

Sikhs and Dementia: cultural and religious constructions in this minority
population.

Submitted April 2012

by

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To the University of Leicester, School of Psychology, Clinical Section.

In partial fulfilment of the degree of

Doctorate in Clinical Psychology.

Declaration

The following thesis is my own original work, except where otherwise stated with reference to the original author(s). It has been submitted in partial fulfillment of the degree of Doctorate in Clinical Psychology.

Sikhs and Dementia: cultural and religious constructions in this minority population.

Section A: **Thesis Abstract**

Submitted by

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South Asians are at a greater risk of developing dementia due to also having a higher incidence of diabetes than the UK population as a whole (Department of Health, 2002). However little is known about this ethnic groups understanding of dementia. A review of the literature on the understanding of dementia in South Asian's living in the community suggests that differences in the perceptions of the causes and treatment of dementia exist within South Asians. Further research has been suggested to explore minority groups within the umbrella term 'South Asian'.

NICE guidelines require treatment for dementia to be culturally, religiously and spiritually sensitive. However, the South Asian population is not an homogenous group, and there may be differences on what constitutes a sensitive approach for different sub-groups. This study sought to focus on one section, the Sikh community. A focus group design was used to explore how culture and religion influences the conceptualisation of dementia in the Sikh community. Six focus groups were undertaken, consisting of 28 participants and data was analysed using constant comparative methodology (Charmaz, 2006). Four themes emerged including awareness and interpretation of the characteristics of dementia, multiple perspectives of the same symptoms, cause of dementia and coping. The findings have been discussed in the context of existing research and provide an introductory insight into informing culturally appropriate interventions for dementia awareness in the Sikh community.

The final section, the critical appraisal, reports an account of the researcher's reflections throughout the research process.

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Section B

South Asians and Dementia: cultural, religious and spiritual constructions in this
community.

A Systematic Literature Review.

Submitted April 2012

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1. Literature Review Abstract

Introduction: The majority of research in the UK on ethnic health inequalities has focussed on African-Caribbean communities. However, South Asians are at a greater risk of developing dementia due to having a higher incidence of diabetes than the UK population as a whole (Department of Health, 2002).

Aim: To provide an overview of research on the perceptions and knowledge of dementia in South Asians in the community and the role of culture, religion/spirituality in these conceptualisations.

Method: Following a systematic literature search, five articles were reviewed and analysed thematically. Study quality and methodology were assessed.

Results: Six themes were observed, with findings suggesting that South Asian participants across the five studies in this review exhibited a lack of awareness and knowledge regarding dementia.

Conclusions: In this under-researched area, the available evidence highlights that South Asians have a poor understanding of dementia. However differences within South Asians in terms of their views about the causes and treatments for dementia were observed. Ideas for future research are discussed.

Key Words: Dementia; Culture; Religion; South Asian; Awareness; Understanding.

Target Journal: Mental Health, Religion & Culture¹

¹ See Appendix A for “Guidelines for Mental Health, Religion & Culture Manuscript Submission”

2. Introduction

According to population estimates derived by the Office for National Statistics (2011) black and minority ethnic (BME) groups constitute 15.8% of the total UK population, however they are often under represented and marginalised in the provision of health and social care (Daker –White, Beattie, Gilliard & Means, 2002). In recent years, several schemes such as Health Action Zones and National Service Frameworks have been launched in order to tackle these inequalities. This is highlighted in the National Service Framework for Mental Health (DoH, 1999) stipulating that services must address the needs of all ethnic groups. According to the Inside Outside: Improving Mental Health Services for Black and Minority Ethnic Communities in England (National Institute for Mental Health in England, 2003) people from BME communities tend to have poorer health, shorter life expectancy and greater difficulties in accessing health care.

2.1 BME research in the UK

The majority of research in the UK on ethnic inequalities has focussed predominantly on African-Caribbean communities (Henderson, Thornicroft & Glover, 1998; McLean, Campbell & Cornish, 2003; Nazroo, Jackson, Karisen & Torres, 2007). However, Birchwood, Cochrane, Macmillan, Copestake, Kucharskaan and Carriss (1992) explored the influence of ethnicity across ethnic groups in the UK and found a lower rate of relapse and readmission in Asians (16%) compared to Caucasian (30%) and African-Caribbean (49%) patients with schizophrenia. Similarly, Bhui et al. (2003) reviewed 38 articles and concluded that variations between admissions and pathways existed across ethnic minority groups in the UK. African Caribbean patients had more complex pathways, as they were less likely to be referred to specialist services by their general practitioner (GP) in

comparison to Caucasian or South Asian patients. Furthermore, of all the included ethnic groups, South Asians with a mental disorder were the least likely to be referred to specialist care. Aspinall and Jacobson's (2004) review of ethnic disparities in health care in the UK indicated that Chinese patients were found to under-utilise GP services, outpatient departments, and hospital services in comparison to South Asian, African - Caribbean and Caucasian individuals.

The number of South Asian and Chinese individuals recruited in these studies tended to be smaller than the number of African- Caribbean participants. Consequently the findings from BME research often reflect information from the more readily available and accessible minority groups (Bhui et al., 2003). It is unclear to what extent these findings can be generalised across other ethnic minorities (Cochrane & Bal, 1989).

2.2 South Asians

According to the 2001 Census, South Asians account for the largest category within the minority population (3.5% of 8% of the ethnic population). More recently there has been an increase in the availability of literature investigating the health care needs of South Asian communities (Barnett et al., 2006; Gerrish, 2001; Katbamna et al., 2001). However it is important to note that South Asians are not an homogenous population and the term includes individuals from Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan and Sri Lanka. In addition South Asians may identify with religious identities that cross these different national groups.

2.3 Ageing South Asian communities

Although South Asian populations in the UK are reported to be younger than the majority population (Office for National Statistics, 2001), the large numbers who came to the UK between 1950 and 1970 for work are now ageing. In

2001 there was 350 000 ethnic minority elders in the UK (Office for National Statistics, 2003), however the number of people aged 85 and over is predicted to rise over the coming years (Age Concern, 2001). Livingston and Sembhi (2003) expressed that many studies investigating dementia prevalence report education as often protective against the development and progression of the illness. They concluded that migrant groups, who are often less educated and socio-economically deprived, might therefore be expected to be more vulnerable to dementia.

Dementia is a serious, progressive and irreversible degenerative deterioration of mental functioning, often characterised by loss of memory, attention, language and orientation (Sloane et al., 2002). Alzheimer's disease (AD) is the most common cause of dementia, and other causes include vascular dementia, dementia with Lewy Bodies, and fronto-temporal dementia. Currently there are 820,000 people living with dementia in the UK, the prevalence of which is predicted to increase rapidly over the coming years (Alzheimer's Research Trust, 2009). According to Matthews and Brayne (2005) 163,000 new cases of dementia occur in England and Wales every year. Due to the fact that longevity is the most significant risk factor for developing Alzheimer's disease, accounting for 60% of all dementias, the prevalence of dementia in South Asians is set to rise. The risk of dementia in South Asians is further increased as a result of the high levels of diabetes and hypertension in this community (DoH, 2002).

2.4 Dementia awareness in South Asian communities

The rise in cases of dementia in South Asians (Lawrence, Samsi, Banerjee, Morgan & Murray, 2011) will greatly impact on the lives of older people and their families in this minority population, however little is known about how South Asian's understand dementia in the UK. It is interesting to note that Punjabi culture

contains no equivalent word for the term 'dementia'. Beliefs about disease aetiology and treatment are important determinants in how individuals view dementia and how they respond to advice given by health professionals. Research indicates a lack of knowledge and understanding of dementia in South Asian communities (Jolley et al., 2010; Jutla & Moreland, 2009). Adamson (2001) reported that many South Asian carers had not heard of dementia prior to their relative being diagnosed with it, suggesting a lack of understanding and appreciation that may exacerbate difficulties in managing the condition. One carer linked the onset of dementia with a visit to Pakistan whilst another blamed the person with dementia for their own condition (Bowes & Wilkinson, 2003). Bowes & Wilkinson (2003) also found that South Asians tended to use the word 'dementia' as stigmatising rather than neutral. Patel et al. (1998) found that when working with South Asian communities, dementia was conceptualised in three different ways, an 'act of God', the result of normal ageing or as a mental illness which was regarded as shameful. Similarly Mackenzie (2006) studied stigma related to dementia in South Asian carers and found that the way in which they managed and understood dementia was linked to religious and 'magical' explanations. Dementia was also seen to induce fear into the family and was often concealed to protect the reputation of the individual diagnosed as well as the family as a whole.

It is therefore unsurprising that studies have found that South Asians are less likely to recognise the words 'dementia' and 'Alzheimer's disease' than White British and Black Caribbean groups even when recruited participants are those who have been diagnosed with dementia (Bowes & Wilkinson, 2003; Lawrence, Banerjee, Samsi, Murray & Morgan, 2011). Lawrence et al. (2011) found that the threat posed by the experience of dementia depended on the individual's own

understanding and attitudes of the condition. In addition, South Asians often conceptualised their diagnosis as memory loss alone, rarely recognising the progressive nature of the condition.

