Understandings of Dementia and Alternative Help-seeking Methods Amongst Christian and Muslim BAME Groups:

Implications for Care Pathways

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To My ‘Anee’ (Farzana)

Lost to covid-19

2021

Abstract

The aim of this thesis is to investigate alternative help-seeking methods for dementia care among Black African and Black Caribbean Christians (BABCC) and South Asian Muslims (SAM) in the UK with a view to develop more effective care pathways. There has been limited research on Black, Asian and Minority Ethnic (BAME) groups and alternative pathways to dementia care. The findings of this thesis allow for a more integrated approach to understanding help-seeking decisions that are made within the BAME community in the UK than has been prevalent, and to give insight to alternative care pathways that can be utilised alongside professional care.

Previous research has found that BAME groups face certain barriers to dementia care, which leads to delayed diagnosis of dementia, underutilisation of services, and people with dementia (PwD) being more likely to be dissatisfied with the services as compared to White counterparts. There are efforts being made to remove these barriers and provide culturally appropriate care. Ethnicity, culture, and religion were found to play an important role in BAME groups' understandings and experiences of dementia.

To understand the current research on dementia care pathways, a critical literature review was carried out, which suggested that there are barriers to professional health care and that individuals utilised alternative help-seeking methods which needed to be further researched. This thesis adopted a mixed method sequential design. Study 1 is quantitative research which examines BAME groups and their White counterparts understanding of dementia. It was found that BAME groups were more likely to believe that religious and spiritual factors were the causes of dementia, and that alternative treatments were beneficial for PwD. Study 2 was qualitative research which explored PwD's understandings and experiences through their caregivers. Four overarching themes were identified: 1) facilitators to care pathways, 2) barriers and obstacles to seeking help, 3) alternative methods to help-seeking and coping and 4) negative perceptions and stigma. Study 3 was also qualitative research which explored the role of religion and religious leaders in help-seeking methods for dementia. Four overarching themes were also identified: 1) dementia beliefs, 2) influence of religion, 3) sources of help and 4) faith and science. These findings are further elaborated to construct a model which illustrates the current help-seeking process (including alternative methods) and its practical application in the UK namely how the knowledge generated can be used to develop better integrated care pathways enabling earlier engagement with services, diagnosis, support and outcomes for PwD and their carers and families.

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Declaration

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

Signed:

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List of Abbreviations

BABC	Black African and Black Caribbean
BABCC	Black African and Black Caribbean Christians
BAME	Black and Minority Ethnic Groups
CR	Critical Realism
ME	Minority Ethnic
PwD	People with Dementia
SA	South Asian
SAM	South Asian Muslims
SIT	Social Identity Theory
SR	Social Representation
SRs	Social Representations
SRT	Social Representation Theory
TA	Thematic Analysis
UK	United Kingdom
US	United States

Scope of the Thesis

"As I often say, I disagree with almost every vision
of what the best self is, according to religions,
but I admire the ambition and the structure
that religions place upon this ambition."
Alaine de Botton

This thesis aims to investigate and shed light on a different perspective on help-seeking methods for dementia. It explores how alternative help-seeking methods are used and can be incorporated as part of the mainstream healthcare pathways used by People with Dementia (PwD) in Black, Asian and Minority Ethnic (BAME) communities. More specifically, this thesis will focus on the communities of South Asian Muslims (SAM) and Black African and Black Caribbean Christians (BABCC) in London. It explores the role of religion and culture in help-seeking. The findings are used to explore how these methods can be incorporated into mainstream pathways to help people from minority ethnic communities.

There are differences between how dementia is understood and experienced between BAME groups and White counterparts (Baghirathan et al., 2020; Bowes & Wilkinson, 2003; Julta, 2015). Research has indicated that there are barriers that BAME groups face when seeking help which may lead to delayed help-seeking, reduced service usage, and higher likelihood of dissatisfaction with services (Bowes & Wilkinson, 2003; Cooper et al., 2010; Mukadam et al., 2013). The current approach to BAME research and dementia focuses on removing barriers and emphasising the need to build culturally appropriate care services. However, this can be considered a 'one size fits all' approach, which may not benefit the whole BAME community as there are numerous differences between groups of people within each community. It is argued that there is a need to approach current research on BAME groups and dementia from a different perspective and further research is needed that explores alternative methods to help-seeking. This thesis focuses on alternative pathways to dementia care that individuals may utilise. Previous research is used to determine help-seeking methods to tackle the issues and gaps in the literature. Subsequently, understandings and attitudes towards dementia from lay perspectives, carers of PwD and religious leaders are also explored. The findings are then used to build on the existing care pathway model to determine possible alternative pathways.

The aim is to shed light on how alternative pathways can be developed which can be used by health professionals and non-health professionals to help PwD from BAME communities. It specifically focuses on religious and cultural influences, which have not yet been explored in terms of alternative help-seeking in the UK. The development of an alternative help-seeking model of dementia care pathways for SAM and BABCC in London is needed. It needs to include alternative perspectives on help-seeking to improving quality of life, encourage earlier diagnosis, and provide alternative service methods for PwD from minority backgrounds. Combining approaches informed by understanding of religion and culture with the typical skills set of healthcare professionals can contribute towards enabling equal access for PwD from minority ethnic backgrounds and provides a unique approach to this research area.

Research Questions

To investigate the aims of this thesis, the following research questions were formed:

1. What are the understandings and experiences of dementia and help-seeking among BAME groups?
2. What are the alternative help-seeking pathways used by people with dementia?
3. How do religion and religious leaders play a role in understandings and experiences of dementia and help-seeking?

4. How can alternative help-seeking methods be used to understand care pathways? What are the practical applications of these alternative methods?

The research questions are addressed throughout this thesis.

Thesis Overview

Chapter 1 introduces dementia and the key factors related to dementia. It explores how dementia impacts people in BAME communities and how dementia care pathways are not the same as the majority group (White counterpart) due to barriers. It illustrates the influence of religion and culture on BAME understandings and help-seeking methods. Research only explores barriers to dementia in BAME communities from a singular perspective of help-seeking and tends to overlook other methods which are utilised. It is argued that dementia research within communities needs to be re-examined to explore the alternative help-seeking methods (which have not yet been researched) that can have practical implications.

Chapter 2 comprises a critical literature review on dementia and minority ethnic groups, with a focus on help-seeking methods. The main aim of this review is to examine the research from a lens that does not explore research in terms of only barriers but also embraces help-seeking methods (including alternative methods) which individuals may use as well.

Chapter 3 explores the foundations of this research. Firstly, it explores the theoretical framework which consists of Social Representation Theory (SRT) and Social Identity Theory (SIT). Adopting SRT in thesis will help understand the representations of dementia within BABCC and SAM groups. It also helps give the space for alternative help-seeking methods to be explored, without disregarding the mainstream healthcare pathway or previous research on dementia on minority ethnic groups. SIT is adopted in this research to explain individuals' understanding and experiences which is embedded in their values. It will help explain the motivations of individuals in their help-seeking process. A phenomenological approach (hermeneutic method) is also used to understand participants' lived experiences of dementia and help-seeking. It allows for participants' narratives to be explored in their own terms. Secondly, a critical realist approach is adopted to address the concepts from both an ontological and epistemological perspective. Thirdly, the method used in this research is explained; a mixed method, sequential design is adopted in this thesis. Study 1 (Chapter 4) is quantitative design and Studies 2 and 3 (Chapter 5 and 6) are qualitative design. Lastly, a personal reflection of the researcher and the research process is carried out.

Chapter 4 (Study 1) explores the understandings and attitudes of dementia amongst 18–40-year-old from BAME groups and White groups. As the current research on dementia and BAME is limited and fragmented, the aim of this study was to provide a foundation for Studies 2 and 3. The research question this study aims to address is, 'What are the understanding and experiences of dementia among BAME groups?'. This was a quantitative study which consisted of nine questionnaires of which were based on two vignettes (depicting someone with mild and someone with severe dementia). Non-parametric analysis was used to analyse the data. It was mainly found that there were some differences between BAME groups and White counterparts, where BAME groups were more likely to believe that religious and spiritual factors were the cause of dementia and that alternative methods are beneficial for treatment of dementia. These findings are further explored in Studies 2 and 3 (Chapter 5 and 6 respectively).

Chapter 5 (Study 2) explores the understandings and experiences of dementia of SAM and BABCC main carers of PwD. It explores their understandings of dementia as well as their care pathway for dementia. It focuses on specific methods and decision making they made that influenced and played a role in the help-seeking methods. SRT and SIT are also used to better understand the aims. This study builds from Study 1. This study's research questions are 'What are the understanding and experiences of dementia among BAME groups?' and 'What are the alternative help-seeking pathways used by people with dementia?’. Twelve semi-structured interviews with 15 carers were conducted. Thematic analysis with a phenomenological approach was adopted to analyse the results. Three main themes were identified: 1) facilitators of dementia, 2) barriers to dementia care and 3) alternative care pathways to dementia.

Chapter 6 (Study 3) explores the understanding and role of SAM and BABCC religious leaders on dementia and their influence on help-seeking processes. SRT and SIT were used to help understand these processes. This study builds on from Studies 1 and 2. A total of 15 semi-structured interviews were carried out where participants answered questions regarding a vignette depicting a person with dementia. The research addresses the question: ‘How do religion and religious leaders play a role in understandings and experiences of dementia and help-seeking?’. Thematic analysis was used to analyse the data. The main themes established were: 1) knowledge of dementia, 2) influence of religion, 3) sources of help and 4) faith and science.

Chapter 7 reviews the rationale of the research and the main findings from the three studies (Chapters 4, 5 and 6). It addresses the research questions ‘How can alternative help-seeking methods be used to understand care pathways?’ and ‘what are the practical applications of these alternative methods?’. It reviews the following findings: 1) knowledge of dementia, 2) experiences of professional care 3) alternative care pathways, 4) faith and science and 5) negative perceptions and stigma. It then illustrates a model which represents the complex help-seeking pathway which incorporates both professional care and alternative care. This model is then revised to illustrate a more effective care pathway when alternative methods are incorporated as part of professional help-seeking methods. These findings are also reflected in the national wellbeing dementia pathway which show how incorporating alternative methods can help target PwD in the BAME groups more effectively. These provide a practical application of alternative methods to mainstream health care.

Chapter 8 summarises and reflects on the findings of this thesis. It then discusses possible implications of the results on existing policies and dementia care practice, followed by a review of the limitations of this thesis. Subsequently, there is a section on future research and finally, a section on the impact of COVID-19 on dementia care services.

1. Introduction to Dementia, BAME and Help-seeking

1.1. Chapter Overview

This chapter begins by defining dementia and dementia-related terms that will be used throughout this thesis. Dementia is then discussed in relation to BAME communities and the barriers that they may face in the UK, alongside the influence of religion and culture on their help-seeking process. A review is carried out on help-seeking methods and the factors that affect minority ethnic groups' decision-making. Finally, the chapter discusses dementia in relation to the Western biomedical help-seeking process and how these will be challenged in reference to the alternative methods.

1.2. Dementia

According to the National Health Service (NHS) (2021), dementia is a degenerative disease defined by a group of symptoms relating to the decline of cognitive function. It can affect an individual's memory, thinking, communication skills, understanding, judgment, mood, movement, and ability to carry out daily activities. Dementia is an umbrella term to describe a range of diseases such as: Alzheimer's disease, vascular dementia, Lewy body dementia and mixed dementia (Alzheimer's society, 2021a). Though the exact cause has not yet been determined, there are some factors that are considered to prevent the onset of dementia, such as being physically active, eating healthily, maintaining a healthy weight, drinking less alcohol, stopping smoking, being socially active, controlling diabetes, and high blood pressure (Alzheimer's society, 2021a; NHS, 2021).

1.2.1. Stages of Dementia

Dementia progression is different for everyone and therefore, how it impacts the individual will vary from person to person. The dementia progression is often viewed in different stages: mild, moderate, and severe dementia (Alzheimer's society, 2021). As dementia progresses, the person with dementia will need more help in their day-to-day life.

Mild dementia is the earliest stage of dementia, and the person's symptoms are often relatively mild and usually last two years. It can include some of the following: memory loss of recent events, changes in personality, difficulties with problem solving, making sound judgments and difficulties in expressing thoughts.

In the moderate stage of dementia, changes in behaviour may become more noticeable, and the individual may need support managing daily life (such as help with getting dressed). These changes are common and individual symptoms may come and go. Common changes that are seen in all types of dementia at this stage can include: agitation and restlessness – for example, fidgeting or walking up and down, screaming or shouting, negative behaviour, disturbed sleep patterns or becoming more agitated.

In the severe stage of dementia, the person with dementia will eventually need full-time care and support with daily living and personal care, such as eating, washing, and dressing. Symptoms include a more severe form of the symptoms expressed in mild and moderate dementia. However, these stages are just a guide and dementia does not follow an exact or certain set of steps that happen in the same way for every person with dementia. Moreover, it is likely that the stages will also overlap. Thus, distinguishing between the stages can be difficult (Alzheimer's society, 2021).

1.2.2. Dementia Prevalence

According to the World Health Organization (WHO) (2022), the number of PwD is increasing worldwide. There are around 55 million PwD, and this number is expected to increase to 78 million in 2030 and 139 million in 2050. In the United Kingdom (UK) alone, there are approximately 900,000 PwD, and this number is expected to increase to over 1 million by 2025 and 1.6 million in 2040 (Alzheimer's society, 2021a). The latest data for dementia diagnosis (Table 1) revealed that 429,052 of people aged

65 years and over were diagnosed with dementia in England (Office for Health Improvement & Disparities, 2022a). The rising numbers indicate the requirement for effective care and therefore, the need to also address any issues faced by PwD.

Table 1

Estimated Dementia Diagnosis Rate (Aged 65 and Over)

Area	Count	Percentage
England	429,052	62%
London region	48,068	67%
Northeast region	22,645	67%
Northwest region	58,485	66%
East Midlands region	39,264	64%
Yorkshire and the Humber region	42,710	63%
West Midlands region	43,826	59%
Southwest region	49,543	57%

Note. From “Public health outcomes framework”, by Office for Health Improvement and Disparities, 2022a. (https://fingertips.phe.org.uk/public-health-outcomesframework#page/3/gid/1000044/pat/15/par/E92000001/ati/6/are/E12000004/iid/92949age/27/sex/4/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1/page-options/car-do-0/fip/3). Copyright 2022 by the Health Improvement and Disparities.

1.2.3. Economic Impact

Dementia care has significant economic impact. The total cost of care for PwD in the UK is estimated to be around £34.7 billion, which is set to rise to £94.1 billion by 2040. The cost of social care for PwD is estimated to be £15.7 billion and is also set to increase to £45.4 billion by 2040 (Alzheimer’s, 2022).

1.2.4. Treatment

The Alzheimer's society (2020) has created a dementia guide which suggests ways for the person to live well with dementia. There is no cure for dementia yet, but it is important to get diagnosed early as it allows people to plan a better future. The treatment available includes pharmacological and non-pharmacological approaches as well as making changes to your lifestyle. Current pharmacological treatments do not cure the illness but can reduce the symptoms or stop them from getting worse. There are non-pharmacological ways to treat or manage the symptoms of dementia as well, which can help PwD live well. These can include cognitive stimulation therapy, cognitive rehabilitation, life story and reminiscence work, music, and creative arts therapy. The main aim is for the person to live well when they develop dementia, which can include ensuring the person stays positive, lives a healthy life, is active and does things that they enjoy, and ultimately, stays independent.

1.3. Black, Asian and Minority Ethnic Groups

Black, Asian and minority Ethnic (BAME), Black and Minority Ethnic (BME) and 'Minority Ethnic') are terms which are often used interchangeably in literature. In this thesis, the author refers to the collective group as Black, Asian and minority ethnic with the acronym 'BAME'. However, when referencing material from a separate author, their respective use of the acronym is used. The terms are used to define multiple ethnic groups which represent a minority within the UK and are widely used by governmental departments, public bodies, and health researchers. One should note that the term 'BAME' does not only refer to people of colour but also incorporates minority White populations (Botsford, 2015). Using the acronym BAME (or another variation) often combines numerous ethnicities into one category. This may be helpful when differentiating against other similarly grouped ethnicities, but it is important to appreciate that there are significant differences between each ethnicity within each group. Some ethnic groups may have common ancestry, shared cultural meanings, symbols and practices, whereas others may be completely different and described as ‘communities within communities’ (All-Party Parliamentary Group of Dementia, 2013; Lane & Hearsum, 2007). Thus, combining all minority groups without ‘qualification’ – i.e., qualifying the generalisation when differences are relevant, is problematic as it can lead to errors within the data. However, Lane and Hearsum (2007) highlight that minority ethnic groups are underrepresented in clinical and health research, and often face similar problems which leads researchers to potentially studying minority groups together. Thus, it is difficult to completely avoid using a grouped acronym (such as BAME). All-Party Parliamentary Group of Dementia (APPG) (2013) stated that the term ‘BAME’ is useful in this context as it focuses attention on groups that share a similar experience and face challenges in getting the support they need. However, it is still important to present the clear differences between each group when necessary. This thesis will refer to BAME groups when referring to minority ethnic groups and would specify individual groups such as Black African and Black Caribbean (BABC) and South Asian (SA) where relevant.

1.3.1. BAME and Dementia

In the UK, minority ethnic groups are at a higher risk of getting dementia as compared to the White majority population (Adelman et al., 2011; Prince et al., 2015). Vascular dementia is the most common among BAME groups due to the higher rate of cardio-risk factors such as cardiovascular disease and type II diabetes (Regan, 2016). It is evident that people from BAME groups may experience and understand dementia in a different way as compared to their White counterparts due to different understandings of dementia and cultural and social concerns (Baghirathan et al., 2020; Mukadam, et al., 2013). BAME groups are also often underrepresented in research due to PwD from these groups delaying seeking help and having low uptake of dementia services (Mukadam et al., 2013). According to

Bowes and Wilkinson (2003), BAME persons are often unaware of available services, unaware of the procedures to apply for these services, and they are more likely to be dissatisfied with the service provided. Despite some efforts to increase inclusion of services, these often do not address issues of dementia in the context of BAME communities, ethnicity, religion, and race, which in some research has been identified as factors which influence dementia care decisions (Mukadam, Cooper & Livingston, 2011; Mukadam et al., 2013). This could suggest low levels of service uptake amongst minority ethnic communities, and thus more work needs to be done to understand these groups.

Research shows growing and ageing populations within BAME groups, which further supports the need to study these communities in detail; the number of PwD from BAME groups in the UK is increasing as people who moved here during the period between the 1950s to the 1970s are reaching their 70s and 80s (AAPG, 2013). Moreover, research data has shown that not only is the BAME community diversifying, but it is also impacted differently by dementia to the White counterpart. For example, within the black ethnic groups, it has been shown that dementia prevalence is higher than the group's White counterpart (Pham et al., 2018), putting further pressure on health services to ensure equal access to dementia care for all groups.

1.3.2. London

According to the Office for National Statistics (ONS) the population of the UK (2021) is estimated to be around 64 million. The most ethnically diverse region in England is London (Table 2), where the population is estimated to be around 3.5 million (ONS, 2021). Differences in pathways to dementia care can be reflected in geographical location of the person. Factors such as admission thresholds and access to care can impact a PwD's help-seeking method. Thus, it seems vital to only focus on one geographical location (Singh et al., 2014). The geographical location of this thesis is London.

Table 2

Different Ethnicity Population in London and UK

Ethnicity	London	England
White British	3,884,800	43,660,800
White Gypsy/ Irish Traveller	1,600	14,800
White Irish	117,300	342,100
Other White	1,305,200	3,399,800
Black African	706,000	1,335,600
Black Caribbean	313,200	601,800
Other Black	64,800	128,700
Indian	623,200	1,647,000
Bangladeshi	340,700	605,000
Chinese	125,400	335,600
Pakistani	269,900	1,327,900
Arab	92,700	250,600
Other Asian	323,000	745,500
Sum of Other	447,600	836,000

Note: From "*Population estimates by ethnic group and religion, England and Wales: 2019*", by Office of National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/populationestimatesbyethnicgroupandreligionenglandandwales/2019. Copyright 2021 by Office of National Service.

1.3.3. Black African and Black Caribbean and South Asians

The terms African Caribbean, Afro-Caribbean, Black African and Black Caribbean (BABC) are sometimes used interchangeably in Western countries. The Black British population is predominantly a descendant of immigrants from West Indies and Africa, who migrated from the 1950s and onwards.

According to the ONS (2021) census, around 2% of the UK population describe themselves as Black African and 1% describe themselves as Black Caribbean.

The term, South Asian is a sub-set of BAME and consists of the nations of Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, Afghanistan, and Sri Lanka (Ahmed & Lemkau, 2000). In the UK, majority of South Asians (SA) comprise of Indians, Pakistani and Bangladeshi. According to the ONS (2021) census, around 1% of the UK population describe themselves Bangladeshi, 3% describe themselves as Indian and 2% as Pakistani.

The focus for this thesis is BABC and SA ethnicities as they represent the largest number of minority ethnic people living in London. Studying the BABC and SA communities together has been combined in previous studies (Adamson & Donovan, 2005; Chinegwundoh et al., 2006., West et al., 2021; Williams et al, 2015), thus this is not a unique approach to researching ethnic groups. This thesis acknowledges that there are within-group and between-group differences in each group and that generalisation at a community-level can lead to discrepancies within research data. It can then become easy for researchers to extrapolate false assumptions on group behaviours. This thesis relies on the shared socio-cultural influences (i.e., challenges in adapting to health services, understanding illness and experience with professional services, barriers to healthcare system and the importance of culture or religion) within the members of each community as the common factor for inclusion. These groups often have common religious beliefs and behaviours which may influence their process of help-seeking for dementia care. This shared decision-making process allows the groups to be treated as homogenous for only this purpose. However, any differences within and between the groups will be specified.

1.3.4. White Counterparts

The term 'White' is often used in research to compare groups to non-White groups. According to Bhopal and Donaldson (1998), the term White includes persons of Scottish, New Zealander, Greek, Spanish, English, Canadian, Welsh, and Irish origin. It has little value in gauging ethnicity or race. It encourages the division of society by skin colour, reinforcing racial stereotyping and hides the heterogeneity of cultures. Using careful description of the population being studied to make clear classification (such as ancestry, geographic origin, birthplace, language, and religion) are essential in understanding cultural values. However, this can be difficult considering the vast variety of cultures, traditions, and values in each group, especially when understanding the majority group. Thus, Bhopal and Donaldson (1998) suggested that when comparing groups from the majority population, the term population is recommended rather than terms such as White or European. It is to say that this will not solve the problem of how population is perceived, but there will be fewer assumptions of the group and does not dismiss the heterogeneity and the origins of the majority population.

In this thesis, the researcher uses the term White and White counterpart inline with previous research. However, the terms 'White' and 'White counterpart' refer to the wider population, unless stated otherwise.

1.4. Race, Culture, Ethnicity and Religion

The UK is often described as being 'multicultural' or 'racially diverse'. The terms 'race', 'culture' and ethnicity' are related to each other and are often used in everyday language interchangeably. These terms refer to individual or group identity, however, they are by no means identical in their meanings, and it is difficult to pin down their definitions due to their lack of consensus (Botsford, 2015). This section will describe these terms, followed by how these terms are relevant to this thesis.

1.4.1. Race

Race derives from a Darwinian notion that biological differences exist between certain groups of human beings, and that these have been passed down genetically through generations, resulting in physical differences which are evident in skin colour, hair, facial and body features. However, the use of race has been a controversial term and has been challenged over the past 50 years. Race as a biological category has been discredited and rejected by most scientists and the internal community since World War II (Muller-Wille, 2014). It over-emphasises nature over nurture, oversimplifies group-level differences associated with both biological and non-biological factors, such as culture, social issues, and migration. However, it continues to function as a social category (Botsford, 2015).

1.4.2. Culture

As societies are becoming multicultural (especially in the West), each cultural group contemporaneously undergoes modifications and mixtures that result in a culture that is different from its origins. Thus, generalisation based upon racial categories should be avoided (Kagawa-Singer et al., 2010). The concept of culture allows the same attribution of unique and fixed characteristics of certain groups that 'race' allowed previously (Ahmad & Bradby, 2007). Culture is the core fundamental organisational system of life which is often shared amongst people. This system comprises beliefs, values, and lifestyles of the people within. Culture also frames attitudes towards concepts of health, illness, life, death, religion, family, and worldly views, and it can inform the decision-making patterns of the group. It can change over time for individuals as well as generationally, especially when interactions occur in multicultural settings (Kagawa-Singer et al., 2010; Botsford, 2015). Culture can be difficult to measure, as it can be an amalgamation of the various cultures that an individual goes through in the host culture.

There are many cultures that have been brought into the UK due to migration and with the focus of this thesis being the BAME community, understanding cultural shifts due to this is vital. Where cultural values are prone to change, aspects of the 'host culture' are adopted to a certain extent or resisted and is done gradually and is almost imperceptible. This process is known as acculturation, whereby ethnic group members will be influenced, consciously or subconsciously, directly, or indirectly by living within a host culture (Berry, 1980; Schwartz et al., 2010; Tadmor et al., 2009). The process of acculturation will be further explored in section 1.5.3.1.

1.4.3. Ethnicity

Ethnicity or ethnic group is a multi-dimensional and dynamic concept, characterised by its relationship to forms of heritage (national, linguistic, cultural), and notions of belonging (Ahmad & Bradby, 2007). Ethnicity can influence each generation differently, and more specifically, it can impact how they deal with their health and social care needs (Cohen, 2009). In the UK census, ethnicity is divided into 5 categories White, Mixed/Multiple ethnic groups, Asian/Asian British, Black/African/Caribbean/Black British, and other ethnic groups. These are further subdivided into categories such as British, Irish, or White Other (for the White ethnicity) (ONS, 2021b). It should be noted that though these categories provide an accurate and systematic way to organise and arrange the data, it can limit understanding of individuals, as the ethnic terms only tell part of the story (Aspinall, 2002; Botsford, 2015). As other factors also significantly contribute to an individual's profile and daily life such as, location, religion, family, and culture. However, according to ONS (2021b), ethnicity should be subjective and self-determined. Whatever terminology is used, it needs to consider factors such as acceptability, alongside usefulness. These are useful terms to help us understand how an individual relates to the world around them, and what their needs may be. It also helps explain behaviour and attitude when it comes to the group level.

1.4.4. Religion and Spirituality

Religion, medicine, and healthcare have been interconnected in one way or another in all population groups. As approaches to health and wellbeing, they have been separated, especially in developed countries. Whereas, in developing countries, there is still little or no separation. Throughout the Middle Ages and up to the French revolution, physicians were often clergy and religious institutions were responsible for licensing physicians to practice medicine (Koeing, 2012). It was later in modern times where religion and medicine began to part. Despite the separation, research examining the relationships between religion, spirituality and the health is becoming increasingly visible in social, behavioural and health sciences (Chatters, 2000; Koeing, 2012).

There is much controversy over the definition of what religion and spirituality is (Koeing, 2012), and the space here does not allow a full discussion of the complex issue. Religion is a multidimensional construct that involves an organised system of beliefs, practices, behaviours, rituals, and ceremonies which are in some way derived from established traditions that developed over time within a community (Chatters, 2000; Cohen et al., 2016; Koeing, 2012; Pargament, 1999). Spirituality refers to individual experiences and is generally linked to private events and transcendence (Hill et al, 2000). It sometimes described in personal or experiential terms, including ‘belief’ or ‘having a relationship with God or a higher power’ (Hill et al., 2000; Koeing, 2012). However, it is also possible for an individual to have levels of religious behaviour due to their culture but not be spiritual (connected to their religion). The opposite is also true. Some may have high spirituality levels but may choose not to carry out the actions such as going to church every Sunday (Pargament, 1999). For the purpose of this research, the term religion will be used to address both spirituality and religion as one and will be specified if used as separate definitions.

1.4.5. Culture, Ethnicity and Religion

Social scientists tend to conceptualize ‘religion’ as a social construct which emerged under historical and political conditions. Timothy Fitzgerald stated that religion is not a discovery but instead a product of the fragmentation of the Christian church. Other cultures lack the concept of two separate entities of culture and religion. For example, there are no terms for religion in Chinese, Japanese, Egyptian or in Native American Languages (Schilbrak, 2012). Therefore, in some countries, the notion of religion and culture being two separate entities is easy to understand and easy to distinguish, whereas in others it may not be. Culture can have an influence on religious practices. This can be seen in Islamabad, Pakistan, where a church carries out two similar yet very different sermons on Sundays. The first is held in English, with male and female attendants sitting together and females dressed in Western clothing. The second sermon is carried out in the local language, Urdu, and males and females are segregated, with females wearing more locally culturally oriented clothing. In the Western world, even though beliefs may be religious, individuals' actions and behaviours, however, can be heavily influenced by culture (Bonney, 2004). It is noted that cultures can 'hollow out' this spiritual content or religious behaviour and fill it with other things such as materialism, nationalism, and functionalism. Due to this, religion can sometime lose its higher purpose (Eckersley, 2007). Thus, it can get confusing as to what is religion-based and what is culture-based. There is an ongoing debate on whether or not there is a relation between culture and religion (Beyer, 2017). Though these may be presented as separate phenomenon, religious themes may manifest into cultural practices as both are intertwined entities.

In this thesis, religion is the focus of study, however, as discussed, cultural elements cannot be completely removed. Beyer (2017) suggested that when studying religion, the study of culture is necessary as one can only understand the nature of religion when one understands its connectedness to ethnicity and culture. The element of ethnic identity includes some sense of shared history, values and a cultural bond which can include religion (Brondolo et al., 2009; Woo et al., 2019). It is important to include all these elements in studies of identity when looking at minority ethnic groups. The interrelatedness and interaction of people from different cultures and background belonging to different religions are the focus here. Thus, throughout the research process, the researcher is mindful of the interplay between religion and cultures (both ethnic and Western culture).

1.5. Help-seeking

Help-seeking is complex and has no agreed definition. At face value, its definition seems self-evident. Within health research, help-seeking originates from medical sociology examining illness behaviour, which includes behaviours that determine how people explore, understand and respond to health symptoms and use health care (Cornally & McCarthy, 2011; Umubyeyi et al., 2016). It is used interchangeably with ‘health-seeking’ and is described as part of both illness and health behaviour (Cornally & McCarthy, 2011). One of the earliest definitions of help-seeking was provided by Mechanic (1961), who saw it as an adaptive form of coping. Later, help-seeking was defined as the behaviour of actively seeking help from other people. It focused on communication with others about assistance in terms of understanding, seeking advice, information, treatment, and general support (Cornally & McCarthy, 2011; Unrau & Grinnell, 2005). As such, it was a form of active and problem focused coping, which relied on external assistance from other people. This is seen as a decision-making process and can include help from informal and formal care systems. Thus, the definition adopted for the thesis is help-seeking behaviours involve a request for assistance from informal supports or formalised services for the purpose of resolving emotion, behavioural, or health problems (Unrau & Grinnell, 2005).

Cornally and McCarthy (2011), found that help-seeking behaviour represents intentional actions to solve problems that challenge personal abilities. It is a complex decision-making process and begins with recognising the problem and assigning a definition. This leads to the decision to act, which in turn, is influenced by socio-cognitive factors. Once a behavioural intention is formed, the person moves to selecting a source of help, makes contact and discloses the problem in exchange for help. Depending on the illness, this process is often mediated by family members who can initiate or delay care. Health services use these care-pathways of health to map out the journey an individual can expect and therefore, can act as a prompt to care. The pathways are described in terms of help-seeking contacts

(Cabassa et al., 2018). Help-seeking for PwD presents a greater challenge due to the nature of the illness. It is important that dementia is diagnosed as soon as possible to help delay the progression of the illness and to reduce the burden on caregivers. However, when and how people seek help is heavily dependent on their understandings and beliefs of dementia, which can vary from culture to culture.

There are various methods which describe the help-seeking process of individuals. Different concepts are used to provide an explanation of factors that could predict 'help-seeking' and 'non-help-seeking' behaviours (Biddle et al., 2007). For example, in the West there is a strong emphasis on the biomedical approach to be used as a dementia care pathway. Researchers use the common dominant positivistic approach to explore the differences in the characteristics of users and non-users of dementia care services, i.e., the pre-set pathways. However, Pescosolido (1992) critiques the biomedical approach as being too rigid, and rather emphasises that importance should be given to dynamic approaches. One such approach is the study of illness from a sociological perspective which identifies help-seeking as part of a broader, socially embedded 'illness career'. The conceptualisation of illness behaviours is then social, and context bound, rather than purely uniform (Ahmed & Lemkau, 2000; Al-Bannay et al., 2014). Thus, it is possible to explore help-seeking from a wider perspective which includes social processes and individuals' care pathways.

Illness behaviour is a process of 'adaptation' of symptoms and help-seeking is one of the various responses to illness alongside self-care (Mechanic, 1968). It is a process that is shaped by agency and a social network rather than a deterministic response. It is not a simple decision about professional help-seeking but a set of behaviours which are composed of strategies for coping with symptoms. These are contingent upon the meanings attributed to the symptoms (Biddle et al., 2007; Pescosolido, 1992). The focus is on how symptoms are interpreted and managed through social interaction and cultural routines. For example, mental illness is a heavily stigmatised topic in various minority ethnic communities. The negative responses to mental illness are problematic as appropriate help-seeking may not be considered. Help-seeking for mental illness may only occur in severe cases and may start with the pursuit of cultural treatment methods in the community (Palvish et al., 2010). Depending on religious or cultural backgrounds, treatment may consist of consulting religious leaders (such as priests or imams) or other healers/non-health professionals (Ahmed & Lemko, 2000; Ellis et al., 2010; Markova & Sandal, 2016).

Furthermore, there are different types of help-seeking methods, which can often be pathways into formal vs non-formal care. Formal (also referred to as professional) help-seeking is assistance from professionals who have a legitimate and recognized professional role in providing relevant advice, support, and/or treatment. These can include specialists, general practitioners (GPs), and primary health care providers, but also non-health professionals, such as teachers and clergy. Informal (also referred to non-professional) help includes those that have a personal relationship with the person asking for help. It can include social networks (such as family and friends) (D'Avanzo et al., 2012).

The researcher has adopted the terms professional health help-seeking and alternative help. Professional (also known as formal) help-seeking entails professionals such as GPs, health and social care workers and reflects the pathway of the biomedical model or the mainstream care pathway. Alternative (also known as non-formal) help-seeking is also adopted in this research, which describes help-seeking methods that do not subscribe to health professionals or the biomedical methods. This can include family, friends, traditional healers and religious leaders.

1.5.1. Help-seeking and Influence

Willingness to seek help and engage in professional health care is influenced by a number of combination factors including family obligations, religious beliefs, cultural values, stigma, and knowledge of illness (Mckenzie, 2006). The following sections explore some of the factors that can impact help-seeking.

1.5.2. Negative Perceptions and Stigma

Individuals can often have negative views and misperceptions of dementia and PwD. These can lead to blaming the person for developing dementia as a result of their lifestyle choices. A parallel of this can be seen with the cases of lung cancer. Bresnahan, Silk and Zhaung (2013) carried out a study on 224 respondents who fit into 1 of 4 categories: heavy smoker, moderate smoker, occasional smoker and non-smoker. They found that lung cancer was stigmatised because of the widely held belief that it can be prevented – even though that is not necessarily the case; even life-long non-smokers can contract lung cancer. Similarly for dementia, Liu et al. (2008) and Milne (2010) also found negative attitudes towards dementia as being related to ageing and mental health illness. When these negative attitudes become severe and widespread among the population, it can cause delays in seeking help, and stigma related to dementia may prevent understanding and compassion towards PwD (Chang & Hsu, 2020).

Goffman (1963, p. 3) defined stigma as "an attribute that makes [the person] different from others in the category of persons available for him to be, and of a less desirable kind... He is thus reduced in our minds from a whole and usual person to a tainted and discounted one." Which can encompass negative beliefs, prejudices and discriminatory structures (Corrigan, Kerr & Knudsen., 2005; Martin, Fleming, Cullum & et al., 2015).

Stigma and discrimination in relation to dementia has a range of implications for people living with dementia and their families worldwide, including barriers to accessing help, negative impacts on quality of life, increasing fear, social rejection, and isolation (Jacobs et al., 2022; Phillipson et al., 2012; Phillipson et al., 2015). Stigma can be categorised into perceived (sometimes referred to as public) and personal (sometimes referred to as self) stigma (Corrigan et al., 2005; Latalova et al., 2014). These are widely adopted in different studies regarding stigma and illnesses including dementia (Livingston, & Boyd 2010; Nguyen & Li, 2020). Perceived stigma is the belief of perception held by others, whereas personal stigma is referred to as stigma held by the individual (Corrigan et al., 2005; Nguyen & Li, 2020). Research on stigma and dementia has been used to research illnesses (Livingston & Boyd, 2010; Milne, 2010; Nguyen & Li, 2020).

Though stigmatization (the social process through which an attribute becomes stigmatized) is an important mechanism impacting dementia's detection and treatment, and therefore in the research of dementia in BAME communities, this thesis will also consider other mechanisms by which negative and inaccurate attributions to dementia that may also be a barrier in understanding and help-seeking of dementia, for example the perceptions that dementia is untreatable or is mostly found in the white community may also lead to delayed treatment but not through the mechanism of stigmatization.

1.5.3. Minority Ethnic groups

A variety of modes of health knowledge and practices co-exist in any society. Attention to this is crucial to improve the quality of healthcare and to challenge patterns of communication between providers and users of health services (Babiker et al., 2014). For minority ethnic groups, culture plays a significant role in shaping individuals' health perceptions, including how members of a given culture conceptualise a disease, recognise its symptoms, and hamper help-seeking behaviour – including diagnosis (Mukadam, Cooper & Livingston, 2011). It is these social actors, who recognise, define, label, and explain illness and on this basis, the health care-pathways are initiated. All such decisions are based on socially transmitted lay beliefs about the structure and function of the body, about the origin and nature of ill-health, about the behaviours deemed appropriate to keep healthy and to avoid illness. Thus, they are based on social representations of health and illness within most BAME communities. When investigating minority groups and their cultures, there are multiple aspects to consider as they may face various obstacles and challenges. For example, within the older population of minority ethnic groups, language barriers, different understandings of healthcare and disease, and conditions due to old age can all influence help-seeking behaviour (Ahaddour et al., 2015; Sadarangani & Jun, 2015) and therefore, they may not abide by prescribed healthcare pathways (Adamson & Donovan, 2005).

Moreover, Abe-Kim et al. (2004) outline how religion may causally influence health through a variety of pathways, including social support, positive health behaviours and effective coping strategies (such as prayer and meditation). Therefore, these need to be explored further to find a way that suits people from minority groups rather than assuming that they will all adhere to the biomedical perspective of help-seeking. Representations of health and illness are grounded in cultural and religious frameworks and are constructed through communication, social integration, and practices of family life. This can be a complex issue, considering that it is in the lay, popular, non-professional sector of society that the vast majority of health-related decisions are made. It is estimated that between 70% to 90% of all health-related decisions are made outside the formal health sector – mainly in the family – but also around social networks and community activities. This is the case in both Western and non-Western societies (Jovchelovitch & Gervais, 1999; Kleinman et al., 1978).

1.5.3.1. Acculturation. Acculturation is an important variable when understanding variations in help-seeking. This process is where one adopts the culture of the host culture (Edege, 2006; Markova et al., 2020; Yoon et al., 2013). It can help explain why and how individuals cope, manage, and seek help. For example, Julta (2015) established that people who were born in the UK or who had lived in the UK for a significant time dealt with dementia, coped, managed, and sought help differently to those who migrated to the UK. This was also evident within the same culture group but between different generations of people. When seeking help, first-generation immigrants are more likely to maintain their traditional caring roles rather than seeking support (Bui, 2003; Bhui & Bhugra, 2010). Whereas the second or third generation from the same culture can have different ways and forms of help-seeking, for example, they are more likely to engage in readily available services as compared to the first generation (Knifton, 2012).

1.6. Dementia and Government Strategy

The Department of Health (2009) produced a strategy which aimed to ensure that significant improvements were made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. Figure 1 illustrates the areas of improvement to enable people to live well with dementia.

Figure 1

A National Dementia Strategy: Key Areas of Improvement

Raising awareness and understanding

- Public information campaign

Early diagnosis and support

- Providing memory services
- Information for people with dementia and their carers
- Supporting people with dementia and their carers

Living well with dementia

- Improved community personal support
- Implementing cares strategy for people with dementia
- Improving care in hospitals
- Housing and improves care home care

Note. The figure was created from the department of health national dementia strategy to represent the key areas addressed. From "Living well with Dementia: A National Dementia Strategy" by Department of Health. (2009). https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf. Copyright 2009 by Department of Health.

Later, in 2016, the 'Prime Minister's challenge of dementia 2020' aimed to implement a plan to make England the best country for dementia care, support, research, and awareness by 2020 (Figure 2) (Department of Health, 2016).

Figure 2

Prime Minister's Challenge on Dementia 2020

Risk reduction

- Including raising awareness on reducing the risk of onset and progression
- Building on and promoting the evidence base for dementia risk reduction and health inequalities.
- Enhancing the dementia component of the NHS Health Check

Health and care delivery

- Improve quality and levels of care (for everyone- including people from different age, race, location)
- People with dementia, carer and family to be at 'front' of mind of those commissioning and providing services

Dementia awareness

- Create more dementia friendly communities and business
- Deliver additional dementia friends

Research

- Provide more opportunities for people to take part in dementia research
- Improve collaboration across sectors
- Encourage inter-disciplinary working and innovation in research

Note. The figure was created from the department of health national dementia strategy to represent the prime ministers challenge on dementia for 2020. From "Prime Ministers Challenge on Dementia" by Department of Health. (2016). https://assets.publishing.service.gov.uk/government/uploads/system/uploads/ attachment_data/file/507981/PM_Dementia-main_acc.pdf. Copyright 2016 by department of health.

The latest dementia plan is the ‘Dementia: Applying All Our Health - NHS England Transformation Framework (The Well Pathway for Dementia)’. The Office for Health Improvement and Disparities (OHID) (2022b) produced a guide that is part of ‘All Our Health’, a resource that helps health and care professionals prevent ill health, promotes wellbeing and can be part of everyday practices (Figure 3). The resource can be used by frontline health and care staff to promote the benefits of focusing on dementia. It will also be referred to in Chapter 7 where improvements are suggested for BAME groups.

Figure 3

NHS England Transformation framework - The Well Pathway for dementia.

Preventing well

- Raising awareness of risks of developing dementia by looking after their health

Diagnosing Well

- Knowing where to direct people for timely diagnosis, health and care services. Support personalised support and help individual remain independent

Supporting Well

- Involving individual and carers in care and treatment plan
- Helping them take part in research and empower to make own decisions
- Consider and support carers needs and knowing where to direct them for support
- Taking on training and e-learning
- Making small adaptations such as adequate signage and lighting to support dementia-friendly environment

Living well

- Promote physical, mental and oral health (both PwD and carers)
- PwD to choose from range of activities tailored to their preference
- Consider language used

Dying well

- Offer different plans that suit individual

Note. The figure was created from the Office for Health Improvement and Disparities (OHID) that shows the current aims that are being addressed in the England. From “Dementia: applying all our health” by Office for Health Improvement and Disparities, 2022b. https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health. Copyright 2022 by Office for Health Improvement and Disparities.

1.7. BAME, Dementia and Government Strategy

The UK government has suggested creating special memory services for minority ethnic groups and making sure services are culturally targeted and appropriate (National Audit office, 2007). Equal access to dementia services for all ethnic groups is important to ensure everyone has access to the same potential health benefits. However, despite effort to be inclusive of the needs of BAME groups, the government's public awareness campaigns to date have had still limited impact on the BAME community (APPGD, 2013), as also reviewed in the 2018/2020 government plans (Department of Health, 2019). Thus, suggesting that more work needs to be done on BAME communities to ensure equal access and limiting barriers to dementia care.

1.7.1. Research on BAME Dementia Care

Everyone should have equal access to healthcare in terms of prevention, assessment, diagnosis, treatment, and care. Studies have shown that there is a lack of equality in relation to dementia diagnosis – especially for minority ethnic groups, as equal opportunities do not necessarily translate to equal outcomes (Gove et al., 2021). There tends to be a poorer health outcome for BAME populations, delayed dementia diagnosis, as well as lower than expected services uptake (Cooper et al., 2010). Blakemore et al. (2018) stated that there needs to be more culturally sensitive services for PwD, as there could be potential barriers hindering people from seeking help and using the services. The literature on dementia in BAME groups found that there are barriers for people from these communities that prevent them from getting diagnosed and equal access to services as opposed to their White counter parts. The Policy Research Institute of Ageing and Ethnicity (PRIAE) (2003) reported that in the UK people from BAME communities face different barriers such as: 1) lower satisfaction of services, 2) language barriers, 3) lack of knowledge of dementia, 4) lack of awareness or 5) services which are culturally inappropriate.

This was supported by Mukadam, Cooper & Livingston (2011), who conducted a systematic review, and found 13 articles on ethnicity and pathways to dementia care, where three were quantitative (Clark et al., 2005; Ortiz & Fitten, 2000; Watari & Gatz, 2004) and ten were qualitative studies (Bowes & Wilkinson, 2003; Braun et al., 1996; Cloutterbuck & Mahoney, 2003; Hinton et al., 2004; Jett, 2006; Jones et al., 2006; La Fontaine et al., 2007; Lawrence et al., 2008; Neary & Mahoney, 2005; Zhan, 2004). They found that there were significant barriers that PwD from BAME groups experience, which often explains why these people delay seeking help. These included negative experiences such as discrimination and feeling that their symptoms were dismissed (by the GP), language barriers, lack of clarity about where or how to access help, and lack of knowledge about dementia and beliefs that nothing could be done to help. These understandings of dementia are important for researchers as this in-turn impacts how people experience dementia. This is supported by Hailstone et al. (2016), who reported that attitudes towards dementia accounted for 77% of the decision-making process to seek-help, suggesting that it is important to understand people's attitudes towards dementia as they may help predict help-seeking processes for PwD.

The literature illustrates that there are certain barriers to care pathways for PwD within BAME communities. Research on health conducted in Western countries have a specific perception and direction of health that are observed in culture and these perspectives influence their scientific inquiry (Al-Bannay et al., 2014). Figure 4 illustrates the 'normal' Western biomedical model pathway to dementia care, which individuals should adhere to, and Figure 5 shows the barriers that people from the BAME community may face to dementia care.

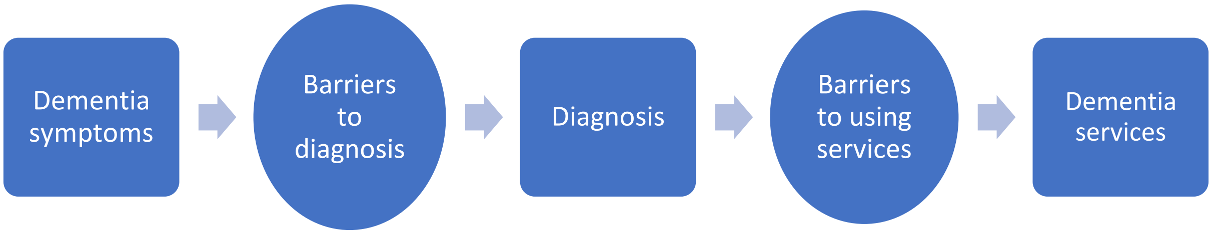
Figure 4

Western Biomedical Care Pathway

Note. The figure illustrates a simplistic route to dementia care and services that is often be utilised by the majority population.

