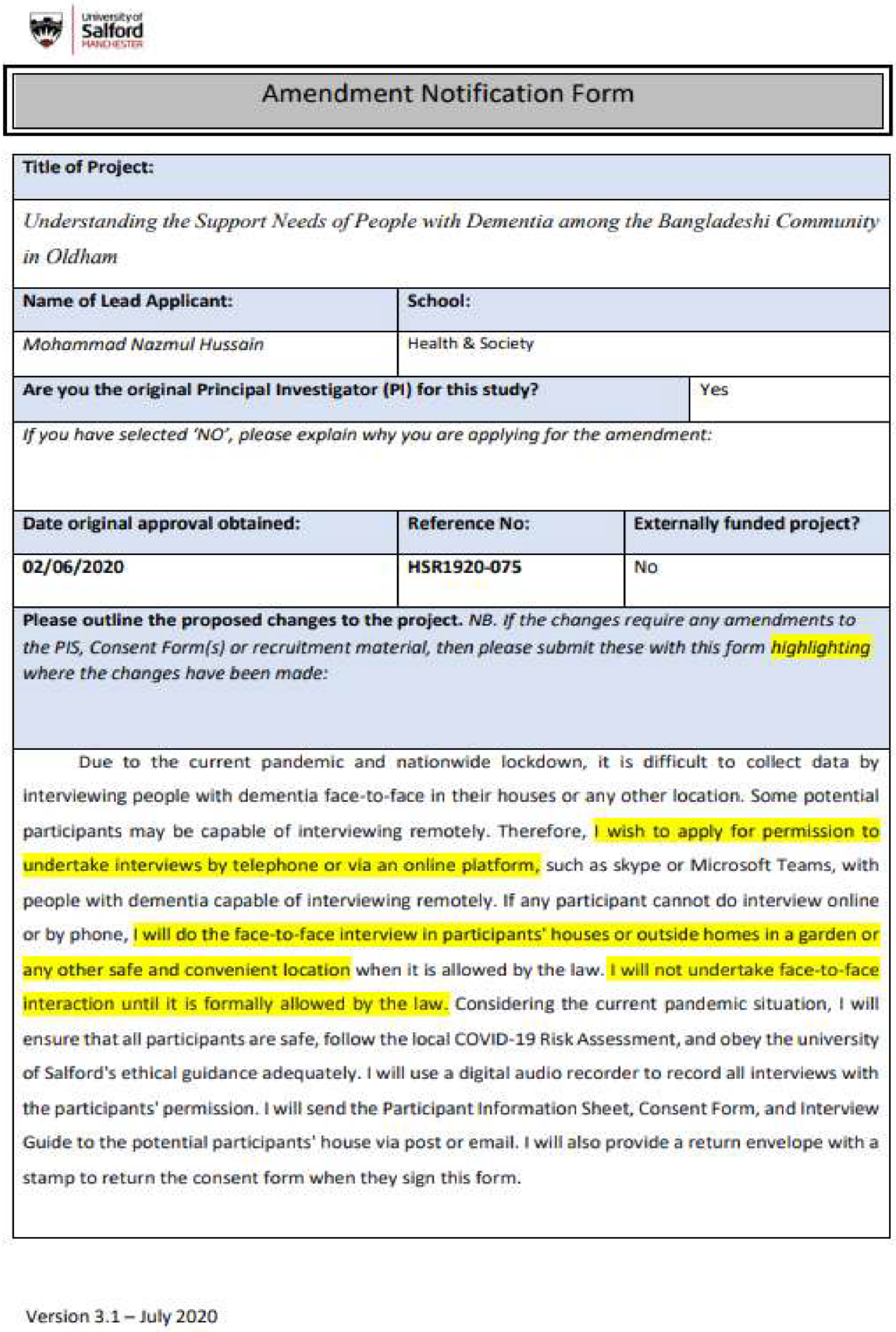
I will be complying with guidance for the Greater Manchester Local Restriction Guidance very carefully.

Amendment Approved:	**YES**	***Date of Approval:***	**05/11/2020**

Chair's Signature:

S. Pearson

4c



University of Salford MANCHESTER

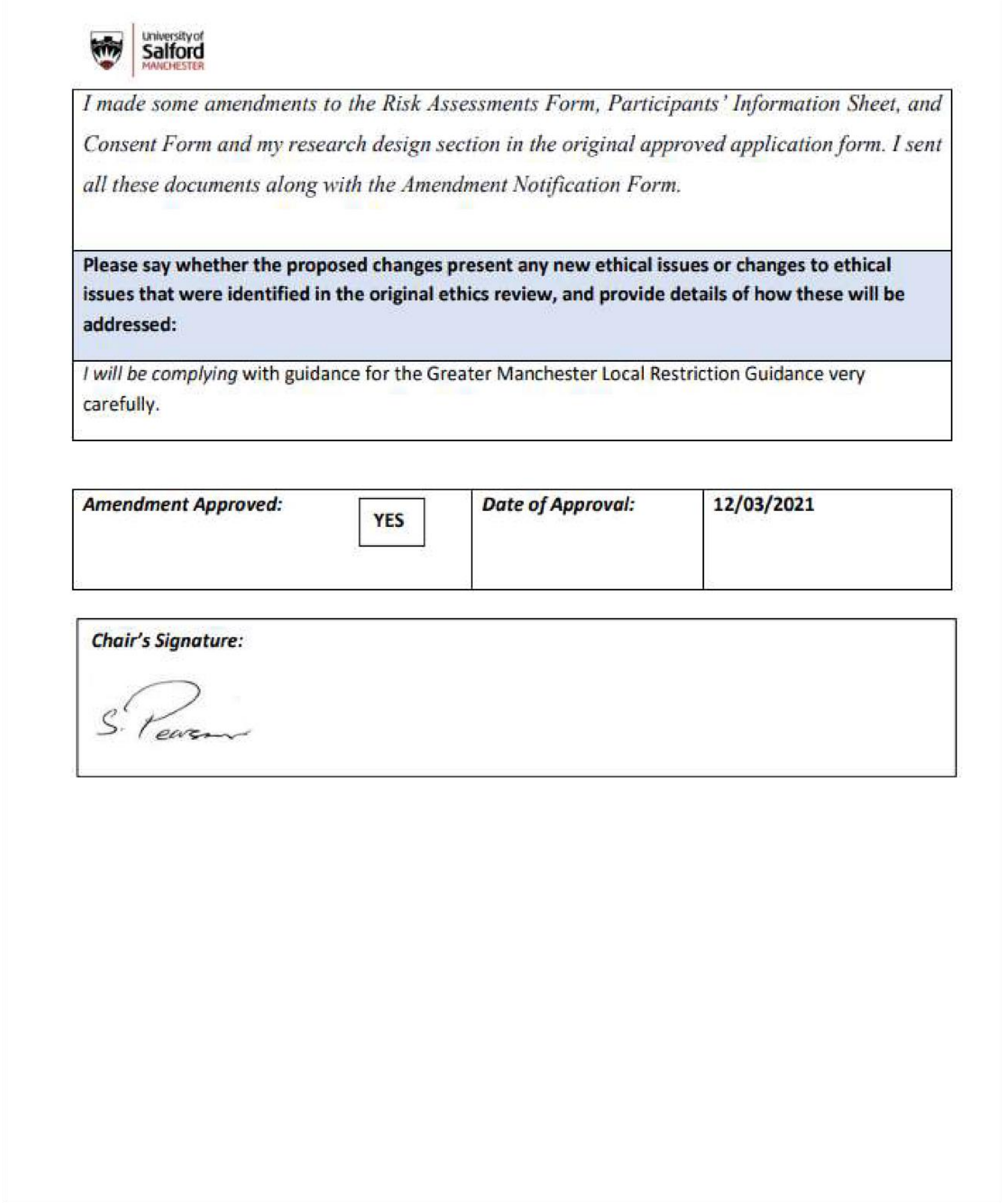
Amendment Notification Form

Title of Project:		
Understanding the Support Needs of People with Dementia among the Bangladeshi Community in Oldham		
Name of Lead Applicant:	**School:**	
Mohammad Nazmul Hussain	Health & Society	
Are you the original Principal Investigator (PI) for this study?		Yes
If you have selected 'NO', please explain why you are applying for the amendment:		
Date original approval obtained:	**Reference No:**	**Externally funded project?**
02/06/2020	**HSR1920-075**	No

Please outline the proposed changes to the project. *NB. If the changes require any amendments to the PIS, Consent Form(s) or recruitment material, then please submit these with this form highlighting where the changes have been made:*

Due to the current pandemic and nationwide lockdown, it is difficult to collect data by interviewing people with dementia face-to-face in their houses or any other location. Some potential participants may be capable of interviewing remotely. Therefore, I wish to apply for permission to undertake interviews by telephone or via an online platform, such as skype or Microsoft Teams, with people with dementia capable of interviewing remotely. If any participant cannot do interview online or by phone, I will do the face-to-face interview in participants' houses or outside homes in a garden or any other safe and convenient location when it is allowed by the law. I will not undertake face-to-face interaction until it is formally allowed by the law. Considering the current pandemic situation, I will ensure that all participants are safe, follow the local COVID-19 Risk Assessment, and obey the university of Salford's ethical guidance adequately. I will use a digital audio recorder to record all interviews with the participants' permission. I will send the Participant Information Sheet, Consent Form, and Interview Guide to the potential participants' house via post or email. I will also provide a return envelope with a stamp to return the consent form when they sign this form.

Version 3.1 – July 2020



University of Salford MANCHESTER

I made some amendments to the Risk Assessments Form, Participants' Information Sheet, and Consent Form and my research design section in the original approved application form. I sent all these documents along with the Amendment Notification Form.
Please say whether the proposed changes present any new ethical issues or changes to ethical issues that were identified in the original ethics review, and provide details of how these will be addressed:
I will be complying with guidance for the Greater Manchester Local Restriction Guidance very carefully.

Amendment Approved:	**YES**	***Date of Approval:***	**12/03/2021**

Chair's Signature:

S. Pearson

Appendix 5: Consent Form; Version 1, Dated: 01/04/2020

Title of study: Experiences of dementia in a UK Bangladeshi community: An exploratory study.

Name of Researcher: x

Please read carefully to understand the study information sheet, then complete and sign this form. Read the following statements and select ‘Yes’ or ‘No’ in the box on the right-hand side.

1. I confirm that I have read and understood the participation information sheet for the above research (Version1, dated 01/04/2020)

   Yes/No

1. I have had the opportunity to contemplate the information and to ask questions that have been answered satisfactorily.

   Yes/No

2. I understand my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my rights being affect

   Yes/No

3. I understand that I can remove permission to use information from my interview within four weeks after the meeting, in which case the data will be deleted. will be deleted.

   Yes/No

4. I understand that my details will be kept confidential and will not be revealed to people outside the research team.

   Yes/No

5. I understand that if I share information that the research considers to be an indication of risk of serious harm, then the researcher will report this to the relevant authorities.

Yes/No

6. I understand that my anonymous data will be used in the researcher's thesis, other academic publications, conferences, presentations and further research.

Yes/No

7. I understand that my interview will be digitally-recorded.

Yes/No

I agree to participate in this research:

Name of participant	**Date**	**Signature**
Name of person taking consent	**Date**	**Signature**

Appendix 6: Participant Information Sheet for Personnel of an Organisation that Supports People with Dementia; Version 1, Dated: 01/04/2020

Title of study: Experiences of Dementia in a UK Bangladeshi Community: An Exploratory Study

Name of Researcher:
X

1. Invitation paragraph

I want to invite you to take part in a research study via an online virtual platform. Before you decide, you need to understand why the research is being carried out and how it will involve you. Please take your time to read the following information carefully. Ask questions if anything you read is not clear, or you would like any additional information. Please take your time to decide whether you would like to take part in the research.
The study is for educational purposes. The researcher is carrying out this for completing a PhD.

2. What is the purpose of the study?

The aim of this research is to explore the experiences of people with dementia and their caregivers and gathers the views of service providers / stakeholders to make recommendations to improve the dementia support needs of the UK Bangladeshi community.

3. Why have I been invited to take part?

You have been invited to take part because you work for an organisation that supports people living with dementia. Your involvement in this research will allow the researcher to successfully generate a distinct understanding of dementia supports needs in a UK Bangladeshi community. The purpose of this research is as follows:

- To explore the lived experiences of people with dementia and their caregivers in accessing and using dementia services among a UK Bangladeshi Community.
- To better understand how stigma may create barriers to accessing UK Dementia Health and Social Care Services; and how to overcome them.
- To explore the understanding of dementia by the people who are diagnosed with dementia and their caregivers.
- To explore the understanding of stakeholders'/service providers about the support needs of people with dementia among this community.

This study is part of a PhD. project.

4. Do I have to take part?

Taking part in the research is voluntary. It is entirely up to you to decide whether you wish to take part in the study. The researcher will describe the nature of the research and go through the information sheet with you. You will then be asked to sign a consent form to show that you have agreed to take part in the study. You are free to withdraw from the study at any point. However, the interview data cannot be removed after four weeks from the data that has been collected.

5. What will happen to me if I take part?

Those taking part in the study will be interviewed one on one occasion. The interview will range from around 50-60 minutes. The researcher will ask a range of questions to you about dementia support needs. The participant will be given time to give answers. The interview will be recorded using an audio device.

6. Expenses and payments?

Your participation in this study is voluntary, and the interview will take place in your convenient location, such as your own house or any other suitable place you recommend. No expenses or payment will be provided to you. However, if you chose a location for the interview where you are required to use a taxi to get there, the researcher will offer you the travel expenses.

7. What are the possible disadvantages and risks of taking part?

There are no risks involved in the study, and the researcher does not intend to cause any harm to the individuals taking part in the research. However, as the topic under discussion concerns issues of health inequalities, cognitive disabilities, or mental health issues, there is a possibility that you may get upset. If this occurs, then the interview will be stopped, and the tape recorder will be switched off to allow you to calm down. If you are distressed, they will be given access to appropriate support services (if further support is required). The links to these services will be provided in a written paper (see appendix 13).

8. What are the possible benefits of taking part?

I cannot promise this study will help you immediately, although it is an excellent opportunity for you to share your experiences. I hope that this study will lead to a better understanding of the support needs of people with dementia in the Bangladeshi community where currently there is little research information.