2.5 Culture, Religion and Spirituality in Healthcare

Holmes and Holmes (1995) claimed that the more conventional an individual is, the more likely they will seek an explanation for their illness within their own cultural, religious and spiritual frame of reference. Culture, religion and spirituality offer different solutions to living and different pathways to healthy living that can shape individual and group behaviour (Ogbu, 1993). As discussed previously, South Asians are a diverse group, however there is a paucity of literature looking at variations within ethnic groups, specifically South Asians. Thompson (2010) studied Sikh older adult's views of mental health providers and found that over 80% reported that they wished for services to account for their religious beliefs.

In order to provide culturally competent care, it is important to consider the interplay of religion/spirituality and health (Labun & Emblen, 2007). Investigation into how religion/spirituality influences one's mental health beliefs, specifically beliefs around dementia is essential (NICE, 2006) However, to date there is no research investigating the Sikh communities understanding and awareness of dementia. Literature reviews have tended to focus on minority ethnic groups in general (Daker – White, Beattie & Means, 2002; Mukadam, Cooper & Livingston, 2011) or editorials looking at the importance of exploring the views of dementia in BME groups (Bowes & Wilkinson, 2003; Dilworth –Anderson & Gibson, 2002; Milne & Chryssanthopoulou, 2005; Moraity, Sharif & Robinson, 2011). Studies have included South Asians with a dementia diagnosis (Lawrence et al., 2011) as

well as South Asian carers experiences of dementia rather than their understanding of the condition (Adamson, 2001; Adamson & Donavon, 2005; Katbamna, Ahmad, Bhakta, Baker & Parker, 2001; Lawrence, Murray, Samsi & Banerjee, 2008; Mackenzie, 2006). Bowes and Wilkinson (2003) included the views of both those diagnosed with dementia and their carers.

The empirical study will focus specifically on the Sikh community but in order to provide a background of related research, this literature review will include all research on South Asian populations.

3. Aim of the Review

This review will assess the evidence investigating the understanding and awareness of dementia in individuals from South Asian communities through the systematic identification of suitable literature. The aim is to (i) provide an overview of recent articles (ii) examine conceptualisations and knowledge of dementia in South Asians in the community and (iii) examine the role of culture and religion/spirituality in their conceptualisations.

4. Method

4.1 Search Strategy

The following electronic databases were searched; PsychInfo, Web of Knowledge, Scopus and ScienceDirect for the period 1991 to July 2011 inclusive. The search terms dementia, Alzheimer and view, perception, understand, aware and Sikh, South Asian, Punjab and religio*, spiritual*, cultur*, ethnic* (Appendix B for full summary) identified 6258881 articles. In order to identify the most relevant papers, major headings were implemented leaving 323 articles. Following this, titles and citation abstracts were then scanned to exclude irrelevant papers resulting in a

shortlist of 24 articles. Reference lists of the shortlisted 24 articles were checked; duplicate studies removed and 5 articles remained (study process in Appendix B). A data extraction pro-forma (Appendix C) was then used to abstract the following information; aims, country of study, methodology, participant sampling, appropriateness of analysis, validity and reliability of results. Findings from each study were compared for any discrepancies or similarities and gaps in the literature were noted.

4.2 Inclusion and exclusion criteria

Articles investigating understanding and awareness of dementia from those living in the community were included in this review. Participant samples excluded those who had a diagnosis of dementia themselves or if they were carers for those diagnosed with dementia. Research that recruited these participants were excluded because these groups are likely to know relatively more about dementia than individuals in the community who have not had any contact with a diagnosis of dementia and this review is interested in how South Asian communities would conceptualise and prepare for a dementia diagnosis in the future. However, studies that recruited both adults in the community as well as carers of those with dementia were included with only findings from the former group being reported here. Similarly research that discussed community perceptions of dementia and another mental illness were included here, reporting the dementia findings only in this review. International as well as UK research was included in this review however studies recruiting ‘Asian’ samples (without clarifying what this consisted of) were excluded as the term ‘Asian’ often includes individuals from China, Japan, Korea and Vietnam. Searches were limited to those articles written in English, ranging from publication dates 1991 to 2012. Books, editorial articles, literature reviews and

correspondence were all excluded. Both qualitative and quantitative peer reviewed literature were included. Studies were included whether or not South Asians were the sole participant sample, due to the paucity of literature focusing on South Asians alone.

The literature search identified twenty-four articles; however twenty-one were excluded on one or more grounds. Six were excluded because research consisted of either theory with no empirical research, seven focused on carers, four recruited those with a dementia diagnosis, and one included Asians without specifying which ethnicities made up this group and there were three duplicate articles. The remaining two articles were found by searching the references of the twenty-four shortlisted articles. Five articles were reviewed here and are marked with an asterisk in the references.

4.3 Data Synthesis

Using the data from the short listed articles, the information was collated into a table (Appendix D) and a narrative of the findings is described within the results. Thematic analysis (Braun & Clarke, 2006) was used to identify recurring themes from the selected articles included in this review. These themes were then aggregated to produce a framework as to how South Asians understand and conceptualise dementia.

An appraisal of the methodological quality of the studies included in this review was not carried out using a standardised assessment tool due to the paucity of literature in this area. The use of a tool such as the Critical Appraisal Skills Programme (CASP) was likely to exclude the small research that was found therefore an inclusive approach was taken as long as papers were not ‘fatally flawed’ and were seen to make a useful contribution to the review (Dixon-Woods et

al., 2006). All studies that were investigating perceptions of dementia in South Asian communities were included. Notes on the quality of the studies are included in the reliability and limitations section of Appendix D and other aspects of the quality of the research are included in the results section of this review.

5. Results

The literature search identified five articles to include in this review, four of which were qualitative and one quantitative all addressing knowledge of dementia in South Asian individuals in the community. Four studies were conducted in the United Kingdom and one in India. Two of the papers focused solely on South Asian communities, whereas the other three looked at South Asians as well as other ethnic groups including Caucasian and African-Caribbean populations. The qualitative studies (Jolley, Moreland, Read, Kaur, Jutla & Clark, 2009; La Fontaine, Ahuja, Bradbury, Philips & Oyebode, 2007; Patel & Prince, 2001; Turner, Christie & Haworth, 2005) consisted of mainly focus groups with one study undertaking 1:1 individual semi-structured interviews. The only quantitative study (Purandare, Luthra, Swarbrick & Burns, 2007) used a questionnaire to assess participants' knowledge of dementia. Descriptions from each study have been tabulated and are numbered from one to five (Appendix D).

A majority of these studies have included other ethnic populations as well as South Asians hence differences between South Asians and other groups will be included in this review. However the aim of this literature review, to elicit levels of awareness and understanding of dementia in South Asians remains.

5.1 Sample demographics

Sample demographics across all five studies are summarised in Appendix D, with a total of 615 participants from the community. Out of these 615 participants, 385 were described as South Asian or Indian. Participants from the community (n = 544) were predominantly South Asian (70%) with 28% Caucasian and 2% African-Caribbean. Overall gender was only reported in two of the five studies, accounting for 54% (n= 295) of the total number of participants across the five studies. The majority were females (63%) with 37% males. Age of participants across four of the five studies ranged from 50 to 89 with one of these four studies recruiting participants across the lifespan (16 – 61). One of the studies did not disclose the age of their participants. Two of the five studies recruited from community, religious and voluntary organisations, one recruited from homes for the elderly as well as the community, one recruited from primary care services such as GP practices and one recruited from day centres in the local area. The study that recruited participants who lived in homes for the elderly in the community was included in this review as admission to these homes was based on the fact that older adults did not suffer from any health conditions; physical or mental.

5.2 Themes

Responses from participants across all five studies demonstrated the way in which South Asians understand and perceive dementia. Thematic analysis of the findings from all studies identified six common components including; South Asians' knowledge of general mental illness and ageing; beliefs about the nature of dementia and its symptoms; beliefs about the causes of dementia; community perceptions regarding dementia; who can help with treating dementia as well as

how service provision could be improved. These are explored in greater detail below.

5.3 Knowledge of age related mental illness

In order to gain a sense of South Asians' understanding about dementia, two studies (La Fontaine, Ahuja, Bradbury, Phillips & Oyebode, 2007; Patel & Prince, 2001) asked participants to discuss their knowledge around ageing and associated mental health difficulties without introducing the term 'dementia'. Participants in both studies described ageing as being dominated by physical health concerns such as diabetes, heart problems, and blood pressure. Seldom did their responses relate to aspects that might be associated with dementia. One focus group of older adults described forgetting things easily as a common problem associated with ageing (Patel & Prince, 2001). Participants from the La Fontaine et al. (2007) study felt that these difficulties were due to a lack of care, increased isolation and loneliness as well as a poor diet. Interestingly, older participants in Patel and Prince's study offered very few suggestions as to the cause of these difficulties reporting only '*God knows*' (2001, p. 31).

