DEMENTIA CARE ACCESS AND EXPERIENCE FOR SOUTH ASIANS IN THE UK: THE INFLUENCE OF HINDU, SIKH AND MUSLIM RELIGIONS

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I, Jemma Regan, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Background: In the UK, South Asian and Black Caribbean communities are more at risk of developing vascular dementia and experience a higher rate of young onset dementia (under age 65 years), compared with the majority ethnic population (Seabrooke & Milne, 2004). Despite this, Black and Minority Ethnic (BME) persons with dementia are underrepresented in health services, receive diagnoses later in disease progression and are less likely to access anti-dementia medication or partake in research trials (Cooper, Tandy, Balamurali *et al.,* 2009).

An emerging theme in culture and dementia research is the impact of religion on dementia in terms of perceiving the illness, accepting the illness, coping with the illness and accessing services (Milne & Chryssanthopoulou, 2005). Religious beliefs and practices offer one explanation for BME underrepresentation in mainstream health and social care services (MHSCS). MHSCS appear ill-equipped to respond to the religious needs of ethnic minority individuals (Bowes & Wilkinson, 2003).

Aim: To conduct an investigation of the influence of religion on access to - and experiences of - dementia care services, for South Asians from the Sikh, Hindu and Muslim communities in the West Midlands.

Method: An exploratory, qualitative study employing Critical Realist Grounded Theory methodology (Strauss & Corbin, 1990) utilising a multi-methods approach of semi-structured interviews and observations,

informing a three-phase data collection and data analysis model with five service user and service provider cohorts.

Results: A two-stage model: "Existing Service Provision" and "Service Improvements" demonstrates religious beliefs influence low knowledge of dementia, stigma of mental illness, isolation and family duty of care. This led to ill-informed care choices and carer burden. Persons with dementia were also under-identified within their religious communities. Regular outreach in to South Asian religious communities is vital to educate and identify underrepresented persons, allow informed dementia care choices and relieve carer burden. Scripture-influenced dementia training is required to dispel stigma and improve care options. Investment in face-to-face communication with translators and a shift away from paper resources is required.

Conclusion: The full potential of religious communities in dementia care provision is yet to be realised. Utilising this resource as a symbiotic channel – firstly, to identify persons with dementia and educate the congregation about dementia - and secondly, to utilise the existing congregation to meet the psycho-social needs of the person with dementia, offers a holistic care package, leading to informed care choices.

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List of Abbreviations

ACP	Additional Care Pathway
ACS	Additional Care Services
AD	Alzheimer's disease
ADLs	Activities of Daily Living
APPGD	All-Party Parliamentary Group on Dementia
AS	Alzheimer's Society
BME	Black and Minority Ethnic
BMEPWD	Black and Minority Ethnic person with dementia
DAA	Dementia Action Alliance
DLB	Dementia with Lewy bodies
DoH	Department of Health
DSM	Diagnostic Statistical Manual
FTD	Frontotemporal Dementia
GP	General Practitioner
GT	Grounded Theory
ICD	International Classification of Disease
MCP	Mainstream Care Pathway
MHSCS	Mainstream Health and Social Care Services
MMSE	Mini Mental State Examination
NDS	National Dementia Strategy
ONS	Office for National Statistics
SAPWD	South Asian person with dementia
VaD	Vascular Dementia
WHO	World Health Organisation

"a key problem in research with South Asian people with dementia is identifying them. This is an example of a hidden population of extremely vulnerable people" (Bowes & Wilkinson, 2002)

Scope of the Thesis

Chapter 1. Introduction describes the researcher and research approach, introduces a dementia definition, and considers dementia aetiology and risk factors. The following study definitions are clarified: "Black and Minority Ethnic", "South Asian", "Immigrant" and "Indigenous", "Ethnicity", "Culture" and "Religion". South Asian religion is explored in addition to issues of culture, religion and national identity in BME populations in the UK and West Midlands. An introduction is made to the importance of recognising the distinction between "Culture" and "Religion" when considering influence on access and experience of dementia services. Dementia prevalence in BME populations is discussed, and the issue of BME underrepresentation in UK dementia care services is stated. Pathways to dementia care presented in *A National Dementia Strategy* (Department of Health, 2009a) are critiqued.

Chapter 2. Literature Review explores three areas: firstly, empirical research on dementia in BME groups, culture, religion, care access and experience; secondly, a brief exploration of dementia in Hinduism, Islam and Sikhism and thirdly, a discussion of national reports, policies and guidelines on dementia care, BME groups, and older adults. The study aims and objectives are presented based on this critical review.

Chapter 3. Methodology and Method describes the methodological position in terms of epistemology and ontology and the multi-method approach chosen, sampling strategy and ethical approval processes.

Chapter 4. Findings present a breakdown of participant demographics and details the qualitative findings from the Grounded Theory using direct quotations from the data.

Chapter 5. Theoretical Models are presented based on the study findings. Model 1: "Existing Service" reflects the influence of religion on the existing dementia services investigated in the study. Model 2: "Service Improvement" presents recommendations for working with religious communities to improve dementia care.

Chapter 6. Discussion of the implications of these findings on each of the study cohorts is presented. The strengths, limitations, empirical and methodological rigour of the study are considered.

Chapter 7. Conclusion for the research project is postulated.

1. Chapter one: Introduction

1.1. Chapter Aim

The purpose of this chapter is to introduce and contextualise the issue of BME underrepresentation in dementia services. The following areas are discussed: the research approach, dementia and dementia care, BME persons in the UK generally and West Midlands specifically, dementia prevalence in BME populations, pathways to dementia care as outlined in *Living well with dementia: a National Dementia Strategy* (*NDS*) (Department of Health, 2009a) and a discussion of "additional" care pathways, such as through religious communities, which are not fully considered in the *NDS*.

1.2. Research Approach

This thesis documents an empirical study conducted from scholarship funding within the Centre for Ageing and Mental Health - a multidisciplinary, applied research centre in the Faculty of Health Sciences, Staffordshire University. The adopted research approach is a result of the parameters of this research setting and the researcher's academic background: an MSc in Memory and its Disorders (Neurocognitive Psychology, University of Leeds) and a BA (Hons) First Class Theology and Philosophy (Durham University). The researcher is a White, British female in her late 20s, who is spiritual but does not subscribe to a specific religious denomination. Her perception to dementia derives primarily from a biomedical perspective and her research approach is informed by psychological methods.

The study is within the discipline of health psychology, investigating the practical impact of religion on dementia care, for South Asian persons in the UK. The perspective of the service users and the service providers are captured. Recommendations for service improvement are offered, based on theoretical models grounded in the study data. The focus is not on formulating a theory of religion. The premise for the study is a consequence of an *a posteriori*, empirical approach to existing research on culture and dementia care; this identified a gap in the research field. Religion is a theme intertwined with "culture" in existing research, yet the pragmatic influence of religion on dementia care is not currently fully explored. Investigating the practical impact religious beliefs and practices exert on dementia care and dementia care access for South Asian persons, demonstrates a novel approach to this research field.

1.3.   Dementia and Dementia Care

1.3.1. Definition

"Dementia" is the medical classification describing a range of degenerative, neurological syndromes affecting cognitive functioning. Alzheimer's Dementia (AD) (Alzheimer, 1906) is the most prevalent variant. Memory loss is a shared symptom across dementia type. Each dementia type demonstrates a subtle variation in neuropathology influencing behavioural manifestation. Dementia is progressive - with an average prognosis spanning a decade - and terminal, although physical co-morbidities often contribute to death. The behavioural and psychological symptoms of dementia (BPSD) are complex and care needs are increasingly demanding as the condition develops.

1.3.2. Dementia Types

Sixty two per cent of UK clinical dementia diagnoses are for AD. Vascular

dementia (VaD) forms 17 per cent of UK diagnoses, with 10 per cent

comprising mixed dementia (Alzheimer's Society, 2013a). The latter

refers to the concurrent presentation of more than one dementia type,

often manifest as VaD and AD. Dementia with Lewy bodies receives 10

per cent of diagnoses. Diagnoses for "Other" dementia types such as

Korsakoff's syndrome, Creutzfeldt-Jakob disease (CJD) and HIV related

cognitive impairment form three per cent. Fronto-temporal dementia

(FTD) and Parkinson disease dementia receive two per cent of UK

diagnoses respectively (Alzheimer's Society, 2013a). Young onset

dementia refers to diagnoses of any dementia type given to persons

under age 65 years. It is important to consider the *diagnosis gap* –

namely, these data may not capture the actual figures of dementia in the

UK. There are underrepresented and undiagnosed persons living with

dementia who do not receive a clinical diagnosis.

Dementia Type	Number of People
Total Dementia Cases UK (2013)	800,000 people
Alzheimer's dementia	496,000 people
Vascular Dementia	136,000 people
Mixed Dementia	80,000 people
Dementia with Lewy Bodies	32,000 people
Other dementias	24,000 people
Fronto-temporal dementia	16,000 people
Parkinson's dementia	16,000 people

Table 1: Total dementia cases in UK by dementia type (Based on Alzheimer's
Society, 2013a)

1.3.3. Aetiology and Risk Factors

The "exact aetiopathogenesis of dementia is still obscure" (Kar, Jolley &

Misra, 2010, p.92), but several risk factors have been identified across

dementia types. Age is the strongest contributory factor (Akinyemi, Mukaetova-Ladinska, Attems *et al.,* 2013); however it is important to consider dementia may be "age-related", not "age-dependent" (Gao, Hendrie, Hall *et al*., 1998). Vascular risk factors have been identified as a contributor to the onset of all dementia types (Blom, Emmelot-Vonk & Koek, 2013) [for further risk factors for all dementia types, see Figure 1] and to the onset of VaD, in particular. VaD can be triggered by ischemic infarction or a series of transient ischemic attacks, linked to cardio-risk factors such as high blood pressure, hypertension (Sharp, Dag, Day et al. 2011), heart disease, arrhythmia or diabetes (Whitmer, Sidney, Selby *et al*., 2005). These health triggers linked to lifestyle factors suggest VaD is arguably the most preventable form of dementia. FTD can result from neurological damage to the frontal and temporal regions such as from a head injury, for example (Fleminger, 2003). Many cases of FTD exhibit in the Young Onset age category.
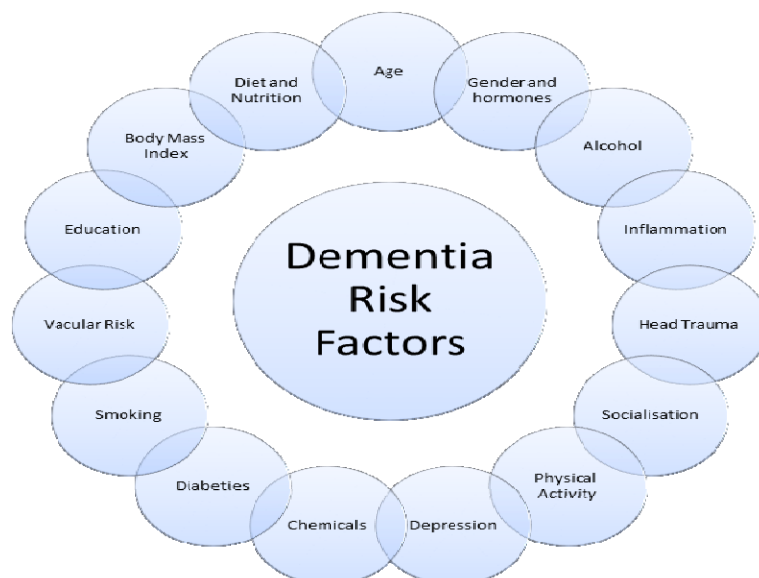
Figure 1: Dementia risk factors (adaptation of data based on Kar, Jolley & Misra, 2010, p.148-149).

1.4.   Black and Minority Ethnic (BME) persons

1.4.1. BME Definition

The term "super-diversity" illustrates the increasing variation in the UK in terms of peoples' country of origin, socioeconomic status, religious and cultural traditions and legal status (Vertovec, 2007). An early definition of BME populations is, "those with a cultural heritage distinct from the majority population" (Manthorpe & Hettiaratchy, 1993). The Department of Health developed this definition in the *Delivering Race Equality in Mental Health Care* report (Department of Health, 2005a), "all people of minority ethnic status in England. It does not only refer to skin colour but to people of all groups who may experience discrimination and disadvantage". The Annex to the report (Department of Health, 2005a) recognised the complexities of using the term "BME", which implies heterogeneity and does not adequately account for all minority groups: "BME as a term did not address the numerous groups who might not be included in any programme of activity, for example, mixed-race people, White minorities, or White communities with distinct cultural lifestyles based on religion, ethnicity, language, age, gender or sexual identity" (Department of Health, 2005a, p.76). This raises the importance of providing a clear etymological definition of "BME" and its consistent and universal implementation in research and clinical practice.

In the 2011 UK Census (Office for National Statistics, 2013b) there is recognition of White minority groups such as, "White Irish" or "Gypsy or Irish Traveller" (Office for National Statistics, 2013b). The latter being a new ethnic category in the 2011 Census (Office for National Statistics,

2013b), reflecting the complexity of the definition. A new definition is needed to accurately capture the complex picture of the many diverse groups "distinct" from the UK majority which considers, "the differences *within* and *between* BME communities" (Lane & Hearsum, 2007) and accounts for Vertovec's (2007) definition of "super-diversity". Building on Vertovec's concept, there are many factors contributing to the shift in cultural and religious identities. Three explanations are as follows: firstly, an influx of immigrants to the UK from Eastern Europe; secondly, the changing perspectives of second and third generation immigrants from South Asia and thirdly, the evolution of cultural, religious, socioeconomic and legal adherences in the UK indigenous population. The term "minority" not only suggests marginality, but has been postulated as mathematically misleading or inaccurate (Parekh, 2000). It is beyond the scope of this thesis to discuss the redundancy of the term "BME" in depth; for the purposes of the study, the accepted understanding of this definition (Manthorpe & Hettiaratchy, 1993) with sensitivity to the heterogeneity it represents, is implemented. The focus of the Manthorpe & Hettiaratchy (1993) definition is on "cultural" groups. This study recognises the multi-faceted influence on "BME" identity (Vertovec, 2007) and focuses specifically on one of those facets – religion; examining religion as a distinct, yet intertwined facet of culture, which may cause disadvantage for BME persons when accessing dementia care services (Regan, 2014a).

1.4.2. South Asian Definition

"South Asian" is one BME sub-set. The categorisation of South Asian

suggests homogeneity, but sensitivity should be displayed to the many

different sub-cultures, languages and religions within this group (Bowes &

Wilkinson, 2003). One definition of "South Asia" comprises the countries

of Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka

and refers to the geographical vicinity only, not political affiliation

(United Nations, [UN] 2011). The population demographic of the South

Asian region is 1.29 billion people (Wheeling Jesuit University, 2013). For

the purposes of this study, the term "South Asian" reflects the UN (2011)

definition of geographical location; namely, an individual who derives

from the regions of Afghanistan, Bangladesh, Bhutan, India, Maldives,

Nepal, Pakistan, Sri Lanka; either from birth, as a first generation

immigrant to the United Kingdom, or is born in the UK from immigrant

parents of South Asian descent.

Figure 2: Map of South Asia (Vbulletin, 2013).

1.4.3.   Religion in South Asia

It is important to consider religious adherences within the South Asian region, to inform an understanding of South Asian persons now living in the UK. South Asia is home to 1.29 billion people. Hinduism is the most practiced religion in South Asia (65 per cent), followed by Islam (29 per cent). The other major religions are Sikhism (two per cent), Buddhism (two per cent) and Christianity (two per cent) (Wheeling Jesuit University, 2013).
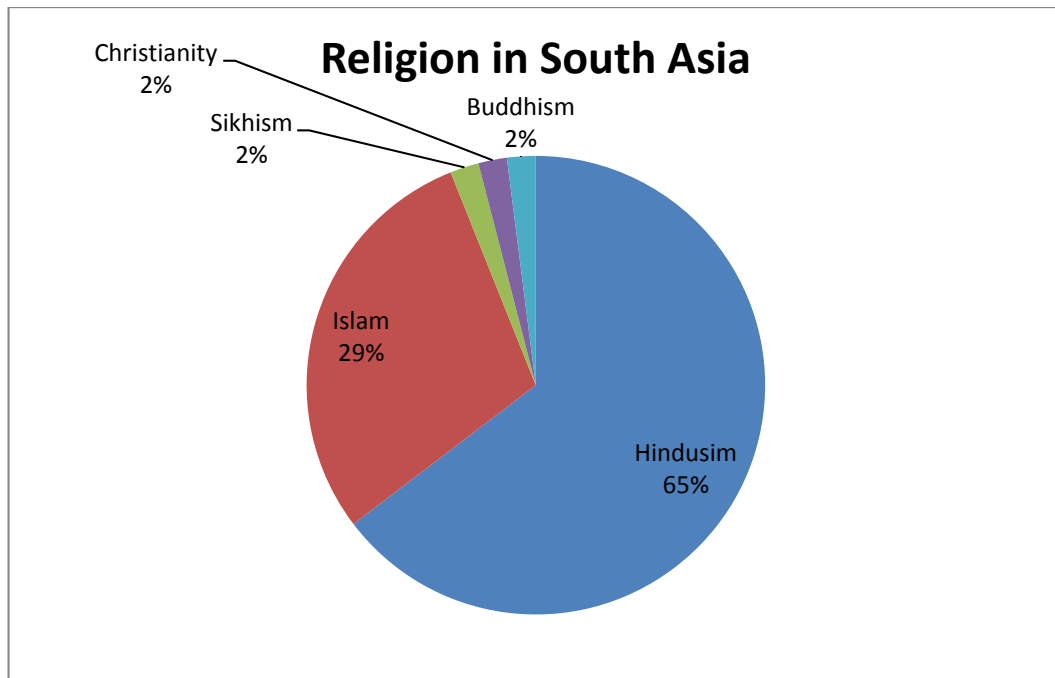
Figure 3: Percentage of religious adherence in South Asia (based on data from Wheeling Jesuit University, 2013).

1.4.4. Immigrant and Indigenous Definition

In this study, the terms "Immigrant" and "Indigenous" refer to religion. For study purposes, "Immigrant" is not necessarily a definition of the individual or their culture - which may have strong British roots (Gardener, 2005) - for example, "Asian British" is an ethnicity category in the 2011 Census (Office for National Statistics, 2013b); rather, it is a person's religious beliefs and associated practices that are immigrant to the cultural setting they are now living within. For example, the indigenous religion – defined in this study as the most prevalent, and historically long-standing - of the United Kingdom, is Christianity (Office for National Statistics, 2013a). The culture of the United Kingdom is arguably, Christianity-orientated. Religious traditions such as Hinduism, Islam, Buddhism, and Sikhism are thus "immigrant" religions in to the "indigenous" culture of the Christian-orientated UK culture.

1.4.5. South Asians in UK

According to the 2011 UK Census, there are approximately 4,214,000 South Asian persons living in England and Wales, comprising 7.5 per cent of the total population (Office for National Statistics, 2013b). Of the UK total population, South Asians of Indian origin form two and a half per cent - around 1.4 million people; Pakistani persons total two per cent of the UK population and Bangladeshis comprise 0.75 per cent. There was an increase of 2,331,423 persons in the South Asian demographic from the 2001 Census (Office for National Statistics, 2004) to the 2011 Census (Office for National Statistics, 2013b). This corresponds with international migration data (Office for National Statistics, 2013b) which discovered South Asian countries maintained a high ranking of the most common non-UK countries of birth (Office for National Statistics, 2013b). It is important that the Office for National Statistics notes that due to discrepancies in phraseology between the 2001 and 2011 Census' for the "Asian" and "Asian other" groups, a direct comparison of the increase of South Asian persons across the decade was not possible, without consulting with the subgroups to gain a more accurate data comparison (Office for National Statistics, 2013b, p.12).

1.4.6. British Asian

The "*British Asian*" ethnic category displayed a large increase between the 2001 and 2011 Censuses (Office for National Statistics, 2013b). People identifying as Pakistani and Indian each increased by around 0.4 million (Office for National Statistics, 2013b). Many third generation South Asians have a strong identity with British culture and choose to

mark "British Asian" in the "Other Asian" section of the Office for National Statistics Census (Gardener, 2005).

1.4.7. National Identity

The concept of "National Identity" was raised as a new question for the first time on the 2011 UK Census (Office for National Statistics, 2013b). This is a, "subjective self-identifying measure which may or may not relate to a person's ethnic group or country of birth" (Office for National Statistics, 2013b, p.13). This gives persons an opportunity to express, "which country/nation they feel most affiliated to" (Office for National Statistics, 2013b, p.13). The ONS stressed the importance of gathering information on National Identity, ethnicity, religion and language, "to provide a detailed picture of the society we live in, and how it is changing" (Office for National Statistics, 2013b, p.13). One factor impacting on national identity are motivations for immigration. Persons who intended to stay in the UK temporarily but became permanent UK residents - for example the Bangladeshi migrants from Sylhet - may hold firm to traditional values and resist assimilation in to UK culture. Others who planned to reside in the UK permanently may forego traditional identities more easily and wholeheartedly embrace UK culture (Lane & Hearsum, 2007). There is some debate whether the former group should be called settlers rather than immigrants (Sheikh & Gatrad, 2000, p.4).

1.4.8. West Midlands

The West Midlands is defined as a geographical region in England covering seven boroughs: The City of Birmingham, the City of Coventry,

The City of Wolverhampton, Dudley, Sandwell, Solihull and Walsall. The

present study focused on the Birmingham, Walsall and Wolverhampton

regions of the West Midlands; in addition to the West Midlands, the Stoke

on Trent region, North Staffordshire, was also included, due to its high

South Asian demographic [see Chapter 1, pp.32-33].

Figure 4: Map indicating the West Midlands region of the United Kingdom

(Microcolour, 2013). Stoke on Trent is north of Stafford (not visible on this map).

1.4.9.   BME Prevalence in the West Midlands

The West Midlands region has demonstrated a higher than average

percentage of BME groups and a lower percentage of White ethnic groups

than the average for England and Wales (Office for National Statistics,

2013b, p.8). Whilst South Asian communities exist across all the UK, the

West Midlands region ranks amongst those areas with the highest

prevalence (Office for National Statistics, 2013b):

o In Birmingham 22 per cent of the population is South Asian.

o In Wolverhampton 14.3 per cent of the population is South Asian.

o In Stoke on Trent 4.1 per cent of the population is South Asian.

The West Midlands County holds the highest population of South Asians of all UK counties:

County	Population percentage South Asian
West Midlands	13.4 per cent
Greater London	12.09 per cent
Leicestershire	11.9 per cent
West Yorkshire	8.7 per cent
Bedfordshire	8.3 per cent
Berkshire	6.8 per cent
Greater Manchester	5.6 per cent
Lancashire	5.3 per cent
Buckinghamshire	4.3 per cent

Table 2: The population percentage of South Asian persons by UK County (based on Office for National Statistics, 2011b)

1.4.10. Ethnicity, Culture and Religion

Questions about religion and ethnicity were posed separately for the first time in the 2011 UK Census (Office for National Statistics, 2013a, 2013b). The importance of sensitivity to the distinction between race, culture and ethnicity when considering cross-cultural aspects of dementia, was discussed by Shah, Oommen & Wuntakal (2005). Regan (2014a) develops this to discuss religion - alongside ethnicity and culture - as separate components, all comprising a person's identity and subsequent dementia care experiences. Defining these as separate components is challenging, since often they are intertwined. Throughout the research process, the researcher was mindful of the interplay

between religion and culture, but aimed to investigate the unique influence of religion on the dementia care experience. It is important to recognise the unique impetus that each of these factors – religion and culture - exerts on a persons' *modus operandi*. Focusing solely on the "cultural" element may overlook the subtle but important influence of the other factors on identity, perceptions, actions and behaviour.

1.4.11. Ethnicity: Definition

Regan (2014a) discusses the ambiguous definition of culture, religion and ethnicity. The term "ethnicity" invites debate and generates confusion when attempting to provide a definition of its meaning (Lane & Hearsum, 2007). Most definitions account for ethnicity as being comprised of a shared culture, language, religion, tradition, heritage and geographical origins (Helman, 2000). However, Regan (2014a) asserts the need to clarify the specific "ethnic-cultural" (Regan, 2014a, p.4) identity from the wider, "more transient cultural identity" Regan, 2014a, p.4). Furthermore, it is important to recognise the fluidity of ethnicity which may change and shift throughout time and life course (Lane & Hearsum, 2007). Dementia, an identity challenging illness is an example of an event in the life course which may impact on ethnic identity.

1.4.12. Culture: Definition

For this study, "Culture" is defined as follows (Regan, 2014a, p.4): "Ostensibly, culture is identification with the practice, thought and behaviour of a region, group or organisation – most notably associated with a geographical locality – but is also prevalent across societal levels

and contexts. These may be expressed at a regional level, family level or organisational level. Culture is the structural process which provides a framework for our own behaviour. To allow us to function within the status quo, we adopt a *modus operandi* according to the rules and principles within the cultural framework of which we find ourselves in. These frameworks derive from birth into a geographical locality, birth into a family structure, or birth into a socio-economic environment. As we progress as adults and widen our reality, our cultural identity is shaped and morphed through adherence to other parts of society. By our very definition as a human, functioning in society, we are by default, a member of the culture of which we function within. Our cultural identity is multi-layered and complex, and may increase and shift throughout life and throughout social contexts. Workplaces, sports teams, friendship groups all provide a cultural framework with rules of functioning and modes of operation. However, the most literal and enduring element of our cultural identity, is that associated with our ethnicity. Ethnicity, in this sense, is comprised of our creed, skin colour [or race], place of birth – of which we were born into – and is maintained at the core of us, as those more transient parts of our cultural identity shift and morph through life's journey. It may be more appropriate to label this as an ethnic-cultural identity. This enduring element is inherent and subconscious, a product of our early upbringing and forms the basis for values, attitudes, language, behaviours. Other parts of our cultural identity are arguably chosen by our decisions in life, such as one job above another, one social group above another. Each of these expresses a distinct cultural framework, but these choices may be driven by the

enduring subconscious ethnic-culture. In terms of organisational culture, a paradigm in this context is the National Health Service (NHS) of the UK. This is an organisation governed by certain principles and practices, which deem acceptability or unacceptability; one example of which is through communication and co-operative practices of persons involved in this culture. The paradigm of an existing cultural theme in dementia care research as a prominent barrier to services for BME persons with dementia is language (Hinton, Franz, & Friend, 2004). Cultural practices are those such as verbal and non-verbal communication. The NHS operates within a cultural framework of Western society, where English is the primary language. The organisational culture of the NHS, whilst accommodating for other languages, primarily functions in an English language setting. Modes of being, i.e. communication between persons are governed as acceptable practices, due to the cultural expectations of the Western society. For example, a female touching a male in a simple exchange such as a handshake is considered culturally appropriate. Conversely, this means of communication may be deemed inappropriate, for instance, in a South Asian cultural setting."

Cultural themes within existing literature are categorised in Regan (2014a, p.4) as: "those which relate to behaviour, thought, belief or practice influenced by the association – either conscious or subconscious – with a geographical locality, ethnic group, institution, or organisation, as distinct from a religious institution." The Office for National Statistics recognises the individuality of cultural identity. Ethnic group classifies people according to their own *perceived* ethnic group and cultural

background (Office for National Statistics, 2013b). The phenomenological aspect of culture must be considered. Providing a definition may overlook the experiences of the individual within their culture and the symbiotic impact of adherence to one or more cultural categories on identity. Yet, categorisation is required to allow structure and understanding of our society, such as in the UK Census, for example. Recognition of the complexity of culture and ethnicity on identity and the expectations this creates both from the participant and the researcher are considered for the study.

1.4.13.   Religion: Definition

For the present research, "Religion" is defined as follows (Regan, 2014a, p.4):

"…behaviour, thought, belief or practice directly influenced by religious ideologies, dogmas, scriptures, with arguably a more conscious, explicit adherence than ethnic-cultural identity. The paradigm for a religious theme identified in existing cultural research is prayer. Namely, the implications the dementia condition has had on the practice of prayer. Prayer is a ritualistic behaviour grounded explicitly in religious beliefs and practices. There are examples in the literature of an increase in prayer rituals to assist with coping for dementia caregivers from the Irish and American and African American communities (Levkoff, Levy & Weitzman, 1999). There are examples of difficulty encountered performing prayer rituals as a result of debilitation on behavioural functioning as a consequence of dementia (Wilkinson, 2002). The notion that a person's religious practices are influenced throughout the dementia experience, is

introduced by the existing literature, but requires a more focused, critical examination in future research. Religious themes may manifest in cultural practices. The acceptability of a handshake between males and females is influenced by cultural frameworks, but may also have an explicit religious influence. For example, the acceptability of touch between non-related, non-married males and females in the Muslim faith. The complexity between religion and culture further exemplifies the importance of considering this distinction and interaction in future research." This "distinction" and "interaction" of religion and culture, and the complexity of distinguishing the two factors is considered in the presentation and discussion of the findings in the present study.

The importance of religion on identity was recognised in the 2001 UK Census (Office for National Statistics, 2004) and reiterated in the 2011 UK census: "Religion is an important defining characteristic of peoples' identity" (Office for National Statistics, 2013a, p.10). Some persons may identify more strongly with a religious adherence than a cultural adherence (Mizra, Senthilkumaran & Ja'far, 2007) and others persons may have both a strong cultural and religious identity (Lane & Heasrsum, 2007); for example, a Pakistani Muslim. The Office for National Statistics recognises the complexity of religion on identity and acknowledges the Census only captures one part: "Religion is a many sided concept and there are other aspects of religion such as religious belief, religious practice or belonging which are not covered in this analysis" (Office for National Statistics, 2013a, p.10).

1.4.14.   Ethnicity: UK

The majority ethnic group (86 per cent) in the UK is "White" ("White British", "White other" and "any other White"). This has decreased from 91.3 per cent of the total population in 2001 and 94.1 per cent of the total population in 1991 (Office for National Statistics, 2013b, p.1). This is a reflection of the incorporation of many diverse ethnic backgrounds within England and Wales in the last 20 years (Vertovec, 2007). There are a range of influences prompting a shift in ethnic group distribution including births, deaths, migration and country of birth: "There are many factors driving changes in religious affiliation including natural growth (for example, some minority religious groups have a younger demographic profile), migration, changes in willingness to report and awareness of the question" (Office for National Statistics, 2013a, p.4). The Office for National Statistics aims to explore these influences further as part of its analysis programme of the census (Office for National Statistics, 2013b, p.6).

1.4.15.   Ethnicity: West Midlands

Outside of London, the West Midlands has a lower than average White population. The "Asian / Asian British" demographic comprises 10.85 per cent of the West Midlands population, with the "Black / African / Caribbean / Black British" category matching the average for England and Wales at 3.3 per cent of the population ([Office for National Statistics, 2013b, p.7). South Asians are an ageing UK demographic due to an immigration boom in the 1950s – 1970s (Katbamna & Chambers 2007).
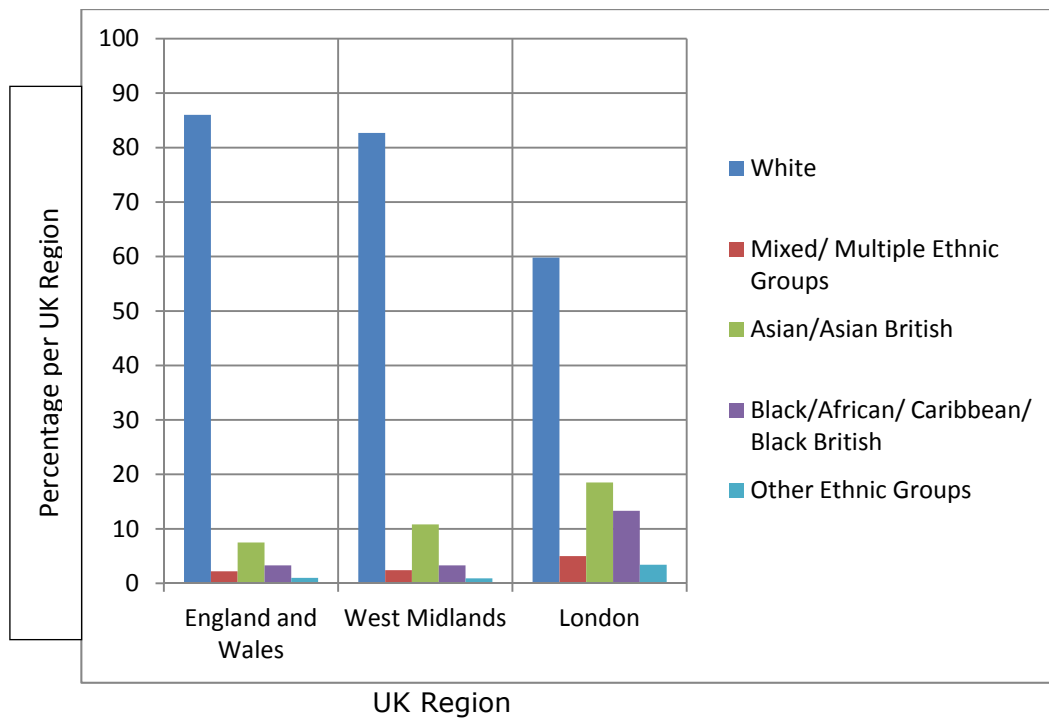
Figure 5: Ethnic groups as a percentage of total population per UK region (based on data from Census 2011 [Office for National Statistics, 2013b, p.7])

1.4.16.   Religion: UK

The UK Census (Office for National Statistics, 2013a, p.10) asks a voluntary question about religion: "what is your religion?" and does not ask further details about how this faith is manifest in practice, or impacts on decisions of daily living or strength of belief. The voluntary nature of this question means that the data may not be representative of the actual population; 7.2 per cent of people did not answer the question (Office for National Statistics, 2013a, p.2).

Christianity continues to be the most prevalent religion in England and Wales (Office for National Statistics, 2013a, p.2) with 33.2 million adherents (59.3 per cent of the population), despite a decrease from 71.7 per cent in the 2001 UK census. Muslims were the second most prevalent category with 2.7 million adherents. A large proportion (25.1

per cent) of the population stated "no religion". This had increased from 14.8 per cent of the population in 2001 (Office for National Statistics, 2013a, p.2). There was an increase in the volume of adherents to all the other main religions. Muslim followers demonstrated the highest increase, from 3.0 per cent in the UK 2001 Census to 4.8 per cent in the UK 2011 Census (Office for National Statistics, 2013a, p.3). Other UK religions are as follows: Hindu 1.5 per cent of population, totalling 817,000 persons; Sikh (0.8 per cent) of the population, equating to 423,000 persons; 263,000 persons identified as Jewish (0.5 per cent of population) and 248,000 people subscribed to Buddhism (0.4 per cent) (Office for National Statistics, 2013a, p.2).

### 1.4.17.	Religion: West Midlands

Outside London, the highest proportions of UK Hindus reside in Leicester (Office for National Statistics, 2013a). The areas with the highest proportion of Muslims were in London. In the West Midlands, 60.2 per cent ascribed to Christianity, 22 per cent no religion, Muslim 6.7 per cent, other 4.5 per cent and not stated 6.6 per cent (Office for National Statistics, 2013a). In the West Midlands, the highest religious affiliations following Christianity are Muslim, Hindus and Sikhs. There are 369,000 Muslims, 125,000 Sikhs and 83,000 Hindus residing in the West Midlands region compared with 3,380,000 Christians and 1,324,000 with no religion (this figure includes those who did not state a religion) (Office for National Statistics, 2013a).

Religion	Numbers in West Midlands	Numbers in England and Wales
Christian (all denominations)	3,380,000	33,200,000
No Religion	1,324, 000	14,100,000
Muslim	369,000	2,700,000
Sikh	125,000	423, 000
Hindu	83,000	817, 000
Any Other Religion	46,000	240, 000
Buddhist	24,000	248, 000
Jewish	2,000	263, 000
Total	4,029,000	50,000,000

Table 3: Religious adherence in the West Midlands compared with England and Wales (based on data from Office for National Statistics, 2013a, p.2)

1.5.   Dementia Prevalence in BME populations

1.5.1. Dementia Globally

There are 36 million people living with dementia worldwide (World Health Organisation, 2012). There are up to 28 million people of the worldwide total living with dementia estimated to have not received a formal, clinical diagnosis (World Health Organisation, 2012). Due to the increase in longevity, the prevalence of dementia cases is predicted to double every twenty years. The projections estimate that by the year 2050, 115 million people will be living with dementia worldwide. The majority of these cases (71 per cent) will be people living in developing countries (World Health Organisation, 2012) In Europe alone, there are in excess of six million people with dementia (World Health Organisation, 2012).

1.5.2.   Dementia in the UK

In the UK there are estimated to be 800,000 people living with dementia (Alzheimer's society, 2013a), yet it is estimated that only 44 per cent of people with dementia receive an official, clinical diagnosis (Alzheimer's

society, 2013b). Of these, 17,000 people are classed as young onset dementia (Alzheimer's society, 2013a). Around 90 per cent of persons who die from dementia are aged 80 years and above (NICE, 2006). In 2007, four per cent of all deaths (c.21, 000) stated the underlying cause as a type of dementia. The quality of life for persons with dementia in the UK is considered low (Alzheimer's Society, 2013a), with 17 per cent of persons stating they are "not living well with dementia at all" (Moriarty, 2008).

1.5.3. Economic Impact

Dementia is predicted to cost the UK economy £34.8 billion by 2026 (King's Fund Report, 2009). Dementia is the fourth biggest killer of the UK population following cancer, heart disease and stroke, but it costs the UK economy more per annum than each of these conditions. The health and social care costs each year for dementia are £22, 723,000. Cancer costs the UK economy £ 11, 998, 000 per annum, coronary heart disease totals £ 7, 848, 000 per year, and stroke costs an annual total of £ 4, 997, 000 (Luengo-Fernandez, Leal, & Gray, 2010).

1.5.4. BME Dementia Prevalence

The UK population is comprised of 63,182,000 people with 5,556,508 persons from the BME population (Office for National Statistics, 2013c). The majority of BME persons live in London, the Midlands and the North West of England (Office for National Statistics, 2013b). Most BME persons with dementia are from Black Caribbean and Asian Indian backgrounds.

One explanation for these high numbers is these cultural groups are the communities with the highest number of people reaching over aged 65 years. There are an estimated 11,860 individuals with dementia in BME groups. This may be a reflection of the ageing population in this cultural demographic as a result of migration from Indian, Pakistan and now-Bangladesh, the Caribbean and China to the UK in the 1950s, 1960s and 1970 (Knapp, Prince, Banerjee *et al*., 2007). Vascular dementia is more common among Asian and Black Caribbean people than the majority White population (Seabrooke & Milne, 2004; Richards, Brayne, Dening *et al.*, 2000; Adelman, 2010; Adamson, 1999). One explanation for this is due to the higher rates of cardio-risk factors for cardiovascular disease (Gorelick, 2004), diabetes (Ahtiluoto, Polvikoski, Peltonen *et al.*, 2010) and hypertension (Kar, Jolley & Misra, 2010) in these cultural groups. In the UK, young onset dementia is especially prevalent in the BME population. From the total BME persons with dementia, 6.1 per cent demonstrated a young onset variant, compared with 2.2 per cent of the total non-BME dementia diagnoses (Alzheimer's Society, 2013a). In BME communities, there is a higher prevalence of dementia in males than females, but research has shown this may just be a reflection of the higher rate of male immigration in to the UK, who are now reaching old age (Moriarty, Sharif & Robinson, 2011).

1.6.   BME underrepresentation and pathways to dementia care

In the UK, BME persons demonstrate higher susceptibility to vascular dementia and young onset dementia than the White majority (Richards, Brayne, Dening *et al.*, 2000; Seabrooke & Milne, 2004). Despite this,

BME persons with dementia (BMEPWD) are less likely to access mainstream health and social care services (MHSCS) than their White British counterparts, are more likely to receive clinical diagnoses at a later stage in disease progression and are less likely to receive dementia medications or take part in research trials than non-BMEPWD (Cooper, Tandy, Balamurali & Livingston, 2010). One explanation is BMEPWD experience cultural and religious barriers to MHSCS. When MHSCS are sought, the provision received is "culturally inappropriate" and "ideologically unacceptable" (Patel, Mirza, Linbald *et al.*, 1998; Bowes & Wilkinson, 2003). A prominent theme emerging from existing research on culture and dementia care - not yet directly addressed - is the impact of religion on dementia (Milne & Chryssanthopoulou, 2005). The importance of recognising the significance of religion within cross-cultural psychology, is identified by Tarakeshwar, Pargament & Mahoney (2003) in the following points:

(a) religion is important in the lives of people across cultures, (b) religion has been found to be a significant predictor of salient variables (e.g. physical and mental well being) across cultures, (c) religion is associated with critical cross-cultural dimensions, and (d) culture also shapes religious beliefs and practices. Point (d) further highlights religion and culture as distinct but interlinking entities. The Western tradition to seek clinical intervention for physical or mental illness, informed by a bio-medical understanding of dementia, illustrates one possible discrepancy between indigenous UK culture and immigrant religious practices and rituals. Religious beliefs and practices offer one explanation for the underrepresentation of South Asians in to mainstream health and social

care services (MHSCS) in the UK. Research suggests MHSCS appear ill-equipped to respond to the religious needs of ethnic minority individuals (Bowes & Wilkinson, 2003).

1.6.1.   Mainstream Health and Social Care Services (MHSCS)

MHSCS is a definition generated by the researcher for the present study to describe forms of health and social dementia care which subscribe primarily to the bio-medical model of dementia, and may also incorporate psycho-social care. These services form part of a "mainstream" care package in the UK and are accessed by a "mainstream" care pathway in to dementia services [see pp. 49-59]. These relate to statutory health and social care services such as the National Health Service (NHS) or private health care, memory clinics, Social Services, in addition to nursing homes, dementia organisations, respite care, care homes, dementia charities.

1.6.2.   Additional Care Services (ACS)

ACS is a definition generated for this study by the researcher to describe forms of care which may not be primarily accounted for within the dementia care package provided by MHSCS, nor accessed via the mainstream dementia care pathway. These alternative care services are sources of support falling outside the parameters of MHSCS and may derive for example, from the family (Katbamna, 2004) or from a religious community. Religion may be classified as an "addition" in the dementia care package, to mainstream health and social care services. However, it

is important to note that many dementia care providers do recognise the importance of religion in the psycho-social care package, once persons have received a diagnosis of dementia. The provision of religious care in the mainstream dementia package varies across health Trust and geographical region. The focus of the present study is the underrepresentation of BME persons within clinical services. Namely, there is a paucity of research investigating how ACS such as religion impact on *access* to MHSCS and the *decision* to seek care. A recent systematic review (Regan, Bhattacharyya, Kevern *et al*., 2013 [full paper in appendix 1a]) identified only two papers dedicated to the specific question of how religion influences access to mainstream dementia care services for BME persons (Levkoff, Levy & Weitzman, 1999; Sun, Roff, Klemmack *et al*., 2008) from a total of 1,234 research sources on dementia and religion [for a fuller discussion see Chapter 2, pp. 73-84].

The researcher is aware generating these definitions of MHSCS and ACS could appear reductionist in approach, and suggests dementia care as a dichotomy of either mainstream or additional services. However, the empirical literature identifies the health inequality experienced by BME persons accessing mainstream dementia services. In order to understand how BMEPWD are currently being supported and to make recommendations to improve support for the person and their carers, research is required to understand whether care offered through ACS such as family or religious community, are sought in isolation by BME persons? If so, does this offer sufficient explanation for the underrepresentation of BME groups in MHSCS? Alternatively, do BME

persons access both MHSCS and ACS? Furthermore, do some BME persons with dementia not access any care service – mainstream or additional? It is important to understand *how* and *why* people arrive at MHSCS in order to identify why some persons do not arrive at MHSCS.

1.6.3.   National Dementia Strategy

The ground-breaking *Living well with dementia: a National Dementia Strategy* (*NDS*) (Department of Health, 2009a) proposes a care pathway for persons accessing dementia care services in the UK (Annex 1 section 4) which forms "a coherent system for local commissioning", based on a three-stage process aiming to encourage people in to services, promote early diagnosis and specialist care and to ensure health and social care services tailor provision to the highest standard. The researcher's opinion is The *National Dementia Strategy* (*NDS*) (Department of Health, 2009a), claims to address inequalities in dementia care (Department of Health, 2009a, p15), but does not adequately account for possible contributors to this inequality. One example is additional care services (ACS) such as religion, or additional care pathways (ACP), influenced by religious belief which may contribute to BME underrepresentation in dementia services (Levkoff, Levy & Weitzman, 1999; Sun, Roff, Klemmack *et al*., 2008). [For further critical analysis of the *NDS* in the Literature Review, see Chapter 2, p.104].

Stage 1. Encourge care seeking and referral

•Primary Care
•Social Care

Stage 2. Locate responsibility for early diagnosis and care

•Diagnosis
•Specialist Care

Stage 3. Enable good-quality care tailored to dementia

•Specialist older people's mental health services
•Primary Care
• Social and health care in the community and care homes
•Acute Trusts
•Peer and Voluntary sector support

Figure 6: Dementia Care Pathway based on data in the *National Dementia Strategy*, (Department of Health, 2009a), displaying a "Mainstream" route in to services.

1.6.4. *Mainstream Care Pathway (MCP)*

The pathway to dementia care as proposed by the *NDS* (2009), reflecting a mainstream route, is formed across three stages, as follows: Stage 1 begins with initial contact with health and social care services such as visiting the GP. Stage 2 focuses on "responsibility" for providing early diagnosis. Stage 3 implements this in to a care package, ensuring "good-quality", specialist dementia care is received.

An illustration of the Mainstream Care Pathway in to dementia services is as follows:

1.6.5. Stage 1

Initially, a person or their family may notice some behavioural changes. Memory impairment is the most common symptom across dementia types, although each dementia type may differ slightly in presentation, especially in the early stages. For example, the behavioural manifestation of AD is often expressed through confusion, mood swings, frustration, withdrawal, communication difficulties and activities of daily living are affected. VaD can present with a sudden onset of symptoms such as difficulties thinking, concentrating, communicating, and anxiety, weakness, paralysis, seizures and confusion. In FTD, a person's personality is often affected more initially than memory. They may appear to have a lack of insight, lack empathy, appear selfish, behave inappropriately and uninhibitedly, or become aggressive, distracted or compulsive. Dementia with Lewy bodies manifests behaviourally through problems with attention, alertness, spatial orientation, executive functioning, slowness, muscle stiffness, trembling, hallucinations or faintness (Kar, Jolley & Misra, 2010).

1.6.6. Stage 2

Once cognitive assessment has taken place by a trained professional such as an old age psychiatrist or cognitive psychologist, a diagnosis of dementia alongside details of dementia type, stage and prognosis can be

made. A specialist care plan is devised, in collaboration with the person with dementia and supportive family members or carers.

1.6.7. Diagnosis

Dementia diagnoses are based on the following criteria: a person presents a range of cognitive deficits over at least six months duration - including memory and more than one of the following - aphasia, apraxia, agnosia or a disturbance in executive functioning. These symptoms are present outside of episodes of delirium and are not manifestations of another psychiatric disorder such as schizophrenia or depression (ICD-10, World Health Organisation, 1992; DSM-V, American Psychiatric Association, 2013).

1.6.8. Assessment

The most frequently used cognitive assessment tools in the UK and USA include the Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975), the Abbreviated Mental Test Score (ABTS) (Hodkinson, 1972) and the Clock drawing test (CDT) (Shulman, Shedletsky & Silver, 1986). The standard MMSE is a 30-item ten minute questionnaire testing memory, orientation, language skills, visual awareness, and cognitive flexibility. The CDT (Shulman, Shedletsky & Silver, 1986) involves a person drawing a clock face and hands representing a specific time. The frequency and error type indicate the severity of cognitive impairment (Shulman, Shedletsky & Silver, 1986; Brodaty & Moore, 1997). Additional assessment tools include the Blessed Information Memory Concentration test (BIMC) (Blessed, Tomlinson & Roth, 1968),

Alzheimer's Disease Assessment Scale (ADAS) (Rosen, Mohs, Davies, 1984), Cambridge Cognitive Examination (CAMCOG), (Roth, Tym, Mountjoy *et al.* (1986). Assessments may be administered in isolation, or combined with further assessments such as a verbal fluency test (Jenkins, 1998) to form a battery for neurocognitive screening, leading to dementia diagnosis.

1.6.9.   Stage 3

Thirdly, the care package draws on several resources such as older peoples' day care or mental health services, regular GP and memory clinic contact, charity organisations such as the Alzheimer's Society, for example. Dementia's prognosis through the mild, moderate and severe stages has implications for the level of care required and impacts on the level of independent living, which can be maintained well into the moderate dementia stage (Kar, Jolley & Misra, 2010; Cummings & Jeste, 1999).

1.6.10.   Care Planning

Care packages for persons with dementia in the UK primarily derive from a bio-medical understanding and are comprised of medication and psycho-social care. The care plan devised is flexible as the person's needs and ability to live independently shifts throughout the progression of the illness at the mild (≤ two years), moderate (two to five years) and severe (four to nine years) stages of dementia. In mild dementia, independent living is possible. Short term memory is affected but long term memory is

generally intact with personal information easily recalled. There are no significant aphasias but vocabulary is reduced with occasional anomia. There may be visuospatial difficulties and misplacing of objects. Routine activities of daily living (ADLs) are not affected, but more complex tasks such as planning, organising, or exercising judgment, are difficult. Depression may be present. In moderate dementia, independent living is possible with carer and community support. There is severe impairment of short term memory. Long term declarative memory is affected. Mistakes are made in personal information recall. There is nominal aphasia, paraphasia, circumstantial and repetitive speech. There are difficulties in ADLs such as dressing and cooking, due to apraxias. Reasoning, judgment and planning are affected. Agnosias could lead to delusions of misidentification or hallucinations. Neurological markers are present. In severe dementia, persons at this stage may require full time institutionalised care, if they do not have a strong support network who can support them fully to live independently. All cognitive functions, long term memory and personal information recall are severely impaired. Speech is incomprehensible and confused. There is apathy or aimless wandering. All ADLs are affected. There is difficulty in chewing, swallowing and drinking. Persons are often doubly incontinent. Extreme agitation, restlessness and severe agnosias are expressed alongside self-misidentification. Neurological symptoms are expressed through seizures, myoclonus and rigidity with primitive reflexes such as shouting and grasping demonstrated (Kar, Jolley & Misra, 2010).

1.6.11. Medication

There is no currently no cure for dementia. Acetycholinesterase inhibitors (AChEI) or N-methyl-D-aspartate (NMDA) receptor antagonists are prescribed only in a small number of cases for the symptom management of AD and may not be suitable for other dementia types, for example due to associated vascular risk factors in VaD (Kar, Jolley & Misra, 2010). Recent medical trials have taken place to investigate the effects of Solaneuzumab – an antibodies medication – on the quality of life on persons with early stage dementia (Alzheimer's Society, 2013c).

1.6.12. Psycho-Social Care

Psycho-social care is thus very important in the dementia care package, especially given the progressive, terminal nature of the condition. Early detection, assessment and diagnosis allow a suitable care package catering for the psychosocial care needs of the person and their family to be devised early, based on fully informed choices. Investigating the benefit of additional avenues of psycho-social support, such as religious communities is important to widen choices in the care network and offer alternatives to persons not presenting to MHSCS.

1.6.13. NDS Care Pathway: Critique

The care pathway outlined in the NDS (Department of Health, 2009a) is commendable in demonstrating a care pathway for persons accessing MHSCS and highlighting the required improvement to services to enable "good-quality care" for dementia. In contrast, it does not adequately

consider those persons with dementia who are underrepresented in MHSCS. Barriers to dementia care services can present at any stage of the care pathways for BMEPWD. At stage 1, there is a presumption that persons will possess enough knowledge of dementia to recognise the early signs and symptoms, such as memory loss. There is a presumption that persons experiencing cognitive difficulties will access their GP or primary care service. This assumes that all persons perceive dementia through a bio-medical perspective and does not account for different cultural perceptions of mental illness. There are a large number of South Asian and African Caribbean persons whose religious adherence influences their perceptions of dementia, expectations of dementia care and subsequent care decisions (Milne & Chryssanthopoulou, 2005). For example, a person experiencing dementia in India may seek spiritual consultation during a period of mental illness instead of visiting the GP (Argo, 2010). Thus, it is conceivable that some persons from India now residing in the UK may interpret their cognitive difficulties through this religious perspective and not present to their GP. Furthermore, at stage two, performing a cognitive assessment leading to an accurate diagnosis of dementia is challenging if a person does not speak English or is illiterate (Shah & Mukherjee, 2000; Shah, 1999; Shah, 1992). Whilst attempts have been made to translate the MMSE in to South Asian languages, this does not account for illiteracy, nor for cultural nuances (Pilgrim and Rogers, 1999; Lindesay, Jagger, & Mlynik-Szmid, 1997; Rait, Morley, Lambat, *et al.*, 1997). Thus, the researcher proposes the NDS model warrants re-classification as a "mainstream" care pathway (MCP).

1.6.14. Additional Care Pathway (ACP)

The researcher states an addition to the MCP which aims to ensure persons with dementia underrepresented in MHSCS are captured. This "additional" care pathway incorporates religion at each stage of the model. Chapter Two explores the empirical literature on dementia care pathways for BME persons and presents evidence for this need. The exact impact of religion on the dementia care pathway and the implications for underrepresented groups in dementia care, warrants investigation. Research in to the role of religion on dementia care in groups underrepresented in MHSCS is required to understand the impact on each stage of the model from identification through to diagnosis to good-quality care. Understanding this impact will enable recommendations about how to assist and support persons with dementia make informed care choices and aims to capture underrepresented groups

Stage 1. Encourge care seeking and referral

- •Primary Care
- •Social Care
- **•Religious Communities**

Stage 2. Locate responsibility for early diagnosis and care

- •Diagnosis
- •Specialist Care
- **•Religious Communities**

Stage 3. Enable good-quality care tailored to dementia

- •Specialist older people's mental health services
- •Primary Care
- • Social and health care in the community and care homes
- •Acute Trusts
- •Peer and Voluntary sector support
- **•Religious Communities**

Figure 7: Researcher's addition to the "Mainstream" care pathway incorporating "religion" at each stage.

The impact of incorporating religion at each stage of the care pathway is illustrated as follows:

1.6.15. Stage 1

In stage 1 of the model, it is important to explore how religious beliefs influence the dementia care decision. Understanding how persons perceive dementia impacts upon whether a decision to seek care is made or not, and where this care is sought. Identifying peoples' perceptions and attitudes towards dementia, and the origin of their understanding, whether from a biomedical or alternative perspective such as their religious beliefs, will gain insight into the motivations for care seeking and care access and the expectations of those care decisions.

1.6.16. Stage 2

Stage 2 of the model focuses on the importance of early diagnosis to allow adequate care planning. Early identification of dementia also is beneficial for the MHSCS and the person with dementia, who may only present to health services at a late stage, through a physical co-morbidity such as a fall. This is distressing for the person with dementia and places an additional strain on MHSCS resources. As discussed, the issue of diagnosis is problematic for non-English speaking persons with cognitive difficulties. This reflects the wider problem of non-English speaking persons using mental health services and the use of translators impacting upon the physician-patient dynamic. Consequently, many BMEPWD do not present to specialist services or if they do, the rate of misdiagnosis is higher than in the White British majority (Adelman, 2010). At this stage in the pathway, it is vital to investigate how religious communities could be utilised as a resource for identifying underrepresented persons with dementia. The location of "responsibility" for recognising persons with dementia, as stated by the NDS may not fall wholly upon MHSCS. Investigating how religious communities and the leaders of religious communities understand, perceive and identify dementia is vital to understanding how and why BMEPWD are under-recognised and underrepresented. Do religious communities recognise members of their community with dementia and how might they take "responsibility" for "diagnosis" and "quality" care? (Department of Health, 2009a).

1.6.17.   Stage 3

At stage three, the focus is on providing "good-quality" (annex to NDS, 2009) care for the person with dementia. The mainstream care pathway proposes a range of health and social care services to support the person with dementia, drawing on both government and voluntary organisations. Whilst "peer and voluntary" (annex to NDS, 2009) support is cited, there is not explicit consideration in the care-pathway outlined in the NDS of how a religious community may be used as a potential resource for care. Investigation is required to whether religious communities comprised of a strong infrastructure and support network, are a potentially underutilised resource in the dementia care service for underrepresented groups. It is important to consider the following: are BMEPWD who are not presenting to MHSCS being adequately supported by an additional care service such as their religious community? An investigation is required in to whether religious communities offer an alternative resource to MHSCS, or do they offer a complementary and co-operative care service to MHSCS? It is a consideration that religious communities may not offer an adequate care provision for the BMEPWD and these underrepresented persons are not just mis-identified in MHSCS, but are also mis-identified in their religious communities. The paucity of current data – to be discussed in chapter two - does not adequately answer the question of how religion influences UK dementia care access and dementia care provision for BMEPWD.

1.7.   Chapter Summary

The West Midlands is home to one of the largest South Asian populations in the UK. South Asian persons with dementia remain underrepresented in MHSCS. The *National Dementia Strategy* (Department of Health, 2009a) asserts a care pathway encouraging persons in to services, promoting early diagnosis and ensuring good quality care. Contrastingly, not all persons follow this mainstream route in to and through the mainstream dementia care service. The care needs of an ageing ethnic population should be considered (Manthorpe, 2010). Further investigation is required in to the specific impact of religion on the care pathway and the care provision for South Asian persons with dementia in the West Midlands. Chapter two will review the empirical literature investigating the challenge of dementia in BME groups on dementia care services and access to dementia services.

2.   Chapter Two: Literature Review

"*Religion can play an important part in the lives of people with dementia and religious organisations may be able to provide a link between individuals and health and social care services*" (Department of Health, 2011e, p.8).

2.1.   Chapter Aim

The aim of this chapter is to demonstrate society's response to the issue of BME underrepresentation in mainstream dementia care services through a critical discussion of dementia and religion. Firstly, through empirical research literature; secondly, through an overview of religious literature in the Hindu, Muslim and Sikh faiths and thirdly, an examination of UK Government reports, policies and guidelines. This investigation forms a platform for devising the aims and objectives of the present study.

2.2.   Access to Services

Shah (2010) highlights the inequity of access to mental health services for depression and dementia in older BME patients. Many of the barriers discussed relate to cultural issues such as language and communication, lack of culturally appropriate screening instruments, withholding of information, previous bad experiences. There is no explicit allusion to religious specific issues. However, this paper is commendable in presenting strategies for addressing this underrepresentation, improving access to services and promoting research: "there is a continuing need to identify services with equitable access and examples of good practice and

to widely disseminate these examples" (Shah, 2010, p.278). Training of clinicians and mental health managers and the implementation of translators were considered important steps forward to encourage access in to care services, stressing the "urgent need for public education campaigns at a local, regional and national level" (Shah, 2010, p.279) and the promotion of education regarding acute risk factors in dementia such as cardio-vascular disease.

2.2.1. BME Access to Mental Health Services

In contrast to the underrepresentation of BME persons with dementia in MHSCS, research demonstrates overrepresentation of BME persons in compulsory detainment in mental health services. A systematic review of 38 quantitative papers recognised: "Black patients had more complex pathways to specialist care" - with Black patients four times more likely to be compulsory admitted to mental health services than their White counterparts (Bhui, Stansfeld, Hull et al., 2003, p.105). This systematic review further identified South Asians in Birmingham demonstrated highest rates of mental illness in the community and were less likely than White people to have their mental illness diagnosed (Commander, Odell, & Sashidharan, 1997). Furthermore, of all ethnic groups with a mental illness, South Asians were the least likely to be referred to specialist care (Commander, Odell, & Sashidharan, 1997). One limitation of the review was the focus on purely quantitative studies. Whilst this allowed the scope of the issue to be captured, the authors recognise the study does not pay enough attention to factors such as "birth, religion, duration of residence in the UK, place and level of education and cultural identity"

(Bhui, Stansfeld, Hull *et al*., 2003, p.114) and that exploring these influences is necessary in further research.

The Aesop study group (Morgan, Hutchinson, Bagalkote *et al.,* 2005) further highlighted the influence of the pathway in to services influencing subsequent care provision in mental health compulsory admissions. Analysis of data from 512 White British, African-Caribbean, Black African and other White participants over a two year period, analysed using Chi-squared tests discovered: "the route by which a patient is referred to services will influence the nature of the contact", i.e. if they are referred from the criminal justice system then they may be more likely to be detained; "conversely, successful general practitioner referral signifies a willingness on the part of the patient to accept intervention by mental health services" (Morgan, Hutchinson, Bagalkote *et al.,* 2005, p.288). However, "differences in the source of referral do not fully account for ethnic variations in compulsory admissions" (Morgan, Hutchinson, Bagalkote *et al.,* 2005, p.288) and there may be further influential factors warranting investigation.

Singh, Greenwood, White *et al.* (2007) investigated the disproportionate detainment of persons in compulsory mental health services from a BME background through a systematic review of 49 studies of Black, BME and Asian samples. A meta-analysis offered explanations for these disproportionate rates. The explanations given were divided into patient related and service related explanations (Littlewood, 1988). An example of patient related explanations is the higher level of psychosis presented by non-White persons at services. The most important finding of stigma

associated with mental illness within minority communities leading to delays in help-seeking and more severe symptoms at presentation (Harrison, Holton, Nielson *et al*., 1989) counteracts the accusation that psychiatric services are institutionally racist. However, the "higher levels of psychosis" presented by non-White patients as a result of "greater delays in help seeking" (Singh, Greenwood, White *et al.* 2007, p.102) result from data from secondary sources and the credibility of these findings should be further considered. This paper is commendable in that it refers to the report: *Delivering Race Equality in Mental Health Care*'s (Department of Health, 2005a) key aim to reduce the disproportionate rates of BME admissions in mental health (Singh, Greenwood, White *et al.* 2007, p.103) and acknowledges the possible "publication bias" (Singh, Greenwood, White *et al.* 2007, p.103) of the review, where papers with significant differences are more likely to be published. This suggests there may be unpublished evidence that non-White patients are not admitted to compulsory mental health care more readily than BME persons. Future suggestions for improving services through "consistency in ethnic categories" and research aiming for "understanding of patients" experiences, and their journey through the services, pathways to care…" (Singh, Greenwood, White *et al.,* 2007, p.104) were positive conclusions from the paper.

A recent quantitative study (Singh, Burns, Tyrer *et al.*, 2013) analysed prospective data of 4,423 Mental Health Assessments from Birmingham, London and Oxfordshire across years 2008, 2009, 2010, 2011 through univariate analysis and multiple logistical regression. This data

contributes to AMEND, which explores changes in clinical practice following the 2007 amendments to the 1983 Mental Health Act. The results suggest: "no evidence that ethnicity has an independent effect on the odds of being detained" (Singh, Burns, Tyrer *et al.*, 2013, p.1) which challenges the view that psychiatric assessments are institutionally racist and contrasts with earlier research in this area. Rather than ethnicity being a factor, the study found, "a diagnosis of serious mental illness and the presence of risk predict MHA detention" (Singh, Burns, Tyrer *et al.*, 2013, p.6) However, one interpretation of this paper and the Singh, Greenwood, White *et al.* (2007) paper, is BME persons are more likely to be given this diagnosis of psychosis, leading to detention, because services were accessed at a late stage. If services were accessed early, allowing the opportunity for early diagnosis and treatment, compulsory detention may be avoidable.

The Singh, Burns, Tyrer *et al.* (2013) paper found the differences in pathways to care reflected the geographical locality of the person and BME persons in London demonstrated a more complex care pathway than BME persons from other areas: "pathways to care in London may be very different from other sites due to differences in threshold for admission, access to home treatment teams, and in-patient provision" (Singh, Burns, Tyrer *et al.*, 2013, p.7). Thus, overrepresentation of BME persons in compulsory detention may be a result of not accounting for the "lack of adjustment for variations in service providers and pathways" (Singh, Burns, Tyrer *et al.*, 2013, p.6). The authors acknowledge the parameters of the research context: "the study only contains information collected at

MHA assessments and so only shows a snapshot of the complex pathways through services" (Singh, Burns, Tyrer *et al.*, 2013, p.7) and raises the important issue about late diagnosis resulting from complex pathways into services for BME persons with mental health issues. Delays in help-seeking through factors such as stigma (Singh, Greenwood, White *et al.*, 2007) mean symptoms are higher when BME persons do present to services, making the rate of compulsory detention in this cultural demographic higher, rather than necessarily being influenced by the ethnicity of the person. These findings demonstrate it is this late presentation, where symptoms have developed in to more complex issues that influences the levels of compulsory detainment. This raises the question, if persons were assisted to access services earlier, would compulsory detention be lower as a result of lower levels or even absence of psychosis? If mental illness is identified earlier and services accessed earlier, would this impact on levels of compulsory detainment across all ethnicities? It is beyond the scope of this thesis to investigate these research questions in detail. Providing an overview of this related area of research highlights the importance of recognising the impact of care pathways on health care provision.

2.2.2.   BME access to dementia services

Whilst the research literature demonstrates the overrepresentation of BME persons in compulsory detainment in mental health services, BME persons with dementia are underrepresented in MHSCS dementia services. The empirical literature on BME dementia care access reflects the pattern of access to general mental health services discussed above;

namely, often access is delayed, presentation to services is late and the illness has developed to an acute level by the time care services are sought. Additionally, BME persons follow complex pathways in to care. Mukadam, Cooper, Basit *et al.* (2011a) conducted a study with 18 male and female family carers of people with dementia from White, South Asian, Black, White Irish, White other, Asian other and Chinese ethnic backgrounds. Data were collected through a Grounded Theory study employing the interview method. The findings demonstrated carers "tended to delay help-seeking until they could no longer cope or until others commented on the problems" and this delay to service access related to "beliefs about the aetiology of cognitive impairment, negative beliefs about psychiatry and their sense of familial responsibility" (Mukadam, Cooper, Basit *et al.,* 2011a, p.1070). This paper suggested further research should focus on exploring these beliefs and developing "interventions to tackle barriers to help-seeking in ethnic minorities" (Mukadam, Cooper, Basit *et al.*, 2011a, p.1070).

BME persons who are caregivers are more likely to use their faith through prayer as a form of religious coping (Connell & Gibson, 1997). This reliance on faith may delay or hinder access to dementia care services for BME persons. Additionally, there is evidence of this across research in to acute care access. A study found White Christian women were more likely to access health services than Christian women from African American communities (Ark, Hull, Husaini *et al.,* 2006). Similarly, African American women who regularly attended religious services were less likely to attend breast cancer screening services (Felix-Aaron, Levine, & Burstin,

2003). One explanation may be that a stronger faith correlates with a less frequent uptake of care services. Further research is required to explore this in the UK.

Existing research has explored the notion of "ethnicity" and dementia care pathways (Mukadam, Cooper & Livingstone, 2011b). This systematic review yielded 13 papers: three quantitative (Clark, Kutner, Goldstein *et al*, 2005; Ortiz & Fitten, 2000; Watari & Gatz, 2004) and 10 qualitative (Neary & Mahoney, 2005; Cloutterbuck & Mahoney, 2003; Lawrence, Murray, Samsi *et al.*, 2008; Zhan, 2004; Hinton, Franz, & Friend, 2004; La Fontaine, Ahuja, Bradbury *et al.,* 2007; Jett, 2006; Braun *et al.,* 1996, Bowes & Wilkinson, 2003, Jones *et al.,* 2006) utilising participants adhering to non-Christian belief systems; specifically, Buddhist, Hindu, Muslim and Sikh persons. Most of these papers derive from the United States with only three studies representing the British health care system (Bowes & Wilkinson, 2003; La Fontaine, Ahuja, Bradbury *et al.,* 2007, Lawrence, Murray, Samsi *et al.*, 2008). The main finding identified was BMEPWD experience significant barriers when accessing dementia services. The lack of medical knowledge and sense of stigma about dementia and available services may impede access to care provision (Patel & Mirza, 2000; Bowes & Wilkinson, 2003). It is evident that "a complex interaction of interpersonal and intrapersonal factors influences pathways into care seeking for South Asian persons entering mental health services" (Bhugra, Thompson, Piracha *et al.*, 2003, p.27).

2.2.3. Barriers to MHSCS

BME persons experience barriers to mental health access (Boneham, 1997). The Policy Research Institute on Ageing and Ethnicity (PRIAE, 1998) conducted a large cross-national study in the UK, Denmark and France to investigate the Care Needs of Ethnic Older People Suffering from Alzheimer's (CNEOPSA). The prominent findings are summarised as follows:

o Non-English speaking persons with dementia and carers experienced barriers at every stage of care.

o Stigma was identified as a barrier to accessing care.

o BME families struggled to communicate successfully with health professionals to acquire information about MHSCS.

o The complexity of service access as a multi-stage and multi-agent process hindered BME persons.

o Often dementia was not understood as an illness but was attributed to "normal ageing" and thus carers did not seek MHSCS to assist them.

o Funding was not substantial to generate and sustain culturally sensitive services for BMEPWD.

o A clear need for policy development, training and research was identified.

Despite these barriers to MHSCS, there is consistent evidence that there is a higher prevalence of some mental health conditions in the South Asian culture than the White British culture (Parkes & Gilbert, 2010); a paradigm of this is the higher rates of suicide and self-harm demonstrated for South Asian women than White women (Husain,

Waheed & Husain, 2006). The reasoning for not accessing MHSCS is given a cultural explanation: "Family problems and emotional problems are kept hidden and not exposed to other people. That is our culture" [Punjabi–Muslim participant in research study conducted by Simich (2009), in Parkes & Gilbert, (2010), p.33]. Thus, there is a need to recognise the suitable treatment for persons of South Asian culture in the UK (Rait & Burns, 1997). Research has recognised the importance of developing culturally competent care for BME persons with dementia (La Fontaine, Ahuja, Bradbury *et al.,* 2007; Iliffe & Manthorpe, 2004; Innes *et al*., 2001; Rait & Burns, 1997) and the importance of person centred dementia care (Kitwood, 1997).

2.2.4.   *Dementia Awareness*

The paucity of knowledge regarding the aetiology and prognosis of dementia in BME groups has been demonstrated strongly in existing research (Seabrooke & Milne, 2003; Brownfoot, 1998; Adamson, 1999; Daker-White, Beattie, Gilliard, J. *et al.,* 2002; Lawrence, Samsi, Banerjee *et al.*, 2011; La Fontaine, Ahuja, Bradbury *et al.,* 2007; Turner, Christie & Haworth, 2005; Azam, 2007). The awareness of dementia, its causes, prognosis and subsequent treatments in BME groups is much lower than the majority White population (Seabrooke & Milne, 2003; Brownfoot, 1998; Adamson, 1999; Beattie, Daker-White, Gilliard *et al.*, 2005; Lawrence, Samsi, Banerjee *et al.*, 2011; La Fontaine, Ahuja, Bradbury *et al.,* 2007; Turner, Christie & Haworth, 2005; Azam, 2007)*.* Both Indian and White British Older Adults in Manchester had poor knowledge of

dementia, but awareness was worse among Indian older people (Purandare, Luthra, Swarbrick *et al.*, 2007). Research has shown lower awareness levels of dementia amongst Irish communities (Brownfoot, 1998) and Black Caribbean persons (Brownfoot, 1998; Adamson, 1999; Ahtiluoto, Polvikoski, Peltonen, Solomon *et al.*, 2010; Adamson, 2001) than White British counterparts. Carers of individuals with dementia in BME groups observed that awareness of dementia and understanding of the causes of dementia was poor (Adamson, 2001).

In many South Asian communities, there is no literal translation for the word "dementia" (Seabrooke & Milne, 2003; Forbat, 2003a; Turner, Christie & Haworth, 2005). This low awareness has implications for the care sought and received. If conditions are not seen as an illness, then the appropriate health channels may not be consulted. Many South Asian communities view the condition as a result of normal ageing (Seabrooke & Milne, 2009; Purandare, Luthra, Swarbrick *et al.*, 2007; Mukadam, Cooper, Basit *et al.*, 2011a; Turner, Christie & Haworth, 2005; Azam, 2007) and therefore because it is not perceived as a medical condition, MHSCS are not sought, or only accessed in very extreme cases where the family are unable to cope (Bowes & Wilkinson, 2004; Purandare, Luthra, Swarbrick *et al.*, 2007). When a dementia diagnosis is received at an advanced stage in disease progression, through late presentation to MHSCS, conflict between service provider and dementia carer can arise regarding care provision for the BMEPWD who lacks capacity to give input in to their future care directive (Patel & Mirza, 2000; Forbat, 2003b).