9. What if there is a problem?

If you have any questions or concerns about any aspect of this study, you can contact the researcher Mr. X, on his mobile or email, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Supervisor XX at the University of Salford. If the matter is still not resolved, please forward your concerns to XXX, the Chair of the Health Research

Ethical Approval Panel, Room C519, Allerton Building, Frederick Road Campus, University of Salford, M6 6PU. Tel: XX. E: XXX

10. Will my taking part in the study be kept confidential?

All information that is collected during the research will be kept strictly confidential, and any names and addresses will be removed. However, if I suspect or learn of any illegal activities or harm during the research process, then as a role of the researcher, implicit consequentiality ethical reasoning, and personal values, I will break this confidentiality. The collection, storage, and disposal of the data will be kept by following the Data Protection Act (1998) and GDPR (2018). Data stored electronically will be saved onto a password protected computer device at the University of Salford with only the research team having access to it. All signed consent forms will be stored in a locked cabinet in the office. Digital recordings will be deleted on completion of the study. The data collected from the interviews will be anonymous and given a research code, known only to the researcher/research team. Data will be used for this study alone, and the only individuals who will have access to the data will include the researcher, supervisors, and examiners. The data will be kept for approximately two years, depending on the completion of the PhD. All data will be destroyed at the end of the study.

11. What will happen if I don’t carry on with the study?

Any decision is entirely voluntary; therefore, you have the right to withdraw from the study if you want to do so without giving a reason. However, the cut-off point from withdrawing is one month after the interview. This will give me time to recruit new participants, analyse the data, and make any necessary changes to my findings. After this date, I will not be able to exclude your data. If you withdraw from the study, your name will be removed from the research files, and all the information and data collected from you will be destroyed.

12. What will happen to the results of the research study?

The result of the study will be presented truthfully and accurately at first in the researcher’s Ph.D. thesis. It will also be disseminated at local community events, such as mosques, temples, Alzheimer’s Society’s activities, and local Mental Health charities/ services, etc. These findings also will be presented in various conferences; and published in relevant journals, e.g., Alzheimer’s & Dementia; and Ageing & Mental Health, etc.

13. Who is organising or sponsoring the research?

I will fund the research myself. All research carried out is in line with the ethical agreement of the University of Salford.

14. Further information and contact details:

Email: x
Thank you for taking the time to read this Information Sheet.

Appendix 7: Interview Guide for Personnel of an Organisation that Supports People with Dementia; Version 1, Dated: 01/04/2020

Interview type: Semi-structured Interview

Interview length: Interview will last from some 50 to 60 minutes (approximately).

Greetings:

Thank you very much for being willing to take part in an interview for this research project. My name is x, and I am a PhD. student at the University of Salford.

You have been invited to take part because you work for an organisation that supports people living with dementia. Your involvement in this research will allow the researcher to generate a distinct understanding of dementia supports needs in a UK Bangladeshi community.

The purpose of this research is as follows:

- To explore the lived experiences of people with dementia and their caregivers in accessing and using dementia services among a UK Bangladeshi Community.
- To better understand how stigma may create barriers to accessing UK Dementia Health and Social Care Services; and how to overcome them.
- To explore the understanding of dementia by the people who are diagnosed with dementia and their caregivers.
- To explore the understanding of stakeholders'/service providers about the support needs of people with dementia among this community.

This study is part of a PhD. project.

There is no right or wrong answer. We want to hear your experience and views, told in your own words – I'm interested in hearing what you have to say.

There is no right or wrong answer. We want to hear your experience and views, told in your own words – We are interested in hearing what you have to say.

Before we begin,

- I will seek permission from you to record the interview with a digital recorder, as this will save all conversation accurately

Interview Questions:

Topic Guides:

The researcher will discuss the following topics with the participant during the interview:

1. Stakeholder’s perception about the knowledge and beliefs of people with dementia among a UK Bangladeshi Community; and their suggestions and recommendations to raise dementia awareness in this community
2. Stakeholder’s view/ experiences about the service use by this community and engaging with services pre/during /post-diagnosis comparing with the homogenous British whites.
3. Support Needs/Gaps
5. Stakeholder’s perception about the stigma of dementia; and suggestions to overcome it.
6. Stakeholder understandings about the barriers to access to dementia services by the people with this community.
7. Stakeholders understanding of the cultural friendly support needs for the people with dementia

Once again, thank you very much for your time and your input. Your participation will be beneficial for our research. Thank you!

Appendix 8: Participant Information Sheet for the Caregiver & Family Member of Someone Living with Dementia; Version 2, Dated: 29/10/2020

Title of study: Experiences of Dementia in a UK Bangladeshi Community: An Exploratory Study

Name of Researcher: X

1. Invitation paragraph

I want to invite you to take part in a research study. The interviews will be carried out via an online virtual platform, "Microsoft Team," or Skype" or via telephone. Before you decide, you need to understand why the research is being carried out and how it will involve you. Please take your time to read the following information carefully. Ask questions if anything you read is not clear, or you would like any additional information. Please take your time to decide whether you would like to take part in the research. The study is for educational purposes. The researcher is carrying out this for completing a PhD.

2. What is the purpose of the study?

The aim of this research is to explore the experiences of people with dementia and their caregivers and gathers the views of service providers / stakeholders to make recommendations to improve the dementia support needs of the UK Bangladeshi community.

3. Why have I been invited to take part?

You have been invited to take part, because you are a carer or family member of someone living with a diagnosis of dementia of Bangladeshi origin. Your involvement in this research will allow the researcher to successfully generate a distinct understanding of dementia supports needs in a UK Bangladeshi community. The purpose of this research is as follows:

- To explore the lived experiences of people with dementia and their caregivers in accessing and using dementia services among a UK Bangladeshi Community.
- To better understand how stigma may create barriers to accessing UK Dementia Health and Social Care Services; and how to overcome them.
- To explore the understanding of dementia by the people who are diagnosed with dementia and their caregivers.
- To explore the understanding of stakeholders'/service providers about the support needs of people with dementia among this community.

This study is part of a PhD. project.

4. Do I have to take part?

Taking part in the research is voluntary. It is entirely up to you to decide whether you wish to take part in the study. The researcher will describe the nature of the research and go through the information sheet with you. You will then be asked to sign a consent form to show that you have agreed to take part in the study. You are free to withdraw from the study at any point. However, the interview data cannot be removed after four weeks from the data that has been collected.

5. What will happen to me if I take part?

Those taking part in the study will be interviewed one on one occasion. The interviews will be carried out via an online virtual platform, “Microsoft Team,” or Skype” or via telephone. It will range from around 50-60 minutes. The researcher will ask a range of questions to you about dementia support needs. The participant will be given time to give answers. The interview will be recorded using a digital audio recording device.

6. Expenses and payments?

Your participation in this study is voluntary, and the interview will take place online or via telephone. No expenses or payment will be provided to you.

7. What are the possible disadvantages and risks of taking part?

There are no risks involved in the study, and the researcher does not intend to cause any harm to the individuals taking part in the research. However, as the topic under discussion concerns issues of health inequalities, cognitive disabilities, or mental health issues, there is a possibility that you may get upset. If this occurs, then the interview will be stopped, and the audio recorder will be switched off to allow you to calm down. If you are distressed, they will be given access to appropriate support services (if further support is required). The links to these services will be provided in a written paper (see appendix 13).

8. What are the possible benefits of taking part?

I cannot promise this study will help you immediately, although it is an excellent opportunity for you to share your experiences. I hope that this study will lead to a better understanding of the support needs of people with dementia in the Bangladeshi community where currently there is little research information.

9. What if there is a problem?

If you have any questions or concerns about any aspect of this study, you can contact the researcher Mr. X, on his mobile or email, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Supervisor Professor Anthea Innes, at the University of Salford. If the matter is still not resolved, please forward your concerns to Professor Andrew Clark, the Chair of the Health Research Ethical Approval Panel, Room C519, Allerton Building, Frederick Road Campus, and University of Salford, M6 6PU. Tel: XX. Email: XXX

10. Will my taking part in the study be kept confidential?

All information that is collected during the research will be kept strictly confidential, and any names and addresses will be removed. However, if I suspect or learn of any illegal activities or harm during the research process, then as a role of the researcher, implicit consequentiality ethical reasoning, and personal values, I will break this confidentiality. The collection, storage, and disposal of the data will be kept by following the Data Protection Act (1998) and GDPR (2018). Data stored electronically will be saved onto a password protected computer device at the University of Salford with only the research team having access to it. All signed consent forms will be stored in a locked cabinet in the office. Digital recordings will be deleted on completion of the study. The data collected from the interviews will be anonymous and given a research code, known only to the researcher/research team. Data will be used for this study alone, and the only individuals who will have access to the data will include the researcher, supervisors, and examiners. The data will be kept for approximately two years, depending on the completion of the PhD. All data will be destroyed at the end of the study.

11. What will happen if I don’t carry on with the study?

Any decision is entirely voluntary; therefore, you have the right to withdraw from the study if you want to do so without giving a reason. However, the cut-off point from withdrawing is one month after the interview. This will give me time to recruit new participants, analyse the data, and make any necessary changes to my findings. After this date, I will not be able to exclude your data. If you withdraw from the study, your name will be removed from the research files, and all the information and data collected from you will be destroyed.

12. What will happen to the results of the research study?

The result of the study will be presented truthfully and accurately at first in the researcher’s PhD. thesis. It will also be disseminated at local community events, such as mosques, temples, Alzheimer’s Society’s activities, and local Mental Health charities/ services, etc. These findings also will be presented in various conferences; and published in relevant journals, e.g., Alzheimer’s & Dementia; and Ageing & Mental Health, etc.

13. Who is organising or sponsoring the research?

I will fund the research myself. All research carried out is in line with the ethical agreement of the University of Salford.

14. Further information and contact details:

Email: x

Thank you for taking the time to read this Information Sheet.

Appendix 9: Interview Guide for the Caregiver & Family Member of Someone Living with Dementia; Version 1, Dated: 01/04/2020

University of Salford
MANCHESTER

Interview type: Semi-Structure Interview

Researcher: x

Interview length: Interview will last from some 50 to 60 minutes (approximately).

Greetings:

Thank you very much for being willing to take part in an interview for this research project. My name is x, and I am a PhD. student at the University of Salford.

You have been invited to take part because you are a career or family member of someone living with a diagnosis of dementia of Bangladeshi origin. Your involvement in this research will allow the researcher to generate a distinct understanding of dementia successfully supports needs in a UK Bangladeshi community. The purpose of this research is as follows:

- To explore the lived experiences of people with dementia and their caregivers in accessing and using dementia services among a UK Bangladeshi Community.
- To better understand how stigma may create barriers to accessing UK Dementia Health and Social Care Services; and how to overcome them.
- To explore the understanding of dementia by the people who are diagnosed with dementia and their caregivers.
- To explore the understanding of stakeholders'/service providers about the support needs of people with dementia among this community.

This study is part of a PhD. project.

There is no right or wrong answer. We want to hear your experience and views, told in your own words –We are interested in hearing what you have to say.

Before we begin,

• I will seek permission from you to record the interview with a digital recorder, as this will save all conversation accurately

Interview Questions:

Topic Guides:

The researcher will discuss the following topics with the participant during the interview:

1. Caregiver's Identity:

a. Name
b. Sex
c. Marital Status
d. Religion
e. Work Status
f. Age

2. T**he Identity of the person with dementia:**

a. Name
b. Sex
c. Marital Status
d. Religion
-e. Work Status
-f. Age

3. Illness Profile of the person with dementia:

a. Nature of illness
b. The severity of illness
c. Duration of the illness
d. Nature of the Treatment
e. Person's Experience

4. Behaviours and attitudes of the Person with Dementia: (How often they feel)

a. Anxious
b. Happy
c. Afraid

d. Intimidated

e. Confident

f. Paranoid/ Angry

g. other atypical behaviour

5. Experiences of engaging with services pre/during diagnosis:

a. Experience with GP services /GP's referral to the memory clinic/ Expression of the symptoms

b. Experience with the memory clinic

c. Uses of other supportive services

6. Access to services post-diagnosis including:

- Social care
- Behaviour of the staffs

7. Support Needs/Gaps in Health Care Services

8. Caregiving Experience:

- Dealing with the atypical actions of the person with dementia
- Big Challenges
- Carer own health
- Employment
- Limitations

9. The Neighbourhood, Leisure and Social Connections

10. Experience of Stigma:

a. Societal reaction

b. Self-Esteem

c. Institutional stigma

d. Stigma by association

11. Knowledge and Beliefs:

a. People's perceptions about dementia

b. Beliefs on supernatural forces

c. Uses of Spiritual Healings

Once again, thank you very much for your time and your input. Your participation will be beneficial for our research. Thank you

Appendix 10: Risk Assessment Form; Version 3, Dated: 29/10/2020

Title of study:

Experiences of Dementia in a UK Bangladeshi Community: An Exploratory Study

Name of Researcher: x

<u>ALL projects MUST include a risk assessment.</u> If this summary assessment of the risk proves insignificant information, you answer 'no' to all of the questions, then no further action is necessary. However, if you identify any risks, then you must define the precautions you will put in place to control these.

1. What is the title of the project?

The aim of this research is to explore the experiences of people with dementia and their caregivers and gathers the views of service providers / stakeholders to make recommendations to improve the dementia support needs of the UK Bangladeshi community.

2. Is the project purely literature-based? - NO

If YES, please go to the bottom of the assessment and sign where indicated. If NO, then please complete section 3 and list your proposed controls.

3. Please highlight the risk(s) which applies to your study:

Hazards	**Risks**	**If yes, consider what precautions will be taken to minimise risk and discuss with your Supervisor**
Use of ionising or non-ionising radiation	*Exposure to radiation* - ***NO***	
Use of hazardous substances	*Exposure to harmful substances* ***- NO***	
Use of face-to-face interviews *Interviewees could be upset by interview and become aggressive or violent toward researcher*	*Interviewing …* *Non-University personnel=High risk* ***YES***	***NB:*** *Greater precautions will be maintained during the interview considering medium &high-risk activities*
Use of face-to-face interviews *Participants or interviewees could become upset by interview and suffer psychological effects*	- ***YES***	Proposed precautions are provided separately.

Sensitive data	*Exposure to data or information which may cause upset or distress to the researcher* - **NO**	
Physical activity	*Exposure to levels of exertion unsuitable for an individual's level of fitness* - **NO**	
Equipment	*Exposure to faulty or unfamiliar equipment.* - **NO**	
Sensitive issues i.e. Gender/Cultural e.g. when observing or dealing with undressed	*Exposure to vulnerable situations/ sensitive issues that may cause distress to interviewer or*	

members of the opposite sex	*interviewee* - ***NO***	
Children	- ***NO***	
Manual handling activities	*Exposure to an activity that could result in injury* - ***NO***	

If you have answered 'YES' to any of the hazards in section 3, then please list the proposed precautions below:

Precautions:

***Concerning communication with the participants and maintaining professional contact*:**

I will form and maintain a high-quality professional relationship with the participants. I will not give out my mobile number, home number, or home email to any participant.

Location of interviews:

Interviews will be held in participants' prepared locations and a safe place.

Participants' support and wellbeing:

I will ensure the welfare of all the participants who can leave anytime if they do not want to continue the interview. Each interviewee will be treated with high respect. If any participant gets upset, then the meeting will be ended immediately to give them time to compose themselves; and they have the right to withdraw from the meeting as well. Nobody will be forced to take part in the interview if they do not show their interest.