5.4 Nature of dementia

South Asian participants across all five studies exhibited a lack of awareness and knowledge regarding the nature of dementia. La Fontaine et al. (2007) used dementia vignettes to try and elicit participant perceptions about what was happening to the individual and found that dementia was not mentioned once as a possible explanation. Patel and Prince (2001) also used vignettes and found that many participants recognised the presentations as typical of people known to them. In addition, Patel and Prince (2001) reported that South Asian participants described dementia as a nervous or psychological illness or a '*brain problem*' or '*absent-*

mindfulness' (p. 33). Similarly both qualitative and quantitative studies (Purandare, Luthra, Swarbrick & Burns, 2007; Turner, Christie & Haworth, 2005) reported that South Asians knew significantly less about dementia than Caucasians. Purandare, Luthra, Swarbrick and Burns (2007) found that South Asians scored lower in their basic knowledge (which part of the body is affected, is there a cure, who is mostly affected in terms of age) epidemiology (types, prevalence) and overall scores on the dementia knowledge questionnaire than Caucasians. In this study, only 21% of South Asians recognised dementia as a disease of the brain. South Asian participants were most commonly found to link memory impairments with dementia whereas Caucasians described dementia in a more detailed way including other aspects such as the recognition of impairments of personality, reasoning and disorientation as well as disconnection from reality (Purandare, Luthra, Swarbrick & Burns, 2007; Turner, Christie & Haworth, 2005).

5.5 Causes of dementia

Several themes were recognised when South Asians were asked to give their opinions as to the cause of dementia, these included; being a part of normal ageing (Prince & Patel, 2001; Purandare, Luthra, Swarbrick & Burns, 2007; Turner, Christie & Haworth, 2005) reduced social support (La Fontaine et al., 2007; Patel & Prince, 2001; Turner, Christie & Haworth, 2005) increased emotional worry (La Fontaine et al., 2007; Prince & Patel, 2001; Turner, Christie & Haworth, 2005) and physical health deterioration (La Fontaine et al., 2007; Prince & Patel, 2001; Purandare, Luthra, Swarbrick & Burns, 2007; Turner, Christie & Haworth, 2005).

It seems that South Asians frequently viewed dementia as part of the '*natural process of decay and people becoming old*' (Turner, Christie & Haworth, 2005, p. 202), followed by the belief that it is caused by a decline in social support

and increased isolation and deterioration in physical health (La Fontaine et al., 2007; Prince & Patel, 2001; Purandare, Luthra, Swarbrick & Burns, 2007; Turner, Christie & Haworth, 2005). South Asians reported that all these causes contributed to presentations seen in a 'severe dementia' vignette (La Fontaine et al., 2007; Patel & Prince, 2001). When asked to discuss the causes of difficulties arising in a 'normal ageing' vignette a similar theme regarding lack of social support and family attention were found. When shown a 'severe dementia' vignette, participants in the La Fontaine et al. (2007) study were more likely to attribute difficulties to an emotional and social problem, whereas in Patel and Prince's (2001) study they spoke about it being a primarily physical problem.

Similar findings were reported by Turner, Christie and Haworth (2005) and Purandare, Luthra, Swarbrick and Burns (2007) as South Asians were significantly more likely to attribute dementia to the process of normal ageing whereas Caucasians were likely to assign it to the onset of a stroke. It is important to note that when South Asians spoke about physical health concerns they were more likely to mention diabetes (La Fontaine et al., 2007; Patel & Prince, 2001).

When South Asians spoke about reduced lack of support as a cause of dementia this was often associated with neglect and abuse by family members with children often described as not caring enough. Patel and Prince (2001, p. 34) described how conflicts arising from '*modern daughter-in-laws*' were viewed as playing a part in the decline of family support. It is important to mention that in South Asian culture a traditional custom is for the daughter-in-law to move into her husband's family home and care for his parents. La Fontaine et al. (2007) also noted a theme of blame, where participants attributed the symptoms of dementia as the individual's own doing.

Interestingly, South Asians in Turner, Christie and Haworth's (2004) study were noted as the only participants across all the studies in this review to mention a cause of dementia being '*God's will*' (p. 202). Additionally, La Fontaine et al. (2007) was the only study to attribute personality and older people's attitudes as a possible cause of dementia.

5.6 Community perceptions of dementia

Discussion regarding stigma and ignorance was common in how dementia may be perceived in the community. (Jolley et al., 2009; La Fontaine et al., 2007). Jolley et al. (2009) described how fear and shame associated with dementia might contribute to the problem being hidden by the family and why help may not be sought. Similarly La Fontaine et al. (2007, p. 609) reported that '*stigma and ignorance is so deeply rooted that mental health generally is rarely recognised let alone dealt with*'.

5.7 Treatments for dementia

South Asians were significantly less likely to know what treatments were available for dementia (Jolley et al., 2009; Turner, Christie & Haworth, 2005) and were more likely to believe that dementia was curable in comparison to Caucasians (Purandare, Luthra, Swarbrick & Burns, 2007). Turner, Christie and Haworth (2005) found that Caucasians were significantly more likely to be aware of and seek medication as a treatment for dementia than South Asians ($p < 0.05$). However, South Asian participants from two other studies (Patel & Prince, 2001; La Fontaine et al., 2007) believed that self help or assistance from family was more important, with medication being taken to address physical health problems alone. These findings indicate inconsistencies in the way in which South Asian participants perceive the treatment of dementia.

Turner, Christie and Haworth (2005) also found that South Asians were more likely than Caucasians to believe that only the family should provide care for the person with dementia due to cultural reasons and viewing it as family responsibility. Other studies (Jolley et al., 2009; La Fontaine et al., 2007; Patel & Prince, 2001) reported similar findings, highlighting the need for South Asian family members needing to be better informed about dementia.

5.8 Service provision

Two of the qualitative studies (Jolley et al., 2009; La Fontaine et al., 2007) in this review asked participants to share their views on how mental health services could be improved, enabling them to contact them for advice and support. Participants commonly addressed the desire for culturally appropriate services involving greater staff awareness of diversity across different cultures and religions. One participant stated that '*we are afraid to come to mental health services because no one will speak our language*' (La Fontaine et al., 2007, p. 610). In addition, South Asian participants wanted more education and information, with one participant commenting '*how do I approach mental health services if I need to?*' (La Fontaine et al., 2007, p. 610). Visits by the Parish Priest as well as clubs for older people were suggested as interventions, '*we don't have clubs for over-50s like white elderly people do...where I could meet people of my age and just talk*' (La Fontaine et al., 2007, p. 610).

5.9 Study Quality and Methodological issues

The studies presented here have been useful in investigating South Asian understanding and awareness of dementia. It has been possible to draw on complementary methods by including both qualitative and quantitative studies in this review. However, the quantitative study (Purandare, Luthra, Swarbrick &

Burns, 2007) did not contribute to the latter sections of the results looking at community perceptions of dementia and views of current service provision. As mentioned previously, the religious membership of the South Asian participants in these five studies was unknown. However, one study did report God as a factor when thinking about dementia (Taylor, Christie & Haworth, 2005). It would have been interesting to note whether this was due to differences in the religious affiliation of the sample however, this data was not available.

Although studies in this review investigated levels of awareness of dementia they failed to explore the underlying reasons for these beliefs and how culture and South Asian heritage may be influencing these perceptions. Three of the five studies (Jolley et al., 2009; La Fontaine et al., 2007; Patel & Prince, 2001) did mention stigma and shame briefly.

Given that family support, specifically support provided by ‘children’ was commonly reported as important in assisting someone with dementia, La Fontaine et al. (2007) were unable to recruit any 20 – 30 year olds in their study. Although Patel and Prince (2001) recruited both community members and older adults, responses from community members were not included as carers of those with dementia were present in the sample. La Fontaine et al. (2007) was the only research to attempt to recruit participants from across the lifespan, with the other three studies recruiting older adults alone (Patel & Prince, 2001; Purandare, Luthra, Swarbrick & Burns, 2007; Turner, Christie & Haworth, 2005) and one study (Jolley et al., 2009) did not disclose age. Differences in the causes of dementia as either emotional or social in participants aged between 16 – 61 (La Fontaine et al., 2007) or physical in participants aged between 50 – 81 (Patel & Prince, 2001) may

highlight the need for further exploration of how dementia is understood across the age span.

Comparisons between studies may not always be valid due to participants being recruited from different countries and different community groups etc. Differences in participant's views about treatment needs in response to 'severe/late stage dementia' vignettes were evident (La Fontaine et al., 2007; Patel & Prince, 2001). A reason for this may be due to the fact that Patel and Prince's (2001) study was conducted in Goa, India whereas La Fontaine et al. (2007) recruited from Birmingham, UK. Participants from India were more likely to attribute a dementia presentation to a tangible physical illness rather than emotional causes such as depression and anxiety. This may be due to the fact that the former is seen as more acceptable in non-western societies with a greater likelihood of stigma and shame being attached to the latter. This difference in findings may also be explained as an effect of acculturation (Berry, 1980). Acculturation is the extent to which an individual adopts the values, beliefs, culture and lifestyle of their host country. Racy (1970) reported that Arabians diagnosed with depression were more likely to report somatic symptoms, however as they became more 'westernised' their symptoms were more psychologically related.