Figure 5

Western Biomedical Care Pathway to Dementia for Minority Ethnic Groups



Note. The figure illustrates a simplistic route for people from minority ethnic groups communities to dementia care with the potential barriers.

They often define several parameters of health by drawing boundaries around factors that are known to influence the attainment of good health and thus help-seeking. These views are based on the biomedicine model or are scientifically rational and usually the first step to help-seeking for any individual (Milne & Chryssanthopoulou, 2005). There is also a presumption that people will possess enough knowledge of dementia to recognise its early signs and symptoms (such as memory loss) and will access their GP or primary care service. The assumptions of the model are deeply ingrained in the ways of thinking in Western medicine, which forgets to view society as a multidimensional system (Ibeneme et al., 2017). This representation, however, forgets that illness is defined in reference to social rather than biological processes.

In the UK, there is a large number of immigrants from diverse cultures and backgrounds. This results in people bringing their backgrounds, lifestyle, and history along with them and passing these values on to their families. The Western health perspective is automatically applied by researchers who may also include personal cultural biases and perspectives into their opinions of people who may not adhere to the same ideologies (Al Bannay et al., 2014; Szczepura, 2005). Thus, researchers are attempting to be more inclusive by carrying out further research into the BAME community to better understand help-seeking approaches (Shanley et al., 2012). Other work such as raising awareness of dementia by recruiting dementia champions (individuals trained to increase awareness of dementia) (NHS, 2022) to increase people’s knowledge and holding Alzheimer society workshops in different languages further remove barriers to diagnosis and dementia services. These mainly focus on the need for education that is inclusive of and directly related to the target population. To tailor the literature and education, simply translating generic versions of patient information may not be adequate. There is a need for a redesign of the literature making it socially and culturally appropriate (Anderson et al., 2003). It is important to recognise that these ideas can be seen as an over oversimplification in terms of dichotomous representations. Ethnic minority groups can either choose the professional care route or not; and when they do choose the Western medicine pathway, they are faced with barriers that prevent proper service use. By removing the barriers, there will be equal opportunities for people to access the professional care system. This view suggests that people from BAME communities must adhere to the biomedical model to seek the ‘right’ way. However, these views have not specified how culturally mediated variables affect the help-seeking process and how complex it is.

This idea of looking at BAME groups and representing them in ways from a Western perspective is very controversial because it forces researchers and health professionals to view BAME groups, in a way that does not correspond with their own personal beliefs or ideas (Al Bannay et al., 2014). This creates problems, as the view is always deemed to be right vs wrong. This can be seen in the "colour-blind" or "one-size-fits-all" models and practices adopted by healthcare professionals in various disciplines (Prajapati & Liebling, 2022). Though not all researchers emphasise this, there is a subtle idea that the way BAME groups adhere to things does not match the Western ways, which is problematic. Therefore, it is suggested that rather than imposing one way on a certain group, it is best to understand the group and how they adapt to the situation. This thesis does not disagree with previous findings, nor does it diminish their value. The focus here is on a different lens through which one can assess help-seeking methods of different people. There is no doubt there will be an element of overlap between previous findings and conclusions drawn within this thesis.

Research in dementia non-help-seeking methods remains couched in terms of 'barriers' to care but broadened to include cultural knowledge and values. Though this enables a dynamic understanding of help-seeking, empirical development of this has been inadequate and the concept of 'barriers' as the main explanation for non-help-seeking has hardly been challenged (Biddle et al., 2007). To understand the whole picture for BAME communities, we need to look beyond these 'barriers' for health service utilisation and look within these communities and understand from their perspective, what help-seeking means for them. Rather than focusing research on the potential reasons why individuals from BAME groups do not utilise services or delay seeking help, we need to explore how they seek help from within their own network. This approach to research is the foundation of this thesis and is a novel way in which to address the BAME community's help-seeking methods for dementia in the UK.

It is important to remember that when studying BAME and White counterparts, it does not mean that all the individuals in that group have the same beliefs and understandings, and therefore, the same help-seeking behaviours. Other factors such as class, race, education, and gender will ultimately have an impact on their understandings of dementia, among other things. For example, someone from the BAME group who is a doctor may also adhere to the biomedical model. Thus, the researcher acknowledges that there are other factors which can play a role that may not have been researched within this thesis.

1.8. Culturally Appropriate Person-centred Care

Dementia is a culturally determined phenomenon that relies upon biomedicine’s ability to name and give form to a collection of changes, behaviours, and experiences (Higgs & Gilleard, 2017). Dementia is not understood in the same way all over the world. Different communities and social groups understand dementia in different ways (Hillman & Latimer, 2017). Zeilig (2015) discussed that currently there is limited pharmacological intervention for dementia and that it is more than just a medical condition. Thus, dementia needs to be discussed from a social and culture perspective rather than treated as a purely medical phenomenon.

A central theme around care for PwD is the importance of preserving their personhood (Kitwood et al., 1992; Santana et al., 2017). This can encompass both the person’s religion and culture. Therefore, in practical terms, this means supporting individuals by ensuring they can continue their pre-symptom activities. Hence, there is an importance on person-centre-care for PwD. The care is not limited to only the person with dementia, but also includes their family and caregivers who are involved (Santana et al., 2017).

The National Institute for Health and Care Excellence (NICE) (2018) offers best-practice advice on care and support for people living with dementia and their families and carers. The principles of person-centred care underpin good practice in dementia care, which focuses on the human value of

PwD, on individuals' personality and life experiences, importance of the person's perspectives, importance of relationships they have, interactions they have with others, and promotion of wellbeing.

As previously discussed, there is a need for culturally appropriate care for minority ethnic groups (Botsford, 2011; Gove et al., 2005; Mackenzie et al., 2005). Cultural and religious competence and patient centeredness are approaches to improving healthcare quality specifically for BAME groups. In this thesis, culturally appropriate care is only referred to as such, when previous research has referenced the same type of care. Otherwise, the researcher's own mention of culturally appropriate care also includes person-centred-care as well when discussing the findings of this thesis.

1.9. Dementia Carers

Dementia carers play a huge role for PwD, specifically family members who are there at the time of diagnosis and those who are the main caregivers. They usually become the main point of contact, make decisions for the person with dementia and may give consent on their behalf. It is estimated that there are around 700,000 unpaid carers of PwD in the UK, which save the UK economy around £13.9 billion a year (Age UK, 2020). In minority ethnic communities, families are more likely to abide to collectivist cultures, where key cultural and traditional values influence decisions especially when dealing with life stressors (Chen et al., 2018; Schwartz, 2007). Younger generations within these cultures may also be expected to take care of their aging parents (Nielsen et al., 2018), highlighting the importance of their role in the help-seeking process. Knifton (2012) reported that ethnic minorities from second and third generations, and those with high levels of education were more likely to seek help and engage more with mental health services than those from the first generation. The generational difference can provide critical insights into how family factors influence individuals' help-seeking strategies (Chen et al., 2018; Nielsen et al., 2018). This is further explored within this thesis to understand these experiences and their help-seeking process after being exposed to Westernised cultures and going through acculturation.

1.10. Chapter Summary

This chapter has carried out a review of dementia, its key elements, and possible coping methods in relation to the BAME community. It establishes key definitions that will be used throughout this thesis. A detailed review of the BAME community has revealed that there are multiple factors (such as religious and cultural values) that influence their decision making when it comes to help-seeking. It also revealed that BAME groups in general are likely to get a delayed diagnosis and are less likely to utilise services for dementia. Research has stated that there are certain barriers to dementia care and one of the ways is to increase services utilisation is to create culturally appropriate care. The chapter also reviewed how the government has aimed to tackle dementia over the last decade. However, it was crucial to note that these strategies do not address how to help BAME groups and reduce barriers.

2. Critical Literature Review: Dementia and Help-seeking in Minority Ethnic Groups

2.1. Chapter Overview

The aim of this chapter is to review existing literature on help-seeking methods that are utilised for dementia within the BAME community. It explores and evaluates help-seeking process for individuals, identifying the potential barriers and help-seeking care pathways. The following sections are explored: stigma, lack of knowledge, inadequacies with professional care and alternative help-seeking.

2.2. Stigma

Research on dementia has found that stigma associated with the disease plays a large role in people's willingness to seek help and that stigma around dementia can lead many individuals from minority ethnic groups to hide or supress their symptoms (Bowes & Wilkinson, 2003 Jones et al., 2006; La Fontaine et al., 2007). Uppal and Bonas (2013) found that Indian Sikhs living in the UK viewed dementia as a psychological illness which therefore led them to having negative perceptions about dementia, often delaying them—if not preventing them—from getting the right help at an early stage when the help can be most effective. Jones et al. (2006) conducted a US study involving 62 Japanese, Korean, and Chinese Asian Americans and identified that there was a fear of being isolated in the community as a result of shame and stigma. The research also concluded that many dementia patients have a fear of being labelled and do not wish to discuss the pain they experience. They also reported that there was a fear of people gossiping and categorising the person as weird and odd. This was also reported by Lawrence et al. (2011), Regan (2014) and Uppal and Bonas (2013). Zhan (2004) conducted a qualitative study with semi-structured individual interviews in the USA with four Chinese carers of PwD. The dementia condition was ascribed to issues such as retribution for an ill deed, fate or "bad feng shui". Furthermore, dementia was also believed to be caused by karma (British Sikhs) (Uppal et al., 2014), a result of divine intervention, an act of God, or a result of a curse (African Americans) (Jett, 2006), and witchcraft (Tanzanians) (Mushi et al., 2014). This demonstrates that dementia understandings, perceptions and access to care services are influenced by cultural and religious factors impacting how people enter care pathways. This shows that there were negative views within minority ethnic groups and various religious groups; most thought that it was the person's fault and is something that can be controlled.

2.3. Lack of Knowledge

The awareness and knowledge of dementia among BAME groups is much lower than the majority White populations (La Fontaine et al*.,* 2007; Lawrence et al., 2011; Turner et al., 2005). This is also supported by Purandare et al. (2007), who conducted a questionnaire to understand people's knowledge of dementia. They found that both Indian and White British older adults in Manchester had poor knowledge of dementia, but awareness was worse among older Indian people especially of how dementia impacted the person (i.e., with symptoms like personality changes, reasoning, and speech). This could suggest that one of the reasons for non-representation in the local dementia treatment clinic is a lack of understanding of dementia as an illness. This is also supported by Nielsen et al. (2021) who conducted semi-structured and group interviews in Denmark with minority ethnic family carers, primary care dementia coordinators, staff in elderly day cares, and multicultural link workers. They explored the barriers in accessing dementia care and found that families' lack of awareness and knowledge about the disease inhibited their access to dementia care. Dementia symptoms were often seen as a normal part of ageing and therefore were not recognised as an illness. Also, their cultural practices and values (such as the family naturally adjusting to changing circumstances) often led to milder cognitive and functional impairments to go unnoticed or be regarded as unproblematic. Barriers to dementia care are also increased by unawareness of existing dementia care services, for example, how to reach them and what exactly their usefulness is (Nielsen et al., 2021). This can often result in different care pathways as compared to the mainstream care pathway.

2.4. Inadequacies with Professional Care

2.4.1. Doctors and GP Experiences

Research exploring experiences with health care professionals discussed how individuals' perceptions of seeking help from healthcare services was heavily based on their previous experiences (Baghirathan et al., 2020; Berwald et al., 2016; La Fontaine et al., 2007). Though individuals understood the importance of seeking professional help, they were often left dissatisfied with services. Studies in the UK (Berwald et al., 2016) and USA (Alexander et al., 2022) found that this was due to a lack of time the doctors had available for them, which led individuals to not be able to fully open up to their professional healthcare service. This also resulted in people seeking alternative solutions, where they would feel they can easily open up and speak about their issues, without wasting their time. From past experiences, they knew that they preferred discussing their problems with someone who had more time to listen to them (Berwald et al., 2016). Memon et al. (2016) found similar results; negative experiences such as poor communication, cultural naivety, and insensitivity were found as barriers to accessing health services for mental health. This can cause people to avoid contacting health services all together.

Moreover, Palvish et al. (2010) found that in the USA, Somali immigrant women who were seeking care expected to develop a relationship with their healthcare providers. This reflects the findings in this research, where people expected to be able to open up to their GPs (in the UK), who in response, would have time to discuss patient's issues. Wellings et al. (2022) reported on public satisfaction with the NHS and social care; they revealed that dissatisfaction with the services had risen from 25% in 2020 to 41% in 2021, suggesting that there needs to be an improvement in the overall NHS service quality that targets the wider population and not just specific groups. This could also explain why individuals were seeking alternative healthcare solutions (such as turning to family members, friends, and religion). This is further explored in Studies 2 (Chapter 5) and 3 (Chapter 6).

2.4.2. Culturally appropriate services

Research indicated that there are challenges with navigating around the professional help-seeking processes that align with individuals' culture and religion (Baghirathan et al., 2020; Bowes & Wilkinson 2003; Hossain & Khan, 2020; Julta, 2015), especially the idea that the services available do not cater for minority ethnic group's needs which causes reluctancy towards using services. For example, Hossain and Khan (2020) reported that finding a carer for PwD in Bangladeshi communities was difficult due to cultural and religious gaps; they needed a carer that could work and understand the Bangladeshi community. The findings imply that there is a need for culturally appropriate care for PwD for both home service and day cares, as they concluded that the services provided to them did not cater for the needs of their religion and culture (Baghirathan et al., 2020; Bowes & Wilkinson 2003; Julta, 2015; Nielsen et al., 2020).

Furthermore, language barriers were found to be another source where culturally appropriate services were not available. For example, in the UK, the NHS is governed by certain principles and practices, which it has deemed as acceptable. It operates within the cultural framework of a typical Western society, where whilst accommodating for other languages, primarily functions in an English language setting (Regan et al., 2013). When seeking dementia care, language is a major reason why people may not utilise services. Unable to communicate their issues prevents people from minority ethnic groups from seeking help. Communication is an identified barrier to disclosing or explaining the diagnosis of dementia (Bradford et al., 2009). Those who did try services, most stated that the services did not fit their cultural needs. Many people would prefer services to be carried out in their native language rather than English (Nielsen et al., 2020). This adds to services not deemed to be culturally appropriate by BAME communities.

However, health care professionals who work with minority ethnic groups also discussed the implications of providing culturally appropriate services that cater to different cultures and religions (Bowes & Wilkinson, 2003; La Fontaine et al., 2007). They discuss that providing day care centres that engage people from difference cultural and ethnic groups and offer services from an informed position would not be sustainable (La Fontaine et al., 2007) as with the high demand of services, providing diversified options for all cultures is not as simple (Bowes & Wilkinson, 2003). Each culture has further internal differences between groups of people and cannot all be catered for with one culture-specific service. The resultant need would be for services designed for each individual subset within a culture – something that would be very difficult to achieve.

Overall, there are barriers and obstacles that individuals face when seeking professional help. It suggests that individuals who do consider professional health care, however, are often faced with barriers that lead them to be dissatisfied or inhibit seeking further help. These findings indicate there is a need for improvement within the services that are offered through professional help-seeking methods.

2.5. Alternative Help-seeking Methods

2.5.1. Family

Research has described the importance of family caregivers for PwD (Berwald et al., 2016; Hossain & Khan, 2020; Mukadam et al., 2015; Mukadam, Cooper, Basit et al., 2011) and stated that they play an important role in the chosen help-seeking method utilised. Various factors motivated family members to become the primary caregiver. For example, individuals believed that family care givers should be the first choice for PwD and that the care should be provided in the family home (Hossain &

Khan, 2020). Mukadam et al. (2015) also found that in some cases, there was an expectation in the communities that families would provide care for the elderly, which was also linked to respect for elders. This resulted in family members becoming the first point of contact and taking care of the elders in the family. This was seen as a 'normal and expected thing to do' (Berwald et al., 2016). They see this experience as an extension of other responsibilities as a partner or child, rather than someone else's responsibility (Botsford et al., 2011), they accommodate any changes associated with dementia and see it as an obligation and identity (Parveen et al., 2011). This can negatively impact the help-seeking method as family members can also become barriers to service use. This is because PwD turn towards family first as opposed to going directly to professional healthcare services, thereby, delaying the help they can receive.

However, individuals also discussed how the view that families would provide the primary care may not be preferred within the majority Western culture and they discussed that they do not see the family caregiving role as something burdensome or negative. Bowes and Wilkinson (2003) and La Fontaine et al. (2007) reported that Individuals compared western cultures with their own culture, and they often referred to differences between the two groups, implying an 'us versus them' mentality.

People from BAME groups recognise their own social networks as a source of support, enabling discussion of problems and access to services. Research has shown that members of the BAME community often find it more appropriate to talk within their social network, i.e., people that they identified with, rather than to a professional (Memon et al., 2016) and one study with the urban Pakistani community (UK) found that formal mental health service is used as a last resort (Tabassum et al., 2000). The possibility of the social network acting as a barrier or alternative avenue to professional mental health services suggests individuals from a BAME background are less likely to contact their GP about mental health issues. In part this may be due to a lack of trust in mental health services which would encourage people to use their friends and family first (Cooper et al., 2013; Memon et al., 2016).

Furthermore, when it comes to seeking help from outside of family, individuals preferred family care in the home and implied that residential homes are something negative for people (Bowes & Wilkinson, 2003). Research has found that individuals usually compared professional health care services (such as residential care, nursing homes and day care centres) to family help (Berwald et al., 2016; La Fontaine et al., 2007). This resulted in people heavily relying on family care and support and not feeling the need to seek for help from elsewhere. However, this did not mean that people would avoid help from services that came into their home which allowed them to fulfil their familial duties as well as attain professional help (Bowes & Wilkinson, 2003).

The notion of caring for family members seemed to be influenced by religious values as well. For example, Nielsen et al. (2021), found that Muslim participants generally represented traditionally collectivist Islamic cultures which are characterised by strong values and norms for piety and pride in taking care of one's own. They stated that this can contribute to barriers to seeking help at early stages as well as delays seeking help from professionals until they can no longer cope. These values shaped the meaning of caregiving and people referred to it as being a *'good Hindu or Christian'* (Berwald et al., 2016*).* Thus, showing the importance of religion when making help-seeking decisions. Overall, the importance of the family care giving role in minority ethnic groups stems from various factors that influence and motivate individuals to take on the care giving role for PwD.

2.5.2. Religion

Religion is seen as an important factor that impacts how people seek help. However, it can be often described as a barrier as well as religious institutions can sometimes discourage people from going to and seeking professional help. Holt et al. (2014) argue that religion can increase anxiety and produce negative thinking and irrational thoughts. Sigmund Freud characterised religious beliefs as pathological, seeing religion as a malignant social force that encourages irrational thoughts and ritualistic behaviours

(Koenig et al., 1993). For example, when faced with a negative life event, individuals may think that they are being punished by God, or that they may have committed a sin. Thoughts such as these can increase anxiety in people, and they focus more on why they are faced with certain problems rather than how these problems can be fixed. These thoughts do not only affect one's thinking about the self but can also lead to people thinking negatively about other people's problems, resulting in stigma against certain diseases. Individuals are rather advised to pray for the illness. This may be because they believe that prayer can cure/heal the person over professional help. For example, Berwald et al. (2016) found that the church system was encouraging individuals to seek help through prayer rather than seeking help through the professional route.

Despite studies stating the negative impact of religion, there are also positive impacts of religion on PwD. Religion is often seen as a form of coping with dementia and where people use God as a reason to accept the disease (Agli et al., 2015). This was also supported by Regan et al. (2013), who conducted a systematic review on the influence of religion on dementia care pathways. They only found two US studies which matched their criteria for the final screening stage. The studies stated that religion hindered access to the traditional health care pathways and also assisted in positive coping and a source of comfort for people with dementia. For example, Regan (2014) described the person with dementia using religion as a source of comfort in coping with the dementia diagnosis and sought this as one alternative care service. Individuals have used religion to accept the illness and the changes that they may be going through. Moreover, the negative experience with doctors and professional help have also led some to seek help from religion and religious sources. Thus, suggesting that religion may have an influence on dementia care pathways. However, there is a lack of research in this area and further studies are required to assess what pathways are taken for PwD. Further research needs to provide a deeper understanding of how religious methods are involved in understanding dementia and help-seeking pathways.

2.6. Gaps in Existing Literature – Conclusion.

The aim of this review was to understand the perspectives on dementia within BAME communities, specifically looking at the care pathways/help-seeking methods for dementia. In this review it was found that help-seeking is not a simple process and there is more to just referring to variables as barriers (Cornally & McCarthy, 2011).

The research suggests that though professional help was considered, there was reluctancy due to previous negative experiences with the doctors. However, as discussed it is also evident that this may not be the only care pathway for people from BAME groups. It was clear that religion was an element in help-seeking for dementia. However, how exactly religion plays a role is unclear. Previous findings suggest that religion acted as both a barrier as well as a form of coping with dementia (Regan, 2013). Though consistent with previous findings, there was a preference for using alternatives such as relying on family and friends, and religious methods. This was supported by the help-seeking preferences of Somali refugees living in Western countries who found a reliance on family, friends, and religious community, and preferred religious sources of help (Ellis et al., 2010; Markova & Sandal, 2016).

Though there is some research on BAME communities and alternative help-seeking, there is a lack of evidence on how people from BAME communities use alternative help-seeking methods for dementia symptoms. It is clear that family plays an important role in help-seeking; however, the research does not determine what exact methods people use to cope with their symptoms. Religion is also deemed to have a positive impact on coping for BAME people. Therefore, these need to be explored in more detail to determine the help-seeking methods that incorporate alternative methods.

It is understood that there are barriers (such as lack of knowledge, stigma, and language inadequacies) even in the professional healthcare route. However, this does not provide all the answers; removing these barriers will not result in people stopping the use of alternative routes. Rather, there is a need to understand the perspective of the BAME community to appreciate why they often prefer the alternative methods of help seeking. This can then inform better decision making within professional healthcare systems to collaborate with alternative sources of help. This will be further explored in the studies as part of this thesis.

There were no geographical restrictions in this critical literature review. However, it is important to be mindful of the differences between the healthcare systems in different countries which can impact how PwD seek help (such as costs associated with healthcare services in the USA). Despite there being various literature on dementia and minority ethnic groups, there is a lack of research on dementia in BAME groups in the UK. Only 11 studies were found while conducting this literature review on help-seeking methods and BAME groups. There also needs to be further research conducted on the exact role of religion in help-seeking methods.

2.7. Chapter Summary

This chapter explored previous research on dementia in minority ethnic communities. A critical literature review was conducted which examined articles on dementia in BAME communities that explored current patterns of help-seeking pathways. Overall, current research has established that 1) Pathways to dementia care are complex and certain barriers may not be always considered a barrier, 2) Religion and culture play a part in dementia understandings and 3) Further research is needed to understand the role of religion and culture. The following themes were discussed: stigma, lack of knowledge, professional inadequacies and alternative help-seeking methods.

3. Theoretical Framework, Philosophical Stance, and Methodology

3.1. Chapter Overview

Chapter 3 will first begin by outlining the theoretical frameworks adopted in this thesis. These include social representation theory (SRT) and social identity theory (SIT). Both theories will be discussed in relation to health and more specifically, BAME groups and dementia where possible. The chapter will examine the two theories separately, followed by how these theories will be used together.

The second section will explore the philosophical stance adopted in this research - critical realism (CR). Then it will discuss the phenomenological approach in relation to help-seeking and dementia. The section will explain how these two stances will be used to explain and understand BAME groups when seeking help for dementia. It will allow the researcher to identify how a new approach to researching BAME groups is needed to gain a better understanding of their help-seeking methods and to provide possible solutions for better and/or different services which may include non-conventional methods.

The third section of this chapter will then go into explaining the methods utilised for this thesis. This thesis adopts a mixed method research approach using sequential explanatory design. It will explain why this method is the most suitable design for approaching and answering the research questions. Each study is described in detail. The chapter will also examine the research process, analytical methods and explain why these specific methods were used. Furthermore, it will introduce the emic and etic approach used in the research.

The last section will reflect on the role of the researcher in the research process. It will explore the researcher's reflections on collecting and analysing the data as well as the reasons/process behind the research. The section will also explore how the researcher's position and experiences may have impacted or influenced the outcome of this thesis.

3.2. Social Representation Theory: Initial Overview

Social representation theory (SRT) is originally based on Durkheim's concept of 'collective representation', which is a general category that refers to common ways of forming, thinking, and evaluating social reality (Descombes, 2000; Hoijer, 2011; Howarth, 2006; Voelklein & Howarth, 2005). According to Moscovici, collective representations is too static to explain representations of dynamic societies (Howarth, 2006). He stated that "*It seems to be an aberration, in any case, to consider representations as homogeneous and shared as such by a whole society"* (Moscovici 1988, p. 219). In other words, the knowledge gained, developed, and circulated in society is characterised by diversity and reflexivity, and needs to be captured in full to reflect on the mobile and heterogenous nature of the modern society which cannot be captured by a static or generally shared notion of collective representations.

There are several definitions of SRT. One of the most common definitions is by Moscovici (1988):

> *Social representations […] concern the contents of everyday thinking and the stock of ideas that give coherence to our religious beliefs, political ideas, and the connections we create as spontaneously as we breathe. They make it possible for us to classify persons and objects, to compare and explain behaviours and to objectify them as part of our social setting. While representations are often to be located in the minds of men and women, they can just as often be found "in the world", and as such examined separately* (p. 214).

In other words, representations of ideas, beliefs and values are sustained and constructed through constant social interactions, allowing us to categorise people and objects. SR is about the process which allows us to create social knowledge, where these contents go from being 'unfamiliar to familiar' (Hoijer, 2011; Voelklein & Howarth 2005). In turn, this can lead to us to understand and explain behaviours, allowing us to make sense of the world around us, acting as supporting evidence for our identities and realities (Calia et al., 2019; Torres et al., 2015). On one hand, these realities are created to simplify objects, people and events by placing them in a familiar context. On the other hand, they serve to influence social behaviours and negotiate social identities (Sammut & Howarth, 2014).

SRT was further developed from Mosocovici's study of the spread of psychoanalytic thinking in French society in the 1960's (Markova, 2017; Voelklein & Howarth, 2005). He studied how scientific knowledge (psychoanalysis) became common knowledge. Specifically, he brought to light the tension between scientific and professional thought and the daily thinking of lay people. Through this work, he did not construct a unified picture, but held a central picture that there is heterogeneity and tension in the data (Descombes, 2000; Voelklein & Howarth, 2005). As psychoanalysis was a controversial and widely talked about topic, it had considerable affinities with common sense thinking and therefore, lay people had their own views about it. Moscovici found that they saw similarities between psychoanalysis and various kinds of daily experiences (Markova, 2017). For example, people found they better understood psychoanalytic interviews when they related them to something familiar, such as a religious confession.

Moscovici deliberately permits the co-existence of competing and contradictory representations even in the same group, culture, community, and individuals. This is also referred to as *'Cognitive Polyphasia'* (Hoijer, 2011; Voelklein & Howarth 2005). It refers to different and incompatible forms of knowledge which co-exist side by side in individuals or within communities and groups (Descombes, 2000; Hoijer, 2011). Thus, SRT was developed to ensure that representations were understood as being multi-levelled, reflecting the processes of a dynamic society (Howarth, 2006).

However, this aspect of SR has been heavily criticised. If the representations are convincing, 'why are there differences in representations between people, and how is it possible for representations to change?’ (Howarth, 2006). The point is that, though representations are ‘relatively’ resistant to change, conflict within and between representations can and does occur, and under certain conditions, may lead to social transformation (Krause, 2002). What is ‘irresistible’ about social representations is the process of ideas re-presenting themselves (Howarth, 2006). It should also be noted that social representations are not necessarily seen as logical or coherent thought patterns. Instead, they can be full of thought fragments and contradictory ideas (Howarth, 2006; Voelklein & Howarth, 2005). This allows for the representations to reflect the diverse society.

Furthermore, though SRT has gained popularity throughout the years for its dynamic approach to understanding knowledge, it has also received extensive criticism for being “fragmented” (Raty & Snellman, 1992). The theory itself lacks conceptual precision to be considered a theory due to its openness to multiple interpretations. However, it is this precise aspect that makes the theory valuable and useful for analysing the representational practices of different social groups (Voelklein & Howarth, 2005). It allows representations to be examined in their own terms and contexts, rather than fixed to an idea. This theory would not be able to be useful to understand the dynamic society if it did not allow flexibility in its approach. Thus, it makes more sense to characterize social representation rather than to define it.

Moreover, there are different types of social representations that can explain and organise these fragmented patterns: hegemonic representations, emancipated representations and polemic representations. Hegemonic representations (or sometimes referred to as ‘imperative’ representations) (Moscovici, 1988) are representations that are shared by the majority, e.g., a political party, or a dominant or elite group or fraction within a nation. They are uniform and ‘prevail in all symbolic or affective practices’ (Moscovici, 1998, p. 221) and cannot be dismissed from common sense-making (such as racialising representations) (Howarth, 2006). Polemic representations are related to social conflicts, struggles between groups, and controversies in a society. They are determined by “antagonistic relations” and are *“intended to be mutually exclusive”* (Moscovici, 1988, p. 221). This can include political ideologies such as liberalism and communism. Lastly, emancipated representations relate to subgroups that create their own versions with *“a certain degree of autonomy with respect to the interacting segments of society”* (Moscovici, 1988, p. 221). For example, representations of health and illness in traditional and alternative medicine. These representations may partly be complementary, and individuals may pick up ideas of both and combine them with their own experiences of health and illness. Thus, emancipated representations will be further explored in this thesis. This will be done by exploring how individuals from BAME groups use both Western (biomedical) and alternative help seeking processes for dementia. It is worth noting that imperative and emancipated representations are heavily valorised, and it is assumed that minority group representations are emancipatory - whereas whether they are or not is an empirical question, depending on one's values.

3.2.1. Socio-cognitive mechanisms: Anchoring and Objectification

SRT specifies how collective cognitions are produced and transformed through communication. The creation of social knowledge is achieved through two socio-cognitive mechanisms: anchoring and objectification (Moscovici, 2008). The anchoring process gives the representation a meaning, whereas the process of objectification produces a figurative aspect of the representation (Hakokongas & Sakki, 2016).

Anchoring is where new ideas or phenomena are classified into pre-established categories, giving the ideas an identity to reduce unfamiliarity (Moscovici, 2008). For example, Jodelet’s (1991) study of mental illness found that mentally ill loggers in rural French communities were classified as ‘tramps’ or ‘idiots’. This allowed the community to attribute the familiar characteristics of tramps and idiots to the new category of mental illness. Another example is when members of the Asian community attribute symptoms of mental illnesses to pre-existing notions of spiritual possession and acts of ‘the unseen’ (Lim et al., 2018).

Objectification relates to transforming the unknown to known by transforming ideas into something concrete that individuals may experience or perceive; these realities enable groups to navigate the world around them (Höijer, 2011; Moscovici, 2008). For example, LaFrance (2007) interviewed women on their accounts of depression and found that the mental illness was objectified as a disorder of the individual’s mind or brain and caused by a chemical imbalance. By doing this, participants were able to reference the illness as something concrete. Through these processes, the perceptions of objects are taken and reinterpreted to fit into what we already know. Social representations may be reinforced, rearticulated, or re-enacted in various ways that fit with one’s stake, position, and identity. Thus, this process cannot be considered static.

3.2.2. Social representation and Health

Social representations within health are complex and essentially embedded within the ‘framework of pre-existing thought’ (Jovchelovitch & Gervais, 1999; Moscovici & Duveen 2000, p. 157). This means they are anchored in pre-existing systems of beliefs and values. Thus, the representation is familiar and acceptable. Through this context, the beliefs about health and illness lead to the larger social psychological factors which shape the choices people make about health behaviours and practices within their community (Jovchelovitch & Gervais, 1999). SRs also help explain people’s illness and thought processes. For example, AIDS was the major focus in the 1980s and 1990s where at first it was considered a punishing illness due to sexual liberty which had become exaggerated within the context of an overly tolerant society, as stigmatised by religious authorities (Markova & Wilkie, 1987). AIDS was deemed out of control and without a cure for the illness, the only way to contain the spread of the virus was to control the behaviour by which it was transmitted. Thus, the media was used to help stop the spread. They used media to transform scientific knowledge into lay thinking by helping people understand what it was and how to prevent its spread. Without the media, the knowledge and understanding of what AIDS was would have only reached a fraction of the population (Joffe, 2002). The media helped spread public awareness of AIDS as well as diffused the stigmatising social representations that were present.

Moreover, the understanding of health in diverse areas such as the West is complex. Many scholars in the West have promoted the idea that science and common sense were not only discontinuous phenomena, but that scientific thinking was 'superior' while daily thought was 'inferior' (Joffe, 2002; Markova, 2016). Western cultures' most dominant ideology – individualism – has pervaded cultural and scientific understandings of health and illness in Western societies, such as attributions of success and failure, or good and bad (Howarth et al., 2004). As discussed in Chapter 1, health and illness has often been closely aligned with mainstream biomedical approaches. As Kleinman (1988) points out, the biomedical approach leaves no room for patient narratives which may be regarded by professionals as barriers to effective treatment. Whereas, as discussed earlier in this chapter, SRT by its nature acknowledges multiple and dynamic knowledge systems about any socially significant object to exist simultaneously and would incorporate patient narratives into the health dialogue (Howarth et al., 2004; Voelklein & Howarth, 2005). The fundamental contribution of SRT, is its ability to help individuals understand how lay people make sense of aspects of illnesses, and how these evolve (Howarth et al., 2004; Joffe, 2002). Thus, allowing us to focus beyond these ideologies, showing an importance of lay knowledge, community cultural practices and social identities.

This is where the advantage of SRs lies. As societies are diverse and fragmented, the resulting implication is that representations have also become less uniform. SRT allows researchers to focus on all forms of representations without giving one more importance over another. Their differences are reviewed, however, are not seen as deficiencies (Moscovici, 1984). When analysing the different representations, it is important to examine them in their own realms and within their own contexts. The differences between them only gives more value to the social groups they come from as it helps us understand the various knowledge system of each group (Howarth et al., 2004).

This can be seen when looking at help seeking strategies used within different communities. Looking at BAME communities within the Western World, people from these groups often have different understandings and experiences with dementia. This reflects the way dementia is understood within the community and can be explained by SRs. Dementia is in part, a culturally determined phenomenon. Similar to mental health, dementia was represented by vast descriptors (George et al., 2011) where meanings of dementia are interpreted, embodied, or resisted by people in their social contexts, and these processes are shaped by different factors (such as age, gender, social class, and ethnicity) (Kontos & Martin, 2013). For example, cross-cultural research identifies how understandings of dementia are culturally shaped, where dementia is seen as either a natural part of the aging process or a type of brain disease (Hinton et al., 2000; Chee & Levkoff, 2001).

3.2.3. Social Representation Theory Application

In this thesis, importance is given to the narrative of individuals, community members, and their practices. The aim of social representations in understanding health is not to invalidate health opinions, but to capture representations which are both dynamic and heterogeneous social phenomena (Markova, 2017). It is not applied to differentiate between right and wrong; instead, it is used to shed light on alternative methods that can be incorporated into Western help-seeking methods. For example, the researcher will discuss how pre-existing notions unrelated to dementia are applied to make sense of the disease by some interview participants. Participants will go on to reference religious reasons and lifestyle choices as reasons for dementia, referring back to emancipated representations within SRT.

Moreover, it will also be seen how representations within a community can be dynamic, i.e., age differences between participants will reveal how representations can change through generations.

The thesis primarily utilises the theory in three ways: first, representations of dementia and help-seeking from lay persons and those impacted by dementia (Chapters 4 and 5); secondly, the impact of these representations on help-seeking (Chapters 5 and 6); and thirdly, its recognition of and perspective on competing systems of knowledge, particularly across lay and professional spheres (Chapter 7).

3.3. Social Identity Theory and Health

The social environment comprises communities, families, neighbourhoods, and different social groups, which all impact an individual's social identity. It is obvious is that social identities are more than a list of socio-demographic groups which can be used to classify individuals (for example, by gender, age, ethnicity, or religion) (Haslam et al., 2009). Social Identity Theory (SIT) suggests that individuals define their own identity by their identification with a social group (Tajfel, 1978; Tajfel & Turner, 1979). This results in them forming a connection with other members who share the same 'identity', giving them a sense of self as a group (in-group) and those outside of this become the out-group. Rather than using the terms "I" and "me", in-group members then utilise terms such as "we" and "us" and begin to develop a natural bias towards the in-group (Jetten et al., 2012).

The role of group memberships and social identities associated with them can influence people's health and wellbeing. Research on health and social identity found that identity plays an important role in understanding the relationship between health and the individual. Typically, health outcomes and behaviours are studied at the individual level and the role of group memberships, shared group memberships and shared social identity is left unexplored (Jetten et al., 2012). At a theoretical level, they serve to reconnect issues of clinical, health, social and cognitive psychology in line with individual visions. At a practical level, social identity informs the development of delivery, management, and promotion of health care (e.g., Craddock, 2000; Harwood & Sparks, 2003). It can also explain how identity can impact symptoms of health and help-seeking behaviours. For example, Haslam et al. (2012) found that when older adults self-categorise themselves as "old", they related their own physical health as poorer, and related more to age-linked stereotypes such as poor cognitive performance (like forgetfulness).

SIT can also explain why group members may not appreciate and accept certain health-related messages if they come from out-group members. This may result in people disengaging from positive health behaviours which they otherwise may not have disengaged from, if the message had come from the in-group or it better aligned with their in-group ideologies (Hasalam et al., 2009). Oyserman et al. (2007) showed in one of their studies that members of minority ethnic groups (African Americans and American Indians) who did not identify with the mainstream majority (White middle class) were less likely to react to the health-related messages that emanated from this source.

This is true for many communities such as minority ethnic groups in the UK as well. They are exposed to traditions that may differ from their own in fundamental ways. The clash between the ways to approach health and illness produces a number of consequences such as miscommunication and ineffective implementation of health care. This extends to some minority ethnic groups experiencing dementia. When exploring dementia in BAME communities, the question arises 'How do beliefs within the BAME community interplay with the Western biomedical system?'. This is further explored in Chapters 5 and 6.

3.3.1. Social Identity Theory Application

The SIT approach can help understand the process of help-seeking decision-making for PwD and their carers. As social identity is anchored in a system of guiding beliefs and symbols, religious beliefs and practices can serve as a function in shaping psychological and social processes (Ysseldyk et al., 2010) for the caregivers and PwD. Identity can help shape why people especially from minority ethnic groups follow certain pathways that are shaped by aspects of their religious or cultural identity and practice. Furthermore, although PwD lose their cognitive ability, they are likely to have some sense of self-hood even in the advanced stages of dementia, and as religious beliefs and practices are often learned in childhood and by heart they may persist after more recently acquired knowledge and dispositions. Often, their sense of self or identity can easily be overlooked, even though this is seen to be a vital element to preserve, to improve the person with dementia's quality of life (Caddell & Clare, 2010). Beuscher and Grando (2009), found that religion and spirituality can help religious PwD have a sense of familiarity which can help keep in place their identity. The influence of religion and culture is further explored in the studies carried out in this thesis. Addressing the social identity of PwD brings its own challenges and raises epistemological concerns (Sabat, 2002). How can we measure the person with dementia's level of self-hood or identity, when individuals may lack the communication skills or cognitive ability for researchers to examine? Further complexities are added when the person with dementia' experiences are examined through proxies (further discussed in section 3.7.4.1).

3.4. Social Representation and Social Identity

This section focuses on how SRT and SIT will be combined to research help-seeking behaviours related to dementia among minority ethnic groups. According to Breakwell (1993), both SRT and SIT together create a more powerful explanatory model of action and could mark a step towards a real paradigm shift in social science. Linking both together would benefit both theories and help better understand BAME groups' help-seeking processes.

Jovchelovitch and Geravis (1999) stated that research on SR of health and illness have found that both concepts are grounded in cultural frameworks which go back to individuals' identities. They are also constructed through communication, social interaction, and practices of daily life. They stated that SRs of health and illness are inseparable from in-group ideologies that individuals subscribe to.

Furthermore, Breakwell (1993) argued that SRs cannot explain why a particular representation takes the form which it does. This is where SIT can help explain the processes that might shape representations. It is identity that explains why specific people draw on particular representations and defend them in the ways they do, ignoring or contesting other representations. For example, in BAME groups, individuals are likely to draw on representations that are from their cultural/ethnic identity to help them make sense of a phenomena.

Combining SIT and SRT allows one to examine how representations are formed and why they are formed in the way they are. Combining the two theories produces a new framework which a) provides a social analysis of health and well-being, b) provides a coherent framework for understanding health and well-being and c) provides theoretical tools that allow us to design and implement interventions that can capitalise on our understanding of the importance of social relationships for health (Jetten et al., 2012).

3.5. Methodology

In this section, the methodological issues of this thesis will be discussed. It will begin by discussing the critical realist approach, which has both ontological and epistemological implications. This will be followed by the phenomenological approach which is concerned with individuals and their experiences. We will then discuss the methods and analysis techniques used for this thesis. Lastly, the section will provide a detailed reflection of the researcher, specifically highlighting how her experiences and identity may have shaped her research.

3.5.1. Critical Realism

This thesis adopts a Critical Realist (CR) approach, which addresses concepts from both an ontological and epistemological perspective (Sayer, 1992). Ontology comprises of what constitutes reality and epistemology relates to what constitutes valid knowledge and how we can obtain it (Coyle, 2015). CR is first and foremost concerned with ontology and starts from questioning about what exists (Bhaskar, 1978) then focuses on the creation of knowledge about the existence (Frauley & Pearce, 2007). Though the focus is primarily within the principle of ontology, it does not diminish any importance from the epistemological position (Bergin et al., 2008). By using both components, it allows CR to be a comprehensive philosophy of science (Brown, Fleetwood, & Roberts, 2002).

Critical Realism emerged in the 1970s/1980s through the work of Roy Bhaskar and was further expanded by other researchers (Bergin et al., 2008). It emerged as a result of a deviation from both the positivism and constructivism stances. Positivism is based on the idea that reality is objective and independent of the researcher. It attempts to find regular patterns or events in order to generate predictions. Whereas constructivism is based on the idea that reality is subjective, unstable and the product of human activity. Reality is socially constructed and what exists is dependent on people's interpretations and undertaking of that reality (Bergin et al., 2008).

Positivism is often argued to be too rigid, not taking into account people's subjective experiences (Bergin et al., 2008). Equally, constructivist perspectives view reality as entirely constructed through and within human knowledge or discourse, disregarding empirical observations (Bergin et al., 2008; Clark et al., 2007). Despite the seeming opposition between the constructivist and positivist perspectives, each reduces reality to human knowledge, whether that knowledge acts as lens or container for reality. These result in a limitation in the epistemological position as research into health often fails to understand the inequalities within a complex social world (Williams et al., 2017).

Unlike other ontologies, CR has been stratified into three distinct domains: The real, the actual, and the empirical. The real domain consists of all that exists despite whether or not we experience it or have knowledge of it. The actual domain consists of what happens in reality when mechanisms of the real domain are activated. Finally, the empirical domain comprises only those elements which are experienced. Thus, it is possible for certain powers to exist without being known (i.e., not having been experienced yet) (Bergin et al., 2008). For example, a researcher may learn about cancer as an outsider and through a realist ontology, they would be able to explore the disease within the domain of the real without actually experiencing it. It is CR's stratified ontology that differentiates it from other ontologies and is why it fits in line with the methods of this thesis.

The current Western approach to health and help-seeking needs to be approached through a critical lens. Critical realism is applied in this thesis to appreciate the process of help-seeking within the BAME community, with the actual disease itself falling into the realm of the real and its symptoms and outcomes (i.e., the resultant events and experiences) falling into the realm of the actual. The help-seeking pathway and its effectiveness would then be within the realm of the empirical (as they would be 'experienced') by the individual and the carer. By having a flexible approach to understanding help-seeking, it allows for deviation from the current mainstream healthcare pathway and looking at alternative methods as viable options as opposed to barriers (as these all exist within the actual realm).

However, this does not take away from what is currently known and accepted (the real realm). Dementia is still seen as a biological illness and can only be diagnosed through professional services (such as the GP). Current treatments and the services available are all still applicable to patients post diagnosis and should not be overlooked. Rather, critical realism can be used to question existing pathways to dementia services while simultaneously interplaying existing methods with new methods, that incorporate or work with religion and culture. The critical realist approach allows to draw on the merits of the positivism and constructivism approaches, whilst reflecting on the complex interplay of individuals, socio-cultural and organizational factors that influence health outcomes (Clark et al., 2007).

3.5.2. Phenomenological Approach

Certain elements of this research are approached through the phenomenological approach, which is the philosophy of experience. Edmund Husserl is regarded as the "fountainhead of phenomenology in the 20th century" (Vandenberg, 1997, p. 11). He rejected the belief that a logical approach can be used to understand our experiences. It sets apart from the more positivist approaches of social research and concerns itself with the way the world appears to the person experiencing the world and to describe the experience as it is from those who have experienced it (Neubauer et al., 2019). The goal of phenomenology is to describe the meaning of this experience—both in terms of *what* was experienced and *how* it was experienced (Teherani et al., 2015). It is interested in the subjectivity of the observer, but it need not be confined to the level of the individual. It is interested in the way we come to share the similar understandings of the world and the way we construct a sphere of intersubjectivity.

Different types of phenomenology are rooted in the ways we conceive human experiences. In this research, the hermeneutic approach to phenomenology is adopted. Hermeneutic phenomenology (also known as interpretive phenomenology) originates from Heidegger and Gadamer's work. Though Heidegger's work began in alignment with Husserl's work, he later challenged certain aspects of Husserl's work. Husserl was interested in the nature of the knowledge whereas Heidegger was interested in the nature of being and temporality (Reiners, 2012). For Heidegger, an individual's conscious experience of a phenomenon is not separate from the world, nor from the individual's personal history. Instead, it is a formation of lived experiences which includes a person's individual history and the culture in which he/she was raised (Lopez & Willis, 2004). In other words, the observer is part of the world and not bias free. As a researcher, the role is to reflect on essential themes of the participants' experiences with the phenomenon while reflecting on own personal experience. It involves an iterative cycle of capturing and writing reflections towards a robust analysis (Neubauer et al., 2019). The researcher has reflected on the research process which shows her development as a researcher and growth as an individual. For this thesis, the researcher's bias, views, and reflection are presented in section 3.9. Nevertheless, this can be seen as a downfall to understanding the research, as results may become overpowered by the researcher's own input. Thus, the researcher needs to be mindful of the position and being aware of the standpoints (Sutton & Austin, 2015).