2.2.5.   Knowledge of MHSCS

A service evaluation investigated the equality of access to MHSCS for

BME persons with dementia and suggested poor communication about

existing services in alternative languages is one reason for low uptake of

services, although there is some evidence that this may be changing

(Odutoye & Shah, 1999; Redelinghuys & Shah, 1997). BME persons are

often unaware of available services, unaware of the procedures to apply

for these services (Manthorpe *et al.*, 2009), and are more likely to be

turned down; if they are accepted in to MHSCS, they are more likely to

be dissatisfied with the provision (Lindesay *et al.*, 1997; Bowes &

Wilkinson, 2003).

2.2.6.   Stigma

Black Caribbean and Irish people have demonstrated to perceive

dementia as a mental illness with supernatural causes rather than as a

biological brain dysfunction (Brownfoot, 1998). Eastern Europeans face

experiences of persecution as a result of stigma and need to "keep face"

(Moriarty, Sharif, & Robinson, 2011). Marriage prospects have been

damaged for the children of the family of the BMEPWD (Seabrooke &

Milne, 2004; Mackenzie, 2006; Mackenzie & Coates, 2003). Carers feel

tarnished by the stigma associated with the person with dementia

(Forbat, 2003c). This can result in less services being accessed to avoid

recognition in society by other members of the community and being

isolated as a consequence. This demonstrated the majority of research on

access to care services is based around cultural factors impacting on

entering care pathways and care provision. An in-depth exploration of religion's role on dementia care and access to dementia care pathways is required in research.

2.3.   BME, religion and dementia care access: A Systematic Review

A systematic review of religion and dementia care pathways in BME populations (Regan, Bhattacharyya, Kevern *et al*., 2013) identified from 1,234 papers on BME groups, religion and dementia; only two addressed the specific criteria of religions' influence on dementia care decisions and access. The remaining papers were split in to five categories [see table 4 for details]. The category with the most number of papers is religious coping in old age, illness and dementia (Pargament, 1997; Pargament, Koenig, Tarakeswar *et al.*, 2004; Koenig, 1997) or religious issues generally. Religious and spiritual coping has been found to assist persons coping with early stage Alzheimer's Disease [see Beuscher & Beck, 2008 for a review]. There is a rich body of literature on religious coping in illness and dementia. However, the primary focus of the current thesis is on the practical impact of religion on access to care and care experiences in dementia; thus, the religious coping literature is not fully discussed here.

The identified papers focusing on religion's influence on dementia care access (Levkoff, Levy & Weitzman, 1999; Sun, Roff, Klemmack *et al*., 2008) were based in the US with Christian BME groups of Irish Americans, African Americans, Chinese Americans and Puerto Rico Americans. This reflects the religious disposition of the US where the

majority faith is Christianity and is associated with a range of cultural identities (Kosmin & Keysar,2008). The findings of this review highlighted: "religion has a negative effect on BME Christians with dementia when accessing care services…religion has a positive effect on improving internal coping processes" (Regan, Bhattacharyya, Kevern *et al*., 2013, p.9).

	Category	Sources
1	Religion, care pathway, BME	2
2	Spiritual or religious coping or religion generally	416
3	dementia generally and ageing generally	213
4	cultural issues	226
5	acute illness in dementia medicine / not main focus / other illnesses	253
6	Cognitive Neuropsychology / Neuropsychiatry	124
Total:		1,234

Table 4: Categorisation of literature sources

A summary of Regan, Bhattacharyya, Kevern *et al*. (2013) systematic review is now presented: (see appendix 1a for full paper)

2.3.1. *Aim*

To systematically review the research literature to answer the following question: how does religion influence the decision to seek existing health care services and does religion offer an alternative care pathway for BME persons with dementia?"

2.3.2.   Method

2.3.3.   Search strategy

The following databases were searched up to early May 2011: Medline (1950-), Web of Knowledge (1950-), PsychINFO (1806-) using the following search terms: "Dementia" OR "Alzheimer* disease" were combined using the AND operands with the following terms: "religion", "spirituality", "Christianity", "Buddhis*", "sikh*", "Hindu*", "Muslim", "Islam", "Black", "Asian", "South Asian", "BME". Free text terms, MeSH terms and subheadings of MeSH terms were used in the Medline search. Titles and abstracts of all studies were read to meet the inclusion criteria for the initial screening. Those that were potentially relevant were examined in their full form and subject to five phases of screening (see table 5). Arising discrepancies regarding a paper's relevance were discussed and resolved with the co-authors.

Screening Phase	Search Terms	Number of Papers	Study Type
1	Dementia' OR 'Alzheimer* disease' were combined using the AND operands with the following terms: 'religion', 'spirituality', 'Christianity', 'Buddhis*', 'Sikh*', Hindu*', 'Muslim', 'Islam', 'Black', 'Asian', 'South Asian', 'BME'.	1234	Unoriginal: 457 Qualitative: 479 Quantitative: 246 Mixed: 52
2	Remove papers according to exclusion criteria	247	Qualitative: 153 Quantitative: 66 Mixed: 28
3	Remove any paper that does not focus exclusively on dementia	180	Qualitative: 119 Quantitative: 43 Mixed: 18
4	Remove duplicates across databases	91	Qualitative: 61 Quantitative: 19 Mixed: 11
5	Include papers that address specifically: 'Religion', 'care pathway', 'BME participants'.	2	Qualitative: 0 Quantitative: 2 Mixed: 0
	Phase 5 UK studies	*0*	

Table 5. Screening phases, outcomes and breakdown of papers by study type (n.b. 'unoriginal' denotes unoriginal or non-scientific research, 'mixed' denotes a combination of qualitative and quantitative methods). [Taken from Regan, Bhattacharyya, Kevern et al., 2013].

2.3.4. Inclusion criteria

All original research which directly addressed dementia, religion and

pathways to care in BME communities from a qualitative or quantitative

approach were included. All perspectives involving the dementia patient, caregiver, community group or health care provider were examined. We included any studies which compared health care usage across cultural groups.

2.3.5. Exclusion criteria

Any studies where dementia was not the exclusive focus of study were excluded. These included research comparing dementia patients with cancer patients; general ageing papers where dementia is a subset of the research; dementia in relation to brain donation, end of life care issues, palliative care, Mild Cognitive Impairment, artificial nutrition, feeding, depression, epilepsy, reviews, spiritual reminiscence therapy. Non-scientific papers were excluded. Books and Literature Reviews were also excluded as they do not present original research.

2.3.6. Screening phases

Papers were subject to five phases of screening. Phase one involved searching across databases with defined criteria. Phase two involved removing papers according to exclusion criteria. Phase three removed any paper that did not focus exclusively on dementia. Phase four removed duplicates across databases. Phase five only included papers which address specifically the following terms: "religion", "care pathway", "BME".

2.3.7.   *Quality assessment*

Papers were assessed for quality based on modified checklists from standardised assessment tools. Quantitative papers were subject to a checklist influenced by Mukadam, Cooper & Livingstone's (2011b) adaptation of Boyle (1998) and supplemented by criteria from the Critical Appraisal Skills Programme (CASP, 2006). Qualitative Papers were subject to assessment using the CASP (2006) checklist [see table 6 for assessment criteria]. Each question on the checklist was converted to a score of one, with a total score of 10. Disputes regarding scoring were reconciled through re-examination and discussion with the co-authors. Points were awarded on the data explicit in the paper. No points were awarded for implied information. For example, for question 7 regarding ethics: if there was no detail given in relation to ethical consideration, the paper would be awarded 0 on this item.

Quantitative Studies		Qualitative Studies	
1.	Target Population: Clear inclusion and exclusion Criteria?	1.	Are the aims clearly stated?
2.	Was probability sampling used?	2.	Is a qualitative methodology appropriate?
3.	Did respondents' characteristics match the target population: i.e. was the response rate ≥ 80%?	3.	Was the research design appropriate to address the research aims?
4.	Were data collection methods standardised?	4.	Was the recruitment strategy appropriate to the research aims?
5.	Was the measure used valid?	5.	Were the data collected in a way that addressed the research issue?
6.	Was the measure used reliable?	6.	Has the researcher – participant relationship been adequately considered?
7.	Have ethical issues been considered?		
8.	Was the data analysis sufficiently rigorous?		
9.	Is there a clear statement of findings?		
10.	How valuable is the research?		

Table 6. Quality Checklists (Taken from Regan, Bhattacharyya, Kevern et al., 2013).

2.3.8.   Results of Review

Two papers adhered to the final screening criteria. These papers directly

address the issue of religion and the dementia care pathway for BME

populations in the US with care-givers of persons with Alzheimer's dementia as participants. The papers are relevant to the health care system of the United States and reflect the ethnic spread of the specific region within that country. One paper adopts a quantitative approach and compares African American caregivers with Caucasian caregivers (Sun, Roff, Klemmack *et al*., 2008). The other paper utilises a qualitative method and compares a mix of different American cultural backgrounds: African-American, Chinese-American, Puerto Rican, and Irish-American (Levkoff, Levy, & Weitzman, 1999) which were chosen due to their predominance in the Boston region.

"During phase one, 1,234 papers were found across all databases. Of these, 457 comprised unoriginal research, 479 utilised qualitative methodologies, 246 implemented quantitative methodologies and 52 employed both qualitative and quantitative techniques, reflecting a mixed-method approach. Some search terms generated more than 10 papers; some search terms generated 0 papers in the initial search. Search terms which generated 0 papers were as follows: Dementia "AND" Sikh; AD "AND" Hinduism; AD "AND" Islam; AD "AND" Muslim; Spirituality, dementia "AND" South Asian; religion, dementia "AND" BME. The most papers generated were in relation to the umbrella terms of dementia "OR" AD and religion "OR" spirituality. In terms of ethnic groups, the majority of research in dementia and religion is in relation to Christianity, followed by South Asian, then Hindu, then Black communities." (Regan, Bhattacharyya, Kevern *et al*., 2013, p.4).

The categorisation of papers in the review was across five screening phases. Initially, a very high volume of papers were identified (> 1,000), yet very few focused on pathways to dementia care. The remainder of these papers were classed in to six categories and were predominantly related to religious coping and dementia. Of these, the majority were based on Christian samples. "Others related to health care issues where dementia was a subset, such as cancer studies. Others did not include the three key terms relating to: "religion", "care pathway", "BME participants" (Regan, Bhattacharyya, Kevern *et al*., 2013, p.4). Thus, the papers relating to religious and spiritual coping in dementia, or those relating to acute illnesses, or not wholly focusing on dementia were discarded as not relevant for the investigation of the review.

In contrast, the data were inconsistent across some cultural groups, "the exceptions identified to this are with Puerto Rican or Chinese Americans, whose experiences vary" (Regan, Bhattacharyya, Kevern *et al*., 2013, p.9). Religion is a complex phenomenon, comprised of different faith traditions, which themselves are heterogeneous, "for example, a White Christian does not experience the same barriers to dementia health care as a Black Christian." (Regan, Bhattacharyya, Kevern *et al*., 2013, p.12) Thus, findings from this review - albeit from a low number of research studies - identified, "even when the religious beliefs of the carer and the cared-for match the country of care, care provision still needs to accommodate for cultural nuances" (Regan, Bhattacharyya, Kevern *et al*., 2013, p.13). Thus, "it is not sufficient to provide block care for persons from a particular religion without considering the cultural interpretation of

that religion (Elliot *et al*., 1996) even when the religion of the individual

and the indigenous religion of the country are the same" (Regan,

Bhattacharyya, Kevern *et al*., 2013, p.12). This strengthens the

argument that religion and culture - whilst indelibly intertwined - are

distinct entities, and persons have respective "religious and ethnic

identities" (Thakrar, Das & Sheikh, 2008, preface).

2.3.9. *Summary of Identified themes*

There were three main themes identified: religion, religion and the care

pathway and religion and coping.

2.3.10. *Religion*

"A distinction arises between "religion", which can be understood as a set

of doctrinal beliefs, and "culture", the manifestation of those beliefs into

particular practice. For example, the basic tenets of Christianity can be

interpreted and practiced within the culture of the individual believer, or

culture of an ethnic community." (Regan, Bhattacharyya, Kevern *et al*.,

2013).

2.3.11. *Religion and the Care Pathway*

This was seen to influence the decision to utilise care facilities: "Religious

obligation is a factor in not accessing external care services. Fear of

culturally insensitive practice towards religious behaviour may also

prevent access to care provision. There is some evidence that when the

decision to seek external care is made, consultation with religious

institutions to assist with information dissemination and decision making is evident across some cultural groups" (Regan, Bhattacharyya, Kevern *et al.*, 2013).

2.3.12.   Religion and Coping

The notions of alienation and prayer were identified: "A disparity exists between firstly, the perception that external religious institutions and its members isolate the caregiver and the cared for; and secondly, the notion that an internal faith manifested in personal ritual provides comfort, reflection and acceptance". (Regan, Bhattacharyya, Kevern *et al.*, 2013).

2.3.13.   Recommendations of Review

Recommendations from Regan, Bhattacharyya, Kevern *et al.* (2013) are summarised as follows:

o Co-operation between religious institutions and dementia organisations is a vital step to improving care provision and the pathway to care provision for BME dementia caregivers (Sun, Roff, Klemmack *et al.*, 2008; Levkoff, Levy & Weitzman, 1999).

o Faith communities could assist in practical ways such as facilitating with patient referral, providing respite care, and using the religious institution as a platform for education and information for dementia caregivers (Sun, Roff, Klemmack *et al.*, 2008).

- o Local dementia organisations and specialist BME services could collaborate with churches to provide educational sessions on dementia care and available services (Levkoff, Levy & Weitzman, 1999).

It is important to note that strong religious affiliations within a cultural group do not necessarily mean that all members of the group want to access services through their churches (Levkoff, Levy & Weitzman, 1999).

2.3.14.   Conclusion of Review

The findings from this review assert that firstly, religion has a negative effect on BME Christians with dementia when accessing care services and secondly, religion has a positive effect on improving internal coping processes. The exceptions identified to this are with Puerto Rican or Chinese Americans, whose experiences vary (Levkoff, Levy & Weitzman, 1999). This highlights the needs to be sensitive to different cultural groups and not categorise "BME" as a homogenous term, of which all its members require identical treatment, regardless of the ethnic and cultural nuances present (Elliott, Di Minno, Lam *et al*., 1996).

2.3.15.   Discussion of Review

The review in question (Regan, Bhattacharyya, Kevern *et al*., 2013) adhered to strict search criteria with a focus on empirically sound, original research projects. Whilst no UK based papers were identified using the five screening phrases and specific search terminology of

"pathways to care", "dementia" and "BME participants", hand searching identified a series of clinical reports documenting work in to dementia and BME faith communities conducted in the West Midlands region of the UK (Moreland, Read, & Jolley, 2001; Moreland, 2003; Jutla & Moreland, 2007). In the first of a series of three reports - *Twice a Child* (Moreland, Read, & Jolley, 2001), two types of cohorts from the Asian and African-Caribbean communities were interviewed. The participants interviewed were community leaders and religious representatives. It is important to note these reports do not focus on how religion specifically influences perceptions of dementia, nor how religion influences pathways to care. Rather, the aim was to investigate the phenomenon of knowledge of dementia and awareness of MHSCS in BME communities from a cultural perspective. The religions of the Asian representatives were from the Sikh and Muslim faiths. The African-Caribbean religious representatives were from various denominations of the Christian tradition - Pentecostal, Methodist and Baptist organisations. An interesting finding from the Moreland, Read & Jolley (2001) study was that knowledge and awareness of MHSCS was low across both the religious and community representatives, yet those from a religious specific organisation demonstrated an even lower awareness. There was knowledge across all participants in the Asian communities that persons with dementia had specific care needs, and a frustration that these care requirements are not satisfied, "doors are opened, needs are identified, but never met" (Moreland, Read, & Jolley, 2001, p. 69*). Further emergent themes were the notion of dementia as a taboo, dementia as a stigma, and dementia generating "spiritual problems" (Moreland, Read, & Jolley, 2001, p.72).

This led to feelings of isolation from MHSCS and a "subsequent desire for privacy" (Moreland, Read, & Jolley, 2001, p.72), reflecting the theme of "isolation" identified in the Regan, Bhattacharyya, Kevern *et al*., (2013) review. Cultural clashes in service provision and care expectation were identified, for example, regarding food and mealtimes, *"In some instances, the reluctance to use services results from the provision not adhering to cultural regimes or inappropriate food choices"* (Moreland, Read, & Jolley, 2001, p. 76). Other research studies support this finding: Cultural barriers to day-care and residential services were evident through inappropriate food or lack of observation of particular religious rituals associated with mealtimes (Patel, Mirza, Linbald *et al.*, 1998).

Overall, the *Twice a Child* (Moreland, Read, & Jolley, 2001) report was a positive addition to the research arena in highlighting the possibility of co-operating with religious communities when disseminating education about dementia and promoting MHSCS. This report documents that religious communities are willing to engage in dementia research and prepared to inform researchers about the needs within their communities, "This report highlights that research in to dementia care within religious and cultural communities is achievable" (Regan, Bhattacharyya, Kevern *et al*., 2013, p.11). This outreach has been demonstrated with variable success in existing research (Azam, 2007; Mackenzie, 2006; Banjeree, 2007). Presently, [post May 2011], the researcher has not identified additional papers focusing specifically on "BME", "Religion" and "dementia care service access". Building on this type of research study within the parameters of a sound methodological

and empirical design, could prove highly beneficial for understanding the impact on care pathways and identifying ways to address current BME underrepresentation in mainstream dementia services.

2.4. Religion and Dementia

2.4.1. Religious Beliefs

Religious beliefs have been suggested as a source of stigma amongst persons of Asian ethnicity, "religious beliefs may account for some stigma amongst Asian people" (Moriarty, Sharif & Robinson, 2011). An example of this is the notion that receiving dementia is a result of reincarnation or punishment for a past life (Mackenzie & Coates, 2003). Negative religious perceptions of dementia as karmic retribution or punishment, present a barrier to help-seeking (Bowes & Wilkinson, 2003; Jett, 2006; La Fontaine, Ahuja, Bradbury *et al.,* 2007; Zhan, 2004); the notion of, "religious duty", influencing care solely in the family, presents a barrier to accessing external care services (Braun, Takamura & Mogeot, 1996; Jett, 2006; La Fontaine, Ahuja, Bradbury *et al.,* 2007; Lawrence, Murray, Samsi *et al.*, 2008; Watari & Gatz, 2004); the stigma and shame of mental illness within faith communities generates a barrier to seeking support within the community (Bowes & Wilkinson, 2003; Braun, Takamura & Mogeot, 1996; Jett, 2006; Jones, Chow & Gatz, 2006; La Fontaine, Ahuja, Bradbury *et al.,* 2007; Watari & Gatz, 2004; Zhan, 2004). The behavioural symptoms of dementia influence the ability to perform religious rituals. For example, incontinence impeded Muslim home prayer as the house was considered "dirty" (Bowes & Wilkinson, 2003).

This demonstrates religious beliefs and practices have an influence on pathways to dementia care for South Asian persons. This study is primarily concerned with the influence of religion on external practices; specifically, the practice of accessing dementia care services. However, there is recognition that the decision to access MHSCS or not, may be influenced by internal religious beliefs. It is beyond the scope of this thesis to provide a theological discussion of religious perceptions of dementia in detail, but it is important to provide a brief overview of the main ideas, values and texts within the religions of investigation, in order to consider how they may impact on perceptions of dementia and the decision to access care services.

2.4.2. Dementia in Hinduism, Islam and Sikhism

The complexity of the Hindu belief system reflects the complexity of sources of literature on which the faith is based. The researcher accessed English translations of the following Hindu texts: Vedas, Upanishads, Puranas, Epics, Mahabharata, Ramayana, Bhagavad Gita and Vedanta translations (Hare, 2010) and could not identify any specific allusions to dementia. However, the Hindu perception of death may provide an understanding of how Hindus accept firstly, dementia as a terminal illness: "Most Hindus will regard their death as insignificant because of their certainty of being at one with God in their life after death" (Neuberger, 2004, p.47), and secondly, dementia as a degenerative, debilitating condition: "the whole Hindu religious outlook is geared to the acceptance of the inevitable (and sometimes, sadly, of the avoidable as well)" (Neuberger, 2004, p.50).

Ill-health can have a significant impact on the ability to perform religious rituals. Puja is the Hindu daily ritualistic adoration of the murti (sacred image) within a temple and involves the offering of food, art and prayer in a shared of devotion (Thakrar, Das & Sheikh, 2008, p.15). Hindu homes have a shrine where Puja can be performed on a smaller scale. Rituals are important and the desire to continue these rituals throughout illness and in old age is strong: "older Hindus, who [may] like to bathe early in the day before saying their prayers, even if they are very ill, and may need a lot of help to achieve it" (Neuberger, 2004, p.48). Other rituals such as modesty and food provision may be difficult to manifest in MHSCS. For example, the Carak Samhita, the guide to healthcare for Hindus, says that a physician may not attend a woman in the absence of her husband or guardian and "few hospitals could guarantee production of food by Hindus of the same caste as the patient" (Neuberger, 2004, p.49). Hindu priests – Brahmins play an integral role in a clinical setting: "They will often come to help dying patients with their acts of worship, called puja. They will also help the dying patient to accept death philosophically, an acceptance of which is a strong feature of Hindu attitudes" (Neuberger, 2004, p.50).

In social behaviour, Islam is based on daily ritual behaviours, and concepts of clean and unclean, influencing "orthopraxy as well as orthodoxy" (Halliday, 2003, p.58). Many aspects of Muslim "culture" such as race, dress, customs, cookery and language "are functions not of the religion proper, but of the specifics of regional culture in the countries of origin" (Sheikh & Gatrad, 2000, p.27). This further highlights the

argument regarding the complexity of practicing an immigrant religion in a country contrasting with its indigenous origin [see Chapter 1, p.29 for fuller definition of "immigrant" and "indigenous" for the present study].

The primary holy text in Islam is the Qur'an, supplemented with Hadith, which are "the canonical accounts of what the prophet said and did" (Tibi, 2012). The researcher found no explicit references to dementia or memory loss in the English translation of the Qur'an (Al Islam, 2013), but there are some passages (Qur'an, 22:5; Qur'an, 36:68; Qur'an 17:23-24) which make reference to "senility" and "helplessness" and notions of returning to a "child-like state" in old age. The following examples illustrate this:

Example 1: "And We settle in the wombs whom We will for a specified term, then We bring you out as a child, and then you reach your maturity. And among you is he who is taken in (early) death, and among you is he who is returned to the most decrepit [old] age so that he knows nothing after once having knowledge" [Qur'an, 22:5].

Example 2: "And he whom we grant long age, we reverse in creation; so will they not understand?" [Qur'an, 36:68].

This serves as a reminder of the blessing of life from God and is an allusion to "the organic curve of man's growth, his acquisition of bodily strength, intelligence and experience, followed by gradual decay" (Asad, 2003). It also exemplifies the cyclical nature of life, deriving from

returning to God: "Allah gives us strength in youth, and then He takes it back and we return to the weakness and dependence of childhood. Old age, besides bringing wisdom and mitigating desires, is a reminder to us humans of the fact that we are mortals, weak and dependant" (Al Jumu'ah, 2006, p.17). These interpretations provide insight into possible positive attitudes towards memory loss in old age as a reflection of "normal" or "healthy" behaviours allowing reconnection with Allah. Contrastingly, the perception of a decline in cognitive function as "healthy" ageing, offers one explanation for why external care services may not be sought.

Respect for elders, importance of family and living in extended family units are strong elements of the Islamic faith (Sheikh & Gatrad, 2000, p.44-45). A further passage in the Qur'an [17-23-24] depicting family duty of care has a "negative impact on family members" (Mair, 2009) who feel compelled to look after elderly parents, even during difficult times such as during dementia, for example:

"Thy Lord hath decreed that ye worship none but Him, and that ye be kind to parents. Whether one or both of them attain old age in thy life, say not to them a word of contempt, nor repel them, but address them in terms of honour. And, out of kindness, lower to them the wing of humility, and say: 'My Lord! bestow on them thy Mercy even as they cherished me in childhood' " (Qur'an 17:23-24).

The notion that a parent should be nurtured throughout old age to show respect for the care bestowed in childhood, potentially offers one explanation for why MHSCS may not be sought by family members.

"The Sikhs call God Waheguru" and Sikhs believe everything happens within the Will (*hukam*) of God (Singh, 2005). Sikh theology relies on a monotheistic approach. Ultimate reality is a unity with God, and as God is without qualities, truth becomes an inadequate description (Cole & Sambhi, 1989). The Sikh holy book is the Gurū Granth Sāhib and the entire basis for worship is inspired by its teachings (McLeod, 1976). Granth means anthology, and was given by the last prophet to the Sikhs as the final teachings in the line of living Gurus. It is written in Punjabi in the Sikh alphabet Gurmukhi, which all Sikhs learn in order to understand "within the structure of Sikh worship the Gurū Granth Sāhib is central in much more than a merely physical sense" (Neuberger 2004, p.57).

Whilst the researcher did not find any explicit references to dementia in the English translation of the Gurū Granth Sāhib (Karandeep Tripod, 2013), there are "various descriptions related to mental well being" (Kalra, Bhui, & Bhugra, 2012). Recent research has investigated the Gurū Granth Sāhib as a resource for understanding depression (Kalra, Kamaldeep, & Bhugra, 2013). Whilst the term "depression" is not used explicitly, the "Gurū Granth Sāhib offers a very useful insight into what is understood by the term equivalent to depression and its phenomenology" (Kalra, Bhui, & Bhugra, 2012). There are references to mental suffering (Gurū Granth Sāhib 23-2), sadness, agony (Gurū Granth Sāhib 125-8)

and offers "karma" as an "etiologically important factor that leads to depression" (Kalra, Bhui, & Bhugra, 2012). Kalra, Kamaldeep, & Bhugra, (2013, p.341) exert the Gurū Granth Sāhib (182-1) makes reference to the indiscriminate nature of mental illness; depression can be experienced by the wealthy and the poor.

Examples of attitudes towards family are evident in the Gurū Granth Sāhib (Page 266, Line 19; p.3, line 10; p 71, Line 9). "The strength of the family and religious values can be a positive advantage in forming therapeutic alliances. It should be possible to use the scriptures as part of the treatment" (Kalra, Bhui & Bhugra, 2010, p.343). In these passages, the teachings express that family and friends should support elderly persons:

"ਬਿਰਧਿ ਭਇਆ ਉਪਰਿ ਸਾਕ ਸੈਨ ॥ बिरधि भइआ ऊपरि साक सैन ॥
Biradẖ bẖaᵇiᵇā ūpar sāk sain.
As you grow old, family and friends are there,
Guru Arjan Dev" (p.266, Line 19).

Care for family is representative of allegiance to God:

"ਮੰਨੈ ਪਰਵਾਰੈ ਸਾਧਾਰੁ ॥ मंनै परवारै साधारु ॥
Mannai parvārai sāḏẖār.
The faithful uplift and redeem their family and relations.
Guru Nanak Dev" (p.3, line 10).

For a Sikh, a pure life is that of a householder. Supporting the family, living well and serving the community is an expression of one's own faith (Singh, 2005). Sikhs believe that God resides in the home and therefore each person has a duty to fulfil household duties, including care for the family (Kalra, Bhui, & Bhugra 2010, p.340). This family duty could

influence care for a person with dementia. The following passage supports this:

"ਗਿਰਸਤੀ ਗਿਰਸਤਿ ਧਰਮਾਤਾ ॥੪॥ गिरसती गिरसति धरमाता ॥੪॥
Girsatī girsat dharmāt̄ā. ||4||
The householders assert their faith in family life. ||4||
Guru Arjan Dev" (p 71, Line 9)

This approach to the Gurū Granth Sāhib offers a useful insight into how the traditional scriptures may influence contemporary perceptions of mental illness and dementia and the provision of care.

2.4.3. Outreach in to Religious communities

Forging links with South Asian religious communities is a positive step to support older adult needs and was suggested in early research: " It is not too soon for health and social services to liaise with minority religious leaders to determine the needs of the elderly both in respect of residential care and community services" (Karseras & Hopkins, 1987, p.124) with practical suggestions for how this may be implemented: "why not halal meals-on-wheels and day centres attached to the Mosque, Temple, or Gurdwara?" (Karseras & Hopkins, 1987, p.124). More recently, creating links with local communities for instance, at places of worship (Mackenzie, 2006; Banjeree, Willis & Matthews, 2007) or through road shows at religious establishments and community centres has demonstrated one way of engaging with underrepresented BME groups to encourage them in to health services (Azam, 2007). For example, radio and poster campaigns to dispel stigma and portray the Gurdwara as a place to receive confidential information and support was effective in the Sikh community (Parkes & Gilbert, 2010). A shift in the

language used from clinical terminology, to a more informal parlance, using words such as "stress" or "emotion" instead of using the word "mental", were effective in dispelling negative connotations (Parkes & Gilbert, 2010). A service evaluation of the Croydon Memory Service Model (Banerjee, Willis & Matthews, 2007) which focused on early intervention and generated links at local places of worship, found this an effective method of identifying and improving care for persons with mild to moderate dementia. The referral rates for BME people in to the dementia services reflected their distribution in the population as a whole. In contrast, a study in Kent presented limited success when engaging with religious communities: a meeting attended by 400 people at a local Gurdwara resulted in just one referral to a specialist dementia service (Seabrooke & Milne, 2009). Better referral results were obtained when GPs invited congregation members to come for a memory problems consultation and then offered to make a referral to the service (Seabrooke & Milne, 2009).

This demonstrates the complexity of this issue and the sensitivity needed towards different faiths, geographical regions and outreach approaches.

2.5. UK Dementia Reports, Policy and Guidelines

National Reports, Policies and Guidelines addressing dementia issues, mental health provision, older adults and BME concerns have been published by Government departments, charities and educational institutions such as the following: Department of Health (DoH), Department of Work and Pensions (DWP), Department of Legislation

(DoL), All-Party Parliamentary Group on Dementia (APPGD), Alzheimer's Society (AS), Care Quality Commission (CQC), Dementia Action Alliance (DAA), National Institute for Clinical Excellence (NICE), Office of the Deputy Prime Minister (ODPM), Care Services Improvement Partnership (CSIP), Social Care Institute for Excellence (SCIE), National Institute for Mental Health in England (NIMHE), King's Fund (KF), Age UK, National Audit Office (NAO), Audit Commission (AC), Royal College of Psychiatrists (RCP), Kings College London (KCL) and London School of Economics (LSE).

Document Number	Publishing Body	Year	Report
1	APPGD	2013	*Dementia does not discriminate: The experiences of* Black*, Asian and minority ethnic communities*
2	AS	2013	*Dementia 2013: The Hidden Voice of Loneliness*
3	DoH	2012	*Delivering major improvements in dementia care and research by 2015: A report of progress*
4	DoH	2012	*Dementia 2012: Prime Minister's Challenge on Dementia - Delivering major improvements in dementia care and research by 2015**
5	DoH	2011	*No Health without Mental Health*
6	DoH	2011	*National Dementia Strategy: Equalities Action Plan*
7	DoH	2011	*Living well with dementia: a National Dementia Strategy – good practice compendium*
8	DAA	2010	*National Dementia Declaration National Dementia for England: A call to Action*
9	DoH	2010	*Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy*
10	DoH	2010	*Equity and Excellence: Liberating the NHS*
11	DoL	2010	*Equality Act* (replacing the *Race Relations Act* 1976)
12	RCP	2009	*Psychiatric services for* Black *and minority ethnic older people (CR156)*
13	DoH	2009	*The use of anti-psychotic medication for people with dementia: Time to act*
14	DoH	2009	*Living Well with Dementia: A National Dementia Strategy*

15	CQC	2005, 2006, 2007, 2008, 2009	*Count Me In Census*
16	KF	2008	*Paying the price: The cost of mental health care in England to 2026*
17	NICE-SCIE	2001 & 2007	*NICE guidelines for cholinesterase inhibitors*
18	NICE-SCIE	2006	*NICE guidelines for dementia*
19	NAO	2007	*Improving services and support for people with dementia*
20	KCL & LSE	2007	*Dementia UK Report**
21	DoH	2006	*A new ambition for old age: next steps in implementing the NSF for older people*
22	ODPM	2006	*A sure start to later life: ending inequalities for older people*
23	Age UK	2006	*Promoting mental health and wellbeing in later life*
24	DoH	2005	*Making it possible: improving mental health and wellbeing in England*
25	DoH	2005	*Securing better mental health as part of active ageing*
26	CSIP	2005	*Everybody's business – integrated mental health services for older adults: a service development guide*
27	DWP	2005	*Opportunity age – meeting the challenge of ageing in the 21st century*
28	DoH	2005	*Delivering Race Equality in Mental Health Care*
29	DoH	2004	*National service framework for mental health – five years on*
30	NIMHE	2003	*Inside Outside: Improving mental health services for* Black *and minority ethnic communities in England*
31	AC	2000 2002 (revision)	*Forget Me Not: Developing Mental Health Services for Older People in England*
32	DoH	2001	National Service Framework (NSF) for older people

| 33 | DoH | 1999 | National Service Framework (NSF) for mental health |

*publication by the Alzheimer's Society (AS), commissioned by the

publishing body.

Table 7: Main national reports on dementia, mental health, older adults and BME issues

These (33) reports are not an exhaustive account but reflect the main

publications and fall in to six main categories: 1. Dementia, 2. Mental

Health, 3. BME, 4. BME & Mental Health, 5. Older Adult and 6. Older

Adult Mental Health. The most recent report (APPGD, 2013) was the only

one identified with a specific, exclusive focus on dementia in BME groups.

Some of the older adult and mental health reports do not address BME

groups at all and when they do, the discussion is not comprehensive.

There is a paucity of national literature directly addressing the

complexities of the underrepresentation of BME persons with dementia in

to MHSCS. Publication of a separate policy may not be required, but a

thorough consideration of care issues for BME persons with dementia is

required to investigate whether dementia care for BME elders should be

specialist or inclusive within existing dementia care policy. The *NDS*

(Department of Health, 2009a) suggests a single care pathway in to

dementia care services [see Chapter 1, p.49]. The influence of additional

pathways in to care, not considered in the NDS, for these

underrepresented groups requires empirical research.

Category	Document Number
Dementia	2, 3, 4, 6, 7, 8, 9, 13, 14, 17, 18, 19, 20
Mental Health	5, 16, 24, 29, 33
BME	10, 11, 22, 29
BME & Mental Health	12, 15, 28, 30
Older Adult	21, 22, 27, 32
Older Adult & Mental Health	23, 25, 26, 31
BME & Dementia	1

Table 8: Categorisation of the main national reports on dementia, mental health, older adult and BME issues

I critically examined the reports in two chronological phases: firstly, documents published before the *NDS* (Department of Health, 2009a) and secondly, documents published post-*NDS*. I focus on documents considered central in terms of impact, with reference to supportive materials. Documents post-2009 began to recognise the potential impact of religion and the impact on dementia care.

2.5.1.   *Reports, Policies and Guidelines (1999-2009)*

The National Service Framework for Mental Health (Department of Health, 1999) was one of the first government policies to recognise inequalities in healthcare provision for working adults aged 18-65. The Department of Health developed the *National Service Framework for Older People* in 2001. One of the key principles (standard seven) promotes adequate mental health provision for persons from BME communities. Current clinical assessments were deemed "culturally biased" (Department of Health, 2001, Standard 7) and thus did not meet

the needs of older BME persons. Analysis of older adults' mental health services assert that BME older adults do not request specific services, but require appropriate adaptation of existing services (Audit Commission, 2002). Whilst highlighting the importance of this issue, no practical recommendations were given in these reports.

Forget me not (Audit commission 2000; Audit commission, 2002) offered an analysis of mental health services for older people in England and Wales. There are several references to BME needs throughout the document and it was recommended that MHSCS, "develop services which are acceptable and appropriate for people from Black and minority ethnic communities" (Audit commission, 2002, p.38). It further reiterated BME persons may not require the development of new services, but appropriate adaptation of existing services, for food, language and religious practices. Similarly, there are no tangible recommendations for improving care specifically for BME populations, other than the generic suggestion to provide informative literature in appropriate language formats (Audit commission, 2002, p.48).

The *Inside Outside* report (NIMHE, 2003) was one of first to address inequalities inside and outside of mental health services for BME groups in detail, in order to develop a culturally capable service, set standards to improve access, improve the care experience and outcome and to enhance the cultural relevance of research and development. The report highlighted key components to be part of this strategy to overcome inequality (Adelman, 2010).

The *Count Me In* Census (Care Quality Commission, 2007) - a survey of all mental health and intellectual disability wards in England and Wales, identified 22% of the patients were from BME backgrounds. The *Delivering Race Equality in Mental Health Care* strategy (Department of Health, 2005a) recognised the mental health needs of persons from BME backgrounds must be accommodated for in the UK care provision. In *Delivering Race Equality in Mental Health Care* (Department of Health, 2005a), religious and cultural beliefs and practices are recognised as important factors when ensuring BME individuals do not "fall between" service gaps. There are a series of reports, policies and guidelines which directly address this issue in a bid to improve care provision (Royal College of Psychiatrists, 2009, p.12-25).

2.5.2. *Delivering Race Equality in Mental Health Care (Department of Health, 2005a)*

This document combines a five-year action plan for reducing inequalities for BME persons accessing and experiencing mental health services, with Government recommendations made as a response to the inquiry of David Bennett, a 38 year old African-Caribbean man who died in a medium secure psychiatric unit following staff restraint.   The policy aims to work with communities in developing services such as the recruitment of new Community Development Workers (CDWs) and better dissemination of information about services.

There is a section dedicated to older adults with two points specifically for dementia. One of these points addresses the dementia needs of BME

persons - section 3.81 refers to standard 7 of *The National Service Framework for Older People* (*NSF*) (Department of Health, 2001) which requires Primary Care Trusts to ensure that every general practice implements a protocol for caring for persons with depression or dementia. This protocol should accommodate "BME age-specific expertise to help them develop services that are responsive and appropriate to the needs of older people from BME communities and gives details of plans to work with BME specific organisations, such as Policy Research Institute on Ageing and Ethnicity (PRIAE), Age Concern and the Alzheimer's Society with the aim to improve care for BME persons with dementia and their carers (section 3.82). In addition, this policy recommends commissioning within NHS trusts should ensure that data on ethnicity, religion, language and gender should be captured in order to adequately identify patients' needs (section 3.126). This influenced the *Count Me In* Census by the Care Quality Commission (CQC) which aimed to capture and record the diversity of patients in mental health services (CQC, 2005, 2006, 2007, 2008, 2009).

2.5.3. NICE guidelines for dementia (NICE-SCIE, 2006)

The *NICE guidelines for dementia* (NICE-SCIE, 2006, p.11) stated in one of the key principles (1.1.1.3), that the needs and preferences of individuals with dementia relating to diversity must be identified and accommodated, where possible. There is Government recognition that existing clinical provision may be culturally biased (Department of Health, 2001). Improved comprehension of BME religious beliefs and practices is

vital to ensure that all persons with dementia who require care receive adequate service provision (RCP, 2009).

2.5.4.   NICE guidelines for cholinesterase inhibitors (NICE-SCIE, 2007)

The *NICE guidelines for cholinesterase inhibitors in dementia* (NICE-SCIE, 2007) states in one of the key principles (1.1.1.3), that the needs and preferences of individuals with dementia relating to diversity must be identified and accommodated with a focus on diversity and providing person centred care (NICE-SCIE, 2007, p.12).

2.5.5.   Reports, Policies and Guidelines (2009 – present)

2.5.6.   Living Well with Dementia: National Dementia Strategy (NDS) (Department of Health, 2009a)

The *NDS* aimed to achieve better awareness of dementia, encourage early diagnosis of cognitive impairment and improve the quality of living with dementia (Department of Health, 2009a). This involved a bid to address inequalities in dementia care, provide support and direction for health and social care commissioners and generate guidelines for planning, implementation and monitoring of services. The *NDS* aims to offer "world class commissioning guidance for dementia" (Department of Health, 2009a, p.75) securing better quality of life for persons with dementia and their families.

Whilst describing itself as "a comprehensive strategy" (Department of Health, 2009a, p.7) aiming to "transcend existing boundaries"

(Department of Health, 2009a, p.7), reduce the stigma associated with dementia, and address health inequalities - despite publishing images of persons from BME communities in the document - the NDS does not explicitly address issues of dementia in the context of BME communities, ethnicity, religion, or race. When stigma is discussed, it is referenced in a generic sense relating to the overall population. For example, "50% of the public believe that there is a stigma attached to dementia" (Department of Health, 2009a, p.27). In contrast, a later publication, *The National Dementia Strategy: Equalities Action Plan* (Department of Health, 2011a) does account for the potential of religion as a link to services, whilst recognising the paucity of data in this area. It is unclear if religion in this context relates to BME groups or to the ethnic majority, or to religious services across all persons with dementia.

2.5.7. The use of anti-psychotic medication for people with dementia: Time to act (Department of Health, 2009b)

The *NDS* was followed by the publication of a report addressing the over-prescription of antipsychotic medication and a drive towards reducing antipsychotics for persons with dementia. This demonstrates a positive shift towards the psycho-social aspects of dementia care and "non-pharmacological methods of treating behavioural problems in dementia" (Department of Health, 2009b, p.41). This potentially generates a channel for a dialogue regarding additional care services such as through religion.

2.5.8.   Quality outcomes for people with dementia: Building on the

work of the National Dementia Strategy (Department of Health,

2010a)

In response to *Equity and Excellence: Liberating the NHS* (Department of

Health, 2010b), separate frameworks with clearer objectives were

implemented to diffuse ambiguity, improve collaboration and

accountability between NHS, public health and social care services

(Department of Health, 2010a, p.11). These four priority objectives are

as follows:

o Good-quality early diagnosis and intervention for all.

o Improved quality of care in general hospitals.

o Living well with dementia in care homes.

o Reduced use of antipsychotic medication.

This inclusive ethos is commendable, but does not explicitly address BME

groups, race, religion, ethnicity, or culture.

2.5.9.   National Dementia Declaration for England: A call to Action

(Dementia Action Alliance, 2010)

This report is a publication from the Dementia Action Alliance, a

community of organisations working together to improve dementia care

provision, including but not limited to the following: Local Government

groups, Mental Health Association, Age UK, Skills for Health, Dementia

UK, University of Worcester, BUPA, Stroke Association, Royal College of

Psychiatrists, University of Bradford, Alzheimer's society, Mental Health

Foundation. The primary aim is as follows: "In 2011 the DAA will seek

support from partners in civic organisations, businesses and professionals to deliver dementia supportive communities" (Dementia Action Alliance, 2010, p.2).

The seven declarations discussed in the report overlap with many of policies in the *NDS* (Department of Health, 2009a). These are as follows: "1. I have personal choice and control or influences over decisions about me. 2. I know that services are designed around me and my needs. 3. I have support that helps me live my life. 4. I have the knowledge and know-how to get what I need. 5. I live in an enabling and supportive environment and I feel valued and understood. 6. I have a sense of belonging and of being a valued part of family, community and civic life. 7. I know there is research going on which delivers a better life for me now and hope for the future" (Dementia Action Alliance, 2010, p.4-p.5).

2.5.10.   No Health without Mental Health (NHWMH) (Department of Health, 2011b)

The strategy in this report aims to promote the Government's objective to achieve parity between physical and mental health, in accordance with the *Health and Social Care Bill* (Department of Health, 2011c) which purports mental health problems should be treated with the same gravity as physical health problems. This is creditable in that there are sections dedicated to the mental health needs of older adults, "Improving the quality of care for people with dementia and their carers is a major priority for the Government" (Department of Health, 2011b, section 6.16). The specific mental health needs of BME persons are also

addressed. Whilst there is no discussion of BME persons with dementia, there is an explicit section on religion and belief:

"If positive outcomes are to be achieved, services will need to incorporate religion and belief into the assessment of individuals. Local services will achieve better outcomes if they make resources and facilities available for people to express their religion or belief" (Department of Health, 2011b, section 6.37).

This is an excellent starting point to highlight the potential influence of religion on mental health during diagnostic assessment. There could be further consideration about how religion may be used positively during recovery and treatment. NHWMH does provide a thorough discussion on how religion influences inequalities across four main ways in mental health services and accounts for religion in BME communities (Department of Health, 2011b, section 6.36). These are as follows:

"[1.] The relationship with other aspects of identity (for some cultures ethnicity and religion are virtually inseparable). Service data shows that more people from BME backgrounds identify themselves as religious. By failing to address religion, services disproportionately affect people from BME backgrounds.

[2.] Potential for people who hold religious or other beliefs to have poorer experiences of services because core aspects of their identity are overlooked or they have no means of religious expression (for example, prayer rooms). This may cause anxiety and prove detrimental to their recovery.

[3.] Evidence indicates that religion may be protective, particularly in relation to suicide.

[4.] The role of religion or belief in peoples' explanations for their mental health problems – different conceptualisations and language between an individual and services will affect engagement and success of treatment and care".

The inability to "address religion" by service providers offers an explanation for underrepresentation to services by BME persons. Highlighting this issue raises the status of "religion" as a factor warranting further investigation. This is positive in that it focuses on religion's multi-faceted influence on dementia care and inequalities experienced. Conversely, the role of religion is portrayed as a negative influence, as detrimental to recovery; more discussion on the potentially therapeutic benefits of religion is required. Religion is discussed in the context of MHSCS, without reference to external religious communities or institutions and their role on mental health. The discussion is expansive and does not account for nuances between different religions or how religion may be experienced by the individual, nor how religion may be used in a practical sense to improve care services.

2.5.11.   *Living well with dementia: a National Dementia Strategy – good practice compendium (Department of Health, 2011d)*

This compendium documents good practice in regions of the UK based on the objectives from the *NDS*. The regions discussed are East Midlands, East of England, London, North East, North West, South East, South West, West Midlands, Yorkshire and Humberside. The West Midlands

region focuses on assistive technology and domiciliary care (Department of Health, 2011d, p.112). Wolverhampton City Council recognises the need for improving and sustaining the quality of care for people across the city and has developed a dementia strategy plan addressing the four primary objectives in the NDS to improve community personal support, to improve the experience of living in a care home, to develop an informed and effective workforce and to develop good quality housing and telecare opportunities as well as discussion around education and training.

The benefits of this report are it emphasises innovative ways of engaging with communities but it does not discuss ethnicity, race, or religion. There is no reference to the mixed cultural demographic comprised in the West Midlands, [see Chapter 1, p.32] nor does it discuss how the needs of these minority cultures may be best served.

2.5.12. *National Dementia Strategy: Equalities Action Plan (Department of Health, 2011a)*

This report considers equality issues from the *NDS* (Department of Health, 2009a) such as learning difficulties, race, age, sexual orientation, religion, or belief. There is a section on "Race" which makes explicit reference to South Asian and Black Caribbean populations whilst acknowledging the gaping omissions of data in this research field for these two minority groups (Department of Health, 2011e, p.7). Reasons given for not accessing services are a lack of awareness of services and a lack of belief that things can be done to help with dementia. There is

recognition that, "at present there is a general lack of data available on religion in relation to people with dementia, although religion is of course closely associated with the cultural and ethnic differences described in the section on race above" (Department of Health, 2011e, p.8). The recognition that religion could play a vital role in connecting individuals and MHSCS is highlighted in this report, based on feedback from a consultation to the NDS:

"religion can play an important part in the lives of people with dementia and religious organisations may be able to provide a *link* between individuals and health and social care services" (Department of Health, 2011e, p.8).

This acknowledges religion can be a positive resource in the dementia care picture. Religion is addressed generically without acknowledgement of the role of religion in minority communities. This is however, a great starting point to explore how religion may be able to provide this "link" in future research, and how this may help to identify underrepresented persons with dementia in BME communities. Additionally, it allows the negative influence of religion as potentially hindering access to dementia care services, to be explored in more depth.

2.5.13.   Dementia 2012: Prime Minister's Challenge on Dementia

(Dementia 2012) (Alzheimer's Society, 2012)

In March 2012, the UK Prime Minister, David Cameron launched a programme of work building on the *NDS* (Department of Health, 2009a) recognising dementia as one of the major challenges faced by an ageing population and for the UK to be a "world leader in dementia care and research" (Alzheimer's Society, 2012, p.5) . An increase in the dementia budget to £66million by 2015 was postulated in response to the recognition of dementia as, "undoubtedly one of the major health and social care issues of our time. Until recently it was also one of the most ignored. The National Dementia Strategy has made a good start in addressing the needs of people with dementia, but we need to make more rapid progress" (Alzheimer's Society, 2012, p.19). The Dementia Commissioning pack was launched in July 2011 by the Department of Health to guide NHS commissioners in getting best possible outcomes for people with dementia. The challenge addresses three main areas:

Raising Awareness

Quality Research

Quality Care

Champion groups for each objective will be developed with the primary focus on improving community support, most notably through the development of a "forget-me-not" symbol and implementation of the "dementia friends" strategy (Alzheimer's Society, 2012, p.10). This scheme, influenced by work in Japan aims to implement one million persons by 2015 with dementia awareness, who can support and signpost persons with dementia to appropriate services. The Prime Minister's assertion that by 2015 everyone will be able to say: "I know what I can do to help myself and who else can help me. My community is working to help me to live well with dementia" (Alzheimer's Society, 2012, p.19) is positive and pragmatic. In this report, the discussion of "community" is generic without reference to how this implementation could differ outside of the ethnic majority.

The empirical literature discussed earlier in this literature review highlighted the underrepresentation of particular cultural groups and demonstrated the need to research how minority ethnic and religious communities require support for dementia care. There is no acknowledgement in *Dementia 2012* of the possibility of BME communities functioning in a different way than the ethnic majority, nor is there recognition of peer-support in different forms, i.e. through religious communities. There is a focus on improving diagnosis, improving care, improving care home standards, improving hospital beds, better information, better support for carers, dementia friendly communities and better research – but there is no mention of religion or cultural issues, nor of using religious communities as a resource.

2.5.14.   Delivering major improvements in dementia care and

research by 2015: A report of progress (Department of Health, 2012)

This report documents the improvements seven months after *Dementia*
2012 (Alzheimer's Society, 2012) was published. There are champion
groups for each of the three targeted areas. There are specific references
to projects involving faith communities in the Dementia Friendly
Communities Champion Group (Department of Health, 2012, p.2). There
have been discussions with inter-faith groups regarding progression
towards improving dementia care in January 2013, "This means creating
local Dementia Action Alliances to bring together community leaders
alongside people with dementia and their carers to identify the changes
and action needed to make their community dementia friendly"
(Department of Health, 2012, p.4). These "community leaders" could be
representatives from the religious communities and this work is a positive
first step towards religious outreach in dementia care.

2.5.15.   Dementia 2013: The Hidden Voice of Loneliness (Dementia

2013) (Alzheimer's Society, 2013c)

Alzheimer's Society and Dementia Action Alliance collated the results of
510 surveys distributed to persons with dementia in the UK and
highlights the isolation experienced by people with dementia in the
community. Whilst this is an increase on the sample size for *Dementia*
2012 (Alzheimer's Society, 2012), there are no details provided about the
ethnicity of the sample. It is acknowledged that the sample may not be
representative of the UK picture as it reflects the views of those persons

already accessing care services. The report documents 63 per cent of people with dementia said they were "able to make choices about their day-to-day life", 28 per cent of people with dementia said they were "not able to make choices about their day to day life" and 7 per cent said they "did not know" (Alzheimer's Society, 2013b, Appendix 1). There is one reference to persons from BME communities potentially experiencing lower diagnosis rates and lower awareness of dementia than the ethnic majority (Alzheimer's Society, 2013c, p.19), but this is not discussed comprehensively. Importantly, it raises the issue that much of the current information on dementia is in electronic format, reflecting the Government's "digital by default" strategy (Cabinet office, 2012) and that a shift from e-communication is necessary; 87 per cent of people who completed the survey did not communicate with friends and family electronically (Alzheimer's Society, 2013b, p.32).

2.5.16.   *Dementia does not discriminate: The experiences of* Black*, Asian and minority ethnic communities (All-Party Parliamentary Group on Dementia (APPGD), 2013)*

This is the only report identified which addresses dementia specifically in ethnic minority groups. It highlights the issue regarding the paucity of data on the "incidences of dementia in different ethnic groups" (APPGD, 2013, p.18). Cultural issues such as language (APPGD, 2013, p.25) stigma (APPGD, 2013, p.26) and the impact of stigma on awareness levels are discussed (APPGD, 2013, p.27). The impact of these issues on access to services is considered, in addition to the lack of culturally sensitive services (APPGD, 2013, p.31). However, the focus is on culture,

and religion is not considered explicitly within this report. There is reference to "myths and misconceptions about dementia" (APPGD, 2013, p.27) where "Jinns" are alluded to in the Black Caribbean population; but this is not discussed in depth, nor is an adequate consideration given of the importance of religious beliefs and the impact on dementia care access.

2.5.17.   *Reports Summary*

Following this policy review, I assert there has been progress on the historical approach to tackling the issues of dementia. Recent reports are beginning to recognise inequalities in mental health care for non-majority cultures and the specific impact of dementia in BME communities. In contrast, the consideration of BME persons within National dementia reports is currently minimal. It has been identified that BME persons with dementia may not require new services, but simply an adaptation of existing services. Yet, full discussion of this is synthesised into existing reports with no full focus on how to meet these needs within the *NDS* (Department of Health, 2009a) or *Dementia 2012* (Alzheimer's Society, 2012). Historically, the focus has been on "cultural" issues as the cause of barriers for BME groups into health services. The consideration of religion's role on accessing mental health and dementia services is very recent, with Government policy just starting to recognise the influence religion may exert on practical decisions about dementia care, and satisfaction with dementia care, as a distinct factor to culture. Further research in to religion and dementia care is required to inform future policy.

2.6. **Chapter Summary**

There is a paucity of empirical data examining the impact of religion on dementia care access for BME persons with dementia. The data which does exist focuses on the Christian faith. Barriers to dementia care have been identified in cultural research; for example difficulty communicating, low knowledge of dementia, low awareness of services, stigma surrounding mental illness. Closer examination of some of the identified "cultural" themes, require reclassification as "religious" specific themes. Re-classification of barriers allows a more focused investigation of BME underrepresentation. In addition, the religious texts of the Muslim, Sikh and Hindu faiths arguably make no explicit reference to dementia. National reports and policies are recently beginning to recognise the potential impact that religion plays on the dementia care experience for BME persons with dementia, yet this impact is not fully explored. Investigating the specific impact of religion on dementia care for BME persons is vital for improving understanding of how best to provide services.

Chapter three discusses how the researcher intended to gain insight into this challenge empirically, guided by the following research questions:

2.7. Study Aims and Objectives

Aims

o   How do South Asian religious beliefs and practices influence:

-      Attitudes and perceptions of dementia?

-      The decision to seek dementia care?

-      The provision of dementia care?

-      The satisfaction with existing dementia care services?

o   Does existing dementia care provision sufficiently cater for South Asian individuals in terms of their religious beliefs and practices?

o   How might South Asian religious beliefs and practices create barriers to accessing UK dementia health and social care services?

Objectives

o   To investigate the perceptions, attitudes and experiences of persons with dementia of South Asian origin, carers of persons with dementia of South Asian origin, healthcare and dementia organisation professionals and South Asian religious leaders.

o   To synthesise and analyse these responses in order to identify areas of success and deficiency in the current dementia care provision.

o   To make recommendations for improvement to dementia care services for South Asian individuals with dementia.

3. Chapter Three: Methodology and Method

3.1. Chapter Aim

The purpose of this chapter is to clarify the ontological and epistemological approach informing the methodological position of the research study. The subsequent method in terms of data collection and data analysis, sampling and recruitment, informed consent and ethical procedures are critically presented as a best fit for the defined methodological approach. The importance of quality qualitative research is discussed and the quality criteria employed for the study is presented.

3.2. Epistemology, Ontology and Methodology

It is imperative to clarify, "the interrelationship between what a researcher thinks can be researched (their ontological position), linking it to what we can know about it (their epistemological position) and how to go about acquiring it (their methodological approach)" (Grix, 2002, p.180). The researcher's ontological stance, epistemological position and subsequent methodological approach will now be examined, "ontology logically precedes epistemology which logically precedes methodology" (Hay, 2002, p.5).

3.2.1. Why a Qualitative Approach?

The study is a Critical Realist Grounded Theory (Strauss & Corbin, 1990; Strauss & Corbin, 1998) study implementing semi-structured interviews and observations in a qualitative research framework. The methodological stance for the study is rooted in a Critical Realist Grounded Theory

ontological and epistemological position. A qualitative stance, allowing an exploratory approach to data collection was adopted as the best fit for the study. The literature review highlighted the paucity of existing research exploring the influence of religion on South Asian dementia access and experience. Thus, to generate a quantitatively testable hypothesis based on these limited data would be driven by conjecture, not empiricism.

3.2.2. Ontological Position

A critical realist ontological position asserts objective truths exist in reality (Strauss & Corbin, 1990). A study from this stance aims to capture objective truth in the data.

3.2.3. Epistemological Position

Attainment of said objective truths is influenced by "the interplay between subject and object" (Crotty, 1998, p.9). Both researcher and researchee have a symbiotic influence on data generation and both parties co-construct the emergent findings. These data may be interpreted differently by different persons, but should not detract from the inherent objective truths within the data itself. The resultant theory is abstract enough for generalisation within certain parameters and limitations (Strauss & Corbin, 1998).

3.2.4. Methodological Position

Following the ontological position, some reflexive analysis is essential to consider the potential anthropomorphic influence on data interpretation by the researcher to limit subjectivity and aim for objective truth (Strauss & Corbin, 1990; Hughes & Sharrock, 1997). Reflexivity is how "researchers reflect about how their biases, values, and personal background, such as gender, history, culture and socioeconomic status, shape their interpretations formed during a study" (Creswell, 2009, p.233). Following the epistemological position, the researcher will account for the limitations of the research study and clarify where, how and why the resultant theory can be generalised.

3.2.5. Grounded Theory Methodology

Historically and methodologically, Critical Realist adopts a "mid-position" in the Grounded Theory approach. It differs from a traditional or "Classic", Realist Grounded Theory (Glaser & Strauss, 1965; Glaser & Strauss, 1967) positivist ontology, which asserts the epistemological position that objective truths are attainable and the discovery of objective truth is not influenced by the researcher. Thus, no reflexive commentary throughout data collection and analysis is required. Furthermore, generalisation of findings is achievable. Critical realist contrasts with the most recent Social Constructivist (Charmaz, 2006) model, which is anti-foundationalist in ontological approach (Marsh & Furlong, 2002); namely, truths are solely constructed by the researcher's interpretation of the environment. The generated theory depends entirely

on the researcher's perspective (Charmaz, 2006, p.130). Thus, a full reflexive analysis is required at every stage of the research process and the resultant theory is ultimately substantive. It is important to consider the research parameters when selecting the most suitable GT approach. Classic GT was established and implemented in Glaser & Strauss' (1965) seminal text, *Awareness of Dying* which documented a longitudinal study of hospice patients, with two active researchers often residing in the hospice premises, utilising a range of research methods, observations, interviews, in a longitudinal study spanning years. This epidemiological approach was systematic, thorough and rigorous, enabling positivist ontology. This led to the generation of GT as providing a framework of "systematic methodological strategies" for the capturing of objective truths in both qualitative and quantitative research (Glaser & Strauss, 1967). Studies with a limited timeframe and resources are more suited to a Critical Realist or Social Constructivist methodology utilising a qualitative methodology.

3.2.6.   Why Critical Realist?

A Critical Realist methodology (Strauss & Corbin, 1990) was adopted as the best fit within the parameters of available resources for the study. A positivist stance was not adopted due to the project being conducted by a single researcher in an allocated time frame. In *Awareness of Dying* (1965), Glaser & Strauss conducted an in-depth, range of qualitative methods in an epidemiological structure with a team of researchers over an extended time frame. This allowed subjective bias to be eliminated and objective truth attainment possible. A Social Constructivist approach

may have been suitable if the project was utilising a single data collection method within a short time period, but was considered incompatible for the present study because the time frame and resources were sufficient to utilise the GT Constant Comparison method (Glaser & Strauss, 1978) of iterative data collection and data analysis over three phrases with different participants. Data was collected through diverse-methods which allowed objective truths to be captured and considered within the parameters of some researcher influence.

3.2.7. The abductive logic of GT

It is important to consider the logical approach informing the ontological stance of the Grounded Theory method. Understanding the fusion of *a posteriori* and *a priori* investigation is useful to clarify the subsequent choice of research methods, to ensure rigour and aim to attain objective truth in the data. The iterative evolution of theory generation in GT marks it as unique in qualitative research methods (Bryant & Charmaz, 2010, p.229). The epistemological approach of GT - which utilises *inductive* and *deductive* logic - has been labelled as an *abductive* (Peirce, 1958) method (Bryant & Charmaz, 2010, p 229). In contrast to the *deductive* platform on which positivist research traditionally stands, GT begins from an *inductive* approach (Reichertz, 2010, p.214; Kelle, 2005) reflecting a "Baconian" epistemology (Haig, 1995). In the later stages of GT, the method becomes more *deductive*: "*adbuctive* reasoning starts with the data and subsequently moves toward hypothesis formation" (Charmaz, 2006). As the theory nears theoretical saturation, so the logic employed shifts as analysis becomes more focused, "*adbuctive* inference

entails considering all possible theoretical explanations for the data, forming hypotheses for each possible explanation, checking them empirically by examining data, and pursuing the most plausible explanation" (Charmaz, 2006, p.104). After examining data, a logical inference is made which offers a theoretical interpretation of the relationships and then the researcher returns to test this in the field: "I see grounded theory as a combination of *inductive* and, to some extent, *deductive* work, I wouldn't say we are exactly testing theory, depending what you mean by testing, but we are testing our hunches" (Hood, 1983, cited in Charmaz, 2006, p.103). "Hunches" are a term in the GT literature referring to the grasp the researcher has in relation to the emerging data, which informs the next phase of data collection and theory development. Theoretical Saturation is an example of the *deductive* reasoning which allows "definition of properties of a category, check hunches about categories, saturate properties of a category, distinguish between categories, clarify relationships between emerging categories, identify variation in a process" (Hood, 1983, cited in Charmaz, 2006, p.104). Strauss stated (in Bryant & Charmaz, 2010, p.231) "that this knowledge is nurtured by experience, but can also derive from theoretical pre-knowledge". The *abductive* label of GT is challenged by Reichertz (2009) who proposes that the logic of GT methodology employed in studies from the 1980s onwards is not actually *adbuctive*. It is beyond the scope of the present study to discuss Reichertz's claim in depth. For the purposes of this study, the researcher subscribes to the *abductive* GT approach.

3.2.8. Why Grounded Theory?

The rationale for GT as the best fit for the present study above other qualitative methods is as follows. GT aims to present a conceptual model based on theory generated from the whole dataset. Firstly, alternative qualitative methods, for example, Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009; Smith, 1996) and Content Analysis (CA) (Berelson, 1952) do not aim for this. The generation of a holistic model permits more robust recommendations for healthcare practice. Secondly, the positivist underpinnings allow the GT conceptual model to be generalised to wider or specific populations. IPA and CA often focus on a small dataset, which is important to gain a depth of understanding of a very specific phenomenon, but may not allow for wider generalisability. Thirdly, the *tabula rasa* approach in GT is exploratory and aims for a purist theory uncontaminated by existing data. Thus, it is suitable for research areas where there is a paucity of data. The literature review for the present study demonstrated the low number of research papers dedicated to the phenomenon of religion and South Asian dementia care. Whereas, GT does not begin from pre-conceived categories, CA aims to fit data into existing identified categories. The low number of research papers meant these categories were not identifiable in this research field. GT aims to generate new categories. Fourthly, the holistic approach in GT applies to groups of participants. Whilst the IPA method can be utilised for up to groups of 15 people (Smith, 1996), it primarily aims to understand a phenomenon from the perspective of an individual. For the present study, it was important to understand the dementia care experience from a broad

perspective, in order to make more rigorous healthcare recommendations, whilst still accounting for the perspective of the individual. The GT methodology allows a range of methods to be implemented to attain depth and breadth of data collection.

3.2.9.   Grounded Theory Method

GT does not subscribe to one prescribed method; rather, it provides a framework for theory generation based on an iterative, systematic approach to data collection and data analysis known as the Constant Comparison method (Charmaz, 2006). Methods employed in GT Health studies often utilise semi-structured interviews (Tove & Cone, 2012; Mottram, 2011), or a combination of methods such as observations and interviews, reflecting a multi-methods approach (Glaser & Strauss, 1965) The term mixed-methods is avoided as this describes research utilising both qualitative and quantitative data collection methods. There is a distinction between mixed methods which employs quantitative and qualitative data types in a single study (Andrew & Halcombe, 2009) and multi method research, which implements more than one method in either a qualitative or quantitative tradition (Bazeley, 2007). Thus, the methods for conducting a GT study are flexible, but must adhere to the following criteria: Appropriate participant sampling, justified method for data collection, data analysis, further data collection and analysis to identify theoretically weak areas of the model through Negative Case Analysis (NCA) (Morse, 1994), and strengthen identified concepts through Theoretical Saturation (Charmaz, 2006), and a final theoretical model.

Grounded Theory Principles	
Constant Comparison	Iterative data collection and analysis focusing on similarities and differences in the data to capture the reality of the phenomenon in the evolving theory
Theoretical Sampling	Targeted sampling strategy allowing further data collection aiming to confirm or challenge themes within the emergent theory
Theoretical Saturation	No new (sub) categories are emerging in data.
Negative Case Analysis	Identification of instances that do not fit the emerging theory. Akin to "outliers" in quantitative research (Bryant & Charmaz, 2010, p.241)
Theory Generation	Ultimate aim of GT Research. Resultant Theory informs conceptual model.

Table 9: Key Principles in GT Method (based on Charmaz, 2006)

3.3.   Method

3.3.1.   Data Collection and Data Analysis

The Constant Comparison method employed three data collection phases, each followed by a data analysis phase. This allowed the researcher time to "reflect and carry (his) thinking to its most logical (grounded in the data, not speculative) conclusions" (Glaser & Strauss, 1978, p.107). Each data collection phase (DCP) and data analysis phase (DAP) aimed to generate theoretical information which contributed to the overall grounded theory: DCP 1 was exploratory, with no preconceived

expectations about emerging theoretical categories. DCP 2 was purposeful towards identified categories and open to new emerging categories. DCP 3 focused on the strongest identified categories without dismissing new categories. DAP 1 explored the theory, DAP 2 defined the theory in to a model, DAP 3 consolidated the theory identified in DAP 2.
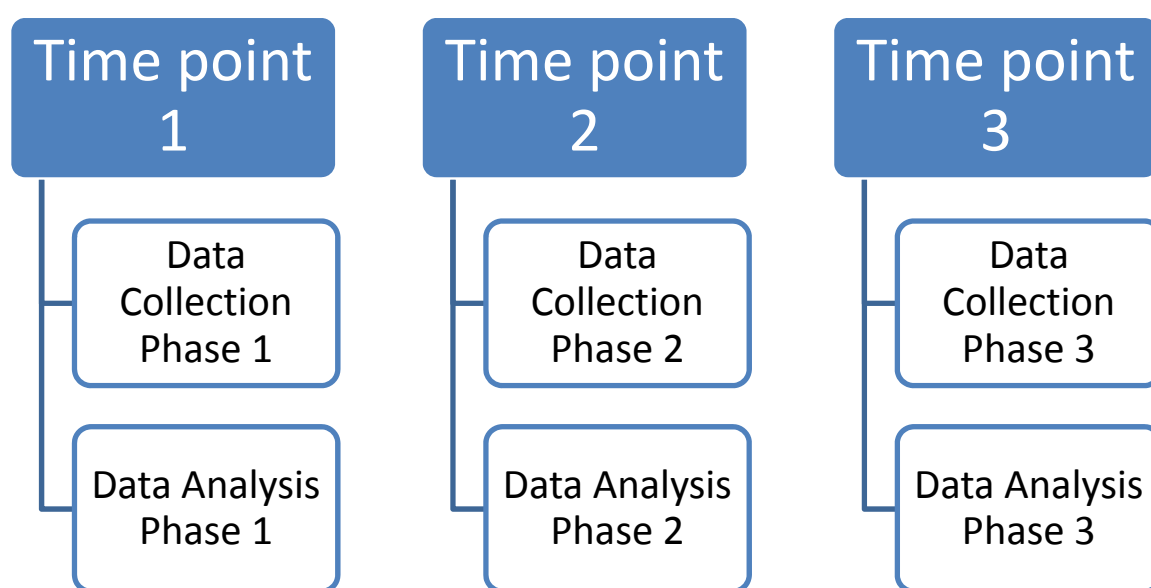
Figure 8: The three Data Collection Phases and three Data Analysis Phases.

3.3.2. Data Collection Methods

This Grounded Theory study was based on the following data sources across three phases. These were semi-structured interviews, formal observations and informal meetings and discussions. All the data methods were used to build the grounded theory. The data from formal interviews were used as the main source for generating theory development. This was supplemented with data from the formal and informal observations and discussions.

	Data Type		Details	Volume
1.	Semi-structured interview: one-to-one		N=17	17
2.	Semi-structured interview: one-to-two		N=4	2
3.	Formal Observation (#1)	Sikh Gurdwara attendance		1
5.	Formal Observation (#2)	Memory clinic services		1
6.	Formal Observation (#3)	Dementia Awareness campaign: Hindu Temple		1
7.	Formal Observation (#4)	Sikh Mental Health and Wellbeing Conference		1
8.	Formal observation (#5)	Memory clinic appointment with pp#17		1
9.	Formal observation (#6)	Alzheimer's Café attendance with pp#17		1
10.	Informal meeting and discussion	pp#17's family		1
11.	Informal meetings, discussion, emails, telephone calls	pp#17's dementia services accessed		10

Table 10: Study data collection methods (N = number of participants,

pp=participant, volume = amount of incidences).

3.3.3. Data Collection Phase 1

At data collection phase one, spanning over a four month time period, five semi-structured one-to-one interviews occurred with five participants (pp#1, pp#2, pp#5, pp#6, pp#7) and one semi-structured one-to-two interview (pp#3, pp#4)

There was formal observation (obs#1) within a Sikh Gurdwara [for a breakdown of participant demographics see Chapter 4, p.173 and appendix 11].

3.3.4. Data Collection Phase 2

At data collection phase two, spanning a four month time period, there were seven semi-structured one-to-one interviews (pp#8, pp#9, pp#10, pp#11, pp#14, pp#15, pp#16). There was one semi-structured one-to-two interview (pp#12, pp#13). Two observations occurred in the West Midlands: one at a NHS memory clinic (obs#2) and one during a Dementia awareness campaign in a Hindu temple (obs#3).

3.3.5. Data Collection Phase 3

During data collection phase three, spanning a four month period, there were five semi-structured one-to-one interviews (pp#17, pp#18, pp#19, pp#20, pp#21). Three observations occurred: one at a Sikh Mental Health Conference (obs#4), one accompanying a Muslim person (pp#17) with dementia during a memory clinic consultation (obs#5) and one accompanying a Muslim person (pp#17) with dementia during an

Alzheimer's café meeting (obs#6). There were also ten interactions across informal meetings, discussion, emails and telephone calls with dementia services accessed by pp#17. Additionally, there was an informal meeting and conversation with the adult children of pp#17.

3.3.6.   Semi – Structured Interviews

The semi-structured interview method occupies a mid-position between structured and unstructured interview methods; the former involving a fixed method of questioning, suited to questionnaire designs, the later involving no pre-conceived line of questioning: "The degree to which interviews are structured depends on the research topic and purpose, resources, methodological standards and preferences, and the type of information sought" (Sarantakos, 2005). The semi-structured approach allows targeted research areas to be explored within flexible parameters, aiming for detailed, in-depth data gathering. This thorough approach was described by Oppenheim, (1999, p.67) as follows: "the job of the depth interviewer is not of *dat*a collection but *ideas* collection". This fitted the Critical Realist GT *abductive* methodological approach of *inductive* investigation, leading to more focused *deductive* enquiry. The researcher adopted the seven criteria defined by Sarantakos, 2005, (p.288) when recruiting and conducting the interviews: "respect", "honesty", "friendliness", "purpose", "trust" ,"approach" ,"explanation" . The following attributes are important during qualitative interviews (adapted from Sarantakos, 2005, p.274) and were considered qualities held by the researcher: Personal qualities such as friendliness and sensitivity, knowledge of the topic and its context, processing ability to understand

and interpret meanings, and respond accordingly, interest in and commitment to the research, clarity in speech and thought, adaptability, independence and initiative, initiative in exploring the respondent's experiences of the phenomenon, creativity in asking questions to generate respondent interest, experience with leading qualitative interviews, personal and professional maturity to encourage trust and respect, building rapport.