Prevention with aggressive/violent behaviour:

To deal with aggressive/violent behaviour, and to prevent this from happening, I will carry out the interviews during an appropriate time of the day when the individuals living with the condition are usually in a good mood considering the participant's wellbeing.

Researcher's health & safety:

I will follow the 'Lone Working Code of Practice accordingly that is designed by the University of Salford. No female participant will be interviewed in a closed-door one on one respecting Bangladeshi culture. My wife will always be informed where the interview will take place; and the expected time of return.

***Disclosure of Potential Risks and Harms*:**

Suppose a participant discloses that, there is a risk of serious harm to either the participant or someone else (including myself). In that case, I will be required to break confidentiality, speak to my supervisor, and report this information to the relevant authority.

Consideration of the current COVID- 19 Pandemic Impact:

SEE BELOW FOR UPDATE IN RELATION TO COVID 19 PRECAUTIONS

Considering the current pandemic situation, I will comply with the University of Salford Guidance and comply with Government national guidance. The Government has insisted on a nationwide lockdown from 5th November 2020. People have been told to “stay at home” except for specific purposes and prevent gathering with people they do not live with. Consequently, interviews with care-givers will be conducted remotely (either online or over the telephone).

Appendix 11: Participant Information Sheet for the Person living with Dementia; Version 1, Dated: 01/04/2020

Note: The researcher will strictly follow this information sheet. However, another dementia-friendly version is available for the participants who are living with the condition (see Appendix 2).

Title of study: Experiences of Dementia in a UK Bangladeshi Community: An Exploratory Study

Name of Researcher: x

1. Invitation paragraph

I want to invite you to take part in a research study. Before you decide, you need to understand why the research is being carried out and how it will involve you. Please take your time to read the following information carefully. Ask questions if anything you read is not clear, or you would like any additional information. Please take your time to decide whether you would like to take part in the research.

The study is for educational purposes. The researcher is carrying out this for completing a Ph.D.

2. What is the purpose of the study?

The aim of this research is to explore the experiences of people with dementia and their caregivers and gathers the views of service providers / stakeholders to make recommendations to improve the dementia support needs of a UK Bangladeshi community.

3. Why have I been invited to take part?

You have been invited to take part because you are a person living with dementia of Bangladeshi origin. Your involvement in this research will allow the researcher to successfully generate a distinct understanding of dementia support needs in a UK Bangladeshi community. The purpose of this research is as follows:

- To explore the lived experiences of people with dementia and their caregivers in accessing and using dementia services among a UK Bangladeshi community.
- To better understand how stigma may create barriers to accessing UK Dementia Health and Social Care Services; and how to overcome them.
- To explore the understanding of dementia by the people who are diagnosed with dementia and their caregivers.
- To explore the understanding of stakeholders'/service providers about the support needs of people with dementia among this community.

This study is part of a Ph.D. project.

4. Do I have to take part?

Taking part in the research is voluntary. It is entirely up to you to decide whether you wish to take part in the study. The researcher will describe the nature of the research and go through the information sheet with you. You will then be asked to sign a consent form to show that you have agreed to take part in the study. You are free to withdraw from the study at any point. However, the interview data cannot be removed after four weeks from the data that has been collected.

5. What will happen to me if I take part?

Those taking part in the study will be interviewed one on one occasion. The interview will range from around 50-60 minutes. The researcher will ask a range of questions to you about dementia support needs. The participant will be given time to give answers. The interview will be recorded using an audio device.

6. Expenses and payments?

Your participation in this study is voluntary, and the interview will take place in your convenient location, such as your own house or any other suitable place you recommend. No expenses or payment will be provided to you. However, if you chose a location for the interview where you are required to use a taxi to get there, the researcher will offer you the travel expenses.

7. What are the possible disadvantages and risks of taking part?

There are no risks involved in the study, and the researcher does not intend to cause any harm to the individuals taking part in the research. However, as the topic under discussion concerns issues of health inequalities, cognitive disabilities, or mental health issues, there is a possibility that you may get upset. If this occurs, then the interview will be stopped, and the tape recorder will be switched off to allow you to calm down. If you are distressed, they will be given access to appropriate support services (if further support is required). The links to these services will be provided in a written paper (see appendix 13).

8. What are the possible benefits of taking part?

I cannot promise this study will help you immediately, although it is an excellent opportunity for you to share your experiences. I hope that this study will lead to a better understanding of the support needs of people with dementia in the Bangladeshi community where currently there is little research information.

9. What if there is a problem?

If you have any questions or concerns about any aspect of this study, you can contact the researcher Mr. X, on his mobile or email, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Supervisor XX at the University of Salford. If the matter is still not resolved, please forward your concerns to XXX the Chair of the Health Research Ethical Approval Panel, Room C519, Allerton Building, Frederick Road Campus, University of Salford, M6 6PU. Tel: XX. E: XX

10. Will my taking part in the study be kept confidential?

All information that is collected during the research will be kept strictly confidential, and any names and addresses will be removed. However, if I suspect or learn of any illegal activities or harm during the research process, then as a role of the researcher, implicit consequentiality ethical reasoning, and personal values, I will break this confidentiality. The collection, storage, and disposal of the data will be kept by following the Data Protection Act (1998) and GDPR (2018). Data stored electronically will be saved onto a password protected computer device at the University of Salford with only the research team having access to it. All signed consent forms will be stored in a locked cabinet in the office. Digital recordings will be deleted on completion of the study. The data collected from the interviews will be anonymous and given a research code, known only to the researcher/research team. Data will be used for this study alone, and the only individuals who will have access to the data will include the researcher, supervisors, and examiners. The data will be kept for approximately two years, depending on the completion of the Ph.D. All data will be destroyed at the end of the study.

11. What will happen if I don’t carry on with the study?

Any decision is voluntary; therefore, you have the right to withdraw from the study if you want to do so without giving a reason. However, the cut-off point from withdrawing is one month after the interview. This will give me time to recruit new participants, analyse the data, and make any necessary changes to my findings. After this date, I will not be able to exclude your data. If you withdraw from the study, your name will be removed from the research files, and all the information and data collected from you will be destroyed.

12. What will happen to the results of the research study?

The result of the study will be presented truthfully and accurately at first in the researcher’s Ph.D. thesis. It will also be disseminated at local community events, such as mosques, temples, Alzheimer’s Society’s activities, and local Mental Health charities/ services, etc. These findings also will be presented in various conferences; and published in relevant journals, e.g., Alzheimer’s & Dementia; and Ageing & Mental Health, etc.

13. Who is organising or sponsoring the research?

I will fund the research myself. All research carried out is in line with the ethical agreement of the University of Salford.

<u>14. Further information and contact details</u>:

Email: x

Thank you for taking the time to read this Information Sheet.

Appendix 12: Participant Information Sheet for the Person living with Dementia -dementia-friendly version; Version 2, Dated: 01/04/2020

What is the purpose of the study?

The aim of this research is to explore the experiences of people with dementia and their caregivers and gathers the views of service providers / stakeholders to make recommendations to improve the dementia support needs of the UK Bangladeshi community.

What is the possible benefit of taking part?

Taking part in dementia research is an opportunity to use your experience to speak about what is important to you and what you think would make a real difference to dementia services. Taking part in the research is voluntary.

Further information.:

Information provided by you will be recorded and dealt with by following the GDPR (General Data Protection Regulation). I will ask you to sign in a consent form at the beginning, but you can withdraw at any point if you want.

For more information, please contact Mr. X on xx or email xxx.

Thank you for taking the time to read this Information Sheet.

Appendix 13: Interview Guide for the Person living with Dementia; Version1; Dated: 01/04/2020

Title of the study: Experiences of Dementia in a UK Bangladeshi Community: An Exploratory Study

Researcher: x

Interview length: Interview will last from some 50 to 60 minutes (approximately, depending on what participant wants to share)

Greetings:

Thank you very much for being agreed to participate in an interview for this research project. My name is xx, and I am a Ph.D. student at the University of Salford.

You have been invited to take part in this research because you are a person living with Dementia of a Bangladeshi origin. Your involvement in this research will allow the researcher to successfully generate a distinct understanding of dementia support needs in Bangladeshi community. The purpose of this research is as follows:

- To explore the lived experiences of people with dementia and their caregivers in accessing and using dementia services among the Bangladeshi Community.
- To better understand how stigma may create barriers to accessing UK Dementia Health and Social Care Services; and how to overcome them.
- To explore the understanding of dementia by the people who are diagnosed with dementia and their caregivers.
- To explore the understanding of stakeholders'/service providers about the support needs of people with dementia among this community.

This study is part of a PhD project.

There is no right or wrong answer; we want to hear your experience and views, told in your own words – I'm interested in hearing what you have to say.

Before we begin,

- I will seek permission from you to record the interview with a digital recorder, as this will save all conversation accurately

Interview Questions:

Topic Guides:

The researcher will discuss the following topics with the participant during the interview:

1. Participants' Identity:

a. Sex
b. Marital Status
c. Religion
d. Work Status

2. Illness Profile of the Person with Dementia:

a. Nature of illness
b. The severity of illness
c. Duration of the illness
d. Quality of the Treatment
e. Person's Experience

3. Feelings: (How often they feel)

a. Anxious
b. Happy
c. Afraid
d. Intimidated
e. Confident

4. Experiences of engaging with services pre/during diagnosis:

a. Experience with GP services /GP's referral to the memory clinic
b. Experience with the memory clinic / Referrals to other supportive services

5. Access to services post-diagnosis, including:

a. Social care

6. Support Needs/Gaps in Health Care Services

7. Family Supports

8. The Neighbourhood, Leisure and Social Connections

9. Experience of Stigma:

a. Societal reaction
b. Self-Esteem
c. Institutional stigma
d. Stigma by association

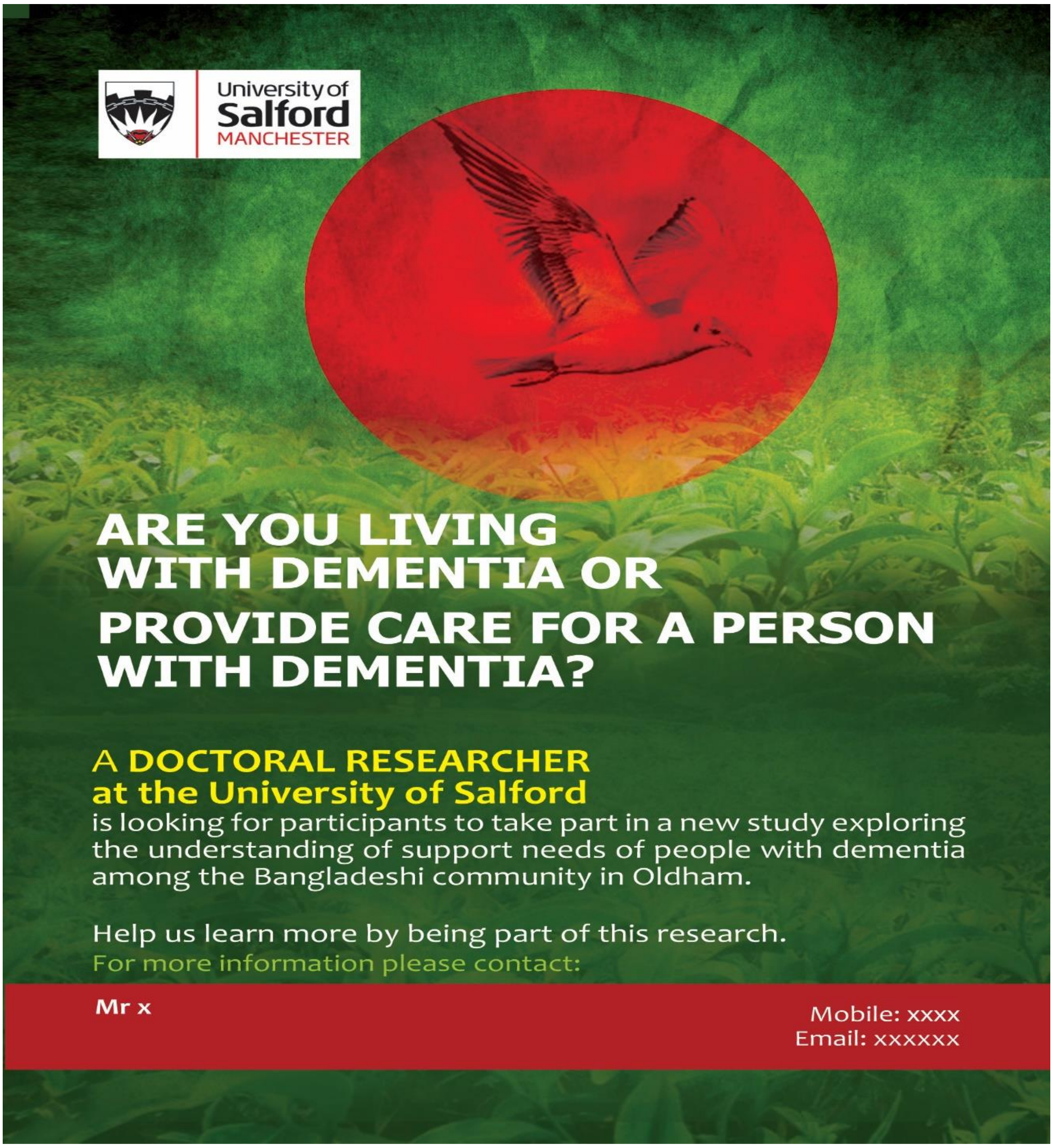
10. Knowledge and Beliefs:

a. People’s perceptions about dementia
b. Beliefs on supernatural forces
c. Uses of Spiritual Healings

Once again, thank you very much for your time and your input. Your information will be beneficial for our research. Thank you!

Appendix 14: Participant Recruitment Poster

University of
Salford
MANCHESTER



University of
Salford
MANCHESTER

ARE YOU LIVING
WITH DEMENTIA OR
PROVIDE CARE FOR A PERSON
WITH DEMENTIA?

A **DOCTORAL RESEARCHER**
at the University of Salford
is looking for participants to take part in a new study exploring the understanding of support needs of people with dementia among the Bangladeshi community in Oldham.

Help us learn more by being part of this research.
For more information please contact:

Mr x

Mobile: xxxx
Email: xxxxxx

Appendix 15: Letter to The Chairman (Mosque)

…………………………..……………….Mosque
Address: …………………………………………………………

Dated: 01/04/2020

Subject: Request to give an announcement to recruit participants for a dementia research study

Dear Sir,
Assalamu Alaikum
I will be grateful if you kindly read the following announcement out in your mosque on my behalf to recruit some participants for dementia research in a Bangladeshi Community.
Thank you.
X

Announcement:

Research Participants Required!