Furthermore, phenomenology in this research is specifically applied to help-seeking methods and people's experiences with dementia. Using this approach helps provide an understanding of individuals' lived experiences which will enable healthcare providers to enhance their understandings of participants' own narratives (Carel, 2011) that would be formed without any pre-existing notion of help-seeking methods. Substantially, the main objective is not only to understand the individual's experience but to also find the 'essential meaning structures' of the phenomenon (e.g., help-seeking) that are experienced by a certain group of people (e.g., BAME group experience with dementia) (Al Kalaldeh et al., 2018). Adopting this approach to understand participants' experiences will allow to capture the complex pathways of help-seeking, which to individuals may not be a straightforward path and requires the researchers to unravel the experiences and the decision-making process.

3.5.3. Emic Vs Etic

Emic and etic approaches are perspectives used when studying various cultures (Fetvadjiev, & Van de Vijver, 2015; Pike 1954). An emic approach refers to research that studies one culture as a whole, with no cross-cultural focus. The view of the culture is formed from an insider's perspective. (Fetvadjiev & Van de Vijver, 2015). Emic investigators attempt to penetrate a culture and see it as its own members do, yielding a description of the cultural system from the inside, from the viewpoint of the participant as opposed to the observer. This is sometimes called “subjective culture” (Sturtevant, 1964; Tripp-Reimer, 1984). An etic approach refers to research that studies cross-cultural differences. The etic view of culture is where the researcher is considered an outsider looking in, observing behaviour without learning the viewpoint of those studied (Fetvadjiev, & Van de Vijver, 2015). Outcomes of etic approaches—often referred to as culture-free features of the world (Pike, 1954; Sturtevant, 1964)—can be applied across cultural studies. The Western biomedical approach can be treated as akin to an etic approach, i.e., data taken from cross-cultural studies is analysed and applied to all individuals. These categories of explanation and definition, embedded in Western biomedicine, may not be appropriate when projected onto different cultural or lay explanatory systems (Kleinman, 1978).

In this thesis, a blend of emic and etic approaches are used. The emic perspective will be used to approach the analysis. The perception of dementia is taken from BABC and SA who have experienced its affects. The aim is to dive into their experiences and understand it from their point of view. It avoids falling into the trap of understanding dementia and dementia experiences from the ‘normal’ or ‘outsider’s’ view. The emic approach describes the phenomenon from the perspective of the individual. It shows what categories particular individuals use and how they classify their own health experience. An emic analysis defines the perceptions and classifications made by members of a particular community (including the choice of criteria for determining adaptive and maladaptive behaviour). The research is carried out with this in mind—more particularly, Studies 2 and 3, which are qualitative studies of main carers of PwD (Chapter 5) and religious leaders (Chapter 6) and are conducted to understand carer’s experiences and religious leaders’ experiences and perspectives on dementia and help-seeking.

The research also adopts an etic approach. It does this by using different methods and different viewpoints to understand the experiences of dementia. For example, a meta synthesis and systematic review (Chapter 2) was conducted to understand and critically explore current research that aligns with the biomedical view. Moreover, Study 1 also utilises an etic approach to better understand BAME and White counterpart's understandings of and experiences with dementia.

3.6. Mixed Method

Mixed method research is defined as a systematic approach to data collection, analysis, and integration. It includes both qualitative and quantitative methods at some point of the research process for the purpose of gaining a better understanding of the research problem (Creamer & Reeping, 2020). The rationale for using the mixed method approach is grounded in the fact that qualitative and quantitative methods are insufficient by themselves to capture the trends and details of the situation. When both approaches are used in combination, they complement each other and allow for a more robust analysis, taking the strengths of each method (Ivankova et al., 2006). This provides a more meaningful interpretation of the data and is a flexible and more dynamic approach between the qualitative and quantitative portions of the study. It also allows for a creative approach to data collection which allows for the emergence of gaps, incongruities, and contradictions (Creamer & Reeping, 2020).

However, mixed method research is complex and researchers such as Greene (2007), argued that mixed methods research is not simply a method of combining both qualitative and quantitative data. It is a way of knowing and making sense of the world- "a mixed method way of thinking" (p. 208). It is about looking at the data from a different perspective, which aids to counteract bias towards the research. Creswell and Plano (2017) discussed how the integration of qualitative and quantitative methods are not simply additive but exponential, and this phase is described as the "the centrepiece of mixed methods research" (p. 220).

Taking into account the criticisms of objectivism (positivism) and subjectivism (constructivism) discussed earlier, one might think that phenomenology would be better poised to include methods coming from qualitative research only rather than quantitative research or a mixed method approach. Mixing methods comes with problems as different methods reflect different epistemologies and ontologies that may not be compatible (Small, 2011). Thus, Denscombe (2008) and Greene (2007), have pointed out that the basic principle in pragmatism for mixed method research is that the findings and discovery of knowledge are the priority rather than the theoretical justifications for knowledge. The researcher is given the flexibility to apply whatever means and methods that help answer the research questions (Creswell & Plano, 2011; Martiny et al., 2021). Although, it is easy to fall into the trap of using the any methodology strategy, i.e., the 'whatever works' approach, which the researcher would need to be mindful of and justify. Thus, working with phenomenology and critical realism allows the researcher to prioritise both the act of discovery and its theoretical justification (Martiny et al., 2021). The following section (3.7) will further explore each study (research) and its methods, in the attempt to justify what and why the researcher chose this method.

This thesis has adopted a pluralistic approach, where different methods are used in a project, which can aid to a more comprehensive understanding of the data. Analytical pluralism enables researchers to produce rich, varied understandings of phenomena and opens multiple possibilities of interpretation as it avoids privileging any specific approach or framework over another (Clarke, et al., 2015) It can also encourage the researcher to be more reflexive to better understand how their own position in the research process or in relation to the topic of research may implicated in the interpretation of the data (Shaw & Frost, 2015).

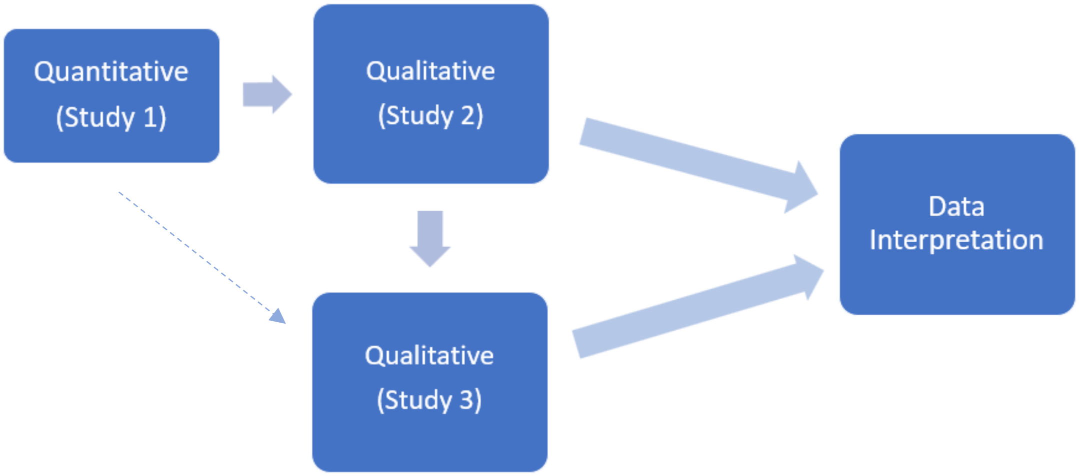
3.6.1. Sequential Explanatory Design

There are various mixed methods research designs that can be found in existing literature. For this thesis, mixed methods sequential explanatory design will be adopted which implies collecting and analysing quantitative data first and then qualitative data in two consecutive phases (Figure 7) (Ivankova et al., 2006). The rationale for this approach is that the quantitative data and its subsequent analysis provides a general understanding of the research problem. The qualitative data helps refine and explain those statistical results by exploring participants' views in more depth (Tenny et al., 2022).

However, this method begs the question, 'who and what decides what the priority is?' (Creswell et a., 2004). For example, who decides the priority or weight given to the quantitative and qualitative data collection and analysis in the study, the sequence of the data collection and analysis, and the stage/stages in the research process through which the quantitative and qualitative phases are connected and the results are integrated? Though priority is given to the first stage of research, whether its qualitative or quantitative, it all depends on the goal of the study. This decision could be made either at the study design stage before the data collection or later during the data collection and analysis process. In this study the priority is given to qualitative research (more specifically, Study 2 of the research). Initially, focus was given to the quantitative research that was carried out first. However, it will be seen in further sections that the data was not normally distributed, thus, limiting the research to a specific analysis. The focus was also shifted towards Study 2, i.e., the qualitative study. This decision was also influenced by the purpose of the study to identify and explain the factors that impact individuals' help-seeking process and behaviours. The following diagram illustrates the mixed method research approach used in this thesis. The design implements a three-staged research process (see section 3.7 for a detailed review). The first stage (Study 1) comprised a quantitative study which informed the second stage (Study 2) qualitative interviews. Both stages one and two then informed stage three (Study 3) qualitative interviews. Study 2 and 3 then informed the illustration of care pathway (Chapter 7).

Figure 6

Sequential Design of the Studies



Note. The figure illustrates the sequential design of the studies adopted in this thesis.

3.7. Research

3.7.1. Age Group

Dementia knowledge and perceptions have found to be affected by different demographic factors including age, gender, education level, and ethnicity. Previous research on health has found that age has an impact on understandings of health (Do et al., 2020; Giebel et al., 2019). Research has also tended to focus on the older population (50 years and over) as dementia impacts older individuals (Ayalon, 2013; Ayalon & Areán, 2004; Milani et al., 2020; Nielsen & Waldemar, 2016; Sun et al., 2014). Not surprisingly, the focus on younger age groups is quite limited; and more specifically, within minority ethnic communities (Kafadar et al., 2021). Moreover, help-seeking methods differ between generations, even within collective families in BAME communities (Hudson et al., 2012; Jones et al., 2010), highlighting the need for further research in this area. Due to the lack of knowledge in BAME communities and the lack of focus on the younger population, this thesis takes into account young adults between the ages of 18 to 40 years for Studies 1 and 2.

3.7.2. Vignettes

Vignettes are short stories depicting a hypothetical person in the context of what is being researched. The information about a person is developed by drawing from previous research or examples and is often used in health-related research. Vignettes are used in this research (Study 1 and 3) to examine participants' understandings, perceptions, and beliefs about dementia. They were used in Studies 1 and 3 and were constructed from previous research findings (Berwald et al., 2016; La Fontaine et al., 2007; Cheng et al., 2011; Cohen et al., 2009; Johnson et al., 2015; Randhawa et al., 2015; Werner & Davidson, 2004; Werner 2005).

3.7.3. Study One

Study 1 aim was to understand the perspectives and attitudes towards dementia within the BAME and White community. It specifically focused on religious and cultural factors that may impact the participants' perceptions of dementia. The data was collected through surveys, which comprised of nine questionnaires. There was two independent variables (BAME and White groups) and severity of dementia (mild and severe). The dependent variables were beliefs about cause of dementia, beliefs about treatment, knowledge of dementia and stigma.

Study 1 had two different vignettes which depicted a person with mild and severe dementia. The word dementia was mentioned in both vignettes. The hypothetical person was represented as

Mr/Mrs A to avoid any gender influences. Each religious group saw both vignettes, but Muslim participants saw the vignette which depicted the person as Muslim, and Christians saw the person as a Christian. Each vignette depicted a different case: the first vignette depicted a person who had mild dementia symptoms and the second vignette depicted a person with severe dementia. The participants were recruited through opportunity sampling, where participants are selected based on naturally occurring groups. The study was advertised on Kingston University's SONA system, and on online social platforms such as Twitter and Facebook groups. The researcher also recruited participants through various mosques and churches in London. To analyse the data, non-parametric analysis was used as the data was not normally distributed. This is explored further in Chapter 4 (Section 4.3.1).

There are elements of SRT which can potentially be seen within the responses received. Incorporating and identifying SRs in health research would allow the researcher to understand a socially shared knowledge used by the community to explain the phenomena of daily life (Juarez-Cedillo et al., 2013). However, it should be noted that this study is a quantitative study, thus, it would be difficult to explore the representations in detail. It could also be argued that through the questionnaires, some predefined representations may have been presented to the participants, making it even more difficult to other representations.

3.7.4. Study Two

The aim of this research was to determine the experiences and perceptions of dementia amongst SAM and BABCC main carers of PwD. The participants were recruited through mosques, churches and community centres. Efforts were made to recruit through social media platforms such as Twitter and Facebook groups, however, no responses were received. The study was also advertised on local religious WhatsApp groups for Muslims and Christians in London. Only two Muslims participants were recruited from this source. Health care systems or services were avoided, as this would have led to recruitment of participants that utilise these services and would marginalise those who did not use the mainstream pathway. Thematic analysis with the phenomenological approach is adopted to understand experience with dementia and their help-seeking process.

3.7.4.1. Research on PwD and carers as proxy. For Study 2, main carers are used as proxies for PwD as many PwD lack the cognitive ability to participate in an interview. Efforts were made (pilot study – see section 5.2.2.2) where PwD were recruited to take part in semi-structured interviews. Due to individuals delaying seeking a dementia diagnosis, recruiting PwD with mild cognitive impairment was difficult (see section 5.2.2.2). Thus, carers as proxies for PwD were recruited. The researcher also set requirements to ensure that all proxies were not only the main caregiver, but also had been present at the time of diagnosis. This ensured they would be able to provide the researcher with a complete account of the person with dementia's experiences.

Studying carers and not the person with dementia does pose some epistemological limitations, as the true experience of the person with dementia is not captured (Sabat, 2002). The main concern here lies with the fact that it is challenging to separate the carer's experiences from the experiences of the person with dementia. Even if the carer is asked in interviews to provide an overview of the person with dementia's experience regarding something, it is inevitable that some of their experience may also be transferred during the discussion. However, avoiding this issue is difficult and it is currently the only way researchers can understand the experiences of PwD, especially within minority ethnic groups where individuals delay seeking diagnosis. It is also the recommended method of carrying out research on PwD and has been used in previous research (Arons et al., 2013; Kwak et al., 2016; Lord et al., 2015).

3.7.5. Study Three

The aim of Study 3 was to understand the role of religious leaders in the help-seeing process for PwD. Clergies were shown vignettes depicting someone with dementia specific to their religion, i.e., Christians were shown a person with dementia who was also Christian, and Muslims were shown a person with dementia who was a Muslim. They were then interviewed to determine what their understandings and perspectives of dementia were to determine how it can impact the help-seeking process for PwD. Thematic analysis was used to analyse the results.

3.7.6. Structure of Findings and Discussion

The findings and discussion of each study has been discussed separately in each of the Chapters 4 (Study 1), 5 (Study 2) and 6 (Study 3). There are several themes that were common within the studies and therefore, they are repeated throughout the chapters. The researcher wanted to ensure that each study and theme were fully covered and thus, it became necessary to repeat commonalities at different times.

3.8. Qualitative Analysis - Thematic analysis

Qualitative Research is increasingly becoming a recognised approach for collecting data. One form of analysing qualitative research is through thematic analysis. It identifies, analyses, organises, describes, and reports themes found in a data sat (Braun & Clarke 2006). A rigorous thematic analysis (TA) can produce trustworthy, precise, and meaningful results (Braun & Clarke, 2006). However, TA is thought to be a poorly branded method and has not been appreciated the same way as other methods in the field, such grounded theory, phenomenology, or ethnography due to lack of literature (Nowell et al., 2017). Some researchers, such as Braun and Clarke (2006), Nowell et al. (2017), and Thorne (2000), have argued the importance of TA and state that it is a foundational method for qualitative research which provides core skills for conducting different forms of qualitative analysis.

The advantage of TA is its theoretical freedom, which allows its flexible approach to the data (Braun & Clarke, 2006; Nowell et al., 2017) (as compared to other analysis such as grounded theory or Interpretative phenomenological Approach - IPA). This allows a more accessible form of analysis, which can be modified and adjusted to the study's aim, without jeopardising the quality, richness, and details of the data. This approach is a useful method for examining the perspectives of different research participants, highlighting their similarities and differences, and generating unanticipated insights. The data is also handled in a well-structured approach (Braun & Clarke, 2006). It can be argued that there a lack of substantial literature on this method as compared to other methods, however, Braun and Clarke (2006) have created a step-by-step guide for researchers that will be also used as a guidance for this thesis.

This thesis adopts a thematic analysis and phenomenological approach to Study 2. It can be questioned why IPA was not adopted when the method is rooted in phenomenology (Love et al., 2020). TA with a phenomenology approach was adopted because of its flexibility. Though IPA would have also been beneficial, due to its idiographic mode of in-depth exploration of each individual's account of their experience, it may not have been as beneficial for study 3. Thus, to remain consistent, TA was used throughout the thesis.

3.8.1. Braun & Clarke six-phase guide

3.8.1.1. Step 1: Familiarization. This step involves the researcher getting familiarised with the data. It involves overviewing the data thoroughly, transcribing the audio, and taking notes of any impressions.

3.8.1.2. Step 2: Generating Initial Codes. This step involves coding the data by highlighting phrases and sentences. It does this by coming up with short labels and codes that describes the data. The research also revisits the data multiple times and is a key stage as it involves reflected and interacting with the data (Maguire & Delahunt, 2017). It is recommended that the data set it worked through systematically, giving attention to small details. Interesting aspects of the data are identified, that may form of the basis of the themes across the data.

It is noted that the codes should have explicit boundaries, so that they are not interchangeable. Many levels of coding can be created, however, too many levels can be considered counterproductive to reaching the goal. Hierarchical coding can be created which allows varies levels of analysis. There can be a higher theme which can provide an overview and detailed subthemes (King, 2004). The use of software can also be implemented to work efficiently with complex coding schemes and large amounts of text, facilitating depth analysis. Thus, for this thesis, NVIVO is used to manage and organise the data.

There are different levels to thematic analysis, such as semantic and latent coding. Semantic coding is identified through the explicit or surface meanings of the data. In other words, the researcher only examines what was said or written. This is often described as descriptive analysis of the data, which aims to solely present the content of the data as communicated by the respondent. Latent coding goes beyond the descriptive level of the data. It attempts to identify hidden meanings or underlying assumptions, ideas, or ideologies that may shape or inform the descriptive or semantic content of the data. This process of analysis becomes much more interpretative and requires an active role on the part of the researcher (Byrne, 2022).

In the analysis process of Study 2, the researcher started with semantic coding, where the themes being derived were based on participants' accounts. However, upon reading and taking on a reflective approach to the research, the coding was later changed to the latent coding approach to move beyond the surface of participants accounts. Familiarising oneself with the dataset helps to move from the semantic to the latent approach. In Study 3, both coding latent and semantic methods were used, and neither was preferred over the other. Latent coding was used where the researcher believed that there was much more to the data, and semantic coding was used where the researcher felt it was relevant.

3.8.1.3. Step 3: Generating themes. This phase begins when all the data has been collected and collated. It involves sorting out the coded data into themes (Braun & Clarke, 2006). Themes can be described as patterns in the data that are important or interesting to the researcher and which address the research question and framework at hand (Maguire & Delahunt, 2017). However, this is not as simple as just summarising the data; it is about interpretating the themes and making sense out of them. The themes bring together components or fragments of ideas or experiences, which often are meaningless when viewed alone (Aronson, 1994). It is not dependent on quantifiable measures, but rather on whether it captures something important in relation to the research context.

Again, there is flexibility to judge the themes in various ways; however, it is important there is consistency in the methods of analysis (Bruan & Clarke, 2006). The process of data collection, coding, organising, and analysis is described in sufficient detail to enable the reader to judge whether the final outcome is rooted in the data generated (Ryan et al., 2007). King (2004) strongly advised that when themes that are not directly related to the research question, they should be disregarded.

3.8.1.4. Step 4: Reviewing themes. Once the themes have been formed, they will require a certain level of refinement. Questions such as ‘Do they make sense?’ or ‘Does the data support the themes?’ will test the validity of each theme and determine whether they hold true meaning within the data set.

3.8.1.5. Step 5: Defining and Naming Themes. During this phase, the researcher questions and explores what aspect of the data of each theme captures and identifies what is of interest about them and why (Braun & Clarke, 2006). A detailed analysis for each individual theme is conducted and the story is identified (Maguire & Delahunt, 2017). The themes need to immediately give the reader a sense of what the theme is about. King (2004) stated that one of the most difficult decisions to make is where to stop the process of theme development as it is possible to go on modifying and refining definitions of themes forever.

3.8.1.6. Step 6: Writing up. This phase begins once the researcher has fully established the themes and is ready to begin the final analysis and write-up of the report. The write-up should provide a concise, coherent, logical, nonrepetitive, and interesting account of the data within and across themes (Braun & Clarke, 2006). It is encouraged to communicate the logical processes of the development of the themes, so the claims made in relation to the data set are rendered credible and believable (Thorne, 2000).

3.9. Personal Reflections

Credibility of research is enhanced when two or more researchers analyse the same data (Côté & Turgeon, 2005; Nowell et al., 2017). To still produce credible data, with one researcher, the researcher is encouraged to practice reflective writing. The purpose of reflective writing is to engage with the notion of creating transparency in the research process and explore the impact of critical self-reflection on the research (Ortlipp, 2008). A reflective approach is widely used in the research process—especially in qualitative research. This process aims for the researcher to reflect on the construction of the outcomes and to make this process visible to the reader. It is inevitable that the researcher's own experiences, values and position influence the research interest and the ways the research findings are represented. Rather that attempting to control the researchers' values and input, the aim is to acknowledge these values and see how they reflect the outcome, especially as the researcher becomes the main 'instrument' of data collection (Ortlipp, 2008). Thus, it is very important to conceptualise the role as a researcher. This process is not considered easy, but it's important for the researcher to conceptualise their own influence. Every researcher has some sort of 'baggage' that they may bring into their research, and it is important that this is acknowledged and put aside where needed (Lyons, 2015). The process of reflection helps to bring the unconscious into consciousness and thus open for inspection. This process of exploratory reflective writing has allowed the researcher to grow and change her role as a researcher, interviewer, and interpreter of the data (Jasper, 2005; Ortlipp, 2008). This process will be explored in the following sections.

The purpose of this thesis is to carry out a review of the existing knowledge available on the BAME community with respect to dementia, dementia care, help-seeking methods, and the perception and availability of healthcare services to the community. The study was inspired initially by the researcher's own experiences. Coming from a South Asian origin and being brought up in the 'Western' world, the mix of cultural values around her and her own experience with acculturation led her to witness a clear schism between the Western method of help-seeking and the method adopted by people within her community, who opted for more cultural methods. She noticed that often, cultural approaches were not backed by science. Rather, they were based on religious and cultural/traditional beliefs combined with some barriers to general healthcare services. This led the researcher to question exactly how these differences between the Western (or 'White') community and the generalised BAME community formed and whether they could be used to provide better service or care for people.

3.9.1. The Researcher and the Research

This section aims to explore the research, the researcher's background, and the motive behind this thesis. It illustrates how the researcher's background journey led to her research.

The researcher identifies herself as a British Pakistani Muslim female. She was born in Pakistan and moved to the UK at the age of six. Though she has lived in the UK for most of her life and may have assumed to have week roots with her Pakistani heritage, she believes that her identity lies both in Western and non-Western roots. However, she always felt a clash between her own culture, and the host culture. She was bought up to believe that her non-Western values were deemed wrong and did not belong in the Western world. She grew up on that idea and saw her Pakistani family and friends constantly trying to negotiate their identities with their behaviours. It was only when she came to university where she was surrounded by multi-cultural people where she started to understand and appreciate each and every culture. It was in her third year of university where her professors taught the module critical social psychology, where she began to question the world around her. It was then, that she realised her passion for social psychology.

During her PhD she began to explore PwD and non-pharmacological treatments of dementia. To understand dementia better and how it impacts individuals she began to work with PwD at day care centres. The researcher then came across the philosopher Alain de Bolton and his book called religion for atheists, where he compared religious practices to atheism and stated how religious practices can have value to the secular world. This was a light bulb moment where she realised the similarities in religious institution practise and secular activities (at the dementia day care centres). It made her question how the practices may have had the same outcome yet different aims or meanings behind them. She began her journey by exploring this in more detail and started to volunteer at day care centres aimed at PwD. She also realised that there was little to no BAME involvement at majority of these day care centres and upon further reading, she found out that service uptake from the BAME communities was much lower as compared to White counterpart groups.

This perspective of day care activities being same as religious institutions came to more useful when reading previous studies, conducting the studies and interpretating the data. How the data on BAME groups and dementia was represented, was often with one narrative, 'people from BAME groups face certain barriers' or 'the need for culturally appropriate services. Where the pathways that they chose were seen as different, but also implied that it was 'wrong'. Previous researchers (Howarth et al., 2014) have argued that people from marginalised groups (such as LGBTQ, non-White, people with disabilities) are often defined as 'other', which are defined in opposition to the norm of 'mentally healthy' privileges middleclass, White and able, heterosexuals, which can often lead to misrepresentation. This same aspect is applied to dementia and BAME group research. Thus, when researching BAME groups and dementia, the researcher was mindful of this stereotypical reaction, and this helped her steer away from this perspective.

Furthermore, during the PhD process, the researcher took part in various research projects. One project where she was working with minority ethnic groups, she was asked to research groups from minority ethnic groups that had no education to ensure that there is maximum difference found with the White group. Upon carrying out the research she questioned why the same was not done for the White groups and when she realised how harmful this form of recruitment could be in research as well as when representing the BAME groups in research. She realised this approach does not seem to represent all BAME groups in the UK and thus their needs be a shift or a justification of why and how the groups from BAME groups are recruited.

3.9.2. The Research Processes: Interviews

In this section, the researcher will aim to explore and reflect on her process of carrying out research and how it contributed to her becoming a researcher. The researcher describes the process as a journey. Though the journey was not a one-way street but more of a journey through a maze, reflecting on her trials and errors allowed her to see the 'maze' through a bird's eye view and has allowed her to grow as a researcher.

The researcher does not know anyone personally that has or had dementia, however, whilst working on her PhD, she has volunteered in various aging/dementia day care centres where the researcher interacted with people with cognitive decline, people at different stages of their dementia, and staff members running the centres/activities. This not only helped her understand how dementia impacts the person, but also understand how carers of PwD are impacted as well. She believed that this gave her valuable experience in understanding PwD first-hand which she applied to her research skills.

In Study 1, the researcher's goal was to use quantitative methods as a foundation for the studies that followed. Upon carrying out the research and beginning to analyse the data, the analysis did not yield the results that were expected (i.e., they were not normally distributed, limiting the types of analyses that were possible to be carried out). Thus, the decision was made to drastically change the direction of the research. For the data that she did have from her first study, she carried out non-parametric analyses to yield results.

In Study 2, the researcher attempted to understand the perspective of carers of PwD and their attitudes towards the help-seeking process and dementia. However, before finalising her participants, the researcher carried out pilot studies (see Section 5.2.2.2). Through this process, the researcher was able to understand her target audience for her research as well as the interview schedule.

For studies 2 and 3, the researcher first began to recruit her participants through social media such as Facebook groups and Twitter. However, the researcher was unable to recruit any participants through these methods. This was not surprising, as the researcher was aware that members of the BAME community may not want to openly discuss something stigmatised.

She then started attending community centres, mosque gatherings/classes and church groups (with permission from the organisers) who warned her about the difficulties of talking to church goers about personal issues, as to them, she would be considered an outsider. The researcher did not anticipate this as being a difficult task when approaching SAM, however, she realised quickly that their willingness to open up to her was based on trust. Thus, spending time at these community centres and volunteering to helping with organising events helped her gain their trust. Through this, she was slowly able to talk to people about her research and was able to recruit participants for the studies. Not all participants were recruited directly through the organisations. Some were recruited through word of mouth.

For recruiting people from BABCC groups, she had help from a secondary researcher who introduced the main researcher to the secondary researcher's church and community members. The secondary researcher identified as a BABCC, and thus, was able to access these groups more easily whereas the main researcher was not a member of this community and was clearly an 'outsider'. The secondary researcher was present with the main researcher at these groups when discussing the research aims. Recruiting people from the BABCC community proved to be significantly more challenging because of this. However, the researcher benefited from this as being an outsider can have its own advantages, where often biases are removed when interviewing participants and therefore can often lead to approaching research (and the interviews) with an open mind.

Furthermore, whilst recruiting and interviewing participants, the researcher realised the influence of her ethnicity on the interviews. Though the researcher's aim was not to explicitly explore the differences between SA and BABC groups, she realised her role as a researcher, her identity seemed to shift from being a 'South Asian Muslim' when interviewing SAs and a person from the BAME group when interviewing BABC. This was considered helpful as she believed that the interviewees were able to connect to her more and thus open up about their experiences.

Whilst interviewing SAMs in Studies 2 and 3, the researcher realised that the participants often assumed that because the researcher was from the same ethnicity as them, they thought there was an unspoken level of understanding between them. They would often include the researcher in words such as ‘us’ or ‘we’ when discussing the differences between them and the White counterparts, who were often referred to as ‘they’ or ‘them’ . The researcher also realised that while interviewing the SA group, she would often have to use extra prompts to delve deeper into the conversation. This was realised after the initial couple interviews, where participants would not provide a full answer. The researcher understood that to be become a better interviewer, she would have to further engage her participants which would also yield more informed responses.

Wilkinson and Kitzinger (1996) discussed how insider vs outsider mentality could pose challenges to researchers when carrying out research on communities which they did not belong to. This was also felt by the researcher in this thesis as she was interviewing members of the BABC community. She had to be very careful as they would often see her as an outsider. To carry out the interviews and not be hindered by this, the researcher approached the community as a representative of the BAME community instead. This ensured that the participants felt that to a certain extent, they had a connection with the researcher. Another step that the researcher took was that she took the help from a secondary researcher who was also a member of the BABC community. This approach was seen beneficial as the researcher could then conduct the interviews as an outsider whilst having the community’s trust.

For recruiting participants for Study 2, the researcher realised that in many cases the caring duty was shared between family members. She also realised that young adults (aged between 18-40) were more willing to partake in the research as compared to 40 years and above. This was due to language and the ‘decision-maker’ role that they played. It was also these people in the families that carried out the research needed to find out what would benefit the person with dementia. It was only in two cases where the participants were aged above 40. However, they also shared responsibilities with their children, who made most of the decisions. In these cases, the children felt more comfortable for their parents to partake in the research as they were living with them.

When the researcher conducted the interviews, she realised that dementia was not usually discussed from a carer’s perspective or a help-seeking perspective. She realised that due to this she would have to go through the process with the participants as they explained their experience. In these interviews, two participants (one SA and one BABC participant) became emotional during their responses and thus, it was decided that the interviews had to be stopped.

3.9.3. Potential Additional research

Originally, interviewing professional health care was also planned as part of this thesis, with the aim to understand their perspectives on minority ethnic groups and help-seeking. During the researcher’s process in gaining more knowledge on dementia in BAME groups, she interacted with many healthcare providers working in this area, where she noticed that many providers’ information would only reflect previous literature or policies and not account for the differences witnessed in BAME communities. Thus, to understand the BAME help-seeking process through their perspective, it did not seem beneficial to also include perspectives which would be echoed within the literature as well.

Social representations research is often examined through media analysis to examine the representations of a topic around a specific context or groups of people (Hoijer, 2011). Thus, one may expect to carry out a media analysis to examine the SRs of dementia within BAME communities within the UK. However, upon researching this area, it was found that there was either none or very limited media coverage on dementia relating to BAME groups. Roche et al. (2021) also found that there was a lack of media representation of public health resources in minority ethnic groups. Thus, it was decided that there would not be much outcome from conducting this analysis either.

3.10. Chapter Summary

This chapter explored the theoretical framework of this thesis (SRT and SIT) and how they are adopted in this thesis to understand the help-seeking process for dementia in BAME groups. It focused on bringing the alternative methods of help-seeking into the picture. To study this, a phenomenological approach to help-seeking and dementia was adopted to help understand the lived experiences of PwD and their carers.

A CR approach was adopted to address the concepts from both an ontological and epistemological perspective. CR's stratified ontology helped it fit perfectly in line with the aim of this thesis. Splitting dementia, the help-seeking process and experiences into the different realms helped establish the fact that alternative means of help-seeking are available to the BAME community.

The methodology of this research was also discussed. A mixed method approach followed by a sequential design was adopted. A total of three studies will be carried out: Study 1 is a quantitative study which will explore the understandings and perceptions of dementia between BAME groups and White counterparts. It will use non-parametric analysis to analyse the survey responses. Study 2 is qualitative research which explores understanding and help-seeking behaviours of dementia of PwD. It adopts the phenomenological approach to analyse the data. It will use thematic analysis to analyse the interviews. Study 3 is also qualitative research and explores the role of religion and religious leaders in the understanding and help-seeking behaviours of dementia within the BAME community. It also uses thematic analysis to analyse the interviews.

The final part of the chapter carried out a reflexivity exercise on the researcher.

4. Understandings and Perceptions of Dementia Between White and BAME Groups

4.1. Chapter Aim and Introduction

People from BAME groups have different experiences and understandings of dementia as compared to White counterparts (Baghirathan et al., 2020; Bowes & Wilkinson, 2003; Julta, 2015). As discussed in Chapter 1 and 2, previous researchers have found that for BAME groups, there are certain factors that impact a person's decision making when seeking help from professional health care for dementia such as stigma, language differences, lack of knowledge, religion, and culture (Bowes & Wilkinson, 2003; Mukadam, Cooper, & Livingston, 2011; Regan et al., 2013). These barriers can delay help-seeking, cause burden on the carers and result in the person with dementia becoming less likely to use services (Bowes & Wilkinson, 2003; Cooper et al., 2010; Mukadam et al., 2013).

Religion and culture not only play a role in understandings of dementia (in terms of the cause), but also influence how an individual seeks help. Evidence suggests that minority ethnic groups have different experiences in accessing health as compared to White counter parts (Haslam et al., 2009). These can act as moderators as well buffers for the outcomes of the research (Woo et al., 2019). Research on mental health illness in BAME communities have found that religion acts as a positive coping mechanism (Agli et al., 2015; Nguyen, 2020) as well as has a negative impact on their understandings and their coping strategy (Nguyen, 2020). This can also be applied to dementia (Regan et al, 2013). Thus, it is important to establish how exactly religion and culture play a role in understandings of dementia as well as help-seeking behaviours. Even though there is research which suggests that there are barriers towards mainstream healthcare, there is limited research explaining how people seek help and what factors impact this process (Bowes & Wilkinson, 2003).

Alternative help-seeking methods for dementia within BAME communities needs to be further explored. Thus, this chapter and study will act as a foundation for study 2 (Chapter 5). It will provide a focus point for the researcher to see what elements should be explored in the next stages of the research.

This study will focus on individuals' beliefs about different causes of dementia as well as the beliefs about beneficial treatments for dementia (focusing on both professional and alternative methods). As well as other factors such as stigma and knowledge of dementia. There is limited research in these areas. For example, Nguyen and Li (2020) conducted a systematic review and found that there were only 4 studies carried out in the UK which investigated stigma in the context of dementia.

The research question that this study addresses is 'What are the understandings and experiences of dementia and help-seeking among BAME groups?'. This will be done by clarifying any differences and similarities between BAME and White counterpart groups, lending to the overall goal of this study, which is to develop an understanding of BAME help-seeking processes and subsequently be able to implement an improved help-seeking model.

4.1.1. Hypotheses

The hypotheses were generated from previous research. The following study will address the following hypotheses.

1. There will be a difference between BAME and White groups in the following areas:
    a. Knowledge of dementia
    b. Cause of dementia (biological, lifestyle and religious/spiritual factors)
    c. Treatment of dementia (professional and alternative)
    d. Stigma (personal, perceived, and social stigma)
2. There will be a difference within each group (BAME and White group) in the following:
    a. Cause of dementia (biological, lifestyle and religious/spiritual factors)

    b. Treatment of dementia (professional and alternative)

3. There will be a relationship between stigma (personal and perceived), knowledge of dementia and the following:
    a. Cause of dementia (biological, lifestyle and religious/spiritual factors)
    b. Treatment of dementia (professional and alternative)

4.2. Method

This section will develop the methodology of the study. First, it will describe the design and procedure of the study, which will elaborate why this design was chosen and the rationale behind it. Then it will go through participant requirements for the study, followed by the materials used.

4.2.1. Design

This was a mixed design study with two independent variables. The first independent variable was ethnicity (BAME and White groups) and the second independent variable was the vignettes (mild and severe) shown to the participants, which was repeated measures. The dependent variables were knowledge of dementia, cause of dementia, treatment, and social, personal, and perceived stigma.

The researcher chose to study mild and severe dementia vignettes because previous research suggested that the severity of the disease impacted dementia perceptions. Thus, the aim was to see if the severity of the disease influenced dementia understandings and help-seeking methods.

4.2.2. Procedure

The study was conducted via Qualtrics platform as well as physical copies were handed out. The participants were presented with an information sheet that explained the study in detail and then were presented with a consent form. Participants had the right to withdraw, and they did not have to answer any given question if they did not wish to without any explanation. Participants were also given a code, which allowed them to withdraw their data until a given time if they wished to do so. Furthermore, participants' information was always stored in a locked or password protected locker to ensure privacy and confidentiality.

At the start of the questionnaire, participants were presented with a series of demographic questions which asked about age, ethnicity, religion etc. They were then asked questions about their religiosity levels, followed by a set of questions regarding their knowledge of dementia. Each religious group was presented with a vignette of a person with mild dementia (see Appendix D.2) and were then asked to fill out a questionnaire which asked them about what they believed was the cause of the disease and the beneficial treatment. This was also done for a vignette depicting a person with severe dementia, followed by similar questions. Social, perceived, and personal stigma were measured based on the participants' responses. Participant information sheet, consent form, debriefing sheet, advert and research questions and prompts can be found in Appendix D. This study was approved by Kingston University Ethic Committee (1617334).

4.2.3. Participants

Originally, 360 participants were collected. However, 322 participants remained once the data had been cleaned. After the decision was made to only include participants aged between 18-40 years, an additional 41 participants were removed. For this study, there was a total of 281 participants with the age range between 18-40 years and (*M* = 24.40, *SD* = 5). Table 5 shows the demographic characteristics of the participants.

Table 3

Sociodemographic Characteristics of Participants

	Sample Characteristics	n	%
Gender	Males	90	32
	Females	191	68
Education	No education	1	0.4
	GCSE	9	3.2
	A level/College	104	37
	Undergraduate	121	43.1
	Postgraduate and/or over	40	14.2
Religion	Christian	108	27.3
	Muslim	173	72.6
BAME vs White	BAME	202	26.3
	White	74	71.9
	Other	5	1.8
Ethnicity	White	74	26.3
	South Asians	98	34.9
	Black African and Black Caribbean	70	24.9
	Asian Other	8	2.8
	Arab	26	9.3
	Other	5	1.8

Note. n = 281

The participants were recruited via opportunity sampling. They were recruited through the SONA system at Kingston University London, social media websites (Twitter and Facebook), and through religious organisations (such as Mosques and Churches), where the questionnaire was emailed, and handed out to individuals. The inclusion criteria were that the participants must identify themselves as either Muslim or Christian (regardless of religiosity level), must be older than 18 years and be living in the UK.

In this study, individuals who identified as White British were also recruited. It is important to remember that the term ‘White’ does not only include any person who identifies as White. The term can also include White minority groups (such as Irish), who may also have similar experiences as BAME groups (Willis, 2015). Thus, any minority ‘White Other’ participants were considered as the ‘other’.

4.2.4. Materials

4.2.4.1. Demographics. The demographics questionnaire was composed of eight questions that were used to understand the socio-demographics of the participants. Gender, age, occupation, education level, country of birth, duration of stay in the UK, ethnic group, and religion were all asked about in the questions.

4.2.4.2. Religiosity. The religiosity levels were measured by using the Koeing and Bussing’s (2010) Duke University Religion index (DUREL). This questionnaire consisted of five questions in total of which two questions measured behavioural religiosity and three measured spiritual religiosity levels. Two separate Likert scales were used for the questions. Cronbach’s alpha value for this sample were .96.

4.2.4.3. Knowledge of Dementia Questionnaire. The knowledge questionnaire consisted of 10 questions where each item was a statement and participants had to tick whether they believed whether each statement was true, false or say they did not know (Shin et al., 2015). Cronbach’s alpha value for this sample were .85.

4.2.4.4. Vignette. There were in total two vignettes which depicted someone with mild dementia and someone with moderate/severe dementia. This is because people respond differently depending on the severity of the dementia. Randhawa et al. (2015) review of dementia symptoms was used, as well as previous research (Berwald et al., 2016; La Fonatine et al., 2007; Cheng et al., 2011; Cohen et al., 2009; Johnson et al., 2015; Werner 2005; Werner & Davidson, 2004) to construct the vignettes.

The vignettes also included religious involvement of the people presented and were changed depending on what religion the person identified with. For example, those who identified with Christianity were shown the questionnaire that depicted a person who was a Christian. The gender of the people in these vignettes was not specified as this would reduce any sort of external factors that may affect a person's answer. Therefore, the individuals in the vignettes were referred to as ‘A’ and ‘N’.

4.2.4.5. Causality of Dementia. The Cause of Dementia questionnaire was based on previous research on mental health (Angermeyer et al., 2013). Historically, people believed that mental health issues were caused by the following factors: 1) brain disease, 2) heredity, 3) stressful life events, 4) work related stress, 5) growing up in a broken home and 6) lack of parental affection. Work related stress, growing up in a broken home and lack of parental affection were replaced with 1) normal aging 2) karma, 3) Gods Will, and 4) not devoted to religion. This was a 5-point Likert scale with 1 being least likely and 5 being most likely. This was then split into biological factors (brain disease and heredity), lifestyle factors (stressful life events and normal aging) and religious/spiritual factors (karma, God’s will and not devoted to religion).

For the mild vignette, the Cronbach’s alpha value for the biological factors was .46, for lifestyle factors was .39 and for religious/spiritual factors was .66. For the severe vignette, the Cronbach’s alpha value for the biological factors was .51, for lifestyle factors was .45 and for religious/spiritual factors was .77.

4.2.4.6. Treatment. This questionnaire was based on previous research on mental health (Angermeyer et al., 2013). The original sources of treatment were 1) psychiatrist, 2) psychotherapists, 3) general practitioner, 4) priest and 5) self-help groups. These were replaced with 1) psychiatrist, 2) doctors/general practitioner, 3) therapy, 4) self-help, 5) family and friends and 6) priests. After data collection, the groups were split into two categories: professional treatment and alternative treatment. Professional help consisted of doctors, psychiatry and therapy, whereas and alternative help consisted of self-help, family/friends and imams/pastors.

For the mild vignette, the Cronbach's alpha value for the professional treatment was .48 and for alternative treatment was .5. For the severe vignette, the Cronbach's alpha value for the professional treatment was .61 and for alternative treatment was .44.

4.2.4.7. Stigma.

4.2.4.7.1. Social Distance. The social stigma questionnaire was composed of six items (Bourkel et al., 2012). The items rate the person's willingness to 1) move next door to A/N, 2) spend an evening socialising with A/N, 3) make friends with A/N and etc. The Cronbach's alpha value was .85.

4.2.4.7.2. Personal and Perceived Stigma. The personal stigma assessed the respondent's personal attitude towards people with dementia and the perceived stigma assessed the respondent's beliefs about other people's attitudes towards dementia. They both had a total of nine items each and presented the same questions. However, the personal stigma questionnaire would address questions from a personal level. For instance, the personal stigma questionnaire had statements such as "I believe that people with dementia are dangerous people" whereas the perceived stigma questionnaire would represent the statement as "most people believe that PwD are dangerous". Questions from the original scale included questions related to politics and occupation, which were removed from the scale (Yap et al., 2014). Furthermore, statements such as 'People with dementia are caring people' were added. This was to make sure that there was not an over-abundance of negative comments. The Cronbach's alpha value for personal stigma was .66 and for perceived stigma was .72.

4.3. Analysis

4.3.1. Non-parametric Analysis

Quantitative analysis will be used for this research. It was determined that the data was not normally distributed. The Shapiro Wilk test for normality of distribution has been violated for majority of the dependent variables, p <.05 (Razali & Wah, 2011; Shapiro & Wilk 1965). Therefore, non-parametric tests will be carried out, as it does not rely on presumptions of the data. Though it is difficult to exactly pinpoint why the data was not normally distributed, a plausible reason is that the study was aimed at participants who have some sort of religious belief (Christian or Muslim), and therefore, participants' responses are deemed to most likely be on the extreme end of the scale. Furthermore, to illustrate where the differences are in non-parametric analysis, the means are shown alongside with the medians in both the Mann-Whitney U test and the Wilcoxon test.

4.3.1.1. Parametric Analysis. Non-parametric tests are applied when certain assumptions cannot be made about the sample dataset. It implies that the nature of parameters is flexible and not fixed in advanced (unlike parametric tests) (Kaur & Kumar, 2015). Parametric tests are considered more robust and usually have a higher statistical power than nonparametric tests and are thus more likely to avoid a false negative (type 2 error) (Grech & Calleja, 2018). Some researchers argue that analysis such as the t-test can be conducted on non-normally distributed data. Le Cassie et al. (2020) argued that when comparing two groups, a t-test can be beneficial regardless of whether the data meets the assumptions of parametric testing (i.e., such as being normally distributed). Applying the t-test with non-parametric analysis can help validate the results as well as provide extra beneficial results where non-parametric analysis may lack (such as the size and direction of the observed effect). An independent t-test (See Appendix A) was carried out alongside a Mann-Whitney U test and a dependent t-test (See Appendix B) was carried out alongside a Wilcoxon test.

Upon reviewing the results of the t-tests, it was noted that most were in line with the non-parametric tests that were carried out. However, the researcher noted that dependent t-tests which tested the relationship within the White group between beliefs about the causes of dementia (specifically, religion and spirituality) and other variables (lifestyle and biological factors) were not significant for the severe vignette. This was inconsistent with the non-parametric Wilcoxon test. Further investigation into this revealed that the dispersion of religious and spiritual beliefs as the cause of dementia within the White group matched a platykurtic distribution. This means that the standard deviation represents a higher proportion of the range and thus, reduces the likelihood of significant differences between other variables.

As part of the parametric analysis, the researcher will still utilise the results of the Wilcoxon analysis. This is done not only because the Wilcoxon analysis does not take standard deviation and dispersion of data points into account, but also because the main aim of this thesis is to review the BAME community specifically. Moreover, Studies 2 and 3 only focus on the BAME group.

4.3.2. Power Analysis

To determine the number of participants required for this study, G*Power version 3.1.9.7 was used. G*Power analysis is a tool that allows researchers to determine the number of participants needed for research that would yield significant results (Faul et al., 2007). As there has been no similar previous research conducted that would determine the effect size that could be used, the standard large effect size of 80% was used and a significance threshold value of a = .05 was used. The G*Power analysis yielded a sample size of *n* = 88 for the Wilcoxon-Mann-Whitney test (two groups) to be carried out. This would be a sufficient minimum number of participants to have. Thus, the obtained sample size of *n* = 281 is adequate to test the hypothesis.