There are advantages and limitations of conducting semi-structured interviews and these were considered when designed the research method. Advantages of semi-structured interviews are the flexibility, high response rate, easy administration, opportunity to observe non-verbal behaviour, personal engagement, environmental control, opportunity to clarifying participant queries, allows complex responses, control over question order, opportunity to record spontaneous responses, control over participant identity, control over time, date and place of interview (Sarantakos, 2005, p 285-286). Disadvantages to the semi-structured interview method are the cost, potential bias, inconvenience, lack of anonymity and sensitive topics may be challenging to discuss face to face (Sarantakos, 2005, p 285-286). These last two points were especially pertinent to the current study where mental illness may be associated with stigma. It was essential to establish a good rapport with the participants and ensure they felt safe within the research environment, were fully informed about the research process and purpose, and that they were free to leave at any point. For the present study, it was considered the advantages of the method outweighed the limitations and

semi-structured interviews were selected as the primary data collection method for the study; the ability to obtain complex responses in a controlled environment justified cost and inconvenience issues. The open-ended interview approach resulted in a "major and costly coding operation" (Oppenheim, 1999, p.83), but this thorough approach to data analysis - whilst time consuming - was imperative to limit subjective interpretation of the data. The primary limitation was the challenge to anonymity. Since the researcher engaged in face-to-face dialogue with the participant, and captured personal details, it is possible that the participant did not feel as comfortable disclosing sensitive information than if they were answering the question on a form, for example. This may have an impact on the integrity of the data collected. However, the nature of semi-structured interviewing allows the participant to guide the dialogue to where they are comfortable. The rapport between interviewer and interviewee is imperative to build this trusting relationship and allow participants to "open up" freely. The researcher believed the face-to-face dynamic, whilst compromising anonymity, allowed a personable relationship to be formed, generating an open dialogue between researcher and researchee, allowing a richer data to be shared and captured. It was considered that rapport was maintained within professional boundaries, "there can be too much or too little rapport, and either would be undesirable" (Oppenheim, 1999, p.89).

3.3.7.   Interview Process

Interviews were semi-structured, allowing the participant to guide the trajectory of data collection. During DCP 1, the *inductive* approach was

exploratory with five open-ended questions aimed at generating dialogue [see interview schedule in appendix 7]. Interviews opened with, "can you tell me about your experiences with dementia and religion? Subsequent questions were based on participant response to this initial line of inquiry. There were some established questions covering possible topics identified from the wider existing literature on BME dementia care such as "barriers to dementia care", which were introduced at appropriate times, but not systematically if it did not fit with participant responses. The researcher facilitated ideas generated by the participant, without guiding them down a preconceived path. At this stage, the impetus was on the participant, with the researcher as a facilitator: "The interviewers will seek to reduce their own role to an absolute minimum, to avoid leading the respondent. If something is not clear, a non-directive prompt will be used or summarizing what the respondent has just said, or maintaining a pleasant, expectant silence" (Oppenheim, 1999, p.67). At DCP 2, the *deductive* approach influenced the amendment of the interview schedule from the exploratory approach in DCP 1, to a more focused method of questioning. This aimed for theoretical saturation of identified categories in DAP 1 and rejection of infrequent categories through Negative Case Analysis (Charmaz, 2006), aiming to generate theory development. Whilst still being semi-structured, allowing the participant to speak freely and direct the trajectory of the interview, the researcher was enabled to use prompts towards categories identified from DAP 1 data, reflecting the semi-structured interview method: "very occasionally, after a topic has been explored in a free-style manner, a deliberately directive probe will be used" (Oppenheim, 1999, p.75). For example, Question 1: "can you

tell me about your experiences with dementia and religion?" had the following prompts added: God's will, Destiny, Karma, Fate, religious coping. For example, Question 3: "what can you tell me about service improvement and dementia care?" had the following prompts added: outreach, chaplains, cultural match. (Full interview schedule in appendix 7). To utilise a fully structured interview schedule during DCP 2 may have presented bias by not allowing new categories to emerge.

3.3.8.   Conducting the Interviews

All interviews were conducted by a single researcher either in a one-to-one researcher-participant dynamic, or in a one-to-two researcher-to-two-participants ratio. The aim was to conduct all interviews on a one-to-one basis. However, there were two one-to-two interviews. These occurred when participants especially requested to be interviewed together. On both these occasions, the participants were colleagues within the same organisation. Whilst this may have impacted on data collection in generating a space where the participant can speak in confidence to the researcher alone, the researcher felt on these occasions, the researcher – researchee dynamic improved as the participants had an existing natural, professional rapport with one another which facilitated the willingness to share information, resulting in rich data collection. During the interview with the person with dementia (pp#17), a chaperone from a dementia organisation was present. This chaperone had also taken part in the research study as a participant (pp#4) and was responsible for introducing pp#17 to the researcher and for overseeing his wellbeing throughout the research process. Interviews

aimed to last around an hour in duration, although this was flexible in accordance with data captured. Interviews lasted between 35 minutes 52 seconds (pp#11) and 95 minutes and 35 seconds (pp#21) [see appendix 12 for details of interview timings and data captured].

3.3.9. *Participant Demographic Questionnaire*

Participant demographics were captured in a questionnaire prior to the formal interview [see questionnaire in appendix 7]. This information aimed to understanding the phenomenon of religion and dementia care as experienced by the individual participant, set the subsequent data in context and assist with interpretation and analysis, by expressing sensitivity to the cultural and religious nuances of the sampling set. All participants were asked their name, age, gender, ethnic origin, spoken languages and religious persuasion. Participants were asked to rate the strength of their religious beliefs on a Likert style scale (Likert, 1932) from (1) not at all strong, to (5) very strong, and the frequency of religious practice from (1) never to (6) more than once a day. Carers of a South Asian person with dementia (SAPWD) were asked for information about the person they cared for in terms of religious adherence and duration of care provision. Healthcare professionals and dementia organisation employees were asked about their role and duration of service in the dementia care team. Religious Representatives were asked to provide their title. This set the individual in context of their role in dementia care provision. It provided relevant information about the participants' potential subjective influence on the data provided, and the

potential influence of the researcher-researchee relationship, according to Critical Realist Methodology (Strauss & Corbin, 1990).

3.3.10.   Participant Rapport

The comfort and confidentiality of the participants during the interview process was a primary factor. It was imperative that the interviews were conducted in a private, quiet room to build rapport and maintain confidentiality. The researcher conducted the interviews in a range of settings and stipulated the importance of having a quiet, undisturbed space to participants prior to attending interview settings. There were instances where the interview process was interrupted, either by people knocking on the door, or the telephone ringing. This was captured both by the audio-recording and in the researcher's field notes to account for the possible disruptive implications this may have had on the interview flow. The researcher then ensured that rapport was re-established and the interview continued smoothly. Field notes were taken by the researcher before and after each interview session to capture information not directly addressed in the session which may have impacted on the interview session or prove insightful to the developing theory, for example: emotional or environmental factors [see p.138 under "observations" for fuller discussion of field notes]. Interviews occurred within the following settings: Domestic home settings; Healthcare settings: Hospitals, Clinics, Medical centre; Organisational settings: Charity or organisation premises; Religious Institutions: Temples, Gurdwaras, and within an Academic Institution at The Centre for Ageing and Mental Health, Staffordshire University.

3.3.11.   Materials

A Dictaphone was used to effectively capture all dialogue including pauses and inflections. This removed the necessity for the researcher to write notes during the interview, enabling a focus on building rapport and data contemplation, "It is essential for exploratory interviews to be recorded on tape. In this way they can be analysed in detail afterwards" (Oppenheim, 1999, p.67). The participants were told in the information sheet [see appendix 3] and verbally about the purpose of using a Dictaphone. There was one instance where a potential participant was comfortable with an informal chat but was not happy to be recorded with a Dictaphone and did not go ahead with a formal interview. This person could not be used in the participant sample.

3.3.12.   Observations

Observations were conducted by the systematic compiling of field notes before, during and following observations. These observational records were, "detailed, non-judgemental, concrete descriptions of what has been observed" (Marshall & Rossman, 2006, p.98).The field notes served as accurate "memorandums… made by the researchers of their impression of events, processes or people they encounter during their field work" (Remenyi, 2012). The purpose of scripting field notes - across all observations - was to create an account of supplementary evidence to inform the development of the grounded theory, "the goal is to capture the interview, archival, or observational evidence in a methodological

manner, later to be compiled and then used as part of the analysis" (Yin, 2012).

The observational method is considered, "a fundamental and highly important method in all qualitative inquiry" (Marshall & Rossman, 2006, p.99). Observations are more than just "hanging out" and require a high level of self-awareness and thorough engagement (DeWalt & DeWalt, 2001). Similarly, "Field notes are not scribbles", and the observer should have a clear note-taking and organisational strategy (Marshall & Rossman, 2006, p.99). The demand on the researcher during observations can raise "ethical dilemmas and even danger", in addition to "difficulty managing a relatively unobtrusive role, and the challenge of identifying the big picture while finely observing huge amounts of fast-moving and complex behavior (sic.)" Marshall & Rossman, 2006, p.99). The researcher experienced "ethical dilemmas" throughout the observations with pp#17. One example was during a clinical observation where the GP did not adequately answer pp#17's question regarding the aetiology of his condition. The researcher was divided between remaining an impartial observer and assisting pp#17 to get the best from his consultation. This is a paragon of the "oxymoron" posed by participant observation which, "implies simultaneous emotional involvement and objective detachment" (Denzin & Lincoln, 2003, p.167). This is more commonly applied to ethnography studies, where the researcher lives amongst persons of the phenomenon under investigation - learning their language and becoming ingrained in the culture of observation - but it also demonstrates the complexities of multiple observations with the

same participant, where a personal rapport is imperative to obtain the depth of data required for a Grounded Theory study. This highlights the importance of a reflexive approach to counter for the possibility of personal bias, "personal reflections are integral to the emerging analysis of a cultural group, because they provide the researcher with new vantage points and opportunities to make the strange familiar and the familiar strange" (Glesne, 1999). It also highlights the importance of adopting a systematic approach for "multiple observations", by generating an observational protocol to limit subjectivity and remain within empirical parameters (Creswell, 2009, p.181).

3.3.13. *Informal Observations, Discussions and Contact*

These types of data collection were documented in field notes and used to supplement the primary interviews with pp#17. They allowed the researcher to gain a more holistic picture of the dementia experience for pp#17, to gain trusts and build rapport, leading to in-depth data generation.

3.3.14. *Data Analysis: Interviews*

Three data analysis levels (DAL) were applied to these data, with increasing theoretical development, according to GT principles: line by line, focused and axial (Strauss & Corbin, 1990). The analysis process was conducted thoroughly and systematically to ensure that each concept added earned a place in the theory (Glaser, 1978). Line-by-line is a low level form of coding using descriptive categories involving the naming of

each line of data (Smith, 2008, p.94). Focused coding is a higher level method of coding which synthesises large amounts of data using more abstract "analytic" categories that occur most frequently or are most poignant (Smith, 2008, p.96). Memo-writing, which enabled the taking "apart" of categories and "detailing processes", and "identifying gaps in the analysis" is defined as "the logical step after you define categories" (Smith, 2008, p.101) was utilised by the researcher during DAL 2 and DAL 3. Axial coding links these identified categories and forms theoretical relationships between concepts and utilises Negative Case Analysis (NCA), where categories that are inconsistent with the overall emerging theory, are discarded (Smith, 2008, p.92-100). NCA is vital as it employs a creative approach by the researcher, forcing them to "break through assumptions and to create new order out of old" (Strauss & Corbin, 1990, p.224). Level 1 coding occurred by the researcher with codes assigned to each line of data by hand [see table 12 for examples]. Coded transcripts were then uploaded to NVivo9 (Bazeley, 2007), a qualitative data computer package and utilised for level 2 and level 3 data analysis [see appendix 13 for example of analysis of religious themes using NVivo9].

3.3.15.   Codes, Categories and Themes

For clarification, the following terminology was used in the present study to define the emerging theory at each DAL. Codes were grouped in to categories which produced interlinking and overlapping themes, informing the overall theory. Codes were the result of low level coding (as described above) and involved the researcher writing a word or short

phase next to each line of the transcript or field notes and were used

across each data type at each data analysis phase. The researcher

analysed these codes and recognised that many of the codes overlapped

to form Categories. These categories formed the theory at DAL 2. During

DAL 3 the identified categories – informed by the codes – demonstrated

themes. These themes began to emerge in the data at DAL 2 and

consolidated the theory at DAL 3. This approach aimed to get closer to

the "objective truth" in the data by ranking the frequency of coding

occurrences in to an ordinal ranking (Stevens, 1946).

Data Analysis Phase (DAP)	Data Analysis Level (DAL)		Theory development
1 Explore	1. line by line coding		Explore the theory and identify salient themes for potential theory development
	Codes		
	2. Focused coding		
	Categories		
2 Define	1. line by line coding		To define or discard identified themes leading to the formation of a theoretical model.
	Codes		
	2. Focused coding		
	Categories		
	3. Axial coding		
	Themes		
3 Consolidate	1. line by line coding		To consolidate the established theory into a final theoretical model
	Codes		
	2. Focused coding		
	Categories		
	3. Axial coding		
	Themes		

Table 11: Data analysis level, data analysis phase and implications for theory development.

3.3.15.a.   Data Analysis Phase One: Interviews

At DAP 1, line by line coding occurred after six interviews with seven participants (for full participant details, see Chapter 4, pp.173-180 and appendix 11). These participants were recruited from Convenience sampling (see Chapter 3, pp. 150-154 for sampling strategy).

The researcher systematically analysed each line of the individual transcripts and assigned codes by hand; 884 codes were identified across six interview transcripts. Two of these codes were duplicates, so this was reduced to 882 total codes. Following this initial stage, focused coding was applied (see table 12 for examples of how codes were applied to transcripts and assigned to a category).

Example 1: (pp#1, interview #1)		
Phrase in text	Coding (line by line)	Category (Focused)
'And that this will happen and to discuss what caused the Alzheimer's, what caused the vascular dementia and explain, ok , all these things, steps were destined to happen that's why they happened and the treatment you are going to give me I might take it but it is destined if I am going to be treated that is my destiny, if I am not, that is my destiny'	Destiny vs. treatment and medication	Religion (Broad)
Example 2: (pp#3, interview#3)		
Phrase in text	Coding (line by line)	Category (Focused)
'probably when someone needs a care home or a nursing home at that stage of dementia and er there are very few ethnic care homes for example. There are some black, Punjabi ethnic care homes I know in some parts of the UK but they are quite limited'	Care homes shortage for Black and Punjabi	Existing Service

Example 3: (pp#6, interview#5)		
Phrase in text	Coding (line by line)	Category (Focused)
'And then she's got her hobbies and interests which is knitting and baking cakes and stuff and then there is the last one about living in the community and a bit more about her life history'	Hobbies and interests, community living	Individual Care

Table 12: Examples of low level and focused coding applied to the transcripts in Data Analysis Phase 1.

The low level, line by line codes were then grouped in to twenty

categories, and ranked according to frequency of codes. "Religion" and

"Existing Service" were the top two identified categories (see table 13).

Ranking	Category	Codes
1	Religion (broad)	233
2	Existing Service	107
3	Communication	91
4	Service Improvement	80
5	Culture	69
6	Presentation to Services	55
7	Family Care	54
8	Education / Knowledge	48
9	Individual Care	40
10	Outreach Services	26
11	Care Expectations	22
12	Delusion (religion)	17
13	Cost and Finance	13
14	'Normal' ageing	6
15	Gender in Care	5
16	Stigma	5
17	Other Illnesses	5
18	Carer Stress	3
19	Vascular dementia	2
20	Trust	1
Total		**882**

Table 13: Data Analysis Phase 1: Categories and Codes by ranking. Categories are ranked according to frequency of codes.

The questions asked by the researcher during the interviews were

analysed. Every question asked during the interviews were listed and

explored. Whilst the interview schedule had 5 broad questions in order to generate dialogue, many further questions were asked, based on participants responses to these exploratory questions. There were 334 questions asked by the researcher across the 6 interviews. The interviews were also analysed for duration and the length of subsequent material. Interviews ranged between 33 minutes to 1 hour and yielded between 4,674 - 9,299 words (see table 14). This analysis contributed to understanding the context of the data findings in light of the emerging theory, to recognise patterns in dialogue, to identify the trajectory of the data, and to recognise strengths and weaknesses in interview technique.

Data Collection Phase 1 Interviews			
interview	Amount of questions asked	Interview Duration	Transcript words
1	42	1 hour	8,218
2	52	58 mins 58 secs	9,299
3	76	54 mins 34 secs	8,289
4	51	50 mins 37 secs	6,521
5	68	33 mins 29 secs	5,350
6	45	36 mins 14 secs	4,674

Table 14: Data Collection Phase 1: Interviews by amount of questions, interview duration and transcript words.

3.3.15.b.   *Data Analysis Phase Two: Interviews*

At DAP 2, line by line coding occurred after eight interviews with nine participants. Persons were recruited according to Purposive sampling based on the data generated from DAP 1 (see Chapter 3, pp. 150-154 for sampling strategy).

Line by line coding identified 1,814 codes across the 9 transcripts, forming 22 categories (see table 15). There was a shift in the ranking of categories from DAP 1 to DAP 2. 'Service Improvement' and 'Religion' were the top two identified categories. Furthermore, two new categories: 'Alcohol' and 'Generational Perspectives' were identified.

Ranking	Category	Codes	Category Ranking Shift (DAP 1 - DAP 2)
1	Service improvement	396	(+ 3)
2	Religion (broad)	371	(- 1)
3	Existing service	152	(- 1)
4	Stigma	148	(+ 12)
5	Communication	129	(- 2)
6	Outreach services	110	(+ 4)
7	Family Care	116	(0)
8	Presentation to services	69	(+ 2)
9	Education / knowledge	65	(- 1)
10	Culture	44	(- 5)
11	Individual Care	57	(- 2)
12	Gender in care	55	(+ 3)
13	Cost finance	31	(0)
14	Carer stress	29	(+ 4)
15	Alcohol	10	*new*
16	Generational Perspectives	9	*new*
17	Normal ageing	7	(- 1)
18	Delusion (religion)	5	(- 4)
19	Trust	5	(+ 3)
20	Vascular dementia	5	(+1)
21	*Care expectations*	*1*	*(- 8)*
22	*Other Illnesses*	*0*	*(- 3)*
Total		**1814**	

Table 15. Data Analysis Phase 2: Categories and Codes by ranking and ranking shift from DAP 1 to DAP 2. (*for example: (+ 3) equates to a shift up the ranking by three places*, (-1) equates to a shift down the ranking by one place, (0) equates to equal ranking in DAP 1 and DAP 2).

The focus at DAP 2 was on defining the theory. Negative Case Analysis (Smith, 2008) was applied to the transcripts and the bottom two ranked categories were discarded: 'Other illnesses' had no codes assigned to this category and 'Care Expectations' only had one code listed. The data from

this one code was not lost, but was synthesised in to the 'Existing Service' category.

At this stage, the interview schedule was amended from being a broad, exploratory approach to a more focused method of questioning, whilst still being semi-structured and allowing the participant to speak freely, the researcher guided the participant towards the twenty categorised areas that had been identified as the most significant and most frequently occurring in DAP 1. The aim of this was to saturate existing theoretical areas and also be open to new theoretical areas emerging which add to the developing theory. To use a fully structured interview schedule even during Data Collection Phase 2 may present bias and prevent new categories from emerging.

Axial coding was applied categories at DAP 2 to recognise overarching themes. Based on these data, the researcher was satisfied with the depth and breadth of data obtained to develop a theoretical model (see Chapter 5, p256). The dominant theme identified was Education – specifically the need to educate about dementia through outreach in to religious communities, by a religious and clinical team, on a consistent basis (see Chapters 4 & 5 for full discussion). Education was identified as a category (category #9) but the overarching theme of Education was prevalent in codes throughout categories 1-10 and in category 17 (see table 15). This allowed the researcher to develop a "hunch" (Charmaz, 2006, p.240) that this theme required further investigation in Data Collection Phase 3 and most specifically from the perspective of the person with dementia.

3.3.15.c.   Data Analysis Phase Three: Interviews

At DAP 3, line by line, focused and axial coding were applied to five interviews with five participants. These participants were specifically recruited utilising Theoretical Sampling methods (see Chapter 3, pp. 150-154 for sampling strategy); specifically, persons with dementia were targeted to saturate the findings in DAP 1 and DAP 2. The researcher was in a position to "test" the hunches based on the defined theory in DAP 2, and the theoretical model – explored in DAP1 and defined in DAP2 was now consolidated. This theory has been emerging iteratively throughout the research study using the Constant Comparison method, but the perspective from persons with dementia had not yet been captured. At Data Collection Phase 3, one person with dementia was recruited; data collection with this participant was maximised and contributed to the theoretical model in the present study and was also developed in to a Case Study, in a separate report to this study (see appendix 1d). There was an instance where the person with dementia perceived home visits to be more important than outreach in to the religious buildings, which challenged the defined DAP 2 model, and this data was incorporated in to the final theory (see Chapter 6, p.320, section 6.4.15. '*discrepancies in hypothesis'* for a fuller discussion for how this was accounted for in the theory).   At this stage, the researcher was satisfied no new categories were emerging and all necessary data has been collected to consolidate the definitive theory.

3.3.16.   Data Analysis: Observations and informal contact

As supplementary material, these data sets were not subject to the same rigorous analysis procedure as the primary data source of interview transcripts, but were analysed thematically to identify themes which may support or challenge the primary data identified in the interview transcripts.

3.3.17.   Sampling and Recruitment: Sampling Strategy

Qualitative research demands an "inherent bias" in cohort selection (Bryant & Charmaz, 2010, p.234) and thus, unlike quantitative research, does not utilise random sampling procedures. Participants are purposefully targeted according to their direct experience and involvement with the phenomenon and are required to be willing, reflexive and articulate (Richards & Morse, 2007). In GT research, the sampling strategy shifts in accordance with the development of the emerging theory and "critical junctures" inform the sampling set required to saturate emerging categories. Main sampling types in GT research are convenience sampling, purposeful sampling, theoretical sampling and theoretical group interviews (Bryant & Charmaz, 2010, p.237). The present study utilised three types of sampling strategy in accordance with the demands of the emerging theory. These were Convenience sampling at DCP 1, Purposive sampling at DCP 2 and Theoretical Sampling at DCP 3. This allowed the researcher to avoid the "common pitfall in qualitative inquiry" of not moving beyond convenience sampling (Bryant & Charmaz, 2010, p.235). Sampling was stopped when the model reached theoretical

saturation and no new (sub) categories emerged (Bryant & Charmaz, 2010, p.231). The researcher was aware that premature ceasing of sampling could ignore relevant data or variation within emerging data. Based on sample sizes for similar, high quality, GT studies of four participants (Lawrence, Murray, Samsi *et al.*, 2008), 11 participants (Bowes & Wilkinson, 2003; Neary & Mahoney, 2005), 20 participants (Patel, Mirza, Linbald *et al.*, 1998) and 24 participants (Hinton, Franz, & Friend, 2004), the researcher was confident that the total sample of 21 participants fulfilled these criteria and was a large enough sample size to generate a rich dataset, enabling theoretical saturation to be achieved.

3.3.18. DCP 1: Convenience Sampling

The seven participants recruited in DCP 1 were obtained through convenience sampling. This allowed a "trajectory of the entire research process" (Bryant & Charmaz, 2010, p.237) to be obtained, reflecting the exploratory approach of the phenomenon in this initial phase. The recruitment strategy involved blanket targeting of dementia organisations and South Asian religious institutions in the West Midlands and within the allocated NHS Trusts to establish initial contacts. From these primary links, further participants were recruited by snowball sampling.

Interview Number	Participant Number	Role
1	1	Old Age Psychiatrist
2	2	Old Age Psychiatrist / Family Therapist
3	3	Dementia Advocacy Manager
3	4	Dementia Advocate
4	5	Consultant in General Adult Psychiatry
5	6	Assistant Team Leader Dementia Champion
6	7	Councillor and Sikh Chaplain

Table 16: Data Collection Phase 1: Participants by Role.

3.3.19.   DCP 2: Purposive Sampling

 The nine participants recruited in DCP 2 were purposively targeted as those representing adherence with particular themes emerging in DAP 1, or were representative of cohort groups not captured in DCP 1. The carer of the person with dementia was targeted and recruited in this phase to saturate the themes from this perspective. The SAPWD was purposefully targeted at this phase. Due to the difficulties in identifying and recruiting a suitable participant in this cohort [see Chapter 6, p. 298]. No SAPWD were successfully recruited at this phase.

Interview Number	Participant Number	Role
7	8	Old Age Psychiatrist
8	9	Chief Executive Dementia Organisation
9	10	Psychiatrist
10	11	Dementia Carer
11	12	Reverend / Head of Diversity & Spirituality
11	13	NHS Sikh Chaplain
12	14	Advocate for BME older adults
13	15	NHS Hindu Chaplain
14	16	Muslim University Chaplain

Table 17: Data Collection Phase 2: Participants by Role

3.3.20.   DCP 3: Theoretical Sampling

The definition of the theory in DAP 2 provided the researcher with comprehension of the development of categories and subsequent theory generation (Glaser, 1978). This allowed an *abductive* approach to recruitment in DCP 3 using theoretical sampling, "in this sense, theoretical sampling entails both of what we commonly refer to as *inductive* and *deductive* reasoning" (Charmaz, 2006, p.103). Participants were chosen according to "purposeful selection according to *specific parameters*" (Bryant & Charmaz, 2010, p.234). The "specific parameters" related to those boundaries established by the theoretical model defined at DAP 2. Further data collection aimed to reinforce analysis gaps and generate a robust theory. It assisted with checking themes and discarding redundant categories. Engaging in theoretical sampling "prompts you to *predict* where and how you can find needed data to fill gaps and to saturate categories" (Charmaz, 2006, p.240). It allowed "hunches" to be tested (Hood [1983] in Charmaz, 2006, p.240). Hood (1983) defines "hunches" as predictions which "arise from your immediate analytic work. They are not off-hand conjectures" (Hood, 1983 in Charmaz, 2006, p.103). Theoretical sampling procedures allow the synthesis of new participants, observation of existing participants in a new context, or re-interviewing of earlier participants with more focused questioning, based on theoretical categories, based on *deductive* reasoning from the obtained data (Bryant & Charmaz, 2010, p.240). There were five new participants at DCP 3 with the inclusion of a SAPWD (pp#17).

Interview Number	Participant Number	Role
15	17	Person with dementia
16	18	NHS Head of Spirituality
17	19	Carer / Wellbeing Leadership Coach / Director SikhHealth
18	20	Senior NHS Manager
19	21	NHS Muslim Chaplain

Table 18: Data Collection Phase 3: Participants by Role

3.3.21. Participants

Participants were recruited across five groups. The purpose of this was to gain a holistic insight of the South Asian dementia experience from firstly, the perspective of persons accessing services; secondly, the perspective of persons providing mainstream health and social care services (MHSCS) and thirdly, from the perspective of persons from non-Christian, South Asian religious communities.

Cohort # (C)	Cohort Type
1	South Asian Person with Dementia (SAPWD)
2	Carer of SAPWD
3	Healthcare Professional
4	Dementia Organisation Professional
5	Religious Representative

Table 19: The five study cohorts

The aim was to build a theory about how religion influences the care experience for the SAPWD. All five cohorts generated data which contributed to the overall grounded theory of this phenomenon.
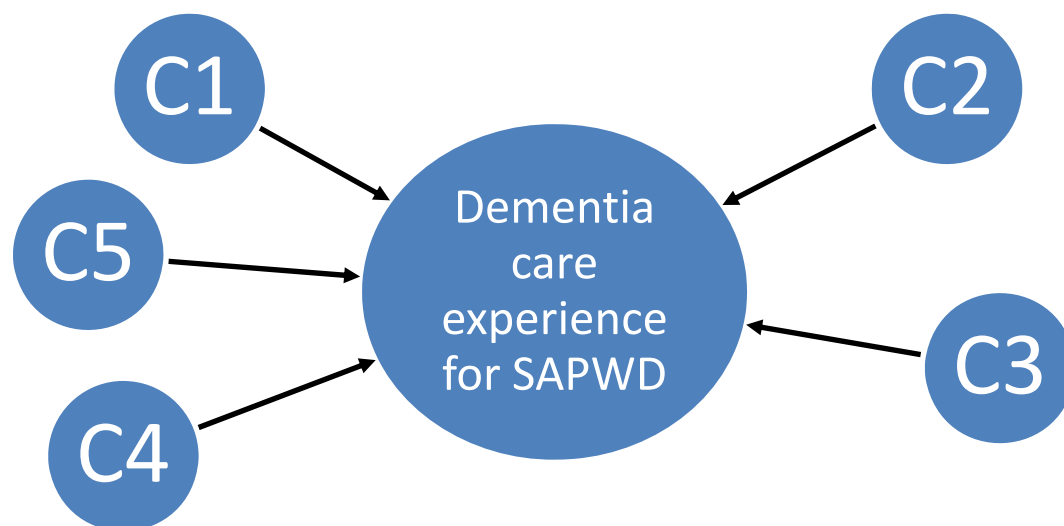
Figure 9: The five study cohorts' contribution to the emerging theory.

There was flexibility across the numbers recruited for each cohort. Whilst an even spread would have been ideal, due to the difficulties capturing SAPWD (discussed in Chapter 6, p. 298-306) it was anticipated that if this cohort could not be saturated, recruitment in the remaining cohort groups would be increased. Participants were successfully recruited across each cohort.

3.3.22.   Inclusion and exclusion criteria

All participants who met the suitable criteria were encouraged to participate. No participants were refused if they met the inclusion criteria, in accordance with the sampling strategy at each phase. Across C1 – C5, males and females were recruited in any age range. There were specific inclusion criteria for each cohort. Exclusion criteria were introduced to

obtain a suitable sample which met the parameters of the research question.

3.3.23.   Inclusion Criteria

C1. Persons of South Asian culture, non-Christian - of any minority religious persuasion or no religion; of any dementia type or stage - having received a formal, clinical diagnosis of dementia according to a cognitive assessment by a trained professional [Mini Mental State Examination (score <26) (Folstein, Folstein & McHugh, 1975)] or equivalent; with capacity to consent according to the Mental Capacity Act, 2005 (Department for Constitutional Affairs, 2007).

C2.   Persons responsible for personal, emotional, practical care of a SAPWD: family and non-family.

C3. Persons providing clinical care for dementia patients at any stage in the illness. Persons involved in the management of dementia care in a clinical setting.

C4.   Persons working in organisations providing dementia care. For example: day centres, residential care centres, volunteer organisations, charity groups, government organisations.

C5. Persons considered as high standing representatives of non-Christian, South Asian religious communities, or Christian representatives involved in dementia care. Hospital chaplains were categorised in C5, to distinguish them from clinicians or management in C3.

3.3.24. Exclusion Criteria

In C1-C5, non-English speakers were excluded. There was no budget for translators in the study. Volunteer translators were recruited but subsequently dropped-out (see Chapter 6, p. 297 for further discussion).

In C1, Christian persons were not included. The study aimed to investigate how South Asian persons from non-Christian faiths experienced dementia care in a country where the most prevalent religion is Christianity.

In C1, persons with dementia who did not possess capacity to consent according to the Mental Capacity Act, 2005 (Department for Constitutional Affairs, 2007) were excluded to protect the wellbeing of persons from vulnerable groups.

3.3.25. Religious Adherence

The study aimed to capture the experiences of dementia care for the SAPWD. "South Asian" are purported as an underrepresented demographic in dementia care services. It was important to capture the perceptions of South Asian persons using dementia services who were members of immigrant religions in the UK. However, it was also important to capture the perceptions of the service providers, and thus Christians and persons of no faith were not excluded across C 2 – C5. Persons in C1 were recruited primarily on their cultural identification as "South Asian" and their association with any non-Christian faith. The study was flexible to capturing persons from any immigrant South Asian religion. Association with a religious group was defined by the individual

and captured in the demographic questionnaire [see appendix 7] where participants were asked to state their religious adherence, strength of faith, and frequency of religious practice.

3.3.26. Sample Size

A formal sample size calculation was not required because quantitative data analysis did not occur. The sample size was influenced by existing research of dementia in South Asian communities, which utilised a qualitative approach employing semi-structured interview methods. Previous studies employed sample sizes of four (Lawrence, Murray, Samsi *et al.*, 2008), 11 (Bowes & Wilkinson, 2003; Neary & Mahoney, 2005), twenty (Patel, Mirza, Linbald *et al.*, 1998) and 24 (Hinton, Franz, & Friend, 2004). The recruitment numbers for the present study ranged from a minimum of five to a maximum of 21 persons. This was a flexible approach according to the sampling strategy of the emerging theory. If only a small number of participants were identified in DCP 1 through Convenience sampling, with no further participants recruited through Purposive sampling, data would have been collected in-depth through three separate interviews with the same participants. Since there were adequate participants identified at each phase, this enabled the maximum number of 21 participants to be recruited, capturing a breadth of data.

3.3.27. Identification and Recruitment of Participants

The recruitment process was three-fold – identification, information, recruitment. Identification of suitable participants lead to the provision of study information to said identified participants, leading to obtaining informed consent to participate. The recruitment of a sample for research in the South Asian demographic is notoriously challenging (Bowes & Wilkinson, 2002) and the present study experienced many barriers to recruitment [see Chapter 6, pp. 300-306]. However, the researcher was determined to access the SAPWD to allow them to have a "direct voice", in addition to the perspectives of the personal and professional carers of the SAPWD and the religious communities.

Figure 10: The three stage recruitment process.

3.3.28. Identification

Initially, informal face-to-face, telephone and email correspondence occurred with current researchers and clinicians of SAPWD. Existing studies were examined to investigate methods of how identifying, accessing and categorising BME persons with dementia. The purpose was to discover the most feasible strategy of recruitment to answer the research question. During this liaison, the categorisation of "South Asian" was determined as offering feasible parameters for recruitment.

Recruiting on the basis of this cultural definition was advised by existing researchers in the field as a more feasible approach, than recruiting on the basis of religious adherence only. The difficulties in accessing South Asian persons with dementia for research are well documented (Bowes & Wilkinson, 2002) so to place a further stipulation on the sampling criteria of just one religious group may limit recruitment opportunities and not provide a large enough sample to generate robust theory.

Participants were targeted in regions of the West Midlands with a high prevalence of South Asian persons, relative to the total population of the area, outside of London (ONS, 2011) [see Chapter 1, pp. 31-33] These areas were Wolverhampton, Birmingham and Stoke on Trent.

C1 participants were identified through MHSCS as existing service users. Whilst this may limit the numbers of suitable potential participants, it was vital to safe-guard vulnerable persons by ensuring a clinical diagnosis had been received, capacity had been assessed and the person was monitored and supported by services throughout the study.

C2 participants were identified through C1 links, or as service users of MHSCS.

C3 participants were identified through the following NHS Trusts: Black Country Partnership NHS Trust, Birmingham and Solihull Mental Health NHS Trust, South Staffordshire and Shropshire NHS Foundation Trust.

C4 participants were identified through dementia organisations, mental health organisations and elderly care services in Wolverhampton, Birmingham and Stoke on Trent.

C5 participants were identified through the NHS trusts highlighted in C3, and through religious institutions such as Temples or Gurdwaras in Wolverhampton, Birmingham and Stoke on Trent.

3.3.29. Information

Identified participants were provided with information about the study. This involved a telephone or email conversation in the first instance, with the study Information Sheet emailed or posted out to them. Persons were offered the opportunity for a meeting in person to further discuss about the study and clarify any queries. Persons were given a minimum of one week to decide to take part in the research. The purpose of this was to inform potential participants about the study, its implications, purposes and objectives and to generate interest in taking part. Communication in healthcare settings also occurred through formal power-point presentations of the research study to clinicians and management.

3.3.30. Recruitment

From this, identified, informed persons were contacted by telephone or in person. If they expressed disinterest in the study, they were removed from the recruitment strategy; if they expressed an interest to participate, the interview was conducted on the same day, following an informed consent procedure, or a future date was set to conduct the interview.
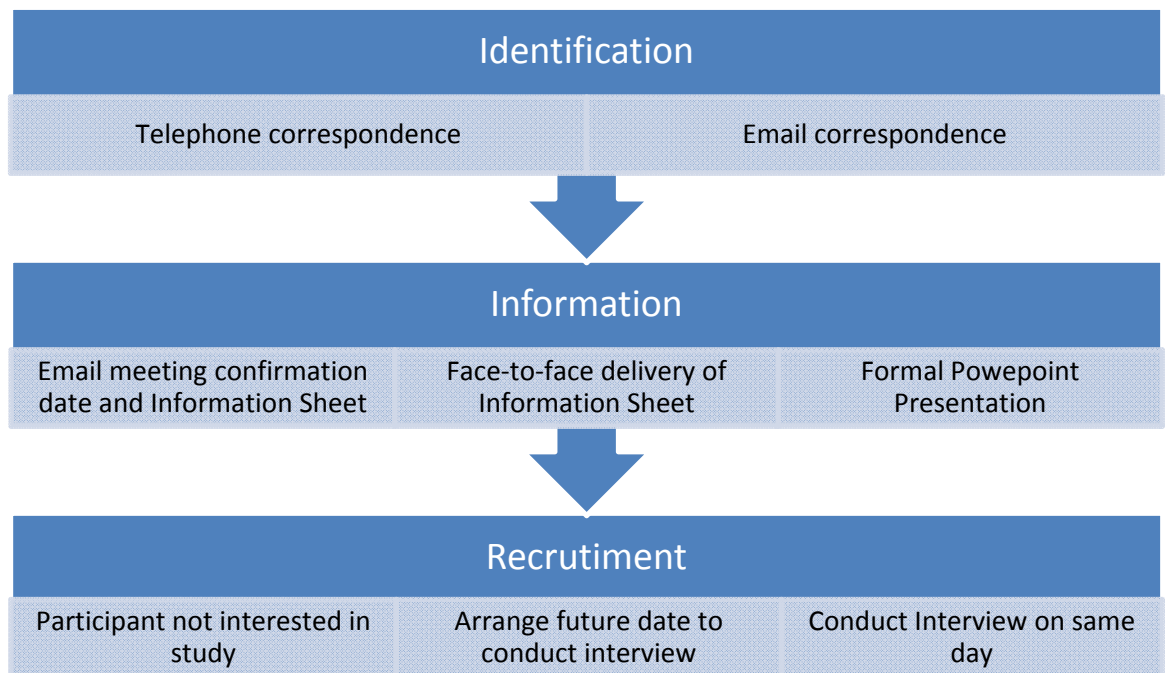
Figure 11: The process leading to successful or unsuccessful recruitment.

3.3.31. Informed consent

The Information stage of the recruitment process enabled informed consent to be obtained from all participants prior to recruitment. The ethical criteria for C1, stated the following: persons with dementia would not be recruited from the offset of the study, if they were not deemed to have capacity. If a participant loses capacity after initial consent has been gained, an appropriate consultee will be approached to assist with the decision to continue (Section [32] Mental Capacity Act, 2005). If consent is not given, the participant will be withdrawn from the study. Participants will be informed of this procedure in the information sheet, prior to initial consent. The SAPWD (pp#17) was assessed by a trained consultee and deemed to possess capacity, based on the following criteria (Mental Capacity Act 2005, Department for Constitutional Affairs, 2007):

understand the information, retain the information long enough to make the decision (to consent), consider the information available to make the decision (to consent) and be able to communicate the decision (to consent). Thus, a nominated consultee was not liaised with in this instance.

3.4. Ethical Approval

Ethical approval for the study was received internally by Staffordshire University on 20th June 2011, externally by the West Midlands – Staffordshire Research and Ethics Committee (REC) on 25th October 2011 and within the Research and Development (R&D) departments of the respective NHS trusts [see table 20 for dates).

Adherence to legal principles	Scientific justification of the research	Robust methodological design	Purpose and importance of the research
Researcher competence	Capacity to Consent	Recruitment and Informed Consent	Research procedures, risks and benefits
Publicity for Study	Translators and use of interpreters	Confidentiality	Storage and use of data during and following the study
Notifications of other Professionals	Incentives and Payments	Insurance and Indemnity	Overview of research sites
Details of research sponsors	Management of the research	Publication and Dissemination	

Figure 12: The main issues considered by the ethical committees

The three fold ethical procedure spanned a time frame of 18 months from initial application at stage 1 to the sign off within the final NHS Trust at stage 3. [Table 20 documents this process].

Stage 1. Independent Peer Review Panel: Staffordshire University		
Date Applied	Date of Panel Meeting	Date Project Approved
April 2011	4th May 2011	20th June 2011

Stage 2. NHS West Midlands – Staffordshire Midlands Local REC		
Date Applied	Date of Panel Meeting	Date Project Approved
June 2011	13th July 2011	Researcher unable to attend meeting
July 2011	13th September 2011	25th October 2011

Stage 3: Research and Development in NHS Trust

o Lead NHS Trust - Black Country Partnership NHS Foundation Trust

Date Applied	Date Honorary Contract and Research Passport Granted
11th November 2011	28th February 2012

o Supplementary NHS Trust - Leicestershire NHS Partnership Trust

Date Applied	Date Honorary Contract Granted
27th March 2012	24th May 2012

o Supplementary NHS Trust - Birmingham and Solihull NHS Mental Health Foundation Trust

Date Applied	Date Honorary Contract Granted
2nd April 2012	17th October 2012

o Supplementary NHS Trust - South Staffordshire and Shropshire NHS Foundation Trust

Date Applied	Date Honorary Contract Granted
27th April 2012	24th May 2012

Table 20. Time line of the study's ethical review process

3.5.   Quality Qualitative Research

All research should be rigorously designed and monitored according to scientific criterion which generates good quality, valuable data. The quality of these data can be measured by assessing the study in terms of scientific merit and adherence to empirical principles. In quantitative enquiry, one way methodological stringency is measured is by reliability and validity testing. Broadly, reliability denotes how replicable the study is, validity determines whether the study tests what it intended to (Cozby, 2001). Qualitative studies should also be subject to quality checks, "qualitative researchers should adopt a rigorous and self-conscious examination for bias at each stage of the research process" (Goulding, 2002, p.18). The findings of qualitative studies can also be assessed for "validity" by checking certain procedures have been adhered to throughout the research process (Creswell, 2009). A rigorous examination has been applied to the design and monitoring of the present research study. Lietz, Langer & Furman (2006) state qualitative research verification procedures include: prolonged engagement, triangulation, peer debriefing, member checking, negative case analysis, audit trail, reflexivity. Charmaz (2006) states the value of a GT study can be assessed in terms of its credibility, originality, resonance and usefulness.

The present study was subject to quality monitoring for qualitative research studies generally and Critical Realist GT studies specifically, according to rigorous criteria [see Chapter 6, pp. 306-321 for full consideration of how these criterion were addressed].

3.5.1. *Qualitative Research Quality Criteria*

The study aimed to adhere to the quality criteria defined by the Critical Appraisal Skills Programme (CASP, 2006) checklist for qualitative research:

	Criteria:	Adhered in study?
1	Are the aims clearly stated?	Yes
2	Is a qualitative methodology appropriate?	Yes
3	Was the research design appropriate to address the research aims?	Yes
4	Was the recruitment strategy appropriate to the research aims?	Yes
5	Were the data collected in a way that addressed the research issue?	Yes
6	Has the researcher – participant relationship been adequately considered?	Yes
7	Have ethical issues been considered?	Yes
8	Was the data analysis sufficiently rigorous?	Yes
9	Is there a clear statement of findings?	Yes
10	How valuable is the research?	Very

Table 21: CASP checklist for quality qualitative research

3.5.2.   *Critical Realist GT Quality criteria*

The researcher generated and aimed to adhere to two sets of quality principles throughout the study design and implementation, based on Critical Realist Grounded Theorists, Strauss & Corbin (1990, 1998). The researcher labelled these "Critical Realist GT quality principles 1" (based on Strauss & Corbin, 1990) and "Critical Realist GT quality principles 2" (based on Strauss & Corbin, 1998) and utilized these as quality benchmarks in the present research study.

	Criteria:	Considered in study?
1	Are concepts generated?	Yes
2	Are the concepts systematically related?	Yes
3	Are there many conceptual linkages and are the categories well developed? Do the categories have conceptual density?	Yes
4	Is there much variation built into the theory?	Yes
5	Are the broader conditions that affect the phenomenon under study built into its explanation?	Yes
6	Has "process" been taken into account?	Yes
7	Do the theoretical findings seems significant and to what extent?	Yes

Table 22: Critical Realist GT quality principles 1

	Criteria:	Considered in study?
1	How was the original sampling selected? On what grounds (selective sampling)?	Yes
2	What major categories emerged?	Yes
3	What were some of the events, incidents, actions, and so on that indicated some of these major categories?	Yes
4	On the basis of what categories did theoretical sampling proceed? That is, how did theoretical formulations guide some of the data collection? After the theoretical sample was carried out, how representative did these categories prove to be?	Yes
5	What were some of the hypotheses pertaining to relations among categories? On what grounds were they formulated and tested?	Yes
6	Were there instances when hypotheses did not hold up against what was actually seen? How were these discrepancies accounted for? How did they affect the hypotheses?	Yes
7	How and why was the core category selected? Was the selection sudden or gradual, difficult or easy? On what grounds were the final analytic decisions made? How did extensive "explanatory power" in relation to the phenomena under study and	Yes

	"relevance" as discussed earlier figure in the decisions?	

Table 23: Critical Realist GT quality principles 2

3.6.   Chapter Summary

The study is defined as a Critical Realist Grounded Theory (GT) approach utilising qualitative multi-methods of semi-structured interviews and observations. Data collection and data analyses were conducted across three iterative phases, reflecting the GT constant comparison method. The sampling strategy at each phase was convenience, purposeful and theoretical, respectively. There were five cohorts: South Asian persons with dementia (SAPWD), carers of SAPWD, healthcare professionals, dementia organisation professionals and religious representatives with clear inclusion and exclusion criteria. Ethical adherence and methodological validity were assessed at a University, LREC and individual NHS Trust level. Three quality checklists were introduced which were implemented in the study to aim for methodological rigour. The findings from these study data are presented in Chapter four.

4. Chapter Four: Findings

4.1. Chapter Aim

The purpose of this chapter is to discuss the study findings. The breakdown of participant demographics is presented. The aims and objectives of the project are used as a framework to demonstrate identified themes, supported with direct quotations from interview transcripts and observation field notes. Themes are discussed in the context of substantive findings and are separated in to religious and cultural categories. Whilst the research began from the standpoint of religion, many of the resulting themes relate to culture. These cultural themes warrant consideration and impact upon policy recommendations and are thus not excluded from the findings. This exemplifies the difficulty in clearly distinguishing religious influences from cultural influences. In the context of this study, the researcher categorised a theme as "religious" by the use of religious specific language, for example: words such as "religion", "pray", "prayer", "faith", "God", "sins", or by allusions to religious scriptures, religious practices or religious beliefs. The researcher categorised a theme as "cultural" if the language used explicitly related to culture, for example: words such as "culture", "ethnicity", "cultural", "South Asian", "society" or to allusions to cultural practices or cultural beliefs. When the language used did not explicitly relate to either religion or culture, this separation was often challenging; some identified themes may be categorised as both "religious" and "cultural". For example, within the cultural themes, allusions are made to the Hindu, Muslim and Sikh religions. Stigma is an example of one theme which is discussed in both a religious and cultural

context. "Generational differences" are alluded to across themes in the chapter [see pp. 201, 213, 225, 237, 245] and in the context of both religion and culture. Furthermore, it is possible that this separation of themes by language used may appear reductionalist in approach and potentially does not account for other influences beyond those of religion or culture. Chapter five will explore the Grounded Theory theoretical models developed from the study data and implications for care recommendations.

| Attitudes and perceptions of dementia | The decision to seek dementia care | The provision of dementia care | Satisfaction with dementia care services | Religious Provision in MHSCS | Barriers to dementia care services |
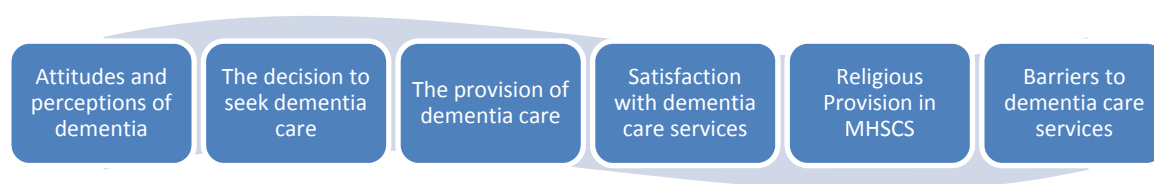
Figure 13: Study aims and objectives as a framework for presenting the findings.

4.2. Participant Demographics

A breakdown of participant demographics for the study is now presented, based on data obtained from the demographic questionnaire [see Chapter 3, p.136]: cohort group, gender, age, role, religious adherence, strength of religious beliefs, religious practice, faith and culture and language. This provides a context for the subsequent findings and allows implications of sample bias to be considered. The researcher is satisfied that the sample obtained for the study meets the defined criteria as stated in the methodology.

4.2.1. Cohorts

An approach to recruitment which utilised convenience, purposive and theoretical sampling methods (Charmaz, 2007, p.235) allowed persons from different South Asian cultures and religions to be recruited across all five cohorts. The breakdown of the number of participants by cohort is as follows:
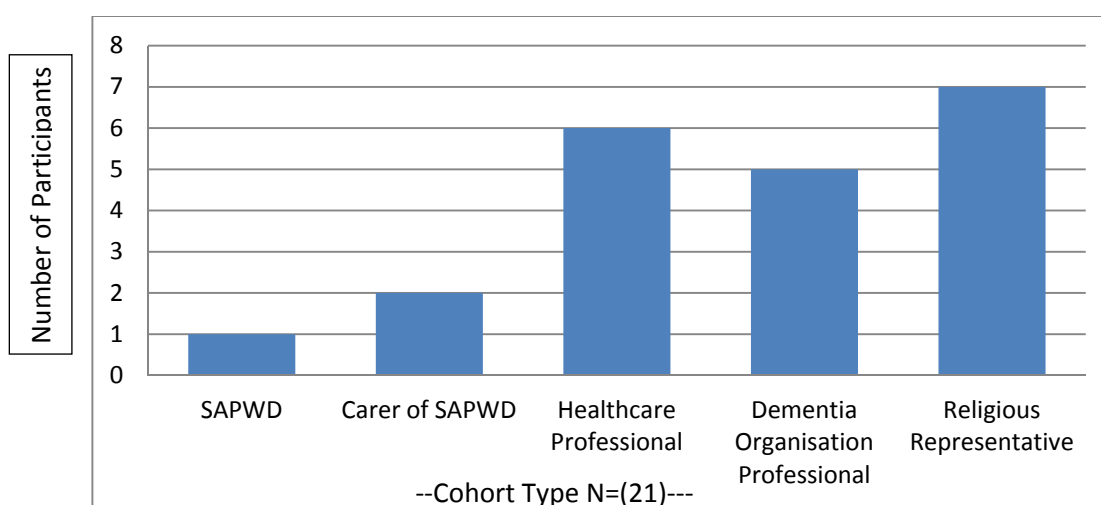
Figure 14: Number of participants by cohort (SAPWD = South Asian Person with Dementia, N=number of participants).

4.2.2. Gender

The sample was balanced between male and female participants.

Gender	N
male	11
female	10
Total (N)	21

Table 24: participants by gender (N= number of participants)

4.2.3. Age

The age range of the participants varied from the 26-35 years age category to the 56-65 years age category, with the majority of

participants falling in the 46-55 year range. There were no participants

successfully recruited in the 18-25 year age range.

Age	N
18-25	0
26-35	2
36-45	3
46-55	11
56-65	5
Total (N)	21

Table 25: participants by age range. (N=number of participants).

The data could be interpreted as being skewed from the perspective of a

particular generation (45-55 years). There were two persons from the

26-35 age group and three persons from the 36-45 age group, which

contributed to balancing this perspective.

4.2.4. Role

The role of the person in the dementia care team was considered. The

healthcare professionals ranged from clinical staff such as old age

psychiatrists to non-clinical senior management positions. Dementia

organisation professionals ranged from positions such as a chief

executive to dementia advocates and a team leader dementia champion.

Religious representatives had capacities either solely in the community or

as multi-faith chaplains working both in the community and as NHS

chaplains.

Role in Dementia Care Services	(N)	pp#
Assistant Team Leader Dementia Champion	1	6
Carer	2	11, 19
Chaplain: Hindu	1	15
Chaplain: Muslim Imam	2	16, 21
Chaplain: Sikh	2	7, 13
Chief Executive	1	9
Dementia Advocacy Manager	1	3
Dementia Advocate	2	4, 14
Director of Community Engagement	1	20
Person with dementia	1	17
Psychiatrist: General Adult	2	5, 10
Psychiatrist: Old Age	3	1, 2, 8
Reverend / Head of Diversity & Spirituality	1	12
Head of Spiritual Care	1	8
Total (N)	21	

Table 26: participants by role in dementia care services. N= number of participants, pp# = participant number assigned for anonymity.

4.2.5. Religious Type

The Religious adherence of the participants ranged from Muslim (N=7), Christian (N=7), Hindu (N=3), Sikh (N=4). The recruitment criteria stated persons of all faiths were permitted to partake in the study, with the exception of the person with dementia who was required to be a South Asian, non-Christian.
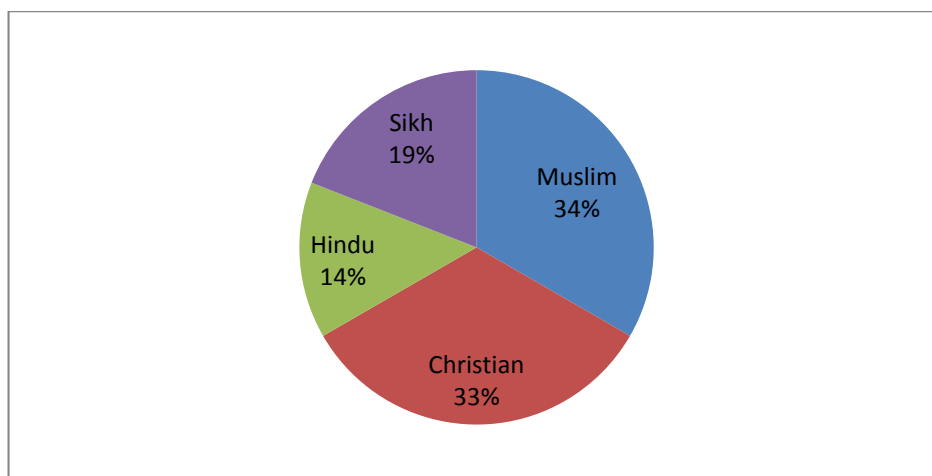
Figure 15: percentage of study participants by religion.

4.2.6.   Strength of Religious Beliefs

There were a spread across responses, with the majority of participants expressing a "very strong" or "strong" religious adherence (N=13).

strength of religious beliefs	(N)
(5) very strong	5
(4) strong	8
(3) not sure	1
(2) quite strong	3
(1) not at all strong	4
Total (N)	21

Table 27: Participants by strength of religious belief (N= number of participants).

It is important to consider that many of the participants were of "strong" or "very strong" faith (N=13) which influenced their daily practice. This reflects the sampling criteria of actively recruiting persons who adhere to faith practices, reflecting the "inherent bias" in qualitative research (Richards & Morse, 2007). However four of the participants across cohorts stated their faith as "not at all strong" and three as "quite strong" which balances this.

4.2.7.   Religious Practice

More than half of the participants (N=11) specified that their religious beliefs influenced their practice more than once a day or daily.

Religious Practice Frequency	(N)
(6) more than once a day	6
(5) daily	5
(4) several times a month	1
(3) several times a year	2
(2) main religious festivals only	6
(1) never	1
Total (N)	21

Table 28: Participants by religious practice frequency. (N=number of participants).

4.2.8. Culture

The participants derived from a range of different ethnic origins.

Ethnic Origin	(N)
Bangladeshi	1
Indian	8
Indian British	1
Pakistani	4
White British	7
Total (N)	21

Table 29: Participants' ethnic origin. (N=number of participants).

4.2.9. Faith and Culture

The complexity of the interaction between faith and culture was demonstrated by seven different types of faith and culture combinations across 21 participants:

Faith and Culture	(N)
Bangladeshi Muslim	1
Indian British Sikh	1
Indian Hindu	3
Indian Muslim	2
Indian Sikh	3
Pakistani Muslim	4
White British Christian	7
Total (N)	21

Table 30: Participants by faith and culture. (N=number of participants).

This range of different backgrounds means the sample is heterogeneous, and this may impact on the potential generalisability of findings. The purpose of this study is to generate a substantive theory which can potentially be applied to other substantive areas within certain parameters; unlike a quantitative study which aims at generalisation, a strictly homogeneous sample is not vital in this instance [see Chapter 3, pp. 150-158]. The recruitment criteria for C2-C5 were flexible on

religious adherence, with only C1 being defined as non-Christian. Adopting this approach enabled 21 persons to be recruited, which met the maximum range for participants for the present study. Restricting this to one religious group may have resulted in a very small sample with not enough data for theory generation. Sensitivity is displayed to the heterogeneity of the sample in the subsequent presentation of results. Whilst an overall theory is discussed, there is recognition of the nuances of the different religions within the sample. The high number of Christian participants (33%) is seen as a positive contribution to the theory. The Christians derive from the dementia organisation professional and healthcare cohorts. These perspectives are vital to comprehending how existing MHSCS are catering for Hindu, Sikh and Muslim persons. Across C3, C4, C5 there are a range of persons with Hindu, Muslim and Sikh faiths. C2 participants were from the Muslim and Sikh faiths, and C1 is from a Muslim perspective. Thus, consideration should be taken that the perspectives of a Hindu person with dementia or a carer from the Hindu faith have not been captured. Whilst every step was taken to recruit persons with dementia, only one person was successfully recruited in C1.

4.2.10.   Language

The range and order of languages varied with many persons speaking more than English (N=15) with one participant speaking six languages (see table 31).

Language	(N)
(1) English	6
(1) English (2) Urdu	2
(1) Punjabi (2) English	1
(1) English (2) British Sign Language	1
(1) English (2) Punjabi (3) Hindi	2
(1) English (2) Bengali (3) Urdu	1
(1) Hindi (2) English (3) Bengali	1
(1) English (2) Hindi (3) Gujarati	1
(1) English (2) Urdu (3) Punjabi (4) Mirpuri	1
(1) Urdu (2) English (3) Hindi (4) Telugu	1
(1) English (2) Odia (3) Hindi (4) Bengali	1
(1) Punjabi (2) English (3) Hindi (4) Urdu	1
(1) English (2) Hindi (3) Gujarati (4) Urdu (5) Arabic	1
(1) English (2) Gujarati (3) Punjabi (4) Urdu (5) French (6) Potwari	1
Total (N)	21

Table 31: Participants by language. (N=number of participants).

4.3.   Qualitative Findings: Attitudes and Perceptions of Dementia
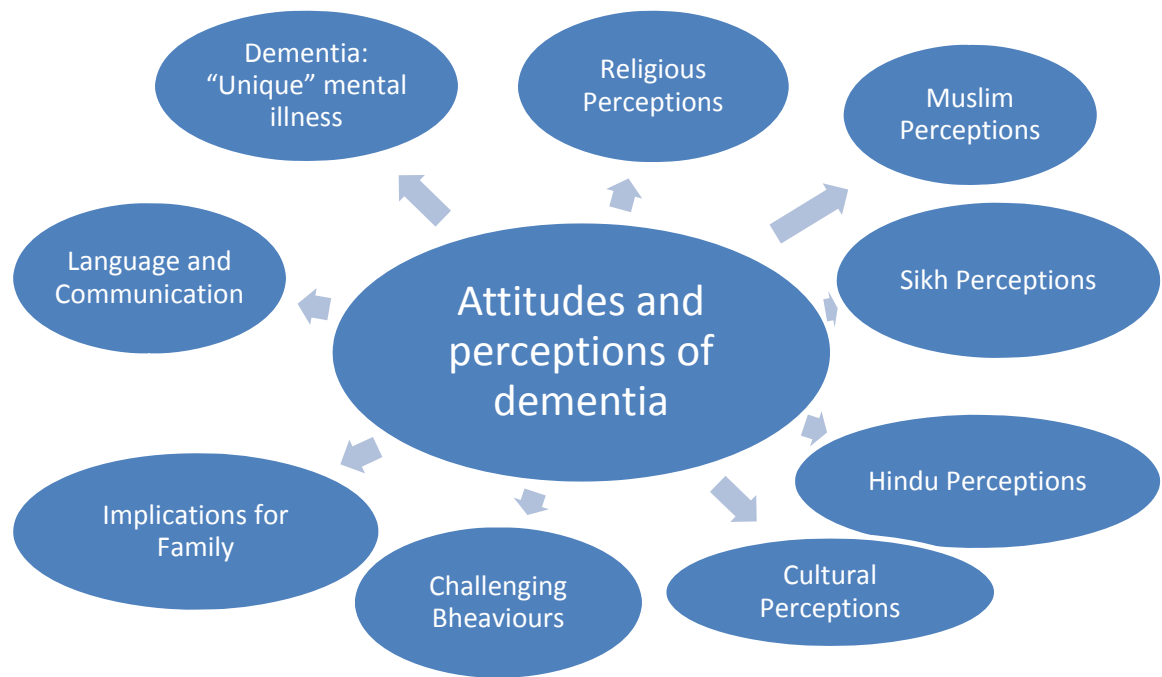
Figure 16: Data themes informing *Attitudes and Perceptions of Dementia.*

The findings imply perceptions of dementia in the South Asian community are often associated with stigma, reflecting negative attitudes towards mental illness broadly. This prevalent theme was identified across data analysis phases one, two and three. It was discussed across all cohorts, in participants of Muslim, Sikh, Hindu and Christian faiths. The data suggests attitudes towards dementia may be inspired by belief systems within the Sikh, Hindu and Muslim faiths and these attitudes influence care seeking decisions. Furthermore, religious-influenced perceptions of dementia and positive religious coping assisted persons to accept and live with the illness. Some participants discussed their experiences of living with dementia as an opportunity to strengthen their faith. In addition, identification of attitudes associated with South Asian culture broadly -

such as language, communication and family structure - offer further insight into South Asian perceptions of dementia.

4.3.1. Religious Themes

Whilst the literature review did not any identify specific allusions to dementia in English language translations of the Hindu, Muslim and Sikh holy texts [see Chapter 2, pp.88-94] , the study participants showed clear attitudes and perceptions towards health and illness - including mental illness - inspired by the scriptures and informing an understanding of dementia. For example, the themes of "Destiny", "God's will", and "God's plan" were identified in data analysis phases one and two. Overlap of these themes occurred in the data across belief systems: "*for the dominant religion there is Hinduism, and the minority is Muslims so they will have similar faiths in relying on destiny and God's will*" (DAP 1, pp#1).

4.3.1.a. Muslim perceptions

In Data Analysis Phase one, the theme of "destiny" was referred to as a possible influence on the acceptance of a dementia diagnosis for a participant in the Muslim faith: "*talking in terms of Islamic beliefs I think, something people have to believe is destiny, that it was destined, and that's why you had this ailment, for example and that it had to happen anyway*" (pp#1, DAP 1). Conversely, a dementia organisation worker described the stigma associated with dementia diagnosis led a Muslim service user (pp#17) to self-isolate from his community: "*he would not want his community to know. He's a very private...and he's an*

elder in the community" (pp#4, DAP 1). In Data Analysis Phase two, a Muslim chaplain discussed his perception of illness as an opportunity to develop patience and allow Allah to grant "shifa" through "holy suffering" (pp#16, DAP 2): *"if we are showing patience in our illness, then it is our belief that our God, Allah almighty will give us Shifa, and Shifa is the term in Arabic, and the meaning of Shifa is you will get cured, you will be recovered"* (pp#16, DAP 2). This understanding informed a perception of illness as a time to reconnect with faith during weakness and is sent by God to encourage patience and offer forgiveness:

"*You will come to health again, you will be active again. So the first thing in our society is people, show their patience in their illness. And our holy prophet also said (peace be upon him), in the illness, our God Allah Almighty will forgive his sins*" (pp#16, DAP 2).

Furthermore, this participant described illness as one way Allah challenges people who have developed pride and may not be showing kindness:

"*A person who has a money, good job, bank balance, luxury home. So ultimately will be proud on these things and might be possible due to this proud he will not kind to other people. When illness comes, his proud will be finished and then he remembers his God, and says God you are my God, so give me Shifa, give me health again and I promise to you I will not feel proud on all these things but I will be generous and kind to the humanity*" (pp#16, DAP 2).

This participant cited the analogy of a criminal who gets punished for his crimes, as a justice-bearing God granting illness or health: *"so actually, seeing this type of system in our beliefs, in our religion, that if we will do these good deeds in our life then God will give us paradise in the life hereafter"* (pp#16, DAP 2). Showing patience during illness will lead to receiving the kindness and forgiveness of God: "s*o if we are showing our patience in our illness, so our sins will be forgiven"* (pp#16, DAP 2). Ultimately, illness was perceived as an opportunity for a person to strengthen their faith: "*YES, Yes, the basic thing is the person faith increases during the time of the illness."* (pp#16, DAP 2) and dementia was also perceived as an opportunity for this.

In Data Analysis Phase two, the perception of illness as part of "God's plan" assisted a Muslim female carer in coping positively with the dementia of her mother:

"whatever happens, it's for the benefit of the person, people don't know, sometimes we desire something really bad and God doesn't give us, but that does not mean this thing is not for you. I always believe it is for my detriment if I can't get this thing maybe it is not good for me, so I believe that" (pp#11, DAP 2).

This participant asserted Muslims believe each part of life is mapped out by God, including ill-health:

Researcher: "*And do you believe, you mentioned there, that the date of death is planned and do you believe that everything else in a person's life is already mapped out by God?*"

PP#11: "*Yes, yes, we do believe that*"

Researcher: "*so every part of it not just the end?*"

PP#11: "*every part, not just the end*"

4.3.1.b.   Sikh perceptions

In this study, Sikh participants discussed the "Will of God" as a theme inspired by Sikh teachings: "*There are scriptures in the Gurū Granth Sāhib. Which do say, there is always two sides of the coin with, there is good and bad*" (pp#7, DAP 2). Adhering to the teachings in the scriptures and accepting God's Will is a way of coping positively in the face of adversity and illness:

"so *they don't take it in anything like that, "why does this happen to me?" because if it is written that way, they take it and with the help of reading the verses of the Gurū Granth Sāhib and listening, coming to the Gurdwara and listening to the hymns of the Guru Granth Sahib*" (pp#7, DAP 2).

This allows a sense of peace and confidence throughout the discomfort and uncertainty of illness. It is an expression of positive coping through faith: "*That gives me a confidence, that gives me an inspiration to listen*

to the Gurū Granth Sāhib and that gives me peace of mind as well"
(pp#7, DAP 2).

4.3.1.c.   Hindu perceptions

In Data Analysis Phase one, the Hindu belief of karma was cited as a
theme influencing perceptions and attitudes towards dementia. There
were examples in the data of dementia being perceived negatively as a
consequence of the belief in karma: *"some people would interpret this as
a sort of a punishment from the God, like you know you lose your sense"*,
(pp#5, DAP 1). The theme of karma influencing negative attitudes
towards dementia continued in Data Analysis Phase two: *"When
someone has got dementia, as a Hindu we strongly believe in the law of
karma. So they strongly believe that in a previous life they have done
something wrong or maybe in this life they have done something wrong,
so that is why maybe God gave a punishment."* (pp#15, DAP 2).
Conversely, the data suggested an alternative perception of dementia as
positive karma; specifically, the renouncement of a physical body and
material relations with the world allows a person to become closer to
God: "s*ome people would interpret it as a sign of becoming a saint or
someone who is not now interested in the worldly affairs, something like
that"* (pp#5, DAP 1). These conflicting perceptions highlight the
importance of recognising the individuality of attitudes towards dementia,
even when these attitudes are influenced by a shared belief system. It is
vital to express sensitivity to individual experiences contained within the
substantive data when considering generalisability of the theory.

4.3.2.   *Cultural Themes*

4.3.2.a   *Cultural Perceptions*

The study suggests low knowledge of dementia influenced a stigmatised perception of dementia in the South Asian community:

- o Example 1: "*dementia is quite a…. not just a stigma, but also, I would say in some* South Asian *communities, quite an unknown term*" (pp#8, DAP 2)

- o Example 2: "*yes it is definitely a reflection of peoples' lack of knowledge, lack of understanding about what dementia actually is*" (pp#15, DAP 2)

This low knowledge of dementia was coupled with a misunderstanding of the role of MHSCS. Families of persons with dementia displayed feelings of being tarnished by the negative associations of mental health: "*having someone in the family might actually be adversely affecting the families' social situation also*" (pp#8, DAP 2). Interestingly, the stigma associated with mental health was postulated by a speaker within the Sikh community as "*a bigger issue than the issue of mental health itself*" (OBS#3, DAP 3).

4.3.2.b.   *Challenging Behaviours*

Dementia can be associated with physical health problems. A Hindu healthcare professional discussed incontinence:

"the issue of stigma arises if there are difficult behaviours, challenging behaviours. Erm, I mean you know, dementia as it progresses it causes a lot of physical health problems, you know. Things like incontinence and those sorts of things which are very, very difficult and sad" (pp#8, DAP 2).

The psychotic symptoms of dementia can add to the negative perception of the illness, and mental illness generally: *"I think it is more to do with the psychotic symptoms or if somebody is quite aggressive in their behaviour and behaving in a different way. Those are the sorts of things where the stigma with mental illness comes I think."* (pp#8, DAP 2). This highlights attitudes towards dementia may not be influenced solely by a religious or cultural perspective, but are susceptible to many factors. For example, challenges surrounding the symptoms and behavioural aspects of dementia impact not just on the South Asian community but on persons from all ethnicities living with the illness.

4.3.2.c   Perceptions of dementia services

A Muslim dementia advocate shared a common fear amongst persons accessing mental health services, namely, that a loved one may be institutionalised if care services are approached for help:

"The stigma is still there that if social services get contacted, or if doctors find out how bad it is, that someone is going to be whipped away and put in an institution or a home and they will be perceived that they can't do

enough for their parents, they can't look after" (pp#14, DAP 2).

Similarly, this fear may not be solely evident in a South Asian community, but could be present across all ethnicities. However, research suggests the lower knowledge and awareness of dementia and available services in the South Asian community than the ethnic majority [see Chapter 2, p.70] may compound this fear. There was a drive from the dementia organisations to change this perception, dispel this stigma and to encourage care seeking: *"Dementia is dementia and it is not a stigma that should be attached to somebody"* (pp#14, DAP 2).

4.3.2.d.   Implications for Family

Dementia was perceived to have negative consequences not just for the individual, but for the wider family unit. A Sikh chaplain working in a mental health setting postulated: *"it affects the whole family"* (pp#13, DAP 2). Marriage prospects are one example where the family are impacted by the dementia of a loved-one: *"if somebody is mental in the family, mentally ill and they will find difficult for the other brothers and sisters, other children to get married. People will think, well they could have the same illness"* (pp#13, DAP 2). A Hindu chaplain also working in a mental health setting conveyed there is a fear the dementia of an elder in the family will pass down to other family members and this may affect their integration in the community: "so *sometimes family believe that like my grandma has got dementia, just example. It could be that it comes to me, and it comes to my children. So it affect my family background, so people want to keep a distance*" (pp#15, DAP 2).

The perception that mental illness should be kept private was discussed: "*When anyone has got a dementia, family try to hiding these things*" (pp#15, DAP 2). Stigma is widespread across mental illness conditions, not just dementia: "*Mental illness generally. Doesn't matter if it is dementia or any... But if it is like a mental illness, family try to keep it aways, aways* [sic] *and everything.*" (pp#15, DAP 2).

A Muslim dementia advocate described family members embarrassment from the BPSD hindered involvement in religious activities:

"*certainly for some of the female* South Asian *patients who are in their seventies, eighties, erm, have gone to the temple and have sort of behaved bizarrely and embarrassed the family and the family hasn't taken them back but that is their source of support*" (pp#8, DAP 2)".

One Hindu chaplain gave details of a family avoiding being seen near the mental health hospital, for fear of being isolated in their community:

"*sometimes it is very, very big stigma, even somebody admitting inpatient in xxx or xxx, and if family can walk from that road, they just avoid, to walk on a main road because if they can see going to hospital it can, community can think, ok they could be admitted to the hospital, or he and she has got a problem, so they avoid. So lots of lots of work we need to do*" (pp#15, DAP 2).

This has negative consequence for the family, thus demonstrating the

widespread effect of stigma: "*leads to the fact that people feel guilty*" (pp#8, DAP 2). There is a need to break some of the stigma surrounding mental health generally to improve dementia services specifically: "*trying to break some of the stigma as well*" (pp#13, DAP 2). From a Sikh perspective, increasing community awareness can be a way to reduce the stigma in the community and work is already being done to tackle this:

"*it is myths, people have to break those….so it is very big sigma* [sic.] *in the community. So this community awareness we will work on those and be on the right track. The stigma has been there for a long time and it is not easy to work on , but I think we are on the right track*" (pp#13, DAP 2).