Dear Audience,

A Doctoral Researcher at the University of Salford is looking for participants to take part in a new study exploring the experiences of people with dementia and their caregivers and gathers the views of service providers / stakeholders to make recommendations to improve the dementia support needs of the UK Bangladeshi community.

If you live with dementia or provide care for any relative who has dementia, please take part in this research and have your say. Some leaflets will be distributed outside. Please read to find out more details. For further queries, please contact ‘x’ on his mobile……………or email him …………

Appendix 16: Letter to The Chairman (Temple)

……………. …………………Temple
Address:

Dated: 01/04/2020

Subject: Request to give an announcement to recruit participants for a dementia research study

Dear Sir,

Namaskar.

I will be grateful if you kindly read the following announcement out on my behalf in your temple congregation to recruit participants for a dementia research study in a Bangladeshi Community.

Thank you.

X

Announcement:

Research Participants Required!

Dear Audience,

A Doctoral Researcher at the University of Salford is looking for participants to take part in a new study exploring the experiences of people with dementia and their caregivers and gathers the views of service providers / stakeholders to make recommendations to improve the dementia support needs of the UK Bangladeshi community.

If you live with dementia or provide care for any relative who has dementia, please take part in this research and have your say. Some leaflets will be distributed outside. Please read to find out more details. For further queries, please contact ‘x’ on his mobile……………or email him …………

I look forward to hearing from you.

Appendix 17: Permission to Contact, Dated: 01/04/2020

Note: The gatekeepers will give this sheet to the potential participants. They will send this back to the researcher later on once it is filled up by the potential participants willingly.

My name is ………………………………………………….
My Address………………………………………………….

…………………………………………………….

…………………………………………………….
My Mobile/ Phone ………………………………………….
My Email …………………………………………….

I am interested in participating in this research; therefore, I would like to know more information about it. Can the researcher contact me by telephone soon.

Appendix 18: Coding

Codes	Interview Text
Good Practice	**Naz:** Hi x I am Mohammad Hussain. Welcome to dementia research study as a stakeholder. I'm very delighted to have you here today. Both of you are in charge of a prominent organisation 'y'. Welcome you all. **x:** Thank you **Naz:** Can you tell me little bit about your organization 'y' e.g. what services this organization provide? And what is your position here? **:** I am the manager of 'y', which is a community-based Care Provider Agency. We provide support to people in the community across all ages, really. Um, across also all abilities including people with learning disabilities, older people, people with mental health, and people who are living with dementia. Um, we have been working in this community since 2003. **Naz:** Wow. So you have been working in this sector for quite a long period of time! **x:** Yeah, it has been. It's been rewarding occasions to be able to work with people across the community. We work in this borough only. **Naz:** x! Can you tell us any of you what type of support your organization provide for people with dementia specifically? I know you do many things, but what do you do specifically for people who are living with dementia? **x:** well. All services required by the individual particularly. What we use the term in general 'Person Centred Care. So we provide personal care to people with dementia. Personal care is often known only with Interim services, like showers and going to toilet and so on. But personal care in this case means really everything that people require. We do range of services according to their ability or disability, as the case may be. So we do everything across the board and often do packages up. They purchase services that include either some element or all the elements of services. So for instance, one is just going out for shopping with a staff. However, full package includes everything a person requires including, toileting, showering. Changing clothes, going out for exercises so on. Sometimes we do recommend this for them.

	Naz: Nahid! How long have you been delivering these services?
	x: 17 years. We started from 2003.
	Naz: x! Is there any background for the name of your organisation 'y?'
Good Practice Good Practice Good Practice	**x:** Yes. Certainly, it has a background of course. In early 2000, new idea has come out from America about how to support older people including people with dementia. These ideas were called initially the Person-Centred Planning. Lots of people came here from America to train people on how to care according to person centred planning. Person center planning concept behind it and so on. When these plans were being done. Their implementation was far from what is intended. When implication was done then, there implication was far from what they actually intended. So, people in services, like care managers and other personnel are saying that we are struggling. There were huge discrepancies between the actual intended plan and its practical delivery of the care. So, we commissioned to do a study of how they can do this. This is how this name emerged.
	Naz: Wow! Interesting! So, is your services designed for any specific ethnic group or generally for all?
Inequality in diagnosis and service uses	**x:** Initially they wanted expertise in areas of mainly other ethnic groups in [the research area], i.e., all that's not white. That was the initial intention. We don't know very much about it. There were people from Bangladeshi, Pakistani, Indian and also [a] few [from the] Arab community as well. We aimed to provide culturally appropriate services. And whatever the issues of experiences, we have to share with other care organisations as well, like send the report to them. Since then we understand all the care services should not be generic, it should be catered-person centred.
	Naz: Can you tell me do people from Bangladeshi community use your service same as another ethnic group?
	x: Yes, yes. They do. They use the services same as others. We came across many barriers such as language barriers. Now we provide bilingual services. We have staff who speak Bangla.
	Naz: wow! you have Bangla speaking staff!
	x: Yes, we do have Bangla speaking staff. So, we do not have language barriers any more. It's easy to provide services for Bangladeshi people now.
	Naz: Thank you. Do you think People with dementia from Bangladeshi background diagnose their dementia on time or accessing to the dementia services easily?
	x. No. I don't think so
	Naz: is there any factor why they diagnose late or not accessing to

	the services easily?
Lack of cultural friendly services Lack of Awareness/ Lack of Knowledge	**x:** Yes. This is why we mean by -'Bridging the Gaps'. One of the biggest issues is ***navigating what they are entitled*** to, or ***understanding the system*** right from the Health Services to Social Care Services. ***They don't understand this specific need***. ***They take generic approaches***, and people feel ***this is more destructive to their lives so they [had] better not have it***. It's supposed to help me in the way I want to be helped, but ***if it's generic and it doesn't meet my needs or even becomes disturbing*** because you [are] coming [up] with ideas that are not suited to the individual, these two added [the] biggest barrier for people wanting to take on services. Sometimes they are aware of this. But people know from other peoples' experiences that these services do not meet their religious and cultural needs. That's why even sometimes they go against it. I am now giving you an example: the person is Muslim who has specific diet needs. He has specific dos and don'ts. For instance, gender/same sex is an issue. If same gender people do not provide the care then they will not take this service. Now if you come and say don't bother with everything. I am providing services, they will not take your services. So, this is partly not understanding the system and partly the system not meeting their cultural and religious needs.
	Naz. Thank you 'x'. What do you know about the knowledge and beliefs of the people with dementia among the Bangladeshi community?
Beliefs/ Supernatural Intervention	**x:** I do feel definitely there is lack of understanding among the south Asian people about dementia, especially among the Bangladeshi and Pakistani and Indian communities. They don't know what dementia is. I think there needs lots of work to be done. There should be more information out there. More help out there. We need to educate the community what dementia is; what are the different types of dementia and how individuals and families can pick up signs early.
Attitudes	**Naz:** x! People of dementia may behave abnormally in their late stage. So, do you think people of the Bangladeshi community may misunderstand and level it to madness, or mental illness, or possession of super natural forces like Jinn, Bhuta etc?
	x: Well, to be honest, that is exactly what people think. They think O God! People may be possessed by some supernatural entities. Therefore, people go to that route instead of coming to proper dementia services. I think lots of people are really scared going out as people may think they are mad.
	Naz: mmm. x! Do you think people may go to the spiritual healers rather than the bio-medical doctors?
	x: Yes, they do. People are concerned, oh my God! What is happening to me. Why am I forgetting things? So, they link it towards that side (i.e., mental illness, supernatural interventions, etc.) instead of going to the doctors. Lots of them are scared to go for help.
	Naz: x! You have mentioned before that some of the care services

	are not cultural friendly. Can you add this a bit more!
Culturally Friendly Services	**x:** Health care professionals and staff needs to improve the cultural understanding and religious understanding, specially the south Asian culture. They need to know people’s religious and cultural needs. Service providers need to understand the specific needs of people. This needs to be improved across the board. but in health and social services, Unfortunately, up to now this has not been treated as more specific. It should be a requirement across all people who deliver these services to have this expertise. They should employ people of those background within the organization so that they have the expertise. Unfortunately, it's not happening this way.
	Naz: why do you think cultural friendly services are so important, otherwise people are not going there? Would you mind to give some examples?
Culturally Friendly/ Gender-Specific Services	**x:** It is very important. It is very important to the people. For example, in our care we had a Hindu gentleman, we [were] looking after his wife. We see, they have a lot of “dos and don’ts”. They don’t cook certain things. They don't mention certain things, etc. Now you are coming and saying that you are going to provide their care. They will not take your services if they do not feel comfortable with your services.
Culturally Friendly/ Prayer Facilities	Let’s think about peoples’ home. Their home is their home. So, we cannot try to impose a general way of approach of supporting and addressing the needs of the individual. Otherwise there will be conflicts. We should respect the cultural norms.
Stigma	All care providers need to provide services in a gender-specific way, but still [this] is not happening in other places. All services should be totally gender-specific. It doesn't matter who are the client; even English clients. Whenever there is personal care involved, male should provide support to male, and female for female. Unfortunately, it is a fact that all (I am saying all not most) of the other providers are not doing this. Even some people who are English, they will ask for this sometimes, and unfortunately the systems still haven't picked up whenever we discuss it. They think it has been raising expectation of people. It cannot be met, but this can be made. We (Bridging the Gap) are providing same gender services since 2003.
	Apart from gender issues, like, prayer facilities and facilities for washing and ritual bathing are also important variables. You need to have people who understand who can assist. An organization needs to restructure themselves to have people who deliver services either by experience or by learning in the organization. But they don't. Unfortunately, that's just part of the barrier to stop people from

Stigma Stigma/ A good example of Self-Stigma Lack of Knowledge/ Misunderstood with Madness Staff Training Requirements	wanting to. **Naz**: Thank you x. Very interesting. Do you want to add more? **x:** In Bangladeshi, Indian, and Pakistani people there is some stigma around them receiving support. They feel that we if we ask, or if we try to ask for support, what people are going to say? There's stigma, definitely around that, but with dementia I think it's just about lack of knowledge. **Naz:** Do you think if any family member has got dementia, and if their son or daughter got marriage proposal do you think their marriage proposal can be affected? **x:** It shouldn't. but Honestly, it is latent; by latent means is not transparent. Families have this fear. What would other people think if they know our elders got this, it is there. We have direct experience of it. In many of these cases, I think, it's rather not what the community actually say; it's what they feel the community may say: that pressure is there. Most definitely people feel, oh, if people know that my father or my mother or my grandfather has dementia, what would be the reaction? But often when it comes to be known [it] is positive. I've been in two cases. I know a lady for years. Nobody actually know that this this lady had dementia, and then she passed away. It became publicly known. When I went to her funeral, I couldn't believe thousands of people turned up. I was amazed about the reception. But the fear from the family, I can tell. I mean, we discussed it. Probably just going to view how. They had this fear that what other people would think! But I think I haven't picked up any negative reaction from society or any bad commenting. However, it is true that people do fear what other people will think. Because of this fear they will hide this and not disclose publicly, but in mental health cases often we can see stigma is there. People often get confused about persons with dementia when they see pretty confusing things. People often might get confused with mental health. For instance, there are certain stages of dementia. Dementia goes [through] too many phases. One of the phases looks very much like mental health. You know, with the person who has dementia really becoming frustrated. They become aggressive and frustrated when they can't remember things. That frustration is misunderstood as mental health. Next phase is hallucination. It is also very much [a] confusion with mental health. **Naz:** Thank you. x! Have you ever been reported by any person with dementia or their family caregivers that they were discriminated against or stigmatized by health professional or by any service providers?

	x: No, not directly. But the misunderstandings often happen as professionals, right from nurses, care managers, and others, they don't have full understanding of the individuals' religious-cultural needs. There should be no excuse for these issues. They need more training. People also need to be aware of available services. If you don't understand something and you don't seek help. To get you to understand, to provide [that] which is appropriate for the person, that will be disagreement. And then it's not surprising to feel that way because I'm different and that's logical. But the intention is not to discriminate against.
Lack of Culturally Friendly Services/ Service inequality Lack of Culturally Friendly Services/ Service inequality	**Naz:** mmm. Great! I will ask you a question about multiculturism. We live in a multicultural society. Multicultural means people of all background should be treated equally. Do you think people with dementia from the Bangladeshi origin have equal opportunities interm of service uses or access towards the dementia services? **x:** No, they don't access equally. Technically the opportunity is the same in paperwork only, and it should be the case in reality. For example, if all services are generic and don't cater for their specific needs, then their services will fail. I'll give you one specific example for this: "Dr. X and his wife had got dementia. They came to our care. Husband (Dr. X) was keen to maintain his Hindu domain and people were coming in effectively against him, and he hated that. He said to me: I'm a consultant and work for [the] NHS [my] whole life. My wife is a consultant too. She was a 'Z'. I'm shocked that we can't navigate the social care system and don't know what to do with it. "That's the problem. Services are too generic. So technically, they are the same for everybody but the same is not equal opportunity. Of course, we need to understand why opportunities are there, but people are not taking this. Because it is not appropriate for them. So, I am giving you another example. You need to know to from examples: "If you have in a care home, where you have 10 people residents. These people have different religious and cultural backgrounds. Now if you say, I [am a] care home and I'm going to do the same for everybody. I'm going to give you all of you a pork or beef sandwich that's the same for everybody. Now Muslim person will say this food is not halal. I will never eat it. Hindu person might say we worship cow as a deity, so we never eat beef. So, though these sandwiches are same, but not equal as a food for all. The only way you could treat them equally is to give each one what is suitable for them to eat. So, the same is not equal. This is how the problem is there, in our social care and all other social integration. More work needs to be done. Definitely a lot needs to be done the same given the law recognizes these simply because something means is the same