4.4. Results

4.4.1. Mann-Whitney U test

A Man-Whitney U test was carried out to determine whether there was a significant difference in the distribution of beliefs about dementia between BAME groups and White groups (Table 6 and Table 7).

Table 4

Mann-Whitney U Test to Determine Beliefs about Cause of Dementia and Beneficial Treatment of Dementia between White and BAME Group.

Category		Severity	White		BAME		*p*	*U*	*z*
			M	*Mdn*	*M*	*Mdn*			
Cause of dementia	Biological	Mild	6.69	7	6.54	7	0.51	6259	-0.66
		Severe	6.96	7	6.91	7	0.991	5723	-0.01
	Lifestyle	Mild	6.27	6	6.32	7	0.438	6163	-0.78
		Severe	6.03	6	6.28	6	0.169	5052	-1.38
	Religious/Spiritual	Mild	5.8	3	7.45	7	.000**	3935.5	-4.84
		Severe	5.8	3	8.53	9	.000**	2788	-5.68
Treatment	Professional	Mild	10.25	10	10	10	0.580	5353	-0.55
		Severe	11.62	12	11.06	11	0.238	4533.5	-1.18
	Alternative	Mild	9.33	9	11.3	11	.000**	3682	-4.81
		Severe	9.51	9	11.42	11	.000**	3164	-4.36
Stigma	Social Stigma	Mild	12.29	12	13.41	14	0.066	4373.5	-1.84
		Severe	14.63	15	15.69	16	0.137	4718.5	-1.49

Note. ***p* <.001

It was found that there was a significant difference between BAME groups and White groups in the belief that religious/spiritual reasons were the cause of dementia for both vignettes. For the mild vignette, BAME groups (*M* = 7.45, *Mdn =* 7, *n* = 184) were more likely to believe that religious/spiritual factors were that the cause of dementia as compared to White groups (*M* = 5.8, *Mdn* = 3, *n* = 70), *U* = 3935.5, *z* = -4.84, *p* < .001. For the severe vignette, BAME groups (*M* = 8.53, *Mdn* = 9, *n* = 167) were also more likely to believe that religious/spiritual factors were the cause of dementia as compared to White groups (*M* = 5.8 *Mdn* = 3, *n* = 64), *U* = 2788, z = -5.68, *p* < .001.

For the mild vignette, BAME groups (*M* = 11.3, *Mdn* = 11, *n* = 173) were more likely to believe that alternative treatments were more beneficial for the person with dementia than the White group (*M* =9.33, *Mdn* = 9, *n* = 70), *U* = 3682, *z* = - 4.81, *p* < .001. Similarly, for the severe vignette, BAME groups (*M* = 11.42, *Mdn* = 11, *n* = 160) were more likely to believe that alternative treatments were more beneficial for the person with dementia than the White group (*M* = 9.51, *Mdn* = 9, *n* = 63), *U* = 3164, *z* = - 4.36, *p* < .001.

Table 5

Mann-Whitney U Test to Determine Knowledge of Dementia and Stigma Between White and BAME Group.

Category	White		BAME		*p*	*U*	*z*
	M	*Mdn*	*M*	*Mdn*			
Knowledge of dementia	3.65	4	3.83	4	0.439	7026	-0.77
Personal Stigma	16.06	15	17.47	20	0.007*	4306	-2.68
Perceived Stigma	20.84	20	21.59	21	0.216	5001.5	-1.24

Note. **p* <.01

The results also illustrate that BAME groups reported a higher level of personal stigma as compared to their White counter part, (*M* = 17.47, *Mdn* = 20, *n* = 163) as compared to (*M* = 16.06, *Mdn* = 15, *n* = 68), *U* = 4306, *z* = -2.68, *p* = .01.

4.4.2. Wilcoxon Test

The Wilcoxon test was carried out to determine whether there was a difference within each group depending on the severity of symptoms in the vignettes. Table 8 and 9 illustrates the results.

It was found that when BAME participants were depicted with a mild dementia vignette, participants were more likely to believe that religious and spiritual factors (*M* = 7.45, *Mdn* = 7, *n* = 184) caused dementia as compared to the biological factors (*M* = 6.54, *Mdn* = 7, *n* = 186), *z* = -3.27, *p* < .001. Similarly, BAME groups were more likely to believe that religious/spiritual factors (*M* = 7.45, *Mdn* = 7, n = 184) were more likely to cause dementia as compared to lifestyle factors (*M* = 6.32, *Mdn* = 7, n = 185), *z* = - 4.03, *p* < .001).

For the White group, there was a significant within group difference when looking at cause of dementia between biological factors and religious/spiritual factors *z* = -1.96, *p* < .001. When looking at cause of dementia between religious/spiritual and lifestyle factors, a significant difference was also found $z = -1.93$, $p < .001$. Biological factors were reported as the most likely cause of dementia ($Mdn = 7$, $M = 6.69$, $n = 71$), followed by lifestyle factors ($Mdn = 6$, $M = 6.27$, $n = 71$) and then religious/spiritual factors ($Mdn = 3$, $M = 5.8$, $n = 70$).

Furthermore, when BAME participants were shown a severe dementia vignette, there was a significant difference between all three factors as a cause of dementia. Biological factors vs. religious/spiritual factors reported $z = -4.37$, $p < .001$; lifestyle factors vs. religious/spiritual factors reported $z = -6.59$, $p < .001$; and lastly, lifestyle factors vs. biological factors reported $z = -3.51$, $p < .001$. Between the three, religious/spiritual factors were most likely seen as the cause of dementia ($M = 8.53$, $Mdn = 9$, $n = 167$), followed by biological factors ($M = 6.91$, $Mdn = 7$, $n = 171$) and then by lifestyle factors ($M = 6.28$, $Mdn = 6$, $n = 170$).

For the White group there was a significant difference between biological and lifestyle factors $z = -3.19$, $p < .001$ and biological and religious/spiritual factors $z = -2.42$, $p < 0.05$. Between the three, biological factors were reported as the most likely cause of dementia ($M = 6.96$, $Mdn = 7$, $n = 67$) followed by lifestyle factors ($M = 6.03$, $Mdn = 6$, $n =67$) and then by religious/spiritual factors ($M = 5.8$, $Mdn = 3$, $n = 64$).

Table 6

Wilcoxon Test to Determine Beliefs about Cause of Dementia within BAME and White Groups.

		White Group				BAME group			
Vignette	Cause of dementia	*M*	*Mdn*	*Z*	*p*	*M*	*Mdn*	*Z*	*p*
Mild	Biological	6.69	7	-1.62	0.106	6.54	7	-1.23	0.219
	Lifestyle	6.27	6			6.32	7		
	Biological	5.8	3	-1.96	.050	6.54	7	-3.27	.001*
	Religious/Spiritual	6.69	7			7.45	7		
	Lifestyle	6.27	6	-1.93	.054	6.32	7	-4.03	.000**
	Religious/Spiritual	5.8	3			7.45	7		
Severe	Biological	6.96	7	-3.19	.000**	6.91	7	-3.51	.000**
	Lifestyle	6.03	6			6.28	6		
	Biological	6.96	7	-2.42	.015*	6.91	7	-4.37	.000**
	Religious/Spiritual	5.8	3			8.53	9		
	Lifestyle	6.03	6	-1.57	0.116	6.28	6	-6.59	.000**
	Religious/Spiritual	5.8	3			8.53	9		

Note. * $p < .05$, ** $p < .001$

Similarly, when White participants were shown the two vignettes (mild and severe) and asked about beneficial treatment, they reported significant differences between both types of treatments (professional and alternative). In the mild vignette case, professional treatment had a higher rank (M = 10.25, Mdn = 10, n = 68) as compared to alternative treatment (M = 9.33, Mdn = 9, n = 70), z = -2.46, p = .01. In the severe vignette case, professional treatment had a higher rank (M = 11.62, Mdn = 12, n = 65) as compared to alternative treatment (M = 9.51, Mdn = 9, n = 63), z = -4.07, p < .001.

For the BAME groups, in the mild dementia vignette, alternative treatment was deemed more beneficial (M = 11.30, Mdn = 9, n = 173) than professional treatment (M = 10, Mdn = 10, n = 165), z = -4.44, p < .001. There was no significant difference when participants were depicted with a severe dementia vignette.

Table 7

Wilcoxon Test to Determine Beliefs about Beneficial Treatments within BAME and White Groups.

Vignette	Treatment	White Group				BAME group			
		M	*Mdn*	*Z*	*p*	*M*	*Mdn*	*Z*	*p*
Mild	Professional	10.25	10	-2.46	.014*	10	10	-4.44	.000**
	Alternative	9.33	9			11.3	11		
Severe	Professional	11.62	12	-4.07	.000**	11.06	11	-1.13	0.258
	Alternative	9.51	9			11.42	11		

Note. * p < .05, ** p < .001

4.4.3. Spearman's Rho Correlation

Spearman's rank-order correlation was carried out to determine the relationship for different variables for the White group (Table 10) and the BAME group (Table 11) (See Appendix C for analysis).

Table 8

Correlation Between Variables for White Groups

Vignette		1	2	3	4
	1. Knowledge of dementia				
	2. Personal Stigma	-.298*			
	3. Perceived Stigma	-0.042	0.172		
	4. Religiosity	-0.118	.255*	.305*	
Mild Vignette	5. Biological Factors	0.224	-.384**	.244*	0.016
	6. Lifestyle	0.044	-0.188	0.088	0.054
	7. Religious/Spiritual	-0.131	0.107	-0.029	.296*
Severe Vignette	8. Biological	0.199	-0.193	.330**	0.139
	9. Lifestyle	0.057	-.291*	0.236	0.109
	10. Religious/Spiritual	0.031	0.178	-0.053	0.190
Mild Vignette	11. Professional help	-0.091	-.343**	-0.098	-0.022
	12. Alternative help	-0.082	0.015	0.122	.453**
Severe Vignette	13. Professional help	0.146	-0.188	0.125	-0.004
	14. Alternative help	-0.084	-0.044	0.185	.495**

Note. * *p* < .05, ***p* <.001

Table 9

Correlation Between Variables for BAME Groups

Vignette		1	2	3	4
	1. Knowledge of dementia				
	2. Personal Stigma	-0.040			
	3. Perceived Stigma	0.030	.370**		
	4. Religiosity	0.073	-0.040	0.046	
Mild Vignette	5. Biological Factors	.172*	-0.083	0.120	-0.036
	6. Lifestyle	0.050	0.087	0.049	-0.003
	7. Religious/Spiritual	-0.125	0.092	0.057	0.139
Severe Vignette	8. Biological	.268**	-0.033	0.114	-0.090
	9. Lifestyle	.189*	0.063	0.027	-0.098
	10. Religious/Spiritual	-0.028	0.147	-0.057	0.087
Mild Vignette	11. Professional help	0.137	-.234**	-.201*	-0.064
	12. Alternative help	.185*	-.183*	-0.007	0.139
Severe Vignette	13. Professional help	0.114	-.265**	-0.161	-0.128
	14. Alternative help	0.093	-0.061	0.020	0.066

Note. *$p < .05$, **$p < .001$

4.5. Discussion

The present study evaluated knowledge, beliefs about causes of dementia, beliefs about beneficial treatments and stigma around dementia amongst the BAME and White groups living in the UK. It was hypothesised that there would be a difference between the BAME and White groups in their knowledge of dementia, stigma (social, personal, and perceived), beliefs about causes of dementia (biological, lifestyle and religious/spiritual) and treatment of dementia (professional health care and alternative care). It was also hypothesised that there would be a relationship between stigma (personal and perceived), religiosity, cause of dementia, and beneficial treatments of dementia. The following section discusses some of the findings in further detail.

4.5.1. Causes of dementia

Firstly, looking at the difference between the BAME group and White counterparts, there was a significant difference in beliefs that religious and spiritual reasons were the cause of dementia. BAME groups reported higher beliefs that dementia was caused by religious and spiritual factors as compared to White groups. This can produce both positive and negative responses (as also discussed in Chapter 2). For example, some researchers have discussed that dementia is seen as 'karma' (Uppal & Bonas, 2013), whereas other researchers have discussed how a form of accepting the illness is by viewing it as 'God's will' (Mushi et al., 2014).

Moreover, it was also found that there was no difference between White groups and BAME groups in other possible causes of dementia (biological and lifestyle factors). This could suggest that dementia is also seen as a 'biological' illness, regardless of other possible beliefs about cause of dementia. Research on ill-health causation have supported this, where they have found that individuals in Ethiopia reported that supernatural (religion) factors and natural (biological) factors were seen as being linked to ill-health causation (Kahissay et al., 2017). When looking at the differences within the groups, BAME groups believed that religious/spiritual factors were more likely to be a cause of dementia as opposed to biological or lifestyle factors. For the White group, biological reasons were the main cause of dementia, followed by lifestyle and then religion. Interestingly, the results showed that there was no significant difference at the between group level for White vs. BAME groups when it comes to the importance of biological factors. However, it should be noted that the BAME group places a significantly higher level of importance towards religion as well.

4.5.2. Beneficial treatments of dementia

This study also found that there was a significant difference between beliefs about treatments of dementia. BAME groups were more likely to believe that non-health care professional treatments were more beneficial for people with dementia, as compared to White counter parts. This includes family members, friends and going to religious leaders (imams/pastors). These finding are also supported by previous research, which suggest the importance of religion and family members as part of the help-seeking pathway (Smolak et al., 2012). Phillips and Stein (2007) also reported that religion is attributed to positive coping for individuals who have serious mental illness. They have also found that people who use religion as a positive coping mechanism have also reported an overall higher well-being.

Furthermore, as discussed in Chapter 2, family members play an important role in helping the person with dementia. This is supported by studies where family care is seen as additional to and not a replacement for professional care. For example, in the SA culture, family members such as children and partners have a responsibility to look after their elders, which is more of a 'traditional' caregiving ideology (Bowes & Wilkinson, 2003; Mukadam, Cooper & Livingston, 2011) and is seen as a natural, expected role and an extension of their responsibility (Botsford et al., 2011; Lawrence et al., 2008). This could be a reason why they may see alternative care as a beneficial source of treatment and may not seek help from professional health care (La Fontaine et al., 2007).

It was also reported that these beliefs change within the BAME group based on the severity of the symptoms. In mild symptom cases, as there was a significant difference between professional and alternative care methods, it shows that the BAME community would be more likely to give importance to alternative practices. However, as symptoms worsened (severe vignette case), it was noted that there was no longer a significant difference between the two care pathways. Thus, it shows that people within the BAME community would be more inclined to treat both pathways equally as a result of the worsening symptoms. Conversely, for the White group, there was a significant difference in the preferred care pathway regardless of the severity of the symptoms (i.e., people were more likely to opt for professional health care services over alternative care pathways regardless of the severity of the symptoms). This could be supported by the fact that previous research has found that people from the BAME community were more likely to delay seeking help until they can no longer cope or accommodate the changing behaviour and cognition (Hinton et al., 2004; Mukadam, Cooper, Basit et al., 2011). Thus, this could suggest why there is no difference in the responses within the BAME group when provided with a severe vignette, as well as show that their help-seeking is different depending on the severity of the illness.

4.5.3. Stigma

As predicted, stigma played a role in the findings. There was a significant difference in personal stigma amongst BAME and White groups, where BAME groups had a higher level of stigma as compared to White groups. These findings are supported by previous research, which found that dementia tends to be more stigmatised in the BAME communities (as discussed in Chapter 2). Further analysis also revealed that there was a positive relationship between personal and perceived stigma within BAME groups. This suggests that there is stigma associated with dementia. This goes in line with previous findings. For example, Uppal et al., (2014) reported the people in Sikh communities (UK) had negative perceptions about dementia, where it was seen as the person's fault.

Furthermore, when looking at different variables and the relationship with stigma it was found that in the White group, stigma was negatively associated with belief that biological factors are the cause of dementia. It was also found that there was a negative relationship between stigma and seeking professional help, suggesting that there is a relationship between stigma and beliefs about cause of dementia, and stigma and beliefs about beneficial treatment. Personal stigma towards dementia may hinder how it is understood and therefore, delay people from seeing help from professionals. Eventually, it may even impact the person with dementia's quality of life (Phillipson et al., 2012).

Similarly, within the BAME groups, it was also found that there was a negative correlation between stigma and the beliefs around the benefits of any treatment (professional and alternative). This goes in line with previous findings which also suggest that stigma can impact how people seek help. It suggests that people would rather not discuss or seek-help for dementia. However, research within minority ethnic groups and stigma is still needed (Nguyen & Li, 2020)

4.5.4. Knowledge of Dementia

There was no significant difference in knowledge of dementia between both groups. In this study, demographic factors were measured to see if there was an impact on the outcome. It should be noted that there was not much variation in participants' education levels, i.e., most had at least A-level or college-level education. This could suggest that like previous research, the average knowledge of dementia was higher as compared to previous studies (Purandare et al., 2007). This barrier may be considered less relevant, as it is possible that people have higher levels of dementia knowledge as a result of the UK's awareness campaigns (Department of health, 2009; 2016; Hailstone et al., 2016; OHID, 2022).

However, when looking at the knowledge of dementia and its relationship with other variables in the BAME groups, it was found that there was a (positive) correlation between knowledge and beliefs that biological factors were the cause of dementia. In the White group it was also found that there was a negative association between knowledge of dementia and personal stigma. Thus, suggesting that knowledge of dementia is associated with beliefs about dementia.

4.5.5. Religiosity

It was also found that levels of religiosity play a role in understanding and beliefs of dementia within the White groups. For example, there was a positive relationship between religiosity and stigma (personal and perceived), and a positive relationship between religiosity and belief that alternative help was beneficial for the person with dementia. Thus, suggesting the importance of religiosity in dementia understandings. As discussed throughout this thesis, this goes in line with previous research which suggests that religion and spiritual beliefs can shape individuals' response to life changing events (Kennedy et al., 2013; Regan et al., 2013; Pargament, 1999)

There was no relationship between religiosity and other variables within the BAME groups. This was due to the fact the majority of the BAME groups reported a high level of religiosity, and thus, there was no distribution of the responses which resulted in no association with other variables.

4.5.6. Limitations

This study provides useful data and some form of foundation for the following studies (Chapter 5 and 6). However, this study has some limitations. Firstly, the data was not normally distributed which impacted the types of analysis that could be carried out. The non-parametric analyses are thought to be less powerful because they rely on either few or no assumptions about the shape or the parameters of the distribution (Grech & Calleja, 2018). To combat this, the researcher also carried out t-tests to determine the validity of the results.

Furthermore, the study only included participants aged between 18-40 years. The researcher did acknowledge this and did attempt to include participants above this age bracket. However, there were a few factors that could have prevented participants above 40 from taking the questionnaire. Firstly, due to the nature of the study, a very small amount of BAME community members were willing to participate. Secondly, the few participants that were in fact over 40, were only from the White community and thus removed.

Thirdly, when looking at the significant relationship between variables, it was found that majority of the correlation strength could be described as weak. Though this raises concerns whether there is a strong association between the two variables, or whether other factors play a role, one plausible reason for the weak correlation could be due to sample size. Another reason could be due to other cofounding factors which could have played a role. If the data was normally distributed further analysis would have allowed to test these in more detail.

Nevertheless, the data generated still provides sufficient foundation for Study 2 and Study 3 to be built upon. It allowed the researcher to identify patterns in the BAME groups. This study contributes to the existing literature on understandings and perspectives of dementia between and within BAME groups. Its focus on the UK specifically, adds to a body of research that is currently limited.

4.5.7. Implications

The BAME and White groups both believe that there are biological causes of dementia, but BAME members also believed that the cause of dementia was linked to religious and spiritual factors as well. This suggests that to understand dementia in BAME groups, other factors such as religion, ethnicity, and culture should be further researched as these play an important role in their help-seeking methods.

BAME groups were more likely to seek help from alternative sources as compared to the White group. When exploring differences within the BAME groups, it was found that when depicted with mild vignette there was a difference between professional help and alternative help, whereas when depicted with the severe vignette, there was no difference between the two. This suggests that help-seeking may be also influenced by the severity symptoms of dementia. When people were depicted with the severe vignette, they felt that professional care was as important as alternative care. This will be explored further in Chapter 5, to understand why certain help-seeking pathways are chosen and how they help the person with dementia.

Though there are a few studies that explored dementia in the BAME group within the UK, there is no research that explores the help-seeking methods directly that individuals may adhere to. This study helps to understand the importance and influence of religion and ethnicity on dementia, in not only understanding dementia, but also provides a useful foundation for the following studies to be built upon.

4.6. Chapter Summary

This chapter investigated the understandings and attitudes towards dementia within BAME and White groups in the UK. This was done through a questionnaire and a total of 281 participants were recruited. As the data was not normally distributed, non-parametric analyses were used (Wilcoxon, Mann Whitney U, and Spearman's Rho). The main findings included the following:

- There was no difference in belief that biological factors were the cause of dementia between BAME and White groups.
- There was a difference in beliefs that religious and spiritual factors were the cause of dementia, where BAME groups were more likely to believe this as compared to White groups.
- BAME groups were more likely to believe that alternative help was more beneficial for PwD.

Overall, this study provides a foundation for the following studies (Study 2 and 3) which helps further justify the importance of religion and culture in understandings of dementia as well as the importance to explore the alternative methods of help-seeking.

5. A Qualitative Investigation into How South Asians Muslims and Black African and Black Caribbeans Christians Understand and Experience Dementia and their Help-seeking Process

5.1. Introduction

Chapter 4 discussed different elements related to dementia that builds a foundation for this chapter to draw upon. It outlined some elements and factors which need to be further addressed in detail. Members of the BAME community were found to draw upon religious beliefs about the causes of dementia (which included karma, God's will, and not being devoted to religion) and to use alternative methods for dementia (which included family, friends, and religious leaders). The findings also found stigma associated around dementia. How exactly these understandings and beliefs play a role within the BAME community in shaping help-seeking pathways for dementia will be explored in this chapter.

Moreover, as previously discussed, the research on dementia and BAME groups in the UK is fragmented and limited. As discussed in Chapters 1 and 2 discussed how research on dementia has mainly focused on the barriers that people from BAME communities face when it comes to accessing help for dementia. Now, efforts are being made to remove these barriers and develop services which are culturally appropriate (Shanley et al., 2012). However, there is limited research focusing on alternative methods that are utilised by individuals to seek help and cope with dementia. This chapter aims to further expand from Study 1 (Chapter 4) findings on alternative help and religious and spiritual beliefs about dementia. This is done by investigating both professional and alternative methods of help-seeking and barriers related to mainstream healthcare pathways.

This study explores how SRT and SIT impact a person's perception of dementia and by extension, their help seeking approach. It focuses on their ethnic and religious identity and how it interplays with their understandings and experiences of dementia (which was briefly explored in Chapter 4). The mobilisation of their religion and ethnic identity when seeking help for dementia can play a meaningful role in strengthening their social identity. These play a key role for PwD and their carers. PwD have been regarded as losing their sense of ‘self’. Through research, it has been found that parts of the ‘self’ are severely affected while other parts remain intact—even in advanced dementia. Thus, it’s important to help PwD retain their identity, as having a sense of selfhood can ensure a high quality of life (Caddell & Clare, 2010).

A phenomenological approach is adopted to better understand PwD’s representations and their help-seeking process. This is done through the interpretative analysis method on their experiences. It is very easy to get into the pitfall of only focusing on the barriers to mainstream (professional) healthcare services, leading one to similar findings of previous research and no doubt, disregarding participants’ narratives on their personal lived experiences.

Furthermore, it should be noted that the dynamics of trying to get the experience of the person with dementia from their carer’s perspective is complicated. Informal carers play a significant role in healthcare decisions for a person for whom they have assumed responsibility (Heath et al., 2018). The approach we have opted for is to obtain the person with dementia’s experiences through a proxy, i.e., the main or informal carers. The researcher needs to be mindful of whose experience the participant is speaking of and to what extent the person with dementia impacts the carer’s experiences. It is inevitable to not gain the carer’s personal experiences; these will need to be considered alongside PwD’s experiences. It can add value to the research as it can determine how their experiences may have also impacted the help-seeking process.

This study aims to address the research question ‘What are the understandings and experiences of dementia among BAME?’ and ‘What are the alternative help-seeking pathways used by PwD?’. These questions are formulated with the influence of religion and culture in mind, and they will help further our understanding of their experiences and the methods that are used to seek help. This will then allow us to establish how these can be used in practical application.

To the researcher's knowledge (as well as found in Chapter 2), there is limited research on BAME groups and dementia in the UK, more specifically exploring the alternative methods utilised by individuals. This study will examine different methods of help-seeking from a different perspective which could potentially have a positive application on health policies. The researcher's aim is to not change current health policies but provide a new outlook at help-seeking methodologies that are currently in practice and shown to be working which can be incorporated into ongoing health policy application within the UK.

5.1.1. Research Questions

The main aim of the current qualitative study was to investigate participants' help-seeking experiences revolving around the following questions:

- How do carers understand their role as the carer for the person with dementia?
    i. What were their motives to become the carer?
    ii. How do they perceive their role as the carer? (i.e., do they see themselves as the decision maker or do they see themselves as a just a helper or aide?
- How do carers and PwD understand dementia?
    i. How do they understand their experiences of dementia?
    ii. At what point did they acknowledge dementia as an illness?
    iii. How was the diagnosis presented to the person with dementia?
- What were the processes of seeking help?
    i. What steps did they take to seek help?
    ii. What were their motives to seek help?
    iii. How did they perceive help-seeking?

    iv. What impact did religion and culture have on people with dementia and their help-seeking process?

- How did they negotiate between religious and cultural understandings with mainstream perspectives?
    i. In what ways are understandings and experiences similar or different between professional and alternative care help-seeking?

5.2. Method

This section describes the requirements of the participants, the recruitment strategy and the sample that was recruited for the study. It will then explain the interview schedule and procedure. Lastly, the analytical approach adopted will be discussed. The documents relevant to this study (participant information sheet, consent form, debriefing sheet, advert and research questions and prompts can be found in Appendix E). The researcher has also reflected on the research, research processes as well as the ethical cautions. These are discussed in Chapter 3 (Section 3.9). This study was approved by Kingston University Ethic Committee (181946).

5.2.1. Participants

In this study, a total of 12 semi-structured interviews were conducted with 15 main carers of PwD from two different religious ethnic groups. There was a total of eight participants who identified as BABCC of which three interviews were carried out with two main carers simultaneously. There was a total of eight participants who identified as SAM of which one interview was carried out with two main carers simultaneously. This was because participants shared the responsibilities of being the carer for the person with dementia. The suggested sample size for a thematic analysis research (including a professional doctorate thesis) is between 6-15 participants (Clarke & Braun, 2013). Thus, the sample size can be deemed sufficient for this research.

The initial goal was to gain at least 20 participants. However, one SAM and one BABCC participant were excluded from the study. One participant withdrew from the study during the interview, as the participant described ‘this is too much for me to talk about’, whereas the other participant did not feel that she had enough experience with the person with dementia to hold a conversation about the topic.

Following the recruitment criteria, all participants had been living in the UK for a substantial time (minimum time was 15 years) or were born in the UK. Participants’ education levels varied (Table 12). All participants were recruited from London. This was to ensure that geographical location didn’t have too much of an influence on decision-making. The following section will state the requirement established to participate in the study, the recruitment process, the sample, the interview schedule and the interview procedure.

Table 10

Demographics Characteristics of the Participants

Pseudonym	Age	Interviews	Ethnicity	Education	Relationship to PwD	Duration of diagnosis	Age of PwD	Type of dementia
Barbara	64	In-person	Black African	A-level	Wife	4-5 years	69	Mixed dementia
Marie	35			Degree	Daughter			
Emily	80	Telephone	Caribbean	GCSE	Wife	11 years	82	Vascular Dementia
Elle	40			Degree	Daughter			
Ethan	24	Telephone	Caribbean	Masters	Grandson	5 years	87	Unknown
Michelle	39	Telephone	Black African	GCSE	Daughter	2 years	78	Unknown
Stephen	38	In-Person	Caribbean	Degree	Son	7 years	84	Vascular dementia
Abdullah	61	Telephone	Pakistani	Degree	Son	9 years	89	Vascular dementia
Zehra	29			Masters	Granddaughter			
Aisha	24	In-person	Bangladeshi	Degree	Granddaughter	4 years	84	Mixed dementia
Elisa	40	In-person	Pakistani	GCSE	Daughter-in-law	3 Years	82	Vascular dementia
Nadeem	28	Skype	Bangladesh	Level 3	Granddaughter	8 years	85	Alzheimer Disease
Sara	44	Telephone	Pakistani	College	Daughter	1 year	85	Unknown
Tania	45	Telephone	Indian	College	Daughter-in-law	3 years	91	Vascular dementia
Zarah	37	In-person	Bangladesh	College	Daughter-in-law	10 years	90	Vascular dementia

5.2.1.1. Requirements. The study aimed to recruit BABCC and SAM carers of PwD, of the same ethnicity. The carers and PwD both had to identify with either one, regardless of their level of religiosity or observance. The carer also had to be the main carer (family member) of the person with dementia, and who was ideally there when the person with dementia was at the process of being diagnosed.

The age groups of the participants were 18-40 years old. The rationale behind the age groups was that there could be differences in how people would seek help for the person with dementia and to avoid differences between different representations due to generational differences. Furthermore, the participants were recruited only if they had been born in the UK or had been living in the UK for a substantial amount of time (20 years). Moreover, the participants were required to be from the Great London area.

5.2.1.2. Recruitment. The study was introduced as an understanding the experiences of dementia to participants. The study was given an accessible title 'Understanding experiences of dementia'. There was no reference of help-seeking as it was felt that any references to help-seeking could discourage potential participants as they may believe they have nothing to offer or add.

Participants were recruited through snowballing, through twitter, religious associations such as church groups and Mosques in London (see Section 3.9.2 for more information). Visiting and emailing dementia cafes was avoided as the goal of the research as to focus on people who use alternative pathways to help-seeking. A small leaflet was designed to advertise the study. When participants showed interest in the study, they were given the information sheet, consent form and answered any questions they had (Appendix E.1).

5.2.2. Interview Schedule

The interview schedule was developed by the researcher and her supervisor. The research questions and the theoretical framework was taken into consideration. A female student who identified as BABCC acted as the ‘key informant’ in the development of the interview guide. This interview schedule (Appendix E.2) was only a guide, with prompts to motivate interviewees to elaborate on their answers.

As discussed earlier and in Chapter 3, a phenomenological approach was adopted. The questions were reflected through a dialogue with questions and answers. The aim was to assist in capturing participants’ meanings and understandings of help-seeking and dementia that explore further than just barriers to mainstream health care as discussed in Chapter 2. Thus, this approach motivates participants to explore further into themselves and their experiences. During the interviews, participants were encouraged to discuss their decision-making process to access help.

5.2.2.1. Interview Procedure. At the start of the interview, participants were given an information sheet and were asked to sign a consent form. The interviewer emphasised confidentiality, anonymity and their right to withdraw without any explanation. Additionally, they did not have to answer or discuss anything they did not wish to. The study aim was repeated before the start of the interview. The interviews were carried out in different settings such as the participant’s homes, the Church, the Mosque, over the phone and at a café. With permission, the interviews were recorded and transcribed (verbatim). The interviews lasted between 40 to 60 minutes and were coded using NVIVO. Thematic analysis was used to analyse the data.

5.2.2.2. Pilot Study. For Study 2, two initial pilot studies were conducted to determine how to approach the research question. The researcher wanted to determine 1) whether it would benefit the research findings if White group were included and 2) whether people with early stages of dementia should be included in the interviews.

In the first pilot study, White Christian carers were recruited through Facebook groups. However, after conducting three interviews, the researcher acknowledged that there was no additional knowledge being added to the outcome as all participants had similar experiences and utilised mainstream health care. All participants believed that mainstream healthcare pathways were the only option. Thus, the researcher decided that this did not add any value to the research, especially because the goal of the study is not to do a comparison between White groups and the BAME community, but to mainly focus on alternative methods.

In the second pilot study, the researcher consulted experts in the field (dementia and BAME groups) to determine how her PwD should be studied. The conclusion was that if the participants are at early stages of dementia, able to consent and hold a conversation, they can be considered to take part in the interviews. In total, four PwD were recruited, however, though all of the participants were able to hold conversations, they had difficulties in recalling their experience with dementia and type of care they preferred. Some participants often went off at a tangent which left them going off topic. Out of the four PwD, only one participant, who identified as a White Christian was able to answer the questions and complete the full interview. However, the researcher realised that this task was not as straightforward as had been anticipated, and thus, the decision was made to remove PwD from the research and to only focus on main carers of PwD as they will have a holistic understanding of the person with dementia's experiences and the overall research purpose.

5.2.3. Analytic strategy

This study was analysed using qualitative thematic analysis using Braun and Clarke's (2006) guide. It was conducted in a similar way as described in Chapter 3 (Section 3.8.1) and is considered useful as it maintains theoretical and methodological flexibility. As discussed earlier in this chapter, the phenomenological approach was adopted to examine participants' decision-making process for help-seeking and to delve into the lived experiences with dementia. It looked for meanings, perceptions, understandings, motivations of participants towards help-seeking, rather than only seeking instances that reveal barriers to mainstream healthcare and only seeking themes that matched pre-existing research on dementia in BAME communities.

The development of codes and themes overall was an iterative process. The researcher began reading and rereading each interview transcript. Then proceeded to conduct the initial exploratory coding using an inductive approach led by the research questions presented in Section 5.1.1. From this, various themes emerged, and a structure was developed. This gave the researcher the unique opportunity to see how their understanding of the data evolved throughout the process. It also allowed the researcher to face and question their own understandings of BAME groups, dementia, health, and help-seeking methods.

The benefit of thematic analysis with a phenomenological approach was that it allowed a flexible approach to the analysis of the data. It gave permission to look for themes across the data as well as a hermeneutic phenomenological approach to individuals' accounts where it was deemed relevant. This gave flexibility to the researcher to approach the data though participants' narratives and to make sense of their lived experiences whilst finding consistency through the data and descriptive themes. Furthermore, taking a phenomenological approach allows one to consider or recognise that the interviewee (in this case the carer) and the person with dementia may be vulnerable, or embarrassed (Sabat, 2002). This is evident in minority ethnic groups when already they do not like to discuss many sensitive issues openly (Elam & Fenton, 2003). Thus, an interview must be seen as a social situation where both the interviewer and the interviewee work as equal partners in constructing the meaning (Sabat, 2002).

5.3. Findings

Table 13 illustrates the identified themes.

Table 11

Main and Subordinate Themes

Main Themes	Subordinate Themes
1. Facilitators to getting diagnosis	a. Generational and cultural factors in shaping participants' help-seeking motives towards dementia b. Shared identity with and trust in the person diagnosing dementia
2. Barriers to seeking help after diagnosis of dementia	a. Old age/lack of knowledge about dementia b. Negative attitudes related to dementia and the person with dementia. Confusing dementia symptoms with mental health issues. c. Previous negative experience of health d. Lack of culturally appropriate services
3. Seeking alternative help and methods of coping with dementia	a. Family carers b. Religion as coping c. Religious behaviours as routine d. Justification and comparison of using alternative methods to dementia coping and help-seeking methods

5.3.1. Facilitators to care-pathway

This theme focuses on the understandings of dementia and ways that people from BAME communities seek help through both professional and alternative means. Two main subthemes were identified when discussing help-seeking for PwD. Participants here discussed how there was a generational difference in understandings of dementia, and how their knowledge of research and perseverance led them to get their family members to getting the correct diagnosis. Also, they discussed the importance of the person's (GP or healthcare professional's) understanding of their cultural background. The following subthemes are discussed: generational differences and trust and identity. The second theme will also assist in understanding the importance of identity, shedding light and elaborating from the findings of the previous study (Chapter 4).

5.3.1.1. Generational differences. For majority of the participants, they describe their position within their family circle from their experience in relation to seeking help for dementia symptoms. Most participants negotiated and accepted their role and the differences within family circles and between generations. It seems from the accounts that there was a clear difference in understandings and motives of getting dementia symptoms checked out and diagnosed between young carers and older carers of PwD. Young carers gave evidence that it was in fact them researching the symptoms and persuading family members and PwD to seek help that led them to seek professional help. It was their motivation to research the symptoms to make these decisions and get the right help. This notion is illustrated in the following extract. It captures Aisha's experience in understanding her grandmothers' symptoms as something more than just normal aging.

> *Aisha: Like she's your granddaughter and you don't know, [laughs] so that kind of like made us go to the doctors and what it was, it was at first, I was the first person to notice that, so I actually put it out there to the doctors saying that this is what happened. I know my mum doesn't understand English and stuff like that but she, in her culture she won't understand nothing, but in me, to me I find something wrong with her (…) she was like, at first, she was like okay it could be elderly age and stuff, but I was like no it can't be, it's something else so she done tests, she was like okay let's wait for the tests to come back. After a week or later, she's like she got mixed dementia (…) you know what some people actually think that they don't see the symptoms of the early dementia. And some people think, it could be the old age. You know what it could be sort of minor, and with my, with my Nan she was like she was having them early symptoms and then if I didn't pick that up, we wouldn't have even known about it (…) So, I'm actually glad that I actually picked that up and told the doctors to do it urm tests and stuff but as she's diagnosed with it and now, we kind of know what's actually wrong with her, we don't have to you know stress about it. We don't need to worry about things like what's actually wrong with her, what is going on with her. So yeah, that's actually really good that, I think, and you know what not many families will do that…*

Aisha was describing her experience of coming across the barrier of everyone seeing her grandmother's illness as only part of old age, as well as comparing her experiences and understandings to her mums, where it was implied that despite both coming from different cultures, there is still a difference between the two (due to generational differences). It was due to this that Aisha acknowledged that there was a difference between their understanding of the symptoms and therefore the pathways and process to help-seeking. She acknowledged that there was something beyond that and something needs to be checked out. She also goes onto to explaining that without her input her grandmother would not have gotten diagnosed at an early stage.

Another example is Barbara, who stated that *'Well, it was my daughter who pushed to get him checked. Otherwise, we wouldn't have done much until it was too late'*. Furthermore, Stephan who illustrated that younger people in their community just accepted dementia as an illness whereas the older generation didn't, '*So, for my aunties, they were more worried about their own vulnerability. Like it could be me because they are around the same age. So, it was them who I found, would talk to me about my mum, rather than talk to mum. She wasn't able to articulate why she was upset and sort of finding it difficult. Whereas the younger people, sort of just accepted and understood that it was dementia.'* Here, Stephan states the frustration of the generational difference again, and how the focus was on dementia. He states that older generation (his aunties) were more concerned in how it could also impact them whereas the younger generation accepted the illness as it is.

Another example, of generational difference is Naila's extract.

> *Naila: I think they, well she got four children and she's my mum's mum. I think they were… like I'm sort of the next generation down from my parents, they are a lot more you know, shy away from feelings type of conversation and emotions. Also, they were all busy, they were you know, my mum had my dad to look after because he was not well. My Uncle and Aunties had their own children to look after, so… I think eventually they would have done something but it's also timing, they didn't really focus on it too much. Whereas I am more like, I want to be safe and find out what it is, rather than leaving if for too long … I think that, no one could deny that she was losing her memory quicker than the average person, but I actually found that the grandchildren, we were better with this, because we grew up in this country we studied in school that we can talk*

> *about things, even if its awkward. But I think, my aunts and my mum are, they for them it was a sad acceptance. They were accepting that they were losing their mum, and to be fair, I didn't want to accept it. I knew it was happening, but I didn't want to accept that it was a start of an end. We are losing her slowly.*

Again, in this extract, it is discussed how there is a difference in approaches and intentions to seeking help. Naila states how the older generations shy away from or avoid talking about illnesses as they have different approaches to discussing these topics without the necessary involvement of feelings and emotions. However, Naila felt differently about the symptoms and felt the need to get help as soon as possible. She also discusses how being brought up in the UK has also impacted how they discuss things to get them solved, whereas the older generation feel differently about this. This thinking process has allowed her to get the help she needs for her grandmother. She also discusses how her generation is able to discuss the grieving process of how they might eventually be losing a family member, whereas the older generations may not feel the same. It seems that sharing and expressing their vulnerabilities was a painful experience for the older generations and hence could explain potential delays in seeking help for dementia.

All these extracts indicate a process of negotiating from their (the carer's) position as the younger one with their elders regarding seeking help. This also shows a level of acculturation, on how their decision to go either directly to, or speak out regarding getting medical attention. The older generations seemed to identify more with 'traditional' ideologies whereas the younger generation identified more with Western methods with regards to help-seeking. However, it was also noticed that the younger generation still displayed an element of cultural identity where they understood the thinking processes behind their parents and grandparents' lack of motivation to seek help and therefore were the first ones to take a step towards getting additional help.

5.3.1.2. Importance of Identity and trust. Participants explored the influence of trust and identity when it came to seeking help from individuals. They found that it was important for them to be able trust the person who was giving them the advice and/or diagnosis. They seemed to want to relate to the person on either a religious or cultural level. Participants showed a greater level of comfort and trust in those people who they identified with. This subtheme captures how individuals' decision to seek help and accept or at the very least, understand dementia.

Marie shares her experience of how speaking to someone about her dads' symptoms who she was able to relate to or identify with helped her get the diagnosis for her dad.

> *Marie: When you speak to someone that you feel like you can relate to, I think it automatically makes you feel like you can be open with them, and that's something we definitely felt when we were getting dad diagnosed.*

Marie voices the importance of speaking to someone they felt that understood their identity and related to them.

Emily also had a similar experience regarding finding or speaking to someone about the symptoms with someone who understood their culture and religion.

> *Emily: Yes. The doctor, the doctor's practice that we go to now they're all Christians. Yeah. So, I think religion is important to them so they can understand why it's important to my husband. They even encourage him to carry on with his daily activities and visit to the church because they know it's important to him and it's something that he likes doing.*

Elisa also had similar experience, when she was getting her father-in-law diagnosed, where she appreciated the understanding of her GP of her culture.

> *Elisa: Well, the doctor that we went to see, he was great. He left now, so we are trying to locate him, because he was really good, he had experience with the Gujrati family up north, he really knew dementia, he wasn't an expert, but it was something he was interested in. So, he said a lot of things which really helped. He was saying he knew our community and he knows how our families work. We don't put out our people; we would really look after them till the end. The last option we have is to put them in a home and he's saying that's the last option that guys would even consider. He made some really good points. You know so culturally really important.*

Elisa discusses how her experience with her GP was positive overall, and how having a GP who had similar culture to her helped her understand dementia better and how to get the right help for her and her family. She also emphasis on how her GP acknowledged her culture, whilst distinguishing her culture from the majority culture (English culture). This seemed to provide her comfort in listening to her doctors and helping to take on board his advice. She also knows that the alternative would be putting her family members in a care home, which was no option.

Elisa also discussed how seeking advice from an imam also helped her family to accept the diagnosis of dementia.

> *Elisa: yeh we have, at the beginning we wanted to know if there's any duas* [prayers] *that we could read to help her. My in laws are Masha Allah* [What God has willed] *religious, so they tried to speak to someone about it, and there was something that you could read, and the imam*

was saying you read to prevent the memory loss thing. So, he was saying It in more terms of to prevent it from happening to someone else. There's nothing that they suggested for her. For me and my husband he just wanted to make sure if there is anything that's messed about with. If you know what I mean. Once he said no, then we realised that it was a medical condition and its nothing to do with anything else.

Furthermore, Elisa discussed her, and her families process of seeking additional help with their local imam and how his input also impacted their understanding of dementia and their experience with seeking further help.

Elisa: Yes, religion is very important, but you know the Mullana [Imam] *clear cut said that this is not something that I can help you with, it's an actual medical condition. That reinforced it to us, that there is no point in us going down that route. Of course, in every dua we make, we ask Allah to make it easier for her and stuff like that. It's a general dua that I do for my parents as well. But because the Mullana has clearly said to us that this is not something that I can help you with, this is a medical and go to the doctor. I am not going to pretend to you and say that if you read this you would get better. So urm that's given us assurance that it doesn't matter if the doctor doesn't know the religious aspect because it's a medical condition. That's a good question, like I wouldn't know how to answer that. Alhumdulillah* [Praise to God] *even we have a lot of faith, our faith teaches us to use our heads. If you know medication is going to help, you use medications. We look at it from all the angles, yes, we do our dua, we give her medications which work fantastic. It's the combination of both and for the doctor to know that the first doctor was amazing, and he knew exactly, what Asian household typically would do. So, he was saying if it was my mum, I wouldn't even want to know what type of dementia she has, for me all I want to*

> *know is that I can look after her and do my best. He did that, he gave us really good medication because she was a heart patient. So, the medication she can have is very limited. It's the quality of the care that's important.*

Elisa shares her experience of seeking additional help which helped her enforce her decision and helped her cope with her mother-in-law's illness. She states how speaking to the imam clarified any doubts her or her husband had. This also enforced how she, after speaking to the imam, was able to trust the diagnosis of dementia. It also shows that she may have had concerns about the dementia symptoms and whether they were something that should be classified as medical or spiritual. She also explains how their faith had an influence on their decisions and enabled them to seek medical help and not pick one method of help seeking over another.

Furthermore, Sara had similar intentions to seeking help from her local mosque. However, her outcome was different to Elisa's.

> *Sara: Well, I asked a lady that is quite closely linked to the masjid – Kingston masjid – very heavily. And I mentioned it to her, and I didn't get a response that I expected. So, I never mentioned it again. I was like I've learnt my lesson I'm not going to mention it from now on.*

Sara explains how she sought help for her mum's symptoms before she was diagnosed with dementia. However, she did not get the reaction she was expecting and therefore delayed seeking help for her mum. Sara discussed how she went to speak to someone at the mosque with the intention that they may be able to understand the symptoms of her mum and advise her on what steps she should take. She believed that they would give sound advice on how she should look after her mum and how to cope with her symptoms.

These subthemes suggest how it was important for the participants to seek help from someone they could trust to potentially give them the right advice. The subtheme also suggests that there is an importance given to people at mosques and churches, and they play an important role in help-seeking behaviours for PwD from BAME communities. As noted from Marie, Emily, and Elisa's responses, they all felt that having someone that they could identify with, and trust, was an important element in enabling their help-seeking process. They all felt that the step towards professional healthcare was made easier after speaking with someone that they identified with. Even in Sara's case, she initially attempted to speak with her local mosque and made it a point that she wanted to speak to someone that she felt would understand her values and background. This goes to show that even though seeking professional medical advice was a route that all the above participants went through, the theme of identity still played an important role in their help-seeking process. It seems that if the participants had not spoken to people that they identified with and trusted, they may not have been as receptive to the medical advice they were given.

5.3.1.3. Shared family care. This theme describes how shared family care is part of the care pathway that plays a role for individuals. Participants described how taking care of family members was an element that helped them in ways to look after the person with dementia.

> *Elisa: I think it's all about management, organisations and trying to work around what works well for you. You can get yourself into routine and I have had a lot of help from my husband and he's extremely supportive and my kids are fantastic as well. So, I have to say Alhamdulillah (Thanks to God). I know it's his mum, but you would expect that, but he doesn't really help out*

with other things as well, so I thinks it's just a teamwork. It's a partnership between me and him and we just get on with it.