4.3.2.e. Language and Communication

A Sikh participant postulated the language used to describe dementia has implications for cultural interpretation and understanding: "*Once you say "mental", people think you are mad, honestly, there is no, er, translation for mental either; mental means mad*" (pp#13, DAP 2). The term "mental" has negative connotations, generating a barrier to care and leading to isolation within the community:

"so*, I do not want to use a word like a mad, but sometimes people believe that and that is the one proper word they have in own language…they just sit and isolated in the one room. Nobody contacts, no one can talk to them, so more and more isolated. So it is like a big*

barrier" (pp#15, DAP 2).

The difficulty of communicating the meaning of mental illness conditions and dementia in the South Asian community is problematic due to the lack of words for direct translation:

"I can speak three, four languages but I could not translate in my own words because we have not heard this type of illness so there are not words, it is very difficult to translate especially in the mental health – schizophrenias, dementias and ok, we can translate the word nervous and depressed and all the things, but that type of word is very difficult to translate in to our own language, so I need to find out similar word, very close to it. I am not saying exactly the same but near the words and everything" (pp#15, DAP 2).

In Data Analysis Phase three, during observation #4 (OBS #4), the Sikh community discussed the importance of listening across three levels: the self, the family and the wider community. Allusions were made to the Christian belief "*love thy neighbour*" (speaker during OBS #4) as a basis for treating people with "*passion and humane care*" (speaker during OBS #4) when care giving, in addition to medication and psychological help. The importance of listening will help dispel assumptions. Further training of clinicians will help people communicate in the "same metaphors" (speaker during OBS #4) so the clinician can understand how the client is communicating. Medical labels may be misunderstood as jargon. The valid point is "*how will the client know the difference between depression*

and anxiety, if they have never heard these terms before or understood

them?" (speaker during OBS #4). Whilst not discussed explicitly by the

persons during this observation, the researcher recognises this argument

also extends to recognising the importance of choosing the right

language and the "same metaphors" when discussing dementia in the

Sikh community.

4.3.2.f.   Dementia: "Unique" mental illness

Following on from the previous point, it was identified during observation

#4, dementia may not be perceived to be in the same category as other

mental illnesses, such as depression, anxiety, or schizophrenia (OBS#4).

This notion was perceived by the researcher during a conference of

mental health in the Sikh community, during which dementia was only

very briefly mentioned. Work could be done to incorporate dementia in to

the realm of mental illness issues, or, alternatively, to recognise its

status as a standalone mental illness and aim to raise its profile in the

same effective manner as the other mental health conditions at the

conference. It was recognised education is needed to dispel assumptions

about mental illnesses, such as depression: "depression is an illness just

like any other" (speaker, OBS #4). A shift towards parity between

physical and mental health conditions in perceptions, attitudes and

treatments is required. A dementia specific conference in the South Asian

community is one positive way to reduce the stigma associated with

mental illness.

4.4. Qualitative Findings: The Decision to Seek Dementia Care
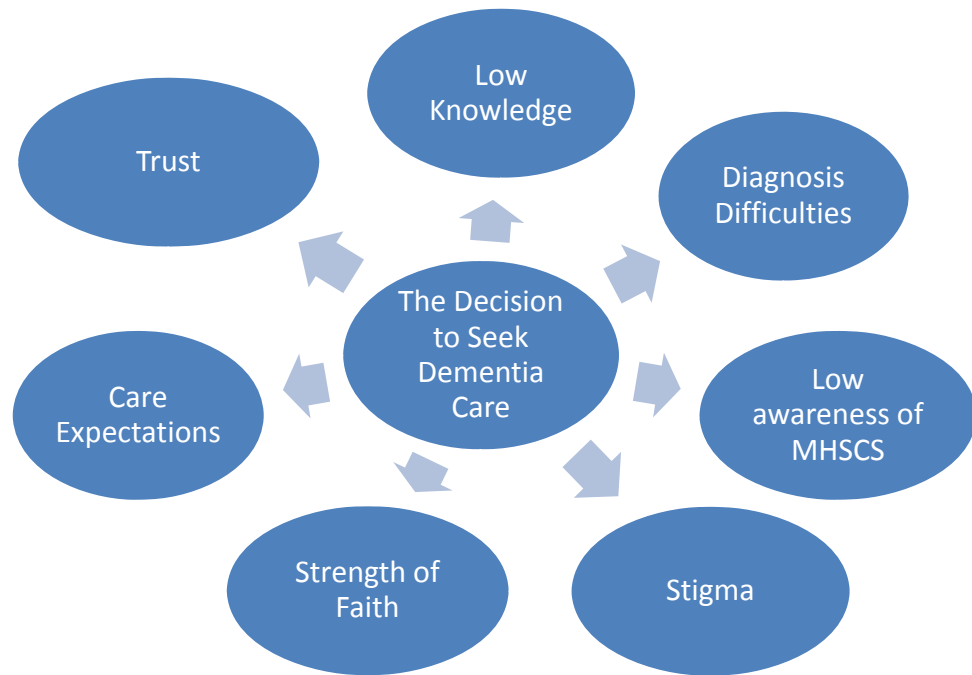
Figure 17: Data themes identified informing *The Decision to Seek Dementia Care*

The study identified perceptions and attitudes of dementia, influenced by religious and cultural understandings impact on the decision to seek dementia care in the South Asian community. Two main explanations were identified for why MHSCS may not be sought. Firstly, dementia as a medical condition is under recognised, as a result of low knowledge and the signs and symptoms of dementia being attributed to "normal" ageing. Secondly, when dementia is recognised, factors such as diagnosis difficulties, stigma, trust and expectations about care services, influenced by cultural outlook contribute to the decision for not accessing MHSCS.

4.4.1.   Religious Themes

4.4.1.a.   Strength of Faith

In Data Analysis Phase one, the theme of "destiny" was prevalent as a potential influence on the decision to seek dementia care: *"if I am going to be treated that is my destiny, if I am not, that is my destiny"* (pp#1, DAP 1). This Muslim healthcare professional suggested a belief in "destiny" may only hinder access to care for persons with an especially strong faith: *"there are patients who are more religious are happy to leave the will with God and say ok, what is destined for me will happen, people who are not that religious may say ok this has happened but I need to seek some help"* (pp#1).

A Sikh representative conveyed willingness to co-operate with healthcare services and encourage members of the congregation to take medical advice, even if this meant putting a person with dementia in a care home: *"It is the patient that is most important. If the health authorities, or we, think that would be better in a care home then we will take that advice accordingly"* (pp#7, DAP 3). Religious representatives in the Sikh community encouraged persons to take medications alongside their religious adherence:

"we do encourage people to take medicine. Because in our community, some people think they are going to be cured by prayers only, and that is when we have to persuade people to take their medicines properly or on time. Pray at same time" (pp#13, DAP 2).

Hindu chaplains have been able to educate about the religious creeds and beliefs in a positive way, whilst encouraging persons to understand the neurological status of dementia and the bio-medical care provision. The multi-faith chaplain is vital to help with the interpretation of religious creeds:

"But (in) that time, my role (is) to just interpret (the) different roles of karma, and I just explain whatever information I have got - dementia it could be related to..it could be age related, it could be something brain ...it is nothing do it like God is punishment, because God is love everybody, regardless of what you have done in the past, the present or the future, but it is nothing to do with the karma or anything like...because the law of karma one side is a good for the Hindu community, but sometimes people misinterpret for a different way, because there is like a punishment," (pp#13, DAP 2).

As established in Data Analysis Phase one, and developed in Data Analysis Phase two, this can have negative implications in terms of care seeking and conforming with medications:

"and when people believe that way that it is like a punishment, they don't do anything because they feel like God has do it and they simply sit at home, do not take any part of the medications, or do not take advantage from the medical professional from health and guidance" (pp#15, DAP 2).

4.4.1.b.   Trust

In the Muslim community, the notion of trust was raised by a person with dementia both in terms of firstly, trusting his own community enough to share the dementia diagnosis and secondly, the subsequent uncertainty when deciding to access care provision: "*I could only do that with somebody I could relate to*" (pp#17, DAP 3). This participant described his previously integral position as a respected elder in the community. He now has renounced his role in the religious community and does not attend the mosque, but has not told the community the reasons why: "*I have isolated myself from all that*" (pp#17, DAP 3). This isolation from the religious community has developed in to anxiety of all social situations; "*consequently I kept myself to myself*" and "*I don't go out at all because I have got this anxiety*" (pp#17, DAP 3). This participant stated no one in his community has ever had dementia and that dementia is a concept "*difficult to understand*" (pp#17, DAP 3). Consequently he has isolated himself:

"*I don't know anybody who has suffered with dementia, so I can't even relate to anybody…or think like that guy has gone through this, within the community of the people that I used to meet*" (pp#17, DAP 3).

4.4.2.   Cultural Themes

4.4.2.a.   Low Knowledge

The study data implied if memory loss and the behavioural and psychological symptoms of dementia (BPSD) are not recognised as signs and symptoms of neurological disease, then medical care may not be

sought. There is a lack of awareness and understanding about dementia in the Muslim community, expressed by a Muslim male with dementia: "*they don't know about it*" (pp#17, DAP 3). Participant #17 stated the first time he heard about dementia was during his diagnosis. There were further examples in the data where the first time a person hears of dementia is through personal, direct experience. One Sikh chaplain said his first knowledge about dementia derived from education in a UK context:

"*that is what I am saying, dementia awareness is very important and we don't know what it is in our community. Maybe people who have been educated in this country and been through education, maybe they will know but I didn't have chance to go through education in this country so that was the first time I have seen dementia*" (pp#13, DAP 2).

4.4.2.b. Normal Ageing

The data suggests the perception of memory loss as normal ageing hindered South Asian persons in recognizing the symptoms of cognitive impairment. This impacted on subsequent decisions to access care:

"*The other problems with ethnic groups and mainly I am speaking of the* South Asian *groups is that the access to the treatment or access to help is delayed because usually the family will not recognise the dementia signs and symptoms, they might recognise that as elderly people going slightly off the track and just forgetting and this is what the Granny will do, not remember things, and those concepts are quite ingrained and as*

people age it is well know people think that it is a normal thing to have the memory problems" (pp#1, DAP 1).

This demonstrates the importance of promoting dementia education and awareness for persons of South Asian culture to allow informed care decisions.

4.4.2.c. Diagnosis Difficulties

Communication was one of the main categories (3rd) which emerged from data analysis Phase one [see table 13 for full category list and rankings]. Specifically, the difficulty diagnosing dementia in non-English speaking persons was recognised as a problematic barrier: *"specifically about people from* South Asian *background, assessment tools are a problem, you have the example of MMSE"* (pp#1, DAP 1*).* Existing tools such as the MMSE (Folstein, Folstein & McHugh, 1975) were not seen as culturally appropriate from the perspective of healthcare professionals.

4.4.2.d. Low awareness of MHSCS

A Muslim male with dementia portrayed low awareness of available health and social care services: *"I don't think anything of this nature is made aware to the community"* (pp#17, DAP 3). There is a *"lack of communication"* (pp#17, DAP 3) about organisations which creates barriers to services, leading to underrepresentation: *"there is a barrier of some sort whereby people who are there to help are not being accessed, not being used"* (pp#17, DAP 3). Services are there but people do not

know about them: "*these organisations are there, they exist because there is a demand for it, but even within the host community, there are not people who know about it*" (pp#17, DAP 3). This participant suggested resources such as an advisory network would be useful for communicating about available services: "*there are people that need help, they don't know where to go, so I think we need something for dementia but as a whole, we need some sort of advisory network, where they are at least made aware of what type of help is available*" (pp#17, DAP 3). There is "*not enough publicity*" (pp#17, DAP 3) and no links between organisations and people: "*There isn't a link between the organisations and the normal, average people out there*" (pp#17, DAP 3). It was discussed that existing services are "*doing the best they can on the resources that they have*" but "*could be improved*" with "*basic education*" (pp#17, DAP 3).

4.4.2.e. Stigma

A Hindu healthcare professional in Data Analysis Phase two cited stigma as directly affecting the decision to access healthcare for South Asian persons: "*There are stigmas and taboos attached to having a mental illness and being under a mental health service as such, so people don't present to us at all. Or they present very, very late when it is too late to do anything.*" (pp#8, DAP 2). This theme was developed by a Sikh, clinical senior manager during Data Analysis Phase three who asserted early intervention was vital to remove stigma and improve the possibility of a "positive recovery" (pp#20, DAP 3): "*It's very much about the preventative work. It's about early intervention. The premise being that*

the sooner you intervene the earlier you intervene, the far more likely a positive recovery at the end of it" (pp#20, DAP 3). This participant expressed South Asian people are presenting at a late stage to mental health services generally: *"I think that when people are in services it is too late, because, particularly for secondary care services"* (pp#20, DAP 3).

Early intervention can be promoted through the education of persons in the religious community buildings and enlisting the support of family and primary care services: *"I think the opportunity to have those conversations is in primary care and at early intervention you know, outreaching into Gurdwaras or community centres or wherever people may be, and it also depends on advocacy and strong family* (pp#20, DAP 3)". The notion stigma might be more prevalent in the older generation was raised: *"I mean there are fantastic psychiatrists there but it is still a big stigma to see a psychiatrist, especially older people with some of their preformed ideas about mental health"* (pp#8, DAP 2). In Data Analysis Phase two, it was identified this stigma can make a person with dementia and their family less engaged with the community in the Hindu faith:

"especially when anyone has got like family has got a dementia, this person could be less engaged with the community and when people ask the questions, ok why your father could not come to the social event, they say they make some excuses; he is not very well today or he needs

to go somewhere else, so this type of…so family also keep this person, is isolated more and more." (pp#15, DAP 2).

Persons with mental health issues will separate themselves from the community also:

"I know one or two people they are not dementia but they have got a mental health issue. So you can see how they are different. Different means they can sit separate when they have a congregation. Some reason and they feel they are all isolated, so they do not engage" (pp#15, DAP 2).

The community in the Hindu temple will welcome the person but the person self-isolates because they perceive themselves as "different":

"Yes, religious practice. But temple and community, they welcome, but the person himself or herself believe that they have got something different so they keep themselves separate. Yes, community has got no problems at all, but the client has got own stigma" (pp#15, DAP 2).

Or, they may visit the temple at a time where there are less people in attendance at a less busy period. Worship becomes more personal and isolating, rather than as part of the congregation:

"No, they go, but LESS, keep separate. They just avoid the time when more people. Temple is open from 6-12 and 4-8, so they just check the time when there is less people then they can come and do their worship and do and go home." (pp#15, DAP 2).

The fear of questioning from members of the community contributes to this self-isolation: *"If it is a long term illness they do not feel like they want to engage in religious affiliation or religious congregation and everything, cos they feel like ok, if I am going to this congregation, maybe people ask the questions"* (pp#15, DAP 2). This stigma prevents access to services for persons from the Hindu community: *"in our community it is very big problem and people just won't admit, they won't seek professional medical help on the right time"* (pp#15, DAP 2). This participant identified even in well-educated persons in the community, who have lived in the UK for a long time and are very much ingrained in British culture, stigma exists and is not easy to tackle:

"so this type of stigma also happens in family. She live in this country, sister live in this country, could be 40-50 years and she is like a British, she speak English, she run a business, she live in a very posh area, but still this is happen. So you can see how much we need to do the work. It's not EASY. It's not easy and it's not straightforward, 1 +1 is equal to 2." (pp#15, DAP 2)

4.4.2.f.   Care Expectations

It was suggested expectations of available care by South Asian persons in the UK may be reflective of care expectations in their native country: *"in India, family need to do each and everything, family needs to do everything. We do not have an NHS, so we need to pay everything from our pocket, ok, so if family is capable to provide each and everything they can provide the service."* (pp#15, DAP 2). The lack of resources in a person's native country offers one explanation for low knowledge of

mental health: *"Especially mental health in India, we haven't got enough hospital in india, either inpatient or outpatient, so if someone diagnosis, very hard and very hard to diagnosis to pick up the mental health"* (pp#15, DAP 2). The difficulty of adjusting to different cultural practices was raised:

"if I come from India, it is very hard for me to accept all these things. I won't make a fuss, I will adjust, but it is very difficult for you to accept them. Is this alright? With an Indian mind you think, this can't be right? But you can't do nothing more" (pp#13, DAP 2).

Expectations of care provision in the UK were seen to be influenced by knowledge and expectations of care in a person's native country, for example, India:

"like a dementia and if it is old age, this old man would say, "don't spend money on me, spend money on something else, which is useful, so these things happen in India. I am only talking about one....I am not talking about all of India, especially talk about one or two town, it is a big town." (pp#15, DAP 2).

One Sikh participant asserted some South Asian people who have migrated to the UK may not expect health and social care to be provided: *"if you are educated in this country it is welfare state and it's the states" responsibility. That has happened in Asian…it hasn't happened in every family, but it has happened in quite a few families."* (pp#13, DAP 2). Thus, it is important for the service user to feel familiarity, recognition

and connection to the care provider: *"when they see you turban, they feel somebody from their OWN background, or somebody from their community has come to see them and they feel good about it."* (pp#13, DAP 2).

A Hindu participant expressed on behalf of his community the gratitude towards health and social care services in the UK:

"Family is their carer, family is their doctor, family is their nurse, family is everything family needed to do this one, so it is very, very difficult, so in this matter we are far better in UK. And especially in my community and especially in the Hindu and I would like to thank God, and thank the British NHS and the Government that they look after mental health and Hindu community" (pp#15, DAP 2).

The differences in health and social service provision in India and the UK were discussed by a Hindu chaplain: *"I always look into the hospital what they do, especially in the acute hospital in mental health and everything, look at what they do and meet people there, but it is totally different, totally different from here"* (pp#15, DAP 2). The provision of mental health services was perceived as inadequate in India, where health care is paid for privately:

"so*me hospital there is like business, corporate hospital, like we have got the corporate hospital here, private, like priory or something, if you have got the money then you can get seen on second day or too quickly. NHS*

you have to wait for some cases, or in India, if you do have money in your pocket you can get the service very quickly, within hour or half an hour, but if you have got no money it is very difficult to access. We have run so many hospital in India, like charity hospitals, Government hospitals and everything but it is like a big population, it is very difficult to get all the resources and help in India" (pp#15, DAP 2).

A Muslim chaplain participant discussed in Pakistani culture there is no concept of care homes and this was a "British" concept:

"there is no concept in our country, in Pakistan about Old care homes. No concept. But here, in British society they make all care home to better look after those persons who are aged, who are more than 65 or 70 or 75, because they need 24 hour look after from anybody." (pp#16, DAP 2).

A Hindu chaplain asserted this led to the isolation of people in nursing homes who were from minority cultures:

"you can see if one or two client from other background, faith background or culture background they could not engage in a nursing home, day to day daily activities. They sit isolated in a chair, or could be in their room all the times and pass by, it is very difficult to engage in the nursing homes and engage day to day concept, in NHS in UK, it is very, very difficult. It is very difficult" (pp#15, DAP 2).

4.5.   Qualitative Findings: The Provision of Dementia Care
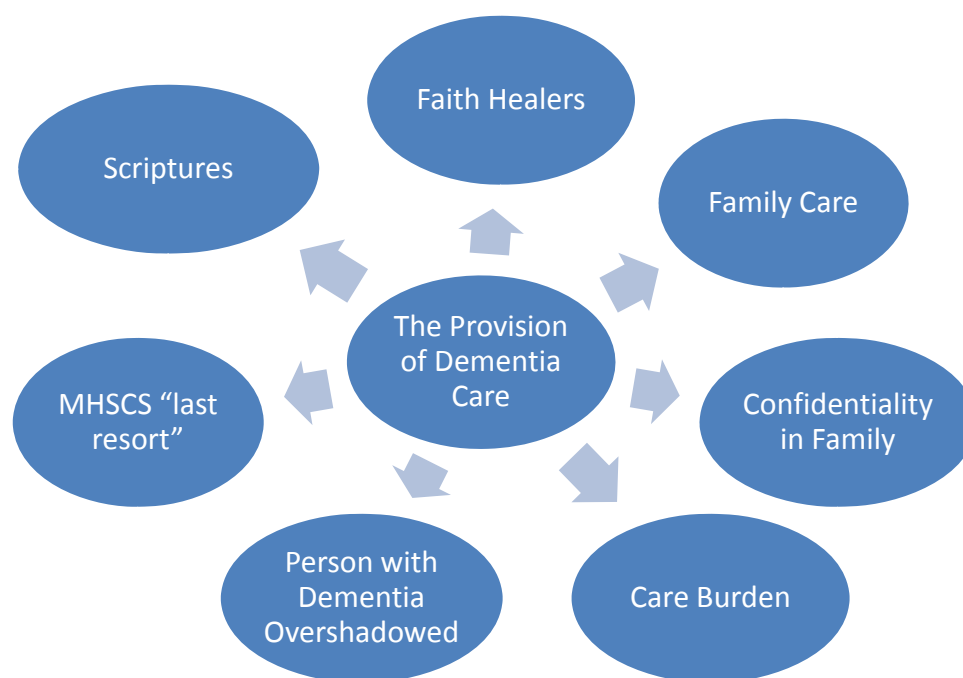
Figure 18: Data themes informing *The Provision of Dementia Care*

The data suggests when the decision to seek care for the person with dementia is made, religious perceptions influence decisions about where this care should be sought; either through MHSCS or through additional care services such as the family or religious community. One explanation is care expectations in the UK may be influenced by perceptions of care provided in the person with dementia's native country. For example, in India "*there is no care provision*", "*no provision for dementia patients*", "*there is no particular place or hospital to look after the dementia*" (pp#7, DAP 1). South Asian persons may not expect MHSCS to cater for their mental health needs.

4.5.1.   Religious Themes

4.5.1.a.   Faith Healers

The data suggests in the advent of mental illness, a Muslim person may go to their religious place of worship first, rather than visiting the GP:

"When you try to separate the medical problem from the religious background it would be difficult to convince because they believe that everything is the destiny, and you cannot do much to intrude. I know quite a lot of people who do go to different areas to seek help, this is going to be cured by this faith healer, but it is clear that they should have gone to the GP to ask for help but they have gone to other places" (pp#1, DAP 1).

This reflects the Indian tradition to visit a faith healer or religious representative for assistance with a mental health condition (Bhatnagar, 1997): *"going to the prophets the faith healers and asking for spiritual help from the leaders and people who are in mosques; the Imams and people do read the verses of the Qur'an to help erm, sort of get the treatment of that"* (pp#1, DAP 1). It is important to consider not all persons from south Asia with a strong faith will share this perspective and this care seeking behaviour may only relate to a small minority of persons: *"so yeah that is still there in some group, maybe in the minority, not the majority of that group will have these thoughts"* (pp#1, DAP 1). Contrastingly, a Sikh participant stated faith healers are not sought instead of health services: *"the majority of the Sikhs won't go to faith healers or anything like that. They will come because they know*

that what happens to their body, or anything like that, it happens in the will of God" (pp#7, DAP 1).

4.5.1.b. Family Care

Religious beliefs influenced care decisions such as keeping care within the family as a result of moral obligation in the Sikh community: *"the family look after that patient"* (pp#7, DAP 1) as a result of a: *"close-knit community and the families like to live together as you know"* (pp#7, DAP 1). This close-knit, family orientated community influenced care provision:

"It is usually, as you know, for the Sikh community I can speak of, the Sikh community. They are very, very closely knitted communities and closely knitted families. The sons and the grandsons if they can we try to live together in a bigger house or, the families very close to each other" (pp#7, DAP 1)*.*

According to Sikh religious doctrine, respect and care should be shown to your mother and father as a result of a person's moral duty:

"I think it is because there, according to Sikhism, mother and father have brought you in this world. It is your moral duty to look after them and that's how we look at that. If it wasn't for their mum and dad or parents, they wouldn't be on this earth. That's why it is there moral duty to look after them" (pp#7, DAP 1).

Respect for parents and elders and the duty bound obligation to provide care, even if this places burden on the caregiver was a theme also identified in data from Hindu participants: "*DUTY. It is my moral, ethics, religious duty to look after him. She could not look after him due to her age. Ok, both are early 70s, 75, so it is very difficult to her to look after, but still she try to do it*" (pp#15, DAP 2).

The Muslim community in this study also subscribed to the duty of family care and one Muslim chaplain participant discussed this in detail: "*in our community, whenever a person has a type of dementia, his children and his relatives basically they take care of him*" (pp#16, DAP 2). The Muslim virtue of patience was discussed when caring for the person with dementia: "*son or daughter of him, they have to listen to him with patience, so that is the actual care of that person. So if they will show their patience, their revere, then they can accommodate that person in their family*" (pp#16, DAP 2).

There are levels of respect in the Muslim faith assigned to all people in the community, with parents as the top ranking: "*first of all we have to take care in our community of our parents, then of our brothers and sisters and our relatives, then other people of community. Then the people who are not Muslim*" (pp#16, DAP 2). There is a saying in the Muslim faith in the Hadith about paradise being "*under the feet of your mum*" (pp#16, DAP 2) as she cared for you as a child it is time to return the favour in adulthood by caring for parents: "*Even the holy prophet (Peace be upon him) said in the Hadith that paradise is under the feet of*

your mum" (pp#16, DAP 2). The fulfilment of filial obligation is the key to the afterlife and key to peace in this life: *"if we are do respect of your mum, our parents, then we will be able to get paradise in the life here after. If we will do respect of them, if we take care of them, then the life in this world will also be peaceful."* (pp#16, DAP 2).

The Muslim religion teaches persons to care for their parents: *"our religion teaches us take care of your parents as they took care of you when you were a child. So our holy prophet, Muhammad (Peace be upon him)"* (pp#16, DAP 2). Expression of the Muslim faith can be seen through demonstrating respect towards others:

"We can get this peace and we can get the reality of our religion by respect of others. So after the respect of God and after the respect of the holy prophet, our Islamic teachings teach us to do respect your parents, do respect your elders" (pp#16, DAP 2).

Expression of faith is especially prevalent through the demonstration of respect to all family members: *"Either is your elder brother or sister, either is your uncle or aunt, either your parent. But we have to do respect"* (pp#16, DAP 2). A strong adherence to the Muslim faith can be demonstrated by caring well for a person's parents: *"I think at that time our community, they take care very, very much of that person and if they have beliefs in their religion, firmly, strongly then we will take care of him very, very much"* (pp#16, DAP 2). This participant asserted Islamic beliefs are based on respect, peace and harmony; not providing care for

parents in their age or illness is not demonstrating this respect: "*He doesn't do the due respect of their parents so basically the Islamic religion and all the Islamic beliefs are based on respect, based on peace and harmony.*" (pp#16, DAP 2). There are Muslim teachings encouraging respect of elders and avoiding materialism: "*If we don't have respect in our hearts of them then ultimately we will be lost in these worldly luxuries, so our teachings, the teachings of our Islamic beliefs, the teachings of our Islamic religion is to take care of your elders*" (pp#16, DAP 2).

The difficulty of staying true to the scriptures in practice and providing care solely in the family was developed in Data Analysis Phase three by another Muslim chaplain participant, who was working in a mental health clinical setting:

"s*adly, due to time changes and peoples' lives being so busy now, across the globe and time moving so fast, people do not have that much time for each other, people do not have time for their own families, so much so, so looking after the elderly, sometimes irrespective of that they have dementia or any other illness they can't really cope for them to be cared for in the homes. So care homes have been provided and lots of places are now coming up with culture specific care home, so that they can be catered for within their culture*" (pp#21, DAP 3)*.*

The scriptures may be used as a guide to care for elderly parents; implementing this in practice requires training and education, particularly

for the younger generation who may hold different values and beliefs than the older generation:

"*Theoretically, like I said to you the Qur'an quite specifically says that when a parent or both parents reach elderly age and the forgetfulness and other aspects of their lives, their eating, drinking. All that needs a lot of care, so a lot of the younger generation are going in to training*" (pp#21, DAP 3).

This participant stated the family is the decision maker regarding the continuation of religious practice for the person with dementia: "*if somebody did receive a diagnosis of dementia, then generally it is the family who get to know that first. So it is not the community who decide, it is the family who will decide whether this person would be able to go to the Mosque, or not*" (pp#21, DAP 3)*.*

4.5.1.c.   Religious Rituals

An important finding was one positive way to help a person with dementia feel valued is by using Sikh rituals as a basis for providing care:

"*The practices in Sikhism are when you go to a temple, you know, you put your hands up and you receive Parshad the sacred food they give you, and you receive the rotis and the food and you receive it in this sense that I am asking for it, please give it to me. So you are requesting it and it gets given to you so the giver's brain is healed and the asker's brain is healed*" (pp#19, DAP 3).

Compassion in care as a result of religious beliefs was discussed. The process of giving and receiving in temples allows both the giver and receiver to be healed:

"so there is that element of being kind and compassionate to all people regardless of where they are at. Making requests instead of demands" (pp#19, DAP 3).

The level of care towards others was dictated by Sikh practices and behaviours within the temples*:*

"Because the thing is in the Sikh temples when you service someone a cup of tea, you can kind of go, there's your cup of tea, there are your two sugars, or you can go here are your two sugars and put them in the cup. It is like there is a level of care that you know is practiced when you are serving people in a temple because those people are symbols of God, you are expressing love and affection and kindness" (pp#19, DAP 3).

The universality of Sikhism has implications for all persons learning to care compassionately from the scriptures*:*

"It is holistic health and wellbeing of which mental health is very important of course. In fact it is primary. But the whole idea that Sikh health and Wellbeing trust is not a religious organisation. You know atheists can come to this and learn a lot. Which is what the Sikh scriptures are about; it is not just for Sikhs, it is for anyone" (pp#19, DAP 3)

4.5.1.d. Care Burden

A theme emerging only in the participants from the Sikh community was the notion that duty of care lay with a single, unmarried person, even if this person is male. The Sikh community differed in this respect from the Hindu and Muslim faiths where caring was traditionally associated with females. The expectation from the Sikh religion was the single, unmarried or divorced sibling should provide care for their parents, regardless of gender:

 "*Now, in our Sikh religion, usually the son or the daughter that is not married is lumbered with the parents. Like you can take care of mum now, you're here, you haven't got any children*" (pp#19, DAP 3).

 This placed a burden on the sole carer who felt unsupported by his siblings: "*And it is remarkable that the other siblings don't even check in, say do you need any help, or should we come over? No. It is expected that everything is for her to do*" (pp#19, DAP 3).

 There are expectations in the Sikh religion that a request should not be refused. This can impact negatively on the sole carer who may feel overwhelmed with the cater burden: "*our way of upbringing is to always say "yes". You know to decline a request is very bad, I mean you can say yes and then in the afterwards don't do it is ok, which is out of integrity*" (pp#19, DAP 3). This arguably contrasts with the western tradition to only make promises that can be can keep instead of committing to an obligation which cannot be fulfilled.

4.5.1.e.   MHSCS "last resort"

The data highlighted instances from the Sikh community where persons go to the GP as a last resort. Religious representatives are encouraging persons to seek help earlier:

"when nothing works out, then they go to the GP at the last stage. They will go to anyone they think they can help and then the GP or medical help, or professional, is maybe the last step they take. We are encouraging people to go to the GP at the first stage so other people in the community don't take advantage of them" (pp#13, DAP 2).

There was discussion of people being exploited by persons offering "*miracle cures*" (pp#13, DAP 2) for illness, including mental illnesses: *"a lot of people pay thousands of pounds to the* Black *magic people and actually trading standards took hold and the person was jailed. He had four houses, 800 thousand, four places and making money off illness"* (pp#13, DAP 2). A Hindu chaplain highlighted the low knowledge of mental health in the community and the implications for care seeking:

 "In my Hindu religious community when any illness happen, especially with the mental health. Firstly they have got less awareness – what is the mental health? Ok, and normally approach to the Priest rather than first go to the doctor or something like that, and they believe that something like Black *magic"* (pp#15, DAP 2).

4.5.2.   Cultural Themes

4.5.2.a.   Confidentiality in family

The theme of confidentiality is one example, articulated by a participant carer in the Sikh community where a conflict between family and community may arise:

"*It is like the notion that in* South Asian *languages there is no notion of confidentiality. What is one of those? Because everybody knows everything about everybody; we live in communities so ...in Punjabi there is no word for confidentiality. However, there is a notion of something being personal*" (pp#19, DAP 3).

4.5.2.b.   Person with Dementia discounted

It was highlighted by a Muslim dementia advocate the person with dementia is often discounted by the family when making decisions about care:

"*And I think that is really important, especially with a person with dementia that services take the effort to speak to that individual in a way that they understand rather than speaking with the families, because often that happens and as nice as families are it is not always what that person will wants or needs*" (pp#14, DAP 2).

The family's expression of the person's needs may be in conflict with the person's actual needs: "*sometimes families ask for what families want*

and not always what the person wants" (pp#14). This participant described the danger of the person with dementia's voice being overshadowed by the family, and the person with dementia may not want to challenge this for fear of threatening their relationship or affecting care received:

"*if it is a son talking about his mother she is not going to talk over her son because her son is the one who is going to be caring for her, she may be asking for something very different and for anyone working in any capacity with a service user who is vulnerable (…) that you listen to what that service user is asking*" (pp#14).

It is important to note that these concerns may potentially be evident within the cultural majority also.

Qualitative Findings: Satisfaction with Dementia Services
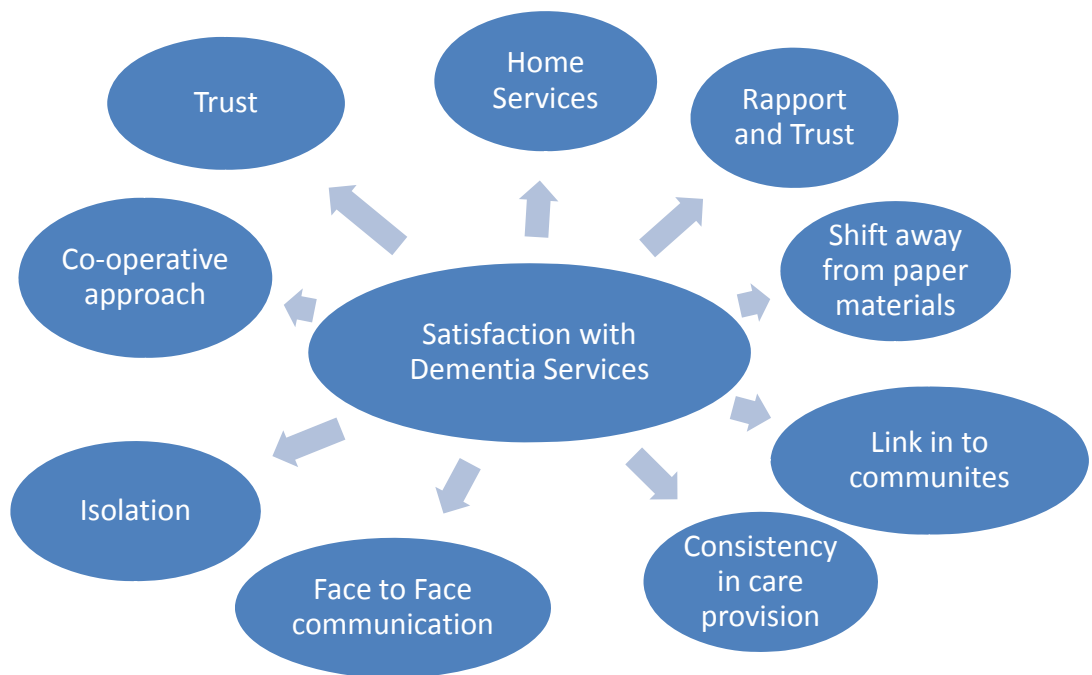
Figure 19: Data themes informing *Satisfaction with Dementia Services*

The literature review identified when South Asian persons with dementia do present to MHSCS, they may be due to dissatisfied with the provision received [see Chapter 2, p.72]. In the present study, there were mixed results regarding satisfaction with dementia services.

4.6.1. Religious Themes

4.6.1.a.   Trust

 The importance of building a rapport and trust with care-providers was raised by a Muslim male with dementia: "*trust factor is built up and maybe he or she would open up and but talking it cushions the blow*" (pp#17, DAP 3). There should be a focus on humanity, passion and honesty across all cultures and religions: "*sharing problems, halving*

problems it does help if you do it with passion, be honest about it. We are human at the end of the day" (pp#17, DAP 3). This participant cited his "*desperation*" (pp#17, DAP 3) for help, which offers an explanation for why he sought MHSCS, despite not fully trusting them: "*Mental illness it's not just physical or psychological, it is also emotional I think*" (pp#17, DAP 3). The local library was suggested as place to disseminate information as was invitations through places of worship: "*invite people to go there through Mosques"* (pp#17, DAP 3). Liaison with GPs was recognised by this participant as most important to promote education and awareness of dementia: "*I think there is nobody better than a GP to actually highlight some of these conditions, because they are actually medical conditions"* (pp#17, DAP 3).

Despite initially suggesting the Mosques as a place for outreach, later in the interview pp#17 does not think reaching people in the mosques would work: "*because of faith, culture and language trying and help people through mosques and public places, would not be successful*" (pp#17, DAP 3). He recommended home visitation is better on a "*one to one level"* to build up trust and "*can talk in confidence"* (pp#17, DAP 3). However, he described it will take time for Muslims to build up this relationship: "*I personally believe that it is going to take quite some time for a Muslim person, male or female to earn that trust"* (pp#17, DAP 3).

4.6.1.b. Co-operative Approach

The importance of a co-operative approach within health services and the community, was raised by a Sikh senior clinical manager:

"I feel that there is within the community development model, a lot of investment in communities, but not enough inside services, so there is almost parallel pieces of work going on where I think it would be far more productive if that work was joined up in some way, so communities and services are learning from each other and working together to improve services" (pp#20, DAP 3)*.*

Services need to be prepared for persons who decide to access them. There is already a lot of good work happening, but a lack of consistency and strategy: *"the community development workers do lots of ad hoc work but there isn't really a strategy sitting behind that, so there is very little"* (pp#20, DAP 3). These projects may not be as prevalent or consistent in the NHS currently: *"certainly last five to six years, training in cultural competency and capacity and cultural sensitivity has really dropped off the agenda* (pp#20, DAP 3). There has been a shift away from generating these projects in to practice: *"equality and diversity work across the NHS has become so formalised, it's become very much about legislation, it's become about principles"* (pp#20, DAP 3).

4.6.2.   *Cultural Themes*

4.6.2.a.   *Home Services*

A Muslim dementia carer communicated satisfaction with services utilised within her home setting, such as professional carer visits (pp#11, DAP 2), although contact with these services was minimal: *"They asked me several times, you know you are entitled to have the carers allowance, why don't you go for it? And all the time I said "no", because it is my*

duty towards my mother" (pp#11, DAP 2). Whilst the majority of care was provided by the carer herself in the family home, the carer was happy with the assistance received from care services:

 "They were very courteous, very polite with my mother, so I can't think of like they can improve….obviously, the way I have seen them they were really nice and I don't think so. Obviously all the time there is a chance of improvement but whatever they were doing was enough for me I think." (pp#11, DAP 2).

This participant stated the feeling services were very helpful: *"they used to send them, like their managers, to check that they were doing the service that they were providing and I always tell them that it's like erm, a very big help to me"* (pp#11, DAP 2). In contrast, a Muslim male with dementia experienced dissatisfaction with several MHSCS he had accessed externally from his home:

 "It could be improved er and the only way it could be improved again, it's involving the cost or whatever is involved, it's they need that basic education" (pp#17, DAP 3). This raises the notion that the setting where care is provided is important. This data suggests some persons with dementia prefer outreach care services in a domestic setting.

4.6.2.b.   Rapport and Trust

 The importance of clear communication to build rapport and trust was raised by a dementia advocate:

"*we will just not ask the question of do I take my shoes off when I come in to your house? Or how do I say hello in your language? Things like that. So sometimes we just avoid the subject altogether and it doesn't build up good relationships that way because if somebody can't trust you, how can they tell you what is going on with them?*" (pp#14, DAP 2).

 There is recognition the culture of the service-users may be different than the culture of the service-provider. For example, a White British, Chief executive of a dementia organisation, expressed awareness of his own limitations when understanding the South Asian dementia care experience: "*I'm not from that community so I can only be go on what people (laughs) tell me*" (pp#9, DAP 2)*.* Trust can be built by service providers by showing consideration of the service-users religious and cultural practices:

"*When I work with the Muslim community especially I always have a scarf. I may not always wear the scarf when I am out and about as a person, but I keep it in the car. If I go to a family that is a very religious family, I would not go into their house wearing things that would be disrespectful. I would go covered. But that may not be the person that I am but it is just saying that I respect your religion, your culture, your faith and that I will behave appropriately*" (pp#14, DAP 2).

Educational literature provided by dementia organisations is created with good intentions, but may not be effective: *"on pen and paper it looks really good and you have tried so hard - you have got everything, you've got DVDs, and you've got CDs and you've got posters, but people don't really understand."* (pp#14, DAP 2). Vitally, there needs to be a shift from a paper format to a face to face approach to generate materials which are: *"in the right format for the right people"* (pp#14, DAP 2). It is important to not just say: *"we have tried our best"* (pp#14, DAP 2) because there are many leaflets in different languages, but it is important to find out what will work best and not make *assumptions"* (pp#14, DAP 2):

"someone will tell you, we have tried our best and we have looked at the Sikh Gurdwara, we took Punjabi and we thought that they would understand Gujarati, but it appeared that they speak Gujarati, but they actually read Punjabi. But we didn't know that, so we went back again and we left them some more written information in the language that they requested. So again it is about making assumptions. We made an assumption that they spoke Gujarati and they read Gujarati. We got Gujarati leaflets made up, but in fact they don't read Gujarati" (pp#14, DAP 2).

Ultimately, *"we just need to look at how any care service needs to keep in mind about the information that they are providing to the people that it is in an accessible format or interpreted or whatever way that that person will understand that"* (pp#14, DAP 2)

4.6.2.c.   Shift away from paper materials

The focus on paper based materials is flawed and may be misunderstood, mistranslated and does not account for illiteracy in the South Asian demographic:

"*the leaflets do work but you will find that a lot of people in ethnic minorities do not read and write to that level.. You could have something like accessible information like we have at XXX where we have the booklets with the very basic pictures and you could work with somebody that way, rather than giving somebody a leaflet, because you are giving them something saying take this leaflet and they have to go home and find somebody who reads that leaflet and they have to translate, and they might not translate it properly*" (pp#14, DAP 2).

A strategy needs to be developed to reach persons who are illiterate: "*You have to keep in mind that the older generation a lot of people don't read and write*" (pp#14, DAP 2). The prevalence of illiteracy affecting the efficiency of delivering messages about services was discussed by the CEO of a dementia organisation:

 "*a failure on our part to communicate effectively, so therefore they may not know we exist and erm again although we have explored and looked at the possibility of putting information in to other languages and things like that erm I then took advise on that and put it in to another language, put it into a* South Asian *language Urdu, Punjabi or whatever but the vast majority of people do not even read their own language so it wouldn't*

actually, you know, you are sort of firing it at the wrong target if you know what I mean" (pp#9, DAP 2).

4.6.2.d.   Link in to communities

Utilising the local religious leaders to communicate with the community was discussed by this participant: "*I think it is about getting a link into community groups certainly*" (pp#9, DAP 2). One method of doing this is to utilise the existing community network:

 "*Yeah, and we were advised that it was better to go to someone like an Imam or elders and do something like a word of mouth process and that's how the open door project really worked for us and I suppose really it's one of those things that you keep trying to work out how is the best way to engage with this group of people*" (pp#9, DAP 2).

Outreach in to the South Asian community groups and translation of materials in to South Asian languages such as Punjabi, Gujarati and Hindi, by this dementia organization, had produced successful outcomes: "*Yeah it was word of mouth more than anything*" (pp#9, DAP 2).

4.6.2.e.   Consistency in care provision

A Hindu participant identified a need for consistency in care provision: "*Recently somewhere in the UK, someone has got a dementia, and 108 different are going to look after*" (pp#15, DAP 2). Inconsistent care provision effects a patient's "*dignity*" and "*willing*" (pp#15, DAP 2) if a good connection is not built up with the care provider: "*if every day new*

face coming to see the dementia, it effect" (pp#15, DAP 2). An improved rapport between carer and cared-for is required to promote dignity: "*they provide care with spiritual care...I just come and make the tea and coffee and then I just go, but go with the dignity*" (pp#15, DAP 2). The Hindu chaplain working in a mental health setting stated regular contact with the same person can help the person with dementia establish a routine:

"*Yes, yes, because if he, if I am going regular and set up a time, client is mentally and physically waiting for me. If I say every Thursday I am going to see 12-2, or 12-1, then he is physically and mentally waiting for me*" (pp#15, DAP 2).

Staff members, carers and family can also develop a rapport with the chaplain, if the same person is visiting on a regular basis:

"*And also staff also know that XXX will come to see this client regular. If staff has got any issue, they can talk to me and we can discuss about it. If patient has got any issue or family has got any issue, they can talk to me*" (pp#15, DAP 2).

4.6.2.f.   Face to Face communication

There were examples in the data where persons using mental health services could not be treated because they were unable to communicate with healthcare professionals:

"I felt that people admitted to hospital really lost out because they could come into hospital because they were extremely ill with whatever, in terms of their mental health, and they might then be in a setting where there was nobody who could actually speak to them" (pp#2, DAP 1).

A Hindu chaplain raised the suggestion South Asian carers may provide a better service for South Asian service users:

*"if these things will be happening, it will be more beneficial for the Hindu Community. Especially if you can find an Asian carer, I am not saying Hindu or Sikh or Muslim, but as long as these people can speak Bilingual because Hindi is the most popular language, especially in the West Midlands" (*pp#15, DAP 2).

Carers with the same language skills as the cared-for would be beneficial: *"so if you can encourage Hindi speaking carer to look after the dementia they can, more good and beneficial for the community"* (pp#15, DAP 2). For English speaking carers, an effort to learn one or two words in a native language would be highly beneficial: *"A few words, just like a welcome, yeah, or it might be like a gesture even a smile"* (pp#15, DAP 2).

Suggestions for improving communication were made by reiterating face to face communication, provision of a forum or dementia café for persons from shared religious backgrounds and languages to meet and *"exchange their thoughts and values"* (pp#15, DAP 2). Recognising illiteracy levels and providing material in an audio format was described as a useful way

of engaging with persons with dementia and supporting them to continue their religious practices:

"*But the only thing is they can't read sometimes they can't even read Punjabi, so I have a lot of CDs I give to them for their prayers, evening prayers. Every patient I see in the trust I have given them CD or I offer them if they are interested*" (pp#13, DAP 2).

Not everyone can understand the English language. Encouraging translators to communicate what is happening in services would be cost effective by promoting early intervention, getting people in to the right services at the right time:

"*there are still big numbers in the community who can't speak or understand English language, so that is the link between them and I think we need to encourage that. I think by spending a little bit of money and resources on that, we will save a lot at the end*" and encourage early intervention: "*Get their treatment very early if they have illnesses, rather than waiting around and it cannot be cured*" (pp#13, DAP 2).

However, in terms of understanding religious adherence, a Christian healthcare professional stated that it was the understanding of faith, not necessarily a shared faith, which was important:

"*if you're a committed Christian there's a sort of commonality with people from other faiths because you can understand why their faith is important*

to them and that makes it much easier to try to talk with them about that and to try and make sure that whatever is being done is appropriate in spiritual and religious terms as well." (pp#2, DAP 1)

From this participant's experience, there had been instances where the service user did not want to work with persons from the same community:

"*for example in XXX you have a large Sikh community and Sikh patients would say that sometimes they wouldn't want a Sikh worker because sometimes they were worried about things coming out in their community*" (pp#2, DAP 1).

4.6.2.g.   Isolation

From a Hindu perspective, non-White persons using nursing homes are very isolated:

"*you can see if one or two client from other background, faith background or culture background they sit isolated in a chair, or could be in their room all the times and pass by, it is very difficult to engage in the nursing homes and engage day to day concept, in NHS in UK, it is very, very difficult. It is very difficult*" (pp#15, DAP 2).

The Hindu community is unlikely to place their parents in to a nursing home due to cultural obligation:

"You hardly see any Hindu patient in to the nursing home, the reason behind it is cultural reason. Because family believe, ok my parents looked after me when I was little, now it is the time for me to look after them. Doesn't matter if ok, i can cope or not cope" (pp#15, DAP 2).

4.7.   Qualitative Findings: Religious Provision in Mainstream Health and

   Social Care Services
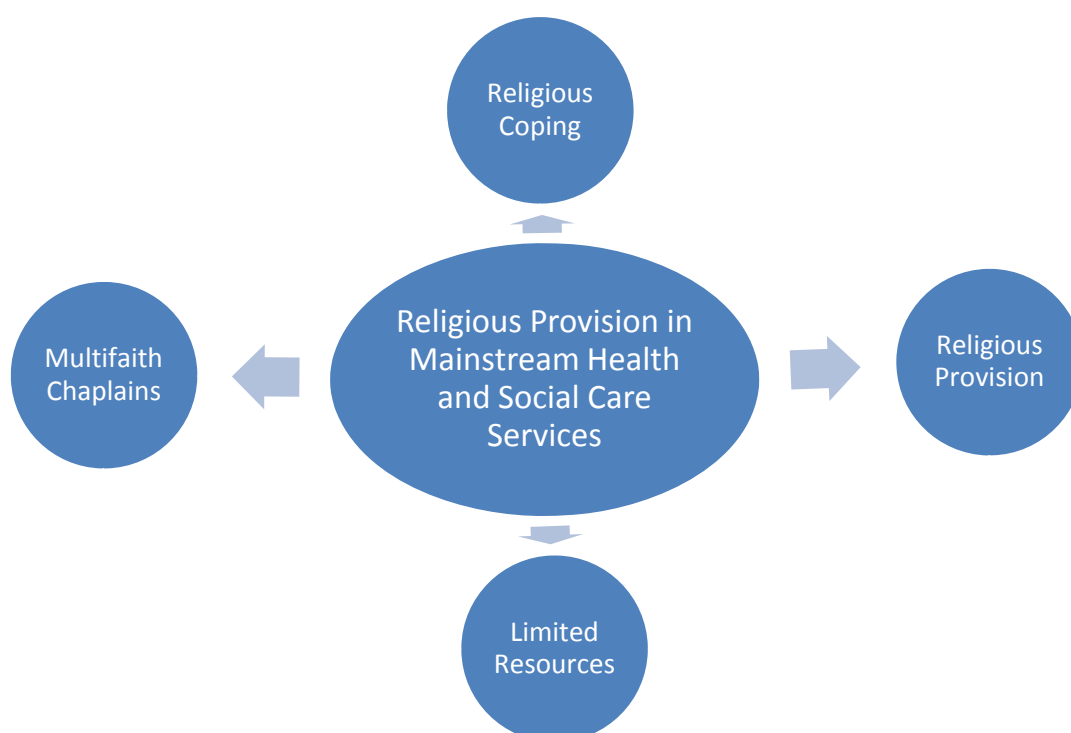
Figure 20: Data themes informing *Religious Provision in Mainstream Health and Social Care Services*

This study suggests faith continues throughout the dementia experience for persons with dementia and their carers. The theme of religious coping in the face of adversity was identified. The provision of support to maintain religious practices within health and social care services is considered.

4.7.1.   Religious Themes

4.7.1.a.   Religious Coping

Attitudes and perceptions of dementia, informed by religious beliefs, were identified to potentially have a negative influence on the uptake of MHSCS for South Asian persons with dementia. However, faith in God

was perceived as assisting with acceptance and coping with dementia. Religious communities offer a support network to the person with dementia:

 "*It can prevent people from accessing services because you know it is a religious thing and that is what God has done and we should accept it, but on the other hand it might also be a protective factor because the community is there to work with the family*" (pp#8, DAP 2).

A Hindu healthcare professional proposed religious coping in dementia may generate an increase in outward religious practice: "*some people go to the temple more*" (pp#8, DAP 2). This increase in religious practice was identified as a way of coping with a dementia: "*so you monitor that individual really, their behaviour. Sometimes there is an increase in their religion as a way of coping*" (pp#8, DAP 2). This healthcare professional discussed the removal religious support can impact negatively on the dementia illness, causing depression: "*people do get depressed, people do miss that support, so a lot of things happen, a lot of behaviours can develop following that thing not being there, the temple, the religion not being there*" (pp#8, DAP 2). Another Hindu healthcare professional explained the continuation of festival celebrations was one way persons could manifest their religious adherence throughout the illness:

 "*It doesn't matter whether how cognitively impaired they are, there will be a feeling of comfort by just continuing to do that, there are a lot of religious ceremonies, festivals in, every month, more than once twice a*

month, so there are a lot of things to do. So if someone has been

religious they might still find these things, activities pretty fulfilling, so

that might help" (pp#10, DAP 2).

This participant stated traditional attitudes towards rebirth in the Hindu community offer one example for how religious beliefs are utilised as a source of coping with terminal illness: "*before death and after death there are a lot of rituals and it becomes a way of coping as well for the community"* (pp#10, DAP 2). Furthermore, the notion of death as the alleviation of suffering, subscribed to by some Hindus, has implications for a positive acceptance of dementia-induced death:

"If a very elderly person is suffering too much, then they do a religious offering for a peaceful death of that person, or worshipping Gods to take this person away so that he doesn't suffer anymore. It's actually says how they are very accepting in this whole community. Our whole religion is. It's fine, they take it as one of the stages of life and because at least in scriptures, most people believe that we go for rebirth. I don't think many people actually believe in these things now, so people who are suffering with dementia are also like the same way, we accept it …." (pp#10, DAP 2).

Religious coping by Hindu elders may be expressed by visiting the temple:

"Yes, oh yes, in Hindu religion, religious coping, coping in stressful

situations in religious ways is absolutely evident, definitely in the elderly and I think until the dementia person forgets the idols, they would continue to feel comfort in being there. That is the most frequently used, and the most helpful coping mechanisms for most Hindus, if not all, going to the temples , seeking you know that kind of thing" (pp#10, DAP 2).

Religious coping can also help the family and carers of the person with dementia anticipate and prepare for the bereavement and loss dementia brings:

"The person is alive but the father figure, the mother figure fades way in dementia so it is a very painful process for the family members, and many times they do use religious coping strategies. It is almost a part of life you know. It is a way of life how they cope with it. I think it is still there. It is there in the very core, whether someone saw it or not and how much one saw it overtly about their religious practices but there is a core there." (pp#10, DAP 2).

One clinician articulated this acceptance, inspired by religious belief, could be problematic and led to a decrease in service access:
 "in general, Hindus are pretty accepting of that kind of thing so they don't find out too many things in old age. They seek help, but they accept more, ok? Yeah these are the problems with Hindus" (pp#10, DAP 2).

The notion that religious adherence can continue throughout the course

of the disease was raised: *"even if it is dementia, the emotional issues, with say Hindu gods and goddesses, that feeling continues, even if they are cognitively declined"* (pp#10, DAP 2). Persons with dementia who may have impaired cognitive faculties can still draw comfort from religious activity:

"They still feel an emotional union with the religious activities, and that helps I think with dementia if they have been religious or affirming some religious activities or being in temple, that might be very comforting for that person. They might feel a lot of comfort doing that" (pp#10, DAP 2).

This participant discussed the social role provided by the community at the Hindu temple. The family is vital for ensuring the person with dementia maintains a link with this spiritual and social source:

"but actually with the dementia [they] *have developed orientation problems and lost their way around and have to depend on the family to take them to the temple, so I think the temple is not just the religious bit, it is also a social community gathering, so it is that source of support and stimulation that is important"* (pp#8, DAP 2).

There was an acknowledgement of respect towards elders across generations by a Hindu healthcare professional:

"I think the usual concept of Hindus is they are very respectful of their elders. I think that is still there pretty much. The degree might have

changed now how much it was happening years back, how much it is

happening now. But usually they are very, very caring and they take care

of their elder people" (pp#10, DAP 2).

4.7.1.b. Religious Provision

In Data Analysis Phase one, there was an expression by a Christian

healthcare professional that health services did not focus on maintaining

the religious practices for persons of all faiths:

"*I think services are rather ambivalent about religion as a whole so I*

think if you are a committed Christian I think they find that difficult and if

you are a committed Muslim or Hindu or whatever" (pp#2, DAP 1).

However, healthcare services promoted the use of multi-faith spaces

within the clinical setting, whilst recognising the limitations of the existing

provision:

"*They are multi faith, plain spaces in terms of nothing obvious from*

different religions but we have a bookcase with lots of resources from

different faiths so that's how we kind of go about it because we couldn't

have a room for everybody" (pp#12, DAP 2).

It was ambiguous whether these spaces adequately catered for services

users' needs:

"*all hospitals now have multifaith rooms which are used by patients and*

erm , again I am not, I am not 100% sure we do everything to enhance religious and spiritual beliefs in people from South Asian *communities in secondary care service setting"* (pp#8, DAP 2).

One Sikh clinical chaplain participant asserted there is enough existing provision within services, but persons are not accessing care due to a lack of ethnically diverse representatives. The resources are available; more needs to be done to facilitate access to these resources:

"there is enough resources but people are not accessing because there wasn't any links in the past, now through the community centres and the religious places and people from different ethnic backgrounds are in the trust through them I think we will get the message through" (pp#13, DAP 2).

In Data Analysis Phase two, dementia organisations described a nurturing attitude towards a person's faith:

"Certainly we are never dismissive of peoples' religious convictions and we have supported people to access churches and communities erm, one of the first ladies that we helped when we set up our advisory service was from a middle European background, erm and she stopped going to the local catholic church because she couldn't remember when to go" (pp#9, DAP 2).

Understanding dementia's effect on the service-user and asking them how they would like to be supported was vital to ensuring persons felt comfortable enough to continue their religious practices:

"To make them feel comfortable and not think because she has forgotten we will not ask her about has she done her prayer or not? You know it is not a taboo subject, if someone has forgotten, then someone has forgotten" (pp#14, DAP 2).

Religious communities were described as welcoming places, offering a place of support for people with dementia and access to religious provision was encouraged by a Muslim dementia advocate:

"There is no religion or faith that won't invite people in to their setting if somebody wanted to go. So even if it was a Sikh gentleman who wanted to go into the Gurdwara just to sit and listen to a sermon or something, then that should be encouraged rather than saying he is not going to participate" (pp#14, DAP 2).

This participant outlined how dementia impacted on the ability to perform religious actions such as prayer:

"… lady that I work with at the moment, doesn't remember the prayer times. She doesn't always remember how to wash, to clean herself before the prayers so that kind of takes a toll because she doesn't

remember very much, or she doesn't remember that she has already

done her prayers" (pp#14, DAP 2).

4.7.1.c.   Limited Resources

There are good intentions to cater for a person's religious needs by
health and social care services, but ultimately the provision is limited by
resources available, as one healthcare professional stated:

"you need to attend to their religion, and all the rest of it but then there's

a gap between saying you are going to do it and actually being able to do

it within the constraints of our services" (pp#2, DAP 1).

This highlights a need to identify a provision of care which caters for a
person's religious needs and remove some of the strain off MHSCS
resources. Increasing co-operation with religious communities and
existing religious resources such as Multifaith Chaplains, offers one
solution.

4.7.1.d.   Multifaith Chaplains

Multifaith Chaplains were identified as a vital resource in building trust
and rapport between South Asian service users and medical
professionals. One Hindu Multifaith Chaplain describes:

"Like the sister can directly approach to the nurse, but she didn't do this

one; she raised the concern with me and not only the first meeting but

when I build up a relation, and they she will open and tell, "ok, XXX I am just a little bit..." (pp#15, DAP 2).

Multifaith Chaplains can build a bridge with the community to educate them about available services: "*The services are there and er just people accessing it is not easy, for people to access it. And I think the community centres and the religious places can be that link to encourage more people to access those services provided by NHS*" (pp#13, DAP 2). Observation # 3 in Data Analysis Phase two occurred in National Dementia Awareness week. This event revealed the success of utilising Multifaith Chaplains alongside clinical staff to present an educational DVD about dementia and answer questions in real time in native languages. This was the very first time a presentation on mental health issues had occurred within this community. The community engaged well and asked many questions. It was evident many persons had never heard of dementia and knowledge was low regarding care options and care access. The importance of outreach in to communities and engagement in ways communities can relate to - as an alternative to inviting persons in to services - was prevalent in the data.

Early intervention and outreach is important for all mental health conditions in the Hindu community, not just for dementia care: "*early interventions and outreach teams and this type of service if we had more for the Hindu community, it would be beneficial*" (pp#15, DAP 2). The chaplain was seen as an imperative link in to the community:

"They can speak to the community; they can take the message to the community. And even we have set up a link between myself and community, like a bridge, community, chaplain and Trust" (pp#15, DAP 2).

Maintaining this link will be helpful to improving care services within the Hindu community and the health care services: *"LINK or bridge between Hindu community and day to day running NHS it will be helpful, it will be helpful"* (pp#15, DAP 2).

4.7.2.   Cultural Themes

No significant cultural themes were identified in the data under this study aim.

4.8.   Qualitative Findings: Barriers to Dementia Care Services
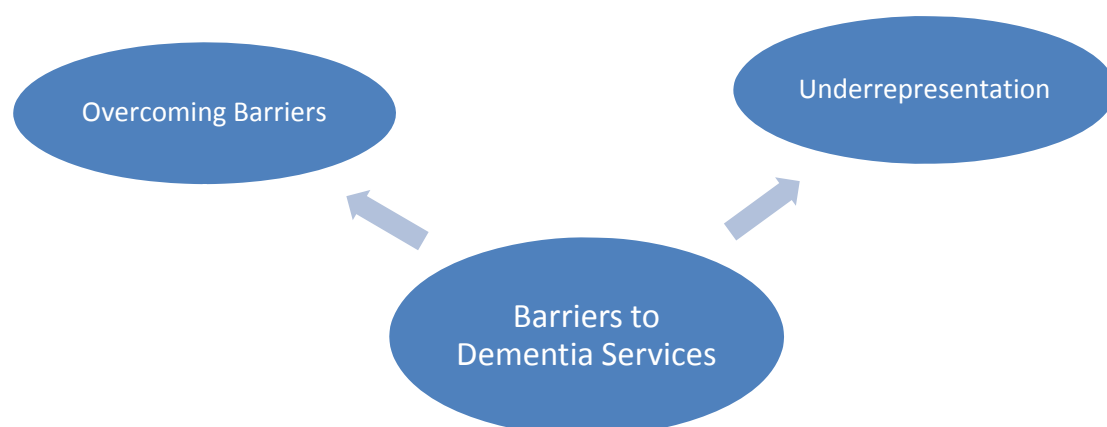
Figure 21: Data themes informing *Barriers to Dementia Services*

It has been suggested South Asian religious beliefs and practices influence the perception of dementia, access to services and satisfaction with dementia services. There is underrepresentation of South Asian persons with dementia in MHSCS [see Chapter 2, p.66]. Furthermore, the data has suggested this underrepresentation extends to misidentification of persons with dementia within religious communities. There is a lack of services catering specifically for South Asian persons with dementia. The data identified a co-operative approach between religious communities and clinics may help overcome barriers to service access.

4.8.1.   Religious Themes

4.8.1.a. Overcoming Barriers

Methods of engaging with South Asian communities were welcomed by

the dementia organisations: "*if somebody could help me to do that I*

would bite their hand off basically" (pp#9, DAP 2). There was some

difficulty engaging with religious communities in the past, and inviting

persons in to use the services has not been successful: "*for us to actually*

be targeting the same group of people, I am very interested to see

whether we get that community in cos it is right next to the new mosque"

(pp#9, DAP 2).

A more informal approach by mental health services promoting well-

being generally, rather than dementia specifically, successfully engaged

Asian males:

"*..had some success erm, we had a project which we ran about three*

years ago now which was open primarily to older, Asian men and the idea

behind that was coming in from the angle of wellbeing and looking at

ways of talking to them about things they could do that may help their

wellbeing so diet, physical exercise, actually taking some time to relax,

yeah, and those sorts of things, because we felt that going in to discuss

dementia isn't going to go anywhere" (pp#9, DAP 2).

There had been engagement with religious communities to advise on the

best way to approach the topic with the community and some of the

successful strategies identified had been continued to be implemented

"*the conversations we've had with local Imams and elders within the Asian community within xxx have said you are not going to get anywhere with that. That is not going to be do-able, but if you go in with 'how are you feeling and would you like to feel better?' - you might get through the door*" (pp#9, DAP 2).

Religious communities offer an untapped resource of support for persons with dementia. Outreach in to the religious communities, to promote education through a "*credible voice*" (pp#14, DAP 2) such as a Multifaith Chaplain, or a respected professional in the community is imperative to draw on this resource in the most effective way. One example of this in practice, is building on the Sikh doctrine of Seva, as a way of increasing volunteer carers. Currently Seva is understood as: "*going to the temple, helping in the kitchens, giving out the food, saying the prayers*" (pp#20, DAP 3). This Sikh tenant could be further developed with the younger generation to encourage volunteering as dementia care giving:

"*but actually if you follow the logical path and I know more and more young people say Seva should be about outreach, it's about supporting vulnerable people, it is about the other things they can do within the temple, within the congregation to support members of the community*" (pp#20, DAP 3).

Younger people in the community could be utilised to give their time, their skills and care to the older generation or those with dementia who need care, as well as skilled professionals:

"so actually we have got loads of people out there who are prepared to give their time, lots of skilled people, lots of professional people. Time is a valuable resource for persons in the community. Many people want to volunteer. It's about using the skills and resources of these people in the best way" (pp#20, DAP 3)*.*

A Healthcare professional in the study highlighted the need to be aware of the limitations of MHSCS and perhaps one way forward is through the outsourcing to other organisations to reach underrepresented groups:

"*My view is that the NHS needs to be subcontracting some of it's services, because there are some things that we do very well, like inpatient care, and there are some things we don't do very well, which is the outreach services, particularly to members of our diverse communities"* (pp#20, DAP 3).

A positive approach to overcoming barriers to mental health care access by one healthcare trust in the study is the successful training of religious representatives to become Mental Health First Aiders (MHFAs). This training offers skills and practical based education to enable persons in the religious communities to recognise the symptoms of mental illness and signpost them to relevant services.

"*We have a programme called Mental Health First Aid and training which we offer out to faith communities to help them. It is not specifically*

dementia linked which is why I have not really touched on it now, but it does raise awareness around mental health issues" (pp#18 DAP 3).

Building on this approach and incorporating dementia specific training would be beneficial. Healthcare services stated a desire to work co-operatively with local mosques in the area to share resources: "*we need to learn from you as much as you think you need to learn from us, so it's about an exchange of information, not about us telling you*" (pp#18, DAP 3). This symbiotic union between MHSCS and additional care services such as religious communities offers an improved package of care for the SAPWD.

4.8.2.   Cultural Themes

4.8.2.a.   Underrepresentation

There is an underrepresentation of South Asian services users presenting to MHSCS. For example, in one dementia organisation with 71 service users, only one person is from the Indian cultural demographic. In another service there are "ten a week" (pp#6, DAP 1) Asian service users from a total of 60 persons. Existing day care services clientele are "predominantly White British" (pp#3, DAP 1). There is "specific work" for Asian carers happening (pp#3, DAP 1) but these are separate to mainstream services. During observation # 2 - a memory clinic service in a geographical area with a very high South Asian demographic - there was only one BME patient from the day's eight consultations and he was Afro-Caribbean. The healthcare professionals commented this was representative of the overall service-user demographic within the clinic.

(OBS#2, DAP 1) In a healthcare setting, one participant stated the number of South Asian persons in the mental health service was low: "*very limited number, far fewer statistically than we would expect to see from the general population. I can only think of 2 individuals who are from a* South Asian *background*" (pp#18, DCP 3).

A service catering for South Asian older adults, but not mental health needs was approached, but did not consent to the study. A participant in a nearby dementia care facility catering for all cultures commented: "*however, they tend to struggle with the person's mental health there. So they go until their mental health has deteriorated and then they will be forwarded to us*" (pp#6, DAP 1). Thus, these two organisations catered either for mental health needs or specifically for South Asian needs. Thus, the existing provision in this vicinity was not adequately catering for the needs of the South Asian person with dementia. There is a demand for a service which caters for both South Asian services users and their mental health needs, in particular dementia.

Furthermore, there are very low numbers presenting to dementia services through official referral channels:

"*I can't think that we have had a formal referral for somebody from a* South Asian *background in to our day care that has come through a social worker. We have had some people come in but they have normally come in, the best way to describe it is through the back door in one way or another*" (pp#9, DAP 2).

Analysis of the data implies South Asian Persons with dementia (SAPWD) also underrepresented in religious communities. For example, within one major, long standing Sikh community, dementia was not widely recognised (OBS#1, DAP 1), with only one person acknowledged as having dementia: "so *in this local community, in this vicinity of (XXX), what I have seen is there's only one dementia person that I know from the experience, and this person has been looked after by their family"* (pp#7, DAP 1). This appears to be a very low figure representing a large South Asian community in the geographical vicinity for a community who has been established in the local area for over five decades. This suggests persons with dementia may not be recognised within their own community, or if they are acknowledged, this information may not be shared with those outside the community, or was simply not shared in this particular context.

When MHSCS services had been accessed by a Muslim male with dementia, the experience had been dissatisfactory (OBS#5, OBS#6, DAP 3). This participant did not tell his family or community about his dementia, and consequently attended these services alone. During a Alzheimer's café evening, as the only non-White attendee, pp#17 voiced he felt "under pressure" due to his skin colour (pp.17, OBS#5); he was frustrated he hadn't "learned" (pp.17, OBS#5) anything about dementia, was upset the group hadn't shared anything "worthwhile" (pp.17, OBS#5). PP#17 said he thought there would have been the opportunity to "offload", but "there was no-one to offload to" and felt the experience was just a place to "have a cup of tea" (pp.17, OBS#5). Accessing

memory clinic services (OBS#6) caused confusion and anxiety for pp#17 because his usual physician was unavailable. PP#17 required reiteration of dementia type, prognosis, care implications and reassurance the dementia was not a result of a "stressful life working two jobs" (pp#17, OBS#6). PP#17 left the consultation relieved, but confused, without a consistent carer to reiterate this information for him.

4.9. **Chapter Summary**

The findings presented in this chapter discuss religious and cultural explanations for the underrepresentation of South Asian persons with dementia in MHSCS. Additionally, the data suggests South Asian persons with dementia may also be underrepresented within their religious community as a result of self-isolation or non-recognition of dementia symptoms. Religious understanding of illness, health and care potentially impacts upon the care provision for South Asian persons with dementia. Health and social care services recognise the need for supporting and maintaining the religious practices of dementia patients but are bound by limited resources to cater for this demand. This highlights the necessity for a system of care which relieves pressure from MHSCS resources, captures persons with dementia and supports them in their religious practices and health care needs. Religious communities are an existing resources which could be utilised to meet these needs. Multifaith Chaplains working in NHS Trusts currently offer a link between community and clinic. The theoretical models presented in Chapter five develop these findings. Collaboration between religious communities and MHSCS aims to allow South Asian persons with dementia and their families make informed care choices and be supported in their decisions.

5.   Chapter Five: Theoretical Models

5.1. Chapter Aim

This chapter builds on the study findings presented in Chapter four. Identified themes are developed and the interlinking relationships within the data are presented across two theoretical models, reflecting the Grounded Theory approach. The study findings reflect two main areas: firstly, existing care provision and experience and secondly, identification of specific areas of success and deficiency within existing care provision informing recommendations for care improvements. Two models are discussed - grounded in the study data - expounding the theoretical synthesis of themes identified in the findings: Theoretical Model 1 presents an Existing Care Provision and Experience Model (Existing Care Model), discussing current care provision and experience for South Asian persons with dementia and their carers, informed by the perspectives of the service user and the service provider. This fulfils the study's aims. Theoretical Model 2 critically considers the theory in a Service Improvement Model. The latter model offers recommendations for the practical application of the theory, informed by data generated from interviews and observations. This model aims to improve the care provision for South Asian persons with dementia. Theoretical Model 2 fulfils the study objectives and expounds a novel system of working based on a collaborative approach between "congregation" and "clinic". The purpose is to promote informed care decisions, to improve care services for South Asian persons with dementia and their carers, and ultimately, to alleviate strain on resources within MHSCS. Additionally,

this model may be applied to other underrepresented ethnic minorities demographics in dementia care such as the Afro-Caribbean or traveller communities; it may also be applied to BME persons underrepresented in other mental health arenas such as depression or schizophrenia and within acute illness. This reflects the Critical Realist Grounded Theory approach (Strauss & Corbin, 1998) where generalisation of the resultant theory is permitted within certain methodological parameters, reflecting the abstract nature of the findings [see Chapter 3, pp. 121-126]. Furthermore, the integration of religious communities as an underutilised existing resource of support for persons with dementia is applicable not only to ethnic or religious minorities, but may potentially be implemented across all populations, such as the Christian White, British demographic, for example.