Good Practices/Good Examples Improve Services/ Culturally Friendly Services Raise Awareness/ Service Improvement	does not necessarily provide equal. Equal is different from the same and the law recognizes this. Unfortunately, practice still have not picked up on. Naz: One of the big risk factors for dementia or particular mental health is social isolation. People live lonely, therefore social engagement is very important. but we can see big segregation in [this town]. Like, this is Bangladeshi area. This is Pakistani area etc. some of the Primary schools have about 90% children from just one ethnic group. one ethnicity and so We don't know talk to each other. Do you want to add something on social integration? x: Same thing to you see in terms of schooling, and everything goes into health and goes into social care. Unfortunately, it's the same template and the social integration is misunderstood because it's seen as a uniformity. You can't have social integration if you impose uniformity. You can only have social integration where you address individual cultural needs. The same way, then You have a proper integration. I eat you are different from my background, but I understand what is essential to your background. You understand what essential to my background, then you are having integration. But if you isolate each individual then there's no exchange. Naz: you know, in our Community, men usually go to work, and women take care everything at home including caring of elders. Do you think this is another cultural barrier in Bangladeshi community that people may think caring is the duty of family members, therefore people do not want to go to the care home? x: That is elements of that, but it is changing. It is changing rapidly. The current generation now, in fact, is changing out in such speed, we think it is beginning to reverse. I can tell you from ages below 24, more of the girls are in employment than boys. And that's quite surprising. The speed of change is significant. Naz: so that means when these girls will want to take job, no one will go to care. x: It's already happening. The older generations are still around, but as they pass away, this is becoming more and more prominent. we can see it. I mean, you know people approach me all this time that my son needs a job, my daughter needs a job, more than four times. Naz: So, you are trying to say that if we can Raise awareness of dementia actually, we will be very successful. x: Yes we will be successful. If you can raise awareness, if you can address the specific needs of Bangladeshi people, so that when you

	come to help them as a doctor or a social worker or as a care worker, you consider their specific care needs, you will make a big inroad; if you don't, they will resist the service. …yeah, this information should be available right at the beginning, so you know when they start going to the GPs, these/all sort of information should be readily available for them, not when things start breaking down. You know, usually you see when things start breaking down, that's when they start, you know or everybody starts coming. All the professionals start coming in “OK. You could do this. You could have done this”. But this information should be there from, you know, from their GPS or nurses, whoever they may contact.
Culturally Friendly Services/ Tailor to the Needs of the individuals Role of Mosques	Naz: some organization arrange dementia cafes. But people from the Bangladeshi community do not go there. Can you tell me why? x: They are not going to the café as the services provided there are not appropriate for them. That's the only reason. The only reason people will choose not to spend their time. They would be rather isolated at home, if they do not feel comfortable. So, for you to refuse to take something like that, it must be something, quite [a] big step. Or if I put a big barrier and the barrier is those cafés, operating such a way that is only suitable for the majority community, it is not suitable for others coming in. Like if you tailor to their needs, they will welcome it. Naz: So, majority of the time there is language barriers. x: yeah. So, you can do something about that. You can make sure that when people come as guests to your café, maybe there are people who can speak Yes, that people can speak those languages. At least one or two around where they can converse. and everything. you think about your staffing. You think about people who come to help your volunteers, employ staff from that community. Naz: You're providing services in [the research location] for quite a long time. Do you know if there is any cafe for people with Bangladeshi or south Asian only? x: No, no. There is not anything specific. They do everything across the board. Unfortunately, some community centres do take some initiative for people with dementia. But they do not have cultural specific services. They will try and do everything across the board. Naz: there are lots of mosques and temples I mean places of worship there. Not even (every mosque), any big mosque like central mosque or central tample, if they arrange any dementia café maybe people with dementia could go for socilisation?

	x: It would be good if the mosques arrange to eat or the temples do it, but unfortunately their gaining funding is another issue. And education is another issue. And many mosques may say it is just a place of worship. Naz: Many mosques, their name is mosque and Cultural Centre, they registered in the council as cultural centres. They need only 15 to 20 minutes for per prayer and whole day is mosque closed. So, when is there not prayer time, they may allocate one room for community functions and some money come they don't have to pay from their own pocket.
Improve Services/ Tailor to the Needs of Individuals	x: they could do it, money would be raised. Money is an issue. They run the mosque just on donation. Yes, they can do it. They have facilities to do it. They registered as a community Centre to fulfil the requirement of the charity commission.
	Naz: Do you want to say more?
Improve Services/ Tailor to the Needs of Individuals	x: If I run an organization with one single ethnic group of people, and I employ staff only from this race, I have volunteers from one single background, and I do not cater [to] any facility mapping with others' needs, then people from other backgrounds will not go there. It's normal practice. It needs to be appropriate for people to come. If you just advertise to go there and I don't see, you are not fulfilling my needs then I am not going there.
	Naz: Can you tell me about your organisation a bit more? what does your organisation do to raise awareness of dementia for the Bangladeshi community? What area of your work was successful? What do you suggest to improve?
Role of Mosques	x: Well, the best way to do it, we get services directed to us by the local authority, so that is the limitation unfortunately. But in terms of what we do, literally we would, even across-community deliver services appropriate for the individual's needs. If our persons have language issues, for instance, we'll see well, we need a Bangla staff to work with the individual and that's the case. We have some other cases and it works. It works really perfectly well. Sometimes there is not wholly language problem, because some of the Bangladeshis also speak reasonable English, Or some other south Asians languages like Urdu or Hindi they speak. even some younger people from Bangladeshi background also sometime speak in urdu or hindi. It is quite surprised. even we have stuff at least nearly 1/3 of the speak both Urdu and Bangla. so you were able to know what is specific to individual's care need, and you be able to do it for them so that they feel it complements them. don't forget that your home is your Castle. If I come to your home to help you, it should be in such a way that it complements. we organize your home. if it goes contrary to it, I wouldn't want to help. So this is

	what's being successful for us. Thing that does not get successful is: our aim to get the local authority to require all providers to implement similar approach. Then people have tochoice. When you do that, people have the choice. But if you don't do that, the You effectively funneling people into segregate the service. We don't want to be segregated service. I spent 2003 to 2012/13, virtually all my service users apart from just a few all of minority ethnic background. Now I can see more balanced, but that's only in the last few years. There's no reason why that should be the case. This is learning hopes.
Role of Mosques	Naz: So now we are now nearly at the end part of the interview. Can you tell me how best we can raise awareness of dementia and remove the stigma attached to it? x: In Friday sermons you can talk, you can organize specific shows in the mosques, or in the temples. Mosque and temples have a big role in educating the community. What is available out there, the mosque congregations can possibly speak to the local authority and say what is available for people with dementia, and to educate community [on] what's available, where there is a gap, or say you need to sell your services this way so our people can have access to it.
Role of Mosques	Naz: Can you add more? x: We have improved a lot, and look at the role of the mosques / Muslim organisations. I was a part of the British Muslim Herritage Centre (a mosque). The NSH commission services merged with [the] heritage centre, including exercise classes, people coming here and there, blood sugar taken, people coming for the seminars to be educated, coming to the workshop on how to control diabetes. When that starts happening things have to change dramatically. Females had exercise classes where they were recommended to do exercises. They have surgeries where doctors come once a week and even some consultant volunteers to come in when you start doing this for diabetes, styles have to change. If you do the similar for dementia, you have to do the same way what it needs. Even the authority went out there to do this. I remember, Commission several time asked people to call me about mental health, somebody came to us that he will be commissioned to do this and then nothing happened, but they need to do this. People will think “wow, this is appropriate for us.” They will join.
Role of CCG	Naz: What should be the role of our community leader in general and the electronic and print media?

	x: Yes, they have a role to pay. Basically, they need to educate the community to engage with the services held by the social care; to let them know what is specific to your community in terms of what they need to deliver. They would be very welcoming. They will welcome them because then they will say “OK, fine if we tailor our services” the way these people say.
Role of CCG / Memory Services	I want to touch it will be able to access the service. You don't have the exchanges unfortunately and that exchange is necessary for more and more people to be able to take this as it is part of the barrier we have. but then the mosque also has their handicap. There's no funding for this. You can get volunteers in you need when the fund is started going into diabetes and part of this being diverted to for these specific services, things have to be changed.
	Naz: For example, we know smoking is associated with cancer, so instead of waiting for cancer and treating them, if you raise awareness about smoking is better than the statement. Same awareness is needed for dementia as well. Is not it?
Improve Services/ Memory Clinic	x: One of these problems we have and we've had actually to be the NHS, If you look at the profile Of the young people; and the profile of smoking instead of smoking is slightly higher and it's becoming higher amongst these communities Now. we said to the the NHS, don’t wait until 50/60. Your smoking cessation campaign should include them. I used to provide funding similar to it. It's hard to do in in diabetes. For this to be addressed, heavy and similar, you need to do for the insurance similar conditions so lost.
Improve the services/ Tailor to the Needs of Individuals	Naz: Can you tell me what should be the role of local government or local CCG towards dementia? What they should do for this community?
	x: They need to be going out to this community and raising the awareness of dementia and directing them to services where they can go and get some help. So they can say “OK, We've got this centre and they've got these classes running,” and we advise you can use these service or you can use this.Or this help is available for you on this.
Inequality/discrimination	Naz: Do you feel if there is any issue with memory services.
	x: Yeah, similar to the dementia services They need to redesign their services. All these services CCG or local authority do is just stage 1 (just basic). They should do stage one, they should get some people from this community but they need to know these people are still in very junior rules. And they're not being empowered to help influence how the services are designed. These services need to be redesigned, not just a case of now we’ve got a few more Bangladeshi, a few more Pakistani staff

	in our team. Those staff are still junior. …You should be involved in how the services are designed. They need to move to the stage1 of redesigning these services, to fit what the meaning of every community. this is not yet been done. Naz: What about any translated materials? x: Yeah, that needs to be done, but to be honest with you, that is the token element of it. The memory clinic specifically, you go to some surgeries, There is a little bit [of] transcript are there, mostly not. So it needs to be done. Nowadays, people, everything they want, they can see in their mobile phone. They will go online (so there should be online bilingual information available). These services need to be redesigned. Services are not only generic, but it is less inclusive. If you redesign it, then services will become inclusive. People will go there. Naz: do you want to add something in this point? I mean in dementia support need. x: They need to tailor the services according to people's needs. They need to really speak to the public, and ask their view, what they feel; see what is needed. If you don't ask, you do not get. Yeah, you need to ask. You need to say OK, there is a gap here we feel. Just say my mum or my dad had dementia and I would need to find out something that helps them. Those services should be available to the people, where you can approach them and you say "listen! My dad, you know I am really worried what's happening to my dad." There should be services out there for the people with dementia and their families.
Improve Services/ Inequality/ Culturally Friendly Services	Naz: Have you ever been reported any incident like GP's referral (for memory clinic) was late, diagnosis was not timely or any negligence? x : (laughingly), Ha ha ha. Oh my God! Yes it happens all the time. Things need to be improved. they are constantly doing that. All the time. Naz: so you are trying to say that we should not blame only people who are living with dementia that they have lack of understanding; even problem happen from the professionals and service providers as well? x: Even don't forget, even in the majority community dementia is only just beginning to be understood. Even the stigma we're talking about is still applies to the majority community. So here we talking double disadvantage when you talk about the minority communities. Even in the majority community, we see there is and lack of understanding there. still people are learning. Naz: You are saying that sometimes GPs referral to the memory

	services are late. memory serves also not cultural friendly. Hospitals are not dementia friendly or services are not cultural friendly. Care homes are not cultural friendly. So, you cannot blame only the people, Am I right? x: Yeah, absolutely. Its from both sides. I will just give an example, of someone who is a consultant of [the] NHS, operated [his] own surgery, his wife was also a consultant, has just retired from consultancy (NHS), and they cannot navigate the social services system. We ask her. This is a real experience. I am talking about a case of an older Dr. Patel. He said to me, “x! I was a consultant. My wife was consultant too. My wife. She was in the hospital for five weeks ago and we can’t navigate care services to get her appropriate care.” Surprise for this. You see they are health experts, work whole life for NHS, and they have no language barrier. They have worked for the system. They’re both consultants. But they can’t now navigate the system. Naz: So you're saying even professional people are also struggling about navigating the services. x: Yeah, they are both consultants. He was a ‘y’. His wife was a ‘z’. specialty doctor Patel, and his wife, both of them needed care. Both of them are health professional. They had no language barrier. But they are not able to navigate the system. Naz: OK, so once again thank you very much. I appreciate that the information you have provided is very beneficial for this research. Thank you very much. x: You are welcome.

Categorising the codes into themes:

Theme 1:

Dementia Risk Factors and Social Context: Bangladeshi Community

Sub-themes	Participants Comments	ID
Depression	Although people don't (realise), this is one of the hidden (problem) particularly amongst our women. There are huge numbers of women who are living with depression. it's a huge stigma to identify that, because I think people call them ‘*Pagol*’ /crazy people, kind of thing; and there are lots of lots of families experiencing difficulties with such conditions, and	SPASHI 5

	I think it's something that we need as a community to have a debate in a discussion around that you know. the reality on the ground is this; we have to deal with it rather than try and Bury it because of stigma, taboo or feeling ashamed, and this time the other.	
Poverty and Mental Health	There is huge numbers of studies which link poverty with depression and other mental health. Stress is a major factor in Depression; not necessarily dementia. Dementia is a slightly different. So mental health and poverty are often linked together. ***Yeah there are some correlation around. But inequality is a contributing factor as is poverty as is poor housing conditions then and so on.*** now different as you know different people react differently to situations and depression can be brought about with stress and and so on.. as you know stress level can be very different in people so we have a very high threshold for trigger so will have low threshold so it depends on the individuals but we do have all those factors prevalent in our community; and coldhurst being one of the poorest wards in the social deprivation indicator in the country you know. it is a factor.	SPASHI 5
Life style	***I saw the small percentage of people that work in the catering industry but they need to look after themselves;*** and maybe one of the things that the health authorities could do is offer some tailored advice and support to people. GPS can actually have more regular annual cheques for those people proactively; making sure that people do have an annual checkup rather than leaving it for them to contact the surgery for a cheque up.	SPASHI 5

Theme 2: The Health Seeking Attitude, Cultural expectations and inequality: Bangladeshi community

Sub-themes	Participants Comments	ID
Crisis Point	With any mental health, it is not just with dementia, but its schizophrenia, whether it's depression, weather is postnatal, whatever mental illness is available within our communities; there is a lot of it; However, people only go for help as a crisis point	SPASHI 3
Folk Healings	We're not first to access the service which are out there. We will try to do our home remedies in majority of the cases and when we [are] struggling and when we think we need to have it diagnosed or as there is no other option	SPASHI 3

for us.

But our people in our community would not go to the doctors, or not go to NHS services. They were trying to do the home remedies first; and then at the last point would go to the doctor.

Immigration

OK. so within our community dementia is very very taboo subject and people who reach the age of 65/70, even if they do develop dementia that's not diagnosed, or that's not seen as a problem within our communities because within our community people who reached the age of 70. We believe they blast the marbles. So we believe that they start to act like children or they forget things and we believe that's part of them. And that's part and parcel of the old age, which kicked in. So that is the reason why we don't see dimension as an issue. When we do see as the issue is when we see problems and we find it difficult to manage and unfortunately our communities will only go for help when water pours the head. Before that they don't go for help. So that's the situation of dementia in the Bangladeshi community.

SPASHI 3

On of the reason why our community is not very much aware of dementia because our people migrated from Bangladesh and India in this country may be in1950s and 60s. they were very young when they came here. They came here to work in cotton mills and other places. They lived in this country whole life, where as their elderly parents lived in Bangladesh Pakistan and India. As they came in this country in very young age and they did not experience looking after their old parents. Therefore, they are not very much experienced about aging or age related diseases. Second generation can see that their parents are getting Old. But we did not see our parents Old age. Because we used to go to see our parents may be once in five years or sometime once in a year may be. But in our generation we married in Bangladesh/Pakistan/India and our wife came from there. They have seen their old parents very closely and looked after them. That’s why majority female carer we have in our communities. Other reseaon is man usually work outside and women stay at home and care for everyone. So this became our culture.