Elisa: Basically, the only time we realised that she had dementia was when she was clinically diagnosed. We didn't actually know before then. My husband plays a big role in the medical side of things, he takes her to appointments, he would accompany her, and one of his sisters does that as well. They have a quite big family, so it's my older brother-in-law and his 6 sisters and my husband. So, we tried to share the care, as much as we can. So, I do it on a three-day bases and I have been doing in for the last three years…

Tania: No, his children and grandchildren know this. Whenever we are around him and he says something, and you know when he says things, or asks something. They will help him, remind him. When we go to his house, we write down the channels of his favourite show and you know helping him like that. My children are used it and they are very helpful, with helping me look after him and helping him out.

Emily: Well, I have counselling every week. Every week. Yeah. Which, which is helpful. And, my daughter is married to a West Indian from Trinidad, and he, is, you know, he's a, suppose my rock really is his, um, his father has the similar sort of temperament to my husband and so, can empathize with how, how it is for me. So, they both also come and help me look after him.

Elisa, Tania and Emily all describe the shared roles in their family for the person with dementia. Elisa describes how looking after her mother-in-law is a partnership between her and her family. She explains how the duties are shared between them which help her cope and manage her caring duties. For Tania, this is experienced with her children.

5.3.2. Barriers and Obstacles to Help-seeking

The second theme illustrates the barriers and obstacles participants faced when seeking help through both professional and alternative means. These themes reflect the findings of previous research as well as findings from Chapter 4. Across all interviews, there was a consensus that the participants faced a barrier or challenge when seeking help. This theme is divided into the following subthemes: lack of knowledge and/or old age, and negative experiences.

5.3.2.1. Lack of Knowledge and/or Old Age. Nearly all narratives discussed the lack of knowledge of dementia and/or the confusion between old age and symptoms of dementia. Participants made sense of symptoms of dementia as something arising due to old age. They inadvertently assigned something unfamiliar with something they already understood. As a result, this delayed them from seeking help for dementia.

Michelle discusses how the symptoms of dementia within her family were seen as a normal part of aging and only when the GP visited her mum, was she diagnosed with dementia.

> *Michelle: I just think that people are not aware of what dementia is. I just think that they are not aware of it. Many people don't know what dementia is in our community, I think they think it's just part of old ageing. Even with us, we did not acknowledge that she had dementia, until the GP came and visited her.*

Michelle states that people around her and in her community are not aware of what dementia is and how the symptoms of dementia are automatically assigned to their concept of old age. Similarly, Naila (below) discusses the lack of knowledge about dementia in her family and community. Here, she acknowledged that there was a lack of knowledge in her Bengali culture, and this was mostly down to a lack of education.

> *Naila: She was going to be around 77 at that time, when she was diagnosed. Everyone just assumed that its old age. They know less about it, in my family or the Bengali community, the education is limited. So, for them, there was comment like she has, she's old and her memories going. But that was the extent of it, but like biological reasons and physiological reasons, they didn't really focus on.*

Naila explains that the lack of knowledge of what dementia was in their family led them to get help much later than they could have. Their automatic response to the symptoms was that it was as a result of old age – a common go-to answer for many of the cases discussed herein.

Elisa and Ethan both also discuss how dementia was an unknown thing for them. Ethan recalls that they didn't pick up the early signs of dementia, and only when it got to a severe stage did, they realise that it was something serious.

> *Elisa: The only time we realised that she had dementia was when she was clinically diagnosed. Prior to that, there was a lot of things she was saying that kind of made us think something was wrong but to be honest, we didn't know anything about dementia before then.*

> *Ethan: No, so we only got him diagnosed but I think looking back we only got him to the doctors because the symptoms were really severe. But I think we should have got him to the GP much earlier.*

All participants in this theme discussed how their and their family's lack of knowledge resulted in them delaying seeking for help. If they were aware of what dementia symptoms looked like, they could have gotten help much sooner and as a result, they could have started treatment much earlier. Another point to note is that participants often had negative representations of the ageing process and old age. This often resulted in individuals developing negative stereotypes of old age as a result of them anchoring dementia symptoms to the ageing process.

5.3.2.2. Negative experiences. In this theme, participants discuss any negative experiences that have inhibited them from seeking professional help. Michelle discusses her mother's reaction to medicine which led her to rely on faith.

> *Michelle: She's had bad experiences after she had a stroke. The medication for all the stroke, they gave her she had a bad reaction to, so, she just decided that she will not take anything and if she dies, she going to stand strong on her faith. She is a strong faith believer, and she believes that will help her. And she's still standing at 95 today at this present time.*

Michelle stated how her mother had a bad reaction to the medicine and discusses how this led her to not rely on medications for her dementia symptoms and thus relied on her faith instead. Interestingly, Michelle emphasised that her mother was standing strong at 95 today and this was as a result of her faith and the fact that she was not taking any medications. This indicates that Michelle –

despite being a care worker – believed that her mother's faith had an impact on her health. It can be noted here that perhaps her mother's faith enabled her to have the choice of an alternative care pathway, which could be seen as an avenue that can supplement professional health care.

Aisha and her family had different experiences when getting their grandmother diagnosed. She explained how the doctors did not discuss all the possible symptoms that dementia could lead to. She implies over here that there was an expectation from her and her family that the doctors would run through everything that her grandmother would possibly experience.

> *Aisha: Yeah, at first what we kind of noticed that she's forgetting every little thing. So, we was just wondering like why she doing that so the doctor, we took her to the doctors and the doctors took a blood test and they found out that she's gotten mixed dementia. They didn't even explain that to us that you know, she will remember what she did in the past, like, when she was little, or what she did in her married life and stuff, but she won't remember anything, what she's going to do now. So, we were like okay that's fine. Urm, but as the time was going…We kind of felt, you know bit difficult. We didn't know what to do anymore.*

It seems that as a result of the doctors not fully explaining to Aisha and her family the potentially advanced symptoms of dementia, it left the family with a view that the doctors would not be able to help them further which led them to being uncertain about the next steps in terms of caring for the grandmother.

Elisa discusses her experiences with social services. Once her mother-in-law was diagnosed with dementia, social services provided them with a care worker to support her mother-in-law at home.

> *Elisa: Through the adult social service centre, we had a worker, and she was rubbish, absolutely rubbish. I felt that she needed more support than my mother-in-law did. She came and just sat there and talked about her own problems. Bless her, her whole idea was to stimulate my mother-in-law because at that time, I remember clearly my mother-in-law wouldn't leave her bedroom. She wouldn't even get out of bed so the whole point was for this person to motivate and stimulate her. My mother-in-law got even more annoyed at her when she saw her. Such a waste of time, obviously she didn't realise she was there to help her. Even as a person as an outsider, I was seeing what she did, and she was an absolutely waste of time and waste of money. We had to stop it.*

Elisa goes on to describing they had a terrible experience with the social worker and how she was not able to do her job. The negative experience led them to stopping a potentially invaluable service which could have really benefited her mother's quality of life.

5.3.3. Alternative Methods to Help-seeking and Coping

This theme is an important and critical theme that explores the alternative methods to help-seeking that people take. It shows the importance of these methods and how they can help individuals who rely on culture and religion. This theme is divided into the following subthemes: looking after their own family members, religious behaviours to create routines, and religion and medicine. These themes also further elaborate on the findings from Chapter 4 where alternative help was deemed to be an important pathway for the person with dementia in BAME communities.

5.3.3.1. Reasons and Motives to Look After own Family Members. This was a recurring theme in all the participants' accounts. Family members were seen as the main carers of the person with dementia and were influenced by either religion and/or culture.

Ethan, Stephan, and Tania discussed how their intentions to look after their family members with dementia were influenced by their cultural values.

> *Ethan: Well, I think it's in our family, it's in our culture. Many people, I'm going to say it like that they, they know, they just care for their parents just they return the favour, just they don't think, or they don't have any hard feelings towards doing, doing it. To them they are just returning that service to their parents because they did that for them. They don't look after them because they want to. I think that's really important in our culture and faith.*

Ethan discusses how he believes it's in his culture to look after their family members. He further explains how he believes that there's a difference in intentions to take care of family member as well, as sometimes, others do not look after their parents for the right reasons. He describes other people's motives as "returning the favour", whereas for him, he believes that people should want to look after their parents. Which also suggests that there are differences within cultural groups.

Similarly, Stephan has the same motivation to be a carer for his mum.

> *Stephan: I think so, but not in a… I think the values that I have, but I feel it's my responsibility to care from my mum. I think culturally, it is interesting because I feel as a value bases to look after your parents. I think a lot of people from the same cultural background, don't*

> *care about parents, so what part of culture is that. Because it is not necessarily shared across everyone. So maybe it's more of our family culture.*

However, Stephan also discusses why this might not be the case for other people from his culture, explaining how this may only be the case in his family's culture.

> *Tania: But you know its cultural reasons as well. You look after your elders, your parents, no matter what happens. Who else would look after them, Plus, we know them better than anyone else. You know it's what we do with our family members. We don't give put them in the care home.*

Here Tania discusses how her intentions to be the main carer were influenced by cultural reasons. She discusses how no matter what happens to the person, it's not in their culture to put the person in a care home. Furthermore, there is also a religious motive for looking after your family members. Here, Elisa and Aisha describe their relationship with religion and how this has influenced their decisions.

> *Elisa: For me I thought well if I can't get into heaven with other activity done in my life. Then Insha Allah [If God Wills] if she is happy with me my mother-in-law and treat her well. I am thinking then Insha Allah, you know. We believe that the mothers are a gateway to heaven and paradise lies at their feet. You know I am talking to you as a fellow Muslim, so you know where I am coming from. You will really get disappointed if you are doing for the person, because that person would turn around and not appreciate it after a while, then you would think 'Why am I even doing this'. So, then I thought I am not looking for appreciation from the person.*

For Elisa her purpose to be a carer for her mother-in-law was influenced by her religious beliefs. She tries to justify being a carer for her mother-in-law using religious values and uses specific interpretations/passages of the Quran to justify her thought process. She also goes on to discuss the importance of having the right intentions when taking on the decision to be a carer. Moreover, it seems that Elisa's true intention to help her mother-in-law related her wanting to gain Heaven through her correct actions in accordance with her religious beliefs as opposed to simply wanting to help her mother-in-law. She specifically mentions that her mother-in-law would likely forget that Elisa was helping. However, knowing that her actions may grant her Heaven enabled her to keep going.

> *Aisha: It's cultural and religious reasons. Cultural is that you know how Asian community is that they would never put any parents to the care home. Also, religious wise, mum thinks that you know it's her mum, it's her birth mother. Who's given birth to her and brought her to this world and brought her, that's why she is, that's the whole reason why she doesn't want to put her to a care home, because she will regret the rest of her life and she will feel guilty for it. Even with me like I would feel guilty cause she looked after me from day one she was there in my life so obviously I won't want her to suffer, and also you know like in care homes like when you see in the news and stuff, the abuse and stuff. So that kind of makes it worse, so we were like, we might do a better job than they might do [Laughs].*

> *Aisha: I know that other people won't think the same but, in my mind, it comes that this is your birth mother; she went through nine months to give you birth. She brought you up, she dressed you, she fed you and everything, like why would you do that to her. So yeah, that's the*

> *whole reason why we don't, why we're against it, and in, the NHS did advise us that you know if it's getting too difficult for you guys, there's always a care home option, but we said no.*

Aisha discusses her reasoning to look after her grandmother. She discusses both cultural and religious values. Aisha first discusses how it's not normal for people in her culture to put their family members/parents into a care home. She further justifies this by pointing out that it's also her religious duty to look after your parents/family members and there's also an element of guilt. Especially when she feels that her being the main carer, she would do a better job than people at the care home. Aisha also discusses how the quality of the care homes are portrayed negatively in the media and how potentially putting her grandmother there would make the situation worse. It should be noted here that the decision to be the main carer for her grandmother was not seen as something burdensome, but instead, something she wanted to do.

5.3.3.2. Religious routine behaviours. This theme explores how religious behaviours such as praying, visiting the Church or the Mosque has an impact on the person with dementia and how they have continued to carry on these activities that have in turn, helped them make a routine in their lives and thus helped them cope with dementia. This theme reflects how the person with dementia's identity is able to continue even after developing dementia.

Tania discusses how visiting the mosque on Fridays has become a weekly routine for her father-in-law.

> *Tania: Yeh Masha Allah we remind him to pray and sometimes he prays on his own. On Fridays he loves going to pray. He gets ready, and come here for lunch, and my husband and father-in-law both go to the mosque. It's like a little outing for him. They meet people there; they*

> *also meet the imam. This way he can socialise with the people there. So, it's really good for him, so yes in a way it helps him a lot.*

Tania shares her father-in-law's experience of visiting the mosque every Friday. She describes how visiting the mosque and socialising with others has had a positive impact on the father-in-law's quality of life.

Emily also discusses how the church has helped her husband cope. She states, *'yeh, they help him a lot. They pray with him, and it sort of gives him a routine and a place, a safe place where he belongs.'* She suggested that going to the church daily gave him a place of belonging and a routine that has a positive impact.

Michelle discusses how her mother is in denial of her dementia diagnosis. She goes onto explain that despite her denial, she visits the church which ultimately helps her cope with her symptoms.

> *Michelle: I think it gives her something to look forward to. Something that she can do to keep her busy. If she stayed at home all the time it could make her lonely and make her upset. Though, I don't really know if they know much about dementia or her condition. If they were more involved with dementia and understood dementia, they might have an effect on opinions and beliefs. She does have a group that meets together. But I don't know as an outsider. But maybe they can help acknowledge that she has dementia. You know that dementia is there, that some of the elderly have been there, and they have had it too.*

Michelle shares how her mother visits the church and has something to look forward to. She states that if her mother did not go and visit the church it would impact her in a negative way. She also acknowledges that the church doesn't really know about her condition but feels that if they did, they would help play a role in her accepting her dementia.

Ethan discusses his grandfather's relationship with religion despite the severity of the disease.

> *Ethan: Oh yeah, that is something that he still enjoys. I know at the nursing home one of the nurses told us that he likes to listen to his church music. Sometimes when they feel he is sad they just put that on the recording. It's sad to see him like that because he used to love going to the church and listen to it there. He was a very devout, devout Christian. He used to pray month, every month, every night for his family, his friends, he was a very selfless man when it comes to prayer. He was always praying and was always speaking about God, always speaking about his people, yeh so a very devoted man.*

Ethan shares his grandfather's experience with dementia and religion. He discusses how before his grandfather's dementia got worse, he had a good relationship with the church and was a very devout Christian. As his dementia symptoms worsened, he was not able to visit the church the same way he used to. However, his relationship with religion and his religious identity is still strong and there are alternatives to going to Church that still allow him to practice and be involved with his religion. For example, he still prays with and enjoys the church music that helps him cope at the nursing home.

Abdullah shared his experience of his dad praying despite his dementia.

> *Abdullah: We would continuously I mean even in spite of suffering from dementia or other illnesses, he would keep offering namaaz [Prayer], keep offering namaaz [Prayer], keep offering Salat any time whenever he makes 'yeah I want to do wudu', ok, let's do wudu. So, that means he was aware of his religious obligations all along.*

Interviewer: And, do you think, in your opinion, like from observing him, that prayer helped him?

> *Abdullah: my belief is erm that of course, you know, your true prayers always benefit you. So, I'm sure, in his case it must have done so, but because this is something an individual act, I can't say anything whether it helped him or not, but my belief it does help, and it would have helped him as well.*

Abdullah speaks about how his dad offered prayer despite his dementia symptoms. He also states how his dad was usually the one to suggest offering prayer. When asked about whether offering prayer helped his father, Abdullah did confirm that they did in his opinion, however, he was very careful to make sure he separated his experiences from those of his father's. We also note Abdullah's own coping method with his father's dementia. He told himself that the prayers would be benefiting his father regardless of his dementia.

Overall, all participants discuss the importance of religious identity for PwD after diagnosis. This theme goes into more detail from the findings of Chapter 4 regarding alternative care pathways. Chapter 4 found that BAME groups were more likely find alternative help as equal, if not more beneficial than professional help. This study expands on these findings by delving deeper into the various forms of alternative care that the BAME community utilises. The study has addressed how individuals' motivations, personal experiences and identity influence help-seeking.

5.3.3.3. Using both/All methods (meaning of help-seeking). This subtheme reveals how participants view both religious help-seeking and mainstream help-seeking methods. Most participants stated how religious behaviours (such as going to either the church or mosque) have a positive impact for the person with dementia, but also mentioned improvements in the community which could give them and the person with dementia extra support.

Michelle states how funding from the government to the church would make a difference in her mum's understanding of dementia

> *Michelle: Well, it's difficult to say because it depends on the borough and how much funding there is. So, where I work, the borough is well funded, and you can see the difference where my mum lives and the funding for the elderly. The funding makes a big difference to how people are treated and the help that is given to them. The government should also help churches and give them the resources, because the elderly out there are not getting the help they need.*
>
> *Michelle: Yeh I think if there was some scheme or if people at churches were more aware of dementia or even other illnesses, they could really help people out in understanding their illnesses. Like for mum, I think if her church knew about dementia or had something available for her, I think she would accept her illness.*

Michelle compares how different boroughs work and how funding can impact the outcome for the location. She states how government funding at church can help increase knowledge of dementia in communities such as the church, and therefore, may be able to help her mother accept dementia.

Naila discusses how options were given to her and her family to get extra support, but they didn't feel it was needed.

> *Naila: They offered her to go this group, where people got together who had Alzheimer's, so she can talk to and be active. We don't really need that. We had in our family we had people that she can talk to and need. And it would have just made her more confused and irritated. She went once and she just said she was in a room with people who she didn't know. Urm so we, in our family she always had me or my grandfather around with her, and she always had family around, so she was never on her own anyway.*

> *Naila: Bottom line, was that she had enough people to look after her, you know she had 4 children and 8 grandchildren, and like 5 great grand kids. We have enough in the family. There was no need for her to be socialising with random people she didn't know. I think taking her out, would have helped her. Even if it's organised by someone else.*

Naila stated how her grandfather had options to visit day care centres where he may be able to interact with other people. However, she felt that this was not ideal for him and compared what services were offering to what the families provided at home. She stated that there was no difference between the two and so there was no point in getting external help when the family already provided the service at home.

Tania goes onto exploring how religion is something that many people use and how it can even be used to prevent dementia.

> *Tania: yeh definitely, I think there's so much thing the religion that we all need to use. You know even praying and reading the Quran can help people with dementia, you know Alzheimer's, depression, and all those mental health problems. I know a lot of ladies and they recite the Quran every day, and it really helps them with their memory, and keeps them sharp. They will remember everything. They can tell you people birthdays, and you just chat to one and they will tell you anything. So, people just need to use and understand the religion. Even my grandfather used to read the Quran, but there were times he didn't have time, but it can help people.*

Tania discusses how people at the mosque use Quran to help them, and it keeps their brain active, and she suggested that people should use the Quran to help them.

This theme explored how different alternative methods (such as supporting the church in increasing their knowledge of dementia, family care and reading the Quran) can help or be used in addition to coping with dementia. This will be further explored in Chapter 6 and 7.

5.3.4. Negative Attitudes and Stigma

This theme provides a more in-depth exploration of participants and the person with dementia's understandings of dementia. Across nearly all interviews, there were some indications or themes of negative perceptions of dementia. Interestingly, these cases did not imply whether this impacted individuals' help-seeking process. Rather, they gave them as a reason why dementia was developed, i.e., even if they did not know the exact cause of dementia, they attributed the cause to something negative. These representations of dementia are further explored in the following extracts.

Aisha describes how dementia symptoms were often confused with mental health illness which impacted how dementia was viewed by others around her.

> *Aisha: I think it should be out there and like, I know like when someone just hear that 'oh she's got dementia,' they always judge you straight away… oh so she's got mental issues. That's the main thing that comes into your head like oh she's got mental issues and there's already so much stigma around dementia. Especially in Islam. They think that you're not religious enough or are just upset for no reason. There you go so, it's just not, okay I just think it should be out there.*

Aisha explained how dementia was judged based on their understandings of mental illness. Therefore, dementia was seen to be the result of not being religious enough. She discusses the stigma related to this and how she feels that this is not okay.

Conversely, for Zara, dementia was a result of not doing a lot in the house and not being independent enough.

> *Zara: She had a lot of illnesses, there was so much going on in her life from the beginning she had low self-esteem, she had anxiety I don't know her husband was always getting re-married. She had a lot of issues, when she came here, she didn't really leave the house much, and she raised her children up by herself. She stayed home as a housewife, raised her child up, she was dependent on her children, and she didn't really have routine in her life, that could be a reason. You know when you have a routine in your life, you do things, have more control over things, when*

> *you don't you tend to do things yourself, you forget. She always got that support and didn't do anything herself and at the end she… brain sort of dies out.*

Zara described how her mother-in-law's cause of dementia was her lifestyle. She explains how her dependency on her children led to her cognitive decline. Zara seemed to be implying that the cause of dementia was her mother-in-law's fault and portrayed it as something that could have been avoided.

Stephan and Ethan also discuss how in their opinion, dementia for them is caused by isolation.

> *Stephan: No not really, we just thought it was another illness. I didn't think really of it. I think… I think for me there was this, an issue of isolation because she had lots of people around her, but her family was all over the place.*

> *Ethan: And I think it's that the lack of company or lack of friends probably made him start to speak with himself and I think that developed his, his condition.*

Both Stephan and Ethan seem to be putting the cause of dementia down to the person's lifestyle. They both discuss how dementia was caused by isolation and lack of company. This assessment reflected some sort of perceived/personal stigma.

Abdullah was the only participant who said that he didn't seek any additional help from members of community.

> *Abdullah: I don’t think so, because that’s another dilemma with our Asian background. I don’t know if you belong to Asian background, but – yeah that’s a sad bit with us people. Sometimes we don’t want to declare ourselves that we are going through this ailment or suffering. It could be that our people, or our certain accept per and now become a cucumber or a cabbage or a useless, so I don’t want to declare to other people, so, I don’t see the connection to anybody. No, no, I don’t think so, no.*

> *Abdullah: With the Asian community is a bit different. We don’t really express our problems to anyone, until we have to. So, with the local community we didn’t really talk to anyone about his health condition.*

Abdullah discussed how members of his community do not talk about problems issues which led him not to discuss any dementia symptoms with them. He also discussed how dementia might be misunderstood and the person with dementia may be seen as ‘useless’, suggesting perceived stigma within the community. This impacted how he sought help.

Overall, this theme discussed stigma around dementia, which reflected previous findings as well as findings of Chapter 4. Interestingly, most participants discussed the negative perceptions on dementia, however, (except for Abdullah) stigma did not seem to impact participants’ help-seeking process. Abdullah stated that the negative perception around dementia in the Asian community and how it stopped him in discussing his dad’s dementia symptoms. However, this did not impact his pathway to seeking professional help.

5.4. Discussion

The present study was designed to examine SAM and BABCC carers' understandings and experience of dementia and help-seeking. A phenomenological approach to help-seeking was adopted and a total of twelve semi-structured interviews were conducted with 15 carers of PwD.

Participants described the help-seeking process through their role within their families. They discussed how this enabled them to seek help and accept dementia. Generational differences in carers seemed to be a factor shaping choices in seeking professional help. Participants discussed how there was a difference in generations and how that impacted how they seek help. They discussed how being the younger generation within the family, they were able to control the narrative of the dementia symptoms and get the help that was needed, despite the older generation or other people believing differently. From a theoretical standpoint, this can be found within SRT where people within the same community hold differing views on the same issues and it highlights the dynamic approach to conceptualisation that SRT can provide. Dodd et al. (2020) also reported that for BAME groups, the main informants were significantly more likely to be identified as adult children rather that the Person with Dementia's spouse or partner suggesting that the younger generation (second and third) are more likely to play a key role in the decision-making process. Knifton (2012) reported that minority ethnic individuals from second and third generations were more likely to seek help and engage with readily available services (for mental health) as compared to the older people from the first generation. This reflects levels of acculturation in individuals when seeking help and shows how they negotiate between their two identities (ethnic identity and Western identities) and acknowledge the differences in their respective contexts. Therefore, they are able make decisions to seek help for PwD.

Additionally, barriers to seeking help were also discussed. These include factors such as misunderstanding of dementia symptoms (due to a lack of knowledge) and drawing from previous negative experiences (with professional healthcare services). Participants discussed how the symptoms of dementia were seen as a normal part of ageing rather than a disease, which often led to delayed help seeking. This goes in line with previous research, which found that SA carers tend to believe dementia symptoms such as ‘memory loss’ to be a part of the normal ageing process (Hossain et al., 2020). Other studies in minority ethnic groups also found that there is a general lack of knowledge regarding dementia symptoms (La Fontaine et al., 2007). This process of viewing dementia symptoms as something ‘unfamiliar’ and attaching them to the negative aspects of something familiar (such as the ageing process) mirrors the anchoring process within social representation theory (Moscovici, 2008, p. 55). Ageism is a great social barrier faced by many older PwD and age can become stigmatized based upon negative stereotypes related the aging process. There are cultural stereotypes associated with age which include powerlessness, decline of memory, sickness, and dependency (Alzheimer’s Society, 2020; Dionigi, 2015). In this context, age itself becomes seen as an incurable illness as the body declines and ‘fails’, and dementia becomes the ultimate symbolic embodiment of death since the mind is assumed to have ‘gone’. These stereotypes are universally negative and are associated with dependency. This suggests that not only are dementia symptoms misrepresented, but they are combined with the general negative stereotypes of ageing, blurring the differences between the two. Healthcare specialists therefore need to address both issues together rather than separately.

Past experiences also shone through participants’ responses. Doll et al. (2021) discuss how familiarity with healthcare services reflected the decision-making process and the likelihood of service use. So, positive experiences (such as with Elisa and the GP) would lead individuals to better utilise the services available to them whereas negative experiences (such as Elisa with the service worker) would lead the same individual to not utilise services. Negative experiences with medication also played a role in participants’ decision making. Believing that medication may not be working led to some individuals turning towards faith and religious practices for help and completely disregarding medical options. It seems that most actions of the participants were in part informed by their previous experiences.

Catering for individuals' experience and making sure they are content with the service they are receiving should be an important element in the grand scheme of healthcare service delivery and not only for dementia but for other illnesses as well.

There was a general shared consensus around the representation of informal care for PwD. This is a common phenomenon with traditional collectivist cultures. Participants discussed the importance of being a carer for the family member which was driven by family values, culture and or religion. Some participants also discussed how this care role was important to them and their cultural identity and values. They did this by implying how their culture and values were different to the majority (White/Western) culture which often portrayed an aspect of the 'us vs them' mentality – very similar to the principles of social identity theory. This shows a form of acculturation where participants recognise but refrain from adopting the majority culture (White/Western culture).

However, some participants also drew comparisons with those in the same culture as them, implying that not every individual will share or uphold the same family, cultural or religious values as them. These beliefs were often portrayed as a lack of family values and were something that was considered negative by the participants. These findings suggests that different levels of acculturation can have an impact on the decisions family members make in terms of becoming a carer and the general help-seeking strategy adopted by the person with dementia and their carer.

Furthermore, shared family care plays an important role within the help-seeking process. Participants discussed that shared family responsibilities regarding taking care of the person with dementia was common practice within their family. These roles were also established in the facilitators to care-pathway theme. Participants discussed how the responsibilities for taking care of the person with dementia was shared amongst family members, which helped cares reduce burden. These findings accord with previous findings which suggests how people from minority ethnic groups share roles within families and that the decision to engage help-seeking pathways is also made between them (Jolles et al., 2019; Mead et al., 2013). This is common in collectivist cultures, where family members share roles. These two findings show that though dementia impacts older members of minority ethnic communities, second and third generations of family groups should also be considered when building policies. This will be further explored in Chapter 7.

The role of family carers is a well-researched topic and most of the research on minority ethnic groups discuss the importance of family carers. Herat-Gunaratne et al. (2020) found that minority ethnic family carers of PwD spoke of their role as a natural, expected role and it was a duty of care that they had. This element of family care reflects a care model that operates at the community level (Calia et al., 2019; Knapp et al., 2007). The responses explore the emotional experience of dementia and saw each individual as a person, rather than a condition to be managed, which captures the importance of relationships (for well-being) and is a key aspect of person-centred care (Calia et al., 2019; Kitwood, & Berdin, 1992). These representations demonstrate the shared values regardless of what the influence which have also been captured by the majority of research in minority ethnic groups.

Participants also highlighted how religious behaviours (i.e., going to the church or mosque) and religious networks play a huge role in their help-seeking process. Their responses showed multiple ways in which religious behaviour influenced PwD’s experiences. It is reported that when religious individuals are faced with difficulty, they use a variety of religious coping resources that are drawn from spiritual, behavioural, social aspects of the individual’s faith (Hathaway & Pargament, 1992; Ysseldyk et al., 2010). The findings of this study suggested that participants were able to refer to God helping them get through the illness, which acted as a source of coping. This was also enhanced by praying which was used by some PwD to help them cope. This was something that they continued from the pre-diagnosis stage. Nearly all participants expressed the importance of prayer for the person with dementia and the benefits it had. Research has suggested that the use of faith in God and prayer are the most common form of coping resource for religious individuals (Pargament 1999; Paragment et al., 2001). According to

Paragment et al. (2001), when individuals deal with life stressors, religion acts as a resource to understanding and dealing with the situations. It provides various ways of coping that are critical to understanding of life crises and general well-being.

Furthermore, religious routines such as visiting different services (for example, services at church or Friday prayers) were also deemed to be beneficial for the person with dementia and was seen as a source of coping. The habits helped PwD retain their social identity and thus, their sense of selfhood. Participants discussed how visiting religious services provided a source of familiarity and allowed the person with dementia to follow their religious identity. Participants also suggested that this allows PwD to look forward to something as well as helps them socialise and get out of the house. This is an example of person-centred-care that PwD can utilise. Previous research found that faith can help with the management of dementia and faith-based activities (such as praying, going to the mosque or church, and reciting hymns or the Quran) should be increased for PwD. MacKinlay (2012) and Timmins et al. (2015) found that religious rituals were in fact comforting for people and helped them preserve a sense of their identity. Moreover, Ødbehr et al. (2014) found that staff members at nursing homes noted that prayer, singing hymns and the use of quiet, sacred spaces can reduce distress in those living with dementia.

The use of religion to not only understand dementia, but also use it as a coping method can be an extension of the findings from Chapter 4. Previous research has reported that religion potentially provides a sense of identity as it offers a set of beliefs, traditions, rituals, and symbols which help define an aspect of the individual (Ysseldyk et al., 2010). Their experience with religion reinforces it as part of their identity, which is in line with SIT. Once the person develops dementia, this part of their identity continues post-diagnosis and can become a source of comfort for them due to their familiarity with it. Dalby et al. (2012) discuss how faith is something that becomes stronger when people get older. This, combined with the fact that their faith forms part of their identity, it becomes one of the centre point elements in their experience with dementia symptoms.

Participants also implied that the diagnosis process was also influenced by their trust in the person diagnosing and advising on the disease. Most participants understood help-seeking as seeking help from different sources including secular, religion, and family. This was influenced specifically by their identity and how they viewed each source. In this study, social identity (specifically, religious, and cultural identity) was an important element when seeking help as it helped individuals build their level of trust and comfort. Individuals discussed how speaking about dementia and their diagnosis with someone who they trusted helped them understand it better and also made it easier to accept the illness as a biological issue. For example, some participants stated they had a connection with the doctors, which made it easier and more likely for them to accept a diagnosis. Participants also sought advice from their religious leaders as they were someone they trusted, and it helped inform their decision-making process. Religious leaders are seen as intimately acquainted with religious resources for problem solving which is often a critical part of their role (Paragment et al., 2001). Heseltine-Carp and Hoskins (2020) found that Christian clergy were identified as frontline mental health workers, suggesting their importance in the help-seeking decisions. Religious leaders' roles for dementia are further explored in Chapter 6. The results of this study demonstrate that one aspect of the help-seeking and decision-making pathway is informed significantly by SIT, i.e., by participants' religious and cultural identity.

There was also evidence which suggested that negative perception and stigma played a role in how dementia was viewed which was also reflected in previous research and Chapter 4's findings. Chapter 4 indicated that stigma can influence individuals' beliefs about beneficial treatment and thus their help-seeking method. Whereas, in this study, only one participant drew on how stigma had an impact on the help-seeking process. The potential reason for this finding could be due to the participants recruited to this study. The PwD in this research had already passed the diagnosis stage and thus, had already sought help. Those individuals with stigma around dementia may have not been recruited due to them not-seeking help or wanting to openly discuss dementia with others. Thus, this suggests that there needs to be further research on the exact impact of stigma on the help-seeking process.

These findings of the study can help play a role in developing person-centred care for individuals from BAME communities. This needs to be explored further, especially the relationship between religious services and person-centred care for PwD. Moreover, incorporating both social identity theory and social representation theory can help better understand the deeper thought processes that are involved within people with dementia's help-seeking processes. Herat-Gunaratne et al. (2020) suggest that culturally relevant psychosocial interventions can not only help PwD, but also help their family members by alleviating their care burden. The role of religion (religious leaders, religion, and religious behaviours) will be explored further in Chapter 6. In Chapter 7 the findings of the studies will be collated together to examine and develop the practical implications of the findings.

In conclusion, this study has depicted how help-seeking processes for PwD are influenced by religious and cultural factors. Participants discussed the importance of religion when seeking help and how it plays a role in their decision-making processes. They also discussed the alternative help-seeking methods they used to make sense of the symptoms. Ultimately, this study showed the decision-making process of people who use alternative help and how it benefits them. These findings are further elaborated on in Chapter 6, and the practical applications are discussed in Chapter 7.

5.4.1. Limitations of Study

As with all studies, there are some limitations present within this study as well. These limitations concern mainly the research process itself. The researcher recruited carers of the person with dementia (as also discussed in section 5.2.1) which may have had an influence on the decision-making process, and the outcome was only from the carer's perspective. The researcher did attempt to recruit participants directly which had dementia. However, as mentioned earlier in this chapter, it was difficult to recruit PwD who were also still capable of participating in the full interview.

The research may have also had participants who had higher levels of acculturation as compared to previous studies (Herat-Gunaratne et al., 2020). Participants requirements for this research were that they were born in the UK or have been living in UK for at least 20 years. All interviews were conducted in English, so the researcher could not capture the perspective of carers who did not speak English fluently.

Another potential limitation of the interview process might lie in the researcher's identity in relation to the SAM participants. Previous authors have described the need for ethnic and language matching in research regarding minority ethnic communities, which would elicit trust and shared understanding (Victor, 2014). However, the researcher in this study had different nationalities to the interviewees (BABC). As addressed in Chapter 3 (section 3.7.4.1), due to her own ethnicity, the researcher had a different relationship with the SAM community than with the BABCC community. When recruiting participants from the BABCC, a secondary researcher was used to 'gain access' to the community, as the primary researcher was not considered an 'insider'. However, due to the researcher's ethnicity, she was considered an insider with the SAM community. This was not always beneficial, as when interviewing the SAM community participants, they would often provide shorter answers as they assumed the researcher would understand what they were saying or implying. The researcher would often have to nudge them and push them towards elaborating their answers further to gain a better insight.

5.4.2. Implications of Study

The role of religion in help-seeking behaviour, especially the role of churches/mosques (and by extension, religious leaders) has been found to have an influence on the help-seeking and decision-making process that people from the BAME community utilise. Therefore, the next stage is to focus on exploring exactly what role they play, and how they may inhibit or facilitate the process. Also, it is key to explore how they can be included in policies to help the overall care pathway systems currently in place to better suit people's needs. This will also be explored in Chapter 6 and 7.

This study showed that the different factors that can inhibit or facilitate people from seeking help. It provides a good view on people's experiences which can also be used by health care professionals to help engage with people from BAME communities. For example, the role of carers in help-seeking was established. The findings discussed that they play an important role in the help-seeking process and thus can allow health care providers to target carers of PwD as well the person with dementia. It was also found the religious leaders can have an impact on the process, thus more efforts can be made by health care providers to work with the religious leaders.

5.5. Conclusion/Summary

This chapter has explored the understandings and experiences of dementia of BAME carers. It aimed to further elaborate from Chapter 4's findings, specifically on alternative methods to help-seeking. The focus on alternative help-seeking methods provides a unique approach to research on dementia within BAME communities in the UK. To understand this further, semi-structured interviews were carried out on 15 carers of PwD. It adopted a phenomenological approach to understandings of help-seeking and dementia. This approach encouraged participants to reflect on their help-seeking experiences and capture their own meaning of help-seeking. More specifically, it illustrated that religion and culture are important factors in help-seeking decisions, as well as built the argument that there are alternative methods of help-seeking that can be beneficial for PwD. Overall, this chapter provides a useful insight to how people seek help and what and why certain methods are utilised. It provides a detailed understanding of help-seeking which will enable the collation of different care pathways. This will be further explored in Chapter 7.

6. Understanding the Role of Religious Leaders in the Help-seeking Process for People with Dementia.

6.1. Introduction

The findings of Chapter 5 established that religious leaders have an influence over understandings of dementia and the help-seeking methods used by people. However, this role needs to be further researched. Heseltine-Carp & Hoskins (2020) discuss how religious leaders play an important role in society and are often ignored regarding the influence they have on individuals, often seen as having very limited roles within the community. A US-based study by Wang et al. (2003) found that clergies were contacted by a higher proportion of people with mental health problems than psychiatric or general medical doctors. This study focuses on the role clergies play within their community when it comes to communicating and working with PwD. At present, most research only focuses on the influential role of clergies regarding mental illnesses in general. However, there is very limited research pertaining to dementia and how it should be treated – particularly within the BAME community.

It should be noted that within the research that does exist in this area, Heseltine-Carp and Hoskins (2020) found that 60-80% of mental health cases were referred on to health-care professionals by clergies – a proportion sizeable enough to potentially be considered an important factor when addressing health policies. However, the opposite was not true, i.e., clergies did not receive referrals from professional healthcare services, despite the proven benefits in quality of life for patients as also indicated in the previous chapter.

To better understand the role of clergies and religious services, social representation theory is adopted. SRs of dementia and help-seeking exist both at the individual and community level. As clergies are often seen as playing an important role in communities (Weaver et al., 2003), their opinion and understanding of how their representations formed are critical to understanding how the community's representation are formed as well. Studying SRs of dementia that are held within the community by their religious leaders may enable healthcare services to provide better and more well-suited services to PwD from the community. Furthermore, adopting SIT will inform how religious identity plays a role in help-seeking decisions for religious leaders as well as for individuals. It will inform on their religious identity and how it may extend to their help-seeking decisions. It will aim to expand on some findings of Chapter 4 and 5 on the importance of religion and cultural values on help-seeking including family carers and religion as coping methods.

Though there is previous research which has explored the role of religious leaders on dementia, most are based in the US (Chadiha et al., 1994; Epps et al., 2019; Kennedy et al., 2014). There is very limited research on dementia and clergies in the UK, especially based on minority ethnic groups. Thus, the role of clergies and religious services needs to be further explored within the UK context. This thesis will focus on qualitative methods to understand help-seeking in these groups and dive deeper into the influence that the religious leaders of the community have. One aim of this thesis is also to help bridge gaps between clergies and health care professionals. This study addresses the research question 'How do religion and religious leaders play a role in understandings and experiences of dementia and help-seeking?'. This will allow us to not only understand the influence of religion and culture, but also the role of religious leaders as well. The findings of this research will help shed light onto alternative help-seeking methods.

6.1.1. Research Questions

The main aim of the current qualitative study was to investigate religious leaders' role in dementia help-seeking methods. It does this by considering the following research questions:

- How do religious leaders understand dementia?

    - To what extent do their understandings reflect lay persons (within their community) of dementia?
- To what extent do their understandings reflect health professionals?
- How do religious leaders’ understandings of dementia impact the decision-making processes of families and PwD?
    - How do they navigate between religious and secular help?
    - How do they navigate between religious/spiritual and biological reasonings of cause of dementia?
- What role do clergies play in the decision-making process?
    - What role do clergies play when individuals seeking help do not use mainstream methods in particular do they encourage or discourage individuals?
- What is the influence of religion on PwD?
    - What are the services that they utilise?
    - Do they cater to dementia?
    - How can these be used to further to help PwD?
- What are their perspectives on family and state care (nursing homes)
    - What methods to they encourage?
- How do they or do they envision them working with health care professionals?
    - How would they like to be better supported?

6.2. Method

In this section, the researcher discusses the participants’ requirements, as well as the research strategy. This is followed by the schedule and the procedure for the interviews. Finally, the analytical approach that will be used for the analysis is discussed.

The documents relevant to this study (participant information sheet, consent form, debriefing sheet, advert and interview prompts) can be found in Appendix F. This study was approved by Kingston University Ethic Committee (181946).

6.2.1. Participants

The data for this study was collected by a total of 15 semi-structured interviews on BABCC and SAM religious leaders. A total of 15 participants were recruited and interviewed, of which seven were BABCC and eight were SAM. The suggested sample size for a medium sized thematic analysis research project, including a professional doctorate thesis is between 6-15 participants (Clarke & Braun, 2013) thus for this study the participant was sufficient. The initial goal was to gain a total of 20 participants, however, with COVID-19 restrictions it was difficult to get more participants. Also, after interviews, transcribing and analysing the data, the researcher realised the data reached saturation. The age range of participants was 27-60. All participants fell in the recruiting criteria (Table 14).

Table 12

Participant demographics

Pseudonym	Interview	Age	Gender	Ethnicity	Role	Duration of role	Know anyone with dementia
Mathew	In-person	37	Male	Jamaica	Church leader	5	No
Danny	Telephone	32	Female	Jamaica	Church and youth leader	4	No
Steven	Telephone	27	Male	Caribbean	Worship Leader	5	No
Amy	In-person	55	Female	African	Pastor	15	Yes
Sahara	In-person	30	Female	African	Church leader	3	No
Peter	Telephone	60	Male	African	Pastor	10	Yes
Sally	Telephone	30	Female	African	Church leader	2	No
Halima	Telephone	48	Female	Indian	Quran teacher and Chaplin	9	Yes
Latif	Telephone	55	Male	Pakistani	Imam	7	Yes
Marwa	Telephone	39	Female	Pakistani	Quran teacher	9	Yes
Qari	In-person	59	Male	Pakistani	Imam	4	Yes
Sanjidah	In-Person	46	Female	Bangladeshi	Quran teacher	5	No
Dua	In-Person	48	Female	Pakistani	Quran and Islamic teacher	7	No
Tanzeela	In-person	55	Female	Indian	Quran teacher	15	Yes
Mohammad	In-Person	45	Male	Pakistani	Imam	5	No

6.2.1.1. Requirements. The study aimed to recruit BABAC and SAM who were religious leaders (e.g. pastor, imam, bible, or Quran teacher) who worked at the church or the mosque. Participants must have been living in the UK for more than 20 years or have been born in the UK. This was to ensure that participants understood British culture and people. The rationale behind the participants' occupation was to ensure that the researcher captured individuals who were in religious leadership positions in the communities and who may have influence over or play a role in PwD's help-seeking methods.

6.2.1.2. Recruitment. Participants were recruited through snowballing, approaching them directly though Church and Mosques. The researcher did advertise on twitter; however, no participants were recruited. It was difficult to get some participants because they felt that they did not have adequate knowledge on dementia. However, they were reassured it was only to get their initial understandings of dementia.

6.2.2. Interview Schedule and Procedure.

The interview schedule was developed by the researcher and her supervisor, taking into consideration the research questions and the theoretical framework. An individual who identified as BABCC acted as the 'key informant' in developing the interview guide and in helping gain BABCC participants (see Section 3.9.2). Like Study 2 (Chapter 5) the interview schedule only acted as a guide, where prompts served to motivate answers. The interview schedule can be found in Appendix F.3.

Before the interview the participants were given an information sheet, which explained the study as well as their right to withdraw at any point of the interview. Once they had agreed to participate, they were given the consent form. Each participant was assured on confidentiality, anonymity and their right to withdraw consent to use their data at any point without explanation.

The interviews were conducted in different settings (e.g church, mosque, community centres, or over the phone). Before the interview, participants were asked some demographic questions, regarding their age, ethnicity. Education, occupation, gender. They were also given a vignette which described a person with dementia (see Appendix F.2) and were told the questions were going to be based around it. Each interview lasted between 35 minutes to an hour. With permission the conversations were recorded and subsequently transcribed verbatim.

6.2.3. Analytic strategy

The data of this study was analysed using Braun and Clarke's (2006) qualitative thematic analysis method as described in Chapter 3 (Section 3.8.1). This method has been adopted in previous research to analyse religious leaders' perceptions of dementia (Epp et al., 2021) and is considered appropriate for the current study as it allows for a flexible approach to the data analysis.

Each transcript was read multiple times and codes were constructed. The analysis was also led by the inductive approach and the research questions of the study. The process of transcribing and analysing the data was time consuming and took over a year to complete. During this time, the data was revisited several times where themes were reworked in various ways. This process of analysing and re-analysing was an iterative process which helped ensure that participants meanings and experiences were expressed in terms of their help-seeking process. This helped the researcher strengthen her analysis skills and build a coherent story for this thesis.

6.3. Findings

From the analysis, various themes and subthemes were developed (Table 15). These have been shown below and discussed further.

Table 13

Main and Subordinate Themes

Main Themes	Subordinate Themes
1. Dementia beliefs	a. Beliefs about the causes of dementia b. Viewing dementia as a White person disease
2. Influence of Religion	a. Looking at religious methods to help the person with dementia cope with dementia
3. Help-seeking sources	a. The importance of family members being caregivers for the person with dementia b. The importance of religious leaders for the role they play in their community (act as trusted source of information)
4. Faith and Science	a. How can faith and science work together to help people with dementia

Note. Table shows the main themes and subordinate themes constructed from the interviews

6.3.1. Dementia Beliefs

This theme is derived from the understandings of dementia that were present within the participants' responses. There was a display of lack of knowledge within their responses throughout the interviews as well. This was also seen in the second study (Chapter 5) where a lack of knowledge resulted in misrepresentations of dementia and its causes. In this theme, there are two subthemes which are discussed: causes of dementia and perceptions of dementia as a 'White person's disease'.

6.3.1.1. Cause of Dementia. This theme sheds light on religious leaders' representations of the cause of dementia. It follows findings from Chapter 4 and 5, where the cause of dementia in the BAME community was associated with religious and spiritual and lifestyle factors.

Participants described the cause of dementia as being due to lifestyle factors. In the following extract, the participant described that dementia was caused by people having busy lives.