Consideration of the role of religious beliefs and religious communities as a source of dementia care and support demonstrates an innovative approach to meet the targets outlined in *Dementia 2012* (Alzheimer's Society, 2012) [discussed in Chapter 2, p112] which asserts by 2015 every person with dementia will be able to say: "I know what I can do to help myself and who else will help me. My community is working to help me to live with dementia" (Alzheimer's Society, 2012, p.19). Furthermore, the study meets the gap identified in the *National Dementia Strategy: Equalities Action Plan* (Department of Health, 2011a) which highlighted a "lack of data available on religion in relation to people with dementia" (Department of Health, 2011a, p.8) [see Chapter 2, p.110]. It also demonstrates a response to the identification made in this report, namely: "religious organisations may be able to provide a *link* between

individuals and health and social care services" (Department of Health, 2011a, p.8). Regan (2014a) built on the issue highlighted in the policy documentation and reiterated the importance of recognising religion as distinct from culture in research and the implications for dementia care, whilst expressing sensitivity to the difficulties in separating the data to reflect this. Theoretical Model 2 clearly demonstrates how this link can be implemented in practice through a co-operative approach to dementia care through a fusion of "mainstream" and "additional" care services, with religious communities working alongside health and social care services. The *National Dementia Strategy* (Department of Health, 2009a) asserted its aim was to, "transcend existing boundaries" (Department of Health, 2009a, p.7) when addressing health inequalities [see Chapter 2, p.104]. The co-operative approach presented in Theoretical Model 2 aims to dissipate the boundaries between perceptions of "mainstream" services such as health and social care, and "alternative" dementia care – such as religious communities - and simply offer an informed, holistic care package for the person with dementia. This aims to allow all persons, regardless of faith or ethnicity, to be "dementia friends" within a "Dementia Friendly Community" (Alzheimer's Society, 2012, p.10) [see Chapter 2, p.113]. In addition to the Grounded Theory Models, a discussion of the implications of the findings on each of the cohorts is presented.
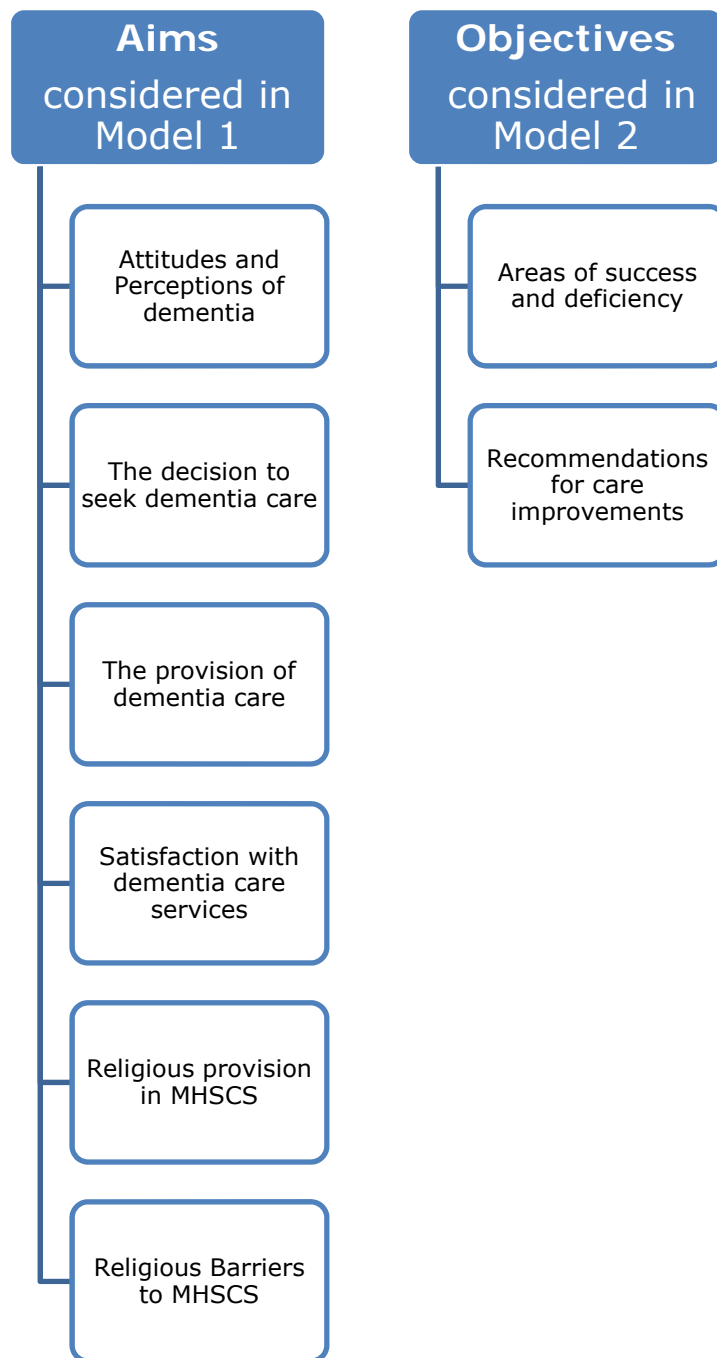
Figure 22: Consideration of study aims and objectives across the two theoretical models grounded in the data.

5.2. Theoretical Model 1: Existing Dementia Care Provision and
Experience Summary

This is a three tiered model with an incremental level of influence. The data presented in the findings suggests religious beliefs and practices (part one) influence and inform understanding and knowledge of Dementia (part two) which influences decisions and practices regarding care and coping (part three).
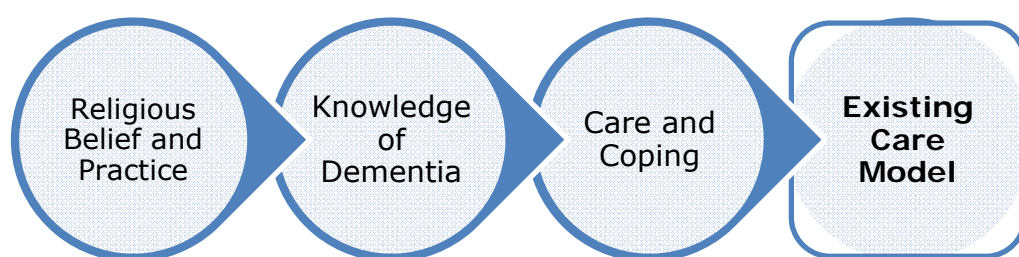
Figure 23: The incremental influence of findings informing a theoretical model of *Existing Care Provision and Experience*.

1. **Religious Beliefs and Practices**. The data suggests religious beliefs and practices influence a person's daily living and continue to influence a person's daily living with the onset of the dementia illness.

2. **Knowledge of Dementia**. Religious beliefs, religious perceptions and religious attitudes influence perceptions and knowledge of mental health generally and dementia specifically.

3. **Care and Coping**. This has implications for the following: firstly, subsequent care provision in terms of whether care is sought, who will provide care, if MHSCS or ACS are accessed or not; and

secondly, coping with dementia for the person with dementia and carers.

5.3. *Theoretical Model 2: Service Improvement Summary*

Grounded in the data of the present study and informed by Theoretical Model 1, the Service Improvement Model aims to provide recommendations for improving care provision for South Asian persons with dementia and their carers. The data demonstrated a three tiered model with an incremental level of influence: Education and information about dementia and available care services was a prevalent theme (part one), low knowledge and awareness of dementia influenced access to dementia care services (part two). Consequently, due to this underrepresentation, MHSCS perceived the demand for South Asian specific services as low and may not always account for this demographic in their care provision (part three).
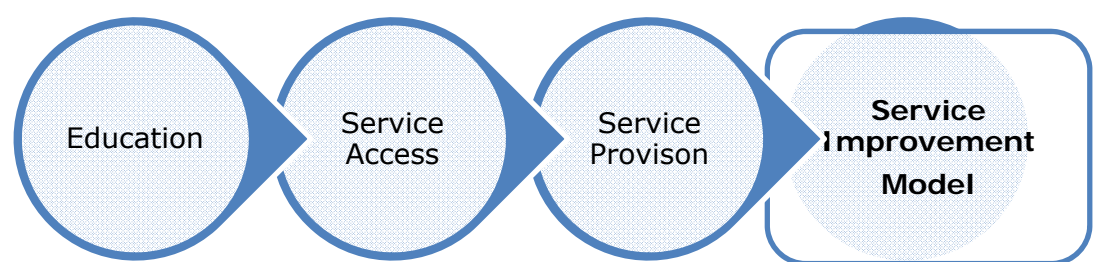
Figure 24: The incremental influence of findings informing a theoretical model of *Service Improvement.*

1. **Education**. Information dissemination about dementia is presented as the most important part of this model and was the primary theme identified in the whole dataset. The study findings suggest knowledge of dementia is low in the Hindu, Muslim and Sikh communities. This leads to underrepresentation of South Asian persons with dementia in both MHSCS and within religious communities. Education through consistent outreach by the MHSCS in to the religious communities' place of worship or community setting is vitally required to educate about dementia, empowering persons to make informed decisions about care.

2. **Service Access**. Persons who then make an informed decision to access MHSCS should be assisted in accessing these services

3. **Service Provision**. Once persons arrive at MHSCS, MHSCS should be prepared to provide a person – centred care plan which accounts for the beliefs and practices of the services user, if this is important to the individual.

The theoretical models are now presented diagramatically - individually and collectively - followed by two examples of interlinkage across themes influencing theory generation. Each model will then be discussed before the implications of the theory on each cohort is outlined.

The themes prevalent in the data influenced the formation of the first theoretical model. Three incremental stages to the theory were formulated, with clear themes identified contributing to the development of each stage.
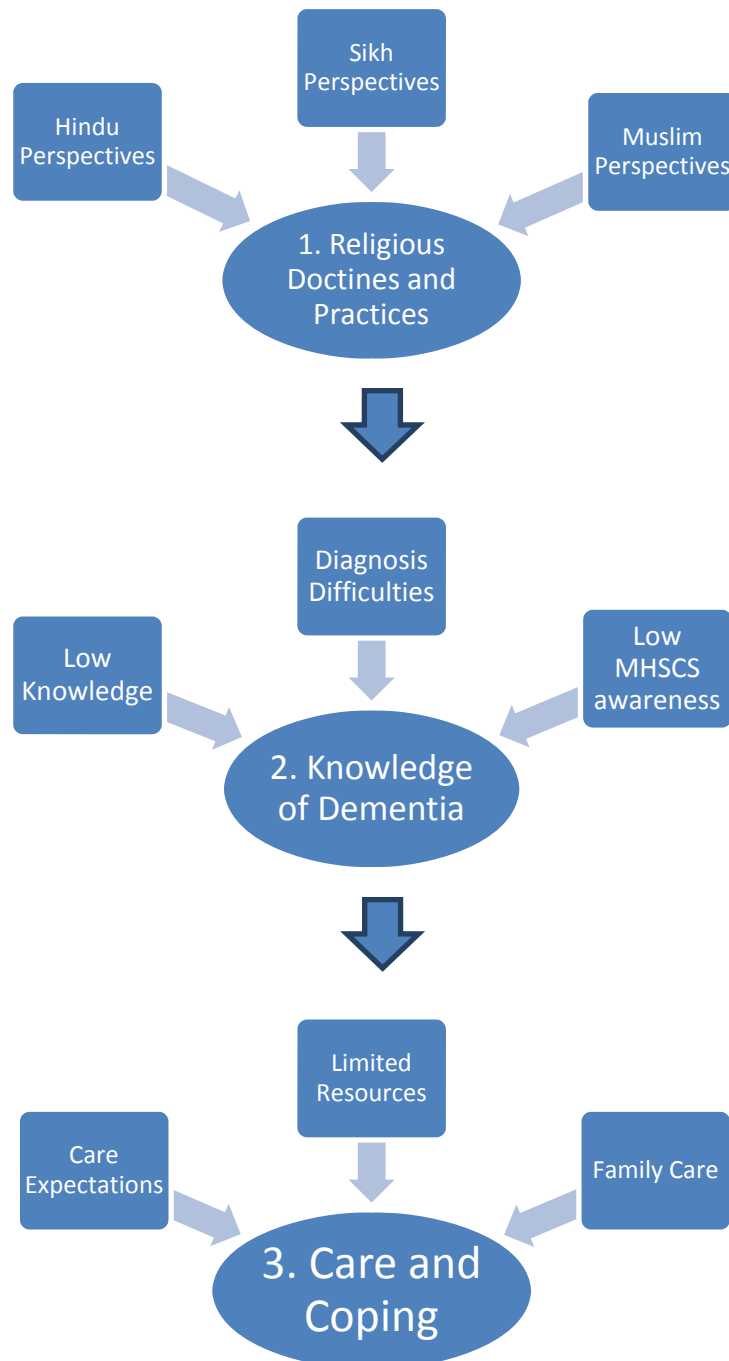
Figure 25: Three examples per stage of data themes informing Theoretical Model 1.

Similarly, three incremental stages to theory 2 were formulated, with clear themes identified contributing to the development of each stage and grouped according to similarity.
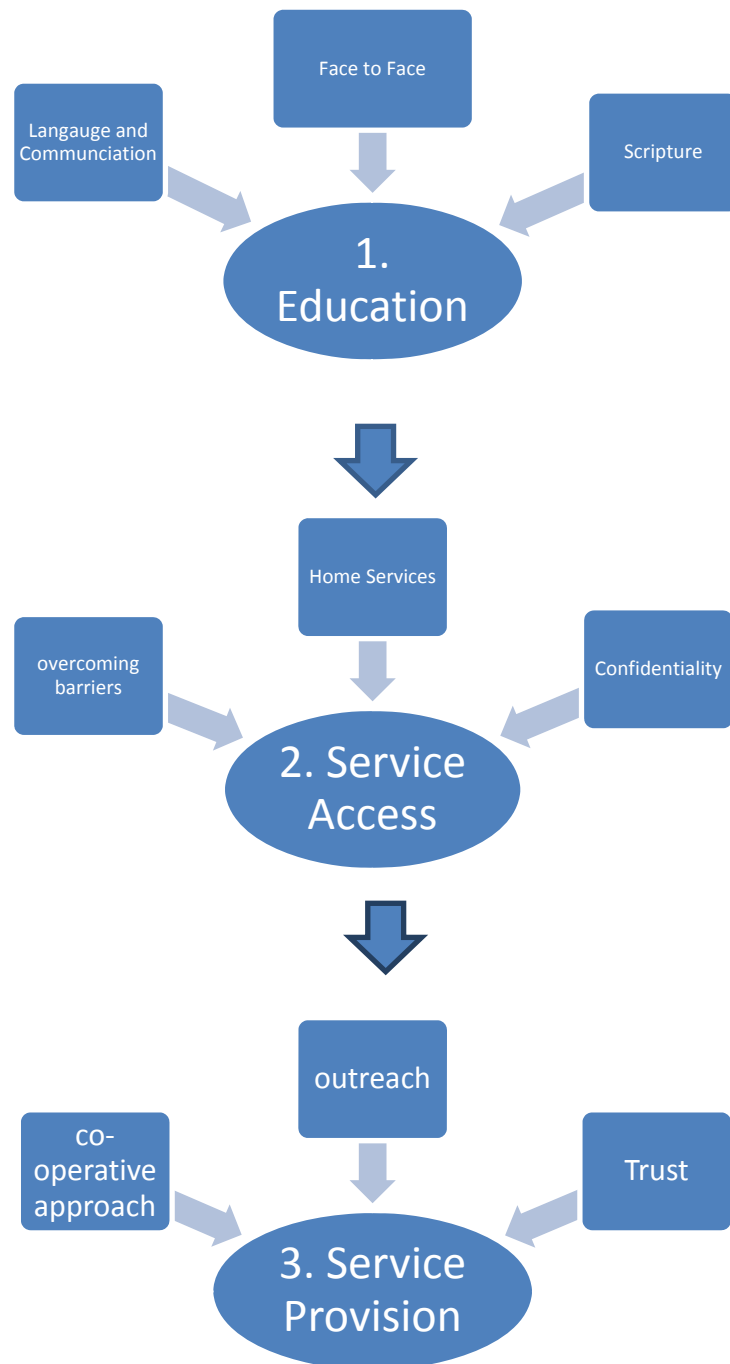
Figure 26: Three examples per stage of data themes informing Theoretical Model 2.

Theoretical Model 1 informs Theoretical Model 2

Theoretical Model 1

Religious Belief and Practice → Knowledge of Dementia → Care and Coping → **Existing Care Model**

Themes in the data generating the two theoretical models

Hindu/Sikh/ Muslim perceptions	Religious Perceptions	Home services	PWD overshadowed	Underrepresentation
Co-operative approach	Family Care	Faith Healers	Trust	Care Expectations
MHSCS last resort	Overcoming barriers	Isolation	Strength of faith	Stigma
Low MHSCS awareness	Scripture	Limited Resources	Diagnosis difficulties	Low knowledge
Dementia: "unique" mental illness	Confidentiality	Face to Face	Language and communication	Implications for family
Outreach	Cultural perceptions	Challenging Behaviours	Care burden	

Education → Service Access → Service Provison → **Service Improvement Model**

Theoretical Model 2

Figure 27: Interlinking of two theoretical models grounded in themes identified in the study data

5.4. Existing Care Provision and Experience Model: Theoretical Relationships

Theoretical relationships between themes were identified in the data. The following is an example of three data themes which demonstrate the incremental interlinking theoretical relationships informing the Existing Care model. Religious perceptions of understanding dementia were informed by low level line-by-line data codes [see Chapter 3, p.141 for coding details] such as "God's will" and "Karma" (stage 1 of model: Religious Belief and Practice). These were suggested to influence low knowledge and awareness of dementia, informed by data codes: "misunderstanding" and "healthy ageing" (stage 2 of model: Knowledge of Dementia) which in turn leads to a burden of care for the person with dementia and their family (stage 3 of model: Care and Coping), informed by codes: "care difficult", "sole carer", "hidden from family".
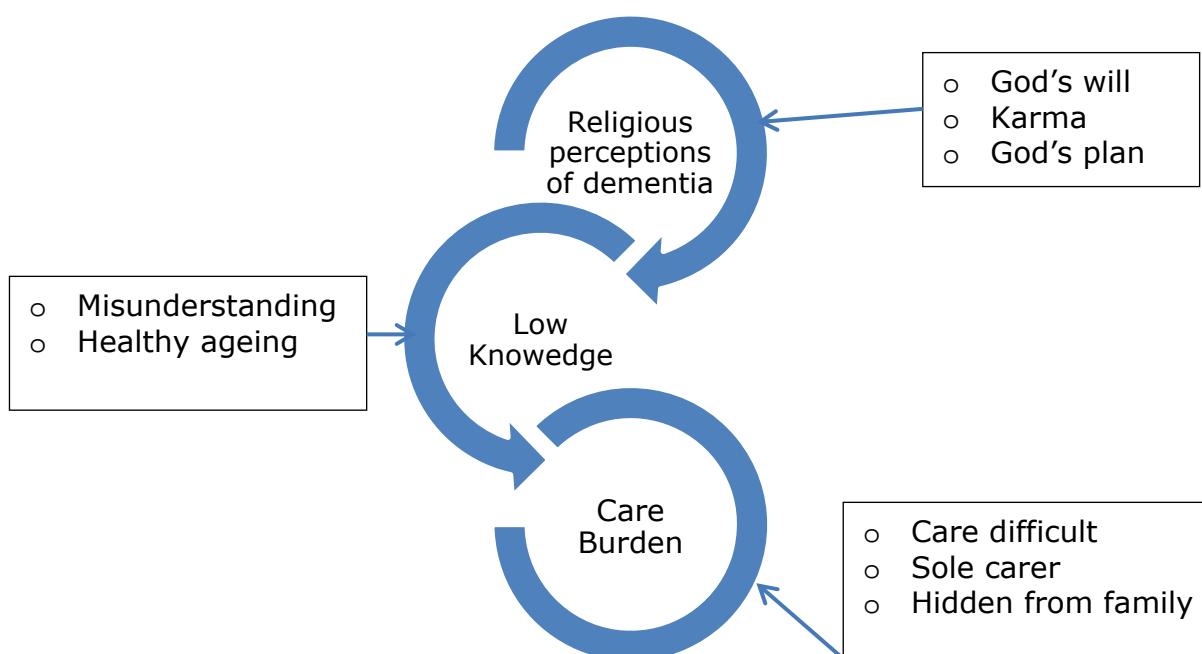
Figure 28: Existing Care Model: An example of theoretical relationships between identified themes, informed by data codes.

5.5. Service Improvement Model: Theoretical Relationships

An example of the incremental, interlinking relationships in the Service Improvement model are as follows. The theme of Outreach generated by the codes: "community engagement" and "successful outreach" (stage 1 of model: Education) exposed a low awareness of available services (stage 2 of model: Service Access) informed by codes: "isolation", "ill-informed about services"; this influenced the theme of co-operative approach (stage 3 of model: Service Provision) with health and social care and religious providers, informed by codes: "enthusiasm from religious representatives", "credible voice" and "community bridge".
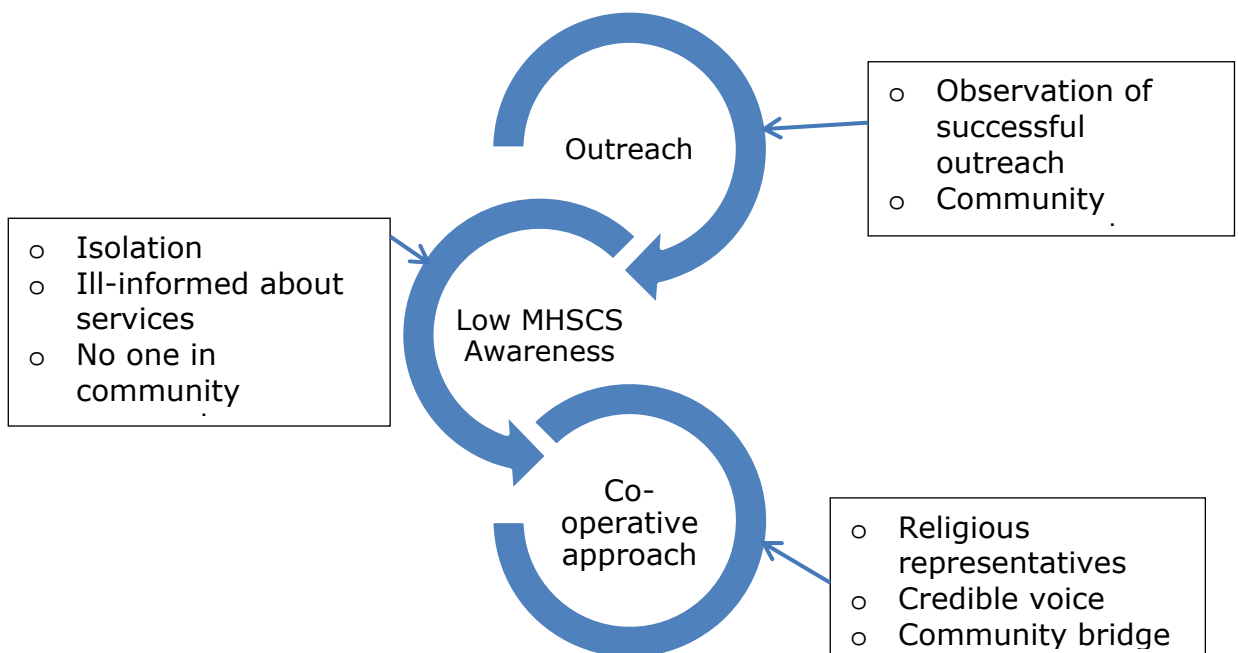
Figure 29: Service Improvement Model: An example of theoretical relationships between identified themes, informed by data codes.

5.6.   Discussion of Theoretical Models

Each incremental stage of the two models, as grounded in the data, will now be discussed in detail.

5.7.   Existing Care Provision and Experience Model

5.7.1.   Stage 1. Religious Belief and Practice

Hindu, Sikh and Muslim religious beliefs and practices influences a person's daily living and continue to influence a person's daily living with the onset of the dementia illness. This religious adherence may increase, decrease or remain consistent throughout the dementia experience, regardless of whether an official clinical diagnosis of dementia has been received or not. Religious doctrines such as Karma, God's plan, God's will, stigma, family care and duty were discussed as explanations for understanding dementia. For carers of a South Asian Person with Dementia (SAPWD), faith also plays a part in the care-giving experience and forms the basis for values and actions. For MHSCS in dementia, an active approach is taken to recognising the importance of religious beliefs within the constraints of financial pressures, deadlines and workloads, dictated by the organisations' resources. Sensitivity has been shown in MHSCS to persons of non-Christian faith and steps taken to cater for this in care-planning. Clinicians demonstrated an awareness of the importance of faith in their own life and considered how religious belief may impact on their professional care giving within a bio-medical setting; adhering to a faith - even if this was in contrast to the faith of a patient - engendered a shared understanding about the importance of religious

belief in one's life, especially as a source of comfort and support during illness. Dementia organisations were actively interested in identifying a person's religious needs and practices and using this information to form individualised care plans, whilst being conscious of the fluctuating needs and demands of a person with dementia. The importance of involving the carer and immediate family to assist with this care planning was discussed. Religious representatives, specifically the Multifaith Chaplains working in a MHSCS setting - whilst being representative of one faith - demonstrated how their training prepared them to cater for a range of service users with different religious beliefs, spirituality and no faith backgrounds. Religious representatives who worked solely in the community actively encouraged persons with mental health conditions to access MHSCS, alongside maintaining their religious convictions and commitments.

5.7.2.   Stage 2. Knowledge of Dementia

For persons of Hindu, Muslim or Sikh faith who understand the world through a religious perspective, this understanding also extends to perceptions about mental illness generally and dementia specifically. Religious doctrines were demonstrated to influence the knowledge or lack of knowledge informing a bio-medical understanding of dementia. There were instances in the data where dementia was not recognised as a neurological illness in the Sikh, Hindu and Muslim faiths, and may be perceived as a person growing old "normally". The cognitive decline in dementia resulting in memory loss and the behavioural manifestations such as incontinence, wandering, aggression and confusion are often

overlooked as "normal" ageing. Religious scriptures have offered explanations such as normal ageing, or returning to a "childlike" or "saint-like" state to explain cognitive decline in ageing. For example, understanding the world as God's plan, leads to the interpretation that memory-loss caused by dementia is an element of said God's plan - or dementia is perceived as a punishment for an ill-deed.

When dementia is recognised as a mental illness it is often associated with stigma, both in acceptance of the mental illness and access to services. This was shown to have negative consequences not just for the person with dementia, but their immediate and extended family. This led to isolation within - and from - religious communities. The data suggest, especially from the Sikh and Muslim perspectives, the person with dementia or their family self-isolates from the community, rather than a rejection of the person or their family by the religious community. This stigma influenced the misconception by carers that if MHSCS are accessed, the loved one may be institutionalised and the family would have no control over care.

5.7.3.   Stage 3. Care and Coping

The data suggested religion has a positive influence on coping with dementia - but this was based on a lack of knowledge about the aetiology of - and prognosis for - dementia, and subsequent available services. For example, one Muslim gentleman with dementia believed he would only have months to live, following the clinical dementia diagnosis. Contrastingly, knowledge of dementia, influenced and informed by

religious beliefs and perspectives was demonstrated to hinder access to MHSCS. This religious-influenced perception of dementia affects care decisions, such as: is care to be given? Who will provide this care? Where will this care be sought? This low knowledge of dementia coupled with stigmatised understandings of mental illness, often influenced by religious beliefs, offers one explanation for the underrepresentation of South Asian persons in MHSCS. This reflects the findings in existing cultural research, where many South Asian persons never receive a clinical diagnosis of dementia, never access external services, never have acknowledgment in the immediate family, nor in the wider community that the person is experiencing a mental illness. The present study recognised some South Asian persons with dementia or South Asian carers for persons with dementia never receive full financial, practical or emotional entitlements, either through active refusal of services or of low awareness of available entitlements.

The researcher asserts it is presumptuous to assume that persons with dementia should be accessing MHSCS if they are already being adequately supported within ACP such as their faith community, but the data for the present study found this not to be the case. It was examined whether religious communities are appropriately catering for the SAPWD's needs. A Sikh community in a large geographical region only recognised one person in their congregation as having experienced dementia. Thus, there is an argument that SAPWD are not only underrepresented in MHSCS but are also unrecognised and underrepresented in ACS. Whether this is a reflection solely of the West

Midlands region - or is nationally representative - should be considered. Generalisation of this argument beyond the substantive geographical region requires further research in other UK areas with a high South Asian demographic, such as the North West and London [see Chapter 1, p. 30]. In the West Midlands region, the data suggests families and communities may not recognise dementia or if they do, this is kept hidden. Thus, SAPWD are unidentified, unrecognised and unrepresented in both MHSCS and ACS. This places an enormous burden of care on the person with dementia and their family - physically, financially and emotionally - and does not give the person with dementia adequate care provision. When MHSCS are sought, the data demonstrated they were accessed minimally, or at a critical juncture, when the person with dementia was "desperate" and did not have the support of family or religious community.

Religious representatives across all faiths encouraged persons to seek MHSCS alongside ACP of faith. This was shown to be especially prevalent in the Hindu and Sikh traditions. Clinicians within MHSCS are encouraging persons to maintain their faith practices. However, in the Muslim communities it was identified more prevalently that care was kept in the home by a female family member. The Muslim cohort seemed less likely to accept help from MHSCS as a result of religious-influenced duty of family care. The researcher perceived a stronger sense of religious duty displayed by the Muslim demographic in the present study, compared with the Sikh and Hindu participants. For example, the carer in the Muslim group stated she did not accept benefits she was entitled to, as

she felt this was going against her religious-influenced duty of care for her mother. The researcher is aware it is possible that this finding was substantive to the present study in this instance, and may not reflect the strength of filial obligation for Sikhs, Hindus and Muslims generally.

Religious beliefs and teachings had supported patients experiencing dilemmas resulting from their inability to continue outward religious practice. For example, a Muslim gentleman with dementia and pre-existing medical problems was unable to fast during Ramadan, but stated he was still fulfilling his religious obligation by donating the cost of the meals to charity. A carer for a Muslim female with dementia described how continuation of prayer rituals were facilitated. This practice had been straightforward to maintain due to the expectation that female worship in the Muslim faith often occurs at home rather than in the Mosque. In contrast, for the Muslim male with dementia, his religious adherence reduced dramatically on receipt of his dementia diagnosis. He no longer attended the Mosques of which he had formally been an integral member and with no consistent carer or family member, he also struggled to maintain his religious practices at home. Religious coping was defined by carers more in terms of duty and obligation - rather than religious coping - although there were instances where faith in God assisted with acceptance of dementia, especially in the Muslim and Hindu communities.

5.8. *Service Improvement Model*

The Service Improvement model was developed from the substantive findings grounded in the Existing Care Model and aims to express

practical service recommendations which can be applied within religious communities in the West Midlands and nationally. Additionally, it is a model which can be used across other health inequalities aiming to reach underrepresented demographics and encourage access in to services. It may also be used as a framework to educate about dementia within ethnic majority Christian communities, for example. This model will be discussed in detail and is presented in three stages, comprised of the main themes of Education, Service Access and Service Provision. The main focus is on expounding stage 1: Education, as the primary theme identified in the study.

5.8.1.   Stage 1. Education

Knowledge of dementia in bio-medical terms is low in the Hindu, Muslim and Sikh communities and offers one explanation for the underrepresentation in services. Thus, persons should be informed about dementia as a neurological illness and the benefits of early intervention and available care packages, to enable them to make informed decisions about which care pathway to take. Carers require education from religious communities, to support them in their decisions, reiterating that care does not operate exclusively within the family, exclusively within MHSCS or exclusively within religious communities. This coincides with Shah's (2010) work on cultural barriers for BME persons accessing mental health services and the importance of educational campaigns to improve awareness of services and reduce stigma. What is novel in this instance is the suggestion of direct involvement with BME religious communities to receive this education and implement religious teachings

in dementia care training.

The lack of direct translation for the word "dementia" generates a challenge in communication and care by MHSCS. Across the West Midlands, throughout National Dementia awareness week, education about dementia through DVD presentations in native languages by a collaborative team of clinicians and South Asian religious representatives in Hindu and Sikh places of worship and religious community buildings, was very well received with a positive, inquisitive response from the congregation who were eager to learn about the illness, about care facilities and about service availability and access.

Education of dementia within underrepresented communities is vital to aim to overcome the barriers to dementia care identified in this study:

o Dispel the stigma associated with mental health generally and dementia specifically.

o Allow SAPWD and their families to make informed care decisions.

o Allow care decisions to be made early following formal diagnosis.

o Benefit the SAPWD and provide them with the right support network and care.

o Allow adequate care planning through increased understanding of dementia prognosis.

o Enable persons to live positively with dementia throughout this prognosis

o Relieve carer burden.

o Relieve burden from MHSCS which are bound by limited resources.

o Acknowledge the positive role of religion in providing acceptance and hope, in addition to the practical function of community support.

5.8.2. What is needed?

Co-operation between faith leaders and health and social care professionals is imperative for communicating that religious care and health care may not be mutually exclusive. The educational strategy is twofold: Firstly, the congregation requires information about the bio-medical status of dementia by healthcare professionals, and secondly, religious communities require training supported by religious teachings about how to accept dementia and understand the impact on the wider family unit and how to provide care for a loved one with dementia. A prominent theme in the data is the demand for a "link" or a "bridge" between the religious community and healthcare trust. This "link" is a person who is a trusted representative of the faith community and has a connection with the healthcare organisation, who can facilitate the delivery of the educational message by healthcare professionals within the place of worship. There has been some work to date of this type during National Dementia Awareness week which aimed to improve knowledge of dementia, and was very well received.

5.8.3. How can this be delivered?

Delivery will be at a "grassroots" level, to the "right people in the right format" (pp#14, DAP 2), through outreach in to the community places of worship. The idea is to inform - not to dictate to - people about dementia

who may have no prior knowledge. A prominent theme emerging from the data was that there needs to be a shift away from paper based information and a focus on face-to-face delivery. Communication in a way that people can understand and relate to is imperative. Tools such as the DVDs in a native language which interject humour were an invaluable introduction for the healthcare professionals to supplement and explain to the congregation, offering an opportunity to answer people's queries face to face, in real time, in a native language. Translators were seen as an invaluable investment for building rapport and facilitating communication. However, limited funding within services meant translators were often not employed for service users. There should be a shift away from relying on paper information and a shift towards interpersonal contact. Paper formats don't account for illiteracy, aphasia, or loss of acquired secondary languages. In the educational material promoting mental health awareness, many of the role models are White British. More work needs to be done in the integration of South Asian role models in the promotion of mental health issues generally and dementia issues specifically, in order to dissipate some of the stigma associated with accessing mental health services. The religious representative may wish to supplement the healthcare professionals by providing a sermon on illness, and using the scriptures as a way of offering a model of care for supporting persons coping with dementia and provide training opportunities for those caring for someone with dementia. There could be discussion on family duty of care and how the religious community can support one another to fulfil this obligation – alongside the assistance of MHSCS - especially in the Muslim faith where this theme was especially prominent.

5.8.4. Where?

Inviting South Asian people in to the MHSCS has not been very successful. However, within the present study, the religious communities across West Midlands were very welcoming to people visiting their religious place of worship to deliver educational messages. The Sikh and Hindu communities were especially receptive to receiving guests to deliver this information. It was demonstrated religious communities are particularly interested in listening to the health professionals if they are introduced by a respected and established member of their own community, such as a trusted representative who can speak with a "credible voice" that the message which is to be given is important, beneficial to the community and requires attention. MHSCS can have information stands and attend the event to provide education, information and support for persons to access instantly.

5.8.5. When?

Whilst one off trial presentations using this format in the Hindu Temples and Sikh Gurdwaras have been successful during National Dementia Awareness week, more needs to be done to make this a regular event. It may take more than one session for people to comprehend that mental illness is a medical condition and requires medical attention. This was seen to vary across generations, with the younger generation being more educated about mental health and subsequent care; and across gender, with females being more accepting of providing care as part of their religious duty. Regular events with the same care team allow the

religious community to build up trust and maintain confidentiality. A facility could be generated in which following the group presentation and group question and answer session, persons are informed that they can ask about the illness privately on a one to one basis with the assigned healthcare professional or religious representative either following that session, or at the regular follow-up session. This gives persons time to process the information and consider their care options, before approaching the external services for assistance.

5.8.6.   Demand

The success of the trial runs in the Hindu Temples and Sikh Gurdwaras has sparked a demand for this. During interviews with faith leaders, especially from the Muslim community who had not yet received such trials, there was a real demand and need for this type of educational message, in this format. Religious communities welcome education and knowledge and the leaders want to work with the healthcare professionals to provide the best for their congregation members.

5.8.7.   Job Role

Community Development Officers within one Health organisation in the study have been successful in creating these events within places of worship. This raises the potential of an existing worker, or new team or individual to co-ordinate these events as regular fixtures within the places of worship in the community. Hospital chaplains are already working as faith ambassadors during outreach in to the community.

Mental Health First Aiders (MHFAs) is a new service generated by an NHS trust in the West Midlands. Persons who are already working in religious communities have received training to recognise the signs of mental disorders and deliver first line support, by providing a space for a trusting dialogue and in terms of signposting to available services. This work is proving effective for general mental health support. It was identified that currently, dementia training is not received by for MHFAs. Further dementia specific training is required. The spiritual care teams already working within the MHSCS can be further utilised for this purpose. There is enough demand to supply this as a regular event across all religious institutions in the vicinity. A new service need not be generated but a strategy to co-ordinate the existing resources from MHSCS and religious organisations in to a central hub where services and skills can be shared and strengthened. This "West Midlands Spiritual Dementia Alliance" aims to provide a resource detailing existing and future projects of which mainstream and additional care services can work in collaboration to improve dementia care. Additionally, NHS organisations may benefit from outsourcing funding to religious communities to offer scripture based dementia care training, as a positive existing resource of psycho-social support.

5.8.8.   Stage 2. Service Access

 Once persons have been educated and informed about dementia, they should be assisted to access the services if they choose to. The data has demonstrated that not many persons will access their healthcare provider unprompted. There are three possibilities: firstly, providing transport

links to the MHSCS by the religious communities and consistently accompanying persons during these visits. Secondly, bringing the clinic to the congregation by setting up mobile memory clinics within the place of worship where people can attend a confidential screening. The complexities of this approach may be limited by time demands and capped resources. In some situations where an elderly person does not have a family, they may prefer to access care in the Gurdwara as a central point for socialising and support, but are unable to due to lack of transport or family assistance. This raises a third alternative where some persons who are unable to attend the religious building would benefit from home visits by a mobile memory clinic team. Improving access to memory clinic services allows an official clinical diagnosis to be received. Early intervention empowers the person with dementia and their families to make informed choices about care. Reaching persons at an early stage allows persons to access adequate care and removes burden from health resources. Early diagnosis aims to prevent the person with dementia presenting to health services at a later stage through a physical co-morbidity or through injury acquired from a fall, for example.

5.8.9.   Stage 3. Service Provision

One reason why services are not adequately catering for the needs of South Asian service users was that the numbers of persons currently accessing MHSCS in this demographic are so low, that there does not appear to be a demand for resources. If this demand is not present then it is difficult to build a case for the allocation of funding to commissioners. It is important to postulate that this underrepresentation does not mean

these persons with dementia in South Asian communities do not exist. Increasing the volume of MHFAs or dementia specific first aiders links in with the Government's "Dementia Friends" (Alzheimer's Society, 2012, p.10) [see Chapter 2, p.113]. This approach supports the business model that people with dementia in South Asian communities do exist and a strategy capturing persons in the community to encourage early intervention to services requires implementation. It is important to ensure MHSCS are able to cope with the demand once people decide to access care. Some clinicians from the Hindu and Christian perspectives pushed for a drive to the non-medicalisation of dementia, since only a small number of dementia cases can be treated medically to stabilise the condition. Rather, a focus should be towards the psycho-social component of dementia care, of which religious communities provide a solid platform to provide this support. Utilisation of this platform is imperative in future care planning to transcend the boundaries identified in the *NDS* (2009) and ensure South Asian persons with dementia and those who care for them are no longer underrepresented and are empowered to make informed choices about care access.

5.9.   *Implications of Theory on Cohorts*

The implications of the Theoretical Models on each of the participant cohorts will be discussed. The data from the Hindu, Muslim and Sikh religions generated many shared themes reflecting the South Asian dementia care experience. These shared themes across religious group are synthesised to describe the impact on each of the cohorts recruited for the study, grounded in the study data.

5.9.1. *South Asian person with dementia*

The SAPWD has been underrepresented in mainstream health and social care services and within additional care services such as religious communities There are two primary reasons identified for this underrepresentation: Firstly, a lack of knowledge about dementia. The term "dementia" is largely unknown in many South Asian communities, especially in persons of older generations. Cognitive decline associated with dementia is often perceived as simply "normal" ageing. This forgetfulness in ageing has been interpreted through a religious lens - often negatively as receiving a punishment from God - or more positively, as being part of God's plan. Secondly, when a dementia is recognised, the stigma attached to mental illness hinders persons sharing the condition with family and friends and paralyses them from accessing care from mainstream or additional services. The person self-isolates from their family and religious community and only accesses MHSCS in desperate, extreme circumstances. When MHSCS are sought, they do not cater adequately for the SAPWD's specific needs.

5.9.2. *Carer of a South Asian person with dementia*

Religious beliefs influence understanding and acceptance of dementia for the carer, in terms of God's plan, returning a person to a saint-like state, bringing them closer to God and renouncing them of material concerns. Religious beliefs impact on how a carer provides care. When SAPWD are identified, care is often primarily maintained in the family, usually by a sole carer who is often a daughter or an unmarried son. This places extreme burden on the carer who themselves is of working age, trying to

juggle commitments such as working life and caring for other family members. When a carer does seek the support of MHSCS, the access is minimal, and often unsatisfactory. The family member is driven by a sense of duty as a result of religious beliefs about respecting elders and caring for persons during illness. Behaviour towards others is an outward expression of internal religious adherence. Access of MHSCS and support is thus interpreted as going against this duty and the carer experiences guilt and anxiety on two fronts: firstly, that the carer is avoiding their duty and responsibility of caring for their loved-one and secondly, a fear of not expressing their religious adherence with conviction. Consequently, carers of SAPWD do not receive full financial, emotional and practical entitlements. They experience isolation and burden during care and fear rejection from their community due to the stigma associated with mental illness.

5.9.3. Healthcare professionals

There is lots of existing work happening in a healthcare setting currently to cater for the needs of South Asian persons with dementia, including their religious requirements. Many of these approaches are positive and successful. Clinicians actively acknowledge a person's spiritual needs and take steps to cater for these, within the resources available. There was a drive towards a shift from the medicalisation of dementia - which can only be offered in a small number of cases to manage, not cure the condition - to a focus on developing and improving psycho-social care. Healthcare management acknowledges that more work needs to be done to generate a strategic, consistent approach to forming links with

religious communities in the geographical area, and utilising existing religious and community groups to fulfil these psycho-social care needs. This may involve outsourcing particular services to these existing resources and maximising on the successful existing work, rather than necessarily generating a new resource. There is a strong business case for early intervention in dementia (pp#20, DAP 3) to allow persons to receive the right treatment at the right time, rather than presenting to health services at a later date through a physical co-morbidity, requiring preventable treatment. Outreach in to the community with dementia education workshops in to places of worship has been successful and could be continued on a regular basis. This may require working alongside the religious representatives or through subcontracting to outreach organisations. This education aims to inform persons about the bio-medical perspective of dementia as a neurological illness which requires medical attention and to dispel stigma associated with negative religious-influenced perspectives. Utilisation of South Asian role models in promoting health services is needed to relate to the appropriate demographic and encourage persons in to services. Training of religious representatives by healthcare professionals to generate more Mental Health First Aiders, with dementia specific training is necessary.

5.9.4.   *Dementia organisations*

There is lots of positive work occurring within dementia organisations. Individual care planning aims to identify and cater for the religious beliefs and practices of the SAPWD. It was recognised that a person's religious beliefs can become very important as the dementia progresses and

organisations support the individual in maintaining these faith practices. Services were identified which either cater specifically for South Asian persons or for persons with dementia. Whilst provision is made to accommodate for the SAPWD within both these settings, there is a demand for a service which caters for the specific needs of the South Asian person who has dementia. Additionally, dementia organisations expressed a need for training when dealing with South Asian persons with dementia of working age, in terms of benefits, entitlements and age appropriate support. Knowledge about dementia services was low for SAPWD. Promotion of dementia services needs to occur through face to face education and a shift away from paper resources which do not account for illiteracy, or language degeneration. The role of translators was considered an imperative investment to build understanding, trust and rapport to encourage persons in to services and support persons using services.

5.9.5. Religious representatives

Persons working in the community as religious leaders encouraged SAPWD to access MHSCS. Despite this, identification of persons with dementia in specific religious communities remains low or non-existent. Religious representatives require training about mental health first aid, and specifically dementia awareness and training by healthcare professionals and to pass this training on to their congregation. Religious representatives across all faiths are vital in delivering sermons or training using religious scriptures and teachings to educate persons about how to care for a person with dementia on an individual, family and community

level, and implementing the tenets of faith in a positive way to inspire a religious-influenced model of dementia care. This aims to dispel the stigma about admitting a mental health condition and remove the stigma of accessing services. Educational campaigns by healthcare professionals in the place of worship, in a native language, allows identification of potential dementia cases and creates informed care choices. Most importantly is the utilisation of an existing network of people within the framework of a religious community, who – alongside mainstream health and social care services - can generate a strong support network for the psycho-social needs of the person with dementia and their family.

5.10. **Chapter Summary**

This chapter demonstrates the relationships identified between data categories and discusses how the findings inform and interlink to create a theory about the influence of religion on South Asian dementia care access and experience. The first model presents an existing picture of dementia care, as informed by the substantive data in the study. The second model identified the practical impact of the findings on making clear care recommendations for service improvement and utilising the opportunity for co-operation between "clinic" and "congregation" in the dementia care package. This model has a substantive as well as a potential wider implication and could be generalised to other underrepresented demographics with dementia in MHSCS, in addition to underrepresented demographics from other health sectors. Utilisation of a religious community as a basis for education about the biomedical correlates of dementia and as a source of psycho-social support, based on teachings from the religious scriptures, also has applicability to majority ethnic and religious groups such as the Christian population, for example.

6.   Chapter Six: Discussion

6.1.   Chapter Aim

This study investigated South Asian underrepresentation in mainstream health and social care dementia services through an exploration of religion's influence on the dementia care experience. A strength of this research is the focus on the practical impact of religion, offering a novel approach to existing research on cultural inequality in dementia services. The study aimed to recruit between 5 – 21 participants [see Chapter 3, p.158]. Twenty one participants were successfully recruited. This enabled the formulation of theory grounded purely in the data obtained. The researcher is satisfied this answered the research questions stated in the aims and objectives.

The findings of the present study suggest South Asian persons with dementia and carers of South Asian persons with dementia are not only underrepresented in mainstream health and social care services but are also misidentified within – and isolated from - religions communities; resulting in insufficient care and support for the person with dementia and their families. Two theoretical models were developed based on these findings; firstly, reflecting the existing care service for South Asian persons with dementia and secondly, offering a strategy for utilising religious teachings and religious communities to educate about dementia and dementia care. This aims to facilitate informed care choices, to assist with access to care services, and to ensure that once persons present to

services, they are equipped to cater for South Asian persons and their religious adherences.

These findings contribute to the knowledge in this research field by defining religion as an important factor – distinct, yet intertwined with culture – influencing dementia care access and the dementia care experience for South Asian persons. The identification of religion as a valuable, underutilised tool for improving dementia care for South Asian persons and their carers - both independently and in co-operation with health and social care services - offers a practical solution to the issue of South Asian underrepresentation in dementia services.

The aim of this chapter is to critically consider the empirical rigour of the entire research process from design to implementation and analysis. Consideration of the following will be discussed: methodological considerations and limitations, clinical implications, alternative study designs, comparison of findings with other studies and discussion of further work and further research.

6.2. Methodological Considerations and Limitations

6.2.1. Reflexivity Statement

The Critical Realist Grounded Theory approach (Strauss & Corbin, 1990) aims for objectivity, but recognises the influence of subjectivity on the interpretation of data. A reflexive approach to the study allows the researcher to identify her potential subjective influence on the research process and demonstrates steps taken to limit this bias (Creswell, 2009,

p.233). The researcher is a White, British female, who during the time of data collection and data analysis, was in her late 20s. She was acutely aware of entering a culture in contrast to her own, to explore a phenomenon with persons who subscribed to a religion she did not personally adhere to, of which persons were often speaking English as a second language. Thus, there was the potential to view and interpret the phenomenon with an *emic* rather than an *etic* (Pike, 1967) perspective. Additional factors of influence on data interpretation may have been the researcher's gender as a female, and socioeconomic status (Creswell, 2009, p.233) by association with a middle class academic institution. These factors may have also influenced on how participants perceived the researcher and impacted on the collection of data. In contrast, it is possible having no personal involvement in the communities of investigation was beneficial. Participant #19 from the Sikh community articulated that a researcher from outside the culture and religion was "a gift" (pp#19, field notes, DCP 3) because the person would be able to offer an "objective, honest analysis" (pp#19, field notes, DCP 3) about what was occurring in the community. Furthermore, the Grounded Theory method is exploratory in nature, aiming to generate theory grounded purely in the data obtained in the research process (Glaser & Strauss, 1967). The researcher's stance – as an outsider to the culture and religion being investigated – was compatible with this method of investigation; it did not allow pre-conceived ideas or convictions to contaminate the extracted data. In contrast, it may be possible that the researcher, as an outsider to the communities of investigation,

misunderstood subtle cultural or religious nuances which may have impacted upon data interpretation.

6.2.2.   Steps to limit bias

A Critical Realist approach does not purport the positivist stance of traditional GT (Glaser & Strauss, 1967), nor the wholly subjectivist stance of social constructivism (Charmaz, 2006), but it does assert that objective truths are possible to obtain, with the proviso that interpretation of these truths is vulnerable to subjective interpretation (Strauss & Corbin, 1990) [see Chapter 3, pp.119-126]. The rigorous, systematic approach to iterative data collection and data analysis utilising the Grounded Theory Constant Comparison method (Charmaz, 2006) intended to limit this bias [see Chapter 3, p.126-128].

The researcher aimed to minimise subjective bias by quantifying transcript data to document the frequency of occurring codes, in an ordinal (Stevens, 1946) presentation of twenty categories [see table 13]. These categories formed the basis of the overall theory. It is important to note these data were not analysed using quantitative methods such as inferential or descriptive statistics, but the categorisation was purely a tool to understand the emerging theory within the qualitative analysis. The researcher allowed each data analysis phase (DAP) to inform the subsequent data collection phase (DCP), utilising the constant comparison method (Charmaz, 2006); the data alone guides the trajectory of the research and informs the overall theoretical model.

Whilst these steps were taken it is recognised that the researcher's experiences, outlook and circumstances guided decisions to conduct the data analysis and data collection in a certain way. For example, the researcher alone constructed the names of the data codes. The researcher alone grouped these codes in to categories and identified the prevalent themes. It is possible that another researcher processing these data, may use different wording for the line-by-line coding, allocate these codes to different categories, have a different decision on whether a category is important or not important. However, reflecting Critical Realist (Strauss & Corbin, 1990) thinking, the researcher believes the prominent objective truths grounded in the overall data would emerge regardless of the researcher influence; however, the labelling or presentation of the theoretical model could vary across researchers. It is possible that the researcher's interpretation of this culture and these religions could vary from a different researcher investigating this phenomenon who adhered to the South Asian culture or to the Hindu, Muslim or Sikh religions. Contrastingly, the researcher holding no prior conceptions or expectations could be seen as advantageous in aiding objectivity. This reiterates the necessity to categorise the emerging codes at each data analysis phase to aim for reliability in the analysis and reporting of the findings.

6.2.3.   *Data collection and Interpretation*

The researcher is satisfied that every effort was made at each DCP and each DAP to achieve the stated aims – namely, to explore (phase 1), define (phase 2) and consolidate (phase 3) a Grounded Theory. The

researcher adopted a rigorous approach to ensure that the interviews in DCP 1 were completely exploratory and began with very open questions, specifically "tell me about your experiences regarding religion and dementia", to generate dialogue [see appendix 7]. The researcher believes skills gained from a counselling qualification allowed her to be non-judgemental and open minded in the participant-led approach of the semi-structured interview. The researcher strove to not introduce her own agenda or expectations during DCP 1 - reflecting the *tabla rasa* (Charmaz, 2006)*, inductive* method of enquiry. At this stage, the focus was exploratory, with the researcher reflecting back and picking out key words and concepts to ensure understanding. In DCP 2, the semi-structured approach was still employed, but once participants had answered a question and guided the trajectory of the interview, the researcher introduced the prompts established in DAP 1 [see Chapter 3, p.133 and appendix 7] to aim for Theoretical Saturation (Charmaz, 2006) of identified categories from DAP 1. DCP 3 was also semi-structured, and interviewee-guided. However, at this phase, prompts were used more frequently to "test" the theoretical models defined model in DAP 2. The aim was to reach Theoretical Saturation (Charmaz, 2006) to consolidate the defined categories in DAP 2 alongside the rejection of no longer occurring categories through Negative Case Analysis (Charmaz, 2006).

6.2.4.   Decision to stop data collection

The researcher is satisfied that no new categories were emerging, nor any further categories dissipating and that theoretical saturation of categories had been achieved at DAP 3. The maximum number of 21

participants had been attained. This figure was based on sample sizes for comparable, rigorous GT studies which recruited four participants (Lawrence, Murray, Samsi *et al.*, 2008), 11 participants (Bowes & Wilkinson, 2003; Neary & Mahoney, 2005), 20 participants (Patel, Mirza, Linbald *et al.*, 1998) and 24 participants (Hinton, Franz & Friend, 2004) [see Chapter 3, p. 150-158].

6.2.5. Robust Grounded Theory

The stated maximum number of participants for the study was obtained (N=21) and participants were spread across all five cohorts. This meant the theoretical model could be "tested" for robustness with new participants across three phases.

6.2.6. Transferability of Theory

The systematic Critical Realist GT approach to data collection and data analysis allows that the theoretical model whilst substantive is abstract enough for transferability to different contexts, within certain methodological parameters (Charmaz, 2006). It may not be possible at this stage to generalise the theory established from this study to represent the influence of religion on dementia care for the whole of the United Kingdom, for example. But it may be possible to apply and test this theory in the following ways: in other geographical locations, in the same location with different mental health conditions or with different South Asian religions or with another set of BME participants, for example.

6.2.7. Presentation of Findings

The researcher decided the presentation of findings by study aim, then by religious or cultural categorisation, then by theme was the clearest format to answer the study research questions. Reflecting the discipline of health research, it was of primary importance to present the perspectives and experiences of the service users and the service providers. If the researcher was representing the phenomenon in the context of a different research discipline - such as within a department of theology, for example, it may be more relevant to present the results by religious group first, then by themes, then by cohort. The purpose of the study was to investigate the influence of religion on the dementia care experience for SAPWD. The purpose was not to investigate the phenomenon of religion *per se,* rather the focus was on the practical impact religion exerts on dementia care and dementia services.

The order of categories presented in the findings reflects the prominence and prevalence of influence to the emerging theory. This meant that sometimes categories are presented interchangeably in the findings. This approach seemed preferable than simply presenting each category in a linear fashion; it demonstrates how the categories link and interact, providing a clearer presentation of the emerging theory.

6.2.8. Choice of Quotations

The researcher aimed to select and present quotations based on those themes most frequently occurring and those most accurately representing categories [see table 13 and table 15 for full category

details]. The total number of words across all interview transcripts in this study is 121,923. Thus, the selection of quotations presented in the findings to support the established theory is a very small insight in to the total volume of captured data. Quotations of themes with the highest volume of codes were chosen, or alternatively if a theme presented with very few codes which contradicted the predominant theory, these were included to present a balanced interpretation of the findings. Poignancy of quotations was also assessed by the emotion underscoring the dialogue, when listening back to the audio file. The Critical Realist approach allows for this researcher interpretation, in contrast with the positivist underpinnings of the traditional GT method (Glaser & Strauss, 1967). This Critical Realist approach accounts for subjectivity. One example of this is in the present study, it is possible another researcher may choose a whole different set of quotations from the 121,923 words in the data.

6.2.9. Religious Adherence

The study recruited persons from the Christian, Hindu, Muslim and Sikh faiths. A homogeneous sample would have allowed a quantitative approach to analysis. This may have increased the ability for generalisation of results. However, existing researchers in the field highlighted the difficulty in recruitment of South Asian persons with dementia (Bowes & Wilkinson, 2002). Initially, the aim was to conduct a quantitative study with a purely heterogeneous Hindu sample in the UK and a heterogeneous Hindu sample in India to compare religions' influence on dementia care experiences. This would have required high sample sizes and the difficulty recruiting this number may have proved

an unsuccessful study. Thus, this approach was discarded. Persons were considered Christian, Muslim, Hindu or Sikh without consideration of the particular denomination or tradition within this broad label. For example, a deeper consideration may have recognised the complexities of the Hindu tradition, in which it's very label as a "religion" may be a Western construct (Neuberger, 2004). It is beyond the scope of this project to discuss this in detail but warrants recognition.

6.2.10. Interview Rapport

The nature of interviewing is dependent on the establishment of a temporary relationship between interviewer and interviewee [see Chapter 3, p. 137]. This is especially important to consider in the Critical Realist GT approach where researcher and researchee have a symbiotic influence on the co-construction of data generation (Crotty, 1998, p.9). The researcher made every effort to develop a good rapport with all interviewees, and was sensitive to the varying dynamics across the five different cohorts, across the four different religious groups and to persons as individuals. The interviews occurred across a range of settings suitable to the context which the participant was situated. These were participant homes, clinical buildings, healthcare offices, dementia organisations and the university research centre. It is possible that the different environments in which the interviews occurred may have impacted on the reliability of data obtained. However, consideration of the role of the person within the dementia experience dictated where best the context for the interview should occur. The environment within which the interview was conducted reflected the person's role within the

dementia care experience. For example, in the Healthcare Professional cohort, interviews primarily occurred within the healthcare setting; for the SAPWD, interviews occurred in the home. Participants were given a choice of where they felt most comfortable and best suited to conduct the interview. Steps were taken to create an environment in which the participant felt comfortable, safe, informed, relaxed and supported, allowing them to speak freely and in confidence. The interviews aimed to last around one hour, but were flexible, and were between 35 minutes 52 seconds (pp#11) and 95 minutes 35 seconds (pp#21) in duration [see appendix 12 for full interview procedure data such as timings, word count and codes captured]. The decision to terminate interviews was gauged by the researcher as to when the quantity and quality of data had been captured with certain themes being saturated or dismissed. The timing was also dictated through sensitivity to the natural progression of the dialogue, for instance - not terminating the interview prematurely and ensuring the participant was able to share all the information they required, or terminating the interview if it was clear the participant was distressed. Interviews were closed by offering participants the opportunity to add anything they wanted to share which may not have been previously discussed, or had not been fully discussed within the interview context. As previously discussed, it is important to consider that the data from these interviews was generated from the dynamic between researcher and researchee, reflecting Critical Realist methodology (Crotty, 1998). Thus, if a different researcher conducted the same interview with the same participant, it is possible that the

generated data could differ, based on the rapport generated by person-to-person engagement.

6.2.11. Demographic Questionnaire

Participants completed a questionnaire capturing demographics relating to religious belief, religious adherences, strength of faith and role within the dementia care experience [see Chapter 3, p. 136 and appendix 7]. Whilst most participants appeared content to complete the questionnaire, one participant (pp#20) shared some concern that ticking a religious category, in this instance – Sikh - would cause the researcher to have preconceived ideas and expectations "about what kind of person she was" (pp#20, field notes, DAP 3). Participant # 20 stated that whilst this was her faith, her interpretation of the religion was very personal and may not involve attendance at the Gurdwara every Sunday. She also stated the argument that one would not expect all persons in a "Christian" category to be the same. It is possible that other participants shared this concern about categorising their religious beliefs, although no other persons stated this. The researcher acknowledges asking persons to tick a religious category by no means fully captures the personal and complex relationship that individual has with their faith; neither does it adequately capture the manifestations of different denominations under the category of one faith. However, the researcher aimed to understand the person's perspective by including questions on strength of faith and outward religious practice. The interview itself very much focused on exploring the personal relationship with faith as understood and described by the participant. Categorisation through the demographic questionnaire was

necessary to contextualise and analyse the responses in the findings. This questionnaire information was supplementary to the main data analysis of semi-structured interviews and observations in the Grounded Theory study. The questionnaire was simply a tool to contextualise participant backgrounds and consider how this may have impacted upon the findings. It is possible that data from this questionnaire and the impact on interview responses could form the basis of a mixed methods study (Andrew & Halcombe, 2009) – incorporating quantitative and qualitative analyses - in future research exploring strength of faith and frequency of practice on perceptions and attitudes of dementia care and access to dementia care services. However, this was not the primary focus of the present study.

6.2.12. Interview Language

All interviews were conducted in the English language. Limited resources did not allow a budget for translators. For some participants, English was not their first language, although all participants spoke English competently. This may have limited access to a sample and may have limited communication with participants. This could have impacted on the data collected. Conversely, it was imperative the researcher built a strong rapport with the participant during interviews to generate trust and enable an open dialogue. The introduction of a third party translator could have impacted on the strength of this dynamic, and raised issues regarding understanding, confidentiality and anonymity.

Communication with participants in their native language may have yielded richer data and potentially offered a further insight in to the

research field. However, out of the 21 participants, 19 persons spoke one or more South Asian languages (see Chapter 4, p179-180) such as Punjabi, Hindi, Urdu, Gujarati, and local dialects. These persons were recruited due to their role within a South Asian community – as a healthcare professional, as a religious representative, as a community member - as persons who have direct contact with communities speaking South Asian languages; thus these persons were taken as spokespersons for persons who did not speak English and could not be recruited for the study.

6.2.13.   Difficulties Recruiting Sample

The sample recruited were from the three main non-Christian religions in the West Midlands region [see Chapter 1, p.41]; namely, Hinduism, Sikhism and Islam. The participants are representative of the ethnic prevalence in the geographical region of investigation.

Buddhists comprise the fourth highest South Asian religion in the West Midlands [see Chapter 1, p.41]. One limitation of the study was Buddhists were not included in the participant sample. This was a result of unsuccessful identification during the recruitment and networking strategy. Furthermore, the difficulty accessing a sample meant initially, convenience sampling had to be utilised with a flexible recruitment strategy across the cultural group of "South Asian". However, the focus on the top three South Asian faiths in the West Midlands allowed a depth of data to be obtained within the participant sampling frame of 21.

The decision to only recruit a SAPWD whom had received a formal, clinical dementia diagnosis may have limited the potential to recruit further persons in this cohort and may have impacted on the robustness of the data and the ability to generalise the findings beyond the substantive research field. Only one person with dementia was successfully identified and recruited for the study. However, the protection of vulnerable persons was paramount in the study, and to recruit a person who is not identified or supported by existing health or social care services would have breached the ethical guidelines stated for the study, specifically the assessment of a person's capacity to consent by a trained healthcare professional [see appendix 10].

Identifying and recruiting a participant sample was challenging. The Level of Difficulty (L.O.D.) for each cohort group ranked from 1 (easy to recruit) to 5 (very challenging to recruit) is presented. Barriers to accessing each cohort and how these barriers were overcome are discussed.

Cohort	L.O.D. Rating	(N) in study
1. South Asian Person with Dementia	5	1
2. Carers of South Asian person with dementia	4	2
3. Healthcare professionals	2	6
4. Dementia organisation professionals	3	5
5. Religious Representatives	3	7
		Total (N) 21

Table 32: The level of difficulty (LOD) recruitment rating for each of the 5 study cohorts (C = cohort, L.O.D. = level of difficulty rating for recruitment, N= number of participants).

6.2.14. C1. South Asian Person with Dementia

Bowes & Wilkinson (2002) recognised many barriers to recruiting SAPWD for research studies. Over a decade later, many of these barriers still stand, "researchers attempting to ascertain the views of South Asian people with dementia face many problems in identifying appropriate research methods" (Bowes & Wilkinson, 2002, p.236). The reasons for which are cited as follows: "dearth of previous research, few background statistics, issues of diagnosis, problem of identifying and contacting respondents, issues attached to the social identity of researchers and respondents and problems gaining informed consent" (Bowes & Wilkinson, 2002, p.236). The researcher encountered barriers to identification and access of SAPWD in the present study.

6.2.15.   Barrier identified: Paucity of Literature

The paucity of research in this area has been discussed in the literature review, and highlights the difficultly accessing a group which does not present consistently to health services. The low volume of research papers in this area is a reflection of that difficulty. Consequently, the research that does exist in this field is dominated by qualitative studies, making application of statistical analysis difficult. Thus, the scale of the issue is not fully quantified.

6.2.16.   Barrier identified: Formal Clinical Diagnosis

To meet the sampling criteria for the study, a person must have received a dementia diagnosis from a trained healthcare professional. The issue of diagnosing dementia in South Asian persons is a documented challenge when persons may not communicate in the English language. Language is the main diagnostic tool used by consultants when communicating with their patients. As examined in the literature review, the Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975) which assesses for cognitive impairment in the English language is often not suitable for South Asian persons. Many of the questions in the MMSE involve reading and writing or deal with concepts of numbers and letters. Direct translation of the tool does not account for the proportion of people from the South Asian community who do not possess literacy skills. There have been attempts to translate the MMSE in to literal translations of Hindi in the HVMMSE (Tiwari, Tripathi & Kumar, 2008) and culturally adapted versions in the Hindi Mental State Examination (HMSE) (Ganguli, Ratcliff, Chandra *et al.,* (1995), but this does not account for the cultural

nuances of the individual (Pilgrim & Rogers, 1999). Thus, there is an underrepresentation of SAPWD in clinical services. Recruitment of C1 was through MHSCS which meant identification of potential participants was problematic.

6.2.17. Barrier identified: Language and communication

Language has been discussed as a fundamental part of communication in dementia diagnosis. It was also a fundamental part of the present study; the ability to build rapport with participants was essential to capture the objective ontology of their experiences of dementia and dementia care. A predominant barrier faced by the researcher was the challenge of personally not speaking any South Asian languages. The resources of the PhD study did not allow any allocated budget for interpretation. The researcher did recruit volunteer healthcare professionals who spoke the main South Asian languages – Gujarati, Urdu, Hindi and Punjabi, to act as translators in August 2011. The ethical approval for the study was a protracted process and when this was eventually received in February 2012, these volunteer translators were no longer available. The GT data analysis method involves close coding of the interview transcripts to capture the subject's voice across each and every line of data (Strauss & Corbin, 1990). Each word used by the person when describing their experiences of the phenomenon has value and highlights the necessity of clear communication throughout the semi-structured interview process.

6.2.18. Barrier Identified: Capacity

Many of the existing studies in to culture and dementia do not speak directly with the person with dementia because the person may not have received a diagnosis or the diagnosis may not be clear. There is also the potential for misdiagnosis. Late presentation to health services correlates with a decline in cognitive function, often to such a degree that the person does not possess capacity to consent to the research. The carer is often taken as the closest possible advocate for the person (Lindesay, Jagger, Hibbert *et al.*, 1997) and much of the existing research focuses on the views of the carer of the person with dementia. South Asian persons with dementia still warrant the title given to them ten years ago as a "hidden population of extremely vulnerable people" (Bowes & Wilkinson, 2002, p.231), with very low numbers accessing health services, making identification for recruitment difficult.

6.2.19. Barriers Overcome

When designing this study, the researcher considered the difficulties of accessing a sample of South Asian persons with dementia. The researcher was aware that this is a group who may be unreachable through the traditional health channels (Bowes & Wilkinson, 2002). Fully informed of the challenges, omission of the person with dementia from the sampling design was not an option. In order to make care service recommendations, the researcher was passionate about hearing the views and experiences from the perspective of the service-user. Whilst the other voices from C2-C5 were vital to gain a holistic perspective of the religion and dementia care puzzle, the most important piece was the

person with dementia, whose voice is often lost due to the difficulties recruiting and researching with persons with dementia (Goldsmith, 2002).

6.2.20.   C2. Carers of South Asian person with dementia

C2 were unexpectedly challenging to recruit. Carers were not successfully identified through MHSCS. Carers were recruited through networking by the researcher at the South Asian events attended, which formed part of the observations component of data collection.

6.2.21.   C3. Healthcare professionals

Recruitment in this cohort was easier than C1 and C2. The sampling criteria stated any cultural or religious background was suitable, which meant wider recruitment parameters. However, out of the six persons in this cohort, only one was a White, British Christian. Two persons were Indian Hindus, one person was Indian Sikh, one person was Indian Muslim, and one person was Pakistani Muslim.

6.2.22.   C4. Dementia Organisation professionals

 Identifying dementia organisations which cater specifically for persons of South Asian origin was difficult. The researcher struggled to identify South Asian specific services in the regions of the West Midlands, despite the high numbers of South Asian persons comprising the population in this region. An organisation identified which catered specifically for older South Asian adults – although not specifically those with dementia - refused to participate. The researcher identified and recruited dementia

organisations which cater for the general population as well as South Asian service users, and implemented snowball sampling of other organisations, staff members or service users from these identified organisations.

6.2.23. C5. Religious Representatives

Initially recruiting in C5 was very challenging. The researcher approached the religious organisations using a range of methods. The researcher sent out hard copy recruitment packs and targeted the majority of religious organisations in the designated regions. This yielded no responses. The researcher then telephoned the organisations in the vicinity and this yielded one or two contacts. From these contacts, snowball sampling was implemented. The researcher learnt that cold contacting communities was not productive and developing a good rapport with one individual within a community was a better method for establishing further contacts. The researcher also built on chaplaincy links within the Black Country Partnership NHS Foundation Trust and the Birmingham and Solihull NHS Mental Health Foundation Trust and also within Staffordshire University. Making contact with the chaplaincy teams within these NHS Trusts opened up many doors to chaplains of the different South Asian faiths and invitations to visit temples and religious community buildings for the observations.

6.2.24. Barriers overcome

A networking and recruitment strategy aiming to recruit participants according to the protocol and within the defined GT method was created.

Unsuccessful strategies were eliminated with Convenience and Snowballing sampling strategies employed in the first instance, then Purposive Sampling, driven by the emerging data, followed by Theoretical Sampling to saturate unconsolidated theoretical areas (Charmaz, 2006). A flexible recruitment strategy was developed which allowed numbers of each cohort to be fluid according to the realistic availability of participants. Recruitment was approached with persistence because with no participants, there is no study. Many networking events were attended and an openness to recruitment through previously unthought-of channels. It was recognised the recruitment process was an evolving entity beginning with Convenience Sampling and subsequently driven by areas in the emerging theory which required Theoretical Saturation (Charmaz, 2006).

6.3.   Quality Qualitative Research

The present research is compared against three quality frameworks to assess for methodological rigour. The first is the quality criteria defined by the Critical Appraisal Skills Programme (CASP, 2006) checklist for Qualitative research. The following points are considered which demonstrates how steps were taken to meet this criterion:

6.3.1.   Clear Study Aims

The aims of this study were stated clearly in the research questions and objectives. The researcher is satisfied that every effort was made, in the time frame and resources for the present study, to answer the stated research questions and meet the aims and objectives [see Chapter 2,

p.118 for full study aims and objectives]. The methods employed to capture data effectively investigated the following, as stated in the aims:

o how South Asian religious beliefs and practices influence attitudes and perceptions of dementia, the decision to seek dementia care, the provision of dementia care and satisfaction with dementia care services.

o how existing dementia care provision currently caters for South Asian religious beliefs and practices.

o how South Asian religious beliefs and practices create barriers to accessing dementia services.

The methods employed to capture data effectively investigated the following, as stated in the objectives:

- to capture the perceptions, attitudes and experiences of dementia from services users and service providers.

- to synthesis and analyse these responses to identify areas of success and deficiency in dementia care provision.

- to make recommendations to improve care for South Asian persons with dementia and their carers.

The perceptions, attitudes and experiences of all five cohorts were investigated and captured, these data were analysed and synthesised in to areas of success and deficiency in the current dementia care provision. Following this, recommendations were given on how the dementia care provision could be improved for the South Asian person with dementia and their carers.

6.3.2. Appropriate Qualitative Methodology

The researcher believed a qualitative methodology was most appropriate due to the paucity of existing literature which focused specifically on religion and dementia care services for South Asian persons [see Chapter 2, pp. 61-84]. This meant that generation of a quantitatively testable hypothesis was not possible, and would have been based on conjecture, not empiricism. Thus, an exploratory approach was considered the most suitable fit and a qualitative methodology was chosen. The qualitative methodology selected was Critical Realist Grounded Theory. Alternative qualitative research methods such as Interpretative Phenomenological Analysis (IPA), (Smith, 1996) and Content Analysis (CA) (Berelson, 1952) were not considered the most appropriate due to their suitability for analysing individual datasets. The aim of the present study was to generate an overarching theoretical model and Grounded Theory was selected as the most suitable method to achieve this [Chapter 3, pp. 120-126 for further discussion of the qualitative methodological approach].