In addition participant samples may have unknowingly excluded hard to reach individuals, as many of the studies recruited from community groups, day centres or GP practices (Jolley et al., 2009; La Fontaine et al., 2007; Patel & Prince, 2001; Purandare, Luthra, Swarbrick & Burns, 2007; Turner, Christie & Haworth, 2005). It is therefore likely that the South Asians included in these five studies, who are currently accessing services in the community, are more aware of dementia and

mental health issues than South Asians who do not access these services (Bowes & Dar, 2000).

The quantitative study (Purandare, Luthra, Swarbrick & Burns, 2007) administered a measure to their participants in order to assess their knowledge about dementia. However it should be noted that the questionnaire was available only in English, Gujarati or Urdu making them inaccessible to South Asians who were unable to read these specific languages. It is known that South Asian populations encompass a variety of groups including those who speak Punjabi, Hindi, Marathi, Sindi, Tamil and Nepali to name a few. In addition, refusal rates and demographics of those who did not wish to complete the questionnaires were not recorded.

Two out of the four qualitative studies (La Fontaine et al., 2007; Turner, Christie & Haworth, 2005) used quotations in their studies, which help justify their findings. The use of verbatim quotes in these studies has been seen to provide deeper understanding and provide participants a voice (Corden & Sainsbury, 2006).

6. Discussion

The aim of this review was to systematically evaluate the literature in the area of South Asians' understanding and awareness of dementia from the perspective of participants living in the community. The literature in the review revealed that there is a lack of knowledge around the nature, cause and treatment for dementia in the South Asian community (Jolley et al., 2009; La Fontaine et al., 2007; Prince & Patel, 2001) and that this minority group is less knowledgeable than Caucasians (Purandare, Luthra, Swarbrick & Burns, 2007; Turner, Christie & Haworth, 2005).

South Asian participants were more likely to report that dementia presentations were a consequence of normal ageing (Purandare, Luthra, Swarbrick

& Burns, 2007; Turner, Christie & Haworth, 2005) or that it was due to deterioration in physical (Patel & Prince, 2001) or emotional health (La Fontaine et al., 2007). It is worrying that many South Asians believe that dementia presentations are caused by a lack of family support, with conflict within families being seen as a contributor (La Fontaine et al., 2007; Patel & Prince, 2001; Turner, Christie & Haworth, 2005). Thinking in this way can lead to a culture of blame and judgmental attitudes towards those with dementia as well as family members caring for them. Interestingly, although family conflict, 'lack of love' and 'attention' was often identified as a cause of dementia, South Asians commonly reported that the most appropriate course of action in such a situation would be to rely on family members to look after you (Jolley et al., 2009; La Fontaine et al., 2007; Patel & Prince, 2001; Turner, Christie & Haworth, 2005). This may exacerbate family difficulties and reduce the likelihood of accessing suitable services for fear of blame from outsiders. In support of this, Adamson (2001) reported that South Asians are likely to assign causes of dementia to intra-familial problems.

Discrepancies in South Asian participants' views around treating dementia were also found, with some believing there to be a cure (Purandare, Luthra, Swarbrick & Burns, 2007) and others believing there isn't (La Fontaine et al., 2007; Patel & Prince, 2001). Differences, as found here, may be indicative of the fact that South Asians are not an homogenous population, highlighting the need for further research to investigate minority groups within the South Asian population.

When researchers did not mention the term 'dementia', participants themselves did not offer it up at any point in the study (La Fontaine et al., 2007; Patel & Prince, 2001). It is important to note however, that although dementia itself was not mentioned in these studies, people were able to recognise support was

required and at times offered further difficulties that someone with this presentation may be experiencing. This indicates that although South Asians may not have been able to explain dementia in a manner similar with the western medical understanding of it, they are able to recognise that the presentation is atypical. Furthermore, it may be that they recognise it as part of a 'syndrome' but they don't have a label for it.

The use of vignettes was seen to enable participants to speak freely about the presentation without feeling the need to discuss their own personal or familial issues (Jolley et al., 2009; La Fontaine et al., 2007; Prince & Patel, 2001). Hughes and Huby (2002) highlight the importance of matching the vignette's character to the participant group's cultural context enabling individuals to identify with them.

Many South Asians felt that the GP would be unhelpful in the event of a dementia diagnosis, however this may be associated more with their lack of knowledge regarding how dementia can be treated (Purandare, Luthra, Swarbrick & Burns, 2007; Taylor, Christie & Haworth, 2005) as well as their past experiences when contacting GPs. GPs were often viewed as people who could not or would not help (La Fontaine et al., 2007; Patel & Prince, 2001). It is also plausible to consider that if dementia is seen as a normal part of ageing, then medication may be considered less helpful if at all.

None of the articles viewed in this review were deemed to be 'fatally flawed' as all made useful contributions to the findings of the review (Miller, Bonas & Dixon-Woods, 2007) as is also noted in Appendix D. One of the aims of the review was to investigate the role of religion/spirituality as well as culture in the conceptualisations of dementia however the studies reviewed here did not take religious influences into account when interpreting the findings. It can be concluded

from the studies in this review that some of the meanings assigned to the term dementia are derived from cultural beliefs. However, the lack of discussion around religion/spirituality may have been due to the fact that participants did not feel able to convey their values and beliefs because of the dominant western biomedical view with regard to dementia (Ahmad, 1996; Lawrence et al., 2006). Religious as well as cultural factors are important to note when investigating a minority group's understanding and awareness of dementia. Often it is difficult to tease out whether beliefs and views are due to culture and/or religion and spirituality. However to the researcher's knowledge few studies have investigated the impact of identifiable constructs of religion/spirituality on dementia and how they may vary from the beliefs and values of the cultural community that the minority group identifies with (Burycka, 2001).

7. Limitations of this review

This review examined the most recent research into the understanding and awareness of dementia in South Asians. Nevertheless, limitations exist within all research including this review. One limitation is that one of the papers included in this review (Jolley et al., 2009) was part of a larger study and although only findings regarding community perceptions of dementia were reported here, this study also looked at the views of carers as well as those who have a diagnosis. Consequently, the methodology of this study and findings regarding community perceptions of dementia were not reported in sufficient detail and therefore this paper did not contribute as much as the other studies to this review. However it was still included due to the dearth of literature exploring South Asians living in the community and their views of dementia, as it was able to make a small contribution. Similarly Patel and Prince (2001), as well as recruiting older adults living in the community also

recruited key informants' and their views of dementia, which were not included in this review. This group of key informants consisted of members from the community including those who were carers for those with dementia hence their exclusion. In addition, the inclusion of papers from India may reduce the validity of comparisons across studies given that different countries may manage dementia presentations and dementia awareness differently.

8. Conclusion

This review indicates that limited literature investigating South Asians' understanding and awareness of dementia exists. The findings in this review highlight South Asians' lack of knowledge and awareness around the nature, causes and treatment of dementia in comparison to Caucasians. Differences in beliefs were found across studies regarding the cause (La Fontaine et al., 2007; Patel & Prince, 2001) and the treatability of dementia (La Fontaine et al., 2007; Patel & Prince, 2001; Purandare, Luthra, Swarbrick & Burns, 2007). Lack of family support and attention was frequently viewed as a cause of dementia, with studies concluding that cultural beliefs impact on South Asians' views of dementia. Differences in findings may be indicative of the heterogeneity in South Asian participant samples, which is why further research is needed to explore minority groups within South Asians. Research demonstrates that culture and religion relate to one another (Saroglou & Cohen, 2011) however, although culture was mentioned briefly none of the studies looked at the impact of religious beliefs. Cultural and religious beliefs and values are often reported synonymously in minority group research, therefore it is important to investigate whether the inclusion of a groups religious beliefs impact on their conceptualisations of dementia.

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Section C

Research Report

Sikhs and Dementia: cultural and religious constructions in this minority
population.

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by

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In partial fulfilment of the degree of

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1. Research Report Abstract

Introduction: Previous literature confirms that older black minority ethnic (BME) populations are less likely than white populations to contact dementia services in the UK (Dementia UK Report, 2007). However it is unknown whether this is due to a higher or lower prevalence of dementia (Odutoye & Shah, 1998) or due to different needs or coping strategies within these communities.

Aim: The aim of this study was to explore the understanding and perceptions of dementia amongst Sikhs living in the community.

Method: This qualitative study involved six focus groups, with 28 Sikh participants who were recruited from Gurdwara (Sikh places of worship). Data was analysed using constant comparative methodology.

Results: Four themes emerged from the analysis, including awareness and interpretation of the characteristics of dementia, multiple perspectives of the same symptoms, causes of dementia and coping.

Conclusions: The findings have been discussed in the context of existing research and provide an introductory insight into informing culturally appropriate interventions to raise awareness about dementia in the Sikh community. This research sheds light on an under researched minority group and provides valuable information to health professionals about culturally appropriate ways of working.