> *Tanzeela: well, it's because they have a very busy life. People are stressed. You know women have a very busy life, sometimes you have to ten things, 15 things and you forget a couple of them, so I would always say there's a different dementia. I think with dementia there's a part of the brain that is not functioning well. Yeh, or if I am extremely busy, and I have to do too much, and I can't do all of it, so I do some of it. So, I can see there's too much to do, or people are just exhausted. I noticed too many sisters, they are too exhausted, with too many things to do for the children. You know so they are tired. I wouldn't call it dementia, you know if a sister has it for some reason, I wouldn't call it dementia. Dementia is a big word. If everyone keeps forgetting something, you know everybody will have dementia in the world.*

Tanzeela describes how she believes that memory loss can be caused by lifestyle factors (such as over-working and tiredness). She implies that this can extend on to cause dementia as well. She discusses how the women in the Muslim community have busy lives which leads them to forget things and become exhausted. She also goes on to explain how someone forgetting things does not necessarily mean that the person has dementia. Tanzeela implies that individuals are prone to forgetting things to a certain extent as a result of their lifestyle and this is a normal outcome. It seems that Tanzeela is aware of the biological effect of dementia when she mentions that "there is a part of the brain that is not functioning well." However, she also hints at potentially a slight amount of stigma towards dementia, saying that she feels it is caused by people's busy lifestyles instead. She downplays the fact that memory problems mean dementia and suggests that memory problems are something common within the community; referring specifically to women, she states that it is because women are nowadays doing too much, implying that the stresses of gendered roles may also influence memory loss and potentially dementia.

Sahara discussed how dementia could be due to the individuals not exercising their mind.

> *Sahara: I think also, us like when we were children, and our younger, the exercise your mind before. I think over here you get away with not using your mind. For long and I feel like that, like I don't know how Alzheimer's work but, I feel like in African countries they kind train your mind. Or to do this, be quick, this is the road signs, you need to know this to get around. Like over here we are so used to our little app, so we never really taking and exercising your brain. So, I think that's why it's think less common* [in Africa]. *But I am not really sure, but I'm not a doctor so I'm not too sure….yeh and I have noticed that over here that people don't read much. Like most people don't even read a book a year. You don't read anything, so your brain after the age of 18, you're done. But like if you read the bible every day, or do other stuff like every day, you are kind of exercising, you know those the hard verses in the bible.*

Sahara describes how she believes that dementia is caused by people not 'exercising' their brain enough. She compares people today in the Western world with those of the previous generation as well as with those that are in Africa, suggesting that today's modern technology and people's reliance on it is one of the causes of dementia. She also feels that the likelihood of dementia can be reduced by activities such as reading (referring to the bible). Interestingly, Sahara's extracts above show how she explains the perceived differences between dementia's prevalence in the UK and Africa based on representations of medical research on dementia.

Another example of a misconception regarding dementia and its cause can be illustrated through Sally's extract.

> *Sally: Well, yeh they can have it, so it might be like due to the environment. So, everyone is always in a rush and there's like no patient. Like if you think about other countries like Africa and Asia, and there you are spending so much time with your family, but here, once you are stuck at home, you don't get to spend do much time with your family and friends. Because you don't have a social life, you are stuck in 9-5, Monday to Friday and so on. You don't get time to do other things, you spend most of your time spent at home and don't know anything or what to do. Whereas, back home, you are constantly, even though you are working 9-5, but when you get back home, you have a family. Here when you are 18 or 20, they move out the house. Other countries, this is not likely to happen, they are more likely to stay home, or even when you move out, you still go back and visit your time with your family, you talk to people, you socialise. You are connected with your family, whereas here its different with people.*

Sally's responses are similar to Sahara's responses, in that they both compare Western life to life in Africa or Asia. Sally, too, implies that dementia is more common in the West due to the environment people are in. She feels that having family members around you can reduce the risk of dementia.

Furthermore, Dua's extract also follows the trend where she discusses how dementia was caused by lifestyle factors (loneliness in this example).

> *Dua: Well initially when I was reading the scenario, I thought that man, or the woman, who the scenario is talking about, might be really lonely, will not have anyone to talk to. So, whenever she sees or has someone around, she would just keep on talking and talking about the past or whatever is going on in her mind. But I also thought that she might have, urm something a*

> *condition, a health condition, because I noticed that she forgets what like she did the day before. Isn't it?*

> *Dua: Urm maybe because they might be lonely, urm they might have been focusing on things that are not important for them, for example like there career, sort of work, maybe their partner who they decided to marry, or if they had kids, maybe they are not happy about their kids' decisions. Anything that is related to their life and lifestyle in general that they are not happy with. What's happening in their life. And yeh loneliness, is present at the moment. So many people decided just to live their own life, by leaving the older people back.*

Dua discusses how she feels that one cause of dementia is loneliness. She takes the person in the vignette and applies hypothetical scenarios to their situation, justifying their dementia symptoms. She states that it is due to the person's loneliness and lifestyle that are causing the symptoms. Overall, all excerpts above have a mutual subtheme which is that there is a lack of knowledge when it comes to dementia and primarily, understanding its causes. All the participants above discussed lifestyle factors such as loneliness, lack of brain exercise, and lifestyle differences between the West and their culture which resulted in people having dementia. Similar to Sahara's excerpt earlier, the participants all showed lay representations of dementia and its symptoms.

6.3.1.2. White person disease. Participants' answers also showed that their perception of dementia was founded within their identity. This theme was mainly found within the interviews with BABCC participants. They described how they saw the disease as a "White person disease" and that it affected the White community more than the black community.

Sahara: I think that they think that it's a White person disease as well, because they only see White people being diagnosed. You don't see a Black person with these illness….Yeh, like I have never heard a black man say that he has Alzheimer's, I have never heard anyone. Never. And in my hometown, like all the old people I see in Ghana, they are quite healthy. And I have never seen them say that I have Alzheimer's, or something else. So, you do think that it's a White man disease.

Peter: Urm with dementia its difficult, like it's there is, isn't black people with dementia, I know that dementia is there, but not in the community especially. Urm so not culturally, so like urm, this is not a disease, like we see this disease as a White person disease that affects White people more than black people.

Sally: Well, I am not sure, urm, usually happens in Western countries. So, I am not sure, so like when you think about other countries and continents, like Africa, Asia, south America, it doesn't happen that much. It's not like that often as it happens in Western countries. So, it could be like they probably that they had the symptoms that are genetic.

Sally: Yeh, like the ones I have seen it happens to more Caucasians, and that why I was saying it happens less in Africa, Asian and those countries. So, what like I have seen around me and my surrounding I have seen in the Caucasian

Interviewer: Yeh, and why do you think that is?

> *Sally: Well, I am not sure. I think sometimes its due to loneliness, and your morals and you values. You are surrounded by your loved ones to support you. Like for us, we have families that will support you during illness and help you out.*

The responses above all indicate the underlying theme of identity. Participants displayed a sense of ‘us vs. them’ when discussing how they all felt that dementia was primarily a “White person” disease. There are a few key reasons why such a feeling may reside within a community. It is evident through the literature review (Chapter 2) and the findings of Chapter 5 that there are barriers to services that the BAME community faces when seeking help. This also means that there would also be lower levels of diagnoses of dementia within the community. As a result, it would seem to the BAME community that naturally, they have lower levels of dementia as opposed to the White counterparts. This would further the divide between them and the White community when looking at the whole concept through the lens of identity. Separately, a lack of knowledge regarding dementia causes would also lead individuals to believe that factors such as lifestyle choices cause dementia as opposed to old age (as found in Chapter 5).

Both factors above can lead to a separate underlying process that runs through this research. Lack of knowledge around dementia not only inclines people towards misrepresenting dementia symptoms as symptoms of ageing rather than the disease and therefore be less inclined to seek help, but also indirectly inclines them to create a further divide between their identity and the White counterpart community in an effort to remove the dementia stigma from themselves.

6.3.2. Influence of Religion

The second theme illustrates participants' beliefs on the role of religion on dementia. This section will explore the following sub-themes which also reflects some of the findings of Chapter 4 and 5: Religion as coping and benefits of services

6.3.2.1. Religion as coping. Participants discussed how religion was used as a coping strategy for dementia symptoms.

> *Mathew: I feel like faith makes the illness more bearable, I don't know like because science just supports that there's something wrong with them and that regards whatever happens, they will be okay. And mentally that could do a lot for someone who is going through illness. So, I think just knowing about the higher power, kind of makes the pain more bearable.*
>
> *Interviewer: So, like allowing faith allows them to cope with the illness*
>
> *Mathew: Yeh exactly*
>
> *Interviewer: In what sense, or how do you think faith actually allows them to cope?*
>
> *Mathew: Well, when you know that there is a higher power that has a plan for you. Whatever you are going through you have faith that it's all for a reason, and like you can pray to get through it. Whereas you can't just keep talking to the doctors about your problems, whereas with God you can.*

Mathew discusses having faith can help individuals with dealing with dementia symptoms. He states that it allows dementia symptoms to become bearable as it gives individuals something to rely on. He compares using faith as a coping method with going to the GP, saying that you can talk to God about your problems as much as you like whereas you cannot do the same with doctors.

Sarah also discussed how using faith can be a coping method for symptoms of dementia.

> *Sarah: Of course, from a personal belief I think that praying for the person, God will obviously help you, to guide you. With my belief that God will help the person. But I'm not saying that's like not solely the case. There are other things you need to do. Like when you're revising for an exam, you rely on Allah, but you also need to revise otherwise you won't be able to pass.*
>
> *Interviewer: Yeh, do you think that's also like why people with dementia use this approach.*
>
> *Sarah: Prayer might be the first base, because like loads of religion, like Christianity as well say the same thing. God will help you. Urm even Hindus, like to help them in times of need. Like with prayers, it's the closest thing to them, whereas with the medical route the person doesn't want to get help, for whatever reasons there are. Like Quran and prayer is something close to them, familiar to them, you know comfort environment. Like if you pray to God, it's between you and God. With medical route, its more people involved, the professionals, the family that need to take you and bring you back. Like prayer you can pray at any time and its more spiritual. Whereas medicine, its physical, so taking at certain times. So, they might forget, and of course their family has to help them. Asking God to help them, its more closer, and its more comforting.*

Sarah discusses how faith is the first step in coping. She states how praying (regardless of religious beliefs) can help individuals as it is the closest thing to them and is something that they are familiar with, going on to explain how this provides a source of comfort. She also compares the professional healthcare route to the alternative, religious and prayer route. She describes how coping is not readily available with the professional healthcare route, i.e., you cannot constantly be going to the GP whereas prayer is something that can be done constantly.

> *Danny: Also, I think it can be very lonely, when you don't have anything to do, or go, but if you have faith and follow a religion, then you are forced to go out and interact with other people. So, you're not isolated all the time.*

Above, Danny discusses how religion being used as a coping strategy does not necessarily mean prayer alone. It also enables and indirectly forces people to go out and be social – whether that's at the mosque or in a church. This is also in line with the previous theme of dementia beliefs regarding loneliness and how people from the BAME community feel that it is one of the causes of dementia.

> *Danny: Using faith as coping can give people a better quality of life, because it allows the person to not always be down and negative. I have seen a lot of people, urh some English people who do not have faith, and they are usually on anti-depressants. Whereas we don't really need to rely on those because we have faith to keep us positive.*

Danny compared English people with people who don't have faith. He stated that they are usually on anti-depressants and stated that we (people in his community) don't need to rely on them as they have faith. Danny also discussed how following a religion can help individuals to interact with others as when following rules, you are not as isolated all the time.

Below, Amy suggests how religious text of the bible can reduce the negative impact of aging (such as removing negative thoughts). Therefore, by reading the bible and engaging with the text, it can potentially have a positive impact on individuals.

> *Amy:* I mean in the Divine healing and the scriptures, the Bible talks about the fruit of the spirit, peace joy hope things like that and that kind of helps. So they are likely going to be reducing the negative impact of ageing….Even now talking about stuff like this, it helps them, it raises more awareness and people want to make sure that they have a sound mind as they age.
>
> *Interviewer:* What do you mean by sound mind?
>
> *Amy: When the person is at peace and no negative thoughts,* pressure, or discrimination. It can affect the mind and emotions. So, you start now. The bible can help you with that. Your mind isn't distracted. Even medical sciences, they are saying that negative thoughts, and all the thoughts can a person down.

Overall, religion has shown to be able to have a positive impact on individuals. It can allow individuals to cope through prayer and reading religious texts. These findings suggests that religious practices (such as prayer, reading the Bible or the Quran, and going to the mosque or church) can therefore be used for PwD.

6.3.2.2. Services. In this subtheme, we see how available services in religious institutions can help PwD. Danny discusses below how people at church can also help individuals with some encouragement and help them when they are feeling down.

> *Danny: There are also social workers who can go and help people with dementia, and motivate them, encourage them when they are feeling sad or down, but there's also the people at church, if they come to pray, the church members are also there to give them encouragement especially when they feel sad.*

Participants discussed the importance of having weekly services at their local church or mosque, which ultimately gave their life a little routine. Having to go to church on Sundays (for Christians) and to the mosque on Fridays (for Muslims) meant that not only did they have something to do, but it also enabled PwD to socialise and reduce any loneliness feelings as well.

> *Danny: From my experience as working in day cares, I think it's important they have some sort of routine, so with the church, they should continue to keep coming to the Sunday services if they have been already coming. The Sunday church services are usually really good because people of all ages come there so it's pretty inclusive….The church also has other services for the elderly, like the over 60s lunch club which may also be useful for them.*

Danny discussed the inclusivity of the services as well as how attending the service provides a routine for people, and that allows them to potentially have something to look forward to. Participants even stated how these services helped the individuals feel more involved within their community and helped bolster their sense of identity as well.

Amy discussed how the church has started separate groups for the ageing population that help them tackle any issues that they may be facing, such as socialising. She discussed how these groups can help individuals feel less isolated.

Amy: I think when it comes to Christianity, I think that the positive aspect off the faith in terms of life, the position of life, if and a community aspect kind of helps a lot. I don't think we have a lot of these kind of issues in the churches especially the churches I have attended. I've seen people ageing, yes, they are in their 80s or something, but it is not an alarming right off mental illnesses or a loss, that kind of things.

Interviewer: So, you are saying its less common.

Amy: Yes, less common, and also now churches have also developed groups for you know ageing population in the church and they go out of their own way even every week or every two weeks to have these groups they even go to their homes some of the volunteers go to their homes and get them ready and even the young people. That in my own church we have a lunch for the over 60s and you are invited. We say Yeah yeah just come and we help and then they come to socialise….My pastor actually developed for the over 60s group, and you know he says, has this person has to be checked out, this old lady hasn't been visiting. So, it takes away the isolation and the loneliness because when you are lonely you tend to worry you tend to think a lot …. For example, the Bible when he says... Do not worry, do not be anxious but I mean people spend time you know memorising the scriptures. I memorize them and it keeps the brain active.

Furthermore, Amy related her own experience with her mother-in-law who was also going through dementia. Amy discussed how her mother-in-law didn't want to go to a care home, so she started making extra effort with the people around her and attending the church. She suggested that she replaced the care that she would have received from the care home, with visiting the church to help her with her isolation and which can keep PwD busy.

> *Amy: Another point of how to make the culture the African Caribbean Community they believe in looking after the elderly. They don't believe in sending the elderly to the care home. You see and that helps. My mother-in-law, she was 83, and we began to notice that she forgot what everything. She refused to get diagnosed because she was too afraid to go into the care home, so she constantly made effort to keep people around her like in the church. It helps and people go out the way in the church to help the people. So, I think culture helps to an extent and church also helps with their part of it. So, loneliness is kind of reduced, the kind of services at the church try to provide and the relationship that the church has to build and its sort of helps to reduce this kind of illnesses and help them with their life. So, a lot of retired people, guess what do they do? They go to the church, almost at every church activity they are there. That's it, it keeps them occupied, it keeps them busy.*

Sally also discussed the importance of community. She believes that spending time with people in the community helps people spend time with others and keeps their brain active.

> *Sally: Oh Okay, like so I will mention things, like in the bible that this … person had depression. Like at the time it wasn't known, and it just says that the spirits left him, and he was feeling bad. So, like at the time it wasn't known, but at that time it wasn't known. And in most*

> *time, it happens, because people don’t spend time with others, so we have a community for a reason, and you know gathering and spending time with people. If you don’t have a community, you are not gathering with other people, and if you spend a lot of time on your own, and your brain is going to stop working. So, if you are not doing anything with your, brain, your brain will think negatively and have these symptoms.*

Marwa suggested that the Muslim community needs to do much more for individuals that may be going through dementia such as workshops. She also suggested that more people should be encouraged to come to the mosque and the Quran classes.

> *Marwa: I think at mosque we need to start becoming aware of these things that can impact the Muslim community. We need to know how to deal with them. I think we need support in these areas. I think at the mosque we need to think about these things so we can help the whole community….It would be good to have people who have knowledge in these areas to come in and talk about these issues. Like it would be good to have even workshops for the people in the community. Even encourage people to take Quran classes so we can help people be social and keep their brain active.*

Furthermore, Quran classes were known to be very beneficial for individuals. Tanzeela discusses how reading the Quran can help individuals as their brain becomes more active. She also believes that reading Quran and attending the classes reduces the chance of someone developing dementia.

> *Tanzeela: Urm I believe, and this is out of our belief as a Muslim, that only way to stop dementia, is to reading Quran, even one verse a week. You can’t do a verse a day, then do one*

verse a week. Repeating it and reading and understanding it. And We know that many, of the companions, of the prophet and the people around them, they said that the people the of the Quran, they are the people that stay sane throughout their life. And many people, sisters, because of my most my class, the people who turn up, most of them, most of them are 50 plus. And the reason is not to get dementia….Its funny, but that's what they tell you, because that's what they tell you. When I start, they say that my brain becomes more active.

Sally stated that both methods are needed such as going to the doctors. However, when discussing alternative help and potentially going to professional healthcare, Sally mentioned that praying and believing in God is enough.

Sally: Well like I said I would pray, but like seek help from dementia. So, I would advise both. Like to go and do activities, we are lacking that in society, especially with the older generation. They don't really go out and walk. You know they can wake up early in the morning and go to café and join a society, it's never too late, you can be learning. Like get involved with the community. They can see the doctors or even go the therapist if they need to talk to someone.

Interviewer: And what about those who does not want to go the doctors?

Sally: If they are not willing to see the doctors, that's fine, because I believe that God is the main doctor anyways, so like I will pray with them and fast with them. Urm and expect for the healing to happen.

It seems that religion overall has a large influence on the BAME community and is not something that should be ignored within any healthcare route (professional and alternative). It has been (and still is being) used as one of the primary go-to coping mechanisms for PwD within these communities. Individuals confirmed that they feel religious services encourage the elderly to socialise more and gives their life routine. Reading the Bible or the Quran can also help keep minds active as reading the scriptures not only promotes the act of reading, but also encourages individuals to think and ponder over the meaning of the text as well.

6.3.3. Sources of Help

This theme discusses the ways of help that religious leaders would suggest and that they think are beneficial. It is divided into the following subthemes: family responsibilities and religious leaders (clergy). Both family members and religious leaders were seen as trusted sources of help for PwD.

6.3.3.1. Families Responsibilities. Many of the participants described the importance of family care, and how families should not only be responsible for the person with dementia but are also the best source of care for them.

> *Mathew: Care homes, can be very good, when those providing the care are responsible, but ultimately, the best care would come from a family member who cares for you not because it's their job, but because they actually love you in their life. So, like, care home, are good and most of them so work well, but you do hear bad stories, but they are very practical.*

> *Interviewer: Do you think that the Jamaican Christian community are responsible for their elders?*

> *Mathew: Yeh, the older ones that raised them, so everyone regardless of faith, or culture has a social responsibility to look after their elders. So yeh I do think they are responsible, and they should always be held to account for type of cares that the elders are being given.*

Some participants even described what they would want for themselves if they were in the same position as the person with dementia. For example, Sahara, related the scenario to herself and mentioned how there is no excuse to put parents into a care home.

> *Sahara: so, your family is responsible for their family. And if you can never put your elderly in care home and it's like frowned upon. And I feel like there's no excuse justifiable, like I wouldn't want that, like when I get older. But I would hate that unless it's really hard to take care of me. But I would prefer a carer coming into the house and doing that.*

Some other participants also gave religious reasoning on being a carer for their parents. They stated that it was important to teach children the value and importance of looking after elders and how this should be more encouraged and taught from a young age.

> *Qari: Every parent should teach their children, about elderly, from a very young age. They teach their children from the importance of parents. So, when these parents become old, the children know their responsibilities. So, they automatically look after their parents. You know we don't put parents in homes and care homes. You know prophet Muhammad if you want to open the doors of paradise, then serve your parents, and serve them at their old age. Because you know that's when their machine starts to slow down, and that when they start to start depending on*

> *other people. If their children aren't there for them, then who is? And so that children should that for them.*

Similarly, Halima discussed the importance of looking after family members, more specifically, parents. She also discussed how the young Muslim community should be taught their own cultural values and that they can differ from Western culture.

> *Halima: I would actually say, you know what I differ it here a bit, but this is my own opinion, I actually feel that as Muslims, we don't understand urm how to serve elderly parents and what their rights are and from us because, perhaps we are in the Western atmosphere if you like, but I feel like because we don't know our Islamic references and where the commands are coming from. For example, in my own belief I believe that your parents, are your responsibility, urm obviously, you have facilities like home and care, but my own belief is that you provide that care yourself, first-hand. And if you have to keep a job, you know because you need to make a living for your family, that's understandable. Then you need to work out a care system. Whereby you can accept help from, the NHS and you would input yourself as well. So, you might be a part time carer, because you are doing a job, you would accept help from the system.*

> *Halima: So, you know you are not springing these things on to them. Unless you have an extended family so they will already know. But you know you need to tell these things to your children from a young age. Whether you seek whatever you help, it's your obligation to look after them. Whether you have a council house, or your own house, you need to take these things into consideration, about where and how you will look after your parents. These things are the stuff that we should be teaching people in the khutba* [Friday Sermon]*, and that so its not a reaction*

because that's when things are difficult to handle. We should be teaching and preparing for our parents before they are getting old. We tell children that we are different form Western culture, and how we look after our elderly, we need to look after them.

Dua also expresses the importance of taking care of family members and uses religion to justify the reasonings.

Dua: So, I never met anyone that is actually going through this. And I have never met, someone that has Alzheimer's and that is Muslim, but I presume what Islam teaches you is to look after the old people. However, I think that there is a shift in society at the moment, and there are so many Muslim people that are having careers, like nowadays, so like they are starting to leave their families behind. I read many articles about, urm Muslim people placing their relatives, parents, in care home. That is something that Islam doesn't teach you. Islam tells you to look after the old people, like your parents especially. When they get old, that is your duty and, I feel like with a modern society, these things are kind of changing, and I don't feel like it's in a good way.

Dua discusses how it is a Muslim individual's responsibility to take care of their elders. She also discusses how there is a shift in the society where Muslim individuals are not taking on responsibilities as being carers. She insists that this goes against the teachings of Islam and is something that should be taught to people. This also suggests that religious leaders see family as part of the help-seeking care pathway for PwD.

6.3.3.2. Religious Leaders as a trusted source. Clergies came out as one of the key people that played a role in help-seeking methods (also found in Chapter 5). Participants in the study discussed the role of religious leaders and why PwD or their carers might go and seek their advice.

> *Mathew: yeh, I think it is their role, because ultimately if they don't, then these people are going to suffer, because they won't have anywhere else to go to, to give them advise. The people in the church are a big part of the community and they are the ones that guide the community. And the people who work at the church, are somewhat very trusted and they are the ones that give you good advice.*

Mathew discusses the role of religious leaders in their community. He discusses that sometimes individuals don't know who or where to go and seek help from. Thus, they end up going to seek help from the pastor as they are likely the ones to give them good advice and are a trustable source of information.

Furthermore, Danny has a similar opinion, where the pastor is seen as a figure or a role model to whom individuals can go to seek help from. Danny talks about identity here and discusses how it helps him feel like a part of the community.

> *Danny: Yeh I think at the church people sort of know that they are not being told any useless stuff that is not for them.*

> *Interviewer: Yeh, what do you mean?*

Danny: In the general public there's a lot of information out there which doesn't really apply to us lot or sometimes you cannot relate to it. You often think ah it's for the White people not us, so you don't really pay attention to it or take it seriously. But when the pastor is talking about something, then you know he's saying it because it can relate to us, and people actually listen…. We had a discussion about mental illness in our church group chat, and we are trying to talk to more younger people about this. Sometimes people will come and talk to us about it whereas they would have not discussed anything with us before…. I think it's all about trust. We have a tight knitted community, and we know we can trust each other.

Participants feel that people from BABCC feel they are different from the majority (White group). This may be why people feel like they are different and therefore may not be able to relate to the majority when it comes to help-seeking as well as using different methods of help-seeking. This can also be seen in Mathew's responses below.

Mathew: For me I feel like part of it is, I guess when you are in community, you don't feel like…I wouldn't say a second-class citizen, but I feel like if you're not part of the main majority you don't feel like you, you really are not aware of those options. It's not really a done thing, because it's never been a done thing. If it's not in your family history, it never comes as an option.

Interviewer: Yeh, that's interesting. Can you elaborate on second-class citizen? What do you mean by that?

Mathew: Well, I think the Caribbean community, or the people don't always feel like part of the majority community. Like with White English people. I think we always know that we are *different and have done things differently. Like also we don't, we haven't seen many people in the community going through these illnesses, so we don't really think much into it.*

Overall, this theme explores why individuals in SA and BABC communities may use religious leaders as part of their help-seeking process. Religious leaders are seen as trusted sources that can be relied upon and are the ones that individuals go to, to seek advice. Moreover, participants also pointed out the significance of cultural differences and used those to justify their decisions with regard to help-seeking.

6.3.4. Faith and Science

Most of the participants mentioned how there needs to be a bridge between faith and science and how this can be done. In their perspective, prayer and science can go hand in hand and people can use both methods when coping with an illness.

Mathew: So, if it's the person, I would come from a logical perspective. I would like to diagnose what is going on. And try and get the most practical help, that I can see from them. I would definitely pray for them, and the faith would be a part of it. But I feel like science and faith need to go hand in hand, so that's the actually big thing about growing up here. But like if you were from back home, in Jamaica, its more emphasis on the faith rather than the science also. So yeh

Mathew: The most important thing is like they faith and science, they need to hand in hand for us to avoid these problems and like people being ignorant. And stuff like that. So ultimately, people, need to think about what they actually believe in, we actually, and like if you *are Christians, then you believe in like god created humans and like created us to be intelligent human beings, and so therefore, how can you reject science, because science is made by the people who God made. So, it surely, if the science is made by the people that God made, then untimely it came through him. If we are God like and, in his image, so then we shouldn't be rejecting science we should be promoting it. And people should change their opinions on prayer, whether they are religious or not, and prayer should not be seen as the only antidote and it should be seen as individual persons role, in the ultimate care and or the ultimate urh praying about what ever thing that are concerned about. It shouldn't be the one thing that rely on, because they are many things that are part of the picture.*

Above, Mathew highlights the importance of religion – especially prayer. However, he also emphasises that prayer alone should not be relied upon and that science should also be used as according to his belief, people's knowledge of science has also come from God. He believes that the approach of science and faith going hand-in-hand will ensure people are not ignorant of these issues in their community. Sahara and Amy below reciprocate similar opinions regarding the use of both faith and science as a source of help and that one should not be preferred over the other.

Sahara: I think my church believes that it's a combination of prayer and medical advice. It's not just one, so like if you break a leg, so you would pray about it, but we want you to see a doctor. So, I think it's both of them.

Amy: I know some people are doing that, but I would still say to them, to go and seek medical advice and get help. But I do know of some people who are doing this now. I know that there are certain situations where Christianity can help more in that case, as I say let the church

> *know and make them aware what is happening. So, we spend a lot more time with the person and help them. So, tell them to go for medicine, but tell them to stay with church. Because they go out of the way to help the person, and they will help them by holding their hands and praying. You know I am being secular, but I believe in divine healing, and it may not happen overnight, but gets them where an induvial is going through this becomes hopeless, and they have spent their years going to church, so this will help them cope and go through the illness.*

Interestingly, Amy gives more importance to faith rather than science, implying that complete healing cannot be achieved without the church. Furthermore, some participants even suggested how there needs to workshop at the mosque that will help raise awareness of dementia. They also suggested using religion to help people understand their responsibilities.

> *Halima: I think, you know first of all, community centres provide these like workshops for elderly people and the elements and etc. Again, I think this is my personal opinion, but I have seen it happen in community centres, and I think, I would encourage those workshops to take in place, within the mosque, you know the community centres within the mosques. So, in that way, If I was giving a khutbah* [Friday prayers]*, or urm advertising events, I would suggest to the younger people we have workshops, come, and see how other people are coping with dementia or come and see other people are coping with parents who have you know cancer, diabetes, dementia, heart patients, and come and speak to others. We have a network, you know we can provide help, we can show you how, it's all linked up to the NHS, how you can get help and so provide that door, does that make sense, like seminars and like educating them really. Through that education that you provide, through the NHS, you can form links with the NHS, but at the same time, urm you know ask the imam, I would be able to link it back to my references in the Quran and the Sunnah…*

> *So, it is showing you that both of them are important, but the parents haq* [rights] *on the child, is important, that they can even leave a duty such as that.*

Halima discusses how the mosque can hold workshops for people to raise awareness about the illness. She also implies that these workshops could also help people understand how to take care of PwD. She goes on to explain the importance and the responsibility of looking after elders. She backs up her statement using religious references and believes that this should be imbedded in the youth, which implies that this is a source of help-seeking. From this, she is also implying how both methods of professional care (through NHS) can be linked with religious beliefs (using Quran text).

Some even suggested both religious methods and medical methods can be used together to help the person. For example, Qari stated that regardless of what the individuals might believe, both methods should be encouraged. He used Islam to back this up.

> *Qari: Urm, so those who believe that its black magic, or nazar. When prophet fell ill, Jibrail [Archangel Gabriel] came down and did ruqiyah [exorcism], ruqiyah is a form of cure. Ruqiyah is done with the words of Allah in the Quran, so urm it doesn't mean that if you are doing ruqiyah, don't mean that you don't use the medicine as well. Like do you get it*
>
> *Interviewer: Yeh, so you use both methods.*
>
> *Qari: yeh, there's nothing wrong with it. Regardless the prophet (saw), says, Quran is a cure for all illness except death. Surah fathiha* [prayer] *is a cure for all illness accept death. So, the*

words of Allah. Now it doesn't mean the other cures that are out there, that you just rely on this. The Sunnah is, the tradition is, the custom is, you use up the other means that is there.

Below, Halima discusses a potentially effective method which can be used for elderly people who only rely on faith, to also utilise science, i.e., professional health care, as well. She helps individuals understand that they don't have to stop their faith activities, and that they can go to professional care simultaneously.

> *Halima: Well certainly you give them room to speak because that's their point of view. Because sometimes you, find older people, with elderly people, they can be stubborn, so you need hear where they are coming from. So, I would say definitely listen to them and hear where they are coming from. Its only once you understand where they are coming from, urh you know then you can say you know I listening to your perspective, but now I would like you to listen to me. That's just to give them that respect, and then you could say look we have evolved a lot, from you know those times and now taking your situation into mind, and you know you reason with them. You say to them that you're not asking them to stop your ruqiyah. Or help your seeking, but here we have medical help available which can improve your life not for yourself but also our family. Because remember it's not only who you are suffering from, but it's the ones around you as well. So really get to see the other persons perspective, so like really get them to see the benefit and to improve their quality of life. It's not like it taking their reliance on Allah, it will only help with the will from Allah, you know if Allah wills it to work*

Steven discussed the importance of praying but also acknowledged that praying would not be beneficial alone.

> *Steven: To be honest I don't think God will do anything just for the sake of it. There's a reason behind everything, there's a reason behind you going through everything. God wants you to see the light through it. He has the power to heal you. I believe that if we can get support from the health services, to gives a medication, to give us some kind of relief, that would be very beneficial. The world is changing, so we don't even just rely on spiritual, we rely on both doctors and spiritual aspects. You know we don't just stay at home and pray.*

Steven acknowledged that people and the way things are done are changing. Above, he refers to how relying on medication alone is not beneficial enough and the professional route must be also considered.

Furthermore, participants also discussed different methods that could be utilised by individuals to cope with the illness.

> *Dua: urm considering that the person is Muslim, I would suggest that person to go a doctor that himself is a Muslim, and who is using both kind of like the Western remedies which is like medicine, and they have the cultural and religious knowledge. So, it can be a doctor, or a psychologist, a psychotherapist or even someone who does cupping. Anyone you know, but I feel like that they will have more insight than just urm suggesting them to go the GP, to see the doctor. I feel like that many other GPS that are not Muslim, some of them try to understand it but most of them, they don't have even any insights, about how a Muslim is like or what is important for someone who is a Muslim. I know many of them don't even understand why, urm Muslim person*

> *would continue to fast, even if they don't have health problems, like not major problems, but it can be related to something like I don't know, blood levels and stuff like.*

Dua discusses how it will be help for individuals to visit a professional who understands the person's faith. She states that if an individual visits a healthcare professional who is also a Muslim, it would be more beneficial for the person with dementia because the professional would understand any religious representations that the person may have. The healthcare professional would also be willing consider alternative methods to healing alongside professional care.

Sarah also explains how people may take on different care pathways such as a medicine free route before they take the GP route. She states that the individuals need to take both routes to help themselves.

> *Sarah: I think it's because many people before the medication, try avoid the medication route. I know a lot of people who have depression, but they are not acknowledging that the fact, and it might be people from their own family, who would say they have depression, they are not processed. They don't need prayer. They need medication. They both go hand in hand with prayer and medication. Also like I mentioned they have strong faith in prayer and obviously where the disease might be interpreted, or perhaps they don't want to go and see the doctors perhaps. They might explore the medicine free route before they go into like GP and medication.*

This theme reflects on community representations of religious leaders and their impact on care pathways for dementia. Participants showed a certain level of acculturation, discussing their own 'cultural' and religious methods of coping and combining them with the Western methods. They also mentioned that further work needs to be done such as workshops in mosques which would help increase the knowledge within the community and provide additional support to PwD.

6.4. Discussion

The present study was designed to examine the role of religious leaders and religious routines on help-seeking processes of dementia care. A vignette was presented to participants depicting someone with dementia and a conversation was held based around it. The findings of this research established the following four key themes: dementia beliefs (including its symptoms), religious influence, help-seeking sources, and faith and science.

Throughout the interviews, it became apparent that the participants had incorrect beliefs about dementia. Within the BABCC community, dementia was often represented as a White person's disease. This was based on the experience that dementia was not often visible within their communities, which led them to believe that dementia did not impact black groups (Berwald et al., 2016). This form of belief conforms with SIT, i.e., individuals' beliefs within the community were shaped through their identification with the ingroup. This resulted them looking at the White counterparts as the outgroup and therefore, turning a disease like dementia into an 'us versus them' concept. The participants also implied that it was because of the Western culture and lifestyle that resulted in them getting dementia. They discussed how lifestyles within African countries and communities encouraged individuals to be more social and exercise their cognitive skills more.

Moreover, participants had different representations of the causes of dementia. The key element that the religious leaders mentioned was that dementia was likely a result of lifestyle factors. They mentioned that individuals within Western communities would become lonelier the older they got and that individuals should go out and socialise more. The participants implied that getting dementia may be partially the person's fault as by socialising, they could have reduced the risk of getting dementia. These beliefs about dementia suggested that clergy believed that developing dementia could be avoided, which suggested negative perceptions towards the person with dementia. This could potentially be the reason why people within the BABCC community do not want to expose dementia or be blamed for it.

The second theme the religious leaders' answers revealed was the influence of religion within their day-to-day lifestyle. Participants indicated that in general, attending services at the church or mosque was beneficial for PwD. Not only did it enable them to socialise more and reduce their loneliness, but it also gave them a routine and gave them something to look forward to. This view was also shared by the carers of PwD as was seen in Chapter 5, where BABCC weekly services at the church and Friday sermons at the Mosque improved the quality of life of PwD. Kennedy et al. (2014) discussed that attending a religious service offers a socially supportive environment in which the various components of the services contribute to a 'stress buffer effect' or by meeting fundamental psychological needs. They also found that the familiarity and structure that worship services offered engendered feelings of security, normality, a sense of belonging and self-efficacy in the person with dementia attending. The use of sensory cues as part of worship was perceived to facilitate comfort, attachment, and a sense of connection (to other worshippers, and to God). The effects of this act as a form of support and were reported to be observed and evidenced in the improved functioning of PwD within the environment of the worship service. For example, in PwDs' direct responses to sensory cues and prompts (e.g., praying, singing), in their active engagement with aspects of the service and with the worship leader, carers and in changes in their emotional state.

Additionally, the participants discussed how PwD's belief in faith seemed to show a positive impact on their lives, helping them cope with their dementia symptoms. This follows on from Studies 1 and 2, which also indicated an importance of religion for PwD, as well as its benefits, helping them in various ways such as emotionally, cognitively and through their relationships. Chapter 5 delved deeper into the role of religion from the perspective of PwD and their caregivers, finding out that religion can also pave a way for people to accept the illness. In the current study, participants discussed the importance of reading the bible, as it has positive words which can encourage people to have a positive outlook of their illness, and therefore, help reduce any negative thoughts they may have. SAM respondents discussed Quranic text which talks about the symptoms of ageing, allowing Muslim PwD to accept the illness as well.

As also found in Chapter 5, religious leaders were seen as a trusted source when seeking help. The respondents of the current study even referred to themselves as trusted individuals within their respective communities and mentioned that people would come to them knowing that the leaders would filter out unnecessary information that the people did not need. Pargament (2001) discusses how the centrality of religion in people's lives inevitably makes religion an influential element within the person's identity. Thus, people turn to religion when searching for coping mechanisms. Religious leaders are often seen as having extensive religious education and naturally become the go-to person within the community as they are likely to be intimately acquainted with resources for problem solving. Participants discussed how many individuals sometimes do not know which information is correct for them and end up believing that information for the public might only be aimed at White people. It is only when they have spoken to religious leaders that they appreciate the information and feel that they can trust it. One BABCC participant also mentioned that some individuals have limited education and thus, only come to the church as it is their only source of information. Kennedy et al. (2014) explained the benefits PwD have because of their relationship with religious leaders; the presence of, and interaction with, worship leaders, carers and relatives were perceived to offer the person with dementia a shared experience incorporating containment, validation of emotions, security, inclusion and validation of the identity of the person (both as an individual for whom relationship, attachment and belonging is important, and as a person of faith, for whom religious expression and ritual were perceived as central).

When it comes to sources of help, family members were seen as the primary source of help and as carers for PwD. Participants referred to religious texts as well as community and family culture as the reasons for why family members had a duty and responsibility towards taking care of the person with dementia. They also discussed how taking care of the elderly would also instil lifelong values within children, as they too would then look after the elderly at some stage. This theme was also reflected within the findings of Chapter 5, where PwD and their carers indicated that family members were often assumed to automatically take up the position of carer for the person with dementia as this was their duty and was also backed by religious sources. From a theoretical standpoint, these points are backed by SIT in that looking after one's elders and learning from family values eventually becomes the 'in-group' members' identity and they then begin to identify with members of the same group.

Interestingly, a few of the religious leaders believed that going to the doctors for dementia symptoms was not necessary as it would not be beneficial for the person. Instead, they felt that healing purely through faith was a possibility. This indicates that the issue of lack of knowledge may be a community-wide issue and may also be a reason as to why some individuals do not even consider the professional healthcare route. It is key to note that religious leaders can play an important role in care plans. However, as has been seen in this chapter as well as Chapter 5, religious or community leaders do not always have the correct understanding of dementia and its symptoms. Thus, healthcare professionals should be aware of the potential dangers of misunderstandings and incorrect beliefs that may spread through a community and act as a barrier to diagnosis or treatment.

The final theme that was uncovered from the respondents of the current study was the bridging of the gap between religion and science, i.e., the alternative approach and the professional healthcare approach. Religious leaders advised that as society changes, there needs to be a greater understanding of scientific principles within their communities. However, they also mentioned that there would equally be a need for professional healthcare providers to learn about the community's religion and culture as this would impact the view that people had of them.

Overall, the result of this research indicates that religious leaders play a key role within BAME communities' help-seeking approaches. Their perspective seems to be positive, in that they encourage professional healthcare services however they also are better poised to understand the community's perspective and lack of knowledge regarding dementia. Moreover, the fact that many members of the SAM and BABCC communities identified with their religion made it easier for religious leaders to have a more important role than they otherwise would have. The religious leaders also advise that professional healthcare services would be potentially more affective if they considered the religious and cultural aspects of a person with dementia's life. In line with Chapter 5's findings, considerations should be given to a mixed approach of help-seeking that would be of greater benefit to both the community (which would receive better services) and professional healthcare providers (who would be able to better provide more catered services). This will be further explored in Chapter 7.

6.4.1. Limitations of Study

Similar to the previous studies, this study does not come without its limitations. Firstly, this study aimed to focus on the role of religious leaders on help-seeking behaviours of dementia. However, not all participants had experience or the same experience with PwD. This can impact religious leaders' views on dementia as well as their influence on individuals' help-seeking methods. A vignette was used to combat this, so individuals had the same scenario to base their reflections on. Though, this may have inadvertently caused them to provide a 'picture perfect' response, as opposed to a real, lived experience.

It became evident to the researcher that the interviewees were largely giving similar responses, thus reaching data saturation at an early stage. The researcher stopped recruiting further participants and realised that in future studies, the ethnography approach could be utilised to further understand the role of religious services.

6.4.2. Implications of Study

The study has found some interesting findings which yielded results that can be used to further improve policies and healthcare pathways. As discussed in Chapter 1, it is important to provide person-centred care which reflects individuals' religious and cultural values. Having analysed the responses of the religious leaders, it is evident that individuals from the BAME community often utilise religious leaders as a source of guidance during their help-seeking process. Therefore, specialised, and catered training provided to the right people, i.e., the imams of mosques or church pastors, for example, could result in key influence over people's help-seeking decisions. Religious leaders could point people right away towards professional healthcare systems and this would result in people utilising services soon, and potentially even having a higher quality of life.

6.5. Conclusion/Summary

The results of this study have shown multiple themes that have arisen through the responses of religious leaders from the BABCC and SAM communities. The primary themes were dementia beliefs, the influence of religion, sources of help, and finally, faith and science. It became evident very quickly that community members would more often than not, come to religious leaders for advice and guidance on their health issues, more specifically, with mental health issues. It was noted how these leaders were in the position to potentially help people in that they could guide them towards the correct professional healthcare services. However, the researcher also noted that some religious leaders did not have full knowledge and/or understanding of dementia and thus, would advise on purely religious methods for coping (such as praying and coming to the church/mosque regularly).

As a potential method of combatting this, specialised training can potentially be provided to religious leaders which would help them not only increase their own knowledge of dementia, but also, the information would filter into the communities as well.

7. Discussion and Application

7.1. Chapter Aim

This chapter aims to bring together the findings of the overall thesis and to discuss their practical implications. It aims to address the research questions, ‘how can alternative help-seeking methods be used to understand care pathways?’ and ‘what are the practical applications of these alternative methods?’

Firstly, the chapter summarises the background and rationale for this thesis, followed by the theories adopted (SRT and SIT). Secondly, the findings of the studies are discussed in overarching/common themes. Most themes relate to the practical implications. Thirdly, it presents a model which reflects current help-seeking pathways for BAME groups, followed by a new model which illustrates how implementing and focusing on alternative methods can provide a more effective pathway for PwD in BAME communities. Lastly, the results are also discussed in terms of the national wellness pathway, where the chapter reviews how the pathway can be adapted to suit PwD from BAME communities.

7.2. Introduction and Rationale

The aim of this thesis was to explore the existing help-seeking methods for dementia that are currently being used by the BAME community. It has focused on alternative methods that people utilise to cope with dementia. The objective was to develop an understanding of these methods which can potentially be incorporated as part of mainstream care pathways. The current literature on BAME groups and dementia in Western countries shows that the understandings and experiences of dementia in BAME groups are to some extent different to their White counterparts (PRIAE, 2003; Baghirathan et al., 2020). BAME groups are more likely to delay dementia diagnosis and more likely to be more dissatisfied with the services available to them (Alzheimer's society, 2022; Cooper et al., 2010; Regan et al., 2013). BAME groups are also more likely to have a lack of knowledge of dementia, have more stigmatized and negative attitudes towards dementia, and face greater barriers to care (such as language barriers, and lack of culturally appropriate care). Cultural and religious factors also further influence the BAME decision making processes (Mukadam, Cooper & Livingston, 2011). To overcome the delay in dementia diagnosis and underutilisation of services by BAME groups, efforts are being made to raise awareness and provide culturally appropriate services for PwD within BAME communities (Blakemore et al., 2018; Mukadam, Cooper & Livingston, 2011).

The researcher found three areas of concern with current research on the approach to dementia within BAME communities. Addressing these areas of concern together provides an alternative perspective into viewing dementia which enables a different approach to dementia research within BAME groups.

Firstly, the current research exploring BAME groups and pathways to dementia has predominantly explored dementia under the light of the Western biomedical model (see Chapter 1, section 1.7.1). This model only looks at what barriers there are within these communities and how they can be addressed. However, it is important to consider that help-seeking methods within BAME communities are complex and some aspects may be beneficial. There are multiple pathways and various elements (such as religion and culture) that can influence it. These factors should not be simplified to just barriers.

Secondly, though there are culturally appropriate services for PwD from certain communities, it is unrealistic to create culturally appropriate services that meet all the needs of different cultures and religions. This is because even within certain cultures or religions, there are further variations such as language, religious sects, and family traditions. Therefore, adapting existing services or creating culturally appropriate services for these groups would be impractical.

Thirdly, it is observed that within the past few years (throughout the researcher’s PhD process), there has been increased effort regarding religion and how it can be used to support PwD and their caregivers. The research within this thesis indicates that more work needs to be done to encourage places of worship to work with PwD. Further, it can be asked ‘what value does this thesis bring?’ if effort is already being made to encourage faith communities to support PwD. The value this thesis adds to the existing body of knowledge is that it brings together different alternative perspectives into looking at research within BAME communities regarding dementia and help-seeking and then suggests methods through which existing services and policies can be adapted to provide improved and more accessible services.

It is important to note that the researcher is not taking a radical stance in her approach where she is disregarding existing literature and findings. The researcher acknowledges that there are barriers and that the current findings – and their implications – are useful as they can provide a great benefit to PwD within BAME communities, as well as improve understanding of BAME groups within the literature of dementia. The researcher’s aim is to provide an alternative light or perspective on dementia research and care pathways for PwD within BAME communities. This method of help-seeking incorporates the role of religion, but it does not undermine professional health care pathways and diagnosis of dementia.

7.2.1. Social Representation Theory and Social Identity Theory

Overall, this thesis incorporated SRT and SIT, using the phenomenological approach to understand individuals’ help-seeking processes and understandings of dementia. Using both theories together helped explain people’s help-seeking process and provided a holistic view of their decision making.

SRT allowed the researcher to explore alternative help-seeking practices with a view to considering how they may be incorporated into mainstream care pathways, rather than just viewing them as barriers. Using this theory, the common mainstream biomedical approach was challenged, as SRT gave permission to look beyond this (Howarth et al., 2004). It allowed the researcher to understand the representations of dementia and help-seeking that people may share within the BAME community where alternative help-seeking processes and narrative were used. The main benefits of adopting SRT was that it allows for different representations to co-exist. It does not favour one representation over the other, and allows for multiple and dynamic knowledge systems to coexist. This was a main concern for the researcher, where the researcher ensured that previous research or methods were not disregarded or undermined.