6.3.3. Appropriate Research design to address research aims

The aims of the research were to identify the influence of religion on dementia care services for South Asian persons. The design adopted was to explore this influence from a holistic perspective by capturing the experiences of a range of five different cohorts involved in dementia care services. This approach aimed to capture a range of views in to a new avenue of research, in an exploratory way. The aim was to represent the phenomenon as closely and accurately as possible, in an unbiased

manner – initially exploratory and becoming incrementally focused as data collection and analysis progressed. This approach effectively answered the questions posed in the research aims. Alternative research designs were considered; for example, a quantitative approach with a homogenous sample of one religious group would have widened generalizability. However, it was not possible to formulate a quantitatively testable hypothesis based on the limited literature in the research field nor guarantee a homogenous sample of high enough numbers to perform robust statistical analysis.

6.3.4.   *Appropriate Research Strategy*

To meet the research aims, a strategy based upon a three year timeline was established. This strategy allowed time in the first year for thorough exploration of existing literature to identify a research gap alongside completion of a post-graduate certificate in research methods (PgCRM). It involved informal discussion with current researchers and clinicians in the field to establish effective methods of investigation and recruitment. The second year was dedicated to building on these established contacts and focusing on recruitment and data collection. This allowed a full twelve months to gather data around three main time periods, interspersed with data analysis periods. The final year involved writing up the project [see table 33].

	0 – 6 months	6 – 12 months	12 – 18 months	18 – 24 months	24 – 30 months	30 – 36 months
PgCRM Course	X	X	X	X		
RDC1 completion	X					
Informal Discussion with researchers	X					
Literature Review		X				
Participant Recruitment		X	X	X		
University Ethics		X				
NHS Ethics		X				
Conference Abstract		X				
Phase 1 Interviews			X			
Analysis Phase 1			X			
Phase 2 Interviews			X			
Analysis Phase 2				X		
Phase 3 Interviews				X		
Analysis Phase 3					X	
RDC 2 completion				X		
Write up Thesis					X	X

Table 33: Strategy for the three year project

6.3.5.   Appropriate Data Collection

The semi-structured interview method and observations allowed insight in to a previously undiscovered phenomenon of the practical impact of religion on South Asian health care underrepresentation. This aimed to conduct an unbiased exploration of the phenomenon, and allow for the theory to emerge and develop freely, without a preconceived hypothesis. These methods were selected as the most appropriate for the present Grounded Theory methodological approach.

6.3.6.   Researcher – participant Consideration

The researcher adhered to a Critical Realist GT (Strauss & Corbin, 1990; Strauss & Corbin, 1998) approach which accommodates for the influence

of subjectivity on the attainment of objective truths. The researcher has given consideration to her influence on the whole project, from the approach to the existing literature, planning a research design and subsequent data collection and data analysis [see Chapter 6, p. 286].

6.3.7.   Ethical Consideration

The study was subject to ethical review across three stages. A full consideration of ethical issues were provided and approved during this review process [see Chapter 3, p.163 for details]. Firstly, an Independent Peer Review was conducted by Staffordshire University on 4th May 2011 with approval on 20th June 2011. Secondly, the West Midlands NHS Local Research and Ethics Committee was held 13th September 2011 and approved on 25th October 2011. Thirdly, Research and Development (R&D) Clearance within the lead Black Country Partnership NHS Foundation Trust was applied on 11th November 2011 and granted on 28th February 2012; and within subsequent trusts on the following dates: Leicestershire NHS Partnership Trust applied on 27th March 2012 and granted on 24th May 2012, South Staffordshire and Shropshire NHS Foundation Trust applied 27th April 2012, granted 24th May 2012, Birmingham and Solihull NHS Mental Health Foundation Trust applied 2nd April, approved 17th October 2012.

6.3.8.   Rigorous Data Analysis

The data analysis was conducted over three phases: to explore, define and consolidate the theory. Quantitative capturing was applied to the

data at each phase to contextualise frequency of occurring categories, in an aim to eliminate bias and offer a thorough analysis. Theoretical Saturation and Negative Case Analysis allowed the theory to be tested at each phase.

6.3.9.   Clear statement of Findings

The researcher describes the complexity of defining themes as either "religious" or "cultural" and takes steps to account for the possible subjectivity in this distinction. The findings are presented as two theoretical models, reflecting the current service provision and providing recommendations for improving the service provision. There is a clear statement of the implications of the findings for each of the cohort groups involved in the study.

6.3.10.   Research Value: Novel Contribution

The research is valuable because it offers a novel contribution to the existing research field of culture and dementia care services. The research investigates the dementia care experience for a group of underrepresented individuals established in the existing research literature as "South Asian" (Adamson, 1999; Bowes & Wilkinson, 2002, 2003; Chandarana & Pelizzari, 2001; Ismail & Mackenzie, 2003) but is novel in its approach to asking how one specific element which was previously considered under the broad definition of "culture" - namely religion - influences care access and experience. This is not to say that only religious themes are considered in the data collection and analysis;

rather, approaching the issue in a unique way aimed to generate undiscovered data - some of which may overlap with cultural themes such as language and communication. However, primary attention was given to those religious specific themes as the potential to offer new knowledge to the field, whilst recognising the inevitable interplay between religion and culture.

6.3.11. Research Value: Religion – Practical Resource for Care

The research identifies religion as a practical resource for dementia care. This offers value in the following ways:

o Religious beliefs, motives and practices were recognised as a key contributor to underrepresentation in health and social care service for the South Asian person with dementia (SAPWD).

o Practical methods utilising religious communities are offered to overcome this health inequality.

o SAPWD are underrepresented across all services, both mainstream health and social care and alternative services such as religious communities.

o It is vital that these persons are captured and educated to make informed decisions about care.

o Carers are experiencing tremendous burden. The research recognises religious communities as an invaluable resource - to outreach in to and educate about - the bio-medical elements of dementia to reduce stigma, allow informed choices, and offer a support network for the person and their carers.

o Faith-based training is a powerful way to improve recognition of the dementia illness within the congregation, alongside encouragement to MHSCS offers a holistic approach.

o Religious communities can be utilised alongside MHSCS to meet the psycho-social needs of the SAPWD by offering a physical building and a support network of people.

6.3.12. Research Value: Holistic perspective

The research offers a holistic perspective from a range of persons and professionals involved in dementia care planning and provision. The research offers a presentation of what is currently occurring in dementia care from the perspectives of the service-user and the service provider, highlighting successes and deficiencies. A synthesis of the findings across cohorts is given, enabling recommendations aiming to have a positive, practical impact on how religious and health communities can collaborate to improve service provision for South Asian persons with dementia and support carers of persons with SAPWD. This is valuable because it approaches the issue from a unique standpoint, and represents different perspectives of a range of persons involved in care, to enable a sound justification for service improvements, with an understanding of how these may practically be able to be implemented in the framework of existing resources. The researcher believes this is valuable in that it captures this perspective from a range of persons and services involved in the dementia care model, and investigated the symbiotic impact these different perspectives have on the overall experience of dementia for a South Asian person.

6.4. Critical Realist GT quality criteria

Based on Critical Realist Grounded Theorists, Strauss & Corbin (1990);
Strauss & Corbin (1998) the researcher aimed to adhere to two sets of
quality principles throughout the study design and implementation. The
researcher labelled these "Critical Realist GT quality principles 1" (based
on Strauss & Corbin, 1990) and "Critical Realist GT quality principles 2"
(based on Strauss & Corbin, 1998) and utilized these as quality
benchmarks in the present research study.

6.4.1. Critical Realist GT quality principles 1

The research will now be discussed in accordance to the quality principles
of a critical realist GT study (based on Strauss & Corbin (1990, p.17-18).

6.4.2. Concepts Generated

There were a total of 3,403 codes across three Data Collection Phases
(DCPs). These codes were grouped into 20 overarching categories. The
themes within these categories were discussed in the presentation of
findings.

6.4.3. Concepts Systematically Related

The categories related to each other to form two interlinking theoretical
models. Themes within categories interlinked across phases, across
cohorts and across religions.

6.4.4. Conceptual linkages and category development

The categories were comprised of many different themes. These themes were identified and explored with incremental depth across data collection and data analysis phases. The main example of linking between categories was in the three most prevalent categories – religion, existing service and service improvement [see Chapter 5]. The researcher aimed to display clear linkage in the model about how each one of these categories informs and influences the next stage of the model and how theoretical model 1 influences and informs theoretical model 2.

6.4.5. Variation in the theory

The presentation of the findings accommodates for nuances within the data which do not fit with the established model. Consideration was given to the varying religions. The most prominent categories and themes which overlapped across religious cohorts were presented in the overarching theoretical model, with recognition of variations built in to the theory.

6.4.6. Impact of broader conditions affecting phenomenon

Consideration of the existing health care provision was discussed in the literature review to place the existing study in a broader context. From this, it was identified that religion was an often overlooked factor in the existing literature on "culture" and warranted specific consideration. The difficulties of accessing a sample of SAPWD were considered and recognition that previous studies had utilised the dementia caregiver.

6.4.7.   Consideration of theory process

The researcher aimed to demonstrate a rigorous exposition of the process taken at each data collection and analysis phase, with explicit details about data method, participant demographics and research influence. The application of quantitative capturing of the coded data demonstrates the adopted process.

6.4.8.   Extent and significance of theoretical findings

The theoretical findings are significant in demonstrating religion requires consideration as an influential factor on the perception of dementia, the acceptance of dementia, the decision to access dementia care services, and satisfaction with dementia care services. The findings demonstrate that religion influences MHSCS and work is being done to accommodate for the religious needs of persons with dementia. The significance of this theoretical discovery allows practical recommendations to be made, which are grounded in the existing care provision, supported by data from both those providing care services, and those accessing care services. It is possible that these recommendations could be applied to geographical regions outside of the West Midlands region.

6.4.9.   Critical Realist GT quality principles 2

The following principles (based on Strauss & Corbin (1998, p.269) will now be considered in relation to the present research. Each heading relates to one of the checklist criteria.

6.4.10. Sampling Selection

The sampling strategy reflected the GT method which is flexible to the development of the research (Charmaz, 2000). Convenience sampling was initially used with a range of strategies. This led to Purposive sampling to those channels which provided successful recruitment. Theoretical sampling occurred in Phase 3 to capture areas which had not been adequately saturated in previous phases, with the recruitment of a SAPWD being the primary focus [see Chapter 3, p. 159].

6.4.11. Major Categories

The most significant categories across all Data Analysis Phases in terms of frequency and poignancy were Religion, Existing Service, Service Improvement, Stigma, Outreach Services and Education and Knowledge.

6.4.12. Identification of Major categories

The frequency of the category of stigma for example, emerged as an introductory theme in DAP 1 and continued to present with increased prevalence and prominence across different cohorts, and across different religious groups and data analysis phases, as the research developed.

6.4.13. Theoretical Sampling

The most frequently occurring categories in DAP 1 allowed prompts to be utilised in DCP 2 and DCP 3 which aimed at the Theoretical Saturation or Negative Case Analysis (Charmaz, 2006) of identified categories. The interview schedule was amended to include prompts in subsequent

phases. On this basis, theoretical sampling occurred to target participants not yet fully represented in previous phases. For example, the SAPWD was targeted for recruitment as result of theoretical sampling in DAP 3, to inform the strength of the defined theory. Following this, the primary categories identified in DAP 1 and DAP 2 were upheld as proving representative of the phenomenon.

6.4.14. Relationships between Categories

It was evident in DAP 1 religion influenced the dementia care picture in several ways - education and low knowledge impacted upon practical uptake of services. This knowledge was informed by religious beliefs. DCP 2 explored this hypothesis and uncovered the impact of stigma associated with mental health conditions, as influenced by religious beliefs hinders persons accessing support both in MHSCS and in the religious communities. Phase 3 consolidated this hypothesis that low knowledge and religion-inspired perceptions of dementia led to underrepresentation across family, MHSCS and religious settings and that this isolation is often self-inflicted. This was "tested" by comparing the frequency and poignancy of references in the data with weaker areas in the transcripts, across all three phases.

6.4.15. Discrepancies in hypotheses

PP#17 disputed that education in the religious places of worship was a way forward. He believed home visits on a one to one basis would be more successful and education in GP surgeries would be more effective

than education in a religious building such as a mosque. This challenged the established theory of outreach education in to religious buildings. This discrepancy was accounted for by the supplementary data from the other cohort groups who had had practical experience of entering religious places for educational campaigns and had been very successful. Data from the remaining four cohorts reiterated that persons are not presenting to the GP and so to capture them this way would be challenging. Whilst pp#17's views were taken in to account, his suggestion of home visits was used as a supplementary arm to the overall hypothesis of education of persons in the religious communities, but these home visits could only occur once persons with dementia were successfully identified and captured in MHSCS.

6.4.16. Core Category

The core category in the data analysis for this study was Education; specifically, the demand for education through outreach in to religious communities, as a result of low-knowledge and awareness of dementia. The categories which informed this were Religion, Outreach Services, and Stigma. Education was selected as a core category due to its prominence - as an emotionally poignant area, and its prevalence - as occurring frequently across the data. The category was identified in DAP 1. In DAP 2, Education was defined as central to the model, and consolidated in DAP 3. This consolidation occurred once data from all cohorts had been attained. The researcher was satisfied – as far as possible within the existing data - that the need for education as a result of low knowledge,

offered robust explanatory power for the underrepresentation of South Asian persons with dementia in care services and religious communities.

The clinical implications, alternative study designs, comparison with other studies and future work and future research are now discussed:

6.5. Clinical Implications

The study identified clinical dementia services may benefit from working co-operatively with religious communities to offer a holistic care package of bio-medical and psycho-social care. This relieves some of the strain off clinical resources and shifts the perspective from focusing on services, to focusing on community. The data suggested the NHS could outsource some of their resources into community services such as religious organisations.

6.6. Alternative Study Designs

Due to the paucity of data, a Grounded Theory, qualitative study was considered the most suitable method of investigation. Alternative study designs may be as follows. Homogeneous sampling of Hindu, Sikh or Muslim demographics may have increased the potential for generalisability and formed the basis for a quantitative investigation. The notorious difficulties in recruitment coupled with an aim to reflect the South Asian dementia experience meant this was discarded.

6.7. Comparison with existing research

Argo (2010) stated a person in India may visit a religious leader rather than health services when experiencing a mental illness. This offers one explanation for underrepresentation in health and social care services for migrants who now live in the UK but adhere to their indigenous religious and cultural practices. However, the present study found persons with dementia were also underrepresentation within religious communities, and tended to self-isolate from their religious communities when experiencing dementia. Carers of persons with dementia from South Asian religions expressed a fear of stigma which contributed to isolation from their religious community. Conversely, when persons were experiencing physical illness, this was shared with the religious congregation who offered care and support.

Bowes & Wilkinson (2003) asserted health and social care services appear ill equipped to respond to the religious need of ethnic minority individuals. The present study identified good work within health and social care services to cater for and to meet the religious needs of South Asian persons with dementia. The issue is that South Asian persons with dementia and their families are not aware of existing services and how to access these services. The data suggests MHSCS are equipped to cater for religious needs. The healthcare professionals in the study stated they actively support these needs as far as possible within their resources, but recognise that catering for the religious needs of a person with dementia may fall outside of their clinical remit. Social care providers were very active in catering for the religious needs of the South Asian service users,

but often these numbers were so low that the demand for funding to support this and encourage more South Asian service users could not be easily demonstrated to commissioners [see Chapter 4, p.240, pp. 248-249].

In Chapter 1 and Chapter 2, the researcher argues the *National Dementia Strategy* (2009) may not adequately account for additional care services such as religion or additional care pathways, influenced by religious belief. The study investigated this phenomenon and found this to be the case. Persons with dementia were very seldom identified within their religious community, and despite the high South Asian demographic in the West Midlands, had a very low or nonexistent presence in dementia services in this region.

The PRIAE study recognised that non-English speaking people experience barriers at every stage of dementia and dementia is often misunderstood as normal ageing (Patel, Mirza, Linbald *et al.*, 1998). The present study replicated this finding and identified a positive way around this with a shift away from paper-based literature and an investment in face to face translators. It offers a positive approach to how these barriers may be overcome; religion and its teachings provide a powerful educational platform to generate a model of care for persons with dementia within the congregation.

Stigma surrounding mental illness generally and dementia specifically was a prevalent theme identified in existing literature (Moriatry, Sharif &

Robinson, 2011). This was reproduced in the present study with the cause of stigma deriving from a misunderstanding about the bio-medical cause of dementia and lack of direct translation for the word "dementia" in South Asian languages with terms such as "mad" and "mental" used to describe the illness.

6.8.   Study Shortcomings

Whilst the researcher took every step to design and complete a robust study, there were some shortcomings identified as follows:

The aims and objectives for the study were rather broad, reflecting the exploratory approach. However, this generated a vast amount of data not specific to religion, but relating to issues of culture broadly. A more refined research question focusing specifically on religion, with fewer components, may have assisted a clearer research direction.

The demographic questionnaire (see appendix 7) would have benefited from the inclusion of questions regarding the person's duration in the UK, and their country of birth. This would have allowed a more accurate picture of the types of persons in the sample and their immigration status is. This would assist in the interpretation of findings in terms of understanding acclimatisation to culture, generational differences, expectations of services and language ability.

The findings could have been presented more clearly in terms of the differences between each religion. This would have strengthened the researcher's argument that religion and culture are two entities, which intertwine, but are distinct. The researcher plans to write papers highlighting the specific themes identified for the Hindu, Muslim and Sikh faiths and the implications on dementia care access and experience.

There could have been more of a focus on the generational differences and the implications of the age sample on the findings. A further study comparing the differences in generational outlooks towards dementia, within the South Asian community, would be beneficial.

To separate more clearly the distinction between religion and culture in the findings, it may have been useful to have a White Hindu, Muslim or Sikh cohort in the sample, or a Christian South Asian. These samples could be recruited in further research to explore the findings and test the strength of the theoretical model in the present study.

Excluding non-English speakers and persons with dementia who lack capacity to consent may have limited the data collected and impacted on the possibility for generalisation. (see Chapter 6, p. 297 and Chapter 3, p156, for further discussion).

6.9.   Chapter Summary

The researcher is satisfied that every attempt was taken in the study to meet the intended aims and objectives in an empirically rigorous manner. Where study weaknesses were identified, these were met with methodological flexibility within the parameters of the epistemological and ontological approach, whilst aiming to retain the study's integrity. The Critical Realist position aims for attainment of objective truths, whilst recognising the co-constructivist nature of generating a Grounded Theory. The researcher took steps to be reflexive at each stage of the study process to be mindful of her potential influence. Two theoretical models were generated, identifying areas of success and deficiency in dementia care for South Asian persons. Practical recommendations were made for how to implement these findings to improve care services, meeting the study objectives. Following this discussion, the conclusions for the study are presented in Chapter seven.

7. Chapter Seven: Conclusion

7.1. Chapter Aim

This chapter presents the conclusions to the research project.

7.2. Further Work

The study identified practical ways of engaging with religious communities to improve care for the South Asian person with dementia and support for carers of South Asian people with dementia. The following are recommendations:

7.2.1. West Midlands Spiritual Dementia Alliance

An alliance of people working in religion and spirituality and dementia care could be established as a registered charity in the West Midlands, operating as a central hub, resource and community to share information about existing projects and to pool skills, experiences, resources and ideas for people working within religion and spirituality for South Asian groups, to generate future projects. The projects within this alliance would comply with the PM's challenge in *Dementia 2012* (Alzheimer's Society, 2012) to generate "dementia friendly communities" and address issues identified in the *National Dementia Strategy: Equalities Action Plan* (Department of Health, 2011a) which recognised the "general lack of data available on religion in relation to people with dementia" (Department of Health, 2011a, p.8). One future project could be the Service Improvement idea expounded in Theoretical Model Two in the present study which offers a project based on education, service access and service provision. Resources and skills are available within NHS

organisations in the West Midlands to take this project forward. This project may be undertaken as a one off venture within the Dementia Action Alliance (http://www.dementiaaction.org.uk/) framework, for example. However, the researcher believes the demand for education in South Asian communities is high enough to generate consistent, on-going work.

Building a central point of existing resources for South Asian persons with dementia allows service users to gain information about existing services and for service providers to signpost people to appropriate care. The South Asian Health Foundation (SAHF) (http://www.sahf.org.uk/) is a fantastic existing resource addressing health inequalities for South Asian persons. There is a mental health component, but a gap was identified within this provision which addresses dementia specific issues. A West Midlands Spiritual Dementia Alliance aims to fill this gap. Many contacts within the study from health and social care professionals were enthusiastic about taking such as provision forward.

7.2.2. National Spiritual Dementia Alliance

Once the charity has been established in the West Midlands, and successful projects implemented, there is the long term potential to establish further contacts throughout the UK and roll out the service improvement model of co-operation between religious community and health and social care providers on a national level.

7.2.3. Dementia First Aiders

A further project required is the training of dementia first aiders. This could be alongside the existing positive training of Mental Health First Aiders within one NHS Trust in the region, or it could be delivered as stand-alone training within religious communities.

7.2.4. Religious Model of Care

The religious scriptures could be used as a model of care when delivering this training. Successful work has been identified using the Sikh model of coaching for Life-coaching and mentoring by one organisation in Birmingham. This type of training using religious beliefs, thoughts and practices could be implemented to provide dementia training for family and carers and congregation members.

7.2.5. Co-operative approach clinic and congregation

Clinical visits with a team of clinicians and religious representatives and health and social care providers in to religious communities on a consistent basis offering education, diagnosis and support in to services are required.

7.2.6. Dementia South Asian Specific Services

The study identified a general lack of South Asian specific dementia care homes and dementia care services. A need was identified for religious specific care provision, such as a Sikh dementia care service, a Hindu dementia café and a Muslim dementia support group.

7.2.7.   Working Age Dementia Training

Training within dementia organisations for persons of working age is required, regardless of culture. The literature demonstrates a high prevalence of vascular dementia and young onset dementia in South Asian demographic, so services may need to be tailored to cater specifically for this demographic.

7.3.   Further Research

The present exploratory study investigated the issue of South Asians – as a cultural demographic – as an underrepresented groups in dementia care services. It was identified in existing literature that this issue is "cultural". This study aimed to investigate how religion impacts on South Asian underrepresentation in dementia care, in the knowledge that whilst religion and culture are separate entities, they are often indelibly intertwined. The study offered a unique approach and provides a platform for further research in to religion and dementia care in South Asian populations. The following may be considered in future studies:

7.3.1.   Religious Homogeneity

Further research with a homogenous sample across three studies aiming to investigate if South Asian persons from the Sikh, Hindu and Muslim communities have respective and specific care needs.

7.3.2.   Quantitative Study

A quantitative study assessing referral and diagnosis rates prior to dementia education (T1) - by the Service Improvement model strategy - and post-education and clinical visits (T2), coupled with a quality of life scale for the carers of the person with dementia at T1 and T2.

7.3.3.   Case Study

A case study approach allows empirical enquiry in to contemporary phenomenon within a real life setting (Yin, 2009, p.8-13). This generates an in-depth understanding of dementia care through personal, direct experiences. Additional data generated from time spent with pp#17, formed the basis for a case study paper (Regan, 2014b), separate to the main thesis. These data were also incorporated in to the main data set analysed for this study. Further work comprised of case studies documenting the experiences of care services from a Sikh person with dementia and a Hindu person with dementia, would be beneficial in complementing the case study from the Muslim perspective (Regan, 2014b).

7.4. Chapter Summary

"…religious values can be a positive advantage in forming therapeutic alliances. It should be possible to use the scriptures as part of the treatment"

(Kalra, Bhui & Bhugra, 2010, p.343)

This study firstly, recognises religious communities as a practical tool in the identification of underrepresented persons with dementia, and secondly, promotes faith based, dementia specific training within religious congregations. These two criterion aim to improve access to, and experiences of, dementia care for South Asian persons. Additionally, the theoretical models presented may be utilised to identify and educate other underrepresented BME groups about dementia, such as traveller communities, and for faith-based education and training across mental health conditions. Care services – mainstream and additional – should form alliances to offer a holistic care package and increase care possibilities. The person with dementia and their carers should be educated about all care options available in order to be empowered to make informed choices about how best to be supported and how to access this support.

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Appendices

Publications

The following are publications by the researcher throughout the PhD research study.

a. Regan, J.L. (2012). The Influence of Religion in Dementia Care in South Asian Populations: A PhD Study. In Chandler, J., Barry, J., Berg, E. (eds) *Dilemmas for Human Services 2011*, 108-114. London: UEL.

b. Regan, J.L. Bhattacharyya, S., Kevern, P & Rana, T. (2013). A systematic review of religion and dementia care pathways in black and minority ethnic populations. *Mental Health, Religion and Culture*. 16, 1-15.

c. Regan, J.L. (2014). Redefining dementia care barriers for ethnic minorities: the religion-culture distinction. *Mental Health, Religion and Culture*. 17, 345-353.

d. Regan, J.L. (2014). Ethnic minority, young onset, rare dementia type, depression: A case study of a Muslim male accessing UK dementia health and social care services. *Dementia*: *The International Journal of Social Research and Practice. (in press).*

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John Chandler, University of East London, United Kingdom
Jim Barry, University of East London, United Kingdom
Elisabeth Berg, Luleå University of Technology, Sweden

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Jim Barry (University of East London, United Kingdom)
Elisabeth Berg (Luleå University of Technology, Sweden)

The Influence of Religion on Dementia Care in South Asian Populations: A PhD study

Jemma Regan
(Centre for Ageing and Mental Health, Faculty of Health, Staffordshire University, United Kingdom)

Background

In the UK alone, dementia costs 23 billion per year in health and social care costs. This is considerably more than the three main causes of death in the Western world; it is twice the cost of cancer, three times the cost of heart disease and four times the cost of stroke (Luengo-Fernandez, 2010). Despite this prolific economic outlay, not all persons with dementia in the UK receive adequate health and social care provision. Black and minority ethnic (BME) patients experience hard times when accessing dementia services. They receive diagnoses later in their disease progression and are less likely to access anti-dementia medication or partake in research trials and care (Mukadam et al, 2011). BME groups are most at risk of developing vascular dementia and express an elevated prominence of young onset dementia (aged under 65 years), when compared with the ethnic majority (RCP, 2009). Current clinical assessments may be 'culturally biased' towards the majority ethnic population making it more difficult for BME individuals to access services. (DoH, 2001). The Western tradition to seek clinical intervention in the case of physical or mental illness highlights the discrepancy between indigenous UK culture and immigrant religious practices and rituals. Existing research has identified cultural differences as a reason for why barriers exist in healthcare for BME persons with dementia. Religion is a specific and fundamental part of culture which dictates outlook, attitudes and behaviour. A prominent theme emerging from existing research, not yet directly addressed, is the impact of spirituality and religion - as one facet of culture - on dementia. Religion in BME communities influences perception of the illness, acceptance of the illness, coping with the illness and service access (Milne and Chryssanthopoulou, 2005).

The present literature cites various cultural reasons why BME persons with dementia experience difficulties. These result from communication and language difficulties (Moreland, 2001) racism, lack of knowledge about dementia, previous bad experiences within the UK health care system leading to a general lack of confidence in the existing care provision (Mukadam et al, 2011). Existing research identifies the impact that religious beliefs and practices have on the dementia experience for BME persons with dementia. The emphasis on familial duty often leads to one family member providing sole care for a person with dementia, or keeping care within the family unit only, and not seeking any outside support. (Lawrence et al, 2008; LaFontaine et al, 2007; Jett, 2006; Braun et al, 1996; Watari and Gatz, 2004). This can place tremendous burden on the caregiver and may mean

that the person with dementia does not receive optimum care. The behavioural manifestations of dementia affect religious ritual. For example, incontinence impeded Muslim home prayer as the house was considered 'dirty'. Communication and translation issues manifested both in clinical communication and in support services (Bowes and Wilkinson, 2003).

Cultural barriers to day-care and residential services were evident through inappropriate food or lack of observation of particular religious rituals associated with mealtimes (Patel *et al*, 1998). Within particular religious communities, mental illness is associated with stigma and is perceived as taboo, and thus prevents family members from seeking support from the wider community (Jones et al, 2006; Zhan, 2004; LaFontaine et al, 2007; Jett, 2006; Braun et al, 1996; Bowes and Wilkinson, 2003; Watari and Gatz, 2004). The stigma associated with mental illness negatively affected religious practices such as arranged marriage (Bowes and Wilkinson, 2003). A lack of knowledge about dementia results from many BME languages not having a direct translation for the word 'dementia' (Moreland, 2001). There are cultural misunderstandings about the aetiology of the dementia condition. In some cultures, the nuances of life, positive and negative are perceived as part of God's plan. Thus, to seek health care to 'cure' or help with the condition may be perceived to interfere with God's will. Other traditions interpret the illness as a result of karmic retribution and thus help for the condition should not be sought. (Zhan, 2004; LaFontaine et al, 2007; Jett, 2006; Bowes and Wilkinson, 2003). Ultimately, mainstream dementia services currently are not catering adequately for persons with dementia from black and ethnic minority backgrounds (Bowes and Wilkinson, 2003).

The author conducted a systematic research review of the literature exploring: 'care pathways', 'BME', and 'dementia' (Regan et al, 2011). Across five screening phases from a total of >1000 papers, there were only two papers which met the inclusion criteria (Sun et al, 2008; Levkoff et al, 1999. These were from research conducted in the US with BME Christian populations. There was no original, scientific research found exploring how religion affects pathways to care for BME religions in the UK. Further study is needed to elucidate the role that religion plays in the help-seeking pathway for dementia, and to improve equity of access to healthcare services. The present study proposes to improve knowledge of the interaction between health and religion in order to improve care provision.

Aims
The research focuses on the South Asian community and aims to answer the following research questions: How do South Asian religious beliefs and practices influence: 1. Attitudes and perceptions of dementia? 2. The decision to seek dementia care? 3. The provision of dementia care? and 4. The satisfaction of existing dementia care services?

Does existing dementia care provision sufficiently cater for South Asian individuals in terms of their religious beliefs and practices?

How might the contrast between South Asian religious beliefs and practices and the UK healthcare provision create barriers to accessing dementia services and being satisfied with dementia services?

Objectives of the project
The research questions will be met with the following objectives: To investigate the perceptions, attitudes and experiences of persons with dementia of South Asian origin, carers of persons with dementia of South Asian origin, healthcare and dementia organisation professionals and South Asian religious leaders. To synthesise and analyse these responses in order to identify areas of deficiency in the current dementia care provision. To make recommendations for improvement to dementia care services for South Asian individuals with dementia.

Participants
There will be a maximum of 20 participants, across five participant groups recruited from West Midlands NHS trusts and private community organisations: South Asian persons with dementia, carers of south Asian persons with dementia, dementia health care workers, dementia organisation workers and religious leaders. Initially, purposive sampling will be implemented, according to Grounded Theory (GT) methodology (Bryant, 2010, p235) and if participant numbers have not reached the required quota, snowball sampling will be used following this. South Asian can be defined as those who originate from the geographical location of South Asia, including: India, Pakistan, Bangladesh, Bhutan, Nepal, Maldives, Afghanistan, Iran and Sri Lanka but now live in the UK. The South Asian culture is not homogeneous and incorporates various religious belief systems such as Islam, Buddhism, Hinduism, Sikhism, amongst many others. Thus, the religious facilitators will be recruited from a range of religious traditions. In this study, the terms 'Immigrant' and 'Indigenous' refer to religion; with religion as one aspect of culture. 'Immigrant' is not a definition of the individual. Rather, it is their religious beliefs and associated practices that are immigrant to the cultural setting they are now living within. For example, the indigenous religion of the United Kingdom is Christianity. The culture of the United Kingdom is Christianity-orientated. Religious traditions such as Hinduism, Islam, Buddhism, and Sikhism are immigrant religions in to the indigenous culture of the UK.

Method
The study is based on an exploratory, qualitative design incorporating semi-structured interviews. Based on GT principles, there is a longitudinal, iterative component, spanning a nine month period. The same participants will be interviewed for a maximum of three occasions. This will allow an initial set of

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pilot interviews which opens up the area of religion and dementia. The second set of interviews will build on the findings of the first interview phase and be tailored according to the results. The third set of interviews will be tailored further based on the results of the second interview phase. Translators will be implemented to assist with interviews, if required.

Analysis

Data will be analysed using GT methods (Glaser and Strauss, 1967). The research does not start from a hypothesis; the iterative approach employs *adbuctive* logic (Peirce, 1903) and allows a theory to be generated from the exploration of the data obtained from the field. The initial enquiry in to the research area will be to gain preliminary data about the investigation. By re-visiting participants, the theory can be developed and refined on each occasion, as a result of closely analysing and coding the data of each interview period. A qualitative data computer package, such as *NVIVO* 9, will be used to analyse and code the data at each stage after interviewing in order to analyse existing themes and allow generation of the next phase in interviewing based on these identified themes. The research method is exploratory. It is not testing religion deductively, as a dependent variable and thus predictions are not expected to be made about the outcome of the research (Strauss and Corbin, 1998, p41). After the third interview session, it is anticipated that a theoretical model will be developed about how religion and spiritual beliefs and practices influence South Asian dementia patients' care experiences in the UK. If a subsequent theory is developed, then it may be possible to generate a quantitatively-testable hypothesis to form the basis for further research.

Predicted Outcomes and Benefits

Increasing knowledge of the effect of immigrant religious beliefs and practices on dementia care experiences aims to improve care provision in the indigenous UK culture by highlighting what is working in existing services, what needs improving and potentially whether religion and health services need to work together to generate a more appropriate care package. An outcome of the study is to promote a positive shift in research from an ethnocentric perspective of dementia by raising awareness of, and sensitivity to, alternative cultural groups in dementia populations with a view to educating care providers and policy makers on methods to develop 'culturally competent practice' (LaFontaine *et al*, 2007).

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A systematic review of religion and dementia care pathways in black and minority ethnic populations

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A systematic review of religion and dementia care pathways in black and minority ethnic populations

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Objective: To investigate how religion influences care pathways for black and minority ethnic individuals with dementia. We conducted a systematic search of the literature to explore how religion affects later presentation to care services, absence of care-seeking and dissatisfaction with care. Exclusion and Inclusion criteria were applied to the research literature. Qualitative and quantitative papers were included. Included studies were assessed independently by four authors according to quality criteria. Two US studies adhered to the final screening stage. Findings from these papers postulated that religion influences care in two polarised ways: (1) Religion hinders access to the traditional health care pathway. (2) Religion assists in positive coping. Collaboration between religious institutions and health care providers is required to improve care referral, provide information dissemination and relieve care-giver burden. UK research in this area is necessary.

Keywords: dementia; religion; BME; care pathways

Background

Dementia is a global and growing pandemic. By 2021, almost one million people will receive a dementia diagnosis in the UK. Black and minority ethnic (BME) groups comprise 8% of the British population and it is anticipated that dementia prevalence will increase at a greater rate in these groups than the majority ethnic population (DoH, 2009). BME communities are more at risk of developing vascular dementia and experience the highest rate of young onset dementia, aged under 65 years, compared with the cultural mainstream (Richards et al., 2000; Seabrooke & Milne, 2004). Despite this, research has highlighted that BME individuals with dementia access health services and receive diagnoses later in their disease progression and are less likely to access anti-dementia medication or partake in research trials and care, as compared with the majority ethnic population (Cooper, Tandy, Balamurali, & Livingston, 2009). Some do not access clinical services at all and when care is sought, the provision received is unsatisfactory (Bowes & Wilkinson, 2003). Government policy recognises that current clinical assessments may be

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culturally biased (DoH, 2001). An understanding of BME community beliefs and practices is imperative to ensure individuals do not fall between service gaps (RCP, 2009).

A recent systematic review of ethnicity and pathways to care (Mukadam, Cooper, & Livingston, 2011) identified 13 exploratory papers which highlighted several barriers for BME individuals with dementia. The participants recruited in the studies held religious beliefs from non-Christian, typically Eastern religions such as Buddhism, Hinduism, Islam and Sikhism. The obstacles identified included the following: racism, lack of knowledge about dementia, previous bad experiences within the UK health care system, lack of confidence in the existing care provision, communication and language difficulties. The present authors categorises these themes as external, organisation-driven barriers, relating to inadequacies within the current care package. Further identified themes are a consequence of internally driven barriers, relating specifically to religious beliefs and practices. Religious specific themes identified are as follows: the religious duty to provide family care creates a barrier to seeking outside help and support (Braun, Takamura, & Mougeot, 1996; Jett, 2006; LaFontaine, Ahuja, Bradbury, Philips, & Oyebode, 2007; Lawrence, Murray, Samsi, & Banjeree, 2008; Watari & Gatz, 2004); the shame and stigma of mental illness within particular religious faiths presents a barrier to seeking community support (Bowes & Wilkinson, 2003; Braun et al., 1996; Jett, 2006; Jones, Chow, & Gatz, 2006; LaFontaine et al., 2007; Watari & Gatz, 2004; Zhan, 2004); religion-led perceptions about the aetiology of the illness leads to the view that dementia is part of God's plan; and therefore to intervene with health care provision, may be seen to challenge God's will. Religious perceptions may label dementia as a form of karmic retribution or punishment, which presents a barrier for seeking help for the condition (Bowes & Wilkinson, 2003; Jett, 2006; LaFontaine et al., 2007; Zhan, 2004). Existing studies have investigated how culture – in a broad sense – influences pathways to care (Mukadam, Cooper & Livingston, 2011). Religion is *one* part of culture, which dictates outlook, attitudes and behaviour. It is important to research how *religion specifically* impacts on the care-seeking pathway in order to understand existing care provision and the pathways to that care provision. The present systematic review focuses on dementia care and religion in BME groups to identify existing knowledge within the current research literature.

Aims

To systematically review the research literature to answer the following question: how does religion influence the decision to seek existing health care services and does religion offer an alternative care pathway for BME persons with dementia?

Method

Search strategy

The following databases were searched up to early May 2011: Medline (1950-), Web of Knowledge (1950-) PsychINFO (1806-) using the following search terms: "Dementia" OR "Alzheimer* disease" were combined using the AND operands with the following terms: "religion", "spirituality", "Christianity", "Buddhis*", "Sikh*", "Hindu*", "Muslim", "Islam", "Black", "Asian", "South Asian", "BME". Free text terms, MeSH terms and subheadings of MeSH terms were used in the Medline search. Titles and abstracts of all studies were read to meet the inclusion criteria for the initial screening. Those that were potentially relevant were examined in their full form and subject to five phases

of screening. Arising discrepancies regarding a paper's relevance were discussed and resolved with the co-authors.

Inclusion criteria

All original research which directly addressed dementia, religion and pathways to care in BME communities from a qualitative or quantitative approach were included. All perspectives involving the dementia patient, caregiver, community group or health care provider were examined. We included any studies which compared health care usage across cultural groups.

Exclusion criteria

Any studies where dementia was not the exclusive focus of study were excluded. These included research comparing dementia patients with cancer patients; general ageing papers where dementia is a subset of the research; dementia in relation to brain donation, end of life care issues, palliative care, Mild Cognitive Impairment, artificial nutrition, feeding, depression, epilepsy, reviews, spiritual reminiscence therapy. Non-scientific papers were excluded. Books and Literature Reviews were also excluded as they do not present original research.

Screening phases

Papers were subject to five phases of screening. Phase one involved searching across databases with defined criteria. Phase two involved removing papers according to exclusion criteria. Phase three removed any paper that did not focus exclusively on dementia. Phase four removed duplicates across databases. Phase five only included papers which address specifically the following terms: "religion", "care pathway", "BME".

Table 1. Quality assessment checklists.

Quantitative studies		Qualitative studies	
1.	Target population: Clear inclusion and exclusion Criteria?	1.	Are the aims clearly stated?
2.	Was probability sampling used?	2.	Is a qualitative methodology appropriate?
3.	Did respondents' characteristics match the target population: i.e. was the response rate $\geq 80\%$?	3.	Was the research design appropriate to address the research aims?
4.	Were data collection methods standardised?	4.	Was the recruitment strategy appropriate to the research aims?
5.	Was the measure used valid?	5.	Were the data collected in a way that addressed the research issue?
6.	Was the measure used reliable?	6.	Has the researcher – participant relationship been adequately considered?
7.	Have ethical issues been considered?		
8.	Was the data analysis sufficiently rigorous?		
9.	Is there a clear statement of findings?		
10.	How valuable is the research?		

Quality assessment

Papers were assessed for quality based on modified checklists from standardised assessment tools. Quantitative papers were subject to a checklist influenced by Mukadam et al.'s (2010) adaptation of Boyle (1998) and supplemented by criteria from the Critical Appraisal Skills Programme (CASP, 2006). Qualitative Papers were subject to assessment using the CASP (2006) checklist (see Table 1 for assessment criteria). Each question on the checklist was converted to a score of one, with a total score of 10. Disputes regarding scoring were reconciled through re-examination and discussion with the co-authors.

Points were awarded on the data explicit in the paper. No points were awarded for implied information. For example, for question 7 regarding ethics: if there was no detail given in relation to ethical consideration, the paper would be awarded 0 on this item.

Results

Two papers adhered to the final screening criteria. These papers directly address the issue of religion and the dementia care pathway for BME populations. Both papers are from research conducted in the United States and utilise care-givers of persons with Alzheimer's dementia as participants. The papers are relevant to the health care system of the United States and reflect the ethnic spread of the specific region within that country. One paper adopts a quantitative approach and compares African American caregivers with Caucasian caregivers (Sun, Roff, Klemmack, & Burgio, 2008). One paper utilises a qualitative method and compares a mix of different American cultural backgrounds: African-American, Chinese-American, Puerto Rican, and Irish-American (Levkoff, Levy, & Weitzman, 1999) which were chosen due to their predominance in the Boston region.

Screening phases

Whilst there were a high number of papers found at screening phase one (>1000), very few of these addressed pathways to dementia care. The majority of papers related to religious coping and dementia. Of these, the majority were Christian based. Others related to health care issues where dementia was a subset, such as cancer studies. Others did not include the three key terms relating to: "religion", "care pathway", "BME participants". The search was conducted using English and English written journals. It may be possible that searching eastern literature in native languages may have proved more fruitful.

During phase one, 1234 papers were found across all databases. Of these, 457 comprised unoriginal research, 479 utilised qualitative methodologies, 246 implemented quantitative methodologies and 52 employed both qualitative and quantitative techniques, reflecting a mixed-method approach (See Table 2 for a breakdown of papers by study type). Some search terms generated more than 10 papers; some search terms generated 0 papers in the initial search. Search terms which generated 0 papers were as follows: Dementia "AND" Sikh; AD "AND" Hinduism; AD "AND" Islam; AD "AND" Muslim; Spirituality, dementia "AND" south Asian; religion, dementia "AND" BME. The most papers generated were in relation to the umbrella terms of dementia "OR" AD and religion "OR" spirituality. In terms of ethnic groups, the majority of research in dementia and religion is in relation to Christianity, followed by South Asian, then Hindu, then Black communities. The following table (Table 3) quantifies the findings of the

systematic literature search, with search terms ranked according to the volume of papers found in screening phases one to three.

Quality assessment

Quality assessment scores of 7 (Sun et al., 2008) and 8 (Levkoff et al., 1999) were awarded. The Sun et al. (2008) paper was strong in that it had clear inclusion and exclusion criteria

Table 2. Screening phases, outcomes and breakdown of papers by study type (n.b. "unoriginal" denotes unoriginal or non-scientific research, "mixed" denotes a combination of qualitative and quantitative methods).

Screening phase	Search terms	Volume of papers	Study type
1	"Dementia" OR "Alzheimer* disease" were combined using the AND operands with the following terms: "religion", "spirituality", "Christianity", "Buddhis*", "Sikh*", "Hindu*", "Muslim", "Islam", "Black", "Asian", "South Asian", "BME".	1234	Unoriginal: 457 Qualitative: 479 Quantitative: 246 Mixed: 52
2	Remove papers according to exclusion criteria	247	Qualitative: 153 Quantitative: 66 Mixed: 28
3	Remove any paper that does not focus exclusively on dementia	180	Qualitative: 119 Quantitative: 43 Mixed: 18
4	Remove duplicates across databases	91	Qualitative: 61 Quantitative: 19 Mixed: 11
5	Include papers that address specifically: "Religion", "care pathway", "BME participants".	2	Qualitative: 0 Quantitative: 2 Mixed: 0
	Phase 5 UK studies	*0*	

Table 3. Total volume of papers across databases according to search terms and screening phase.

		>10 Papers in initial search		
		Volume of papers per screening		
Ranking	Search terms	Phase 1	Phase 2	Phase 3
1	Dementia+Religion	537	81	61
2	Spirituality+Dementia	212	54	40
3	AD+Religion	192	53	33
4	Christianity+Dementia	88	16	16
5	South Asian+Dementia	63	15	8
6	Dementia+Hinduism	52	2	2
7	Black+Dementia+ Religion	35	12	7
8	Christianity+AD	20	1	1
9	Black +AD+Religion	19	7	6

for the target population, the data collection methods were standardised and the measure used was valid. The data analysis was rigorous. There was a clear statement of findings and relevant discussion of how these findings could be applied for further research. Weaknesses of the paper were it did not utilise probability sampling, it was unclear whether characteristics of respondents matched the target population in terms of response rate, and it was unclear whether the measure used was reliable. The scale was created by the REACH research team, who supported the project. There was no discussion about the reliability of the scale. Additionally, there was no acknowledgement of ethical issues. The Levkoff et al. (1999) paper's strengths were as follows: its aim was clear; the methodology, research design, recruitment strategy and data collection were all appropriate with a clear statement of findings. There was an adequate discussion of the contribution of the study to the wider research arena. Its weakness was the data analysis may not have been sufficiently rigorous to reach theoretical saturation. There was neither discussion of ethical considerations nor an appropriate discussion of potential researcher bias. See Table 4 for a breakdown of the final papers.

The papers were at the higher end of the quality scale. This positively impacts interpretation of their data. However, due to the small number of papers present, the findings can only be interpreted as a starting point. How these papers fit into the wider research arena will be discussed.

Themes

The themes resulting from the findings of the two research papers (Levkoff et al., 1999; Sun et al., 2008) will now be reported:

1. Religion

The religious affiliation of the participants in the final studies is not explicitly stated. Sun et al. (2008) makes reference to "church" service and attendance and thus participants can be labelled generically "Christian". Religion is defined as identification with a particular religion or as personal spiritual beliefs (Levkoff et al., 1999) and refers to Roman Catholicism for the Irish Americans, Pentecostal and Baptist for African Americans and Confucianism for the Chinese Americans. Puerto Ricans do not have a religious affiliation stated explicitly. Thus, the majority of participants whilst from ethnic minority backgrounds are associated with Christianity. This reflects the religious distribution of the United States where Christianity is the majority religion and is associated with many different cultural groups and identities (Kosmin & Keysar, 2008). A distinction arises between "religion", which can be understood as a set of doctrinal beliefs, and "culture", the manifestation of those beliefs into particular practice, is evident. For example, the basic tenants of Christianity can be interpreted and practiced within the culture of the individual believer, or culture of an ethnic community.

2. Religion and the care pathway

Decision to seek care. The theme of religious duty is expressed across many religions, from Catholic doctrine to the moral imperatives of Confucianism (Levkoff et al., 1999). Religious and ethnic perceptions have been shown to influence all four stages of the decision making process when assessing and seeking help for an illness, from stage one: disease and symptom experience; stage two: symptom appraisal, through to stage three: decision to seek care and stage four: contact with care providers (Levkoff et al., 1999). In antithesis to the notion that religious duty is a hindrance for care-seeking, some religious

Table 4. Breakdown of phase 5 papers and quality assessment score.

Authors and year	Country	Study type	Research question	Method	Sample	Religion	Number and ethnicity of participants	Quality score (see Table 1 for criteria)									
								1	2	3	4	5	6	7	8	9	10
Levkoff, S; Levy, B; Weitzman, P. F. (1999)	USA	Qualitative	How does religion (and ethnicity) influence help seeking?	in-depth interviews	Caregivers of AD patients	Catholicism, Pentecostal, Baptist, Confucianism, Christianity	10x4 groups (total n = 40): African-American, Chinese-American, Puerto Rican, and Irish-American. 32 female, 8 male.	1	1	1	1	1	0	0	0	1	1
Sun, F; Roff, LL; Klemmack, D; Burgio, L.D. (2008)	USA	Quantitative	How does religiousness (and gender) influence use of support services?	REACH I research team used scales to measure the use of formal services (Gitlin, et al., 2003) and informal services (Krause and Markides, 1990). Religiousness was measured using a Likert scale questionnaire (Koenig & Futterman, 1995)	Caregivers of AD patients	Christianity implied; not stated explicitly	295 African American and 425 Caucasian participants. 165 male, 555 female.	1	0	0	1	1	0	0	1	1	1

institutions were identified as serving an "organisational" function, by providing caregivers with information and access to social support (Levkoff et al., 1999). This was not consistent across all ethnic groups. All of the Irish American participants who sought long term care did contact Catholic church-affiliated facilities to assist with their decision. Conversely, many of Puerto Rican Americans discussed religious affiliation during the interview process, but none expressed accessing, or wanting to access services through their churches, nor did they hold the expectation that church communities should provide assistance (Levkoff et al., 1999).

Use of care facilities. The Sun et al. (2008) paper documents the following outcomes in Christian carers of ethnic minority individuals with dementia. Religion has been shown to influence uptake of care services when assessed across three measures. These are the frequency of attendance at religious services, the frequency of prayer and the personal importance of religion (Koenig & Futterman, 1995). Findings show differences in how BME male and female carers access care services and that religious faith helped explain these differences. Females scored higher than males across all measures of religiosity and females were more likely to use informal support services than males (Sun et al., 2008). Females were more likely to attend religious services than males. Those females who attended church less frequently were more likely to use formal health transportation services. A statistically positive correlation was found between the frequency of church attendance and the use of informal health transportation services. However, Sun et al. (2008) do acknowledge that the correlation could be a result of practical necessity rather than causation of service uptake, "...these could be caregivers who never learned to drive or those who currently found themselves unable to drive with a disabled care recipient" (Sun et al., 2008, p. 949). One practical explanation may be that they did not attend church as regularly because they did not possess the transport to do so.

When long term care facilities are sought, carers discussed misunderstandings of behavioural nuances related to religion. One carer described her African American mother embarking on a religious experience in a nursing home. The woman was filled with the "Holy Ghost", became excitable and fainted (Levkoff et al., 1999). This behaviour, typical of Pentecostal worship was misunderstood by the care home staff as hysteria and the woman was restrained unnecessarily. This is a paragon of how insensitivity to religious beliefs and practices has a negative impact on care provision. This offers some explanation for why the admission of BME individuals with dementia to care services is much lower than majority ethnic individuals with dementia (Mukadam, Cooper & Livingston, 2011). The carer describing this incident expressed her distress that the nursing staff did not recognise this cultural behaviour and her relationship with the care home was fractured as a result (Levkoff et al., 1999).

To summarise: Religious obligation is a factor in not accessing external care services. Fear of culturally insensitive practice towards religious behaviour may also prevent access to care provision. There is some evidence that when the decision to seek external care is made, consultation with religious institutions to assist with information dissemination and decision making is evident across some cultural groups.

3. Religion and coping: alienation and prayer

The psycho-social needs of African and Irish American caregivers may be unmet by church groups (Levkoff et al., 1999). Irish American and African American carer narratives showed themes of alienation from religious groups and described suffering spiritual crises as a result. In this instance, the needs of caregivers were unfulfilled by the external

institution of religion. Despite this, religion also serves a "non-organizational" function (Levkoff et al., 1999), influencing internal religiosity in terms of thoughts and feelings about the self. Internal manifestations of religion are employed when coping with dementia, in BME communities. One predominant religious ritual utilised is prayer. Irish American and African American caregivers expressed using private prayer as a means of coping with the demands of dementia care (Levkoff et al., 1999). Prayer is utilised as an outlet for alienation from religious organisations. One African American caregiver said she hid her husband's dementia from Church leaders and other members of the congregation, only revealing her husband's condition to the "Good Lord" (Levkoff et al., 1999). Conversely, none of the Chinese American participants discussed using prayer, beliefs about deities or other religious imagery to cope with the illness (Levkoff et al., 1999). Thus, for members of BME communities, religious faith contributes to the wellbeing of caregivers on a personal reflective level, contributing to allowing acceptance of a difficult situation (Levkoff et al., 1999).

Strength of faith has found to negatively correlate with uptake of in-home services. Women who prayed and attended services regularly were less likely to use in-home services than women who prayed and attended services less frequently (Sun et al., 2008). This suggests religious coping. Prayer may reduce stress levels, thus reducing the need for formal support. This finding should be treated with caution because these caregivers also attended services more frequently. One explanation may be attending services provides community links and shared care giving, thus reducing the need for formal support. Since prayer and church visiting take up time, it is possible that those who had this time were caregivers of a person who required less demanding care (Sun et al., 2008).

To summarise: A disparity exists between firstly, the perception that external religious institutions and its members isolate the caregiver and the cared for; and secondly, the notion that an internal faith manifested in personal ritual provides comfort, reflection and acceptance.

4. Recommendations

The authors of these data (Levkoff et al., 1999; Sun et al., 2008) suggest that co-operation between religious institutions and dementia organisations is a vital step to improving care provision and the pathway to care provision for BME dementia caregivers. Faith communities could assist in practical ways such as facilitating with patient referral, providing respite care, and using the religious institution as a platform for education and information for dementia caregivers (Sun et al., 2008) Local dementia organisations and specialist BME services could collaborate with churches to assist in disseminating information about existing provisions and educate the religious institution about how to offer appropriate care (Levkoff et al., 1999). However, it is important to note that strong religious affiliations within a cultural group do not necessarily mean that all members of the group want to access services through their churches (Levkoff et al., 1999).

The findings from this review assert that firstly, religion has a negative effect on BME Christians with dementia when accessing care services and secondly, religion has a positive effect on improving internal coping processes. The exceptions identified to this are with Puerto Rican or Chinese Americans, whose experiences vary (Levkoff et al., 1999). This highlights the needs to be sensitive to different cultural groups and not categorise "BME" as a homogenous term, of which all its members require identical treatment, regardless of the ethnic and cultural nuances present (Elliott, Di Minno, Lam, & Tu, 1996).

Discussion

The wider research arena: care and coping

These results are reflective of the wider research arena regarding the influence of religion on BME individuals and their uptake of health services. As identified, [see Table 3] the majority of research in to dementia and religion is dedicated to Christian, typically protestant, white, ethnic majority individuals. Studies exploring religious influence and uptake of other health services also focus primarily on the ethnic majority demographic. In antithesis to religion and BME health service use, the research demonstrates religious beliefs positively influence health care usage in the ethnic majority. A study employing Presbyterian women established that frequency of service attendance correlated with increased frequency of mammogram service use. Women who attended weekly services were almost twice as likely to attend mammogram screenings compared with women who attend services less frequently or never (Benjamins, Trinitapoli, & Ellison, 2006). Women who attended church regularly were more likely to attended cervical cancer screenings than women who never attended religious services (Naguib, Geiser, & Comstock, 1968). Similarly, a US study involving a nationally representative sample of preretirement-age adults reported that religious service attendance was positively associated with the use of cholesterol screenings (Benjamins, 2005). The research involving BME individuals does not find a positive effect of religion on wider health service usage. A study found that the effect of health service uptake and religious coping styles differed by race. White women were predominantly more likely to use health services when adopting particular religious coping styles, than were African American women (Ark, Hull, Husaini, & Craun, 2006). Similarly, African American women who regularly attended religious services were not found to be more likely to attend breast cancer screening services (Felix-Aaron, Levine, & Burstin, 2003). Thus, the research in to religion and health service uptake prevents conflicting results depending on the cultural identity of its participants and their respective religious beliefs. However, existing research involving BME and white dementia carers demonstrated non-white caregivers were more likely to use prayer, faith, or religion as coping mechanisms than white caregivers (Connell & Gibson, 1997). In a study with Belize participants, the caregivers' religiosity was salient to how they viewed and coped with their caregiver role. Culture was cited to positively influence caregivers' beliefs and perceptions of care giving (Vroman & Morency, 2011). Similarly, in a study involving African American caregivers, religious involvement in general and church attendance in particular, offered spiritual and social psychological benefits to dementia caregivers (Sun, Kosberg, Leeper, Kaufman, & Burgio, 2010). African American caregivers gave more hours of care, used religion and denial as coping styles, and were less burdened than white family caregivers (Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007).

It is not within the scope of this review to discuss in depth the reasons why the disparity between white and non-white experiences of religion and health care uptake exists. Possible explanations previously discussed assert religions associated with BME cultures have tenets such as the influence of familial duty of care as a barrier to seeking external services (Braun et al., 1996; Jett, 2006; LaFontaine et al., 2007; Lawrence et al., 2008; Watari & Gatz, 2004), illness perceived as God's will or karmic retribution (Bowes & Wilkinson, 2003; Jett, 2006; LaFontaine et al., 2007; Zhan, 2004); or from notions of shame and stigma surrounding mental illness generally (Bowes & Wilkinson, 2003; Braun et al., 1996; Jett, 2006; Jones et al., 2006; LaFontaine et al., 2007; Watari & Gatz, 2004; Zhan, 2004). It is within the scope of this review to assert BME individuals with dementia

are not accessing health services as frequently as their majority ethnic counterparts, and are dissatisfied with the care provision when it is sought. The limited amount of research papers found as a result of the present systematic review clearly highlights the paucity within the current research field.

The present systematic review found no scientific papers from the UK which adhered to screening phase five: "pathways to care", "dementia" and "BME participants". However, hand searching discovered clinical reports (Jutla & Moreland, 2007; Moreland, 2001, 2003), which were not scientifically rigorous enough to be included in the resulting data, but do offer a useful insight in to religion and dementia in BME populations in the UK, specifically the Wolverhampton region of England. In the first of a series of three reports, (Moreland, 2001) interviews were conducted with leaders of religious institutions and community groups from the African-Caribbean and Asian communities. Sikh and Muslim institutions were included as representatives of the Asian communities. The African-Caribbean representatives derived from Christian organisations ranging from Methodist to Baptist and Pentecostal denominations. The purpose was to assess knowledge of dementia, awareness of dementia services and current care provision within these institutions, not "pathways to care" specifically. The participants were interviewed as cultural representatives. They were not asked about how religion in particular influences perceptions of dementia. The resulting data postulated there was a lack of knowledge about dementia and its effects and existing services available within the communities interviewed. One explanation by an African-Caribbean leader was that there is no word for dementia in patois (p. 59). Many of the Asian languages also possess no direct translation for "dementia". Knowledge of dementia is low in all of the Asian communities interviewed; the religious leaders were less informed about the condition than the workers within the non-religious organisations. There was awareness of the needs of older Asian people with dementia, but these requirements are not fulfilled adequately. The process was described by one organisation worker as, "doors are opened, needs are identified, but never met…" (p. 69). Dementia was perceived as a taboo issue in Asian communities interviewed. Dementia was perceived as "socially unacceptable" and associated with "stigma" (p. 72). This lead to a "subsequent desire for privacy" (p. 72), leading to "spiritual problems" (p. 72). In some instances, the reluctance to use services results from the provision not adhering to cultural regimes or inappropriate food choices (p. 76). The report discusses the importance of utilising religious communities for dissemination of information about dementia and the associated cultural specific services. This report highlights that research in to dementia care within religious and cultural communities is achievable. Further research conducted in a scientifically rigorous manner in to how religion specifically, not just culture, influences dementia care pathways would be beneficial.

Immigrant religion: indigenous culture

The most important finding of this study is that it has highlighted cultural incompetency in care even when the religion of the dementia carer matches the indigenous religion of the country. The two resulting papers (Levkoff et al., 1999; Sun et al., 2008) were research based in the United States with Christian participants. The indigenous religion of the United States is Christianity. As discussed, the wider research picture suggests that Christian individuals experience religion as having a positive effect on their uptake of health services. However, these studies were with ethnic majority, white Christians. In the

present review, cultural interpretations of Christianity across minority ethnic groups meant did not demonstrate that religion positively impacted on the uptake of health services (Levkoff et al., 1999; Sun et al., 2008). Thus, it is not sufficient to provide block care for persons from a particular religion without considering the cultural interpretation of that religion (Elliot et al., 1996) even when the religion of the individual and the indigenous religion of the country are the same. The ethnicity and culture of the persons who are practicing a religion are important factors to be considered. For example, a white Christian does not experience the same barriers to dementia health care as a black Christian.

Strengths and weaknesses of the study

The quality of the studies found was high which means the resulting data holds credibility. The resulting data also reflect the wider researcher arena of religions' influence on care pathways in other health areas. The number of papers is too small to assert generalisations about how religion influences barriers to health care access in persons with dementia from BME backgrounds. The data presented relates to the US health care provision. The paucity of data in this field in general, and specifically relating to UK papers, highlights the desperate need for research in the UK and world-wide. It is unclear whether theoretical saturation was obtained with the Levkoff et al. (1999) study, demonstrating the need to replicate and expand upon this research. Subsequently, the research question: "how does religion influence the decision to seek existing healthcare services and does religion offer an alternative care pathway for BME persons with dementia?", could not adequately be answered. This does not weaken the present studies rigour; rather it reiterates the necessity to perform empirical research in the area. It is important to survey existing literature, even if this is small in number, to thoroughly identify how to proceed in the field. Whilst the initial search of papers proved fruitful, very few adhered to the criteria of "BME", "pathways to care", "religion". The stringent inclusion and exclusion criterion of the present study provides in-depth knowledge about the gaping omissions in the research field. This creates an essential platform to design and implement a focused, empirical study.

Dementia and culture is a relatively embryotic research arena. The two papers document research conducted in 1999 and 2008. This reflects the cultural spread of the ageing population. Post-war immigrants who arrived in the UK and US in the 1950s now comprise a large percentage of the ageing population (US Department of Homeland Security, 2011). Coupled with this, certain BME communities are more at risk of developing vascular dementia and experience a greater rate of young onset dementia than their ethnic majority counterparts (Seabrooke & Milne, 2004). In the UK, dementia prevalence is rising more rapidly in BME persons than the majority ethnic population (DoH, 2009). Consequently, the interplay between religion and health care is a novel and growing research field.

Both papers were from the caregiver's perspective which could limit the data. The data set could be improved by widening participant samples to include religious communities, health care professionals and of paramount importance, the person with dementia. However, accessing BME persons with dementia who possess capacity to partake in experimental research (Mental Capacity Act, 2005) is difficult due to low service-uptake and late presentation to health services (Bowes & Wilkinson, 2003).

The final papers identified implement quantitative (Sun et al., 2008) and qualitative (Levkoff et al., 1999) methdologies. The resulting data provide information about the correlation between religious adherence and pathways to dementia care for BME persons. Further research using qualitative methodology or a mixed-methods approach would be beneficial to discover *how* and *why* religion influences the attendance of – and satisfaction with – service uptake within BME communities. A phenomenological examination of the attitudes and experiences of those involved with religion and dementia care may address the following questions during semi-structured interviews or focus groups: How do religious communities perceive and understand dementia? How has religion influenced the decision to seek dementia care? How does religion influence who should provide care, and when and how this should be provided? How are BME religions catered for within existing care health care and social organisation packages? The resulting knowledge aims to form the basis for policy recommendations to improve care provision and make care pathways more accessible.

Overall, the findings from these data provide a strong platform on which to stand and survey the gaping omissions and unchartered territories in this research field.

Conclusion

Religion has been found to be influential on dementia care services in terms of perceiving the illness, deciding on subsequent care provision and deciding which pathway to take to obtain appropriate care. Religion offers an alternative care pathway in the sense of religious coping. Prayer and faith offer internal personal support through the dementia journey. This study provides a new insight: even when the religious beliefs of the carer and the cared-for match the country of care, care provision still needs to accommodate for cultural nuances. Sensitivity to different cultural manifestations of indigenous religions, including Christianity needs to be implemented to improve dementia care provision. These results reflect the findings from the wider research arena. Religion influences the experiences of dementia care received and given and that existing care does not cater appropriately for persons of BME descent. Religion contributes to a sense of internal religious coping. Religion hinders the pathways to external care. Co-operation between religious institutions and care providers is the next vital step to lowering the barriers to improve care provision and relieve care-giver burden. Research in to how best to form this synergy is vital to ensure BME persons with dementia do not "slip through the net" and receive optimal care provision. Further research is required in to how this might best be provided. Existing health services may need adaptation (Mukadam, Cooper & Livingston, 2011) or alternative care pathways and provisions may need to be created.

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Mental Health, Religion & Culture

Redefining dementia care barriers for ethnic minorities: the religion-culture distinction

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Redefining dementia care barriers for ethnic minorities: the religion–culture distinction

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Barriers to healthcare services experienced by black and minority ethnic (BME) persons with dementia are labelled as "cultural" in existing research. This is a promising shift from an ethnocentric approach to dementia care provision, yet very little research is dedicated to specifically how religion – as distinct from culture – influences healthcare practice. Further consideration of the religion–culture distinction is required; religion and culture are two distinct entities, which inevitably interlink. Cultural themes such as "God's will", "Religious Ritual" and "Religious Duty", warrant re-categorisation as "religious". Sensitivity to the nuances between cultural and religious themes will provide clearer knowledge of how and why BME persons with dementia experience barriers to accessing care services. Further research is needed with regard to the role of religion specifically on dementia care access for BME persons to aim to improve care provision for this underrepresented demographic.

Keywords: dementia; barriers; BME; culture; religion; healthcare

Background

Early gerontological research recognised the importance of forging links with religious organisations to improve care provision for underrepresented older adults, "It is not too soon for health and social services to liaise with minority religious leaders to determine the needs of the elderly both in respect of residential care and community services" (Karseras & Hopkins, 1987, p. 124). More recently, the emphasis on developing "culturally competent practice" (La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007, p. 613) to remove barriers for black and minority ethnic (BME) persons accessing dementia healthcare services, offers a promising shift from an ethnocentric healthcare provision. In antithesis, the nomenclature of "culture", whilst implying a shared identity, overlooks individual nuances. One distinct, yet interactive facet of cultural identity is religion. The practical impact of religious coping on general health service use has been identified; for example, white women expressed a higher inclination than African American women to access health services when adhering to defined religious coping styles (Ark, Hull, Husaini, & Craun, 2006). This has also been considered in relation to Alzheimer's disease specifically, but focuses primarily on Christian populations (for a review see Beuscher & Beck, 2008). An exploration of the impact of non-Christian belief systems on dementia care requires consideration. The tradition in India to visit a place of worship as a first port of call for a mental condition

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(Argo, 2010) is an example of a religious practice which contrasts with a Western bio-medical perspective of accessing healthcare primarily. Whilst it is interesting to explore how religion is used as a coping mechanism in the face of mental illness, this does not adequately account for the logistical implications religious beliefs exert on healthcare provision and healthcare access. Very little research is dedicated specifically to how *religion* influences healthcare *practice*. For example, in the field of dementia, a recent systematic review (Regan, Bhattacharyya, Kevern, & Rana, 2013) exploring religion's influence on pathways to care for persons with dementia from BME communities identified only two papers (Levkoff, Levy, & Weitzman, 1999; Sun, Roff, Klemmack, & Burgio, 2008) from a total of 1234 research sources, which specifically focus on religion, care pathways and BME. Both of which were US-based research. The remaining papers relate to issues of mental health and culture broadly or to mental health and religious coping. This paper presents a case for the importance of recognising religious specific barriers which have previously been labelled as "cultural" in existing literature, to inform a more focused approach to future research and future care planning in the UK healthcare system.

Research has recognised the barriers to dementia care services for BME groups as deriving from "spiritual, psychological, physical health or social causes" (Mukadam, Cooper, & Livingston, 2010, p. 12) and suggests further study is needed "to elucidate the role that ethnicity and culture play in the help-seeking pathway for dementia" (Mukadam et al., 2010, p. 12). These belief led influences are synthesised within the parameters deriving from exploring "ethnicity" (Mukadam et al., 2010). I purport that a focus is required not only on the roles that ethnicity and culture play, but on the distinct factors identified within this broad categorisation, namely the spiritual – or more specifically – the religious, on pathways to care and access of care services. Existing studies have grouped "religiosity" as one of several "culture-related factors", such as "family duty, beneficial outcomes, adoption of positive reappraisal strategies" (Milne & Chryssanthopoulou, 2005, p. 319) contributing to the barriers experienced for BME persons using dementia care services. I argue that religion is not just a factor related to culture, but it warrants an equal classification to culture. Critical examination of the cultural barriers identified in existing research warrants a re-classification of those barriers which are actually religious-specific. Three examples of religious-specific principles labelled as cultural principles in the Mukadam et al. (2010) review are God's will, religious duty and religious rituals. These will be examined in greater depth later. Recognition of the religion–culture distinction, when it does occur in existing papers, does not given an adequate account of this dichotomy in the presentation of the findings and results. One example of this is identified in Argo (2010), who introduces the religion and culture distinction in the title of the paper, "The influence of culture and religion on first-generation Hindu Asian Indian American perspectives on psychotherapy", but does not discuss the concepts as two separate entities explicitly throughout.

This critical exploration thus identifies a new approach to research in the field of BME dementia care barriers; namely, to address the question of religion specifically, as distinct from culture generally. This approach aims to explore a potentially overlooked avenue on the cultural map of existing research. This novel approach may yield undiscovered data. As Tarakeshwar, Pargament, and Mahoney (2003) recognise, "In fairness to cross-cultural researchers, there exists much cultural work where religion has occupied an implicit role" (p. 378). If this is a debate of semantics, and religion *per se* is adequately considered within the cultural literature, researchers still needs to provide clearer classification to avoid the dilution of "religion" in to "culture". Tarakeshwar et al. (2003) considered this: "we argue that cross-cultural psychologists could improve theory and research by explicitly considering the influence of religion on cross-cultural dimensions" (p. 379). Re-categorisation of the barriers to dementia care aims to improve understanding and make more informed care recommendations.

Religion and culture distinction

The importance of recognising the "unique significance" of religion as a distinct principle in cross-cultural psychology is eloquently expounded:

> (a) religion is important in the lives of people across cultures, (b) religion has been found to be a significant predictor of salient variables (e.g. physical and mental well being) across cultures, (c) religion is associated with critical cross-cultural dimensions, and (d) culture also shapes religious beliefs and practices. (Tarakeshwar et al., 2003, p. 390)

Point (d) in this definition further highlights religion and culture as distinct entities, which inevitably interlink. To confuse someone's cultural identity with their religious identity overlooks the nuances of ethnicity. The categorisation of a diverse range of minority ethnic groups into one single "BME" classification is reductionist. This approach does not account for the specific identity of each individual ethnic group, nor for their varying care needs. The Annex to the Delivering Race Equality in Mental Health Care (DoH, 2005) recognises the complexities of this label:

> BME as a term did not address the numerous groups who might not be included in any programme of activity, for example, mixed-race people, white minorities, or white communities with distinct cultural lifestyles based on religion, ethnicity, language, age, gender or sexual identity. (DoH, 2005, p. 76)

A new definition is required to capture the "super-diversity" (Vertovec, 2007, p. 1024) of ethnicity in the UK majority which considers, "the differences *within* and *between* BME communities" (Lane & Hearsum, 2007, p. 3). The term "minority" not only suggests marginality, but has been postulated as "mathematically misleading or inaccurate" (Parekh, 2000, p. 23, cited in Culley & Dyson, 2010, p. 3). It is beyond the scope of this paper to discuss an alternative classification in detail. The parameters of this paper do allow this danger to be highlighted whilst acknowledging that until an improved language exists, the author too falls within these semantic trappings.

Within particular cultures, there are many different religious beliefs, and the same religion can be interpreted differently by different cultures. For example, someone may define themselves culturally as "Pakistani", but in terms of religion, there are multiple adherences, such as Pakistani Muslims, Pakistani Sikhs, Pakistani Hindus, or no religious affiliation. Religion is part of a person's culture but it is only one part. In the 2001 UK Census (Office for National Statistics, 2004), questions about religion and ethnicity were asked as separate components for the first time and continued in the 2011 UK Census (Office for National Statistics, 2013a, 2013b). The predominant religion in the UK is Christianity, with 59.3% of the population adhering (Office for National Statistics, 2013a). This has dropped from 71.7% in the last decade (Office for National Statistics, 2013a). The remainder of the populations' religious affiliation is as follows: 25.1% stated "no religion"; Muslims comprised 4.8%, an increase from 3% in the last decade; Hindus 1.5%; Sikhs 0.8%; Jewish 0.5%; Buddhist 0.4% and "other" 0.4% (Office for National Statistics, 2013a). A proportion (7.2%) did not respond to the question and were unaccounted for. In terms of ethnicity, White (British, Irish, other) comprise 86% of the UK population in the 2011 Census (Office for National Statistics, 2013b), demonstrating a decrease from 92.14% in 2001 (Office for National Statistics, 2004); "Mixed/Multiple Ethnic Groups" denote 2.2%; "Asian/Asian British" reflect 7.5%, "Black/African/Caribbean/Black British" stated 3.3% and "Other Ethnic Groups" comprise 1.0% of the total UK population. Within these groups, "Gypsy or Irish Traveller" (0.1% of White British category) and "Arab" (0.4% of "other ethnic group") are two new cultural categories added in the 2011 Census (Office for National Statistics, 2013b).