SPASHI2

Cultural Expectation	Within our Muslim tradition, within our Muslim culture, it is absolutely mandatory and necessary if you've got family members to take care, take care of people. … In my whole community, I know of one individual who has been / who's gone to a care home, and she didn't have any family... Immediate family. I think that's what the reason was. Who got dementia or any form of mental health? ***So that is another reason why you don't get started on [the] Bangladeshi community as much, because people are shielding and guarding them at home. And that's the best place to be for them.***	SPASHI 3
	If any person has dementia whose children are working and it's very hard to manage, then [an] option could be for them to go into care, but as far as I am aware we've got children who have got days off, so alternative days they will manage the parents who have got dementia or loved ones who have got dementia, as a last resort.	SPASHI 3
Inequality	However, ***there is a concern if someone does not go to their GP regularly or does not go to memory services on time then they can be delayed of course. So delay can be from both sides: either for the service provider's negligence or people's attitudes.***	SPASHI 2
	No, they don't access equally. Technically, the opportunity is the same in paperwork only, and it should be the case in reality. For example, if all services are generic and don't cater for their specific needs, then their services will fail. I'll give you one specific example for this: "Dr. Patel and his wife had got dementia. They came to our care. Husband Patel was keen to maintain his Hindu domain and people were coming in effectively against him, and he hated that. He said to me: "x! I'm a consultant and work for the NHS whole life. My wife is a consultant too. She was a gynecologist. I'm shocked that we can't navigate the social care system and don't know what to do with it." That's the problem. Services are too generic. So technically, they are the same for everybody but the same is not equal opportunity. Of course we need to understand	SPASHI 4

	why opportunities are there, but people are not taking this, because it is not appropriate for them.	
	I am now giving you an example: the person is Muslim who have specific diet needs. He has specific dos and don'ts. For instance, gender/same sex is an issue. If same-gender people do not provide the care then they will not take this service. Now if you come and say "don't bother every thing. I am providing services." They will not take your services. So this is partly not understanding the system and partly the system not meeting their cultural and religious needs.	SPASHI 4
	I believe that if I run an organization with one single ethnic group of people, and I employ staff only from this race, I have volunteers from one single background, and I do not cater [for] any facility mapping with others' needs then people from other backgrounds will not go there. It's normal practice. It needs to be appropriate to people [for them] to come. If you just advertise to go there and I don't see, you are not fulfilling my needs, then I am not going there.	

Theme 3: Lack of Awareness

Sub-themes	Participants Comments	ID
Lack of Knowledge	***If you ask most of the people from Bangladeshi community what dementia is, they don't understand. The first thing is they don't understand. They don't know there is some condition called dementia.***	SPASHI 1
	… ***there is a massive massive lack of knowledge about it. They do not know what are the symptomps of dementia, how to help, how to get the help from their dementia.***	
	…***it is always lack of awareness, lack of information; and they don't know when to ask, what to ask, who to ask, so that they don't understand (the system***	

SPASHI 4

I do feel definitely there is lack of understanding among the South Asian people about dementia, especially among the Bangladeshi and Pakistani and Indian communities. T***hey don’t know what dementia is. I think there needs [to be] a lot of work to be done. There should be more information out there. More help out there. We need to educate the community what dementia is; what are the different type of dementia and how individual and families can pick up signs early.***

It may well be that when they do access the service some people may not understand the context. because they've always relating to the way of life. So, making a cup of tea in the 60s in Bangladesh would be very different to making a cup of tea in the UK at that time. Yeah? So, unless somebody actually [helps]. SPASHI 5

Eventually they will realise they have a memory problem. And when they realise, sometimes it will be too late.

SPASHI2

Yeah, this information should be available right at the beginning. so you know when they start going to the GPs, these/all sorts of information should be readily available for them; not when things start breaking down. You know, usually you see when things start breaking down, that's when they start, you know or everybody starts coming. All the professionals start coming in “OK. You could do this. You could have done this.”

Failure to Navigating the system

One of the biggest issues is navigating what they are entitle to, or understanding the system right from the Health Services to Social Care Services. They don't understand this specific need. They take generic approaches, and people feel this is more destructive to their lives so they better not have it. It's supposed to help me in the way I want to be helped, but if it's generic and it doesn't meet my need or even becomes disturbing because you coming with ideas SPASHI 4

	that are not suited to the individual, these two added biggest barrier for people wanting to take on services. Sometimes they are aware of this. But People know from other peoples' experiences that these services do not meet their religious and cultural needs. That's why even some time they go against it.	
Rural Bangladesh	There are a number of factors. One is that people don't necessarily understand dementia. …huge lack of knowledge in terms of what to do, how to go about supporting people. Remember all the training in this country is about [the] British way of life. So when you / when somebody from a Bangladeshi background probably came to this country in the late 60s /early 60s/ mid 60s and 70s. When they do actually have dementia they are living a life in rural Bangladesh rather than here. So when talking about cooking if they're going back to their early 20s and so on cooking is not necessarily on a gas stove or oven fire. Unless you're trained you won't be able to recognise it and that's one of the things when we do the training we tailor it to that the audience. So your early memories will not necessarily be a setting in this country, it'll be a setting somewhere else, and that doesn't always correspond to the training that people have in this country.	SPASHI 5
New Generations	People don't exactly understand dementia, and a lot of people don't want to understand dementia; ***however, there are a lot of people within our communities who have grown up in this culture/this country who understand what's happening.*** More and more people would take their concern towards services. *So that is changing, not at the speed that we wanted to change.*	SPASHI 3

Theme 4: Misconception and Believes

Sub-themes	Participants Comments	ID
Normal Part of Aging	***Some people would think [it] is later on in life and the elderly and when people become aged become childish. So it's part of the life cycle. And people will manage it in all situations with all mental health.***	SPASHI 3
	Most people put it [down] to old age; and older is naturally	

	people lose their memory so it is something that is taken as a given rather than as something that can be medically supported. There are cultural issues, stigma you know. Other old people don't necessarily see dementia as a condition [such] that people can live a reasonable life, with a good life. People see it as an illness and not necessarily something good to have.	SPASHI 5
	I think there are assumptions that it is age related; and part of aging; part of getting older, that is the natural part of aging and you can't do anything about it. I think that the assumption that [it] is part of ageing means people don't necessarily take any further action.	SPASHI 5
Mental Health Problem	People often get confused about persons with dementia when they see pretty confusing things. People often might get confused with mental health. For instance, there are certain stages of dementia. Dementia goes through many phases. One of the phases looks very much like mental health. You know, when the person who has dementia really becomes frustrated. They become aggressive and frustrated when they can't remember things. That frustration is misunderstood as mental health. Next phase is hallucination. There is also very much confusion with mental health.	SPASHI 4
	There are a lot of misconception about dementia. People often think it is just about forgetfulness. Their behavior and cognition is often misunderstood. **This is a neurodegenerative condition, people don't understand most of the time. They think they are all like psychotic.** ***So they're mixed up with whether it's a psychosis, psychotic, or it is a neurodegenerative condition.***	SPASHI 1
Black-Magic & Madness	***Sometimes we have views around black magic or the possession of supernatural forces such as*** **Jinn, Bhuta** ***etc. some people may think dementia is a madness. However this is not the case with everyone, so we can't generalise this. But there are people who think like this.***	SPASHI 2
	Some people think it's a spiritual need. Some people may	

	think that someone has done some form of black magic on them; this is making them feel that way, and they would go to a religious scholar and they would get blessed water or talisman to wear around the neck and they would deal with [it] that way.	SPASHI 3
Supernatural Intervention	Well, to be honest, that is what people exactly think. They think “O God!” People may be possessed by some supernatural entities. Therefore, people go down that route instead of coming to proper dementia services. I think lots of people are really scared going out as people may think they are mad.	SPASHI 4
	The Hindu community also believes in supernatural entities. We come from same sort of background. We believe in the spirituality. We believe in too much on religion. So, there are beliefs that they, rather than understand that this is a a elderly people’s brain is shrinking, and there is a changing of the nervous, changing their cognition, ***we really believe in those spiritual influences. People think it is happening because of any spiritual influence; or because of some actions in their past lives they became mad, so they started treating these people very badly.***	SPASHI 1
	If you ask me that question a few years back then I think that would have been a reasonable assumption, but now it's less and less. particularly with the second generation. Although this issue around *jinn-bhuta* is there, it's not as strong as it was previously, and with medical diagnosis so as you know depression is quite prevalent in the community.	SPASHI 5
Punishment of God	O yeah yeah ***Hindu people believe that anything bad happens because of the Karma and the past sin. There are this sort of belief. There are some groups of people who believe these things. I am not saying that everybody believes this, many people have this perception. Particularly those who follow the religion very much, they believe in that way.***	SPASHI 1

Theme 5: Stigma

Sub-themes	Participants Comments	ID
Public Stigma	I see a lot of stigma with dementia patients. There's a lot of stigma within the community, because when you see someone who has been well all the life, when you see someone who has been providing for his family all his life, when you see someone who's been a community leader for all his life, and all of a sudden, the onset of dementia puts him in a weak position, so obviously then the people in the community, some with bad intentions, some just generally, would start talking, and that stigma is hard for the person who's been diagnosed with dementia to manage.	SPASHI 3
	People feel as embarrassed. So when people are embarrassed, they try to keep everything under the carpet. …could be socially isolated. from the community. … They may stop coming to the mosque, or they may not come frequently to the mosque. The activities would change for that person.	
	I think socially now people are more accepting because they are beginning to acquire more understanding. When somebody repeatedly asks you the same questions 2 three minutes apart or 5 minutes apart, some people get annoyed. some people get frustrated, so we can get angry. You just asked me why, I don't know what it is that they don't know why they're asking the same question time and time again, when I've just given you an answer 2 minutes ago. But the way people respond, the way people behave with the person with dementia, people's immediate feelings are whatever the feeling they get they may not remember, how that feeling came about, but they can experience the feeling. So if it's sad they get upset and angry. They feel that. They may not remember why they're feeling like that. With a good feeling, they have good feelings. They will experience that there and then, but will probably not remember why they've got the good feeling, so it's frustration on both ends rather than just one side. There are some concerns around that, and ***I think more people have quiet awareness around those conditions. I think those concerns are beginning to recede***. But some people do see if somebody has advanced dementia, then they see that as a liability for the family and so on, and that can trigger a whole range of reactions, which you know you won't be able to quantify, but	SPASHI 5
		SPASHI 5

most of that reaction will be quite negative.

There's a whole taboo around putting people into homes. There is huge pressure within the community not to put people into a home, and those that do for whatever reasons, and they know best, are not looked upon very well in the community. Practicalities apart, if the family where both husband and wife were working, nobody at home during the work time, and it is difficult to manage, so only the individuals will know why they made that decision, but it's not something that's encouraged, is not something that's looked [on] favourably in care centres. SPASHI 1

We know that ***there are a lot of safeguarding issues in these dementia patients as they are very vulnerable. Many people (with dementia) may get insulted in many, many ways. Actually, I would say they have got so many ways they get neglected, be it mentally, physically, so on.***

Self-Stigma

I think yes. There are some stigma in the communities for the diagnosis of dementia. It is definitely yes. …it can affect the person socially. A lot of people may think that they may lose their driving license, so they will become housebound, and their social interaction will be completely destroyed. SPASHI 1

Within our communities’ people who have got dementia won't necessarily come to the mosque; because they don't want to be judged or because they don't want to be seen as someone who has got this mental health illness. … As we've been talking about isolation, isolation is very, very damaging for people with dementia. Now it's very hard to get a person who's got dementia within our communities to engage. As I said, if he was going to mosque five times a day before dementia, that would drastically drop because he would think by me going to mosque, by me doing such an action, people would laugh at me, people would judge me, that is a stigma. So that's where the insulation bubbles grow. Now, when the isolation bubble grows, the person himself gets affected and that is the work we're trying to do in the mosque: we’re trying to take them out from this stigma. SPASHI 3

Normalize it more, talk about it.

Just like mental health, there is stigma attached to dementia in our South Asian communities. People will try to keep it secret within the family. They will not share with other people that they are living with dementia. …now see what happens sometimes. Suppose if in my family, if my father had dementia, and my daughter is 25 years old and I am waiting for a good marriage proposal for my daughter then I will worry that the family who are coming to see my daughter will find out that my father has got dementia/acting or behaving differently; therefore they can have a perception that gradually this can go to other members of my family and everyone will be like this. Thus a good marriage proposal can be deteriorated.

SPASHI 2

When it comes to care homes, first it comes from our own culture. We don't want out elders to go to care homes, because we have these community things. 'Oh my god, why isn't he looking after his father?'

SPASHI 2

But I do feel a lot of our own, I mean, in Bangladeshi, Indian and Pakistani people there is some stigma around them receiving support. They feel that we if we ask, or if we try to ask for support, what people are going to say. There's stigma, definitely around that, but with dementia I think it's just about lack of lack of knowledge.

SPASHI 4

In many of these cases, I think, it's rather not what the community actually says; what they feel the community may say, that pressure is there. Most definitely people feel, or if people know that my father or my mother or my grandfather has dementia, what would be the reaction. But often when it comes to be known [it] is positive. … I've been in two cases. I know a lady for years. Nobody actually know that this this lady had dementia, and then she passed away. It became publicly known. When I went to her funeral, I couldn't believe thousands of people turn up. I was amassed about the reception. But the fear from the family I can tell. I mean, we discussed it. Probably just going to view how. They had this fear that what other people would think!

	But I think I haven't picked up any negative reaction from society or any bad commenting. However, it is true that people do fear what other people will think. Because of this fear they will hide this and not disclose publicly, but in mental health cases often we can see stigma is there.	
Stigma with Association	When people grow older, they lose friends. When people grow older and they've got dementia, they're not always in the right frame of mind, so others feel “Is it right for me to go and visit?” And that's where the problem is.	SPASHI 3

Theme 6: Lack of Culturally Friendly Services

Sub-themes	Participants Comments	ID
No Dementia friendly environment	I don't think we are even (living) in the Western World, and there are still have caught (many things need to improve). Where not every hospital is dementia friendly. Not every care home is a dementia friendly. So every service is not even (catering people’s needs).	**SPASHI 1**
Not Understanding the culture	I have reported that the culturally appropriate service needs of South Asian people (or Bangladeshi you say) are not often met. The service providers need to understand the cultural expectations and needs of people the people of dementia first. Now I will mention more about the service needs.	SPASHI 2
	It is very important. It is very important to the people. For example, in our care we had a Hindu gentleman, we looking after his wife. We see, they have a lot of “dos and don’ts”. They don’t cook certain things. They don't mention certain things, etc. Now you are coming and saying that you are going to provide their care. They will not take your services if they do not feel comfortable with your services.	SHASHI 4
	So the care homes need to be religious and cultural friendly. You know like if one older man, Asian, Bangladeshi old man is 75 years old. So he is in a care home, and for his domestic needs, he needs a male person. In terms of feeding or giving medicine, a female is giving. But if it comes to changing clothes of having a bath then obviously it has to be male-to-male. When it	

comes to a female older person, then there is always a female to be there again in terms of hygiene and personal things but when taking medication its okay. So gender specification is very important.