SIT was also beneficial for addressing the aim of this thesis. SIT was useful in helping to make sense of participants' motivations. Adopting SIT with SRT allowed representations of dementia and help-seeking to be understood and examined in line with each individual's narrative. It served to reconnect the social and health issues that they were facing with the cultural resources they brought to the situation, and which are woven into the foundations of their identity. The connection between identity and individuals' narratives of health turns out to be a useful connection as it can help explain multiple variables and phenomena within BAME communities as well as provide practical implications. This approach can inform the delivery, management and promotion of health care (Craddock, 2000; Harwood & Sparks, 2003). This will be later illustrated in the care pathway models developed (sections 7.4.1 and 7.4.2).

7.3. Summary of Research

To understand previous work on alternative methods of help-seeking, the researcher carried out a meta-synthesis and systematic review (Chapter 2) of existing literature. The aim of this was to address the research question: "What does current research show us about dementia and help-seeking in BAME communities in the UK?". The literature found for this analysis was re-examined to determine the help-seeking process and methods of PwD in BAME groups. From the findings, two main themes were derived: professional inadequacies and alternative help. These findings suggested that individuals may use certain care pathways to seek help which would need to be explored further.

To help explore the help-seeking pathways, a further three separate studies were conducted, using a mixed method sequential design. Study 1 (Chapter 4) was a quantitative study which aimed to answer the research question: "What are the understandings and experiences of dementia among BAME groups?". This study aimed to look at the differences between BAME groups and White counterparts and their understandings and perceptions of dementia in 18–40-year-olds. This study acted as a foundation for studies 2 and 3 by providing a pathway of topics to further explore. Study 2 (Chapter 5) was a qualitative study which aimed to answer the research question: ""What are the understanding and experiences of dementia among BAME groups?" and "What are the various alternative help-seeking pathways for people with dementia?". This study was a semi-structured interview on BABCC and SAM and their understanding and experience with help-seeking for dementia. This study found that there was an importance of religion and religious leaders in the help-seeking pathway that people chose. Study 3 (Chapter 6) was also a qualitative study which aimed to answer the research question: "How does religion play a role in understanding and experiencing dementia?". The main findings of the three studies revealed key themes which have been explored in the next section.

7.3.1. Theme 1: Knowledge of Dementia

In line with previous findings, Studies 2 and 3 illustrated a lack of knowledge around dementia symptoms within the BAME community. Lack of knowledge is a common issue seen across previous studies and the symptoms of dementia are perceived differently across BAME communities. Though Study 1 did not find any difference between knowledge of dementia in between the BAME community and their White counterparts, it can indicate that there is a general lack of knowledge for dementia and not just within BAME groups. Additionally, the lower levels of knowledge may also be at the same level but in culturally distinctive ways, i.e., both groups could have the same level of knowledge, however, because of cultural differences, the groups may look at the same element as two completely different ideas.

However, it is important to note that dementia was not measured in the same way in all studies. Aetiology of the disease was addressed in Study 1, whereas in Study 2, participants were able to address any element of knowledge of the disease they preferred. Also, there are inconsistencies even in previous research in their methods to studying knowledge of dementia within BAME communities. For example, Purandare et al. (2007) found that though there were differences in knowledge of dementia between SA older people and White counterparts (regarding basic knowledge and epidemiology), there was no difference between SA and White counterparts in terms of knowledge of dementia aetiology and symptomatology. Another example (Turner et al., 2005) is where they found that in minority ethnic groups, there was a general lack of knowledge. However, all these studies researched knowledge of dementia in different ways. Purandare et al. (2007) used quantitative methods whereas Turner et al. (2005) used qualitative methods to gain knowledge of dementia within minority ethnic communities. Therefore, this suggests that there is need for a revised method to assess not only capture dementia knowledge, but also cultural differences as well. This would ensure uniformity between the different findings.

7.3.1.1. Old Age. Representations of dementia were informed by people's stereotypical beliefs about old age. Participants (especially in Study 2 findings – Chapter 5) stated that the symptoms of dementia were often mistaken for old age. This often led them to delay seeking professional help in terms of getting diagnosis. These findings reflect previous research which suggested that dementia symptoms were confused for old age (Botsford et al., 2011; Chaouni, & De Donder, 2019; Hossain et al., 2020). The findings also can be explained using the SRT's socio-cognitive process of anchoring, which suggests how individuals use previous knowledge to assign it to new items (Moscovici, 2008). This shows that individuals used pre-established categories of knowledge incorporating negative stereotypes of ageing to interpret the dementia symptoms. This association of old age with dementia symptoms suggests that knowledge not only of dementia needs to be increased, but efforts need to be made to reduce negative stereotypes of old age as well, in an overall effort to tackle the lack of understanding of dementia.

7.3.1.2. Lifestyle. Lifestyle factors were also thought to be one of the main causes of dementia. The participants implied that dementia was more the fault of the individual, again indicating that they held negative representations of certain types of lifestyles (in this case, loneliness and not making the effort to socialise). For example, in Studies 2 and 3, participants reported that isolation was one of the major causes of dementia and that one method that could be used to combat this would be to have more activities within churches and mosques that PwD could participate in.

7.3.1.3. White Person's Disease. In the BABCC group, participants often referred to dementia as a 'White person disease'. In Study 3, religious leaders stated that dementia was not common within their communities and thus believed that dementia impacted mainly the White counterpart. This also reflected previous findings where BAME groups were likely to view dementia as a 'White person's disease' (Berwald et al., 2016).

This theme corresponds with SRT and SIT, where individuals' representation of dementia is associated with the person's race. This could also reflect various factors such as 1) why individuals may have no knowledge or a lack of knowledge on dementia as they have not encountered people who had dementia previously within their community, 2) The representations around dementia being associated with a race coheres with the lack of racial and ethnic diversity within public health and media representations of dementia (Roche et al., 2021). Thus, efforts need to be made to ensure that ethnicity, race, and culture are reflected in media campaigns to ensure that there is increased representation of BAME communities in these campaigns. This will not only decrease the representation of dementia as a 'White person's disease' but can also help tackle any negative attitudes associated with dementia or the PwD, as it can help increase knowledge and awareness which can therefore help reduce any negative beliefs about dementia.

7.3.2. Theme 2: Experiences of Professional Care

This theme discusses how previous experiences with healthcare can have an impact on individuals' perceptions and decision to seek help. In Chapter 5, it was established that participants based their decisions to seek help for their symptoms of dementia on their previous experiences with the healthcare system. They reported they were less likely to seek help from healthcare professionals if their previous experience was negative. They also stated how this led many individuals to delay further help or seek alternative forms of help (such as using faith as a coping mechanism). This is also in accordance with previous findings (as also discussed in Chapter 2) (Kovandzic et al., 2011; Memon, et al., 2016). The findings also implied that there was an element of trust that played a role when seeking help with healthcare professionals. Where individuals discussed if the healthcare professionals were deemed to be trustable, it would impact how individuals viewed the diagnosis and how they sought further help. This trust was based on shared identity between the individual and the healthcare provider.

However, it can be argued that these findings do not only reflect dementia care pathways for BAME groups but reflect the healthcare system as well. Studies have also found that there is general mistrust toward healthcare services within both BAME groups White groups in the US (Whetten et al., 2006). It is likely that this may also have relevance in the UK. This suggests that there needs to be an improvement within the healthcare system in general to ensure that individuals do not face any negative experiences. This could also reflect a bigger problem within the UK healthcare system.

7.3.3. Theme 3: Alternative Care Pathways

This theme explores care pathways that are considered alternative pathways to mainstream health care. It explores why individuals chose these specific routes in their help-seeking process over the standard or the accepted mainstream healthcare routes. This thesis in general challenges some of the claims that religion is a barrier to seeking help (Nielsen et al., 2021; Regan et al., 2013); for example, PwD use religion as a source of coping, or use religious services to improve quality of life, or go to religious leaders for guidance and as trusted sources of advice on help-seeking. The research has discovered that instead, what are seen as barriers to seeking mainstream healthcare may actually be alternative care pathways that individuals use as part of their health seeking process.

7.3.3.1. Importance of family care. The importance of family caregivers was a key finding in all the studies. The findings in Study 2 suggested that they play an integral part for the person with dementia in helping them understand dementia and in their help-seeking decisions. The responsibilities individuals took on to be a carer for the person with dementia were influenced by religious, cultural and/or family values. This is an integral role for many individuals in the BAME community and is an important part of their identity. Respondents claimed that their approach to looking after their elders tended to differ from their White counterparts and went as far as expressing an ’us versus them’ mentality, highlighting the differences that they believed exist. This also led many to have negative perceptions about residential care homes. In Study 3, participants also stated the importance of family caregiving, where this was influenced by religious values. Religious leaders suggested that these values should be taught to individuals within their communities and also suggesting that family caregivers were an integral part of the dementia care pathway for PwD. The findings resonate with earlier studies which show the importance of family caregivers within BAME communities (Botsford et al., 2011; Lawrence, et al., 2008).

There was some reference to care burden, however, the focus of this research was not solely on the carer’s experiences, but rather the experiences of the person with dementia. Thus, there may have been some further revelations regarding care burden if participants were probed in this direction.

7.3.3.2. Generational and/or acculturation influence. The findings also showed different levels of generational differences and acculturation when it came to seeking help. Study 2 found that second and third generation individuals can act as facilitators to accessing dementia care. The participants discussed the role they played in seeking diagnosis for the person with dementia and their help-seeking process in general. The overall help-seeking process was also affected by the participant's level of acculturation, i.e., the balance between their ethnic culture and Western culture influenced their level of acceptability of services. There are various factors that can determine these patterns and the acceptance of formal services in the country of settlement. Where first generation immigrants may have a link to their origin country, they are more likely to hold on to more traditional care pathways, such as family caregiving roles (Bhui & Bhugra, 2002; Bhui & Sashidharan 2003). Younger members that have moved more towards Western culture on the acculturation scale (2nd and 3rd generation individuals) are more likely to be accepting of 'newer' (professional) healthcare methods (Chaouni & De Donder 2019). Thus, it makes it easy for these new generation family members to act as gate openers or gatekeepers that enable the rest of the family to get professional healthcare. This suggests that alongside targeting healthcare services at carers and PwD, the younger generations from these communities can also be targeted as a means to get to PwD.

7.3.3.3. Importance of Religion

The studies found that religious influence also plays an important role in help-seeking and people's understandings of dementia. Participants detailed how religion played a part in helping them understand dementia, cope with its symptoms, and provided them with a sense of continuity of their selfhood and identity. Having religion also meant that religious leaders within the community became trusted sources of information and guidance, and in some cases helping individuals to better utilise professional healthcare services. Religious duties (such as Friday prayers or Sunday church) meant that

PwD had a routine that they could follow and which helped them socialise as well, further helping them with their symptoms.

7.3.3.3.1. Religion as Coping (Improving Quality of life). Findings from Study 2 established that for many PwD, religion gave them a sense of identity and enabled them to cope by preserving their selfhood. They were essentially able to continue a part of them from before the diagnosis throughout their dementia, as faith is something that is familiar to them and thus, helps them have a better quality of life during and post-diagnosis (Agli et al., 2015). However, the issue of religion can be complex, in that, religion can have a negative impact on coping as well as help-seeking pathways (Regan et al., 2013). For example, helping people coping better may result in them not needing help at an earlier stage, thereby delaying their help-seeking. People may also believe that their religion tells them that they should be self-sufficient, again, delaying them from seeking help.

However, this can be extension from other factors, such as negative experience within professional health care as also found in Study 2, which led individuals to seek alternative care pathways. This suggests that individuals may not be using religious methods just for coping but may also use them as forms of alternative help-seeking. Moreover, it suggests that the help-seeking process is more complex than previously thought, as there are numerous variables that can impact the help-seeking decision and individual makes.

7.3.3.3.2. Religious Leaders. Religious leaders were seen as a trusted source for caregivers. In Study 2, it was found that individuals sought advice from religious leaders to either seek guidance on dementia symptoms or to get a second opinion on the dementia diagnosis. This shows that religious leaders play a role in people's decision-making process to seek help. This also shows that religious leaders can act as gatekeepers and gate openers, like the younger generation individuals within the community. If religious leaders lack knowledge on dementia, along with how to get help and possible treatments, they could potentially incorrectly advise those seeking help, and push them towards an alternative care pathway that could potentially be harmful for the person with dementia and could ultimately cause delays in their dementia diagnosis. There is limited research available on the role of religious leaders on dementia care and the few studies that do cover this are mainly conducted in the US and amongst African Americans (Chadiha et al., 1994; Epps et al., 2019; Kennedy et al., 2014). Thus, this research provides a new approach to dementia research for UK BAME communities.

7.3.3.3.3. ***Services.*** Religious services such as Sunday services, Friday prayers, Bible or Quran studies were seen as a useful resource for PwD in many ways. Participants (Study 2 and Study 3) stated that religious services provided individuals with dementia a place of comfort and it provided them with a routine. It was also found that attending the services allowed PwD a place where they can also socialise. Furthermore, participants in Study 3 also expressed that the religious services can help PwD as it can help keep individuals' brain active. Current limited research on dementia and religious services has also found positive impact on PwD. For example, Epps et al. (2019) conducted a longitudinal study, where 30 caregivers and PwD attended six modified worship services together over 6 months. They found that church services had an overall positive impact on the caregivers and PwD. However, the research on dementia and religious services has mostly been in the US (Epps et al., 2019), and on improving experiences of family caregivers (Herbert et al., 2007). Though there are efforts being made to consider faith in the delivery of dementia services, there is still limited research how religious organisations or services can be used to help PwD and their caregivers.

7.3.4. Theme 4: Science and faith

Findings from Study 3 suggest that there needs to be better understanding between religion and secular care practitioners and how both need to work together to provide better services for PwD. It seemed that participants understood the importance of seeking professional help (Western culture) as well as seeking help through religion and family (ethnic culture). There were some participants who also suggested that there needs to be more training and workshops conducted at churches and mosques to raise awareness, and how both religious methods and science need to be understood together. This suggests that individuals from minority groups need to use both methods that can help their religious/ethnic identity work with their Western identity, showing how integration can help both areas. Research has also suggested that despite the new advances in medicine, there is still influence from faith or spirituality in healthcare for many individuals (Cox et al., 2007; Puchalski, 2001; Sullivan et al., 2014). Using this approach to dementia provides a unique approach to health care pathway identification, and more specifically, a practical role and approach to dementia coping/help-seeking methods. Research on mental health and religious leaders in the US has stated that regardless of religious tradition, coordinating spiritual and mental health care provides a holistic approach to care (Sullivan et al., 2014). Many religious leaders are unaware of how to address the needs of individuals who may be dealing with mental health illnesses and vice versa, where health care providers are unaware of how to deal with the spiritual needs of the individual's suffering. Thus, collaboration between healthcare professionals and religious leaders is needed.

7.3.5. Negative Perceptions and Stigma

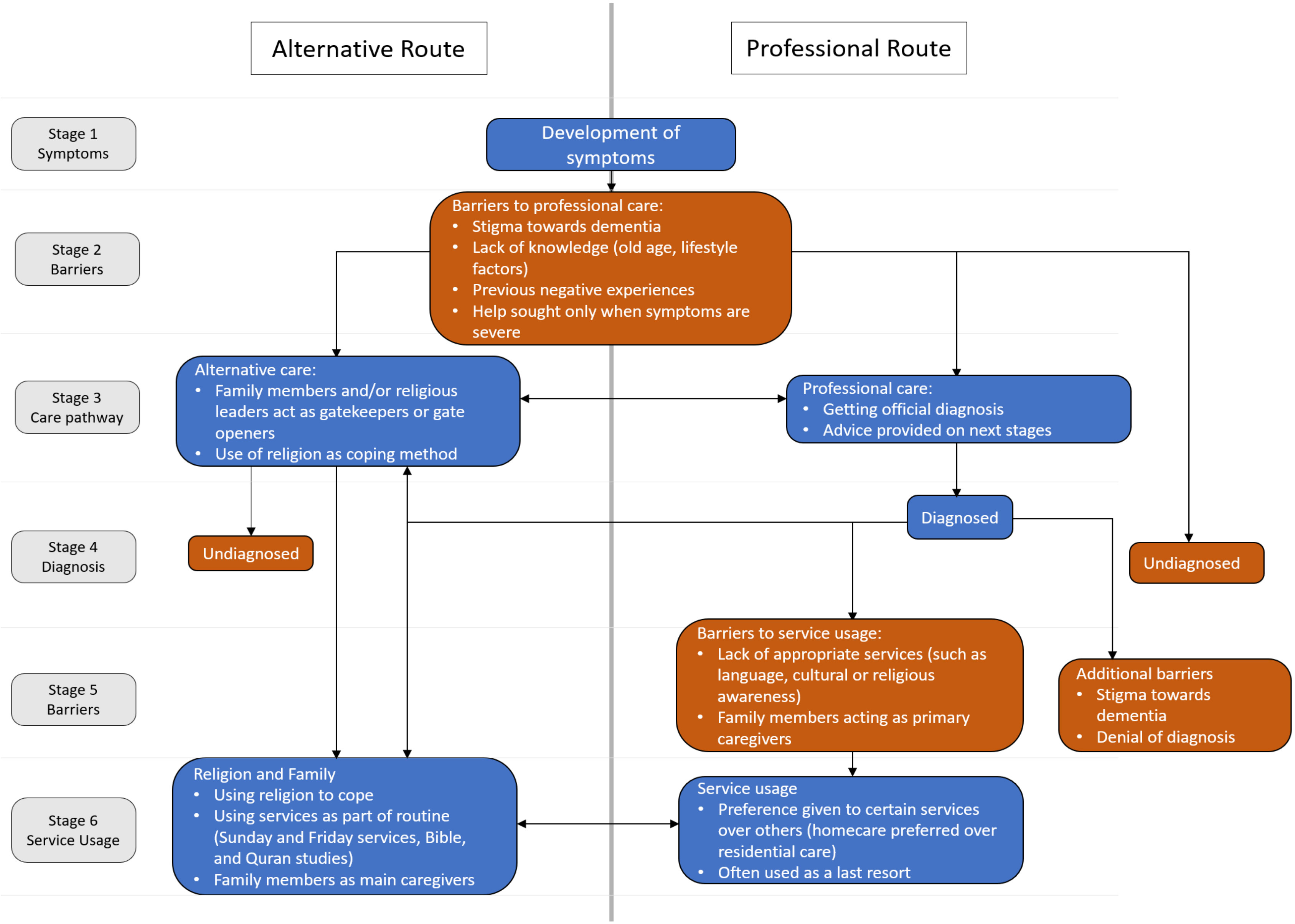
Negative views on dementia and the person with dementia were found to be a consistent theme throughout chapters 5 and 6. Participants very often blamed the person with dementia's lifestyle as being a primary cause of the disease. In studies 2 and 3 (Chapters 5 and 6 respectively), factors such as not being active enough, not being social enough, and not being independent enough were key elements that were blamed as the reasons for dementia, showing that there was an underlying theme of the negativity towards it. Chang and Hsu (2020) discuss how even though there is no direct relationship between these negative attitudes and stigma, it is possible that these negative attitudes can lead individuals to stigmatising beliefs about people with dementia. Though there was no clear evidence of Stigma and discrimination when seeking help, it may be better understood from the perspective of the person with dementia, rather than their carer.

7.4. Implications of research

From the findings of all the studies, a model was constructed that illustrates the current help-seeking method (Figure 8). It shows the different pathways which include barriers that people may face in seeking help. A second model (Figure 9) was also constructed to show how these barriers can be removed by using religious methods or by tackling the issues which delay people from getting help.

Figure 7

Existing Care Pathway Model



7.4.1. Existing Model Description

Stage 1

- Acknowledging some symptoms (individuals may not acknowledge that these are dementia symptoms).

Stage 2

- There are certain barriers that individuals may face when they acknowledge the symptoms of dementia which may inhibit them from seeking professional help, leading to delayed diagnosis.

Stage 3

- PwD and their caregivers may take the professional health care (can include GPs) or the alternative care route (which can include family members and health care professionals).
- If the person with dementia take the alternative route this can sometimes lead them back to the professional care route via religious leaders or the younger generation (within their family) who can be considered either gate openers or gatekeepers.

Stage 4

- If the individual takes the professional route, this can lead them to getting a diagnosis.
- If the individual takes the alternative route, this can also lead them to seeking professional help and thus getting a diagnosis. They can also remain undiagnosed as a result of high levels of stigma or lack of knowledge of the illness.
- Equally, if faced with barriers, the individual may not choose to take any care-pathway and the symptoms may also remain undiagnosed.

Stage 5

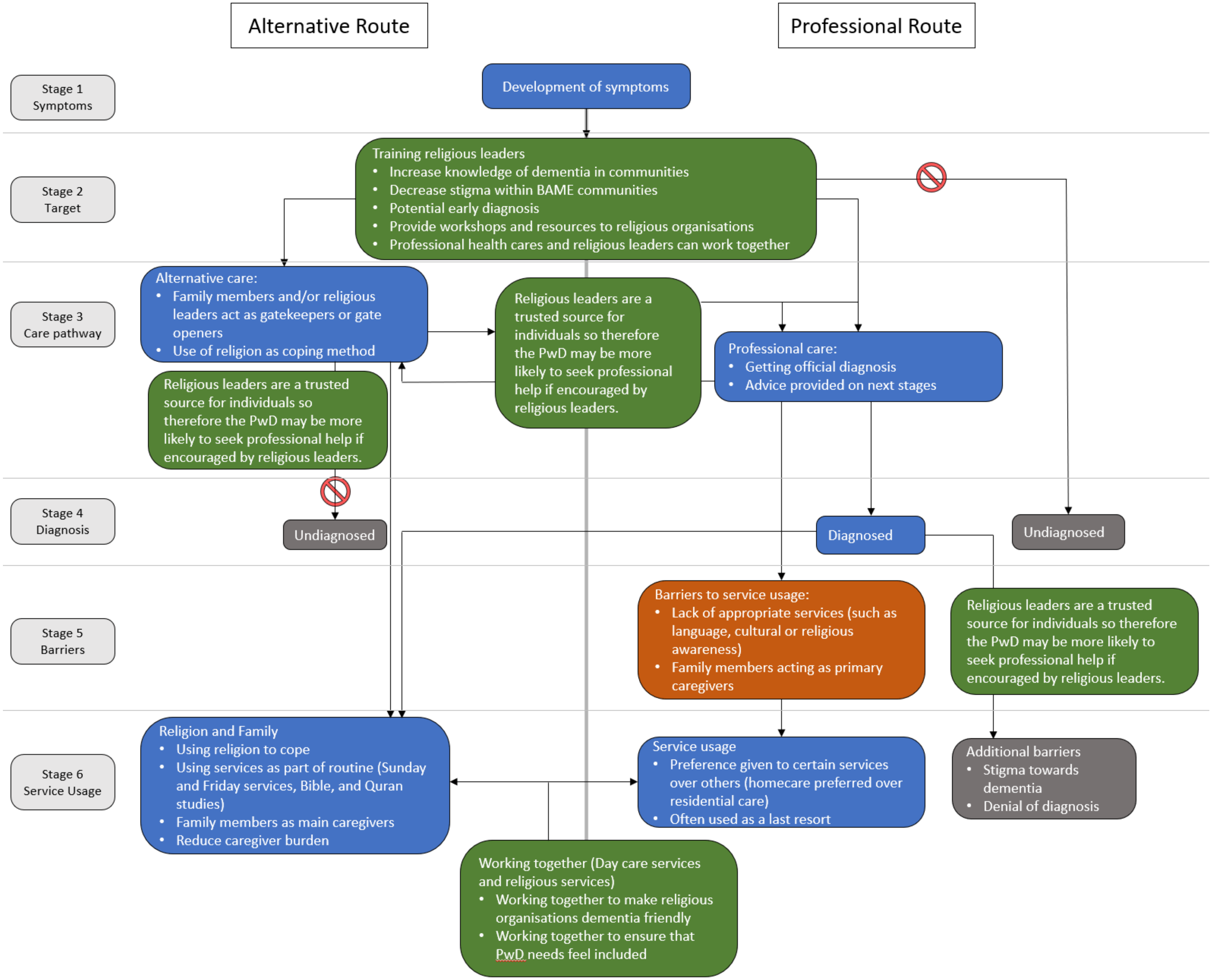
- When the individuals are diagnosed, they may face additional barriers such as denial or have stigma towards dementia which may also lead them to not seeking additional help.
- They may also face barriers to professional services due to a lack of appropriate services (such as day care service or residential care).

Stage 6

- Individuals may use professional services out of desperation.
- Individuals may use religious methods that can help them cope with dementia.

Figure 8

New Care Pathway Model



7.4.2. New Model Description

Stage 1

- Acknowledging some symptoms (individuals may not acknowledge that these are dementia symptoms).

Stage 2

- Training religious leaders can help reduce the barriers to professional health care and alternative pathways. For example: Increase knowledge of dementia and thus religious leaders can better guide PwD and their carers to professional routes and available services.
- Help increase knowledge of the community and thus reduce stigma towards dementia, increase awareness of dementia symptoms and prevention.
- Opportunities for religious leaders and health care professionals to work together to help improve overall quality of and access to dementia services.

Stage 3

- PwD and their caregivers may take the professional health care (can include GPs) or the alternative care route (which can include family members and health care professionals).
- If the person with dementia take the alternative route this can sometimes lead them back to the professional care route via religious leaders or the younger generation (within their family) who can be considered either gate openers or gatekeepers.

Stage 4

- If the individual takes the professional route, this can lead to getting a diagnosis
- If the individual takes the alternative route, this can also lead the individual seeking professional help and thus taking a diagnosis.

Stage 5

- Having information about dementia from a trusted source (such as religious leaders) can also help individuals accept dementia and have reduced stigma around the illness.
- They may also face barriers to professional services due to a lack of appropriate services (such as day care service or residential care).

Stage 6

- Individuals may use professional services out of desperation.
- Individuals may use religious methods that can help them cope with dementia.
- Religious organisations can work together with health care professionals to make religious organisations and services dementia friendly.

7.4.3. National Current Pathway for Dementia (Existing and Improvements)

Table 16 illustrates the current Well pathway for dementia devised by NHS England. This includes the column titled ‘Individual Level’ and ‘Aims and Action’. Through the findings of this thesis, a column titled ‘Additional Elements’ has been added with suggestions of further additions or alterations to the existing pathway that can help improve the care pathway aimed at PwD from minority ethnic groups. These are further explored in detail below.

Table 14

NHS England Transformation framework- The Well Pathway for dementia (Adapted)

Individual Level	Aims and Action	Additional elements
Preventing well	- Raising people’s awareness of dementia and its causes - Advising people to look after their health	- Mosques and churches to run seminars or raise awareness about dementia
Diagnosing Well	- Knowing where to direct people for timely diagnosis, health and care services. - Provide personalised support and help individuals remain independent	- Provide religious communities with knowledge and guidance - Educating religious and community leaders about dementia symptoms and advising them on services available to their communities
Living well	- Promote physical, mental and oral health (both PwD and carers) - PwD to choose from range of activities tailored to their preference - Consider language used (ensuring positive language is used)	- Have religious tailored activities (Sunday services, Friday prayers, Bible studies and Quran studies) - Work with religious and community leaders to develop better and more catered services/activities for PwD in their communities

Supporting well	- Involving individuals and carers in care and treatment plans - Helping them take part in research and empower them to make their own decisions - Consider and support carer's needs and knowing where to direct them for support - Taking on training and e-learning - Making small adaptations such as adequate signage and lighting to support dementia-friendly environments	- Training religious leaders on methods of support for PwD and their carers
Dying well	- Offer different plans	- Train and provide religious communities with knowledge and guidance (can use religious methods to incorporate both care pathways)

Note. The figure was created from the Office for Health Improvement and Disparities (OHID) that shows the current aims that are being addressed in the England as well as the improvements that incorporates elements of religion. From "Dementia: applying all our health" by Office for Health Improvement and Disparities, 2022b. https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health. Copyright 2022 by Office for Health Improvement and Disparities.

7.4.4. Person Centred Care and Religion

Person-centred care for PwD is vital – especially for BAME groups, where efforts are being made to incorporate culturally appropriate services. Integrating religious factors (more specifically, religious services) in person-centred care can be beneficial for PwD and healthcare providers.

Day care centres for PwD can have a positive impact for the person with dementia as well as their caregivers. They can contribute to the provision of activities and social support, prevent isolation, and enhance practical and cognitive functioning (Rokstad et al., 2017). Similarly, religious services can also have positive impacts on PwD if they are catered for PwD. They can provide familiarity, help retain their sense of selfhood, identity, and further religious understanding for PwD (Strandenaes et al., 2018).

Kennedy et al. (2014) studied worship leaders' attitudes towards PwD attending religious services in the US. Using a grounded theory approach, they established 5 themes: 1) familiarity and structure, 2) enhanced sensory cues, 3) significance of the worship leader's approach, 4) social support from and for family and carers and 5) personality and characteristics of the people with dementia. By addressing both elements of religion and science, it allows representations of dementia with different elements to be accepted and makes way for person-centred care.

7.4.5. Interplay of Religion and Cultures on Help-Seeking

Study 1 (Chapter 4) showed that BAME groups were influenced by religion and culture when making decisions regarding their help-seeking strategy for dementia. This was used as a key factor when preparing for Studies 2 and 3, which further highlighted the importance of both religion and culture within the BAME community.

The findings of this thesis acknowledge the interplay of religion and cultures (ethnic and Western) for individuals in terms of help-seeking methods. Though the aim was not to distinguish between the two, findings revealed that individuals negotiated these in terms of help-seeking. The results of all three studies indicate that the BAME community places a significant importance on religious teachings and cultural elements. In Studies 2 and 3, participants discussed the importance of religion where carrying out religious actions such as praying and going to the church or mosque improved their quality of life and helped individuals as well as enabled them to seek help from health care professionals. When it came to caregivers' reasons in looking after the person with dementia, the SAM discussed how they felt no burden when providing the care as this was part of their culture. Moreover, Muslim carers also mentioned how taking care of the elderly—especially their parents—was also part of their religion and was something that they simply would not turn against. Both groups also discussed how this may not be the case for all people in their community and maybe influenced by their ethnic and western cultures.

Furthermore, in study 2, it was also found that carers stated how they sought help despite the differing opinions in their family. They discussed how being from a younger generation and also having Western culture (along with their ethnic culture) helped them make their decisions to seek help.

When interviewing Christian and Muslim religious leaders, it was found that even the religious community leaders felt that religion was a very important factor and would be beneficial to the person with dementia. However, the religious leaders also did largely support the use of professional care as well, alongside religious practices.

It goes to show that an effective dementia care system for the BAME community would certainly need to have various religious and cultural elements incorporated in order to fully achieve its goals of improving quality of lives of those individuals affected (i.e. PwD and their carers). Moreover, existing healthcare systems can utilise the fact that BAME participants are more likely to follow professional healthcare methods alongside their own religious and cultural practices when prescribing treatment plans.

7.4.6. Training Religious Leaders

Training religious leaders and providing religious organisations with the tools and information on dementia about the potential causes, treatments, and potential pathways to dementia care can provide many benefits. It is one step closer for healthcare professionals to work with and understand the BAME community. Religious leaders can help raise awareness of dementia symptoms and its prevention, which can have positive impacts on other factors such as:

- Raising awareness about prevention of dementia and therefore, potentially preventing onset of dementia.

- Raising awareness of dementia symptoms to potentially prevent any delays in diagnosis.
- Reducing stigma around dementia within their communities.
- Identifying symptoms of dementia that may be confused with other illnesses.
- Guiding individuals who may be dealing with illnesses to diagnosis and preventing delayed diagnosis.
- Ensuring dementia friendly environments to ensure PwD attending religious services are better understood and more catered for.
- Ensuring that PwD have opportunities to be included in religious services.
- Providing opportunities for health care professionals and religious leaders to work together.
- Increasing the chances of people within BAME communities to partake in research.
- Supporting individuals in taking care of PwD at home.

This shows how by training and increasing knowledge of religious leaders in dementia can provide greater benefits to the community.

7.4.6.1. Implications of training leaders

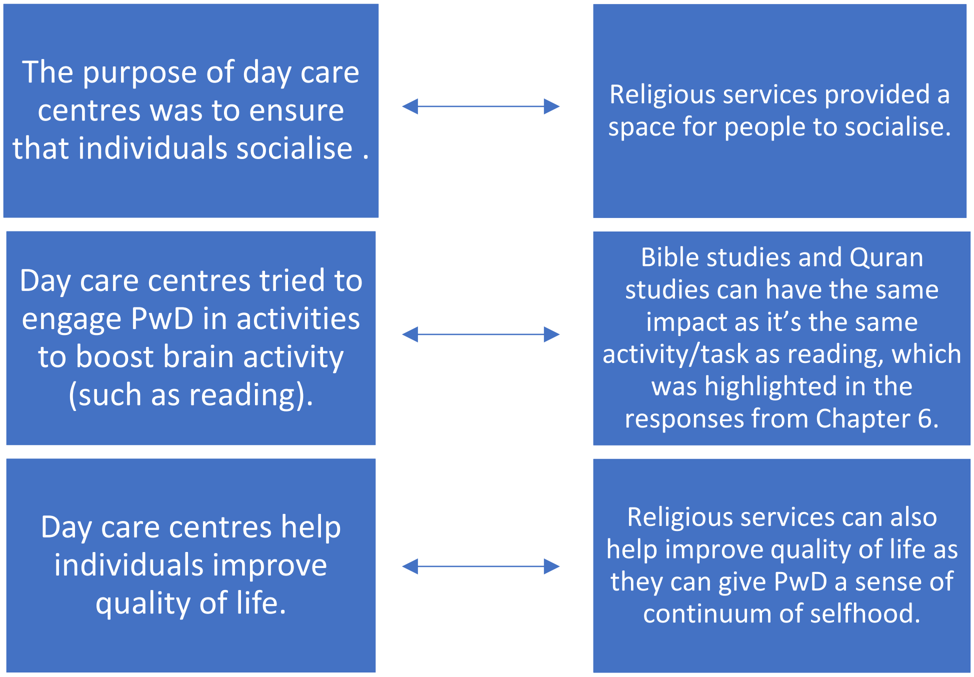
Though there are many benefits of working with religious leaders and organisations, there are also some implications which need to be considered. Firstly, health care professionals need to ensure or monitor that religious leaders are following the guidelines that are provided to them. It is possible that religious leaders may add on additional religious and spiritual elements which may not be in line with the healthcare professional’s aims. Thus, it is important to ensure that religious leaders have the same aim as health care professionals as well as are willing to work alongside them. Secondly, as found in study 3, only clergy who were open to the idea of working with people with dementia, and healthcare professionals were keen on giving their perspectives. However, there were many potential candidates who did not want to be interviewed. Thus, it is likely that not all religious organisations and leaders would want to participate with health care professionals which may result in a large portion of the targeted population left unaddressed. Thirdly, as found in study 2, those who reached out to religious leaders responded to the person giving advice. Therefore, it is likely that when working alongside with religious leaders, they may not all understand the illness. This was also seen in Study 3, where participants viewed dementia as a 'white person disease' because they did not see people in their community with the illness. Lastly, it is important that religious leaders and organisations are well supported by health care professionals, to ensure that they are not overburdened. This may mean additional funding from either public and government (such as the NHS) or private sources.

7.4.7. Similarities Between Dementia Day Dare and Religious Services

There is no doubt that there will be challenges when combining the two approaches together. It then begs the question: 'if we train religious leaders to be knowledgeable about dementia, does it mean they need to be trained in all illnesses (such as other mental health conditions)?' And do religious leaders have the capacity to be taking on more roles? How can they be supported to ensure that there is no extra burden on religious leaders? Though these questions are reasonable, it is important to consider that the goal here is not to have religious leaders working by themselves or have complete responsibility for PwD within their community. In fact, health care professionals should work more closely with religious communities and religious leaders to ensure that they are supported. Furthermore, during the research process, the researcher acknowledged that there were many benefits for PwD in the services that were already in place. The researcher volunteered for over a year in different dementia day care centres and during her recruitment process for Studies 2 and 3, she spent time in various churches and mosques (Section 3.9.2). She noticed that there were similarities between day care centre activities and the various services. For example:

Figure 9

Comparison Between Day Care Centres and Religious Organisations



The purpose of day care centres was to ensure that individuals socialise .

Religious services provided a space for people to socialise.

Day care centres tried to engage PwD in activities to boost brain activity (such as reading).

Bible studies and Quran studies can have the same impact as it’s the same activity/task as reading, which was highlighted in the responses from Chapter 6.

Day care centres help individuals improve quality of life.

Religious services can also help improve quality of life as they can give PwD a sense of continuum of selfhood.

Additionally, religious services can help provide a source of culturally appropriate services for individuals which is not as easily possible in day care centres, unless they are catering for a specific group of people. It may also reduce work for healthcare professionals as religious services are already in place and cater for individuals’ religion, culture and often, language.

7.4.8. Family Caregivers

Though caregiver burden has not been directly measured, it can be noticed that providing a service which meets the needs of PwD can help reduce the burden on family caregivers. It can also help the person with dementia get diagnosed earlier, which could lead the person with dementia to take part in the decision-making process and therefore be independent for longer. It has also been reported that unpaid informal (family) caregivers save the UK economy £13.9 billion a year (Age, 2020), which can additionally help the UK economy.

7.5. Chapter Summary

This chapter has discussed the main findings of the three studies. It has also provided the practical applications of the findings of the thesis. First, it provided an account of the rationale behind this thesis, addressing the aims, any potential concerns, and the contribution to knowledge. It then followed on by reviewing the studies carried out (Chapters 4, 5 and 6) and the overarching themes, which were as follows: 1) knowledge of dementia, 2) experiences of professional care, 3) alternative care pathways, and 4) faith and science. From this, through the findings, a help-seeking model is devised which shows the existing help-seeking pathway model. This is then re-worked into a new model which considers the incorporation of religious influence within the BAME community. It shows the benefits of working with religious leaders and organisations in reducing barriers to health care professionals as well the benefits of incorporating religious methods to dementia care. The implications of the findings are also applied to the current national dementia pathway, which indicates the different levels of dementia care as outlined by the NHS. Finally, the benefits of incorporating religious methods with healthcare professional methods are discussed, where similarities and differences are explored.

8. Conclusion and Summary

8.1. Introduction

The aim of this thesis was to explore the alternative help-seeking methods for dementia that are utilised within BAME communities. Current research within BAME communities has found that there are differences in their understandings of and experiences with dementia as compared to the White counterparts (Baghirathan et al., 2020; Bowes & Wilkinson, 2003; Julia, 2015), and that religion and culture both play an influential role in the help-seeking methodology selected by the BAME community. Current research has explored dementia understandings and experiences within minority groups with the single overarching narrative of barriers to dementia care (such as delay in dementia diagnosis and lack of service utilisation). These findings suggest that there is a lack of knowledge regarding dementia, negative attitudes around the illness, and a lack of culturally appropriate care for PwD within BAME groups. Baghirathan et al. (2018) has suggested the local uptake of post-diagnostic support is also influenced by ethnicity. They found that many people draw on support networks with which they are familiar with (such as religious organisations) rather than specific services ran by dementia groups (Dodd et al., 2020). This thesis has explored the understandings and help-seeking pathways which are actively utilised within the BAME community (referred to as ‘alternative care’). This approach aimed to tackle or find types of alternative care that were culturally appropriate, provided practical application and provided different and new perspectives into dementia research within BAME groups in the UK. The goal of this thesis was not to provide a method or evidence-based approach that uses religious texts to justify or bring into light the involvement of religion, but rather, it was to show the usefulness a structured element of religion can bring to PwD in minority ethnic groups.

Initially, a critical review was conducted (Chapter 2) to determine the current literature on dementia in minority ethnic groups. This review provided a useful insight into the existing gaps in knowledge. It was found that BAME groups face certain barriers to professional healthcare in the UK. It was also found that though there were factors that could be considered as barriers to dementia care, the same barriers could be perceived differently. Additionally, more importance is given to family caregivers and religion. However, research in this particular area was quite limited. Thus, this thesis further explored the role these 'alternative' care pathways played with the BAME community.

To assist in approaching the aim of the thesis, the following research question were addressed:

1. What are the understandings and experiences of dementia and help-seeking among BAME groups?
2. What are the alternative help-seeking pathways used by people with dementia?
3. How do religion and religious leaders play a role in understandings and experiences of dementia and help-seeking?
4. How can alternative help-seeking methods be used to understand care pathways? What are the practical applications of these alternative methods?

In the attempt to address these research questions, SRT and SIT were adopted to help explore and understand the help-seeking process (Chapter 4). SRT (Descombes, 2000; Hoijer, 2011; Moscovici, 1988) was adopted to understand the representations of dementia within the BAME community. It gave importance to the narratives of the individuals and their practices. It allowed the alternative help-seeking pathways to be examined in their own 'context', without disregarding previous findings. Adopting SIT (Tajfel, 1978; Tajfel & Turner, 1979) gave meaning to these representations and helped explain how representations are formed and why they are formed in the way they are. Social identity is engrained in individuals' beliefs and values and thus, can help explain and understand the help-seeking decision-making process. Using SRT and SIT provided a coherent framework to understand the BAME groups' understandings of dementia as well as helped build a model that capitalises on individuals' values.

8.2. Summary of Research

To explore the help-seeking process for PwD, a mixed method sequential design was adopted.

Study 1 (Chapter 4) was a quantitative study which explored the differences between White and BAME groups in their understandings of dementia. It explored knowledge, stigma, beliefs of cause of dementia and beneficial treatment for dementia. It was found that BAME groups were more likely believe that religion and spirituality were the cause of dementia and that non-professional treatments were beneficial for PwD. There was also a difference between personal stigma; BAME groups had a higher personal stigma score as compared to their White counterparts. This study provided a foundation for Studies 2 and 3.

Study 2 (Chapter 5) was a qualitative study which explored the experiences of help seeking amongst PwD and their caregivers. Using the phenomenological approach, it explored participants' accounts on their experiences with dementia and their help-seeking method. Thematic analysis was used to establish the following overarching themes: 1) facilitators to dementia care, 2) barriers to dementia care and 3) alternative help-seeking methods. This study explored the representations around dementia and help-seeking pathways using the phenomenological approach. It attempted to understand participants' experience with the process. SIT was also adopted to understand these representations and how identity played a role in their help-seeking behaviours.

Study 3 (Chapter 6) was also qualitative study which explored the role of religious leaders with regards to help-seeking behaviours. Thematic analysis was used to establish the following themes: 1) dementia beliefs, 2) influence of religion, 3) sources of help and 4) science and faith. It also adopted SRT and SIT which explored how the representations of dementia and how identity played a role in these representations. It also explored how their role may have an impact on individuals' help-seeking process.

8.3. Contributions and Implications for Policy and Practice

As discussed, previous research has largely focused on barriers to service usage within the BAME community, without addressing their actual help-seeking strategy. This results in one-sided research which only shows that there is a lack of service usage by the BAME community. However, as found in Chapter 2, there is limited research focusing on BAME help-seeking methods and dementia in the UK, with even less focused on alternative care pathways. This thesis identified the importance of alternative care pathways in the help-seeking methods of PwD and their caregivers within minority ethnic communities in the UK. The findings of this thesis identified practical ways of engaging alternative methods of care as part of the mainstream help-seeking pathway (detailed method in Chapter 7 section 7.4). It explored the benefits of religion and religious leaders and incorporated their role into the dementia care pathway. The importance of family care is also captured and more specifically, the important role that the younger generation from these families play. Employing these findings into mainstream health care techniques may not only improve service utilisation but will also improve PwD's quality of life as well as reduce the burden on carers.

If collaboration between healthcare professionals and religious leaders can be established, then central 'information' points can be formed (such as at churches or mosques), where awareness of dementia can be raised, stigma around dementia can be reduced, and professional services which are recommended by the community leaders can be discussed.

8.3.1. Beyond BAME groups

Overall, this thesis has mainly focused on BAME groups and their help-seeking process. BAME groups face various obstacles to professional healthcare. For example, it was found that BAME groups had negative experience within mainstream healthcare. This goes in line with previous research which stated that minority ethnic groups are likely to face discrimination (Chaouni & De Donder, 2019). However, this does not only affect individuals from minority ethnic groups but can impact the wider population, and thus, suggests that there needs to be efforts made within health care systems for everyone. For example, Wellings et al. (2022) reported that dissatisfaction with the services had risen from 25% in 2020 to 41% in 2021 in UK, indicating the need for improvements in health care.

8.4. Limitations of the Thesis

As with any research, this thesis comes with its own limitations. This research did not include PwD and their first-hand perspective. As discussed in Chapter 3 (Section 3.7.4.1), this has its own epistemological limitations. Though the researcher did attempt to include PwD in Study 2 (Section 5.2.2.2), the participants' cognitive abilities did not allow for a coherent interview to be conducted. Future research could focus on interviewing participants (PwD and their carers) at the time of the diagnosis and follow their help-seeking methods (for example, carry out a longitudinal study). Though this would also mean that people from minority ethnic groups would need to get diagnosed on time, which on its own has its challenges.

The sample chosen in this research were BABCC and SAM. However, it is important to remember that BAME groups are not homogenous, and that even within each group there are various factors (such as religion, sects, language, level of acculturation and age). The researcher's approach was not to combine these groups based on their ethnicity, rather, it was to focus on the shared experiences in the healthcare pathways they chose. Future research should focus on a single ethnic group which would allow them to draw on specific cultural understandings of and experiences with dementia.

It can be argued that the model is not a perfect fit as the researcher does not address the barriers to professional services. Though this is true, and more work stills needs to be done to remove these barriers, it also acknowledged that the researcher's aim was not to only address the professional route, but to address alternative methods of help-seeking. This included looking at how religious services can be used. Furthermore, this also shows that there can be more than one pathway to help-seeking for PwD.

This research did not take into account those individuals who remained undiagnosed for their dementia. This meant that their perspectives on the factors discussed as part of this thesis remain unaccounted for. Moreover, the participants that were interviewed (in Study 2) were already diagnosed, i.e., they were already entered their help-seeking pathway. The model constructed in Chapter 7 section 7.4.2 allows for input from only these individual experiences and thus, does not fully include the help-seeking process of those who are not diagnosed. However, this is difficult to measure because how would one know that someone has dementia before they develop symptoms or get diagnosed? One option would be to research people's perspective aged 65 and over and those who are experiencing some form of cognitive impairment. Though, this would not mean that they have dementia, but they would be potential candidates to study as they may develop dementia at later stages.