This demonstrates the multi-faceted nature of identity, of which culture and religion are often distinct components. Following this, recognition and re-categorisation is required of cultural themes and religious-specific themes in the existing research, to further understand the impact on dementia care.

Culture

Ostensibly, culture is identification with the practice, thought and behaviour of a region, group or organisation – most notably associated with a geographical locality – but is also prevalent across societal levels and contexts. These may be expressed at a regional level, family level or organisational level. Culture is the structural process which provides a framework for our own behaviour. To allow us to function within the status quo, we adopt a *modus operandi* according to the rules and principles within the cultural framework of which we find ourselves in. These frameworks derive from birth into a geographical locality, birth into a family structure, or birth into a socio-economic environment. As we progress as adults and widen our reality, our cultural identity is shaped and morphed through adherence to other parts of society. By our very definition as a human, functioning in society, we are by default, a member of the culture of which we function within. Our cultural identity is multi-layered and complex, and may increase and shift throughout life and throughout social contexts. Workplaces, sports teams, friendship groups all provide a cultural framework with rules of functioning and modes of operation. However, the most literal and enduring element of our cultural identity, is that associated with our ethnicity. Ethnicity, in this sense, is comprised of our creed, skin colour, place of birth – of which we were born into – and is maintained at the core of us, as those more transient parts of our cultural identity shift and morph through life's journey. It may be more appropriate to label this as an ethnic-cultural identity. This enduring element is inherent and subconscious, a product of our early upbringing and forms the basis for values, attitudes, language, behaviours. Other parts of our cultural identity are arguably chosen by our decisions in life, such as one job above another, one social group above another. Each of these expresses a distinct cultural framework, but these choices may be driven by the enduring subconscious ethnic-culture. In terms of organisational culture, a paradigm in this context is the National Health Service (NHS) of the UK. This is an organisation governed by certain principles and practices, which deem acceptability or unacceptability; one example of which is through communication and co-operative practices of persons involved in this culture. The paradigm of an existing cultural theme in dementia care research as a prominent barrier to services for BME persons with dementia is language (Hinton, Franz, & Friend, 2004). Cultural practices are those such as verbal and non-verbal communication. The NHS operates within a cultural framework of Western society, where English is the primary language. The organisational culture of the NHS, whilst accommodating for other languages, primarily functions in an English language setting. Modes of being, i.e. communication between persons are governed as acceptable practices, due to the cultural expectations of the Western society. For example, a female touching a male in a simple exchange such as a handshake is considered culturally appropriate. Conversely, this means of communication may be deemed inappropriate, for instance, in a South Asian cultural setting.

Thus, this paper categorises cultural themes in the existing literature as those which relate to behaviour, thought, belief or practice influenced by the association – either conscious or subconscious – with a geographical locality, ethnic group, institution, or organisation, as distinct from a religious institution.

Religion

This paper categorises religious themes as those which relate specifically to behaviour, thought, belief or practice directly influenced by religious ideologies, dogmas, scriptures, with arguably a

more conscious, explicit adherence than ethnic-cultural identity. The paradigm for a religious theme identified in existing cultural research is prayer. Namely, the implications the dementia condition has had on the practice of prayer. Prayer is a ritualistic behaviour grounded explicitly in religious beliefs and practices. There are examples in the literature of an increase in prayer rituals to assist with coping for dementia caregivers from the Irish and American and African American communities (Levkoff et al., 1999). There are examples of difficulty encountered performing prayer rituals as a result of debilitation on behavioural functioning as a consequence of dementia (Bowes & Wilkinson, 2002). The notion that a person's religious practices are influenced throughout the dementia experience, is introduced by the existing literature, but requires a more focused, critical examination in future research. Religious themes may manifest in cultural practices. The acceptability of a handshake between males and females is influenced by cultural frameworks, but may also have an explicit religious influence. For example, the acceptability of touch between non-related, non-married males and females in the Muslim faith. The complexity between religion and culture further exemplifies the importance of considering this distinction and interaction in future research.

Cultural barriers to dementia care

The Mukadam et al. (2010) systematic research review explored the notion of "ethnicity" and dementia care pathways and expounded the experiences of persons of Buddhist, Hindu, Muslim and Sikh faiths entering traditional health services for dementia care. This paper is chosen to be examined in depth due to its focus on the practical impact of service access in dementia care and its synthesis of the research in this area. This systematic review warranted 13 papers as meeting the inclusion criteria. These were comprised of three quantitative studies (Clark et al., 2005; Ortiz & Fitten, 2000; Watari & Gatz, 2004,) and 10 qualitative studies (Bowes & Wilkinson, 2003; Braun, Takamura, & Mougeot, 1996; Cloutterbuck & Mahoney, 2003; Hinton et al., 2004; Jett, 2006; Jones, Chow, & Gatz, 2006; La Fontaine et al., 2007; Lawrence, Murray, Samsi, & Banerjee, 2008; Neary & Mahoney, 2005; Zhan, 2004). The main finding identified was persons from minority ethnic groups experience significant barriers when accessing dementia services. Ten of the 13 papers reviewed derive from the USA with only three studies representing the British health care system (Bowes & Wilkinson, 2003; La Fontaine et al., 2007, Lawrence et al., 2008). This is a very low volume of research representing a vast and growing problem, with a particular paucity demonstrated in UK-based research. This review was commendable in expounding the barriers to healthcare services. This paper was successful in identifying that beliefs can have an impact on dementia healthcare access, "beliefs about the aetiology of symptoms were important in determining whether ME groups accessed healthcare. Those who did not perceive dementia symptoms to be an illness were less likely to seek help" (Mukadam et al., 2010, p. 17) but the report did not examine the distinction between explicit religious-specific beliefs and implicit ethnic-cultural beliefs in detail. Themes identified in the Mukadam et al. (2010) review which warrant classification as cultural barriers are as follows: healthcare services were perceived as being dismissive of symptoms for African American carers (Cloutterbuck & Mahoney, 2003); black and Chinese dementia carers in the USA expressed difficulties with communication and language and experiences of racism and discrimination as factors preventing service-use (Hinton et al., 2004). Normal ageing as a result of low knowledge of the condition was identified as a barrier to healthcare services in a quantitative study with African American Carers in a suburban memory clinic, with 57% of 79 participants believing cognitive decline is as part of normal ageing (Clark et al., 2005). Further critical discussion of what exactly constitutes a "belief" and the potential religious or cultural aetiology of this belief would have been beneficial to greater understand how this may impact

on dementia care provision. What follows is a re-classification of three "cultural" themes identified in the literature into "religious" themes.

Theme 1: God's will and God's plan

Several of the papers in the Mukadam et al. (2010) review identified themes surrounding misconceptions of the aetiology of the dementia condition. Specifically, understanding dementia was not understood through a biomedical lens, as a result of neurological decline, but was understood as God's will or as forming part of God's plan (Bowes & Wilkinson, 2003; Jett 2006; La Fontaine et al., 2007; Zhan, 2004). This had negative implications in terms of care access. The cognitive decline was either not perceived as an illness, and thus health care provision was not sought – or, if it is was perceived as an illness, then the person felt it was going against God's plan to interfere with the path God had set out for them, by seeking the assistance of healthcare services. Bowes and Wilkinson (2003) conducted a UK-based qualitative study with Pakistani and Indian participants, comprised of 11 professionals and four case studies. The data method was through discussions and interviews with persons with dementia, their families and dementia professionals. The quality rating ascribed to the paper by the authors (Mukadam et al., 2010) was two out of six. The findings expressed that the symptoms of dementia were attributed to alternative factors such as visiting Pakistan, or the basis of the cognitive impairment was given a spiritual explanation such as the "evil eye" (Bowes & Wilkinson, 2003, p. 388). Care was only sought in crisis situations when the family felt unable to cope with behavioural manifestations of dementia such as wandering. Jett (2006) conducted research in the USA with 14 African American participants. The sample comprised people who knew someone with dementia from senior centres, persons from the local clinic, and church members utilising semi-structured individual interviews as the data collection method. The assigned quality rating was three out of six. The basis for cognitive impairment for participants in this study was understood as the result of divine intervention, an act of God or a result of a curse. Zhan (2004) embarked upon a qualitative study with semi-structured individual interviews in the USA with four Chinese American participants who were carers of persons with dementia, recruited through the researcher's personal contacts and the use of a promotional flyer. The quality score given was four out of six (Mukadam et al., 2010). The dementia condition was ascribed to issues such as retribution for an ill deed, fate or "bad feng shui" (Zhan, 2004). Consequently, the misconception that the dementia condition may be contagious was evident.

Theme 2: Religious ritual

Studies discussed the rituals associated with religious practice being impeded by the dementia condition, such as prayer and marriage rituals and the implications on the wider family unit. The behavioural manifestations of dementia affect religious ritual, incontinence impeded Muslim home prayer as the house was considered "dirty" (Bowes & Wilkinson, 2003, p. 389). This affected both the person with dementia and the wider family unit.

Theme 3: Religious duty

Religious duty which influences families to provide holistic care, presents a barrier to accessing external care services (Braun et al., 1996; Jett, 2006; La Fontaine et al., 2007; Lawrence et al., 2008; Watari & Gatz, 2004). Papers which identified religious duty and family care as a theme are as follows: Braun et al. (1996) performed a US-based study comprising focus groups and eight individual interviews with 39 Vietnamese participants. The study received a three out of

six quality rating (Mukadam et al., 2010). Participants expressed the familial duty of care for the person with dementia as a result of their religious beliefs. Lawrence et al. (2008) conducted a UK-based study utilising in-depth interviews with 10 black Caribbean, 10 South Asian and 12 white British carers from a range of Community Mental Health Teams for older people, carer services, and BME organisations. This study received a quality rating of five out of six. A prominent finding was that the duty attributed to keeping care within the family as a result of religious obligation prevented a barrier to accessing healthcare services, except when situations had reached a "crisis point" (p. 243). Watari and Gatz (2004) present a quantitative study in the USA with 109 Korean Americans who were members of the Christian Korean Church, involving a Vignette about dementia followed by investigation into the knowledge of dementia and subsequent care-seeking behaviours. The study received a two out of six quality rating (Mukadam et al., 2010). It was discovered that a religious-led familial obligation had a negative impact on care-seeking behaviour for cognitive impairment.

This offers just three examples to highlight the prevalence of religious specific themes in the existing literature, which have previously been categorised as cultural broadly. It is not always easy to clearly distinguish a culturally specific from a religious-specific theme in the existing research. Often cultural and religious practices overlap. Stigma is a paradigm of a theme prevalent in existing research which has both religious and cultural explanations.

Stigma

The notion of stigma surrounding mental health issues for BME persons offers the strongest barrier for underrepresentation in dementia care services and was discussed across many of the papers in the Mukadam et al. (2010) review (Bowes & Wilkinson, 2003; Braun et al., 1996; Jett, 2006; Jones et al., 2006; La Fontaine et al., 2007; Watari & Gatz, 2004; Zhan, 2004). It is unclear from this examination whether stigma derives from a cultural perception, or is influenced by religious-specific beliefs, or is a combination of both. A common theme was that stigma derived from fear of negative perceptions within the community. Jones et al. (2006) conducted a US study involving 62 Japanese, Korean, and Chinese Asian Americans comprising medical students and bi-lingual staff of Asian American organisations. This study received a quality rating of two out of six. A primary theme identified was the behaviour of not seeking the assistance of mental health services throughout a cognitive decline derived from fear of being isolated in the community as result of shame and stigma. A quantitative US-based study (Ortiz & Fitten, 2000) with 65 Hispanic carers utilising a structured interview method received a three out of six quality rating score and identified that fear of discrimination was a primary barrier for not accessing the memory clinic and mental health services.

Religious barriers to dementia care

A recent systematic review (Regan et al., 2013) refined the question of the effect of ethnicity on dementia care pathways, and approached the issue from a religious-specific perspective. Only two papers (Levkoff et al., 1999; Sun et al., 2008) were identified which investigated the specific question of "religion", "BME" and "care pathways" for persons accessing dementia care services. Both of these papers reported research from the USA, which may not be applicable to a UK care setting. These papers also focused on Christian ethnic minorities and do not reflect the diversity of non-Christian faiths within ethnic minority communities. Despite the paucity of research in this specific area, the Regan et al. (2013) review was successful in identifying that religion impacts upon the dementia care pathway for Christian ethnic minorities, in terms of the decision to seek dementia care and the use of dementia care facilities for BME persons with dementia. It

successfully identified religion impacts upon coping with dementia in terms of using prayer to cope with alienation from religious institutions. For example, "One African American caregiver said she hid her husband's dementia from Church leaders and other members of the congregation, only revealing her husband's condition to the 'Good Lord'" (Levkoff et al., 1999, p. 349). Strength of faith was identified to negatively correlate with the uptake of in-home services, "women who prayed and attended services regularly were less likely to use in-home services than women who prayed and attended services less frequently (Sun et al., 2008, p. 949). This suggests religious coping" (Regan et al., 2013, p. 9). Recommendations were made to improve care provision for BME persons with dementia by utilising the resource of the religious institution "co-operation between religious institutions and dementia organisations is a vital step to improving care provision and the pathway to care provision for BME dementia caregivers" (Regan et al., 2013, p. 9). The first step for this co-operative approach is for researchers to express further sensitivity to the religion–cultural divide when investigating its impact on dementia care provision.

Conclusion

There is excellent work already happening to promote a shift from an ethno-centric approach to dementia care provision. Further consideration is required to understand how religion specifically impacts on this phenomenon. If a religious influenced ideology is identified to impact on care-seeking behaviours, then understanding the nuances of such an influence aims to supplement the existing work on culture and improve care provision. One approach may be to focus on what religion specifically can bring to the dementia care toolbox in a two-phase approach. Firstly, through utilisation of scriptures and teachings of faith to promote care-giving within members of the community; and secondly, through education of the bio-medical correlates of dementia by a religious leader to reduce stigma and promote access to health and social care services. Through these two pronged methods, the "church" and clinic can be seen to be in co-operation. Faith may be a valuable resource to improving care services. If faith is seen to have a practical impact on dementia care service uptake, then it could be utilised in an optimum way to work alongside existing services to dispel barriers, remove the burden from health and social care services and to ultimately improve care provision.

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Ethnic minority, young onset, rare dementia type, depression: A case study of a Muslim male accessing UK dementia health and social care services

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Abstract
A case study comprised of formal interviews, formal observations and informal discussions investigated the motivations and experiences accessing dementia care health and social care services for a Muslim, Pakistani male with dementia. Motivations derived from 'desperation' and an inability to access support from family or religious community. Experiences of accessing services were mostly negative. Dementia services were ill-informed about how to support persons with young onset dementia, with pre-existing mental health conditions, from an ethnic minority. Education and training to remove barriers to all dementia care services is required for persons with dementia, their families and within dementia services and religious communities.

Keywords
dementia, traditional health and social care services, barriers, Muslim, ethnic minority

Introduction

South Asian persons with dementia are underrepresented in UK health and social care services (Cooper, Tandy, Balamurali, & Livingston, 2010). Despite this, vascular dementia is more common in the UK among Asian and black Caribbean people than the majority white population (Adamson, 1999; Adelman, 2010; Richards et al., 2000; Seabrook & Milne, 2004). One explanation for this is due to the higher rates of cardio-risk factors for cardiovascular disease (Gorelick, 2004), diabetes (Ahtiluoto et al., 2010; Ott, Stolk, van Hanskamp, et al., 1999) and hypertension (Oveisgharan & Hachinski, 2010; Spence, 2004)

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in these cultural groups. Young onset dementia is especially prevalent in the UK Black and Minority Ethnic (BME) population (Seabrook & Milne, 2004) with 6.1% of all reported BME cases deriving from a young onset dementia variant, compared with 2.2% of cases from the majority ethnic population (Alzheimer's Society, 2013). In BME communities, there is a higher prevalence of dementia in males than females, but research has shown this may just be a reflection of the higher rate of male immigration in to the UK, whom are now reaching old age (Moriarty, Sharif, & Robinson, 2011).

BME persons are often unaware of available services, unaware of the procedures to apply for these services, and are more likely to be turned down; if they are accepted in to services, they are more likely to be dissatisfied with the provision (Bowes & Wilkinson, 2003; Lindesay, Jagger, Hibbert, Peet, & Moledina, 1997). The *Living Well with Dementia: National Dementia Strategy* (NDS) (Department of Health, 2009) aimed to achieve better awareness of dementia, encourage early diagnosis of cognitive impairment and improve the quality of living with dementia in the UK. This involved a bid to address inequalities in dementia care, provide support and direction for health and social care commissioners and generate guidelines for planning, implantation and monitoring of services. The NDS aims to offer 'world class commissioning guidance for dementia' (Department of Health, 2009, p. 75) securing better quality of life for persons with dementia and their families.

Whilst describing itself as 'a comprehensive strategy' (Department of Health, 2009, p. 7) aiming to 'transcend existing boundaries' (Department of Health, 2009, p. 7) reduce the stigma associated with dementia, and address health inequalities – despite publishing images of persons from BME communities in the document – the NDS does not explicitly address issues of dementia in the context of BME communities, ethnicity, religion, or race. When stigma is discussed, it is referenced in a generic sense relating to the overall population. For example, '50% of the public believes that there is a stigma attached to dementia' (Department of Health, 2009, p. 27). In antithesis, a later publication, *The National Dementia Strategy: Equalities Action Plan* (Department of Health, 2011) does account for the potential of religion as a link to services, whilst recognising the current paucity of data in this area. It is unclear if religion in this context relates to BME groups or to the ethnic majority, or to religious services for all persons with dementia. Further research is required in to religion and dementia care in BME persons, to inform policy documentation.

Ethnicity and religion have been identified as factors influencing perceptions of and attitudes towards dementia, and influencing dementia care decisions (Milne & Chrysanthopoulou, 2005; Regan, Bhattacharyya, Kevern, & Rana, 2013), yet many services are not perceived as being culturally appropriate or as delivering 'culturally competent practice' (La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007). Regan, Bhattacharyya, Kevern, and Rana (2013) discuss cultural practices in the context of the National Health Service (NHS) in the UK:

> 'The NHS operates within a cultural framework of Western society, where English is the primary language. The organisational culture of the NHS, whilst accommodating for other languages, primarily functions in an English language setting. Modes of being, i.e. communication between persons are governed as acceptable practices, due to the cultural expectations of the Western society. For example, a female touching a male in a simple exchange such as a handshake is considered culturally appropriate. Conversely, this means of communication may be deemed inappropriate in a South Asian cultural setting, for instance.'

The relationship between culture and religion is complex and personal and subject to many factors such as country of origin, country of residence and social setting. It is beyond the scope of this paper to explore this issue in depth, but an overview of the culture–religion distinction and the implications on UK dementia care, is as follows:

Culture

UK based research from the Buddhist, Hindu, Muslim and Sikh faiths (Bowes & Wilkinson, 2003; La Fontaine et al., 2007; Lawrence, Murray, Samsi, & Banjeree, 2008) identified BME people with dementia experience significant barriers when accessing dementia services. The lack of medical knowledge and sense of stigma about dementia and available services may impede access to care provision (Bowes & Wilkinson, 2003; Patel, Mirza, Lindblad, Amstrrup, & Samaoli, 1998). Despite these barriers to dementia services, there is consistent evidence that there is a higher prevalence of some mental health conditions in the south Asian culture than the white British culture (Parkes & Gilbert, 2010); a paradigm of this is the higher rates of suicide and self-harm demonstrated for South Asian women than white women (Husain, Waheed, & Husain, 2006). The reasoning for not accessing health and social care services is given a cultural explanation: 'Family problems and emotional problems are kept hidden and not exposed to other people. That is our culture' (Punjabi–Muslim participant, in research study conducted by Simich, Maiter, Moorlag, & Ochocka, 2009 in Parkes & Gilbert, 2010, p. 33). Thus, there is a need to recognise the specific mental health care needs for persons of South Asian culture in the UK (Rait & Burns, 1997).

The paucity of knowledge regarding the aetiology and prognosis of dementia in BME groups has been demonstrated strongly in existing research (Adamson, 1999; Azam, 2007; Beattie, Daker-White, Gillard, & Means, 2005; Brownfoot, 1998; La Fontaine et al., 2007; Lawrence, Samsi, Banerjee, Morgan, & Murray, 2010; Seabrook & Milne, 2003; Turner, Christie, & Haworth, 2005). Eastern Europeans face experiences of persecution as a result of stigma and need to 'keep face' (Moriarty et al., 2011). Marriage prospects have been damaged for the children of the family of the BME person with dementia (Mackenzie, 2006; Mackenzie, Coates, Ashraf, Gallagher, & Ismail, 2003; Seabrook & Milne, 2004). Carers feel tarnished by the stigma associated with the person with dementia (Forbat, 2003a). This can result in low service uptake. Both Indian and white British older adults in Manchester had poor knowledge of dementia, but awareness was worse among Indian older people (Purandare, Luthra, Swarbrick, & Burns, 2007). Research has shown lower awareness levels of dementia amongst Irish communities (Brownfoot, 1998) and Black Caribbean persons (Adamson, 1999, 2001; Ahtiluoto et al., 2010; Brownfoot, 1998) than white British counterparts. Carers of individuals with dementia in BME groups observed that awareness of dementia and understanding of the causes of dementia was poor (Adamson, 2001). In many south Asian communities, there is no literal translation for the word 'dementia' (Forbat, 2003b; Seabrook & Milne, 2003; Turner et al., 2005). This low awareness has implications for the care sought and received. If dementia is not perceived as an illness, then the appropriate health channels may not be consulted. Many South Asian communities perceive dementia as normal ageing (Azam, 2007; Mukadam, Cooper, & Livingston, 2011; Purandare et al., 2007; Seabrook & Milne, 2009; Turner et al., 2005) and therefore because it is not recognised as a medical condition, care services are not sought, or only accessed in very extreme cases where the family are unable to cope (Bowes & Wilkinson, 2003; Purandare et al., 2007). When a dementia diagnosis is

received at a late stage in disease progression – as a result of late presentation to health services – conflict between service provider and dementia carer can arise regarding how best to care for the BME person with dementia (Forbat, 2003a, 2003b; Patel & Mirza, 2000).

Religion

More recent research identified that many of these 'cultural' issues identified in the empirical literature, as barriers to dementia care access for BME persons, are actually 'religious' specific. Further consideration and investigation of the impact of religious specific issues on dementia care experience for the individual with dementia is required (Regan et al., 2013). The Muslim faith asserts a strong duty of family care and respect for elders which offers one explanation for not presenting to services (Sheik & Gatrad, 2000). As Moriarty, Sharif, and Robinson (2011) exert, 'religious beliefs may account for some stigma amongst Asian people'. An example of this is the notion that dementia is a result of reincarnation or punishment from a past life (Mackenzie et al., 2003). Negative religious perceptions of acquiring dementia as a result of karmic retribution or punishment, present a barrier to help-seeking (Bowes & Wilkinson, 2003; Jett, 2006; La Fontaine et al., 2007; Zhan, 2004); the notion of 'religious duty', leading to sole care within families, presents a barrier to accessing external care services (Braun, Takamura, & Mogeot, 1996; Jett, 2006; La Fontaine et al., 2007; Lawrence et al., 2008; Watari & Gatz, 2004); the stigma and shame of mental illness within faith communities generates a barrier to seeking support within the community (Bowes & Wilkinson, 2003; Braun et al., 1996; Jett, 2006; Jones, Chow, & Gatz, 2006; La Fontaine et al., 2007; Watari & Gatz, 2004; Zhan, 2004). Black Caribbean and Irish people have demonstrated to perceive dementia more as a mental illness with supernatural causes rather than as a biological brain dysfunction (Brownfoot, 1998). The behavioural symptoms of dementia may influence the ability to perform religious rituals, for example, incontinence impeded Muslim home prayer as the house was considered 'dirty' (Bowes & Wilkinson, 2003). Stigma associated with mental illness negatively affects religious practices such as arranged marriage; misconceptions regarding the aetiology of the dementia condition, as a result of religious views about God's will or God' plan, may prevent people accessing care provision.

South Asian dementia research

Recruitment of people from south Asian communities with dementia in research is notoriously challenging. Bowes and Wilkinson (2002) recognised many barriers to recruiting this particular cohort of people, and 10 years later, many of these barriers still stand: 'researchers attempting to ascertain the views of south Asian people with dementia face many problems in identifying appropriate research methods' (Bowes & Wilkinson, 2002, p. 236). The reasons for which are cited as follows: 'dearth of previous research, few background statistics, issues of diagnosis, problem of identifying and contacting respondents, issues attached to the social identity of researchers and respondents and problems gaining informed consent' (Bowes & Wilkinson, 2002, p. 236). Identification of persons with dementia is especially problematic due to underrepresentation in UK health and social care services. The carer is often taken as the closest possible advocate for the person and much of the existing research focuses on the views of the carer of the person with dementia (Lindesay et al., 1997). South Asian persons with dementia still warrant the title

given to them 10 years ago as a 'hidden population of extremely vulnerable people' (Bowes & Wilkinson, 2002, p. 231), with very low numbers accessing health services, making identification for recruitment difficult.

Importance of case study

A person's own experience of dementia is unique and is influenced by their worldview, outlook, religion and sense of identity; consequently, the care needs of each person with dementia may be equally idiosyncratic. Decisions about *how* and *why* to access care for dementia can be a reflection of, and impact upon, the individual's dignity and ownership of the condition. It should not be presumed that each person follows the same pathways to care, or even perceives 'care' in the same way. In antithesis, persons should be fully informed about what care services are available when making decisions about which services to access.

The present study investigates the experiences of a Muslim, Pakistani service user accessing UK dementia health and social care services and aims to understand *why* and *how;* namely, why did he chose to access health and social care services solely, despite having a strong footing in a religious community and a supportive family? How did he experience these services once he made the decision to access them? The case study method has a 'distinct advantage' when asking a 'how' or 'why' question (Yin, 2012). The case study aimed to investigate:

- Why would a service user from an underrepresented cultural and religious group be motivated to access UK dementia health and social care services?
- How are people from ethnic and religious minorities supported in UK dementia health and social care services?

Method

The case study was based on the following 17 data sources formed from 7 data types (see Table 1):

The data forming this case study derives from a larger PhD study investigating the impact of religion on dementia care access and experience for south Asians from the Sikh, Muslim and Hindu communities; focusing on attitudes and perceptions of dementia,

Table 1. The data collection methods utilised to compile the case study

Type	Method	Volume
i.	Semi-structured one on one interview with Mr Q	1
ii.	Clinical observation attended by Mr Q	1
iii.	Dementia services observation attended by Mr Q	1
iv.	Formal interview with dementia organisation accessed by Mr Q	1
v.	Informal meetings and discussion with Mr Q	5
vi.	Informal meeting and discussion with Mr Q's family	1
vii.	Informal meetings and discussion with dementia organisations accessed by Mr Q (face to face meetings, emails, telephone calls)	7

decisions about dementia care, provision of dementia care, satisfaction with care services, adequate provision of religion in existing services and barriers to care, influenced by religion. The larger study is a Critical Realist (Strauss & Corbin, 1990) Grounded Theory (Charmaz, 2006; Glaser & Strauss, 1967) approach ($N = 21$) utilising semi-structured interviews and observations in a three phase iterative data collection and data analysis method implementing the Constant Comparison method (Charmaz, 2006), over a 12 month period. The warrants recognition as a 'stand-alone' study due to the depth and breadth of data obtained and provides a unique insight into the Muslim perspective of the dementia experience. In addition, this contributes a valuable addition to the overall formation of a theoretical model in the larger study.

Mr Q

Mr Q was initially recruited to participate in an interview for the overall PhD study. The researcher developed a natural rapport with Mr Q and he invited her to accompany him to appointments and to chat with his family and was receptive to attending a dementia peer support group. Mr Q was identified and introduced to the researcher through a dementia organisation already participating in the larger study. This dementia organisation supported and monitored Mr Q throughout the entire research process.

Case study method

The case study method enabled a depth of data to be obtained with a single participant. Recruitment of persons with dementia from the south Asian community is challenging (Bowes & Wilkinson, 2002). It was important to maximise the data collection possibilities once a south Asian person with dementia was identified. Yin (1989, p. 2) defines the case study method as follows: 'an empirical enquiry that investigates a contemporary phenomenon within its real life context... in which multiple sources of evidence are used'. The case study of Mr Q investigated the experiences of a South Asian person with dementia in their own home and accessing dementia services. This case study employed the biography approach (van der Blonk, 2002) focusing 'on the life and work of an individual or perhaps group of individuals' (Remenyi, 2012, p. 134). The multi-faceted approach to data collection strengthened the quality of the resultant theory, 'case study research is not limited to a single source of data...in fact, good case studies benefit from having *multiple sources of evidence*' (Yin, 2012, p. 10). The range of data sources adds 'methodological value' to 'policy analysis and public administration' (Marinetto, 2012 in Exworthy, Peckham, Powell, & Hann, 2012, p. 332). Klein (1974) recognises the value of 'methodological and intellectual pluralism' (in Exworthy et al., 2012, p. 332).

Mr Q's case study formed part of the third phase in a larger body of data sources and consolidates the defined theory in phases one and two of the overall study, 'a case study that starts with some theoretical propositions or *theory* will be easier to implement that one having no propositions' (Yin, 2012, p. 9). The case study is considered as *one piece in the puzzle* towards the overall theory development, 'case studies are often used for theory development. In this case the answering of the research question is a step in the formulation of a theoretical conjecture' (Remenyi, 2012). Hellström, Nolan, and Lundh (2005) postulates case studies do not permit generalization *per se*, but may provide insights that can be transferred or 'recontextualised' to other like situations.

The strength of the case study is the plurality of data sources enables it to be 'positivist or interpretivist in orientation' (Remenyi, 2012, p. 21). Yin (2009, p. 8–13) asserts 'case studies have a distinct advantage when a 'how' or 'why' question is being asked about a contemporary set of events over which the investigator has little or no control'. In this sense, a case study can contribute to development of new theory, warranting it a suitable fit for a Critical Realist GT study. 'In intellectual terms, this methodological flexibility allows researchers to generate theoretical insights' (Marinetto, 2012, in Exworthy et al., 2012). This case study was constructed to meet the following criteria for exemplary case studies: 'be significant, provide completeness, consider alternative perspectives, display sufficient evidence and be composed in an engaging manner' (Yin, 2009, p. 8–13).

Ethical approval and considerations

A three phase process accessing the methodological and ethical rigour of the study was completed prior to data collection to ensure the participants were protected and supported throughout the research. Ethical approval for the overall study was received internally by XXX University on 20th June 2011, externally by the West Midlands: Staffordshire Research and Ethics Committee (REC) on 25th October 2011 and within the Research and Development (R&D) departments of four respective NHS trusts between 28th February 2012 and 17th October 2012.

Informed consent in dementia

Persons with dementia are classed as vulnerable adults who require safeguarding. A topic raised at the West Midlands LREC panel to be addressed was: what measures are in place to account for a person with dementia, who may lack capacity to take part in the research study? The ethical criteria for persons with dementia stated persons with dementia would not be recruited from the offset of the study, if they were not deemed to have capacity. If a participant loses capacity after initial consent has been gained, an appropriate consultee will be approached to assist with the decision to continue (Section 32 (3) Mental Capacity Act, 2005). If consent is not given, the participant will be withdrawn from the study. Participants will be informed of this procedure in the information sheet, prior to initial consent. Mr Q was assessed by a trained consultee and deemed to possess capacity, based on the following criteria (Mental Capacity Act, 2005): understand the information, retain the information long enough to make the decision (to consent), consider the information available to make the decision (to consent) and be able to communicate the decision (to consent). Thus, a nominated consultee was not liaised with in this instance. There were two stages of informed consent for the case study. Mr Q was deemed to have capacity to consent at both stages. Initial consent was obtained prior to the formal interview; subsequent consent was attained prior to the additional data collection methods informing the case study.

Findings

Introduction

The purpose of this case study is to generate an understanding of the experiences and motivations of Mr Q, a Pakistani, Muslim service user accessing UK dementia health and

social care services. Existing research postulates south Asian persons with dementia often do not present to dementia health and social care services and may access support from a religious community for a mental health condition, in the first instance (Argo, 2010). Thus, Mr Q's care seeking behaviour could be viewed as atypical. The purpose of this case study is to understand the motives and circumstances surrounding this expression of atypical care seeking behaviour. It is anticipated that this understanding will have positive implications for dementia care recommendations.

Participant background information

Mr Q is a Pakistani, Muslim male aged 56. He has lived in England most of his life. Currently unemployed, Mr Q worked hard with two jobs, 'he hired and fired' in sales and enjoyed people based roles with social contact. At one stage he ran his own business. He speaks seven languages, including English, Gujarati, Urdu, Punjabi, French and local dialects and has worked as a translator. He completed a driving instructor's course, although he no longer drives. He has excellent writing skills and edited a friend's book for publication. He has assisted others in a variety of voluntary capacities. He is a very articulate, bright, intelligent and modest person with a dry sense of humour, good manners and social skills.

Family

Mr Q is a widower with three sons, one daughter and one grandchild. He lives with two of the youngest sons and his daughter lives close by. Following the death of his wife, he had a relationship with an English lady for four years but is currently single.

Physical health

Mr Q suffers from a heart condition and received major heart surgery at age 53. Despite appearing outwardly smart, Mr Q said he did not maintain his appearance or his personal hygiene and experienced difficulty bathing.

Mental health

Mr Q has experienced severe anxiety, social phobias and suicidal depression throughout his life and felt this has contributed to his dementia onset. He described himself as an 'emotional, physical, psychological, every other –ogical there is – wreck – but I am still here', and had suffered a lot 'physically, mentally, emotionally and spiritually' as a result of his mental ill health. Consequently, he rarely leaves the house despite previously being a very confident, sociable person. Mr Q said he has developed a 'social phobia' and feels 'nervous at social gatherings'. He expressed that dementia contributed to him feeling he was 'losing his identity'. This was very distressing for Mr Q: 'I sometimes cry myself to sleep because of that'. He expressed his 'suffering' and articulated: 'mental illness, it's not just physical or psychological, it is also emotional I think'. Mr Q used the following words to describe his mental health difficulties: 'useless', 'limited', 'hopeless', 'down', 'suicidal', 'suffered emotionally', 'scary', 'that wasn't me', 'aching sort of nerve', 'salt in wounds', 'feel it so much'.

Mr Q described attitudes to mental illness within his Muslim community. He perceived mental illness as a 'taboo subject' with a lack of understanding and acceptance and those persons 'probably think that it doesn't exist'. Despite this, he articulated that 'everyone suffers from one form or another' (of mental illness) as a consequence of our humanity: 'we are human at the end of the day'. Admitting this is a problem, not only within the Muslim community but across all ethnic groups, 'it's admitting that you have a problem, is a problem within all races and culture'. Sharing of problems allows them to be 'halved' and that people should be encouraged within their own community to be 'honest' and 'passionate' about their mental health.

Interestingly, Mr Q was comfortable sharing details of his mental illness with health professionals, but not within his family or friends, 'I admitted it in front of my GP, but I couldn't mention it to my family and friends; that was difficult you know'. He discussed 'shame' and 'stigma' in revealing mental health difficulties to his family and community. Mr Q stated mental illness is a 'broad term' that can be 'misunderstood' and has 'assumptions of loopy…madness'. Furthermore, Mr Q's perception was stigma was prevalent across all ethnicities: 'I think with any community people would assume, top end of the scale, loopy'.

Diagnosis

Mr Q received a clinical diagnosis of fronto-temporal dementia at age 53. Acetylcholine medication is helping him manage the condition. The diagnosis was received during a check-up scan following heart surgery. Mr Q struggled to accept the clinical diagnosis of dementia he had received: 'I used to say that I wanted a second opinion'. Mr Q stated the primary reason for this was that he was still at an age where he could work and be useful in society: 'I couldn't pinpoint it to dementia, I couldn't relate to the fact that it is an illness'. Mr Q explained: 'I thought that was just me, I am forgetful'. Mr Q believes dementia does not affect his daily life but his family notice a decline in memory and behavioural effect. Health services told him he was the 'youngest person with dementia they know'. In antithesis, Mr Q explained that the diagnosis was useful as he felt comfort in receiving medications, but he had struggled with managing the dosage on his own and found the patches uncomfortable.

Accessing care services

Mr Q offered explanations for why he had sought UK dementia care services, instead of accessing support from family and friends and religious community. This decision derived from 'desperation' and 'pain' and the ability to 'open up and admit I had a problem'. He described that he was 'fortunate to have good knowledge of the (English) language' which made it an easier decision to use UK services.

Mr Q articulated the difficulty in accessing UK dementia care services once a decision had been made to utilise these services, with 'transport' and 'accompaniment to and at support groups is a problem'. Services are available, but they are not being accessed by members of the Muslim community: 'there is a barrier of some sort whereby people who are there to help are not being accessed, not being used'. A further barrier to service access was identified through Mr Q's social phobia: 'But my problem is to first get in somewhere I have to know somebody, otherwise I will be in pieces'. Mr Q wanted to attend a local dementia café, but

expressed a fear of going alone 'I would go if somebody was there to take me', 'if I had somebody I would love to do that'.

Isolation

Mr Q had lost confidence since his dementia diagnosis and did not want people in his community to know about his mental condition, despite informing them of his physical illness. He had become withdrawn and isolated, he 'hides things very well', not wanting to 'burden' family: 'I can't talk to my kids, to my children, I don't want to bother them'; it is 'not a childrens' place to worry about dementia'. Mr Q expressed 'embarrassment' at the prospect of sharing his mental illness with the community, of which he had previously been an integral member and a figurehead through 'embarrassment': 'I haven't told them this is the reason because I find it embarrassing because they know me as someone who has been there for them all the time'. He postulated 'nobody has dementia' in the Muslim community he was involved with: 'I don't know anybody who has suffered with dementia, so I can't even relate to anybody'.

This led to feelings of isolation, 'I have isolated myself from all that' and 'the only real problem that I have is that I feel alone', Mr Q stated he needed 'somebody that I can talk to' and craved 'social contact' but felt 'apprehensive', a 'bit scared' and 'unsure' about how socialise.

Trust

Mr Q stated the importance of 'building rapport' and trust between service provider and service user and the effect on accessing services 'I could only do that with somebody I could relate to'. He felt that home visits from services may be better than the person with dementia accessing external services as this allowed 'trust to build up on a one to one level'. Building this trust between person with dementia and service providers would 'take time' to 'talk in confidence'. The importance of communication in building trust was expressed: 'trust factor is built up and maybe he or she would open up and talking cushions the blow'. Mr Q did not feel that language would be a problem in establishing trust for most Muslims desiring to access services, except 'those over age 80 years who may experience a language barrier'.

Gender

Issues of gender were prevalent in the data. In terms of trust between care services and persons with dementia, Mr Q believed that this would take time, regardless of gender: 'I personally believe that it is going to take quite some time for a Muslim person, male or female to earn that trust'.

In terms of care providers, Mr Q stated he felt more comfortable receiving care from females who he perceived as being 'more sympathetic, more caring than men' and this impacted on his level of trust and comfort within services he had accessed. He had received care from a female doctor during his heart surgery and perceived female care givers as being 'more patient' and a 'different manner to male (doctors)' and that female caring was a 'skill'.

Religious adherence

Mr Q rates his religious beliefs as a strong, constant influence in his life and his faith influences his practice and behaviour more than once a day. He previously held a very influential role in the community as a religious leader, and his father was a respected elder in the Muslim community. He formerly had links with eight main mosques in his local area. His home is furnished with many volumes of religious texts and scriptures, of which he used to pride himself on knowing exactly where to find specific references. His dementia has now affected his ability to read these texts. However, he expressed strategies for keeping track of which volumes he had read. Mr Q's faith appeared as a source of comfort in coping with the dementia diagnosis, 'I believe that whatever, whoever is controlling all this has intended for you, you will have'. Despite this, Mr Q did not want to visit the mosques for fear of 'doing wrong' during worship.

Low knowledge

Mr Q's knowledge of dementia was low at diagnosis and continued to be minimal. He was not aware of the prognosis, progression or how to manage dementia, nor was he aware of anyone in his community who had experienced dementia. Mr Q expressed an understanding that once he had received the diagnosis of dementia, he would die from the condition within a few months. Even with assistance from dementia services, Mr Q was unclear about how to manage the condition.

Motivations for accessing health and social care services

Mr Q presented to the dementia services and received his diagnosis, as a result of a physical co-morbidity. What may be considered atypical in this instance is his decision to access health and social care services primarily and solely, without enlisting the support of family, carers, friends or religious community. The reasons Mr Q gave for accessing services were: he had 'lost the will to live', he needed to 'open up' and admit that he 'genuinely needed help'.

Perception of dementia services

Mr Q stated there is a 'lack of communication' about dementia organisations to the general public:

> 'There isn't a LINK between the organisations and the normal, average people out there'. Organisations do exist but knowledge of them is low: 'these organisations are there, they exist because there is a demand for it, but even within the host community, there are not people who know about it'. There was recognition of the scale of the issue and that it could 'take years' to raise awareness of services and there is simply currently, 'not enough publicity'.

Despite this, Mr Q felt the services he had accessed were 'doing the best they can on the resources that they have'. Interestingly, Mr Q articulated that services '*could* be better, not *should* be better'. He had received 'brilliant' care as an inpatient, but that 'aftercare' services needed improving: 'it is not as good as it could be'. Suggestions for improvements were through 'basic education', improving 'rapport' in care and 'consistency' in care providers.

Experiences of dementia care services

Mr Q experienced frustration and dissatisfaction with the eight dementia services he had accessed and felt that his needs had not been met. Three of these services, as observed by the researcher, are described below:

Dementia advocacy service. Mr Q was atypical to their usual service-user base; he was the only non-white service user out of 60 total persons. South Asian persons did not typically access their services, despite the prevalent south Asian demographic residing in the locality. This dementia service admitted being ill-informed about how to provide support for person with young onset dementia, who may be of working age, such as benefit entitlements and with multiple mental health conditions.

Dementia cafe. All attendees were White British in the age 65 years and above age range. The facilitator appeared surprised to see Mr Q and was honest about not being sure how best to offer him help. Mr Q expressed dissatisfaction that he had not 'learned' anything about the dementia condition, that no experts were there to speak about the condition, nor that the peer group had shared their own experiences. He felt it was just a place for people 'to have a cup of tea' and offered no practical support, information, education or even a space to share anything 'worthwhile'. Mr Q was expecting an opportunity to 'offload' but 'there was no-one to offload to'. The facilitator made reference to his ethnicity, which was upsetting as he wished to relate to the others on a 'person-to-person' level, regardless of culture. THSCS admitted being ill-informed about how to provide support for Muslim persons with a rare dementia type.

Memory clinic visit. During a clinical visit, Mr Q's usual physician was not available which caused confusion and anxiety. Mr Q required clarification and reiteration of dementia type, prognosis and implications for care, and reassurance that his dementia was not a result of a 'stressful life working two jobs'. Mr Q was satisfied that he was not given medication for his depression and anxiety. Mr Q left the service relieved but confused; with no consistent carer to reinforce this information to him if the need arouse at a later date.

Future outlook

Mr Q described his feelings of uncertainty towards his future: 'what's going to happen is uncertain still'. His low knowledge of dementia and low confidence in how to live with the condition was articulated through fear of hurting people accidently: 'I've helped God knows how many people, and now that I am suffering from this particular illness, I don't want to hurt anybody, because I might do that without me knowing'. This fear hindered all elements of Mr Q's daily living, including his attendance at prayer services in the Mosque for fear of 'doing the wrong thing'.

Positively, Mr Q perceived a role for himself in the future as assisting others in the Muslim community recognise and live with dementia and mental health issues. He expressed a need to develop a 'platform for people to have their say' and a strong desire to assist in working alongside existing health and social care providers to generate a Muslim specific service: 'if I started something like that on my own and recruited people…go out there and promote the thing in some way'. Furthermore, Mr Q recognised the need to establish a network for all

persons with dementia to act as a central hub about existing services and how to access them: 'there are people that need help, they don't know where to go, so I think we need something for dementia, but as a whole, we need some sort of advisory network, where they are at least made aware of what type of help is available', and Mr Q was very enthusiastic about generating such a resource: 'if I had assistance, someone who understands me 100% and he or she stood by me, I think I could do it'.

Service access disadvantage

UK dementia health and social care services did not meet adequately cater for Mr Q's care needs. Mr Q presents a unique case for disadvantage across four levels:

(1) Under age 65 years;
(2) Cultural and religious minority;
(3) Rare dementia type;
(4) Mixed mental health needs.

Recommendations

This presents a complex picture but a simple solution is offered. Education is required on three levels:

(1) The person with dementia

On dementia diagnosis, a person should be educated in detail about the condition, the aetiology, available medication and implications, prognosis and care planning in terms of services available and how to access these and feel supported enough to not self-isolate from the religious and wider community.

(2) Dementia services

Health services require education about local care available; incorporating alternative care pathways such as religious communities and promoting psycho-social care. Consistency in clinical consultation is important. Dementia services, advocacy services, dementia cafes and support groups require training on supporting persons with young onset dementia, supporting persons of minority ethnic groups, supporting persons who have rarer forms of dementia and supporting persons who have a multiple mental health issues. It is important to consider the emotional support needs of the individual – alongside the physical and physiological – when generating a care package.

(3) Religious communities

Religious communities are an existing infrastructure which could be utilised as an invaluable resource of social, practical, economical and spiritual support for persons with dementia. Education in religious buildings to the congregation by health and social care professionals, facilitated by a respected leader is imperative for dispelling the stigma of

mental illness and generating a strong psycho-social support network. This approach enables the religious practices of the person with dementia alongside practical support for daily living.

Discussion

Case study rigour

A Critical Realist Grounded Theory approach states the symbiotic influence of researcher and researchee on the data collection process, requires researcher reflexivity, to minimise subjective bias (Glaser & Strauss, 1990). Factors such as gender, socioeconomic status and age (Creswell, 2009, p. 233) may impact on the researcher's interpretation of data and detract from its objective truth. The researcher – investigating a religion and culture outside of her own – took steps to avoid subjective bias, by utilising a multi-methods approach to data collection (see Table 1). The inclusion of formal interviews, informal contact and observations with Mr Q's family and service providers, alongside interviews and contact with Mr Q, aimed to fulfil Yin's (2009, p. 8–13) criteria to 'consider alternative perspectives', 'display sufficient evidence' and 'provide completeness' when designing and completing an empirically rigorous case study.

Generalisability

The objectives of the case study were to answer 'why' and 'how' questions: the 'why' question explored motivations for service access from an atypical service user. The findings demonstrated Mr Q accessed services through 'desperation'; he did not have support from a spouse, chose not to 'burden' family with his care needs and did not access religious support through fear of embarrassment or 'doing the wrong thing'. The 'how' question was twofold: firstly, how did Mr Q experience dementia care services, and secondly, the wider remit aimed to understand how people from ethnic and religious minorities are supported in UK health and social dementia care services. The latter may not be easily answered in a single case study. The researcher is not aware in the empirical literature of any other case studies of dementia focusing on access and experience, from a Muslim perspective; the researcher believes this is the first case study of its kind, which potentially warrants the findings as wholly substantive. Hellström et al.'s (2005) claim that case studies – whilst not able to provide a basis for generalisation – provide useful insights which may be recontextualised to other situations, is considered for the present research: This case study provides useful insights in to the experiences of a Muslim male with dementia, who self-isolated from his religious community and whose experiences with health and social dementia care services were predominantly negative. Based on this single case study, the ability to generalise Mr Q's experiences is limited, but may potentially be reflective of experiences for South Asian persons with dementia from other faiths.

Furthermore, not only is there a lack of case study data for BME persons with dementia, there is a paucity in the wider research field of dementia and culture, exploring the specific issue of religion's influence on service access for BME persons with dementia. A systematic review of the literature investigating the influence of religion on access to services for BME persons with dementia (Regan et al., 2013) identified from 1234 papers researching religion and dementia, only 2 papers directly investigated the influence of religion on BME persons with dementia access to services (Levkoff, Levy, & Weitzman, 1999; Sun, Roff,

Klemmack, & Burgio, 2008) Both these papers were from research in the United States with Black, Christian communities.

Case study in wider research context

The findings from this case study replicate findings from the wider dementia and culture literature: Mr Q demonstrated low knowledge of available services and when services were accessed, he was predominantly dissatisfied with the provision; reflecting Lindesay, Jagger, Hibbert, Peet, and Moledina's (1997) and Bowes and Wilkinson's (2003) research. Mr Q expressed upset that his ethnicity was referred to whilst accessing a dementia cafe; this mirrors Milne and Chrysanthopoulou's (2005) findings that dementia services may not be culturally appropriate. Mr Q described many personal and professional barriers to accessing existing services, replicating findings by Bowes and Wilkinson (2003); La Fontaine, Ahuja, Bradbury, Phillips, and Oyebode (2007) Lawrence, Murray, Samsi, and Banjeree (2008) and Patel, Mirza, Linbald, Amstrrup, and Samaoli (1998). Bowes and Wilkinson's (2002, p. 236) nomenclature of South Asian persons with dementia as a 'hidden' demographic highlights the subsequent difficulties identifying and recruiting South Asian persons with dementia in research. The researcher also experienced challenges identifying South Asian persons with dementia for potential recruitment and Mr Q described his ability to 'hide things very well', when describing his mental illness. Stigma is a prevalent theme in existing literature to explain the underrepresentation of BME persons in to dementia health and social care services (La Fontaine et al., 2007; Moriarty et al., 2011; Watari & Gatz, 2004; Zhan, 2004). Mr Q expressed a fear of stigma as one explanation for why he hid his dementia from his religious community; he was 'scared' of the response from the congregation and the impact of this on his family.

Implications

This highlights the need to focus on the influence of religion on access to care services for BME persons with dementia. Recent research is beginning to investigate perceptions of dementia in the Sikh community (Uppal & Bonas, 2014; Uppal, Bonas, & Philpott, 2014), demonstrating a shift in the research field from cultural influences in dementia care generally, to religious influences in dementia care specifically. The recognition of religion and culture, as two distinct yet intertwined entities is promising (Regan, 2014), but further research is required regarding the practical impact religious beliefs exerts on the motivations to access dementia care services and experiences of these services, once accessed.

Conclusion

This case study highlights the importance of recognising the motivations and experiences of a service user from an underrepresented cultural and religious demographic in to UK dementia health and social care services. Motivations to access health and social care services in the UK should not derive from 'desperation', but from an informed choice. Educating all services about dementia and dementia care – traditional and alternative – alongside the person with dementia and their carers is imperative. Whilst Mr Q's experiences were often negative, investigation of his experiences provided an opportunity to promote the role religious communities, as one alternative care service. Utilisation of a

person with dementia's religious community as an existing untapped resource of support aims to reduce stigma, reduce self-isolation, remove strain from health and social care resources, and improve the dementia care experience, not only for underrepresented groups in dementia care services, but for all persons of faith experiencing dementia.

Author's note

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Declaration of conflicting interest

None declared.

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Jemma Regan is a Lecturer in Health Psychology at the London School of Hygiene and Tropical Medicine. This case study was conducted during her time as a PhD student at the Centre for Ageing and Mental Health, Faculty of Health Sciences, Staffordshire University.

Her research interests focus on the practical impact of religion, philosophy and psychology on dementia care in underrepresented groups, identity and quality of life in dementia. She holds an MSc in Memory and its Disorders (neuropsychology) from the Faculty of Psychology at the University of Leeds and a BA (Hons) First Class in Theology and Philosophy from Durham University.

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Participant Study Invitation Letter

Black Country Partnership **NHS**
NHS Foundation Trust

STAFFORDSHIRE
UNIVERSITY

Participant Invitation Letter

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (Version 2.1)

Researcher: Miss J.L. Regan

Telephone: 01785 353 742

E-Mail: J.Regan@staffs.ac.uk

Supervisor: Professor Paul Kingston

Centre for Ageing and Mental Health

Faculty of Health
Staffordshire University
Blackheath Lane
Staffordshire
ST18 0AD

Dear (insert name),

I am a PhD student researcher at Staffordshire University. I am conducting a study exploring South Asian experiences of dementia in the UK, focusing on how religious or spiritual beliefs and practices impact upon these experiences. It is anticipated that the results of this study will influence and improve dementia care provision.

I am contacting you to invite you to participate in the study. I would be interested in hearing your views and perspectives on religion and dementia. The research will be conducted through informal one-to-one interviews which will last around an hour. You may be invited to participate in a second and third interview to explore your responses in more depth.

If you agree to participate in the study, the interviews will take place at a mutually convenient location. All information provided will be treated as confidential and anonymous, according to stringent ethical guidelines.

Thank you for taking the time to read this.

I look forward to hearing from you.

Yours Faithfully,

Jemma Regan

<u>Appendix 3</u>

Participant Information Sheets

Appendix 3a

Dementia Participant Information Sheet

Volunteer Information Sheet: Dementia Participant

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (Version 3.1)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
Telephone:	01785 353 742	Faculty of Health Staffordshire University Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire ST18 0AD
Supervisor:	Professor Paul Kingston	

Who am I?
My name is Jemma Regan. I am a PhD researcher in the Centre for Ageing and Mental Health, Faculty of Health at the University of Staffordshire. I would like to invite you to participate in my study. This sheet will provide you with information about the study to allow you to make an informed decision about consenting to be involved.

What is the purpose of this study?
This study aims to investigate how religious beliefs and practices effect how persons with dementia from South Asian origin are cared for. Knowledge of this will contribute to improving the care provision.

Why have I been asked to take part in the study?
You have been identified as someone who has received a diagnosis of dementia and is of South Asian origin.

Do I have to take part?
Participation is entirely voluntary - it is up to you to decide to join this study. If you agree to take part, you will be asked to sign a consent form. You may withdraw from this study at any time, without giving a reason.

What will happen to me if I take part?
This study involves participating in an informal, one-to-one interview with the researcher, which will last for around sixty minutes. You can decide if you would like a carer to be present during the process. This time is flexible and may last for a shorter duration if required. Your interview will be audio recorded, for which you will be asked to provide consent. Following the initial interview, you may be invited to take part in a second and third interview, spaced three months apart, to develop your responses in more depth.

What will I have to do?
You will be invited to discuss your opinions and experiences of religion and dementia based on topics suggested by the researcher. A guide to potential topics for discussion is available on request. At the end of the interview you will be given the opportunity to discuss your participation including your thoughts and feelings about the interview questions.

Where will the research take place?
Interviews will be carried out at a setting most convenient to yourself and could be in your own home, healthcare trust setting or at Staffordshire University. Interviews will be in a quiet, private room.

What are the possible benefits of taking part?
Participation in the study allows you an opportunity to express your own views and experiences about religion and dementia. You will have a chance to recommend improvements and highlight omissions within existing dementia care services. It is anticipated that the information obtained from the study will influence and improve dementia care provision.

How will I be protected during the research?
This research is subject to ethical guidelines stipulated by an NHS Research Ethics Committee. These guidelines include principles such as obtaining your informed consent before research starts, notifying you of your right to withdraw, and protection of your anonymity.

How do I withdraw?
Participation in the study is entirely voluntary. If you agree to take part, you will be asked to sign a consent form. If at any time during the interviews you do not wish to respond or you wish to leave, you may do so without question. Please note following the submission of a manuscript for publication the withdrawal of data will not be possible.

What happens if my health changes throughout the research?
If throughout the study, your capacity to consent deteriorates (Mental Health Act, 2005), an appropriate consultee will be contacted to declare on your behalf that they are happy for you to continue with the research, if it is deemed to be in your best interests. If the consultee does not feel continuing with the research would be in your best interests, you will be withdrawn from the study.

What will happen if I am harmed during this research?
In the unlikely event that something does go wrong and you are harmed during this research, due to negligence, then you may have grounds to take legal action for compensation against Staffordshire University or Wolverhampton NHS Trust, but you may have to pay your legal costs.

Will my responses be confidential?
If you decide to participate with the study, please note that your GP and / or healthcare professional responsible for your care will be informed of your participation. All personal information which is collected during the course of this research will be kept strictly confidential. Your identity and all responses given will remain anonymous and pseudonyms will be used where appropriate. Throughout the study, access to personally identifiable data will be restricted to the researcher and her supervisory team. All audio-recorded interviews and transcripts will be anonymously filed in locked storage in the Centre for Ageing and Mental Health at Staffordshire University. Following completion of the study, raw data will be destroyed and anonymised interview transcripts will remain in locked storage within the Centre for Ageing and Mental Health. You will be given the opportunity to review your interview transcript for errors.

What happens if I disclose something that may need reporting?
If there is a cause to discuss cases of abuse or neglect, anonymity of all parties concerned must be maintained. However, if unreported information regarding abuse or neglect is disclosed, the researcher is bound by ethical principles which dictate breaking confidentiality to ensure this neglect or abuse is reported to the appropriate body.

What will happen to the results of this study?
The data gathered during this study will be grouped, then analysed and submitted for publication at a later date in relevant journals. The information given could form part of

presentations at academic conferences and articles in academic journals. No-one should be able to identify you from these extracts and at no point will your identity be divulged.

What if there is a problem?
If you have concerns about any aspect of this study, you should contact the researcher using the details provided, who will endeavour to answer your questions. If you remain unhappy and wish to complain formally you can do this through the Wolverhampton NHS Trust complaints process by contacting the patient liaison department on 01902 445378. (http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.as px).

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the West Midlands Research Ethics Committee.

If you require further clarification at any point before, during or after testing, you are very welcome to ask me for this information or contact my supervisor on the contact details above. If you are not satisfied with the responses, you may choose to discontinue.

Thank you for reading this information.

This research is funded by Staffordshire University

Carer Participant Information Sheet

Volunteer Information Sheet: Carer

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (version 3.1)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
Telephone:	01785 353 742	Faculty of Health Staffordshire University Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire ST18 0AD
Supervisor:	Professor Paul Kingston	

Who am I?

My name is Jemma Regan. I am a PhD researcher in the Centre for Ageing and Mental Health, Faculty of Health at the University of Staffordshire. I would like to invite you to participate in my study. This sheet will provide you with information about the study to allow you to make an informed decision about consenting to be involved.

What is the purpose of this study?

This study aims to investigate how religious beliefs and practices effect how persons with dementia from South Asian origin are cared for. Knowledge of this will contribute to improving the care provision.

Why have I been asked to take part in the study?

You have been identified as someone who provides care for a person of South Asian origin with dementia.

Do I have to take part?

Participation is entirely voluntary - it is up to you to decide to join this study. If you agree to take part, you will be asked to sign a consent form. You may withdraw from this study at any time, without giving a reason.

What will happen to me if I take part?

This study involves participating in an informal, one-to-one interview with the researcher, which will last for around sixty minutes. This time is flexible and may last for a shorter duration if required. Your interview will be audio recorded, for which you will be asked to provide consent. Following the initial interview, you may be invited to take part in a second and third interview, spaced three months apart, to develop your responses in more depth.

What will I have to do?

You will be invited to discuss your opinions and experiences of religion and dementia based on topics suggested by the researcher. A guide to potential topics for discussion is available on request. At the end of the interview you will be given the opportunity to discuss your participation including your thoughts and feelings about the interview questions.

Where will the research take place?

Interviews will be carried out at a setting most convenient to yourself and could be in your own home, healthcare or organisation setting or at Staffordshire University. Interviews will be in a quiet, private room.

What are the possible benefits of taking part?

Participation in the study allows you an opportunity to express your own views and experiences about religion and dementia. You will have a chance to recommend improvements and highlight omissions within existing dementia care services. It is

anticipated that the information obtained from the study will influence and improve dementia care provision.

How will I be protected during the research?
This research is subject to ethical guidelines stipulated by an NHS Research Ethics Committee. These guidelines include principles such as obtaining your informed consent before research starts, notifying you of your right to withdraw, and protection of your anonymity.

How do I withdraw?
Participation in the study is entirely voluntary. If you agree to take part, you will be asked to sign a consent form. If at any time during the interviews you do not wish to respond or you wish to leave, you may do so without question. Please note following the submission of a manuscript for publication the withdrawal of data will not be possible.

What will happen if I am harmed during this research?
In the unlikely event that something does go wrong and you are harmed during this research, due to negligence, then you may have grounds to take legal action for compensation against Staffordshire University or Wolverhampton NHS Trust, but you may have to pay your legal costs.

Will my responses be confidential?
All personal information which is collected during the course of this research will be kept strictly confidential. Your identity and all responses given will remain anonymous and pseudonyms will be used where appropriate. Throughout the study, access to personally identifiable data will be restricted to the researcher and her supervisory team. All audio-recorded interviews and transcripts will be anonymously filed in locked storage in the Centre for Ageing and Mental Health at Staffordshire University. Following completion of the study, raw data will be destroyed and anonymised interview transcripts will remain in locked storage within the Centre for Ageing and Mental Health. You will be given the opportunity to review your interview transcript for errors.

What happens if I disclose something that may need reporting?
If there is a cause to discuss cases of abuse or neglect, anonymity of all parties concerned must be maintained. However, if unreported information regarding abuse or neglect is disclosed, the researcher is bound by ethical principles which dictate breaking confidentiality to ensure this neglect or abuse is reported to the appropriate body.

What will happen to the results of this study?
The data gathered during this study will be grouped, then analysed and submitted for publication at a later date in relevant journals. The information given could form part of presentations at academic conferences and articles in academic journals. No-one should be able to identify you from these extracts and at no point will your identity be divulged.

What if there is a problem?
If you have concerns about any aspect of this study, you should contact the researcher using the details provided, who will endeavour to answer your questions. If you remain unhappy and wish to complain formally you can do this through the Wolverhampton NHS Trust complaints process by contacting the patient liaison department on 01902 445378. (http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx).

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the West Midlands Research Ethics Committee.
If you require further clarification at any point before, during or after testing, you are very welcome to ask me for this information or contact my supervisor on the contact details above. If you are not satisfied with the responses, you may choose to discontinue.

Thank you for reading this information. *This research is funded by Staffordshire University.*

Healthcare Professional Information Sheet

Volunteer Information Sheet: Healthcare Professional

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (version 3.1)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
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Supervisor:	Professor Paul Kingston	

Who am I?
My name is Jemma Regan. I am a PhD researcher in the Centre for Ageing and Mental Health, Faculty of Health at the University of Staffordshire. I would like to invite you to participate in my study. This sheet will provide you with information about the study to allow you to make an informed decision about consenting to be involved.

What is the purpose of this study?
This study aims to investigate how religious beliefs and practices effect how persons with dementia from South Asian origin are cared for. Knowledge of this will contribute to improving the care provision.

Why have I been asked to take part in the study?
You have been identified as someone who works as a healthcare professional for persons of South Asian origin with dementia.

Do I have to take part?
Participation is entirely voluntary - it is up to you to decide to join this study. If you agree to take part, you will be asked to sign a consent form. You may withdraw from this study at any time, without giving a reason.

What will happen to me if I take part?
This study involves participating in an informal, one-to-one interview with the researcher, which will last for around sixty minutes. This time is flexible and may last for a shorter duration if required.   Your interview will be audio recorded, for which you will be asked to provide consent. Following the initial interview, you may be invited to take part in a second and third interview, spaced three months apart, to develop your responses in more depth.

What will I have to do?
You will be invited to discuss your opinions and experiences of religion and dementia based on topics suggested by the researcher. A guide to potential topics for discussion is available on request. At the end of the interview you will be given the opportunity to discuss your participation including your thoughts and feelings about the interview questions.

Where will the research take place?

Interviews will be carried out at a setting most convenient to yourself and could be in your own home, healthcare or organisation setting or at Staffordshire University. Interviews will be in a quiet, private room.

What are the possible benefits of taking part?
Participation in the study allows you an opportunity to express your own views and experiences about religion and dementia. You will have a chance to recommend improvements and highlight omissions within existing dementia care services. It is anticipated that the information obtained from the study will influence and improve dementia care provision.

How will I be protected during the research?
This research is subject to ethical guidelines stipulated by an NHS Research Ethics Committee. These guidelines include principles such as obtaining your informed consent before research starts, notifying you of your right to withdraw, and protection of your anonymity.

How do I withdraw?
Participation in the study is entirely voluntary. If you agree to take part, you will be asked to sign a consent form. If at any time during the interviews you do not wish to respond or you wish to leave, you may do so without question. Please note following the submission of a manuscript for publication the withdrawal of data will not be possible.

What will happen if I am harmed during this research?
In the unlikely event that something does go wrong and you are harmed during this research, due to negligence, then you may have grounds to take legal action for compensation against Staffordshire University or Wolverhampton NHS Trust, but you may have to pay your legal costs.

Will my responses be confidential?
All personal information which is collected during the course of this research will be kept strictly confidential. Your identity and all responses given will remain anonymous and pseudonyms will be used where appropriate. Throughout the study, access to personally identifiable data will be restricted to the researcher and her supervisory team. All audio-recorded interviews and transcripts will be anonymously filed in locked storage in the Centre for Ageing and Mental Health at Staffordshire University. Following completion of the study, raw data will be destroyed and anonymised interview transcripts will remain in locked storage within the Centre for Ageing and Mental Health. You will be given the opportunity to review your interview transcript for errors.

What happens if I disclose something that may need reporting?
If there is a cause to discuss cases of abuse or neglect, anonymity of all parties concerned must be maintained. However, if unreported information regarding abuse or neglect is disclosed, the researcher is bound by ethical principles which dictate breaking confidentiality to ensure this neglect or abuse is reported to the appropriate body.

What will happen to the results of this study?
The data gathered during this study will be grouped, then analysed and submitted for publication at a later date in relevant journals. The information given could form part of presentations at academic conferences and articles in academic journals. No-one should be able to identify you from these extracts and at no point will your identity be divulged.

What if there is a problem?
If you have concerns about any aspect of this study, you should contact the researcher using the details provided, who will endeavour to answer your questions. If you remain unhappy and wish to complain formally you can do this through the Wolverhampton NHS Trust complaints process by contacting the patient liaison department on 01902 445378. (http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx).

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the West Midlands Research Ethics Committee.

If you require further clarification at any point before, during or after testing, you are very welcome to ask me for this information or contact my supervisor on the contact details above. If you are not satisfied with the responses, you may choose to discontinue.

Thank you for reading this information. *This research is funded by Staffordshire University*.

Dementia Organisation Professional Information Sheet

Participant Information Sheet: Dementia Organisation Worker

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (version 3.1)

Researcher: Miss J.L. Regan

Telephone: 01785 353 742

E-Mail: J.Regan@staffs.ac.uk

Supervisor: Professor Paul Kingston

Centre for Ageing and Mental Health

Faculty of Health
Staffordshire University
Blackheath Lane
Staffordshire
ST18 0AD

Who am I?
My name is Jemma Regan. I am a PhD researcher in the Centre for Ageing and Mental Health, Faculty of Health at the University of Staffordshire. I would like to invite you to participate in my study. This sheet will provide you with information about the study to allow you to make an informed decision about consenting to be involved.

What is the purpose of this study?
This study aims to investigate how religious beliefs and practices effect how persons with dementia from South Asian origin are cared for. Knowledge of this will contribute to improving the care provision.

Why have I been asked to take part in the study?
You have been identified as someone who works for a dementia organisation.

Do I have to take part?
Participation is entirely voluntary - it is up to you to decide to join this study. If you agree to take part, you will be asked to sign a consent form. You may withdraw from this study at any time, without giving a reason.

What will happen to me if I take part?
This study involves participating in an informal, one-to-one interview with the researcher, which will last for around sixty minutes. This time is flexible and may last for a shorter duration if required. Your interview will be audio recorded, for which you will be asked to provide consent. Following the initial interview, you may be invited to take part in a second and third interview, spaced three months apart, to develop your responses in more depth.

What will I have to do?
You will be invited to discuss your opinions and experiences of religion and dementia based on topics suggested by the researcher. A guide to potential topics for discussion is available on request. At the end of the interview you will be given the opportunity to discuss your participation including your thoughts and feelings about the interview questions.

Where will the research take place?
Interviews will be carried out at a setting most convenient to yourself and could be in your own home or organisation setting or at Staffordshire University. Interviews will be in a quiet, private room.

What are the possible benefits of taking part?
Participation in the study allows you an opportunity to express your own views and experiences about religion and dementia. You will have a chance to recommend improvements and highlight omissions within existing dementia care services. It is anticipated that the information obtained from the study will influence and improve dementia care provision.

How will I be protected during the research?
This research is subject to ethical guidelines stipulated by an NHS Research Ethics Committee. These guidelines include principles such as obtaining your informed consent before research starts, notifying you of your right to withdraw, and protection of your anonymity.

How do I withdraw?
Participation in the study is entirely voluntary. If you agree to take part, you will be asked to sign a consent form. If at any time during the interviews you do not wish to respond or you wish to leave, you may do so without question. Please note following the submission of a manuscript for publication the withdrawal of data will not be possible.

What will happen if I am harmed during this research?
In the unlikely event that something does go wrong and you are harmed during this research, due to negligence, then you may have grounds to take legal action for compensation against Staffordshire University or Wolverhampton NHS Trust, but you may have to pay your legal costs.

Will my responses be confidential?
All personal information which is collected during the course of this research will be kept strictly confidential. Your identity and all responses given will remain anonymous and pseudonyms will be used where appropriate. Throughout the study, access to personally identifiable data will be restricted to the researcher and her supervisory team. All audio-recorded interviews and transcripts will be anonymously filed in locked storage in the Centre for Ageing and Mental Health at Staffordshire University. Following completion of the study, raw data will be destroyed and anonymised interview transcripts will remain in locked storage within the Centre for Ageing and Mental Health. You will be given the opportunity to review your interview transcript for errors.

What happens if I disclose something that may need reporting?
If there is a cause to discuss cases of abuse or neglect, anonymity of all parties concerned must be maintained. However, if unreported information regarding abuse or neglect is disclosed, the researcher is bound by ethical principles which dictate breaking confidentiality to ensure this neglect or abuse is reported to the appropriate body.

What will happen to the results of this study?
The data gathered during this study will be grouped, then analysed and submitted for publication at a later date in relevant journals. The information given could form part of presentations at academic conferences and articles in academic journals. No-one should be able to identify you from these extracts and at no point will your identity be divulged.

What if there is a problem?
If you have concerns about any aspect of this study, you should contact the researcher using the details provided, who will endeavour to answer your questions. If you remain unhappy and wish to complain formally you can do this through the Wolverhampton NHS Trust complaints process by contacting the patient liaison department on 01902 445378. (http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx).

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the West Midlands Research Ethics Committee.

If you require further clarification at any point before, during or after testing, you are very welcome to ask me for this information or contact my supervisor on the contact details above. If you are not satisfied with the responses, you may choose to discontinue.

Thank you for reading this information. *This research is funded by Staffordshire University.*

Religious Representative Participant Information Sheet

Volunteer Information Sheet: Religious Worker

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (version 3.1)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
Telephone:	01785 353 742	Faculty of Health
		Staffordshire University
		Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire
		ST18 0AD
Supervisor:	Professor Paul Kingston	

Who am I?
My name is Jemma Regan. I am a PhD researcher in the Centre for Ageing and Mental Health, Faculty of Health at the University of Staffordshire. I would like to invite you to participate in my study. This sheet will provide you with information about the study to allow you to make an informed decision about consenting to be involved.

What is the purpose of this study?
This study aims to investigate how religious beliefs and practices effect how persons with dementia from South Asian origin are cared for. Knowledge of this will contribute to improving the care provision.

Why have I been asked to take part in the study?
You have been identified as someone who is involved in a South Asian religious community.

Do I have to take part?
Participation is entirely voluntary - it is up to you to decide to join this study. If you agree to take part, you will be asked to sign a consent form. You may withdraw from this study at any time, without giving a reason.

What will happen to me if I take part?
This study involves participating in an informal, one-to-one interview with the researcher, which will last for around sixty minutes. This time is flexible and may last for a shorter duration if required.   Your interview will be audio recorded, for which you will be asked to provide consent. Following the initial interview, you may be invited to take part in a second and third interview, spaced three months apart, to develop your responses in more depth.

What will I have to do?
You will be invited to discuss your opinions and experiences of religion and dementia based on topics suggested by the researcher. A guide to potential topics for discussion is available on request. At the end of the interview you will be given the opportunity to discuss your participation including your thoughts and feelings about the interview questions.