2. Introduction

2.1 National Context

In recent years, there has been emerging interest in the inclusion of the views of marginalised groups in research, policy and health service development. The White Paper ‘Caring for People’ (DoH, 1989) document recognised that individuals from different cultural backgrounds might have diverse health care requirements that service providers need to be aware of. More recently, the National Service Framework for Older People (DoH, 2001) reported that mental health services for older adults should be able to recognise and respond to individual social and cultural factors affecting treatment, recovery and support. As discussed in the review chapter, the number of individuals with dementia is set to rise in the UK (National End of Life Care Intelligence Network, 2010).

2.2 Ethnic Minorities & Dementia Services

The limited uptake of ethnic minority groups in dementia services is a long-standing issue. Research suggests that people from ethnic minorities who have dementia are less likely to receive a diagnosis and if they do, they are more likely to receive it at later stage than their Caucasian counterparts (Adelman, 2010; Bowes & Wilkinson, 2003). Furthermore, Badger, Cameron and Evers (1988) noted that when individuals from ethnic minority groups were diagnosed with dementia they were likely to under-utilise services in comparison with other groups. In an attempt to uncover possible reasons for the under-utilisation of services, a review of 67 studies was undertaken (Daker-White, Beattie, Gilliard & Means, 2002). This review concluded that language was the fundamental barrier to the uptake of services as well as the fact that many did not consider dementia to be a significant

enough concern when faced with other, more pressing matters such as poor living conditions, lack of employment and social isolation. However it is important to note that forty-four of the sixty-seven articles included in this review originated from the United States, with African Americans being the most frequently recruited ethnic population.

2.3 Diversity within Ethnic Minorities

Vertovec (2007) suggested the need for dementia services to account for the ‘super diversity’ of ethnic minority populations. ‘Super diversity’ refers to the rising diversity in aspects such as country of origin, socioeconomic status as well as religious and cultural traditions within a group. Due to differences in individual, cultural and religious frames, people can simultaneously be group members whilst holding some beliefs that are not shared by other members of the group (Goodenough, 1981). This assumption of homogeneity within ethnic minorities, with insufficient consideration given to the possibility of intragroup diversity has been discussed in the review chapter. Variations in the history, culture and religion of groups can impact greatly on defining individual norms, values and experiences. This demonstrates the continued need to identify and understand conceptions of mental illness in different ethnic and religious communities in order to promote a better understanding of help-seeking behaviour.

2.4 Religion and Dementia

Religion has often been used as a source of comfort and security (Mackinlay, 2001) and may provide a framework to aid the reappraisal of a difficult situation. Katsuno (2003) noted that participants with early stage dementia believed practices such as prayer, enhanced their quality of life and ability to cope. On a similar note, Stuckey and Gwyther (2003) found that religion enabled participants

to search for meaning in the face of dementia. However, whilst the multi-dimensionality of religious coping has been recognised, few studies have investigated whether particular religious groups hold religious based beliefs about the causes and treatments of illness and how these beliefs sit with the western model of illness (Cinnirella & Loewenthal, 1999). Studies focussing on mental illness in general have made no reference to Sikhs, providing greater understanding in the context of other religions such as Islam, Judaism and Christianity (El Azayem & Hedayat – Diba, 1994; Littlewood & Dein, 1995).

2.5 Sikhs

Sikhs form part of the global classification of ‘South Asians’ as many originate from Punjab, India. Approximately 0.6% of the UK population is Sikh, making it the fourth largest religion in the UK (Census, 2001). Sikhism is a monotheistic religion and was founded in 1469 by the first Guru (teacher/enlightener), Guru Nanak Dev Ji with Sri Guru Granth Sahib Ji (SGGSJ) as the current living Guru. Guru Nanak Dev Ji was the first to break the dichotomy between the spiritual life and the empirical life of man and proclaim a religion of life-affirmation; with emphasis on leading a spiritual existence and that of a householder.

Sikhs (student/disciple) are unique in several ways; their view of the temporal world acknowledges that attachment (physical and emotional) in this world is false, and one should recognise that these things are inconsequential in death, as the relationship with God is the most important. Within Sikhism there exists Amritdhari² (baptised) and Sehajdhari (non-baptised) Sikhs. Guru Gobind Singh Ji (10th Guru of the Sikhs) introduced the ‘Amrit initiation ceremony’ in

¹A glossary is available in Appendix Q and provides information on terms that readers may not be familiar with.

1699, where those who received Amrit (nectar) then became Amritdhari (meaning one who has received the baptismal vows and abides by these vows).

Sikhs are encouraged to employ Naam Simran (loving remembrance of God through meditation) which is a form of meditation, and read the Holy Scriptures (SGGSJ). These aim to promote peace of mind and achieve a super-conscious state where one finds themselves close to, or one with God. Interestingly, studies have found that practices such as meditation have been found to elicit better health and more rapid recovery (Schneider et al., 2002; Wallis, 1996).

Another tenet of Sikhism that makes it distinctive is the focus on seva (selfless service), where one expects no rewards and has no attachment with the duty that is being undertaken. Guru Arjan Dev Ji (5th Guru) reported, *“One who performs selfless service without thought of reward shall attain his true Lord and Master”* (SGGSJ, Ang. 286). When an individual follows these tenets of faith, they develop a state of ‘Chardi Kala’ (to have a positive, buoyant and optimistic attitude to life and the future). Similarly death is considered part of God’s will and marks a day of union with God; *“Win the game of life, let your mind surrender and accept death”* (Guru Nanak Dev Ji in SGGSJ, Ang. 153) and *“First accept death and give up any hope of life. Become the dust of the feet of all and then you may come to me”* (Guru Arjan Dev Ji in SGGSJ, Ang. 1102). Given that these beliefs and practices are specific to the Sikh religion, it is important to investigate whether they influence individual’s mental health beliefs and perceptions, specifically around dementia.

2.6 Why Sikhs?

Although minority populations may face greater disparities when accessing these services it is unknown whether this is due to a higher or lower prevalence of dementia (Oduoye & Shah, 1998) or whether differences exist in the perceptions of

the symptoms, coping strategies or a general reticence to use health and social care services within this community. The first Sikh migration occurred in the 1950s, which would mean that these individuals are likely to be reaching their seventies or eighties. Consequently insights into the beliefs about dementia as held by members of the Sikh community can be useful in the formulation of more sensitive health service provision. Jolley et al. (2009) found that cultural stereotyping occurred regularly when individuals came in contact with services as many health professionals failed to identify their unique needs. Very few studies have recruited Sikh participants and it is likely that the experiences of Sikhs who have been recruited represent the exception rather than the norm (Bhopal et al., 2009; Bowes & Wilkinson, 2003). To the researcher's knowledge, no studies have been published that have exclusively explored the Sikh understanding of dementia. Furthermore, the researcher in the proposed study is a member of the Sikh community and has the language skills to facilitate data collection from this group.

3. Aims of this research

The aim of the proposed research was to investigate understanding and awareness of dementia in the Sikh Community, and how this their religious and cultural background facilitates this understanding. It is noted that other religions, as well as other types of spiritual beliefs or spirituality may also be implicated in how people understand illness and how they cope with it. However, this thesis has focussed on issues around religious belief and Sikhism in particular.

Sikhs are an important focus as a poorly researched but significant minority group who are underrepresented in services. Findings may highlight factors that could account for the lack of Sikh presence in dementia services and may help inform NHS practice and policy.

4. Methodology

4.1 Design

This was a qualitative study using a focus group methodology. Focus groups are widely used in health research and increase understanding in a defined area of interest whilst offering an open forum for natural discussion (Krueger & Casey, 2000). Focus groups do not discriminate against people who are unable to read or write and have been identified as an approach that empowers minority groups (Kitzinger, 1995). This method of recruiting can also help researchers identify cultural knowledge that is shared among group members as well as appreciating differences in experiences (Morgan & Krueger, 1993). In research involving ethnic minorities in particular, focus groups are useful as they provide researchers with direct access to the language and concepts participants use to structure their experiences; the way they think and talk about certain topics (Flick, 2002).

4.2 Inclusion and Exclusion Criteria

All participants were over the age of eighteen, were able to understand and converse in either Punjabi or English. They had sufficient cognitive capacity to give informed consent to participate in the research process. This capacity was demonstrated by questions that were asked about the research, individual's ability to understand the research aims and acknowledge what participants in this study were required to do. Participants identified themselves as a Sikh who lived in the community. The cities of Derby and Leicester were chosen for recruitment due to their large 'Indian Asian' populations, with Sikhs being the second largest religion in Derby and the fourth largest in Leicester (Census, 2001).

4.3 Participants

A purposive sampling strategy was identified as the most effective way of recruiting participants. Participants were placed in groups according to their age

using a life-stage approach i.e. young adult, family and retired, however difficulties arose around recruiting individuals who fit the 'retired' category therefore the categories were assigned in parallel to the response options on the age question of the demographic questionnaire; 25 or under, 26 – 40, 41 – 55 and 56 or older. Krueger (1994) stated that in order to obtain rich data, individuals in a group need to be prepared to engage fully in the discussion hence advocated the use of homogenous age groups. Recruiting individuals from across the life span is likely to represent the views of those who may be supporting family members with dementia in the community, as Asians are likely to have higher rates of informal care than Black Caribbean and Caucasian groups (Hutton & Hirst, 2000).