All care providers need to provide services in gender-specific ways, but still [it] is not happening in other places. All services should be totally gender-specific. It doesn't matter who are the clients; even English clients. Whenever there is personal care involves, male should provide support to male, and female for female. Unfortunately, it is a fact that all (I am saying all not most) of the other providers are not doing this. Even some people who are English, they will ask for this sometimes, and unfortunately the system still haven't picked up whenever we discuss it. SHASHI 4

Apart from gender issues, like prayer facilities and facilities for washing and ritual bathing are also important variables. You need to have people who understand who can assist. An organization needs to restructure themselves to have people who deliver services either by experience or by learning in the organization. But they don't. Unfortunately that's just part of the barrier to stop people from wanting to. SPASHI 4

I think there isn't service provided tailored to our needs, so that is the biggest problem. …and that's why I was talking about cultural sensitivity. If the people who are suffering from dementia don't get a culturally sensitive or religiously sensitive service, they won't be interested in it, straight away that will be put off. A lot of people who don't put their parents in cares homes, this is one of the main reasons: because the care homes are not providing a service which will benefit the people who are suffering.

SPASHI 3

“if you have in a care home, where you have 10 people residents. These people have different religious and cultural backgrounds. Now if you say, I [am the] care home and I'm going to do the same for everybody, I'm going to give you all of you a pork or beef sandwich that's the same for everybody. Now a Muslim person will say this food is not halal. I will never eat it. Hindu person might say we worship cow as a deity, so we never eat beef. So, though these sandwiches are same but not equal as a food for all. The only way you could treat them equally is to give each one what is suitable for them to eat. So, the same is not equal. This is how the problem is there in our social care and all other social integration. More work needs to be done. SPASHI 4

If someone who is a consultant of NHS, operated own surgery, his wife was also a consultant, has just retired from consultancy (NHS), and they cannot navigate the social services system. we ask her. This is a real experience. I am talking about a case of an older Dr. Patel. He said to me, "Mohammad! I was a consultant. My wife was consultant too. My wife. She was in the hospital for five weeks ago and we can't navigate care services to get her appropriate care." Surprise for this. You see they are health experts, work whole life for NHS and they have no language barrier. They have worked for the system. They both consult. But they can't now navigate the system.

So, I think a lot of if we can provide (to improve the services). I know our NHS is quite multicultural. If someone from [the] same language and same culture comes and help these people, probably we could improve our services more. Rather than learning and development needs for social care, I think it is important to build up the awareness. Raise more awareness to the community people.

Muslim community could benefit where a carer comes at home and takes the dementia patient out for couple of hours for respite. That's not happening, so the social care in general in this country is lacking for the BAME community. For the Bangladeshi community [it] is extremely difficult to access support services.

Staff Training I had once been called into the [town name] Hospital at the mental health unit, and the doctor was just in the SPASHI 3

Needs	process of sectioning someone, and I said, well why you sectioning them for? he said, I saw him he washed his body, water all over his body, and he started to bang his head on the floor. In reality, this patient was just doing his prayers because the doctor didn't understand that he was doing the prayers. He was going to section him, so it's very important that wherever you work, you represent the community that you live in. You look at the community and you make sure that you understand the needs of the community. That is the best way to serve them. By doing that, individual patients feel respected, valued, and enjoy the fact of going into a service where they know the cultural and religious needs will be met so [it's] absolutely necessary for all staff to be trained on the religious and cultural sensitivities. Every organization should have a trained person who understands the needs of the BAME community and when they understand the needs of the BAME community, they can serve them better.	
	(staff training required): No, not directly. But the misunderstanding often happens as professionals, right from nurses, care managers and others, they don't have full understanding of the individuals' religious-cultural needs. There should be no excuse for these issues. They need more training. People also need to be aware of available services. If you don't understand something and you don't seek help. To get you to understand, to provide which is appropriate for the person that will be disagreement. And then it's not surprising to feel that way because I'm different and that's logical. But the intention is not to discriminate against.	SPASHI 3

Theme 7: Language Barrier

Sub-themes	Participants Comments	ID
Risk of misdiagnose	I think perhaps language barrier is one of the important things. A lot of people of our community, they cannot properly communicate with NHS health professionals. … Recently I have one of our patients who has got (some memory problem), and he is from Bangladeshi background; and his family, both (mm) sons are actually live away from him and he is quite forgetful.	SPASHI 1

He's got no diagnosis of dementia, but he's quite forgetful; and he's being struggling to get even communicate with the doctors. It's very difficult for him. so Luckily it was me who was looking after him, so he could actually communicate with me, because I was from Bangladeshi background and I could actually help. So, it is a massive problem for our community and not getting the right help. And they actually struggle.

For example, their first reference point is GPs. GP needs to ask some questions. On the basis of questions, they will refer to memory services or in other places... So, if the person doesn't speak English then of course it can be a problem.

SPASHI 3

Absolutely. Even not only delayed, there is misdiagnosed. People getting misdiagnosis because of the language barriers. What patients want to say, doctor may not understand, and sometimes doctor is trying to explain, patient may not understand.

Hassle to book interpreters

However, these ***translating or interpreting services are sometimes not accessible all the time. So if you wanted to (mm) book an interpreter, you probably have to wait for two/three months to find an interpreter. And sometimes there is a telephone line. You use telephone line and you get to speak with the interpreter and they are OK. I would say the service are OK. you still can risk of missing the right information when you doing the Interview. I*** would [have] thought if we could see the interpreter face to face all the time, that is much better than using the telephone line. However, think about the practicality. It is not always possible to get the interpreter on time.

SPASHI 1

Reason for not using care home

I don't think the people who are born & brought up here, they would happily send their parents into the care home, where they might not be able to communicate with anybody. If someone works full time and his wife or daughter-in-law also works then it would be a big, big challenge for them to look after and care [for] these elderly parents who are living with dementia. To be honest,

SPASHI 1

in my experience, I've not seen many of our Bangladeshi community willing to send their parents to the care home.

Theme 8: Good Practices

Sub-themes	Participants Comments	ID
Dementia Link Worker	CCG [town name] has funded a 'Dementia link worker' post which I am employed, based in TOGMIND. So, I'm not directly employed by CCG but I am employed by TOGMIND and doing services from TOGMIND for CCG as a Dementia link worker. … I work as a Dementia link worker. My work involves raising awareness of Dementia amongst the people in South Asian communities and people who are from Africa in different languages such as Urdu, Gujrati, Bangla, Kachi, English, Punjabi. So, one role is to raise awareness. My other role is to work with carers, and give all information and develop carer's forums, [a] WhatsApp group at the moment because of the Covid-19 situation. The third role is to deliver short two-hour training courses for dementia service providers, professionals, including memory services. I give them basic ideas about cultural and religious needs of South Asian communities including Bangladeshis in relation to dementia and its diagnosis.	SPASHI 2
Memory Services initiative	***Our memory service is really doing a good job. They have got one clinical phycologist appointed from a South Asian background who is working with translating many things. He is working on developing some sorts of courses for Pakistani, Bangladeshi and Indian communities in regards to supporting the memory problems.*** They have got interpreters. Also, CCG [town name] developed five years strategic plan to prevent dementia. They have got specific services for the people with dementia from the South Asian background. CCG made consultation with all communities of [the town] including Bangladeshi community and I was involved with this. We had to find out what are the challenges these South Asian people with dementia and their carers face, and what kind of cultural friendly services they need. Based on that, local CCG made a five-year strategy that will be published very soon. Bangladeshi people need some information centres in their area where they can go and find information in their language, so CCG is working on that. Memory services working on different short	SPASHI 2

	courses which will help people with dementia and their carers and South Asian origin people are also working on there.	
Dementia support organisations	But I see ***lots of work is going on in our borough***. Many organisations are providing dementia support. For example, Age UK [is] working for all including people with dementia. Another organisation is ‘Making the Space’. There very committed to work for [the] ethnic minority community. I worked with Age UK and Making the Space both.	SPASHI 2
Next Generation	My children will not hesitate to send me in a care home how much I will hesitate to send my parents. They will see things a bit different way. Although they may hesitate a bit, but their hesitation will be less than my hesitation of course, because they are going out with their friends here, going to the universities and colleges and integrating themselves better to the Western culture.	SPASHI 2
Initiatives of Mosques Council & Interfaith Forum	So in our mosque, we've talked about dementia. the Imams have done *khutbah* (Friday sermons) on dementia. and widely, in the [town] Mosque council, we've talked about how most can become Dementia Friendly. Now I know in our town there are 3 / 4 mosques have become dementia friendly and they've got specially trained officers who can look after the needs of dementia people. … some must have taken you on board straight away, so they've done these speeches. They bring these sermons and they put on the notice board that we are a dementia-friendly mosque. So that is achievement for some of the mosques.	SPASHI 3
	…However, in the Interfaith Forum, once every three months we have a discussion meeting. And one of the discussion meeting was support for dementia people, from all faith’s aspect. So, within the Interfaith Forum discussion meeting, we've talked about the issue of dementia and how different communities, different faiths talk about dementia, and support clients or customers, or parishioners with dementia to come into the church, or the	SPASHI 3

	mosque, and how best to support them. So, the raising of awareness is definitely started. We need to be more active in terms of providing a service in the mosque for dementia people.	
Luncheon Club	If you look at the Indian community, the Hindu temple on x Rd, of this town, they have a luncheon club, twice a week where people from all age people with dementia, non-dementia, everyone from elderly people can go there; enjoying 4 hours, twice a week, and that is something that I really like.	
Cultural friendly Care services	We provide support to people in the community across all ages really. Um, across also all abilities including people with learning disability, older people, people with mental health and people who are living with dementia. Um, we have been working into this community since 2003. … We aimed to provide culturally appropriate services. And whatever the issues of experiences we have to share with other care organisations as well, like, send the report to them. Since then we understand all the care services should not be generic, it should be catered-person centred. …Now we provide bilingual services. We have staff who speak Bangla. … So we do not have language barriers any more. It's easy to provide services for Bangladeshi people now.	SPASHI 4
Dementia Friendly Mosque	Most of the queries we get around dementia is, people obviously have issues around memory. So what happens when they can't remember Surahs (chapter or verses of the holy Quran, as what happens when they cannot remember how many *rakaat* (unit of prayer) they've done and so on, so usually like theological Islamic guidance, rulings, Hadith, on how to perform prayers, how to conduct themselves, and then in addition to that we provide training for people, our congregation on dementia. So, raising awareness - how do you deal with people, how do you cope with some of the issues, where these support mechanisms around, so we run a number of sessions around how to live and support people living with dementia.	SPASHI 5
	if anybody came to our mosque they would get dealt with in an appropriate and sensitive manner. Our congregation	

are trained to deal with that. Just to give you an example, in the fasting month of Ramadan, people with mental health issues, people with other issues when the pattern of taking medication changes because of fasting, they react very differently. Some people react more aggressively some people start talking and we have that in our congregation. so initially people started saying you know why you doing this? But because we've actually educated and made people aware and will remind people, part of our risk assessment when we do those lead up to identify those who talked to people in general and also individually so that we can manage the whole thing, so our mosque is slightly different in that we do actually take proactive steps to accommodate people rather than react all the time.

We virtually run training sessions for female people who actually have people living with dementia and their family, so we've run dedicated sessions for women, but on a day to day basis, unfortunately we don't have anything; and there's something that we can plan in future. we may think about. But then that goes back to resources.

Theme 9: Role of Mosques/Temples and Religious Leaders

Sub-themes	Participants Comments	ID
Dementia Café	Mosques can play very important role. That’s why I contacted Mr x and y earlier. They can ***run a Dementia Café in the central mosque, which will be very much culturally friendly***. I can be there once in a month in the beginning. My plan was to go to x area (the Central Mosque) once a week, ***the next week in Werneth European centre, once in a month in Indian Association Hindu Temple***. So all these are planed already, but because of the Covid-19 everything is on hold. In this dementia café some tea and biscuits will be provided. There will be some chairs where people are coming in and sit. May be in first week or in first whole month none of the persons living with dementia or their caregivers will come. But when people will know each other and know about these facilities then they will start coming. When I started my surgeries for Mental Health in European Islamic Centre, first one month nobody came or talked to me, but now I have 35 people there.	SPASHI 2

I want to add about developing services for people with dementia in Bangladeshi community. We need to develop dementia cafés for Bangladeshi people. Mosques are the best place compared to community centre. Now when you come to the mosque, we are attracting only men. Then we need to work with women's organisation and develop something for women as well. In the mosque we cannot run men and women together

SPASHI 2

The thing is because people live in different areas, you can't expect someone living in 'x' area will go to other (farthest) area mosque because of the traveling; and they won't do that because they're already down with the stigma for them to go and meet new people. That's not going to happen, so that's why I said back in when you asked me the question: we need at least three mosques in three different areas to provide these services. Whether they'll be successful, no, I don't know. But that is something that we are talking about and see if we can facilitate something like this.

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Luncheon Club

I think the mosque should look into that and open up [for] them luncheon clubs so family members can bring their loved ones into our atmosphere where they know they would be looked after and cared for and they can have a nice hot meal and socialise, because within our community that aspect is missing, so that is what we are working on and that's what we intend to have in the years coming. … That's why I said that the mosques need to do something similar. We need to do a luncheon club. We need to get these people together. We need to put on activities for them, so at least they know that in within people who they can relate to. … we don't want all the mosques to do it. If we've got two/three mosques in different areas, who would do this, then that would be sufficient/enough for people to come out, and to join.

SPASHI 3

SPASHI 4

It would be good if the mosques arrange to eat or the temples do it, but unfortunately, they gaining funding is another issue. And education is another issue. And many a mosque may say it is just a place of worship.