Where will the research take place?
Interviews will be carried out at a setting most convenient to yourself and could be in your own home, healthcare or organisation setting or at Staffordshire University. Interviews will be in a quiet, private room.

What are the possible benefits of taking part?
Participation in the study allows you an opportunity to express your own views and experiences about religion and dementia. You will have a chance to recommend improvements and highlight omissions within existing dementia care services. It is anticipated that the information obtained from the study will influence and improve dementia care provision.

How will I be protected during the research?
This research is subject to ethical guidelines stipulated by an NHS Research Ethics Committee. These guidelines include principles such as obtaining your informed consent before research starts, notifying you of your right to withdraw, and protection of your anonymity.

How do I withdraw?
Participation in the study is entirely voluntary. If you agree to take part, you will be asked to sign a consent form. If at any time during the interviews you do not wish to respond or you wish to leave, you may do so without question. Please note following the submission of a manuscript for publication the withdrawal of data will not be possible.

What will happen if I am harmed during this research?
In the unlikely event that something does go wrong and you are harmed during this research, due to negligence, then you may have grounds to take legal action for compensation against Staffordshire University or Wolverhampton NHS Trust, but you may have to pay your legal costs.

Will my responses be confidential?
All personal information which is collected during the course of this research will be kept strictly confidential. Your identity and all responses given will remain anonymous and pseudonyms will be used where appropriate. Throughout the study, access to personally identifiable data will be restricted to the researcher and her supervisory team. All audio-recorded interviews and transcripts will be anonymously filed in locked storage in the Centre for Ageing and Mental Health at Staffordshire University. Following completion of the study, raw data will be destroyed and anonymised interview transcripts will remain in locked storage within the Centre for Ageing and Mental Health. You will be given the opportunity to review your interview transcript for errors.

What happens if I disclose something that may need reporting?
If there is a cause to discuss cases of abuse or neglect, anonymity of all parties concerned must be maintained. However, if unreported information regarding abuse or neglect is disclosed, the researcher is bound by ethical principles which dictate breaking confidentiality to ensure this neglect or abuse is reported to the appropriate body.

What will happen to the results of this study?
The data gathered during this study will be grouped, then analysed and submitted for publication at a later date in relevant journals. The information given could form part of presentations at academic conferences and articles in academic journals. No-one should be able to identify you from these extracts and at no point will your identity be divulged.

What if there is a problem?
If you have concerns about any aspect of this study, you should contact the researcher using the details provided, who will endeavour to answer your questions. If you remain unhappy and wish to complain formally you can do this through the Wolverhampton NHS Trust complaints process by contacting the patient liaison department on 01902 445378. (http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx).

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the West Midlands Research Ethics Committee.

If you require further clarification at any point before, during or after testing, you are very welcome to ask me for this information or contact my supervisor on the contact details above. If you are not satisfied with the responses, you may choose to discontinue.

Thank you for reading this information. *This research is funded by Staffordshire University.*

Nominateed Consultee Participant Information Sheet

Information Sheet: Nominated Consultee

The Influence of Religion on Dementia Care in South Asian Populations
28/10/2011 (version 3.1)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
Telephone:	01785 353 742	Faculty of Health Staffordshire University Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire ST18 0AD
Supervisor:	Professor Paul Kingston	

Who am I?
My name is Jemma Regan. I am a PhD researcher in the Centre for Ageing and Mental Health, Faculty of Health at the University of Staffordshire. I would like to invite you to participate in my study. This sheet will provide you with information about the study to allow you to make an informed decision about consenting to be involved.

What is the purpose of this study?
This study aims to investigate how religious beliefs and practices effect how persons with dementia from South Asian origin are cared for. Knowledge of this will contribute to improving the care provision.

Why has (INSERT PP NAME) been asked to take part in the study?
(INSERT PP NAME) has been identified as someone who has received a dementia diagnosis and is South Asian.

Does (INSERT PP NAME) have to take part?
Participation is entirely voluntary. If they agree to take part, they will be asked to sign a consent form at the outset. Withdrawal from this study may occur at any time, without giving a reason.

What is a consultee?
Based on Section 32 (2, 3) of the Mental Capacity Act (2005), a person who has originally consented to be involved in research, may continue to participate even if their capacity to consent declines throughout the duration of the study.

A consultee is invited to give their opinion on the best interests and wishes of the participant regarding continuation or withdrawal from the research.

A consultee may be a personal contact: friend, family member or carer; or be a nominated consultee such as a healthcare professional.

What will happen to (INSERT PP NAME) if they take part?
This study involves participating in an informal, one-to-one interview with the researcher, which will last for around sixty minutes. This time is flexible and may last for a shorter duration if required.   The interview will be audio recorded, for which **(INSERT PP NAME)** will be asked at the onset of the study to provide consent. Following the initial interview,

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(insert pp name) may be invited to take part in a second and third interview, spaced three months apart, to develop their responses in more depth.

What will the participant have to do?
They will be invited to discuss their opinions and experiences of religion and dementia based on topics suggested by the researcher. A guide to potential topics for discussion is available on request. At the end of the interview the participant will be given the opportunity to discuss their participation including their thoughts and feelings about the interview questions.

Where will the research take place?
Interviews will be carried out at a setting most convenient to the participant and could be in their own home, healthcare or organisation setting or at Staffordshire University. Interviews will be in a quiet, private room.

What are the possible benefits of taking part?
Participation in the study allows you an opportunity to express views and experiences about religion and dementia. The participant will have a chance to recommend improvements and highlight omissions within existing dementia care services. It is anticipated that the information obtained from the study will influence and improve dementia care provision.

How will I be protected during the research?
This research is subject to ethical guidelines stipulated by an NHS Research Ethics Committee. These guidelines include principles such as obtaining your informed consent before research starts, notifying you of your right to withdraw, and protection of your anonymity.

How do I withdraw?
Participation in the study is entirely voluntary. If at any time during the interviews the participant does not wish to respond or wishes to leave, they may do so without question. Please note following the submission of a manuscript for publication the withdrawal of data will not be possible.

What will happen if the participant is harmed during this research?
In the unlikely event that something does go wrong and you are harmed during this research, due to negligence, then you may have grounds to take legal action for compensation against Staffordshire University or Wolverhampton NHS Trust, but you may have to pay your legal costs.

Will my responses be confidential?
All personal information which is collected during the course of this research will be kept strictly confidential. Identity and all responses given will remain anonymous and pseudonyms will be used where appropriate. Throughout the study, access to personally identifiable data will be restricted to the researcher and her supervisory team. All audio-recorded interviews and transcripts will be anonymously filed in locked storage in the Centre for Ageing and Mental Health at Staffordshire University. Following completion of the study, raw data will be destroyed and anonymised interview transcripts will remain in locked storage within the Centre for Ageing and Mental Health. The participant will be given the opportunity to review your interview transcript for errors.

What happens if I disclose something that may need reporting?
If there is a cause to discuss cases of abuse or neglect, anonymity of all parties concerned must be maintained. However, if unreported information regarding abuse or neglect is disclosed, the researcher is bound by ethical principles which dictate breaking confidentiality to ensure this neglect or abuse is reported to the appropriate body.

What will happen to the results of this study?
The data gathered during this study will be grouped, then analysed and submitted for publication at a later date in relevant journals. The information given could form part of presentations at academic conferences and articles in academic journals. No-one should be able to identify you from these extracts and at no point will your identity be divulged.

What if there is a problem?
If you have concerns about any aspect of this study, you should contact the researcher using the details provided, who will endeavour to answer your questions. If you remain unhappy and wish to complain formally you can do this through the Wolverhampton NHS Trust complaints process by contacting the patient liaison department on 01902 445378. (http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx).

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the West Midlands Research Ethics Committee.

If you require further clarification at any point before, during or after testing, you are very welcome to ask me for this information or contact my supervisor on the contact details above. If you are not satisfied with the responses, you may choose to discontinue.

Thank you for reading this information.

This research is funded by Staffordshire University

Participant Consent Forms

Dementia Participant Consent Form

Centre for
Ageing and
Mental Health

Black Country Partnership **NHS**
NHS Foundation Trust

STAFFORDSHIRE
UNIVERSITY

Individual Participant Consent Form: Dementia Participant

The Influence of Religion on Dementia Care in South Asian Populations

31/8/2012 (version 3.2)

The purpose of this form is to inform you of the research procedure and gain your consent to be involved. If you are happy to continue, please initial the box next to each of the following statements:

1. I confirm that I have read and understand the Patient Information Sheet dated 31/08/2012(version 3.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical or legal rights being affected.

3. I understand that individuals from Staffordshire University or from the NHS Trust may look at relevant sections of data collected during the study, where it is relevant to my taking part in the research. I give permission for these individuals to have access to my study records.

4. I understand that observations of my care activities will occur and anonymous direct quotes from these observations may be used in the study report and may be used in subsequent publications.

5. I agree to participate in a case study which involves a combination of audio-recorded interviews and naturalistic observations.

6. I would like to receive summary of results from this study

7. I understand my GP or other healthcare professional will be informed about my participation in the study

8. I am aware that if I lack capacity to consent, a nominee will be contacted to assist with the decision to continue with the study.

9. I agree to take part in the above study.

Thank you very much for agreeing to take part in my research.

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
 Name of Person taking consent   Date   Signature
 (If different from Principal Investigator)

2 copies: 1 for participant, 1 for the project notes

<u>Appendix 4b</u>

Individual Participant Consent Form

Black Country Partnership *NHS*

NHS Foundation Trust

STAFFORDSHIRE
UNIVERSITY

Individual Participant Consent Form

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (Version 3.1)

The purpose of this form is to inform you of the research procedure and gain your consent to be involved. If you are happy to continue, please initial the box next to each of the following statements:

1. I confirm that I have read and understand the Patient Information Sheet dated 28/10/2011(version 3.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical or legal rights being affected.

3. I understand that individuals from Staffordshire University or from the NHS Trust may look at relevant sections of data collected during the study, where it is relevant to my taking part in the research. I give permission for these individuals to have access to my study records.

7. I understand that interviews will be recorded and that anonymous direct quotes from the interview may be used in the study report and may be used in subsequent publications.

8. I agree to the use of audio recording.

9. I would like to receive summary of results from this study

7. I agree to take part in the above study.

Thank you very much for agreeing to take part in my research.

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
 Name of Person taking consent   Date   Signature
 (If different from Principal Investigator)

Appendix 5

Nominateed Consultee Declaration

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (version 3.1)

The purpose of this form is to inform you about the role of the nominated consultee and to obtain your declaration that you are happy to become a nominated consultee on behalf of (participant name). Please initial the box next to each of the following statements:

1. I have been consulted about (participant name's) participation in the above research project and have read the information sheet (dated 28/10/2011 version 3.1) relating to the consultee role. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I agree to become the nominated consultee on behalf of (insert participant name) ☐

3. In my opinion the above named person would have no objection to continuing within this project as a participant ☐

4. I understand that I can request for the above named person to be withdrawn from the project at any time, without giving any reason and without his/her care or legal rights being affected. ☐

5. I understand that individuals from Staffordshire University or from the NHS Trust may look at relevant sections of data collected during the study, where it is relevant. I give permission for these individuals to have access to these study records. ☐

6. I understand that interviews will be recorded and that anonymous direct quotes from the interview may be used in the study report and may be used in subsequent publications. ☐

7. I advise that it is within the best interests of (insert participant name) to continue with the research study. ☐

Thank you very much for assisting with the research.

_____   _____   _____
Name of Consultee   Date   Signature

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
 Name of Researcher   Date   Signature

GP Letter

GP / Healthcare Professional Letter

The Influence of Religion on Dementia Care in South Asian Populations

28/10/2011 (version 2.1)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
Telephone:	01785 353 742	Faculty of Health
		Staffordshire University
		Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire
		ST18 0AD
Supervisor:	Professor Paul Kingston	

Re: (*Insert participant name*) participation in dementia research.

Dear (insert *GP / Healthcare professional* name),

I am a PhD student researcher at Staffordshire University. I am conducting a study exploring South Asian experiences of dementia in the UK, focusing on how religious or spiritual beliefs and practices impact upon these experiences. It is anticipated that the results of this study will influence and improve dementia care provision.

I am writing to you to inform you that your patient, (INSERT PATIENT NAME) has voluntarily consented to participate in the research. (INSERT PATIENT NAME) has been screened for capacity to consent, according to the Mental Capacity Act (2005). The research will be conducted through informal one-to-one interviews which will last around an hour. (INSERT PATIENT NAME) will be interviewed about their views and experiences on religion and dementia. This initial interview may be followed up with a second or third interview where the participant will be given an opportunity to expand on their answers in more depth. (INSERT PATIENT NAME) will be screened for consent prior to each interview session. If (INSERT PATIENT NAME) capacity diminishes throughout the study, and an appropriate consultee cannot be located, or advises that it is not in the best interests of the participant to continue with the research, they will be withdrawn.

All information obtained will be treated as confidential and anonymous, according to stringent ethical and methodological guidelines.

Thank you for taking the time to read this.

Yours Faithfully,

Jemma Regan

Appendix 7

Interview Schedules

Appendix 7a

Dementia Participant Interview Schedule

Interview Schedule: Dementia

The Influence of Religion on Dementia Care in South Asian Populations

(Version 2: 20/07/2011)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
		Faculty of Health
Telephone:	01785 353 742	Staffordshire University
		Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire
		ST18 0AD
Supervisor:	Professor Paul Kingston	

Participant Details:

Name:

Age Range (years): 18 - 25 ☐   26 - 35 ☐   36 - 45 ☐   46 - 55 ☐   56 - 65 ☐ 66 - 75 ☐   76 - 85 ☐   86 - 95 ☐

Gender: Male   ☐   Female   ☐

Ethic Origin:

Afghani	☐
African	☐
African Caribbean	☐
Bangladeshi	☐
Bhutanese	☐
Chinese	☐
Indian	☐
Maldivian	☐
Nepalese	☐
Pakistani	☐
Polish	☐
Sri Lankan	☐
White: British	☐
White: Irish	☐
White: Other	☐

Other (please specify):_____

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Spoken Languages: (denote 1st, 2nd, 3rd…)

English	☐
Hindi	☐
Gujarati	☐
Urdu	☐
Bengali	☐
Mandarin	☐
Cantonese	☐
Hakka	☐
Fukienese	☐
Other (please specify):_____	

What is your religious persuasion?

Christian	☐
Muslim	☐
Hindu	☐
Sikh	☐
Buddhist	☐
No religion	☐
Other (please specify)_____	

How would you rate the strength of your religious beliefs?

Not at all strong	☐
Quite Strong	☐
Not sure	☐
Strong	☐
Very Strong	☐

How frequently does your religious or spiritual belief influence your practice or behaviour?

Never	☐
Only during main religious festivals	☐
Several times a month	☐

Several times a year	☐
Daily	☐
More than once a day	☐

Person with Dementia

Question 1: Can you tell me about your own experiences of religion and dementia?

- How has your diagnosis of dementia affected your religious beliefs? (prompt: increased / decreased / God's will or purpose, God's plan / punishment)

- How has your diagnosis of dementia affected your religious practice? (prompt: increased / decreased / source of comfort / coping)

- How do you use your religious beliefs and practices to help you cope with your dementia?

- Have your religious beliefs or practices affected how you access (traditional) dementia services such as healthcare or dementia support groups? (Prompt: i.e. why you may or may not access some services and not others)

- Have these experiences been positive or negative?

- Do you think health care services cater for your cultural and religious beliefs and practices?

- Do you think other dementia services (e.g. support groups) cater for your cultural and religious beliefs and practices?

- How do you think your own cultural and religious communities support your dementia?

- Have you experienced any communication difficulties accessing dementia services as a result of your cultural heritage?

- How do you think traditional dementia care provision in the UK could be improved to accommodate for your religious beliefs and practices?

Dementia Carer Interview Schedule

Interview Schedule: Carer

The Influence of Religion on Dementia Care in South Asian Populations

(Version 2: 20/07/2011)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health Faculty of Health Staffordshire University Blackheath Lane Staffordshire ST18 0AD
Telephone:	01785 353 742	
E-Mail:	J.Regan@staffs.ac.uk	
Supervisor:	Professor Paul Kingston	

Participant Details:

Name:

Age Range (years): 18 - 25 ☐   26 - 35 ☐   36 - 45 ☐   46 - 55 ☐   56 - 65 ☐   66 - 75 ☐   76 - 85 ☐   86 - 95 ☐

Gender: Male ☐   Female ☐

Ethic Origin:

Afghani	☐
African	☐
African Caribbean	☐
Bangladeshi	☐
Bhutanese	☐
Chinese	☐
Indian	☐
Maldivian	☐
Nepalese	☐
Pakistani	☐
Polish	☐
Sri Lankan	☐
White: British	☐
White: Irish	☐
White: Other	☐

Other (please specify):_____

Spoken Languages: (denote 1st, 2nd, 3rd…)

English	☐
Hindi	☐
Gujarati	☐
Urdu	☐
Bengali	☐
Mandarin	☐
Cantonese	☐
Hakka	☐
Fukienese	☐

Other (please specify):_____

What is your religious persuasion?

Christian	☐
Muslim	☐
Hindu	☐
Sikh	☐
Buddhist	☐
No religion	☐

Other (please specify)_____

How would you rate the strength of your religious beliefs?

Not at all strong	☐
Quite Strong	☐
Not sure	☐
Strong	☐
Very Strong	☐

How frequently does your religious or spiritual belief influence your practice or behaviour?

Never	☐
Only during main religious festivals	☐
Several times a month	☐

Several times a year	□	
Daily	□	
More than once a day	□	

Please answer the following questions about the person you care for:

Age Range (years): 18 - 25 □   26 - 35 □   36 - 45 □   46 - 55 □   56 - 65 □ 66 - 75 □   76 - 85 □   86 - 95 □

Gender: Male   □   Female   □

Ethic Origin:

Afghani	□
African	□
African Caribbean	□
Bangladeshi	□
Bhutanese	□
Chinese	□
Indian	□
Maldivian	□
Nepalese	□
Pakistani	□
Polish	□
Sri Lankan	□
White: British	□
White: Irish	□
White: Other	□

Other (please specify):_____

Spoken Languages: (denote 1st, 2nd, 3rd…)

English	□
Hindi	□
Gujarati	□
Urdu	□
Bengali	□
Mandarin	□
Cantonese	□
Hakka	□
Fukienese	□

Other (please specify):_____

What is the religious persuasion of the person you care for?

Christian ☐

Muslim ☐
Hindu ☐
Sikh ☐
Buddhist ☐
No religion ☐

Other (please specify)_____

How would you rate the strength of the person who you care for religious beliefs?

Not at all strong ☐
Quite Strong ☐
Not sure ☐
Strong ☐
Very Strong ☐

How frequently does the religious or spiritual belief of the person who care for influence their practice or behaviour?

Never ☐
Only during main religious festivals ☐
Several times a month ☐
Several times a year ☐
Daily ☐
More than once a day ☐

How long have you cared for the (*person with dementia's name*)?_____

Carer

Question 1: Can you tell me about your own experiences of religion and dementia?

- o How do your religious beliefs influence how you care for (*the person with dementia's name*)? (Prompt: duty / obligation / ritual)

- o How has caring for (*the person with dementia's name*) affected your own religious beliefs? (Prompt: increased / decreased / God's will or purpose / God's plan / punishment)

- o How has caring for (*the person with dementia's name*) affected your own religious practice? (Prompt: increased / decreased / source of comfort / coping)

- o How do your religious beliefs or practices help you care for (*the person with dementia's name*)?

- o How might your religious beliefs influence who should provide care for (*the person with dementia's name*)?

- o Have the religious beliefs or practices of (*the person with dementia's name*) affected how they may access (traditional) dementia services such as healthcare or dementia support groups? (Prompt: i.e. why you may or may not access some services and not others)

- o Have these experiences been positive or negative?

- o Do you think health care services cater for the cultural and religious beliefs and practices of (*the person with dementia's name*)?

- o Do you think other dementia services cater for the religious beliefs and practices of (*the person with dementia's name*)?

- o How do you think your own religious community supports (*the person with dementia's name*) or yourself as a carer?

- o Have you experienced any communication difficulties accessing dementia services as a result of your cultural heritage or (*the person with dementia's name*) cultural heritage?

- o How do you think traditional dementia care provision in the UK could be improved to accommodate for the dementia patients religious beliefs and practice or your own religious beliefs and practices?

Healthcare Professional Interview Schedule

Interview Schedule: Health Professional

The Influence of Religion on Dementia Care in South Asian Populations

(Version 2: 20/07/2011)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
		Faculty of Health
Telephone:	01785 353 742	Staffordshire University
		Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire
		ST18 0AD
Supervisor:	Professor Paul Kingston	

Participant Details:

Name:

Age Range (years):   18 - 25 ☐   26 - 35 ☐   36 - 45 ☐   46 - 55 ☐   56 - 65 ☐   66 - 75 ☐   76 - 85 ☐   86 - 95 ☐

Gender: Male   ☐   Female   ☐

Ethic Origin:

Afghani	☐
African	☐
African Caribbean	☐
Bangladeshi	☐
Bhutanese	☐
Chinese	☐
Indian	☐
Maldivian	☐
Nepalese	☐
Pakistani	☐
Polish	☐
Sri Lankan	☐
White: British	☐
White: Irish	☐
White: Other	☐

Other (please specify):_____

Spoken Languages: (denote 1st, 2nd, 3rd…)

English	☐
Hindi	☐
Gujarati	☐
Urdu	☐
Bengali	☐
Mandarin	☐
Cantonese	☐
Hakka	☐
Fukienese	☐
Other (please specify):_____	

What is your religious persuasion?

Christian	☐
Muslim	☐
Hindu	☐
Sikh	☐
Buddhist	☐
No religion	☐
Other (please specify)_____	

How would you rate the strength of your religious beliefs?

Not at all strong	☐
Quite Strong	☐
Not sure	☐
Strong	☐
Very Strong	☐

How frequently does your religious or spiritual belief influence your practice or behaviour?

Never	☐
Only during main religious festivals	☐
Several times a month	☐

460

Several times a year	☐
Daily	☐
More than once a day	☐

Healthcare Professional:

What is your role within the dementia care team?

GP	☐
Doctor	☐
Nurse	☐
Psychiatrist	☐
Psychologist	☐

Other healthcare professional (please

state)_____

How long have you worked in the dementia care service, both in your current role and in other roles?_____

Question 1: Can you tell me about your own experiences of religion and dementia?

- o In your experiences of dealing with people with dementia, can you tell me about how the current health care system supports the religious and cultural needs of a person of south Asian descent, throughout their dementia journey?

- o How might this provision differ from someone who is British, from a Christian background, for example?

- o Do you think the current healthcare provision for south Asian dementia patients is acceptable?

- o Do you think current healthcare supports ethnic minority groups?

- o Do you think current healthcare supports non-Christian dementia patients?

- o Do you think the health service available to south Asian dementia patients sufficiently caters for their religious and spiritual needs?

- o Have you had any experiences of difficulty communicating clinical information to a south Asian dementia patient? How have these difficulties been addressed? How do you think they could be improved?

- o Do you incorporate a spiritual component in to your clinical assessment? Does this assessment cater for south Asian individuals?

Dementia Organisation Professional Interview Schedule

Interview Schedule: Organisation Worker

The Influence of Religion on Dementia Care in South Asian Populations

(Version 2: 20/07/2011)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
		Faculty of Health
Telephone:	01785 353 742	Staffordshire University
		Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire
		ST18 0AD
Supervisor:	Professor Paul Kingston	

Participant Details:

Name:

Age Range (years): 18 - 25 ☐   26 - 35 ☐   36 - 45 ☐   46 - 55 ☐   56 - 65 ☐ 66 - 75 ☐   76 - 85 ☐   86 - 95 ☐

Gender: Male   ☐   Female   ☐

Ethic Origin:

Afghani	☐
African	☐
African Caribbean	☐
Bangladeshi	☐
Bhutanese	☐
Chinese	☐
Indian	☐
Maldivian	☐
Nepalese	☐
Pakistani	☐
Polish	☐
Sri Lankan	☐
White: British	☐
White: Irish	☐
White: Other	☐

Other (please specify):_____

Spoken Languages: (denote 1st, 2nd, 3rd…)

English	☐
Hindi	☐
Gujarati	☐
Urdu	☐
Bengali	☐
Mandarin	☐
Cantonese	☐
Hakka	☐
Fukienese	☐

Other (please specify):_____

What is your religious persuasion?

Christian	☐
Muslim	☐
Hindu	☐
Sikh	☐
Buddhist	☐
No religion	☐

Other (please specify)_____

How would you rate the strength of your religious beliefs?

Not at all strong	☐
Quite Strong	☐
Not sure	☐
Strong	☐
Very Strong	☐

How frequently does your religious or spiritual belief influence your practice or behaviour?

Never	☐
Only during main religious festivals	☐
Several times a month	☐

Several times a year	☐
Daily	☐
More than once a day	☐

What is your role within the dementia care team?

Director	☐
Manager	☐
Care Worker	☐
Social Worker	☐
Day care worker	☐
Residential care worker	☐

Other (please specify)_____

How long have you worked in the dementia care service, both in your current role and in other roles?_____

Question 1: Can you tell me about your own experiences of religion and dementia?

o   In your experience, how does your organisation cater for the spiritual or religious beliefs and practices for the dementia service user?

o   How does your organisation cater for the spiritual or religious beliefs and practices of south Asian service users?

o   Have you experienced any situation where services users of south Asian descent may experience difficulty accessing services as a result of their religious or cultural heritage? Or why they may attend some services and not others?

o   How many service users of south Asian descent access your organisation's services?

o   Do any services exist that tailor for south Asian cultural dementia patients in terms of cultural or religious activities?

o   How do you think service provision could be improved within your organisation for south Asian service users specifically?

<u>Appendix 7e</u>

Religious Representative Interview Schedule

Interview Schedule: Religious Facilitator

The Influence of Religion on Dementia Care in South Asian Populations

(Version 2: 20/07/2011)

Researcher:	Miss J.L. Regan	Centre for Ageing and Mental Health
		Faculty of Health
Telephone:	01785 353 742	Staffordshire University
		Blackheath Lane
E-Mail:	J.Regan@staffs.ac.uk	Staffordshire
		ST18 0AD
Supervisor:	Professor Paul Kingston	

Participant Details:

Name:

Age Range (years): 18 - 25 □   26 - 35 □   36 - 45 □   46 - 55 □   56 - 65 □   66 - 75 □   76 - 85 □   86 - 95 □

Gender: Male   □   Female   □

Ethic Origin:

Afghani	□
African	□
African Caribbean	□
Bangladeshi	□
Bhutanese	□
Chinese	□
Indian	□
Maldivian	□
Nepalese	□
Pakistani	□
Polish	□
Sri Lankan	□
White: British	□
White: Irish	□
White: Other	□

Other (please specify):_____

Spoken Languages: (denote 1st, 2nd, 3rd…)

English	☐
Hindi	☐
Gujarati	☐
Urdu	☐
Bengali	☐
Mandarin	☐
Cantonese	☐
Hakka	☐
Fukienese	☐

Other (please specify):_____

What is your religious persuasion?

Muslim	☐
Hindu	☐
Sikh	☐
Buddhist	☐

Other (please specify)_____

How would you rate the strength of your religious beliefs?

Not at all strong	☐
Quite Strong	☐
Not sure	☐
Strong	☐
Very Strong	☐

How frequently does your religious or spiritual belief influence your practice or behaviour?

Never	☐
Only during main religious festivals	☐
Several times a month	☐
Several times a year	☐
Daily	☐
More than once a day	☐

What is your title?

Imam   ☐

Swami   ☐

Guru   ☐

Other (please specify)

_____

Question 1: Can you tell me about your own experiences of religion and dementia?

- o How does your religious community view dementia?
  (prompt: God's plan / punishment / karma)

- o How might your religious beliefs influence care for the dementia patient?
  (prompt: duty of family care / religious consultation vs. health consultation)

- o How would a dementia diagnosis of a member of your religious community
  influence how they practice their faith within your religious institution?
  (i.e would the religious community offer more support to the person,
  encouraging them to practice more at the religious building, or would they
  encourage more home care?)

- o What do you think about the care provision provided to dementia patients of
  (*religious affiliation i.e. Hindu / Sikh / Muslim / Buddhist*) descent in the UK?

- o How does the care provision in the UK compare with the care provision
  provided in the (origin country)?

- o Do you have any first hand experience of a member of your religious
  community with dementia?

<u>Appendix 7f</u>

Amended Interview Schedule Example: Health Professional

1	(What can you tell me) about religion and dementia care?							
prompts	practices	beliefs	religious coping	faith	God's will	Karma	Fate	community care

2	What can you tell me about communication and dementia care?			
prompts	language tools	assessment difficulties	aphasia	translators

3	What can you tell me about service improvement and dementia care?		
prompts	outreach	chaplains	cultural match

4	What can you tell me about education and knowledge of dementia?
prompts	God's will

5	Culture and dementia care?
prompts	cult apt service?

6	presentation to services and dementia care?	
prompts	late	physical ailment

7	family provision of dementia care?		
prompts	duty	gender	extended family

8	existing dementia care services?		
prompts	adequate?	sufficient?	address real needs?

9	outreach services for persons with dementia of south asian origin?	
prompts	mosques / temples	engage leaders

10	providing individually tailored care for persons of south asian origin?	
prompts	culture homogenous	avoid stereotyping

11	about peoples expectations of care?
prompts	no expectations of faith / culture?

12	about dementia and religious delusion or deluded religious practices?			
prompts	how assess?	increased faith?	practices encouraged?	safeguarding?

13	dementia care in terms of costs and finances?		
prompts	hindrance?	feasible?	practical solutions?

14	dementia seen as 'normal ageing' in south asian groups?		
prompts	scriptures	childlike'	lack of understanding of condition

15	dementia care compared with other health conditions such as depression / schizophrenia / diabetes?			
prompts	knowledge?	acceptance?	care?	perceptions?
16	dementia and stigma in south asian communities?			
prompts	barrier to care?	secret in community?		
17	dementia and carer stress in south asian communities?			
prompts	external services withdraw?			
18	dementia and gender issues in care in south asian communities?			
prompts	female patient / male physician	female carers	male role elder in community	
19	vascular dementia in south asian communities?			
prompts	high incidence	knowledge		
20	clinician trust with south asian persons with dementia?			
prompts	interested in culture?			

Actual Interview Questions Example: pp#3 and p#4

	Interview #3 with pp3 and pp4
1	Ok so can you tell me just a little bit about your organisation here in terms of what services you offer and particularly about the advocacy service please?
2	So did it originate in housing
3	Yes, ok, so can you tell me a little bit more about the advocacy programme please?
4	Ok, so how many people work within the advocacy team at the moment and what do their roles involve?
5	And you wouldn't use volunteers anymore?
6	So it's more the case that people might need more specialist training for working with people with dementia than perhaps volunteers who have different expectations and require more training to do that job
7	And what would you say the ethnic background is of people who use the dementia advocacy service?
8	And would that third party be like the GPs or other social care organisations?
9	People who are sort of already in to the system and they are captured and received a dementia diagnosis, or do you get some people who might not have received that?
10	Right, so they might not necessarily be going in for a dementia diagnosis (6.08) but an associated condition, right
11	So how would you disseminate that information about your service, do you work with different organisations and institutions?
12	Sure, so do you advocate for the whole, it said multinational, but is that just the projects that are going on around the country or do you just focus within your particular region?
13	do you think that explains why your services users are white predominantly, because of the geographical area
14	or do you think it might be more that they're not accessing the associated services as much, or perhaps a bit of both?
15	and can you offer any kind of explanation why that might be?
16	So is it sort of a formal assessment you do with the person with what needs or requirements they might have and then direct them to the appropriate services that are available.
17	And would you work with their family and carers as well or is it more you just want to hear the voice of the person?
18	and is that difficult?
19	So are some people that come to you at this late stage, do they not have the capacity?
20	And what sorts of methods would you use to …do that
21	And are there churches or other groups that you work with regularly to inform people about, or…
22	So you might find out what church THEY used to go to and perhaps…
23	Would you actually make contact?
24	how smoothly does that transition work?

25	are these volunteers that come from the churches?
26	right, and do you think this is something that you come across a lot, is it obstacles within the care homes, maybe they have the best intentions but maybe can't facilitate what you advocate ?
27	is that because they don't have the resources to cater for the individual as much and they are trying….
28	and how do you think that might be improved?
29	And how long might you work (15.27) with an individual with dementia
30	So is there a point where you ever withdraw your services, or would you just keep working with that person until, as long as they need?
31	Do you think that might be that people are not that knowledgeable about what the advocate does or the role of advocacy within the care system?
32	Sure, so how many service users have you got currently?
33	And are all of those white british?
34	Right, and have you find that you need to provide different types of services for this gentleman?
35	Is that a result really of his culture or is it a result of his individual needs?
36	And is his care, if you're allowed to say, has he been referred through the health channels?
37	And has he got family who are supporting him as well at the moment?
38	And is he is quite an early stage of diagnosis?
39	Yes, yes, and is that something that you just use your common sense or have you had to do a bit of education for it?
40	Do you know what religious background this gentleman is from?
41	Is that something that he has put across as important
42	I don't know what the issue is you are working on with him, but would you involve his religious (23.47) community to help support him at this time
43	So did he have knowledge about what dementia is?
44	And did you have difficulty communicating with this gentleman, was his English
45	So do you use interpreters
46	Right, and do any services exist that cater for religious and cultural activities for south Asians?
47	So you do have outreach services?
48	So how is that specifically going to work? What ideas have you got around that project?
49	So can you say what the top issues are you come across when you offer a service for somebody, what sorts of issues are people presenting to you with?
50	And I know you mentioned the Italians, more Europeans, is it the same sorts of problems you get with those people you work with or culturally different?
51	Was that dementia advocacy?
52	I was going to ask you how you think that impacted on her provision

	of care in that way?
53	And is that something that you might do yourself working with this Pakistani gentleman?
54	Is it planning on using the advocacy service when he comes back?
55	And have his family had no part in this up to date?
56	It's interesting that you said about the responsibilities he has within a family and do you think that is something that is stronger within this person of this background rather than a white British one and how accepting they might be of care or services and the impact that might have?
57	I mean that's something part of this research is about really, is people from south asia aren't accessing the services does that mean that we should be encouraging them to do so or are they happy with the structure that they have?
58	So was it a physical condition that he presented to the health services for, is that what you said and the dementia was picked up as a side line, is that what you said?
59	Is it vascular dementia that he's got as a result of the health conditions?
60	So, how do you think that service provision could be improved for south asian service users specifically?
61	It's a specialist resource?
62	How is this organisation supported, is it government funding or?
63	And is that secured then , is the funding...?
64	Oh right, so you kind of get these things going and then ...
65	And what other ideas have you got for future projects?
66	And do you ever do any work with the university of the third age at all?
67	I am just trying to think if we have covered a lot of things. Is there anything you want to ask me at the moment?
68	Or anything else that you would like to add
69	Ok, i'll just ask something again about this gentleman from Pakistan, did you actually incorporate a spiritual assessment when you went to do the interview, is that something, you mentioned that earlier?
70	And did he give you any indication about how his spirituality might impact specifically on the dementia condition?
71	And did he mention that it would be a female who he would like to provide the care?
72	He would prefer a female as the main carer, that that might be perhaps why he wants to get a wife?
73	Right , is that in the UK or Pakistan?
74	when you find that you advocate for people with a white British background, would it generally be female carers or would you have men providing the care as well?
75	Is there anything else you would like to add we have not yet covered or anything more you would like to share?

Appendix 8

Recruitment Flyer

NHS

STAFFORDSHIRE
UNIVERSITY

A Research Study:

The Influence of Religion on Dementia Care in South Asian Populations

Background

A study is taking place to investigate how religion influences care given to people with dementia in South Asian communities in the West Midlands.

The information from this study aims to improve the care provision for South Asian Individuals.

South Asian

South Asian people originate from the geographical location of South Asia including India, Pakistan, Bangladesh, Bhutan, Nepal, Maldives, Afghanistan, Iran and Sri Lanka, but now live in the UK.

There are many different religious and cultural beliefs and practices within South Asia.
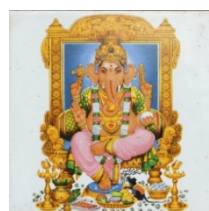
What is Dementia?

Dementia is a medical condition associated with brain dysfunction. Symptoms include memory problems, difficulty communicating, unclear thinking, challenges to day to day activities such as cooking and getting dressed. There are many types of dementia. The most common form is Alzheimer's disease.

Can I get involved?

➢ You are South Asian and have memory problems which affect your day-to-day living or you have received a dementia diagnosis.

- ➢ You look after a person with dementia from a South Asian community, and you may or may not be South Asian.
- ➢ You work in dementia services, either in an NHS Setting or a dementia organisation setting.
- ➢ You are a religious community leader or worker.

What do I need to do?

Take part in a relaxed, informal interview where you will be encouraged to talk about religion and dementia. This can take place at your home, NHS trust, workplace or at Staffordshire University. The interview may last up to an hour but could be much shorter. You may be invited to take part in a second or third interview at a later date, to develop your initial responses in more detail.

Confidentiality and consent

Participation is entirely voluntary and you may withdraw at any time. All information given is strictly confidential and your name will not be used.

This study has received favourable approval from the NHS West Midlands Local Research and Ethics committee.

Images courtesy of ©shutterstock.com

Thank you very much for your interest. If you would like to take part in the study, or you require further information, please contact the researcher:

Jemma Regan
Centre for Ageing and Mental Health
Faculty of Health
Staffordshire University
Blackheath Lane
Staffordshire
ST18 0AD
Telephone: 01785 353 742 Email: J.Regan@staffs.ac.uk

Appendix 9

Insurance Documentation

ZURICH MUNICIPAL

To Whom It May Concern

Our ref: DD/IND   15 July, 2011

Zurich Municipal Customer: Staffordshire University

This is to confirm that Staffordshire University have in force with this
Company until the policy expiry on 31 July 2012 Insurance
incorporating the following essential features:

Policy Number: NHE-02CA03-0013

Limit of Indemnity:
Public Liability:	£ 25,000,000	any one event
Products Liability:	£ 25,000,000	for all claims in the
Pollution:		aggregate during
		any one period of
		insurance
Employers' Liability:	£ 25,000,000	any one event
		inclusive of costs

Excess:

Public Liability/Products Liability/Pollution: £ 1,000 any one event
Employers' Liability: Nil any one claim

Indemnity to Principals:
Covers include a standard Indemnity to Principals Clause in respect of
contractual obligations.

Full Policy:
The policy documents should be referred to for details of full cover.

Yours faithfully

Underwriting Services
Zurich Municipal
Farnborough

481

Appendix 10

Ethical Approval Documentation

Appendix 10a

Staffordshire University Ethical Approval Documentation

Faculty of Health

Staffordshire University
Blackheath Lane
Stafford ST18 0AD
United Kingdom

+44 (0) 1785 353766 (Enquiries)
+44 (0) 1785 353673 (fax)
www.staffs.ac.uk

To whom it may concern

Application for Independent Peer Review Approval

Researcher: Jemma Regan

Study Title: The Influence of Religion on Dementia Care in South Asian Populations

I can confirm that Staffordshire University supports this research project proposal being put forward by the above research project applicant, and that the University is willing to act as sponsor of the project if it received LREC approval.

Our support for this project takes account of the outcome of an independent peer review of its scientific merit undertaking within the University.

I can also confirm that the University has generic indemnity/insurance arrangements in place as stated on the attachment to this letter, that arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed, that arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts and that the duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

Dr Jim Radcliffe
Chair,
University Academic Ethics Sub-Committee

CREATE THE **DIFFERENCE**

INVESTOR IN PEOPLE

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Appendix 10b

NRES West Midlands Ethical Approval Documentation

NHS

NRES Committee West Midlands - Staffordshire

Prospect House
Fishing Line Road
Redditch
Worcestershire
B97 6EW

Telephone: 01527 582537
Facsimile: 01527 582540

25 October 2011

Miss Jemma L Regan
Centre for Ageing and Mental Health
Faculty of Health
Blackheath Lane
ST18 0GJ

Dear Miss Regan

Study title:	**The Influence of Religion on Dementia Care in South Asian populations**
REC reference:	**11/WM/0256**
Protocol number:	**n/a**

Thank you for your letter of 05 October 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

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You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
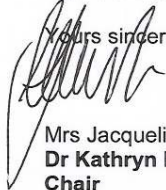
Further information is available at National Research Ethics Service website > After Review

11/WM/0256	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Mrs Jacqueline Sedgwick Assistant Coordinator on behalf of
Dr Kathryn Kinmond
Chair

Email: Jacqueline.sedgwick@westmidlands.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: *Miss Emma Neil*
Penn Hospital
Penn Road
Wolverhampton
WV4 5HN

Black Country Partnership NHS Foundation Trust Ethical Approval
Documentation

Project No: 326
(Please quote on all correspondence)

Research and Development
Governance Office
Lower Corridor
Penn Hospital
Penn Road
Wolverhampton
WV4 5HN
Tel: 01902 442544

28/02/2012

Miss Jemma L Regan
Staffordshire University
Centre for Ageing and Mental Health
Faculty of Health Blackheath Lane
Staffordshire University
ST18 0AD

Dear Miss Regan,

Honorary research contract issued by Black Country Partnership NHS Foundation Trust

I am pleased to offer you an honorary research contract in **Black Country Partnership NHS Foundation Trust**. I should be grateful if you would sign the attached three contracts, keep one yourself and return the other two to Sue Beardmore, at the above address. We will send a copy of the contract to your substantive employer.

The contract if accepted by you begins on 28/2/2012 and ends on 31/10/2014 unless terminated earlier in accordance with the clauses in the contract. Please note that you cannot start the research until the Principal Investigator has received a letter from us giving permission to conduct the project.

We will not reimburse any expenses you incur in the course of your research unless we have agreed to do so by prior arrangement. Similarly, we accept no responsibility for damage to or loss of personal property.

Your Research Passport may be subject to random checks carried out by us within the lifetime of the project. The information it contains must therefore remain up to date and accurate.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your employer through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Once you have signed and returned two of the attached contracts, you should contact the R&D Department of this organisation, who will arrange for you to be issued with an ID badge.

Yours sincerely

Sue Marshall,
Director of Children and Young Peoples Services, BCPFT

c.c.   R&D Office, BCPFT

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Appendix 10d

Leicestershire Partnership NHS Trust Ethical Approval Documentation

Leicestershire Partnership NHS
NHS Trust
A University Teaching Trust

Research & Development Office
Lakeside house
4 Smith Way, Grove Park
Enderby
Leicestershire LE19 1SS

Direct dial: 0116 295 7641
Email: david.clarke@leicspart.nhs.uk

DC/JLR/04-12

Miss Jemma I Regan
Centre for Ageing and Mental Health
Staffordshire University
Faculty of Health
Blackheath Lane
ST18 0GJ

Dear Miss Regan,

Re: The influence of religion on Dementia Care in South Asian populations.
REC reference: 11/WM/0256

Thank you for supplying the Research and Development Department with the requested documentation. I am pleased to inform you that the formal review of the project is now complete, and has been formally approved to be undertaken at Leicestershire Partnership NHS Trust in line with the submitted protocol.

Your responsibilities are set out in the attached agreement, which must be signed and returned to the Research Office. You should keep a copy for your records. All research must be managed in accordance with the requirements of the Dept. of Health Research Governance Framework (RGF), and to ICH-GCP standards. In order to ensure compliance with these standards, the Trust may randomly select your study for audit against these standards at any time, and may employ an external agency for this purpose. It is therefore important that all records are kept up-to-date and secure, especially any documentation relating to informed consent for your participants.

The duration of this approval extends only to the date specified in your NRES submission, and you should inform the Trust if this is to be extended. Action may be taken to suspend Trust approval if not conducted to these standards, and the study must commence within two years of the REC approval date, and within six months of R&D Approval.

If there are any changes to your research, any difficult incidents or if you have queries about conducting the research, please inform R&D office immediately on 0116 295 7641. We look forward to hearing the outcomes of your research and receiving a copy of the final report. Good luck with the project.

Yours sincerely

Dr. Dave Clarke
[Associate Director of Research & Development]

Chairman: Professor David Chiddick CBE   Chief Executive: John Short

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Appendix 10e

South Staffordshire and Shropshire NHS Foundation Trust Ethical Approval Documentation

South Staffordshire and Shropshire Healthcare NHS

NHS Foundation Trust

A Keele University Teaching Trust

Our Ref: AB/R222

29 May 2012

Human Resources
Trust HQ, Mellor House
St George's Hospital
Corporation Street
STAFFORD   ST16 3AG

Telephone: 01785 221 487

Ms Jemma Regan
Staffordshire University
Centre for Ageing and Mental Health
Faculty of Health, Blackheath Lane
Stafford
ST18 0AD

Dear *Jemma*

Letter of access for research

This letter confirms your right of access to conduct research through South Staffordshire and Shropshire Healthcare NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on **17 May 2012** and ends on **31 October 2013** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at South Staffordshire and Shropshire Healthcare NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to South Staffordshire and Shropshire Healthcare NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through South Staffordshire and Shropshire Healthcare NHS Foundation Trust, you will remain accountable to your employer **Staffordshire University** but you are required to follow the reasonable instructions of **Professor Eleanor Bradley** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with South Staffordshire and Shropshire Healthcare NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with South Staffordshire and Shropshire Healthcare NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on South Staffordshire and Shropshire Healthcare NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

South Staffordshire and Shropshire Healthcare NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Helen Emery
Recruitment Services Manager

Copies: Audrey Bright , R&D office
         HR department, Staffordshire University, Blackheath Lane, Stafford ST18 0AD

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Birmingham and Solihull Mental Health NHS Foundation Trust Ethical Approval Documentation

PAUL McDONALD

Birmingham and Solihull **NHS**
Mental Health NHS Foundation Trust

Our Ref: SE/SN

17 October 2012

Strictly Addressee Only
Jemma Regan
15 Bluebell Hollow
Walton On The Hill
Stafford
Staffordshire
ST17 0JP

Recruitment and Retention Department
Trust Headquarters
B1
50 Summerhill Road
Birmingham
B1 3RB

Telephone: 0121 301 1111
Fax :0121 301 1234

~> File

RECRUITMENT DEPARTMENT

0 1 NOV 2012

RE: HONORARY AGREEMENT

1.   **Status of Honorary Agreement**

  1.1   I am pleased to offer you an Honorary Agreement with Birmingham and Solihull Mental Health NHS Foundation Trust (hereafter referred to as the **"Trust"**) with effect from 01/10/2012 until 31/12/2013

  1.2   The Honorary Agreement, for which you will not receive remuneration, is personal to yourself, and in no way implies an obligation on the Trust to provide a paid appointment at a later date.

  1.3   You will fulfil the position of Honorary Researcher at the Trust. For the avoidance of doubt you shall not under any circumstances be entitled to make any claim against the Trust in respect of maternity rights, sick pay, redundancy or unfair dismissal or any other right associated with employment whether as a result of common law or statute.

2.   **Professional Registration**

  "Not relevant to this post"

3.   **Duties**

  General researcher duties.

Chair: Sue Davis, CBE   Chief executive: Sue Turner

PALS Patient Advice and Liaison Service Customer Care   Mon – Fri, 8am – 8pm
0800 953 0045   Text: 07985 883 509   Email: pals@bsmhft.nhs.uk   Website: www.bsmhft.nhs.uk

HSJ
AWARDS 10
WINNER

getting better t⊙gether

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18.2 Trust's Property

You have a duty to take care of the Trust's property, especially any entrusted to you. Theft or inappropriate use by you or permitted by you of the Trust's property will result in the termination of this agreement. Unauthorised removal of equipment and property from the Trust's premises will be regarded as a serious matter. The Trust reserves the right to inform the Police of any such occurrences.

19. Research Governance

The Trust manages all research in accordance with the requirements of the Research Governance Framework for Health and Social Care. Under this honorary agreement you must comply with all reporting requirements, systems and duties of action put in place by the Trust to deliver research governance.

20. Disclosure of Concerns

If you have any concerns about quality of service, health and safety, use of NHS money, or believe a colleague's conduct, performance or health may be a threat to patient care or to members of staff, you have a responsibility to raise these concerns without prejudice directly with your Clinical Director and/or the Medical Director. If you are unable to, or wish not to raise these concerns directly with the Clinical Director or Medical Director, you are encouraged to seek the advice of the Human Resources Department or your staff representative.

21. Termination of the Honorary Agreement

21.1 This Honorary Agreement may also be terminated by either you or the Trust by giving one months written notice.

21.3 The Trust may also terminate this Honorary agreement if you breach any of the terms set out in this letter.

If you agree to accept this Honorary Agreement, I should be grateful if you would sign both copies of this letter, returning one copy to me and retaining the other for your own information.

Thank you for your kind co-operation in this matter.

Yours sincerely

Sarah Emery
Senior Resourcing And Staff Experience Lead
Human Resource

Appendix 11

Participant Data

Interview Number	pp no.	Role	Age range	Gender	ethnic origin	religion
1	1	Old Age Psychiatrist	36-45	male	Indian	Muslim
2	2	Old Age Psychiatrist / Family Therapist	56-65	female	white British	Christian - church of England
3	3	Dementia Advocacy Manager	56-65	female	white British	Christian - church of England
3	4	Dementia Advocate	46-55	female	white British	Christian - church of England
4	5	Consultant in General Adult Psychiatry	46-55	male	Pakistani	Muslim
5	6	Assistant Team Leader Dementia Champion	46-55	female	white British	Christian
6	7	Councillor and Sikh University Chaplain	56-65	male	Indian British	Sikh
7	8	Old Age Psychiatrist	36-45	female	Indian	Hindu
8	9	Chief Executive	46-55	male	white British	Christian
9	10	Psychiatrist	46-55	male	Indian	Hindu
10	11	Carer	46-55	female	Pakistani	Muslim
11	12	Reverend / Head of Diversity & Spirituality	36-45	female	white British	Christian
11	13	Sikh Gianni / Chaplain	56-65	male	Indian	Sikh
12	14	BME Advocate	26-35	female	Bangladeshi	Muslim

13	15	Hindu Chaplain	46-55	male	Indian	Hindu
14	16	Muslim Chaplain	26-35	male	Pakistani	Muslim
15	17	person with dementia	56-65	male	Pakistani	Muslim
16	18	Head of Spirituality	46-55	female	white British	Christian
17	19	Carer / Wellbeing Leadership Coach / Director SikhHealth	46-55	male	Indian	Sikh
18	20	Senior Manager	46-55	female	Indian	Sikh
19	21	Muslim Chaplain - Trust Imam	46-55	male	Indian	Muslim

Appendix 12

Interview Data

Interview Data Phase one

Interview Component	Quantity
Total Interview time	293 minutes 52 seconds
Interview time (minimum - maximum)	33 minutes 29 seconds - 60 minutes
Average Interview Time (mean)	48 minutes 79 seconds
Total words across full data set	42,351
Individual Transcript word volume (minimum - maximum)	4,674 – 9,299
Average Individual Transcript word volume (mean)	7058.5
Total Volume of questions asked (N=7)	334
Volume of questions asked per interview (minimum - maximum)	42-76
Average questions per interview (mean)	55.7
Total codes generated	882
Total categories from these codes	20
Volume of codes generated per transcript (minimum - maximum)	86-219
Healthcare professionals (N=3) total codes generated	512
Dementia organisation professionals (N=3) total codes generated	284
Religious Representatives (N=1) total codes generated	86

Interview Data Phase Two

Interview Component	Quantity
Total Interview time	418 minutes 39 seconds
Interview time (minimum - maximum)	35 minutes 10 seconds – 70 minutes 46 seconds
Average Interview Time (mean)	52 minutes 30 seconds
Total words across full data set (N=9)	38,227
Individual Transcript word volume (minimum - maximum)	3,671 - 11, 878
Average Individual Transcript word volume (mean)	4778
Total Volume of questions asked (N=9)	400
Volume of questions asked per interview (minimum - maximum)	8-79
Average questions per interview (mean)	50
Total codes across cohorts (N=9)	1814
Total categories from these codes	22
New Categories	2
Discarded / merged Categories	2
Volume of codes generated per transcript (minimum - maximum)	81-376
Healthcare professionals (N=2) total codes generated	434
Dementia organisation professionals (N=2) total codes generated	495
Religious Representatives (N=4) total codes generated	739
Dementia Carer (N=1) total codes generated	146

Interview Data Phase Three

Dataset Criteria	Quantity
Total Interview time	324 minutes 74 seconds
Interview time (minimum - maximum)	47 minutes 23 seconds – 95 minutes 35 seconds
Average Interview Time (mean)	64 minutes 95 seconds
Total words across full data set (N=5)	41,345
Individual Transcript word volume (minimum - maximum)	5,466 – 10,820
Average Individual Transcript word volume (mean)	8269
Total Volume of questions asked (N=5)	325
Volume of questions asked per interview (minimum - maximum)	40 - 91
Average questions per interview (mean)	65
Total codes across cohorts (N=5)	707
Total categories from these codes	20
New Categories	0
Discarded / merged Categories	0
Volume of codes generated per transcript (minimum - maximum)	102 - 178
Healthcare professionals (N=1) total codes generated	102
SAPWD (N=1) total codes generated	157
Carer of SAPWD (N=1) total codes generated	178
Religious Representative (N=2) total codes generated	287

Appendix 13

DAP 1 (NVivo 9): Health Professional Religious Themes

Nvivo phase 1 health cohort – religion

<u>\<Internals\\Raw Transcripts\\1. FK transcript RAW\></u> - § 36 references coded [31.12% Coverage]

Reference 1 - 0.46% Coverage
It's quite difficult I imagine convincing someone who is not literate and has a very strong erm, (religious?) background, from a village in India perhaps to convince them to take medication for something

Reference 2 - 0.65% Coverage
I know that place has a room which is for the prayer so the holy book the Gudrun (?) is kept in that place an people are willing to go and read that book, there'll be sort of music and songs which are sort of Punjabi, and so those are also a spiritual guru who comes in to talk to those people

Reference 3 - 0.47% Coverage
Yeah I think more talking in terms of Islamic beliefs I think , something people have to believe is destiny that it was destined and that's why you had this ailment for example and that it had to happen anyway

Reference 4 - 0.29% Coverage
So that believe is there and whatever will happen will happen anyway and I think that's a believes that people have not just in

Reference 5 - 0.82% Coverage
And that this will happen and to discuss what caused the Alzheimer's, what caused the vascular dementia and explain, ok , all these things / steps were destined to happen that's why they happened and the treatment you are going to give me I might take it but it is destined (16.46) if I am going to be treated that is my destiny, if I am not, that is my destiny

Reference 6 - 0.89% Coverage
There may be two three thoughts again one of the thoughts might be the religious aspect that believing in god that god will help the second aspect of this is going to the prophets the faith healers and asking for spiritual help from the leaders and people who are in mosques the imams and people do read the verses of the Qur'an to help erm sort of get the treatment of that to get the recognition

Reference 7 - 0.29% Coverage
but discussing some religious foundations to it some cultural and also some of the help available some of the patient families,

Reference 8 - 0.56% Coverage
Well it depends on the patient there are patients who are more religious are happy to leave the will with god and say ok, what is destined for me will happen, people who are not that religious may say ok this has happened but I need to seek some help

Reference 9 - 0.55% Coverage
Again the understanding of this as an illness there are people who will say er, (19.47) they might be spiritual they might be religious but they have some understanding. They might take   but also get the help of the spiritual side so they might

Reference 10 - 0.52% Coverage

Yes they will go in and that is a common practice and most of the time you do not disturb either, you say ok, see what you are doing at the moment, take in to consideration that they are not vulnerable or financial or that side cos

Reference 11 - 1.12% Coverage
This is common practice in psychiatry and erm practice for 4 years in psychiatry in India for four years and this was a very common theme for the dominant religion there is Hinduism erm and the minority is Muslims so they will have similar faiths in relying on destiny and god's will so you don't have erm erm you don't say anything on that you continue that side of it, you say, keep going to the temple, or mosque but just come to the clinic as well and take the medications for erm you need them.

Reference 12 - 0.53% Coverage
I think er being more erm sensitive towards the religious sides I've seen trusts having the Imams , having the temple priests erm the chaplain to come and help most of the religious ideology I think that is there in most of the places

Reference 13 - 0.69% Coverage
where I work in the hospitals I have seen the population in Coventry I have seen Sikh and Muslim and ? Chaplains and all separate rooms for them and the Imams and the temple leader for all of them. So in most of the places that side is important and consideration and what are the needs of these people.

Reference 14 - 0.64% Coverage
No I think it is useful it is quite useful. I have seen central mosque in Birmingham have done a programme on smoking with the NHS which was quite liked / white people(?) but they had a stall about two years back around Ramadan time when people fast so they give up smoking at that time

Reference 15 - 0.95% Coverage
there is no such outreach service approaching people erm through the mosques or community centres or temples and community centres erm going to the synagogues or places where people go for prayers or having their close links with the community elders or spiritual leaders who can have influence themselves and understanding the disease model first of all and then encouraging the communities to accept and approach for help

Reference 16 - 0.89% Coverage
see a lot of people who have come over first generation who have come here during that stage of 65, 70, 80 years of age now, you'll find that them in temples and mosques because they'll be spending most of their times there and erm, they can be picked up from there or the religious leaders can be a lot of help in the (27.54) liaising with them and helping them understand that they need some help.

Reference 17 - 2.12% Coverage
If someone has schizophrenia and has delusional beliefs, so delusional beliefs are quite linked to culture and religion many times (30.44) so people sometimes see prophets or they hear the voice of the god speaking to them or giving commands now there might be a Muslim psychiatrist who doesn't know many things about the Hindu religion for example, so the patient is a Hindu patient who speaks about a goddess who is ? of something in her mind / in his mind and this person will not be able to know the name of that goddess and say he is talking about this lady he may not be able to name ? and say this is influencing the patients understanding of the treatment or the risks associated with that (31.29) so it might be true for other religions as well so I think a lot of people do go for similar cultural doctors

or similar group of psychiatrists in the communities so that they can understand things at that level and also giving advice I think.

Reference 18 - 0.58% Coverage
Giving advice erm, also does have this religious element to it that I said to you earlier, continue to go to the temple continue to go to the mosque, continue to take advice from the spiritual leaders as you doing it, whiles you take the medications as well.

Reference 19 - 1.27% Coverage
i think patient tailored care again so if we have a south asian gentleman or lady who er in that age group who is having that strong cultural or religious background I think asking the help for the hospital chaplain, advising to get an imam , or someone who with the consent of the person might be helpful and I think in some places it is done (32.52) i have seen this practice being done in many places, I've seen people, Sikh people religious leaders they come down to speak to them about their problems and I've seen arm priests here coming and talking to people.

Reference 20 - 0.67% Coverage
So you can take that into consideration the person's believes and whether that person wants that at this point in time and if it would be beneficial for the person, if that understanding is still there in the person that they are able to talk to them and understand and be helped, that's the idea

Reference 21 - 0.49% Coverage
I don't think there are very clear and strict guidelines on the chaplaincy that is available I have seen everywhere i've worked i've seen a chaplain there. I've used that myself so erm i think referral processes, i'll

Reference 22 - 1.67% Coverage
The conflict might arise if I as a doctor (34.56) tell them not to fast and they may be saying 'you cannot tell me what to do , I am Muslim, this is the month of Ramadan, I want to 35.05 fast. So probably what will happen is, what happened was we had to involve the Imam of the place, yeah, I was involved as well in the discussion with some of them, so we drafted a sort of protocol all these people who want to fast, how many of them are diabetics, how many of them need insulin, what sort of insulin, what medications they are on and what times, so things that we can alter and manage, so we changed the times of the medications, we changed the kitchen was opened in the morning at 3 o clock for them to use at that time under supervision.

Reference 23 - 0.96% Coverage
So we spoke to the Imam and sat down with the individuals concerned and said it is difficult you have to take insulin because your sugars will go down quickly and they had a good understanding of that after some time and then 36.09 they said ok you can continue once your diabetes is better, you can continue afterwards when it is well controlled. So, these are examples when things can be done with the help of the chaplains.

Reference 24 - 0.31% Coverage
Yes it's both, it's also saying it in the religious terms as well I think. So you say that erm God has given you permission not to fast

Reference 25 - 1.72% Coverage

Because it says very clearly in the Qur'an people who are travelling and people who are unwell are exempt from fasting so travellers can fast afterwards after they have finished

the travelling, when they have gone back (36.56) to the place and people who are ill they can continue fasting once they have got well obviously so the people and the main people are diabetics because they can't fast. 37.11 diabetes in continuous so they can't fast. But some people have also altered the medications and so they can fast. There is also an exemption for people who can't fast, so you explain both in medical terms and also take help of the religious concepts where you can explain to them ok it doesn't you know ???

Reference 26 - 1.53% Coverage

and it was not a good thing for you to be controlled. We have to be careful especially 38.03 doctors in psychiatry, what is part of it is a delusional belief sometimes, so it becomes preoccupied with whatever anybody is saying may not be able to comprehend what is happening because it is deluded probably or has delusions of delusions that they have to do something, they have to do it. It might be a false belief something like that quite strong and you can't shake that belief. So you have to consider all these aspects probably when you are assessing, especially in psychiatry it might not just be beliefs but it might be a psychotic condition when you have to control that as well.

Reference 27 - 0.37% Coverage

You have to take the family into consideration and you get more information from them about was this person religious person or you have seen the religiosity just now

Reference 28 - 1.94% Coverage

 I am talking about the asian background when they age they take spiritual activities more often and more regularly than the time before, so that might be normal pattern for them, but just having a distinction whether this is having an like an obsession for those people which was not there before at all and this is coming quite irrational at this point in time. So you have to take individual things like for example someone wants to go to the temple at 2 o clock in the morning but it might be closed and they want to go to the temple those sort of things I think, will be important for dementia I think. They might be vulnerable at places they go sometimes so take family on board and speak to them to discover if they were religious before, if they were religious what happened, just getting that longitudinal history. 40.20 from them what happened will help.

Reference 29 - 0.45% Coverage

I have seen examples of someone who was a priest and he used to preach at people and when I we admitted him on the ward he was gathering all the patients together and was giving a sermon to them (laughs)

Reference 30 - 1.38% Coverage

if somebody was doing something or overdoing something that was having an effect on the persons health (41.28) and their mental state i would be very concerned about them. Any ritualistic behaviour, for example that was, if someone prays more for example that's fine, but if someone prays sort of at 2 o clock in the morning and at 3 4 o clock then (41.44) that is not actually required, so I think discussing with them both ways that God is not actually expect you to do that is what is said so you must know or someone must know what God has said on this or this is unnecessary for you to do. And when you are unwell

Reference 31 - 0.98% Coverage

but I think sometimes the behaviour you are talking about which are religious in on the beads, some people are reciting on the beads, if that's erm bothering or having any problems I don't see any reason to stop that at all or trying to stop that, unless it's impacting the sleep or something like that and other risk issues like wandering out in the night, going to the temple or mosque and wanting to go out (42.58) and speak with them

Reference 32 - 0.47% Coverage

this is my responsibility to look after my dad or mum and that's religious as well it has a very strong religious aspect, religious side to it, so that's why I think a lot of people will care for their loved ones

Reference 33 - 0.64% Coverage

second thing is i think they do have, all the hospitals have a spiritual leaders and the priest and the chaplaincy there, most of the religious groups will have there and erm where they need to do more is education and awareness, approaching them and researching where you'll find them .

Reference 34 - 0.77% Coverage

one of the er places to get it as you mentioned earlier, the temples, mosques and community centres. 45. 40 where people can meet and having days like half a day dementia day for that community, for that community centre, so people have access to come in and look into what dementia is, same with substance misuse and or, ??? or any such thing

Reference 35 - 0.97% Coverage

When you try to separate the medical problem from the religious background it would be difficult to convince because they believe that everything is the destiny, and you cannot do much to intrude that and so it would be quite difficult, adn I know quite a lot of people who do go to different areas to seek help, but it is clear that they should have gone to the GP to ask for help but they have gone to other places. I know somebody,

Reference 36 - 1.51% Coverage

 I think it is something to do with the spine they have to go to the neurosurgeon to get it checked, CT, MRI should be done but I think quite a religious person, so for them, a doctor telling them to go in the mind it is quite strong, this medical help may not solve my problems, I will have to go to
Also the preconception is there they will have for a long time in the mind that erm, this s is going to be cured by this faith healer, they have done hundred such people have gone to them and got cured and taken the medication and it's stopped nothing so yeah that is still there in some group, maybe in the minority, not the majority of that group will have this thoughts.

Appendix 14

Field Notes Examples

Field Notes – Interview participant 1

o   Conducted in CAM, checked lights were ok, turned them off to be more comfortable, familiarised self with the recorder.
o   First interview, bit nervous
o   Questions at start were not clear – specifically about 'influence your practice' – not clear that this was about daily personal beliefs, not necessarily influencing career / professional practice. – RE-WORD
o   Didn't know how much time had passed – have a watch or way of knowing the time, checking the Dictaphone could be distracting to the pp.
o   Generally went well, covered a lot of ground
o   Perhaps tick the questions on sheet when asked them as I had trouble keeping track of what I had asked and what I hadn't, although listening back, I did not ask the same question twice.
o   Maybe group the questions into categories such as 'carers', 'personal opinions', 'career experiences / examples', 'spiritual / religious specific questions'.
o   Was concerned about the time / repeating questions
o   Make questions more RELIGION FOCUSED – currently more a general 'culture' discussion, think about how to bring out more religious *per se* examples.
o   Aim for saturation with the other interviews.

Extra info after tape, discussion followed on after the tape had stopped. Checked with pp1 that could use this material and he agreed.
Carers – at home, issues at home
Religious practice at home – prayer – external
Carers – walking on the prayer mat accidently, for example.
Religiosity in the home – context of a person's belief in the home
How practically get the patient to access the services – can't get everybody – those who are not interested. Not neglecting – the patient should have a choice whether to accept care and what type and in understanding.
11,000 BME dementia registered. BME in care home won't fall through the net. cost of late onset with dementia to NHS systems is higher than catching people earlier in early stages and want to capture beforehand. Long term cost of coping with late onset groups.
NHS wants to capture early onset to save costs. xx and xx presentations – Missing persons? Where are these missing persons? BME & of dementia population in the UK. 6.1% of BME dementia early onset, captured 2.2% of the UK as a whole (check figures!!) Knapp, 2007. [Martin prince 1066 dementia study]

Field notes of interview with PP11

09.05.2012

First interview with a carer

Took place in her home

Pp little nervous at start and slightly upset at end, so interview terminated after 36 mins

Enjoyable to hear first hand experiences of care over a 6 year period and the influence of duty over care decisions and satisfaction with care

End of life and date of death issues raised in relation to religious perspectives – Muslim – interesting. Care female. Family support and obligation.

Person with dementia using religion right until end of life. Prayer rituals important

Field Notes Thursday 30th August 2012 – 7.30pm Alzheimer's café, XX with pp17

Walking to the group not possible, too far with his heart problems

XXX Peer support Group – carers and pwd invited

c.20 people all carers, all white British, male and female, most age 50+, one lady (older) and younger daughter? Didn't look well – cancer?

volunteer leader said 'I presume this is not your daughter', seemed unprepared for how to handle us. Said volunteered for 22 years – only come across one afro-Caribbean lady in that time from BME organisations. Was 'surprised' to see you sitting there.

Asked ' do you know someone with dementia?' PP17 said 'me' she seemed surprised 'alzheimers?' he said yes, then no fronto something, she said fronto-temporal, there is another man who comes here with that but he is not here tonight, said he was very unique in that sense

PP17 expressed frustration / dissatisfaction that hadn't 'learned' anything from it about the condition, that no experts were there to speak about the condition. Just seemed like a place for people 'to have a cup of tea' for carers, in his opinion.

Had ten minutes with 'B' – volunteer, said not sure how to help but he could offer a lot and has a lot to offer. He said he wanted to give back, used to do lectures, training, hiring and firing people. Anxious throughout, felt better having someone he knew there. Said lost confidence and the thought of standing in a room to speak in front of it now, was terrifying. She said she could tell he was a people person and had a lot to offer.

Said he'd done an experiment to see if he could get a job, got the interview, got the job and then declared the condition, they said he didn't think he could do the job and they also agreed.

Said feels useless, wants to feel useful and give something back

FTD type – expressed it was this type of diagnosis, received 2 years ago, perhaps been suffering longer, and hides things (his condition?) well.

Married 4 years to English lady

5/4 children – 1 daughter, 2/3 sons. 1 grandson 18 months. Daughter married age 27, works with children, he struggled to say in what capacity – nursery nurse? . Maq said she had said she could take him to a group in the future if it was in the evenings

Off to marry in Pakistan in a month for 6 month period

Expressed desire to the volunteer to set up a group, wouldn't know how to . want to train people to care for people with dementia, from the perspective of someone who has dementia

Case study ??? invited to accompany him to docs apt on Monday. He said it would be interesting for the research because he has a lot of questions for the doctor. JR – possibly interview him again about experiences / thoughts / expectations. He said he would like to speak to me again to 'brainstorm' the evenings events. Accompany to the approach café – sept 9th? Check the date…..and where….JR – during the next interview – focus on religion and faith more, ask more about why he does not go to the mosque and would this be possible, how would they support him if he did go, what would his expectations be about where to go for care and support, interview the family if they were interested and ask about duty of care, what their expectations were. Religion might be muslim, but culturally British? Pakistan but what does this mean??? He has expressed a little bit in the first interview about using it as a comfort, but then not being able to remember where all the references were in the holy books like he used to , so this takes much longer to remember which book he has looked in and has his own technique by moving each book to know which one to look in first.

Going to Pakistan for in about 1 month for 6 months with all his children – cost £3,000. Expressed anxieties which had kept him awake at night about bringing his wife in to the country, whether she would be allowed in.

Doesn't drive anymore, but directed me as a passenger to the day centre, and did so very well. Had taken an instructors course but could not practice due to the condition,

Worked as a translator in the past – social services, citizens advice

No real discussion about support in the group. Just politics of the alzheimer's society and data protection gripes and notices about upcoming trips. None of the group shared anything 'worthwhile', mr q said he thought there would have been the opportunity to 'offload', but 'there was no-one to offload to'.

He said in car at the end that he felt nervous because of his skin colour in situations like that, or reference being made to his skin colour, he felt 'under pressure', for that like all eyes are on him. Whereas he just sees people as people

Said when she'd said you're not his daughter, that I could have been anyone 'his daughter, step daughter, partner, neighbour, whoever…'

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Said he'd been to various support services. Disappointed with approach because he hasn't been deemed fit to volunteer with them after he wanted to volunteer.

Future plan:

- Monday 3rd September: Accompany to doctors appointment

- Interview 2: Date tbc

- Approach café – xxx –- Friday 7th September 10.30 – 12.30pm (11 minutes drive)

Study Poster

The Influence of Religion on Dementia Care in South Asian Populations

Background

In the U.K., Black and Minority Ethnic (BME) communities are most at risk of developing vascular dementia and experience a higher rate of young onset dementia (under 65 years), compared with the majority ethnic population (Seabrook and Milne, 2004). Despite this, BME dementia patients access health services and receive diagnoses later in their disease progression and are less likely to access anti-dementia medication or partake in research trials and care (Mukadam et al, 2011).

A prominent theme emerging from existing research, not yet directly addressed, is the impact of spirituality and religion on dementia; in terms of perceiving the illness, accepting the illness, coping with the illness and accessing services (Milne and Chryssanthopoulou, 2005). The Western tradition to seek clinical intervention in the case of physical or mental illness highlights one discrepancy between indigenous U.K. culture and immigrant religious practices and rituals. Mainstream dementia services appear ill-equipped to respond to the needs of ethnic minority individuals (Bowes and Wilkinson, 2003).

Aims of the investigation

The main aims of this research project are:
- Identify and analyse how religion and culture influences the experiences of care and coping for South Asian individuals with dementia, in the UK.
- Discover and evaluate the potential deficits in - and benefits of - existing dementia care provided for South Asian groups.

Objectives of the project

Research and critically evaluate the views and experiences of religion on dementia from the perspectives of:
- The South Asian dementia patient
- The dementia carer

- The N.H.S. healthcare professional
- The non-N.H.S. dementia organisation worker
- The religious leader

Method

The study is based on a qualitative design incorporating semi-structured interviews, to be analysed using Grounded Theory (Glaser and Strauss, 1967):
- Phase 1   T1
- Phase 2:   T1 + 3 months

- Phase 3:   T1 + 6 months

Outcomes and Benefits:
Promoting a positive shift in research from an ethnocentric perspective of dementia will improve knowledge of how immigrant religious beliefs and practices affect experiences of indigenous care provision. This awareness of, and sensitivity to, alternative cultural groups in dementia populations, will allow improvement of this care provision by educating both policy makers and care providers with a view to developing 'culturally competent practice' (LaFontaine *et al*, 2007).

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