Participants were recruited via Sikh Gurdwara (Sikh places of worship) in the East Midlands. They were able to speak English and/or Punjabi and were born in the UK, India or Canada. Although 68 individuals consented to participate during recruitment many failed to attend on the day the focus groups were being held, resulting in a final sample of 28 participants. Full demographic information of those who participated as well as those who consented but did not participate is available in Appendix E. Of those that did not participate, 12 (30%) were aged 25 or under, 12 (30%) were between the ages of 26 – 40, 12 (30%) were 41 – 55 years old and 4 (10%) were aged 56 and over. Non-participants consisted of 27 (67%) males and 13 (33%) females. Of those who did participate in this study, 14 (50%) were female and 14 (50%) were male, with the majority aged 18 – 25 ($N = 14$, 50%), then 26 – 40 years old ($N = 10$, 36%) and 41 – 55 years old ($N = 4$, 14%). Fifteen (54%) were Amritdharis (baptised Sikhs) and 13 (46%) were Sehajdharis (non-baptised Sikhs). There were 6 focus groups in total (Table 1)

Table 1. Characteristics of the 6 focus groups.

Focus Group Location	Men (n)	Women (n)	Age	Amritdhari (baptised) or Sehajdhari (non-baptised) Sikh?	Primary Language
1. Leicester	1	3	18 - 25	3 Amritdhari 1 Sehajdhari	English (4)
2. Derby	5	1	18 - 25	3 Amritdhari 3 Sehajdhari	English (5) English & Punjabi (1)
3. Derby	2	2	18 - 25	4 Sehajdhari	English (4)
4. Leicester	2	2	26 - 40	3 Amritdhari 1 Sehajdhari	English & Punjabi (3) Punjabi (2)
5. Derby	4	2	26 - 40	6 Amritdhari	English & Punjabi (4) English (2)
6. Derby	0	4	41 - 55	4 Sehajdhari	Punjabi (3) English (1)

4.4 Position of the Researcher

It is important to note the researcher's position in this study in order to aid transparency and to acknowledge her frame of reference (Appendix F). All research is potentially influenced by the researcher's decision about what to investigate, which aspects of the data to concentrate on and how to report this (Stiles, 1993). However an advantage of qualitative analysis is that it recognises this and advocates the use of reflections to evaluate the impact that these may have on the research process. Further details of which are discussed below and in the subsequent chapter.

4.5 Procedure

Key people such as the presidents of the Sikh Gurdwara (Sikh places of worship) and other prominent Sikh members of the community were approached in order to facilitate access to participants. They were initially sent the study information sheet outlining the purpose and nature of the research (Appendix G), then face-to-face meetings were arranged to further discuss the research and strategies for recruitment. Recruiting from minority ethnic religious groups can be challenging which is why multiple recruitment strategies were used (Mohammed, Jones & Evans, 2008). In addition to contacting specific members of the community, posters (Appendix H) were placed on the notice boards in all Gurdwara (Sikh places of worship) in Leicester and Derby in order to generate interest in the study. Information sheets were placed near the posters displaying the researchers contact details so that interested individuals could call or email the researcher if they wished to participate in the study and/or to discuss any questions and queries they might have had. The researcher also held a stall on a Sunday (busiest day at the Gurdwara) throughout February and March and visited several youth groups and a Vaisakhi (Sikh New Year) event to enhance recruitment. All study literature was available in either English or Punjabi.

Individuals who were interested in taking part were given a consent form to sign (Appendix I) after which they were asked to complete a demographic questionnaire (Appendix J) that included information such as age, gender, language, education, marital status, ethnicity and living arrangement. Following this, the researcher contacted individuals by phone or email with a time and date for when the focus group was scheduled to occur. A week before the group was due to meet, a reminder text message was sent out to all individuals who had agreed to

participate. Six focus groups took place on either a Friday (youth group) or a Sunday in a quiet room in the Gurdwara (Sikh place of worship) and lasted between thirty-seven minutes and an hour and four minutes. Groups consisted of between 4 and 6 participants ensuring that the group was large enough to gain a variety of perspectives and small enough not to become disorderly or fragmented. Given that the researcher was the only facilitator during these discussions it was felt that this number of participants was suitable.

Introductions regarding the aims of the research were made prior to the start of each focus group (Appendix K); this was undertaken in English for five of the groups, with one (41 – 55 year olds) being spoken in Punjabi. During this time, participants were asked whether their discussions could be audio recorded and were reminded that their identities would remain anonymous in the research write up. Participants were also asked to adhere to rules of confidentiality around any issues discussed within the group. As many of the participants were able to converse in both English and Punjabi, all of the focus groups naturally included some discussion in both languages, allowing for a more inclusive dialogue.

The groups were then given a hypothetical dementia vignette in either English or Punjabi (Appendix L). Vignettes are commonly used in research to elicit perceptions, opinions, beliefs and attitudes to a particular scenario (Hughes, 1998). The vignette used in the current study was adapted from one that was devised in a previous study (La Fontaine, Ahuja, Bradbury, Philips & Oyebode, 2007). The vignette aimed to illustrate the levels of understanding of dementia in the Sikh community and to reflect on the issues that arose from this. A focus group guide (Appendix M) was used to ensure that similar vignette based discussions occurred throughout all groups. After each group ended leaflets were distributed from the

Alzheimer's Society, Department of Health as well as information regarding the role of Clinical Psychology in dementia care.

4.6 Data Management

All focus group discussions were digitally recorded and transcribed by the researcher in order to facilitate immersion in the data. All recordings and transcripts were stored securely. Care was taken to ensure anonymity and to remove any potentially identifying information from the transcripts. When discussions occurred in Punjabi, these were transcribed verbatim followed by the English translation of what had been said.

4.7 Data Analysis

The current research involved an inductive rather than deductive approach in data analysis, specifically with the use of the grounded theory method of constant comparative methodology (Glaser, 1978). Constant comparative analysis is inductive as it promotes an understanding of individuals' experiences directly from the data (Charmaz, 2006). Although this study is not presenting a grounded theory, the methods used in conventional grounded theory are commonly used as pragmatic 'tools' in exploratory qualitative research studies seeking to investigate and describe social situations and phenomena (Galdas & Kang, 2010). The use of this methodology enabled a flexible and transparent approach when exploring the influence of culture and religion on the construction of dementia in members of the Sikh community.

Data collection occurred alongside data analysis so that previous focus group discussions were able to inform subsequent ones (Glaser, 1978). Statements about Sikh's perceptions of dementia were identified using line-by-line coding

(example available in Appendix N; Charmaz, 2006), which were then extracted from the transcripts. Following this, the statements were compared to each other for similarities and differences, with similar extracts being grouped together to form themes. The analysis of the data was cyclical, consisting of reading, re-reading, coding, reflecting and then sorting through the codes and assigning them to a relevant theme. This method ensured that coding was consistent whilst enabling the researcher to be mindful about why particular responses belonged to one theme over another. This process of data analysis also involved purposeful sampling of deviant cases, evident in the contradictory experiences arising alongside emerging themes (Strauss & Corbin, 1998). To illustrate, a theme emerged regarding the benefits of religious coping with deviant cases (those who questioned the use of religion in coping) being recruited to provide greater insight into potential differences within the Sikh community and their coping strategies in relation to dementia.

4.8 Quality Checks

As this is a qualitative study it is important to consider factors that relate to the credibility of the results. Interpretations of arising themes were discussed with the researcher's supervisors. Theoretical memos (example available in Appendix O) were used alongside data analysis to ensure that the evolving nature of themes and their definitions as well as the researcher's own thoughts and interpretations of these were being recorded. This has resulted in a clear documentation of decisions made about coding and categorisation of emerging themes. Reflexivity was implicit throughout this process, evident in discussions during supervision but also in keeping a reflexive diary (example available in Appendix P). Reflexivity enables a researcher to become aware of what allows them to make sense of data in the study as well as what hinders them (Russell & Kelly, 2002). This has resulted in a

heightened awareness of personal values and preconceptions that the researcher may have held regarding the data (Barbour, 2001). Regarding trustworthiness of the findings, quotes and verbatim extracts from the transcripts are included in the results to illustrate the themes that emerged. This enhances the transparency of the research, enabling the reader to evaluate whether the researcher's interpretations were 'reasonable' (Meyrick, 2006, p. 805). Peer review was also utilised as both supervisors simultaneously audited one of the transcripts. An agreement of the themes occurred between the researcher and supervisors, demonstrating triangulation of the data.