Raise Awareness	Shakoor: Imams and priests can run some informal sessions and raise awareness of dementia. They can talk about dementia in their Friday/religious sermons as well. Previously they did it for mental health issues when we used to go to them. Imams are OK with this. There is no problem with the Imams whatsoever in any area. They will do the same for dementia, I believe. People listen to whatever they say and they also do whatever	SPASHI 2
	It is very important thing. There is a massive influence of *purohits* (religious leaders). They can talk about the dementia, how we can best help them, if they have got the problem, who there to ask? They can play a big role. But at the same time as a community not only *purohit* should take part. As a community in whole we must make people aware of dementia.	SPASHI 1
	Like you said we can actually use a whole range of mediums; the *khutbah* (sermons) on Friday is one vehicle. Mmm seminars, anything that we publish on social media we can actually raise awareness and around that, but when people come for advice, particularly to Imams, looking for guidance on how to practice Islam, and live with the condition, best when they can actually provide a much more sympathetic and supportive service.	SPASHI 5 SPASHI 5
	As educators, we are playing role. Maybe we can play a greater role; but we would not / I would not decline any opportunity to raise awareness. if I can contribute to something I do, any of our imams will approach, they would do. I think the electronic media locally haven't actually gotten down to the issue where they have because it's not the high interest area or something that they have to sort of push out rather than mmm.	
Training and workshop	Because we need people in there who understand how to manage someone with dementia, and that's the problem that we've got, but we need to train people and we need to do maybe a workshop with people or committee members of the mosque in what to look out for a dementia client and patient	SPASHI 3

in terms of supporting them when they come to the mosque, so they feel comfortable coming to the mosque.

In Friday sermons you can talk, you can organize specific shows in the mosques, or in the temples. Mosque and temples have big role in educating the community. What is available out there, the mosque congregations can possibly to speak to the local authority and say what is available for people with dementia, and to educate [the] community what's available, where there is a gap, or say you need to tell your services this way so our people can have access to it.

SPASHI 4

Look at the role of the mosques / Muslim organisations. I was a part of the British Muslim Heritage Centre (a mosque). The NSH commission services merged with heritage centre, including exercise classes, people coming here and their blood sugar taken, people coming for the seminars to be educated, coming to the workshop on how to control diabetes. When that started happening, things had to change dramatically. Females had exercise classes where they were recommended to do exercises. They have surgeries where doctors come once a week and even some consultant volunteered to come in when you start doing this for diabetes, styles have to change. If you do the similar for dementia, you have to do the same way what it needs. even the authority went out there to do this. I remember, Commission several times ask people to call me about mental health, somebody came to us that he will be commissioned to do this and then nothing happened. But they need to do this. People will think “wow, this is appropriate for us.” They will join.

SPASHI 4

SPASHI 5

To be positive about it, rather than calling people dementia sufferers call it people living with dementia, so language is very important. One, to one counselling, tailored counselling, so if somebody is at early stage would be able to give some advice. If somebody is at late, advanced stage then have different advice. But not to cut people off. Try to provide support their families. Families support is very important. If their families don't understand that, the people become more and more isolated and so on. So, support those. Education, raising awareness, even working with some of the professionals so we can act as sign posting people to other

	agencies where there is more expertise around, but just drop-in sessions for people to come in to be with people, they understand me, with people they can relate to.	
Advise care service	Yes, they have role to pay. Basically, they need to educate the community to engage with the services held by the social care; to let them know what is specific to your community in terms of what they need to deliver. They would be very welcoming. They will welcome them because then they will say “OK, fine if we tailor our services the way these people say”.	SPASHI 4

Theme 10: Role of Community Leaders & Others

Sub-themes	Participants Comments	ID
Role of community Leaders	Community leaders can play big roles. Whenever they organise any community event they can give a small stall for dementia awareness or they can invite somebody who will talk five minutes about dementia. Community leaders or faith leaders or media personas can arrange some talk show about dementia on community TV channels. Person like x can be invited on the show and talk about dementia.	SPASHI 2
	Raise awareness, raise awareness of dementia. Tell people what dementia is; the symptoms and signs of dementia; and how to cope with dementia. Information for the patients themselves, and for the loved one and the family. It is is very important. So, when you raise the awareness people [are] aware about this illness and people can tackle with it better.	SPASHI 3
	All we could play some roles. Our community leaders, print and electronic media, religious leaders, all we need to play our role to raise awareness of dementia. We all have to play roles. Even health professionals like us, we have big role, massive, massive role to play to make people aware about dementia.	SPASHI 1
Role of CCG	But investment in people's health will make whatever life they have comfortable, and the health authorities need to need to take a very careful look at how they actually invest	SPASHI 5

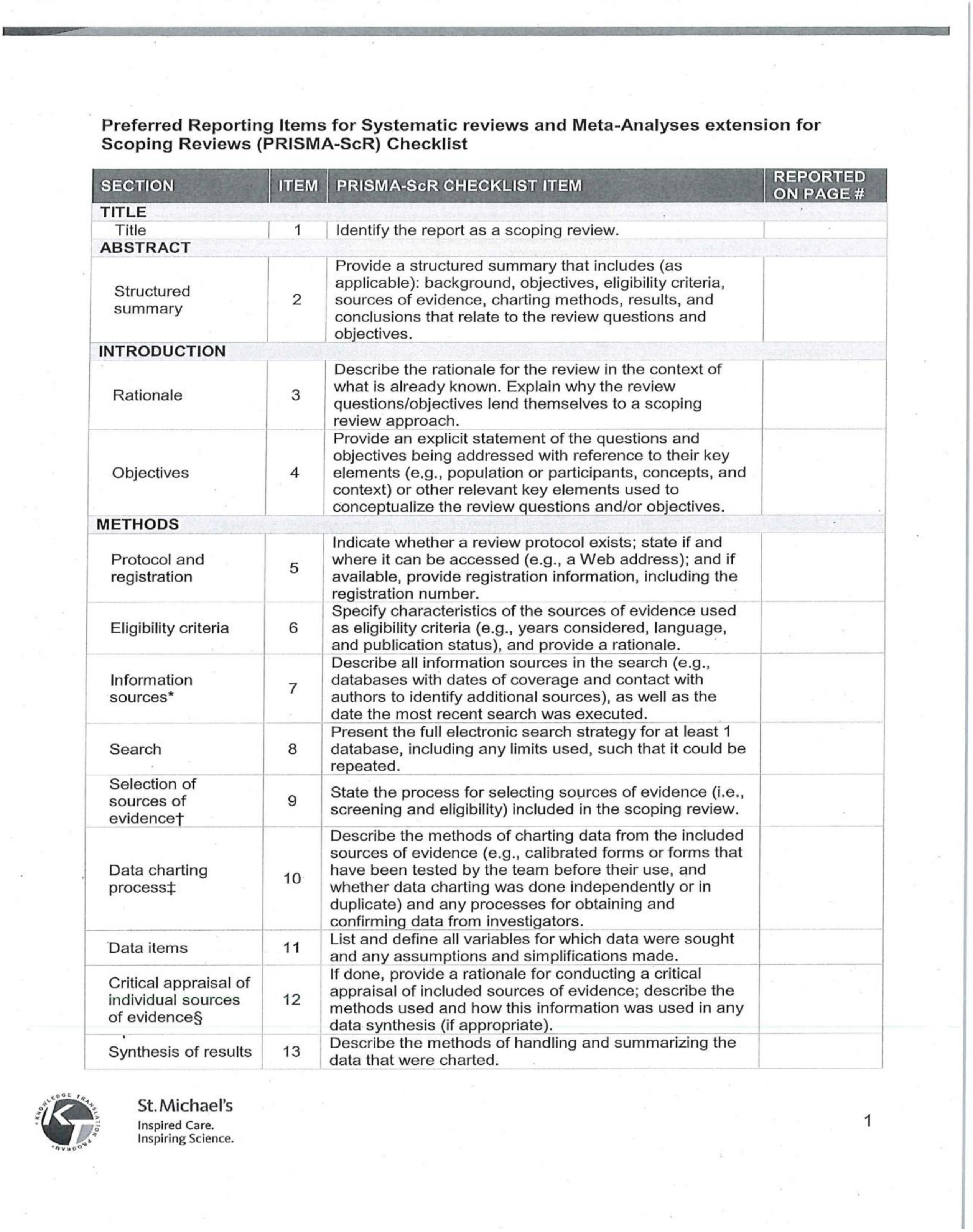
money.

They need to be going out to this community and raising the awareness of dementia and direct them to services where they can go and get some help. So, they can say “OK, we’ve got this centre that they've got these classes running, and we advise you can use these services or you can use this.” Then to direct the people / direct the community. So just say if they go out and they see there's a need and they need to direct him, or this is this help is available for you on this. Help is available for you. …memory services: Yeah, similar to the dementia services. They need to redesign their services. All these services CCG or local authority do is just stage 1 (just basic). They should do stage one, they should get some people from this community, but they need to know these people are still in very junior rules, and they're not being empowered to help influence how the services are designed. These services need to be redesigned, not just a case of now we got a few more Bangladeshi, a few more Pakistani stuff in our team. Those staff are still junior. You should not be involved in how the services are designed. They need to move to the stage1 of redesigning these services, to fit, what the meaning of every community. This is not yet been done. SPASHI 4

We will start working with mosques and community centres, and organise activities, talk to the people there about how they know and understand once a month. We will give out information verbally and give leaflets out. The second would be to go to shops such as small takeaways, and dementia: maybe they have come across people at the beginning of dementia symptoms and they might not understand what it is asking for. So at least they can spot the signs. Then, working with pharmacies. These are the steps I am going to take and all these are in mind for a plan, for my job. … What I am planning for [the] future is that we will work very closely with mosques and temples, community leaders and local media along with memory centre. Also, if any organisation like ‘Making the Space’ offering some activity weekly based or monthly based in any area where Bangladeshi community is living nearby, then I can advise ‘Making the Space’ do this and that to attract more Bangladeshi people, and then I can raise awareness amongst the Bangladeshi community that these things are happening in your local area. SPASHI 1

	We need to develop a WhatsApp group within the community where these audios will go. Suppose at the moment, our organisation ‘x’ has developed one WhatsApp group called [town name] Dementia Forum.	
Role of Memory Services	The memory clinic specifically, you go to some surgeries, there is a little bit transcript are there, mostly not. So, it needs to be done. Nowadays people, everything they want, they can see in their mobile phone. The will go online. So, there should be online bilingual information available. These services need to be redesigned. Services are not only generic, but it is less inclusive. If you redesign it, then services will become inclusive. People will go there.	SPAS HI 4
Role of Doctors	Doctors have massive role. You can start from the GPs’ point of view first. These are the doctors often go to their (patients’) families. They have direct connection with them. They can get the information from their families. Families can give them feedback. I have seen many GPs who have displayed many big posters in their chambers to raise awareness. I think, if they translate these posters in different languages... So, GPs should do many things. There are roles for the community nurses. They have [a] massive role to identify the patients’ problem and needs. So, making the people aware is very, very important. As a geriatric doctor we do many things. We encourage the patients and tell them “if you see something happening on you, or you are worried about your GPs to ask, you can ask us. We can refer you to the memory clinic.” So, doctors have massive role. Not only the diagnosis, they also help the patients as well as their families. For example, lots of people forget to take their medication on time, so pharmacies play big roles, like reminding them how to take medicine. There are services available who just actually call the people and ask has the patient taken the medicine. … So doctors are not only diagnosing people, they are also helping to make the neighbourhood dementia friendly. Yes, doctors can do many things and we are already doing this.	SPASHI 1

Appendix 19: PRISMA ScR Checklist, 2022



Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	

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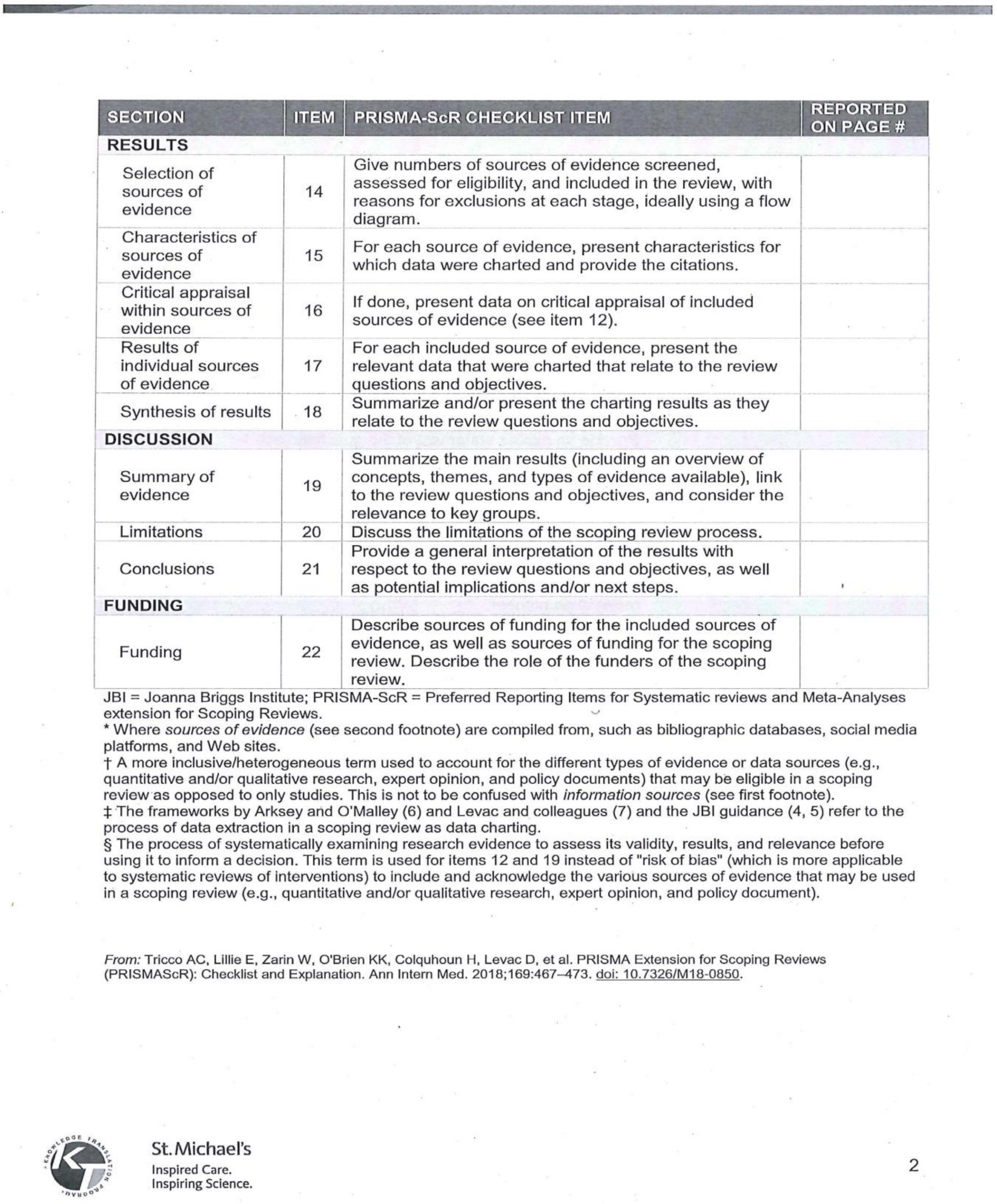

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	
Limitations	20	Discuss the limitations of the scoping review process.	
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.