8.5. Future Research

This study focused only on the experiences of the help-seeking process from the perspective of caregivers. Future research could explore the impact of being a carer on the help-seeking methods of PwD. Various studies have found that carers sometimes do not have the choice to be carers and usually are instigated by guilt. This can often lead to carer burden, ultimately impacting the carer's quality of life

(Caldwell et al., 2014; Hossain and Khan, 2020; Sodders et al., 2020). Though these were not the main focus or the findings of the studies, it is important to note that carer burden may lead to a different approach to help-seeking as opposed to a carer who does not look at their role as having any burden.

Furthermore, it is also acknowledged that family members were the main caregivers for the person with dementia. Though this may be the case for majority of the BAME groups where a traditional ideology is adopted, more work could be done to explore those who do not take this route and may take a route which include residential care. It would be interesting to see how they are utilised by BAME groups and how help-seeking methods are negotiated with their religious and cultural values.

Lastly, this thesis provides a useful insight into the help-seeking methods of dementia which incorporates faith-based methods. This method or perspective can also extend to other illness and diseases that could be useful to improve people's quality of life.

8.5.1. Impact of COVID-19

There is no doubt that Covid-19 had a huge impact on many lives and services, and how the world works has changed since then. COVID-19 also caused challenges, in terms of response time, shift of remote working for health care professionals and rate of diagnostic support. It also meant that there was a lack of access to support, which impacted PwD and their carers negatively. Some day care centres provided support depending in geographical location whereas others did not. Thus, the NHS is now playing catch up in terms of ensuring that people are diagnosed at the right time and people are still provided with right support (Wheatley et al., 2022). This increases the additional barrier to services and diagnosis, especially for the BAME community.

8.6. A Final Conclusion

This thesis provides a unique contribution to knowledge of dementia with the BAME community in the UK. It sheds light on to the alternative pathways to dementia and thus provides a practical way to incorporate it in mainstream pathway. This thesis recognises the importance of religion and cultural values to BAME groups which is considered in its application.

It should also be noted that a lot of work needs to be done within BAME groups and dementia. There needs to be more representation of BAME groups within media, targeting of younger adults when increasing awareness of dementia, research on new methods to help PwD retain their sense of self and be able to make independent decisions.

Overall, the work towards dementia is not complete and global efforts need to be made to ensure that PwD live well and have a good quality of life.

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Appendices

Appendix A – Independent T-test (Chapter 4)

Table 15

Independent t-test to Determine Beliefs about Cause and Beneficial Treatment of Dementia Between BAME and White Groups.

Vignette	Factors	White		BAME		*t*	*df*	*p*	
		M	*SD*	*M*	*SD*				Cohen's *d*
Mild	Biological	6.69	1.53	6.54	1.62	0.66	255	0.509	0.09
	Lifestyle	6.27	1.8	6.32	1.83	-0.22	254	0.823	-0.03
	Religious/Spiritual	5.80	4.21	7.45	2.84	-3.02	93.81	0.003**	-0.50
Severe	Biological	6.96	1.73	6.91	1.83	0.19	236	0.851	0.03
	Lifestyle	6.03	1.78	6.28	1.76	-0.99	235	0.322	-0.14
	Religious/Spiritual	5.80	4.23	8.53	3.33	-4.65	94.52	0.000**	-0.76
Mild	Professional	10.25	2.17	10	2.89	0.72	164.99	0.471	0.09
	Alternative	9.33	2.99	11.3	2.62	-5.1	241	0.000**	-0.72
Severe	Professional	11.62	2.4	11.06	2.95	1.45	145.97	0.150	0.2
	Alternative	9.51	2.95	11.42	2.64	-4.48	103.13	0.000**	-0.7
	Mild Social Distance	12.29	4.24	13.41	3.92	-1.9	221	0.059	-0.28
	Severe Social Distance	14.63	5.28	15.69	5.38	-1.35	229	0.179	-0.2
	Personal Stigma	16.06	4.5	17.47	4.25	-2.26	229	0.025*	-0.33
	Perceived Stigma	20.84	5.46	21.59	5.15	-0.99	230	0.320	-0.14
	Knowledge of dementia	3.65	1.82	3.83	1.91	-0.72	274	0.475	-0.1

Appendix B– Analysis (Chapter 4)

Appendix B.1

Table 16

Dependent t-test to Determine Beliefs about Cause and Beneficial Treatment of Dementia Between within White Group.

Vignette	Cause of dementia	*M*	*SD*	*t*	*df*	*p*	Cohens *d*
Mild	Biological	6.69	1.53	1.49	70	0.142	0.18
	Lifestyle	6.27	1.8				
	Biological	6.67	1.53	1.5	69	0.138	0.18
	Religious/Spiritual	5.80	4.21				
	Lifestyle	6.29	1.8	0.93	69	0.357	0.11
	Religious/Spiritual	5.80	4.21				
Severe	Biological	6.96	1.73	3.36	66	0.001*	0.41
	Lifestyle	6.03	1.78				
	Biological	7.00	1.75	1.83	63	0.072	0.23
	Religious/Spiritual	5.80	4.23				
	Lifestyle	6.06	1.81	0.46	63	0.648	0.06
	Religious/Spiritual	5.80	4.23				
Mild	Professional	10.25	2.17	2.7	67	0.009*	0.33
	Alternative	9.21	2.93				
Severe	Professional	11.56	2.43	4.79	61	0.000**	0.61
	Alternative	9.55	2.96				

Note. *$p < .01$, **$p < .001$

Appendix B.2

Table 17

Dependent t-test to Determine Beliefs about Cause and Beneficial Treatment of Dementia Between within BAME Group.

Vignette	Cause of dementia	M	SD	t	df	p	Lower	Upper	Cohens d
Mild	Biological	6.55	1.63	1.34	183	0.182	-0.11	0.58	0.10
	Lifestyle	6.32	1.83						
	Biological	6.55	1.63	-3.53	182	0.001*	-1.38	-0.39	-0.26
	Religious/Spiritual	7.44	2.84						
	Lifestyle	6.33	1.84	-4.54	182	0.000**	-1.59	-0.63	-0.34
	Religious/Spiritual	7.44	2.84						
Severe	Biological	6.91	1.83	3.68	169	0.000**	0.29	0.97	0.28
	Lifestyle	6.28	1.76						
	Biological	6.93	1.80	-4.92	166	0.000**	-2.23	-0.95	-0.38
	Religious/Spiritual	8.53	3.33						
	Lifestyle	6.32	1.74	-7.66	166	0.000**	-2.77	-1.64	-0.59
	Religious/Spiritual	8.53	3.33						
Mild	Professional	9.98	2.90	-4.80	158	0.000**	-1.83	-0.76	-0.38
	Alternative	11.28	2.65						
Severe	Professional	11.03	2.96	-1.21	150	0.229	-0.86	0.21	-0.10
	Alternative	11.36	2.61						

Note. **p* < .01, ***p* < .001

Appendix C - Correlation Output (Chapter 4)

Appendix C.1 - Spearman's Rho Correlation -White Group

When looking at the relationship between knowledge of dementia and stigma, it was found that there was significant negative relationship between knowledge of dementia and personal stigma, r_s (68) = -.3, *p* = .014. When looking at religiosity and stigma, it was found that there was significant positive relationship between religiosity and personal stigma, r_s(67) = .26, *p* = .037 and positive relationship between religiosity and perceived stigma, r_s(67) = .31, *p* = .012. When looking at stigma and cause of dementia. It was found that there was a was significant negative relationship between personal stigma and the belief that biological factors were the cause of dementia r_s (66) = -.38, *p* = .001. There was a was significant positive relationship between perceived stigma and the belief that biological factors were the cause of dementia r_s (66) = .33, *p* = .007 in the severe vignette. It was found that there was a was significant negative relationship between personal stigma and the belief that lifestyle factors were the cause of dementia (r_s (66) = -.29, *p* = .02). When looking at the relationship between stigma and beneficial treatments of dementia, it was found that there was a was significant negative relationship between personal stigma and the belief that professional treatment was beneficial for the person with mild dementia, r_s (64) = -.34, *p* = .006. When looking at religiosity and beneficial treatment, it was found that there was a positive relationship between religious and alternative treatments in the mild vignette case, r_s (70) = .45, $p < .001$. Similarly, it was found that there was positive relationship between religiosity and alternative treatments in the severe vignette case r_s (63) = .5, $p < .001$.

Appendix C.2 - Spearman’s Rho Correlation - BAME Group

When looking at the relationship between knowledge of dementia and beliefs about causes of dementia, it was found that there was a significant positive relationship between knowledge of dementia and the belief that biological factors were the cause of dementia, r_s (186) = .17, p = .019 in the mild vignette case. Similarly, it was also found that there was a significant positive relationship between knowledge of dementia and the belief that biological factors were the cause of dementia, r_s (171) = .27, p < .001. in the severe vignette case. It was also found that there was a significant positive relationship between knowledge of dementia and the belief that biological factors were the cause of dementia, r_s (70) = .19, p = .014 in the severe vignette case.

When looking at the relationship between knowledge of dementia and beliefs about beneficial treatments of dementia, it was found that there was a significant positive relationship between knowledge of dementia and the belief that alternative help was beneficial r_s (173) = .19, p = .015 in the mild vignette. When looking at stigma and beneficial treatments for the person with dementia, it was found that there was a significant negative relationship between personal stigma and the belief that alternative help was beneficial, r_s (148) = -.23, p = .004 in the mild vignette case. As well as personal stigma and alternative help in the severe vignette case, r_s (153) = -.18, p = .024. When looking at stigma and professional help, it was found that there was a significant negative relationship between perceived stigma and professional help, r_s (148) = -.20, p = .014 in the severe vignette case. It was also found that there was a significant negative relationship between personal stigma and professional help, r_s (148) = -.27, p = .001 in the severe vignette. There was also a positive relationship between personal and perceived stigma, r_s (186) = .17, p = .019.

Appendix D - Study One (Chapter 4)

Appendix D.1

Information Sheet

Understanding dementia knowledge and attitudes amongst
Researcher: Jawaria Farooq
Supervisor: Professor Evanthia Lyons and Dr Sabira Mannan

I would like to invite you to participate in this project which concerns aging and dementia. I am interested in finding out how people understand dementia and ageing. Before you decide to fill out the questionnaire, please take time to read the information below carefully, as this provides all the details about the study. Please do not hesitate to email the researcher if anything is not clear or if you need further information.

Why am I doing the project?
This project is part of my PhD project at Kingston University. We are interested in gaining people's perspective about aging and dementia. This information will be used in the rest of my PhD project as well as providing useful information for healthcare services.

What will you have to do?
You will be asked to fill out a questionnaire that consists of 5 questionnaires. Before you begin the questionnaire, you will be asked to sign the consent sheet to make sure you have understood every part of the study. You will also have to fill out a demographic form. You will be asked to answer questions like, *'Dementia is part of normal ageing (True or false)'* and '*To what extent do you think Mr T is going through stressful life events (Very likely or not likely)'.* The whole questionnaire should not take any longer than 30mins.

Will your participation in the project remain confidential?
If you agree to take part in this study, your responses will not be disclosed to any other person and will remain anonymous. The only people who would have access to the information would be the principle researcher and the two supervisors. Your responses to the question will only be used for the purpose of this project only.

A participant number will be assigned to you to ensure anonymity. After the project, all raw data will be destroyed. In the reporting of the project, no information will be released which could enable a reader to identify participants. Please keep your participant number safe if you wish to withdraw your data after completing the study.

What are advantages of taking part?
We don't anticipate any direct benefit. However, you may find this project interesting and can find more information about it once you have finished.

What are the disadvantages of taking part?
There are no disadvantages in taking part in this study. However, it could be that you may not feel uncomfortable talking about aging and dementia. Details of organisations where you could seek further information regarding these issues are provided.

Do you have to take part in the study?
Your participation for this project is entirely voluntary. You don't have to take part if you do not which to. If you do agree to participate in the study, you may still withdraw at any time of the study without giving any reason. After completing this study, if you want your answers to be withdrawn from the date you can withdraw by September 2017. You simply have to provide us with your participant number and contact us. Please see the contact details at the end of this sheet.

What if there are any problems?
If you have any concerns about this study, please feel free to contact the researcher. You may also wish to contact the supervisors Professor Evanthia Lyons and Dr Sabira Mannan. All details are provided on this information sheet.

Kingston University Student
Researcher's Contact details:-
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Consent Form

Understanding dementia knowledge and attitudes amongst BME Population in the UK.

Please tick all the boxes

☐ I confirm that I have read and understood the information sheet/letter of invitation for this study. I have been informed of the purpose, risks, and benefits of taking part.

☐ I understand what my involvement will entail, and any questions have been answered to my satisfaction.

☐ I understand that my participation is entirely voluntary, and that I can withdraw at any time without prejudice.

☐ I understand that all information obtained will be confidential.

☐ I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.

☐ Contact information has been provided should I (a) wish to seek further information from the investigator at any time for purposes of clarification (b) wish to make a complaint.

☐ I give consent to have the audio of this interview recorded (Only for the interview)

☐ I understand that I can withdraw my data anytime until September 30th 2017.

Participant's Signature ___________________________

Date ____

Name of Investigator ____________________________

Signature of investigator _________________________

Kingston University Student
Researcher's Contact details:-
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Debriefing sheet

Thank you for participating in this study. The study aimed to identify people's perspectives and knowledge about dementia. Also to determine whether there is stigma attached to dementia amongst the sample groups chosen.

The number of people developing dementia is known to increase to around 1 million by 2050 as compared to 750,000 today (Philipson, et al 2014). Previous research has focused on the knowledge and attitudes towards dementia in many cultural and religious groups. However, no research has been conducted on Pakistani Muslims living in the UK.

All the information that has been collected with be kept confidential and all information will be anonymous. All the data will be kept on secure files. Only the researchers will have access to the data. All the information collected will be deleted and destroyed after analysis. If you wish to withdraw from the research at any point please provide your participant number to the researchers up at any point till October 31st 2017

The results will be written up for my PhD thesis. The information provided will not be identifiable. We hope that these findings will be able to advance our understanding of the current knowledge and perspectives on dementia.

This study was designed to minimize any form of distress. However, if you experience any physical or psychological distress, please contact the researcher via email or over the phone (contact details are provided below). You should also contact the researcher if you have any further question on this study, or if you want to withdraw your data.

If you would like more information on dementia then please refer to the NHS page or the Alzheimer society page.

NHS Page:
http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx

The Alzheimer's Society Page:
https://www.alzheimers.org.uk/

Also, if you felt distressed and would like help, please contact the Good Samaritans:
Direct dial: 116 123
Website: www.Samaritans.org

Contact details are below
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Department of Psychology, Faculty of Arts and Social Sciences
Kingston University
Penrhyn Road
Kingston Upon Thames
Surrey KT1 2EE
Email**:**

Appendix D.2 - Vignettes

Mild Vignette

My grandmother/grandfather is 60 years old. He/she lives alone with his/her three children. She/he was always active and never missed any opportunity to visit any of the extended family. However, he/she is now beginning to forget small and simple things such as the names of his/her children and even needs to be reminded to carry out simple tasks such as brushing his/her teeth. He/she is no longer able to handle personal finance and has to get help from the children. He/she has difficulties making simple decisions such as ordering food at restaurants. He/she also forgets simple words and cannot express his/her thoughts when he/she gets down. He/she still enjoys reading and praying every day. Everyone is telling me to take her/him to get checked. However, others assume that she/he is getting old. He/she is in denial that anything is wrong with her/him and believes that everything is fine.

Severe Vignette

My Uncle/Aunty is 63 years old. He/she lives with his/her wife/husband alone. For the past few years, we have noticed that he/she has become very withdrawn, inactive and careless. He/she has become very forgetful and is unable to remember any names of relatives but remembers detail of his/her younger days and spends hours talking about the events of youth, even though he/she forgets the things that have happened yesterday. He she does not read anymore or even pray.

He/she is unable to do basic chores such as eating, dressing and even toileting. He/she always needs help with everything and gets moody and agitated over small things. This makes is difficult for people to get along with him/her. He/she is unable to go out alone and often spends time alone in the room doing nothing. When He/she is alone he/she always mutters to herself /himself and gets agitated very easily and gets paranoid at everything. He/she always seems to be in her own world and seems depressed. He/she has started to wonder around at night without any reason and is often persuaded that its morning. His/her wife/husband has recommended that he/she should get extra help as something is not right.

Appendix D.3

Demographics

Gender: Male Female Prefer not to say

How old will you be on your next birthday?

What is your highest level of education?
- GCSE
- A-levels
- Undergraduate
- Postgraduate
- Doctorate
- PhD
- Other

What is your occupation? *(Click any that applies to you)*
- Student
- Part time job
- Full time job
- Unemployed
- Retired
- Other

Where were you born?
- Pakistan
- India
- Bangladesh
- Sri Lanka
- United Kingdom
- Other

How long have you been in the UK?
I was born here ( ) or ( ) years

Are you a Britain Citizen?
Yes No Prefer not to say

What is your social class?
Lower class
Working class
Middle class
Upper class

Has anyone you known well had dementia or Alzheimer Disease?
Yes No

Have you ever cared for a family member of friends with dementia or Alzheimer Disease?
Yes No

Religiosity

How often do you attend Mosque/Church or other religious meetings?
Never

1. Once a year or less
2. A few times a year
3. A few times a month
4. Once a week
5. More than once a day

How often do you spend time in private religious activities, such as prayer, meditation or Quran/Bible study?

1. Never
2. Once a year
3. A few times a year
4. A few times a month
5. Once a week
6. More than once a day

The following section contains 3 statements about religious belief or experience. Please mark the extent to which each statement is true or not true for you

In my life, I experience the presence of a God

1. Definitely not
2. Tends not to be true
3. Unsure
4. Tends to be true
5. Definitely true to me

My religious beliefs are what really lie behind my whole approach to life

1. Definitely not
2. Tends not to be true
3. Unsure
4. Tends to be true
5. Definitely true to me

I try hard to carry my religion over into all other dealings in life

1. Definitely not
2. Tends not to be true
3. Unsure
4. Tends to be true
5. Definitely true to me

Dementia Knowledge Questionnaire

The brain is affected when someone develops dementia (**True**, False, don’t know)

Everyone develops dementia when they get past 50 years of age (True, **False**, don’t know)

Alzheimer's disease is the most common cause of dementia (**True**, False, don’t know)

Stroke may lead to dementia (**True**, False, don’t know)

There is no way to prevent dementia (True, **False**, don’t know)

Drugs are useful to treat dementia (**True**, False, don’t know)

Regular exercise reduces the risk of dementia (**True**, False, Don’t know)

If a person remembers well what happened a long time ago, he or she does not have dementia (True, **False**, don’t know)

If a person develops dementia, he or she may experience change in his or her personality.
(**True**, False, Don’t know)

Dementia can be determined only when strange behaviours appear (True, **False**, don’t know)

Knowledge and Beliefs about possible causes of dementia

To what extent do you think he/she has dementia because of Brain Disease?
1 2 3 4 5

To what extent do you think he/she has dementia because of heredity factors?
1 2 3 4 5

To what extent do you think he/she has dementia because of Stressful life events?
1 2 3 4 5

To what extent do you think this is part of normal aging?
1 2 3 4 5

To what extend do you believe that this was gods will?
1 2 3 4 5

To what extent to you believe that this was because of evil eye?
1 2 3 4 5

To what extent do you believe that this was because he/she was not devoted to Islam enough?
1 2 3 4 5

Treatment about dementia

Psychiatrists	Psychotherapists (Therapy)	Doctors	Local Mosque Imam	Self-Help	Family and friends	Prayer
1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

Personal Stigma

People with dementia should snap out of the problem					
Dementia is a sign of personal weakness					
Dementia is a real medical illness					
People with Dementia are dangerous					
It is best to avoid people with Dementia					
People with dementia are unpredictable					
People with dementia are caring people					
If I had this dementia, I would not tell anyone					

Perceived stigma

Most people believe that PwD could snap out of the problem					
Most people believe Dementia is a sign of personal weakness					
Most people believe Dementia is a real medical illness					
Most people believe People with Dementia are dangerous					
Most people believe It is best to avoid people with Dementia					
Most people believe People with dementia are unpredictable					
Most people believe People with dementia are caring people					
Most people believe that people with dementia should be support in every way					

Social distant questionnaire

To have A/N child marry one of your children
1 2 3 4 5

To spend an evening socializing with A/N
1 2 3 4 5

To live near my A/N
1 2 3 4 5

Willingness to support my A/N
1 2 3 4 5

To make friends with A/N
1 2 3 4 5

To ask my A/N for a favour.
1 2 3 4 5

Appendix E - Study Two (Chapter 5)

Appendix E.1

Information Sheet

Understanding dementia experience and perception amongst carers of Christians/Muslims with dementia

Researcher: Jawaria Farooq
Supervisor: Prof David Herbert

I would like to invite you to participate in this project which concerns aging and dementia. I am interested in finding out how people understand dementia and ageing. Please take time to read the information below carefully, as this provides all the details about the study. Please do not hesitate to email the researcher, if anything is not clear or if you need further information.

Why am I doing the project?
This project is part of my PhD project at Kingston University. We are interested in gaining the perspective of the main carers of Muslims with dementia about dementia. This information will be used in my PhD project as well as providing useful information for healthcare services. We are recruiting ten cares of Christians/Muslims with dementia to allow us to get a deeper understanding of understanding the experiences of dementia.

What will you have to do?
This is qualitative study where you will be interviewed. You will be asked a few questions regarding you/the Person with dementia's experience and services with dementia. The interview will approximately last around 30 minutes to one hour. Before beginning the interview, your consent will be taken. This can take place of your choice, either face to face or online.

Will your participation in the project remain confidential?
If you agree to take part in this study, your responses will not be disclosed to any other person and will remain anonymous. The data will be transcribed and analysed. The only people who would have access to the raw data would be the principle researcher and the two supervisors. A participant number will be assigned to you to ensure anonymity. After the project, all raw data will be destroyed. In the reporting of the project, no information will be released which could enable a reader to identify participants.

You have the right to withdraw at any point during the study and your data until December 2019. Please keep your participant number safe if you wish to withdraw your data after completing the study.

What are advantages of taking part?
We don't anticipate any direct benefit. However, you may find this project interesting and can find more information about it once you have finished.

What are the disadvantages of taking part?
There are no disadvantages in taking part in this study. However, it could be that you may not feel uncomfortable talking about aging and dementia. Details of organisations where you could seek further information regarding these issues are provided.

Do you have to take part in the study?
Your participation for this project is entirely voluntary. You don't have to take part if you do not which to. If you do agree to participate in the study, you may still withdraw at any time during study without giving any reason. After completing this study, you can still withdraw by 30th of December 2019. You simply must provide us with your participant number and contact us. Please see the contact details at the end of this sheet.

The research has received a favourable ethical opinion from the Research Ethics Committee of the Faculty of Business and Social Sciences at Kingston University London.'

What if there are any problems?
If you have any concerns about this study, please feel free to contact the researcher. You may also wish to contact the supervisor Dr Sabira Mannan. All details are provided on this information sheet.

If you wish to complain about any aspect of how you have been treated in this research, please contact Professor Jill Schofield who is the Dean of the Faculty of Business and Social Sciences at Kingston University London.

Professor Schofield's

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Researcher's Contact details: -
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Supervisors Contact details:-
Prof David Herbert
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Dean's Office, Faculty of Business and Social Sciences
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Penrhyn Road,
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KT1 2EE
Email:
Tel:

Understanding dementia experience and perception amongst carers of Muslims with dementia

Please carefully read each statement and tick the if you agree to each one.

I confirm that I have read and understood the information sheet/letter of invitation for this study. I have been informed of the purpose, risks, and benefits of taking part. ☐

I understand what my involvement will entail, and any questions have been answered to my satisfaction. ☐

I understand that my participation is entirely voluntary, and that I can withdraw at any time during the study or any time before the 30th September 2021 without prejudice. ☐

I understand that all information obtained will be confidential. ☐

I agree that research data gathered for the study may be published provided that I cannot be identified as a subject. ☐

Contact information has been provided should I (a) wish to seek further information from the investigator at any time for purposes of clarification (b) wish to make a complaint. ☐

I understand that the project will adhere to the data management requirements specified in the 2018 Data Protection Act. ☐

Participant's Signature---
Date --

Statement by investigator

I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that he/she understands the implications of participation. ☐

Name of investigator --
Signature of investigator ---
Date --

Debriefing sheet

Thank you for participating in this study. The study aimed to identify people’s perspectives and knowledge about dementia.

The number of people developing dementia is known to increase to around 1 million by 2050 as compared to 750,000 today (Philipson, et al 2014). Previous research has focused on the knowledge and attitudes towards dementia in many cultural and religious groups. However, no research has been conducted on Pakistani Muslims living in the UK.

All the information that has been collected with be kept confidential and all information will be anonymous. All the data will be kept on secure, and password protected computers. Only the researchers will have access to the data. All the information collected will be transcribed and the raw date will be deleted and destroyed after analysis. In the reporting of the project, no information will be released which could enable a reader to identify participants. If you wish to withdraw from the research at any point, please provide your participant number to the researchers up at any point till December 2021.

The results will be written up for my PhD thesis. The information provided will not be identifiable. We hope that these findings will be able to advance our understanding of the current knowledge and perspectives on dementia.

This study was designed to minimize any form of distress. However, if you experience any physical or psychological distress, please contact the researcher via email or over the phone (contact details are provided below). You should also contact the researcher if you have any further question on this study, or if you want to withdraw your data.

If you would like more information on dementia for you and your family, please refer to any of the below:

NHS Page:
http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx

The Alzheimer’s Society Page:
https://www.alzheimers.org.uk/

Also, if you felt distressed and would like help, please contact the Samaritans:
Direct dial: 116 123
Website: www.Samaritans.org

The research has received a favourable ethical opinion from the Research Ethics Committee of the Faculty of Business and Social Sciences at Kingston University London

'If you wish to complain about any aspect of how you have been treated in this research, please contact Professor Jill Schofield who is the Dean of the Faculty of Business and Social Sciences at Kingston University London.

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Supervisors Contact details:-
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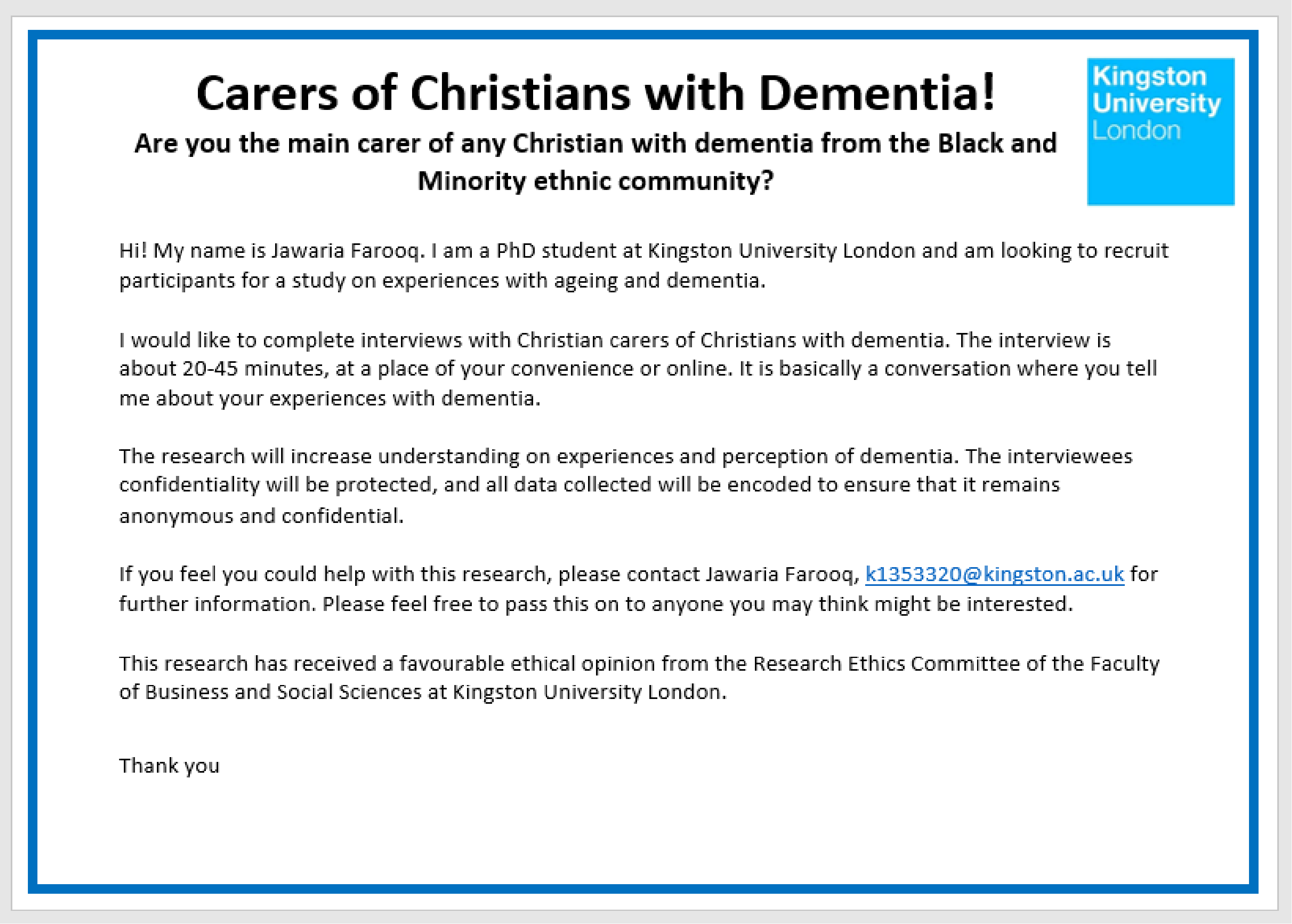


Carers of Christians with Dementia!

Are you the main carer of any Christian with dementia from the Black and Minority ethnic community?

Kingston University London

Hi! My name is Jawaria Farooq. I am a PhD student at Kingston University London and am looking to recruit participants for a study on experiences with ageing and dementia.

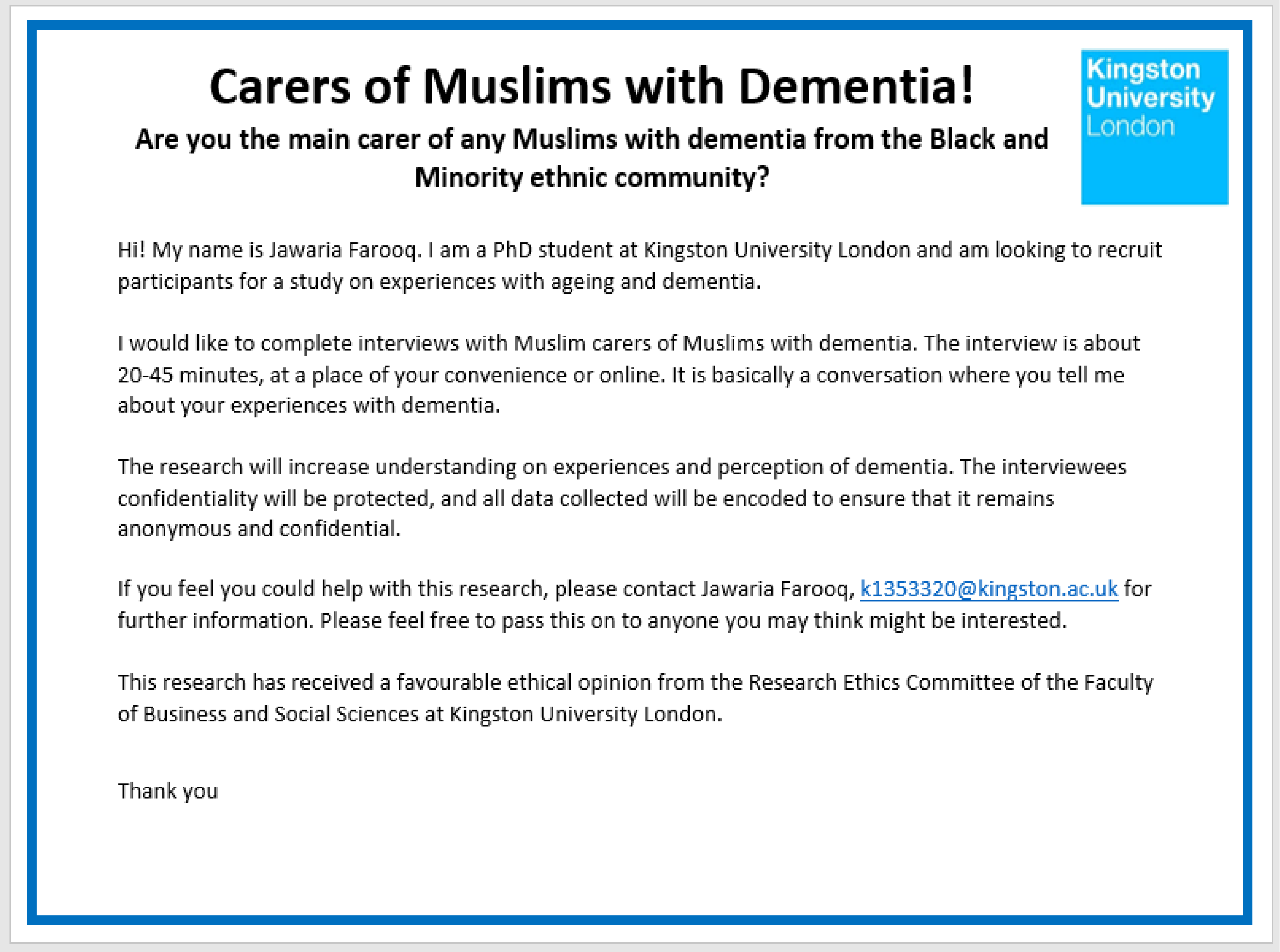
I would like to complete interviews with Christian carers of Christians with dementia. The interview is about 20-45 minutes, at a place of your convenience or online. It is basically a conversation where you tell me about your experiences with dementia.

The research will increase understanding on experiences and perception of dementia. The interviewees confidentiality will be protected, and all data collected will be encoded to ensure that it remains anonymous and confidential.

If you feel you could help with this research, please contact Jawaria Farooq, k1353320@kingston.ac.uk for further information. Please feel free to pass this on to anyone you may think might be interested.

This research has received a favourable ethical opinion from the Research Ethics Committee of the Faculty of Business and Social Sciences at Kingston University London.

Thank you



Carers of Muslims with Dementia!

Are you the main carer of any Muslims with dementia from the Black and Minority ethnic community?

Kingston
University
London

Hi! My name is Jawaria Farooq. I am a PhD student at Kingston University London and am looking to recruit participants for a study on experiences with ageing and dementia.

I would like to complete interviews with Muslim carers of Muslims with dementia. The interview is about 20-45 minutes, at a place of your convenience or online. It is basically a conversation where you tell me about your experiences with dementia.

The research will increase understanding on experiences and perception of dementia. The interviewees confidentiality will be protected, and all data collected will be encoded to ensure that it remains anonymous and confidential.

If you feel you could help with this research, please contact Jawaria Farooq, k1353320@kingston.ac.uk for further information. Please feel free to pass this on to anyone you may think might be interested.

This research has received a favourable ethical opinion from the Research Ethics Committee of the Faculty of Business and Social Sciences at Kingston University London.

Thank you

Appendix E.2

Demographics
To begin, I'd like to get some basic information about you. Any information that you will give will never to be used to identify you in any way because this research is entirely confidential. However, if you don't want to answer some questions, please don't feel that you have to.

1. Are you
Male Female other

2. How old are you?

3. How would you describe your ethnic origins?

4. What religion would you identify with?

5. What is your highest education qualification?

None
GCSE/O level (s)/CSE (s)
A-level (s)/AS-Level (s)
Diploma
Degree
Postgraduate
Other

6. How long have you been living in the UK for?

7. How long has X had dementia for?

8. What religion does X identify with?

9. What is your relationship with your carer/ Person with dementia?

10. What's your religion?

INTERVIEW FOR CARERS

1. Could you tell me about your experiences when you first found out that X had dementia?
a. How did that make you feel?

2. Aetiology: When and how did it start? What do you think is the reason why person A has dementia?
3.

4. What are your experiences in being a carer for X?
a. How does that make you feel?
b. Do you seek support from anyone else? (What makes you say that?)

5. How do you think dementia has affected X?
a. Could you tell me more about their Quality of life?

6. Aetiology: When and how did it start? What do you think is the reason why person A has dementia?

7. Pathophysiology: What is the problem with Person A? What does it do the mind? Address vulnerability? Coping? Resilience

8. Why do you think it started when it did?

9. What do you think the sickness does? How does it work?

10. How severe is the sickness? Will it have a long or a short course?

11. Diagnosis? Get X checked out by the doctors?
a. What made you do that?
b. Did you know any information about dementia
c. Who did you ask for information?

12. Have you disclosed this to anyone besides from your family members?
a. What made you do that?
b. How did they respond to X? Or how would they have reacted?
c. In your opinion do people in your community understand dementia?

13. Who did you turn for support during that time?
a. Did you seek help from doctors?
b. Did they recommend any treatments?
c. What did you find most helpful or unhelpful about them (Can you give me an example?)
d. Are you still using these services?

14. Thinking about your experiences with dementia, what do you think it would have been useful for them to know about Islam?
a. What makes you say that? (Can you give me an example?)

15. I would now like to turn to person X religious beliefs and practices. How important is Islam to X?

16. Do you think Islam played a role in shaping how X understood and experience the dementia?
a. How has person X experienced changed since then?
17. What kind of treatment do you think the patient should receive? What does person A need? What has so far proved effective in the treatment?

18. Do you seek help from any religious groups for person x?
a. Have you disclosed person x dementia to members/Imam?
b. What do you think would be helpful for the Mosques to know about dementia?

19. I would not now like to discuss how you use religion to cope with dementia? Have you used any religious or even traditional methods for person x to cope with dementia? (If so then why did you use these methods?)
a. How was that helpful/ Unhelpful? (Can you give me an example?)
20. What do you fear most about the sickness?

Appendix F - Study Three (Chapter 6)

Appendix F.1

Information Sheet

Understanding dementia experience and perception amongst BME Christians/Muslims Religious Leaders.
Researcher: Jawaria Farooq
Supervisor: Prof David Herbert

I would like to invite you to participate in this project which concerns aging and dementia. I am interested in finding out how people understand dementia and ageing. Please take time to read the information below carefully, as this provides all the details about the study. Please do not hesitate to email the researcher if anything is not clear or if you need further information.

Why am I doing the project?
This project is part of my PhD project at Kingston University. We are interested in gaining the perspective of the main carers of Muslims with dementia about dementia. This information will be used in my PhD project as well as providing useful information for healthcare services. We are recruiting BME Christians/Muslims with dementia to allow us to get a deeper understanding of understanding the experiences of dementia.

What will you have to do?
This is qualitative study where you will be interviewed. You will be asked a few questions regarding you/the Person with dementia's experience and services with dementia. The interview will approximately last around 30 minutes to one hour. Before beginning the interview, your consent will be taken. This can take place of your choice, either face to face or online.

Will your participation in the project remain confidential?
If you agree to take part in this study, your responses will not be disclosed to any other person and will remain anonymous. The data will be transcribed and analysed. The only people who would have access to the raw data would be the principle researcher and the two supervisors. A participant number will be assigned to you to ensure anonymity. After the project, all raw data will be destroyed. In the reporting of the project, no information will be released which could enable a reader to identify participants.

You have the right to withdraw at any point during the study and your data until the December 2019. Please keep your participant number safe if you wish to withdraw your data after completing the study.

What are advantages of taking part?
We don't anticipate any direct benefit. However, you may find this project interesting and can find more information about it once you have finished.

What are the disadvantages of taking part?
There are no disadvantages in taking part in this study. However, it could be that you may not feel uncomfortable talking about aging and dementia. Details of organisations where you could seek further information regarding these issues are provided.

Do you have to take part in the study?

Your participation for this project is entirely voluntary. You don’t have to take part if you do not which to. If you do agree to participate in the study, you may still withdraw at any time during study without giving any reason. After completing this study, you can still withdraw by 30th of December 2019. You simply must provide us with your participant number and contact us. Please see the contact details at the end of this sheet.

The research has received a favourable ethical opinion from the Research Ethics Committee of the Faculty of Business and Social Sciences at Kingston University London.’

What if there are any problems?
If you have any concerns about this study, please feel free to contact the researcher. You may also wish to contact the supervisor Prof David Herbert. All details are provided on this information sheet.

If you wish to complain about any aspect of how you have been treated in this research, please contact Professor Jill Schofield who is the Dean of the Faculty of Business and Social Sciences at Kingston University London.

Professor Schofield's

Kingston University Student
Researcher’s Contact details:-
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Supervisors Contact details:-
Prof David Herbert
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Kingston upon Thames
Surrey KT1 2EE

Dean's Office, Faculty of Business and Social Sciences
Kingston University London,
Penrhyn Road,
Kingston upon Thames
KT1 2EE
Email:
Tel:

Consent form

Please carefully read each statement and tick the if you agree to each one.

I confirm that I have read and understood the information sheet/letter of invitation for this study. I have been informed
of the purpose, risks, and benefits of taking part. ☐

I understand what my involvement will entail, and any questions have been answered to my satisfaction. ☐

I understand that my participation is entirely voluntary, and that I can withdraw at any time during the study or any time before the 30th of December 2021 without prejudice. ☐

I understand that all information obtained will be confidential. ☐

I agree that research data gathered for the study may be published provided that I cannot be identified as a subject. ☐

Contact information has been provided should I (a) wish to seek further information from the investigator at any time
for purposes of clarification (b) wish to make a complaint. ☐

I understand that the project will adhere to the data management requirements specified in the 2018 Data Protection Act. ☐

Participant's Signature---
Date ---

Statement by investigator

I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that he/she understands the implications of participation. ☐

Name of investigator --
Signature of investigator --
Date ---

Debriefing sheet

Thank you for participating in this study. The study aimed to identify people's perspectives and knowledge about dementia.

The number of people developing dementia is known to increase to around 1 million by 2050 as compared to 750,000 today (Philipson, et al 2014). Previous research has focused on the knowledge and attitudes towards dementia in many cultural and religious groups. However, no research has been conducted on clergy views of dementia.

All the information that has been collected with be kept confidential and all information will be anonymous. All the data will be kept on secure, and password protected computers. Only the researchers will have access to the data. All the information collected will be transcribed and the raw date will be deleted and destroyed after analysis. In the reporting of the project, no information will be released which could enable a reader to identify participants. If you wish to withdraw from the research at any point, please provide your participant number to the researchers up at any point till 30th September 2021.

The results will be written up for my PhD thesis. The information provided will not be identifiable. We hope that these findings will be able to advance our understanding of the current knowledge and perspectives on dementia.

This study was designed to minimize any form of distress. However, if you experience any physical or psychological distress, please contact the researcher via email or over the phone (contact details are provided below). You should also contact the researcher if you have any further question on this study, or if you want to withdraw your data.

If you would like more information on dementia, please refer to the NHS page or the Alzheimer society page.

NHS Page:
http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx

The Alzheimer's Society Page:
https://www.alzheimers.org.uk/

Also, if you felt distressed and would like help, please contact the Samaritans:
Direct dial: 116 123
Website: www.Samaritans.org

The research has received a favourable ethical opinion from the Research Ethics Committee of the Faculty of Business and Social Sciences at Kingston University London

'If you wish to complain about any aspect of how you have been treated in this research, please contact Professor Jill Schofield who is the Dean of the Faculty of Business and Social Sciences at Kingston University London.

Professor Schofield's contact details:
Dean's Office, Faculty of Business and Social Sciences,
Kingston University London,
Penrhyn Road, Kingston upon Thames
KT1 2EE.
Email:
Tel:

Researcher's Contact details:-
Jawaria Farooq
PhD student
Department of Psychology, Faculty of Business and Soical Science
Kingston University
Penrhyn Road
Kingston Upon Thames
Surrey KT1 2EE
Email:

Supervisors Contact details:-
Professor David Herbert
Department of Sociology, Faculty of Business and Social Science
Kingston University
Penrhyn Road
Kingston Upon Thames
Surrey KT1 2EE

Are you from the Black Minority and Ethnic community?
Are you a religious leader?
Do you teach others about Christianity?
Or do people come to you for guidance?

If you are from the BME community and identify your self with any religious involvement, please participate in an interview about health.

It will last between 30 to 60 minutes.

Please contact Jawaria Farooq for more information

K1353320@Kingston.ac.uk

This research is ethically approved by Kingston University

Are you from the Black Minority and Ethnic community?
Are you a religious leader?
Do you teach others about Islam?
Or do people come to you for guidance?

If you are from the BME community and identify your self with any religious involvement, please participate in an interview about health.

It will last between 30 to 60 minutes.

Please contact Jawaria Farooq for more information

K1353320@Kingston.ac.uk

This research is ethically approved by Kingston University

Appendix F.2

Vignette

Person A is 60 years old. He/she lives alone with his/her three children. For the past few years we have noticed that he/she has become very withdrawn, inactive, and careless._He/she has become very forgetful and is unable to remember any names of relatives but remembers detail of his/her younger days and spends hours talking about the events of youth, even though he/she forgets the things that have happened yesterday. He she does not read anymore or even pray. He/she is unable to do basic chores such as eating, dressing and even toileting. He/she always needs help with everything and gets moody and agitated over small things. This makes is difficult for people to get along with him/her. He/she is unable to go out alone and often spends time alone in the room doing nothing. When He/she is alone he/she always mutters to herself /himself and gets agitated very easily and gets paranoid at everything. He/she always seems to be in her own world and seems depressed. He/she has started to wonder around at night without any reason and is often persuaded that its morning. His/her wife/husband has recommended that he/she should get extra help as something is not right. Everyone is telling me to take her/him to get checked. However, others assume that she/he is getting old. He/she is in denial that anything is wrong with her/him and believes that everything is fine. The doctor suggest that it might be dementia.

Appendix F.3

Demographics

To begin, I'd like to get some basic information about you. Any information that you will give will never to be used to identify you in any way because this research is entirely confidential. However, if you don't want to answer some questions, please don't feel that you have to.

11. Are you
Male Female other

12. How old are you?

13. How would you describe your ethnic origins?

14. What religion would you identify with?

15. What is your highest education qualification?

None
GCSE/O level (s)/CSE (s)
A-level (s)/AS-Level (s)
Diploma
Degree
Postgraduate
Other

16. How long have you been living in the UK for?

17. How long have you been in this religious position?

Interview schedule and prompts for religious leaders

1) How familiar are you with dementia?
a. How familiar are you with this situation?

2) Have you come across people with dementia?
a. Have people come to you relating to these issues?

3) Why so you think people get dementia?
Discuss: religious and non-religious reasoning

4) Do you see this as a part of your role to guide them?
a. What kind of questions are asked?

5) Is this something people usually come and talk to you about?
a. Why do you think they might come to you?
b. Why do you think they might be reluctant?

6) How do you think people face this?
a. Is it a private matter? Why
b. Discuss: Shame
c. Respect for the elderly

7) What's your knowledge on the support services
a. What do you think of them?
b. Would you encourage people to access them?

8) What treatment do you think can be effective?
a. Discuss: Doctors
b. Medicine

9) How do you think the condition can be best managed?
a. Discuss: religious vs non-religious