As the focus group discussions occurred in English, Punjabi or both, the researcher (who is able to read, write and speak Punjabi) was responsible for the translation and transliteration of the Punjabi text in the transcripts into English. Although there is a lack of agreement in how one should translate and transliterate, Brislin's (1970) model of translation suggests that at least two bilingual individuals should be recruited to translate transcripts, however researchers have acknowledged that this is not always possible (Ercikan, 1998). Prior to beginning of this research a quote was obtained from a professional translation service, however as it was higher than the total research budget it was not purchased. To ensure the validity of the translations, the researcher compiled a glossary of the Punjabi words (Appendix Q) found in the transcripts, verified them against definitions available at a website known as the 'Sikh encyclopaedia' (www.sikhiwiki.org) and then sent them to several Sikhs, not linked with this study to further authenticate the translations.

4.9 Ethical Approval

This research was approved by the School of Psychology Ethics Committee (Appendix R). Some ethical issues were noted to require consideration, including

the sensitive nature of the discussions in the focus group. It was important to consider the possibility of group members recognising the symptoms exhibited in the vignette, with the discussion raising concerns about themselves or relatives. It was decided that if this were to occur, participants would be signposted to discuss this further with their General Practitioner (GP).

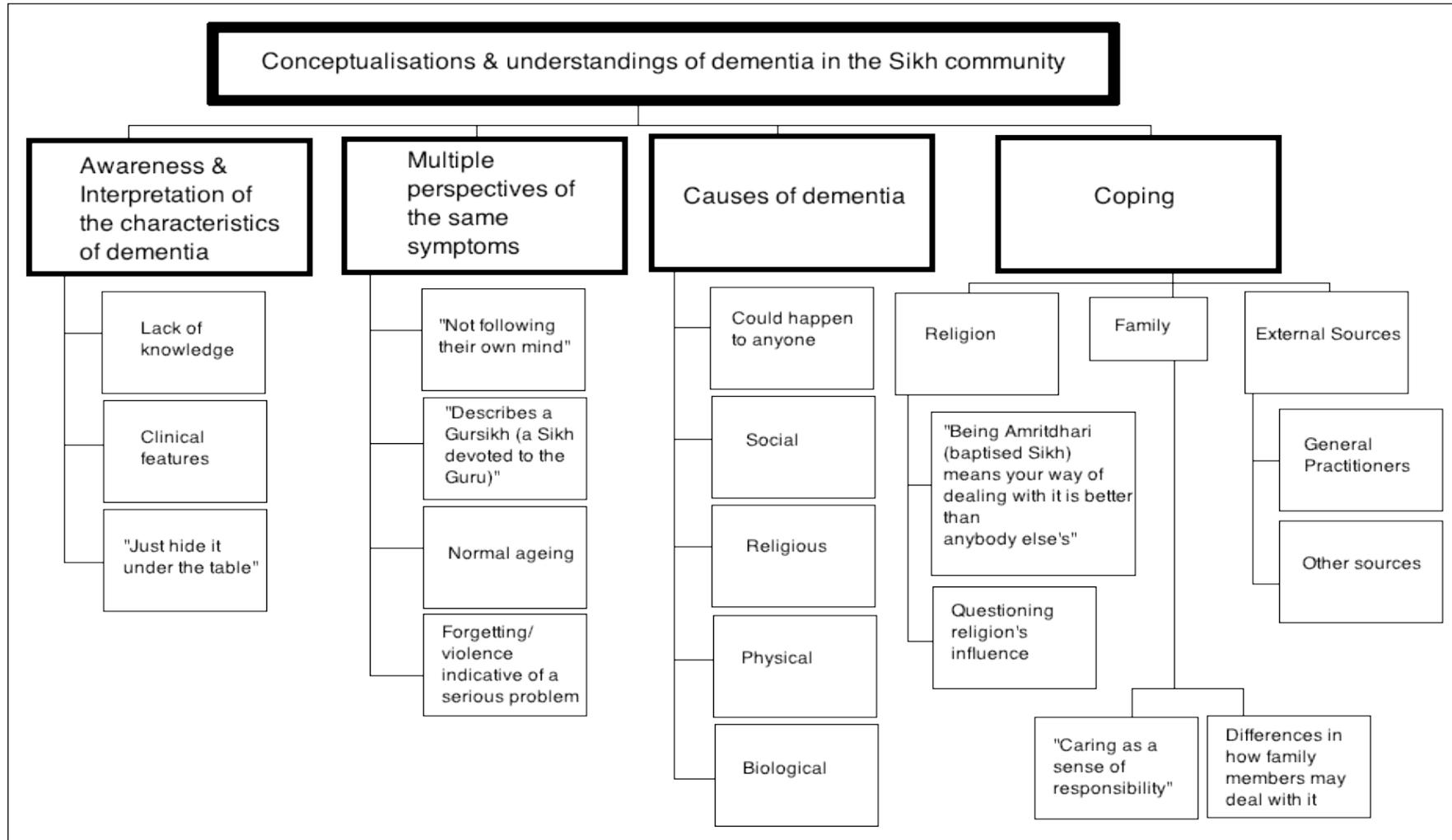
Due to the Sikh community being small and close knit, it was important to consider issues such as confidentiality and anonymity. It may be difficult to avoid using participants who know each other, however during initial contact with potential participants they were asked whether this would be an issue for them.

5. Results

The themes that emerged in this research were grounded in the participant's words as is central to the method of constant comparison. Four main themes: 'Awareness and Interpretation of the Characteristics of Dementia', 'Multiple Perspectives of the Same Symptoms', 'Causes of Dementia' and 'Coping' emerged from the data. Figure 1 below illustrates the main themes and their related sub themes, each of which is explored in greater detail below.

To ensure confidentiality, all quotations have been anonymised and personal and identifying information has been removed or altered. The letter following the participant number in that group denotes the participant's geographical area (i.e. L for Leicester and D for Derby). It is important to note that the terms 'Sehajdhari' and 'non-Amritdhari' both mean 'non-baptised Sikh'. The original responses in transliterated Punjabi and their English translations are included in the quotations below. A glossary of Punjabi terms is available in Appendix Q.

Figure 1. The themes that emerged from the focus group discussions



5.1 Awareness and Interpretation of the Characteristics of Dementia

Participants pre-existing knowledge and awareness of dementia varied as some admitted to knowing very little whilst others were able to identify a few clinical features of dementia. An additional dialogue within this theme focused on the community's perceptions of dementia and how this might impact on the identification and interpretation of the symptoms.

5.1.1 Lack of Knowledge in the Sikh Community

Participants in this study, as representatives of the Sikh community had very little awareness of dementia, having seldom, if ever encountered it previously.

“I've never really come across dementia, never really thought about it. I don't really know much about it” (3D, 18 – 25 year old Amritdhari; L672 – L673).

They queried whether dementia was a psychological or mental illness, not perceiving it as a holistic, all encompassing illness.

“It's not emotional though is it, dementia its not erm a psychological problem” (5D, 26 – 40 year old Amritdhari; L159 – L160).

Those that viewed dementia as a mental illness reported that community knowledge about physical illness superseded mental ill health.

“I don’t think it’s well explained in the Asian community as to what dementia is. Everyone knows what diabetes and heart er heart attacks and strokes are” (1L, 18 – 25 year old Amritdhari; L350 – L351).

A further comment suggested that physical illness was more acceptable than mental illness, due to the possible negative associations with the latter.

“Sometimes you can get a stigma attached to being not quite right mentally because physically, people will accept if something is wrong” (2D, 41 – 55 year old Sehajdhari; L313 – L314).

Focus on physical health was prominent in one participant’s response, believing that as the woman in the dementia vignette was physically fit, other symptoms that she exhibited (confusion, forgetting, mumbling) were likely to be temporary.

“If she’s eating and she’s physically healthy then it’s probably just a mental thing for her. It could just be a phase that she’s going through right now” (4D, 18 – 25 year old Amritdhari; L640 – L642).

For many, dementia was seen to be associated with memory loss alone demonstrating an unclear understanding of dementia.

“I always thought dementia was to do with memory, I didn’t know that someone would be withdrawn, careless about their appearance or other things

like that. I didn't think it affected other areas" (1D, 18 – 25 year old Sehajdhari; L354 – L357).

5.1.2 Clinical features of Dementia

A variety of symptoms associated with dementia were identified, with memory difficulties being the most commonly reported. Other symptoms included lack of clarity, behavioural and personality changes. Memory loss was reported to lead to further problems such as an increase in the individual's vulnerability to dangerous situations, exacerbating feelings of anxiety.

"With her short-term memory loss, sort of it can be quite dangerous for herself and maybe for others as well. Like she's put the hob on and just left it or something. That can be quite dangerous" (2D, 18 – 25 year old Sehajdhari; L26 – L28).

"Je ohnu nu memory di problem hai fir anxiety ohne nu vi ho sakhdi ya because je ohna nu chetha nai ounda fir una nu mushkal ladga ya fir hor vi problems ho sakhdi ya, depression, anxiety. [If they have problems with their memory then they will probably also have anxiety because if they don't remember then everything becomes harder for them and then they are more likely to have more problems like depression, anxiety]" (1D, 41 - 55 year old Sehajdhari; L242 – L247).

5.1.3 *‘Not talking about certain things just hide it under the table’*

A consensus throughout the focus groups was that the Sikh community and Asian communities were unlikely to speak up if family members exhibited dementia symptoms or if they experienced these problems themselves.

“It’s very quiet though, it’s all behind closed doors, shoved under the carpet kind of thing, you don’t really know too much about it” (4D, 26 – 40 year old Amritdhari; L55 – L57).

The negative perceptions of a dementia diagnosis made it more likely for it to be concealed from their community. This seemed to be indicative of historically established ways of managing.

“No one really sits there and talks about dementia and their problems and issues. They’re not as open, they feel like it’s a flaw if someone has this kind of problem, they hide it more instead” (1D, 18 – 25 year old Sehajdhari; L387 – L389).

“I think if you go back to our history its more traditional, we have our traditional ways of dealing with it which is more to like shun it hunna [slang term for yes]” (Participant 2D, 26 – 40 year old; L635- L639).

Symptoms may even be concealed from family members for fear of the repercussions.

“For an elder person they think jey may dusia fir that shahid mainu kadh joun gay ki patha fir [If I tell them they may kick me out, then what]” (6D, 26 – 40 year old Amritdhari; L640 – L643).

Others believed that the community might reproach the family for causing the dementia.

“Yeah I think that’s the first thing, like oh what have they done to her. That sort of thing, like they must have been neglecting her for her to sort of breakdown” (2D, 18 – 25 year old Sehajdhari; L407 – L409).

5.2 Multiple Perspectives of the Same Symptoms

This second theme emerged as participants made sense of the dementia vignette. The four sub-themes depicting different possible explanations for the presentation included, “not following their own mind”, “describes a Gursikh (a Sikh devoted to the Guru)”, “normal ageing”, “forgetting/violence as indicative of a serious problem”.

5.2.1 “Not following their own mind”

The older focus group (41 – 55 year olds) believed that the character in the vignette (with the dementia symptoms) had experienced years of unexpressed unhappiness due to wanting a different lifestyle and felt that this explained her withdrawn and careless presentation.

“Ho sakhda oh vi jidha uhna wargun rehna chounde par oh reh nai sakhdi. Kosh ohdia problems hon uhna karke, ihda ya. [It may be that she wants to live like they (the son and daughter-in-law in the vignette) do but she can’t live like them because she might have her problems]” (3D, 41 – 55 year old Sehajdhari; L78 – L83).

They believed that the woman in the vignette did not follow her own mind in becoming Amritdhari (baptised Sikh) and was now having second thoughts about the life she wanted to live. However living the preferred life was likely to result in negative feedback from within herself and from her community.

“Par badh’cho feel kar deya...oh kosh nahi oh daye ch par kuch kar nahi sakh dey. Fir oh sochde ya je use morke pehle vare lavaar ch jayea, chad raye kosh sanu pap lugu ga ja lokhe sade bare kosh sochu gaye. [Sometimes its because a lot of people don’t follow their own mind but do it because of other people but afterwards they feel it and they are not happy with it but they can’t do anything about it. Then they think that if they wear things they used to wear, they think they will have sinned or other people will talk about them]” (3D, 41 – 55 year old Sehjadhari; L90 – L97).

5.2.2 “*Describes a Gursikh (A Sikh devoted to the Guru)*”

A common interpretation of the dementia symptoms in the vignette was indicative of an increase in piety. Many participants believed that the symptoms signified a higher state of being with the focus on being closer to God.

“What you’ve described in there of not caring about your appearance too much, erm being forgetful, a lot of the people whose kind of focus is changing more from maya [material wealth/money] to internal have been increasing their Nitnem [daily morning prayers] and everything. They won’t care about their appearance we’ve got enough proof of that in history erm and they do start to forget...quite a bit, they start to get free mind.... They see it as pointless as they seek a higher meaning in life, because of that they just get so free minded their energy focus is somewhere else” (1L, 26 – 40 year old Amritdhari; L357 – L370).

Other behavioural descriptions in the vignette were also explained in terms of an increase in religious devotion.

“The fact that she wakes up at odd hours sometimes, that could be maybe for getting up to do Simran [meditation/constant remembrance of God]” (6D, 26 – 40 year old Amritdhari; L170 – L172).

However some participants argued that this presentation was inconsistent with someone who was becoming closer to God.

“Its hard to see it. If you do Simran [constant remembrance of God] like kind of like Naam [the need to remember God by focusing the mind on His name] and er Gurbani [sections of the Holy Scriptures] kinda like makes your thinking clear” (2D, 26 – 40 year old Amritdhari; L178– L180).

5.2.3 Normal ageing

A number of participants described the presentation in the vignette as a normal consequence of ageing.

“I just thought it was the older you get. You know, obviously your body disintegrates and everything starts wearing off and your brain gets a bit slower” (1D, 18 – 25 year old Sehajdhari; L447 – L449).

Interestingly, talking about the past was seen as culturally normal for adults in the community.

“My grandma she’s very, she remembers a lot of er things from say years ago and stuff so quite similar but just simple things like you saying Sat Sri Akaal [Punjabi greeting meaning ‘God is true and timeless’] to her she’ll forget that you’ve said it. So for me it’s like a familiar thing in the older generation” (5D, 18 – 25 year old Sehajdhari, L52 – L55).

5.2.4 Forgetting/Violence as indicative of a serious problem

Whilst it was common to interpret many of the symptoms and behaviours in the vignette as part of normal ageing or indicative of increasing religiosity, when the presentation involved a failure to recall family members or violent behaviour it was then deemed a problem.

“You could say she’s getting older, that she’s becoming a bit careless and stuff, she’s withdrawn and inactive. Once she starts you know forgetting stuff

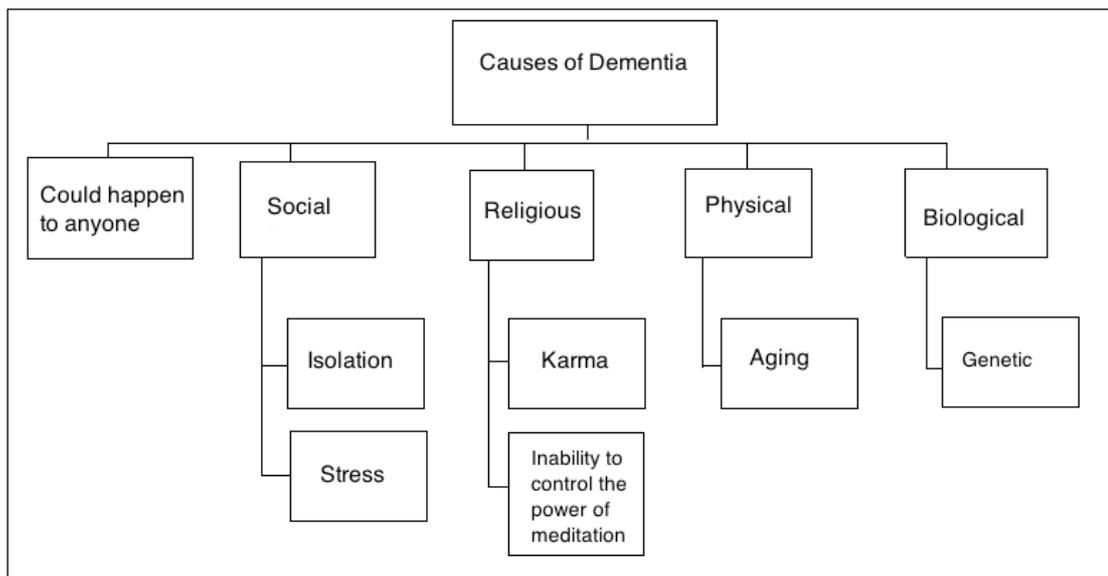
and not recognising family and stuff like that, then it's bad" (3D, 18 – 25 year old Sehajdhari; L658 – L662).

"Maybe if violence came into it or something I would start thinking something else" (2L, 18 – 25 year old Amritdhari; L179 – L180).

5.3 Causes of Dementia

Potential causes for the onset of dementia were grouped into five sub-themes as displayed in Figure 2 below.

Figure 2. Causes of dementia as identified by Sikh participants



5.3.1 "Could happen to anyone"

Some individuals were unable to identify a cause for dementia, believing that anyone could get it, irrespective of religiosity.

"The person who I saw who had dementia he was Amritdhari [baptised Sikh], he was doing his Paath [reading of religious text], he was doing Simran

[constant meditation/remembrance of God] all the time, it still happened to him. It could happen to anyone” (2D, 18 – 25 year old Sehajdhari; L354 - 357).

However, another participant disagreed with this as they felt it was unlikely that Amritdharis (baptised Sikhs) would get dementia.

“The ones with the higher level they probably wouldn’t be in there anyway” (2D, 26 – 40 year old Amritdhari; L502).

5.3.2 Social

Participants reported that dementia was potentially caused by isolation or stressful experiences.

“There’s something there that maybe she is probably feel rejected, no one is talking to her properly” (2D, 26 – 40 year old, Amritdhari; L122 – L123).

A reduction in the demand placed on individuals’ cognitions as a consequence of isolation was expressed as a potential cause of dementia.

“Someone whose a bit of a recluse like so maybe, I was thinking cos she’s (woman in the vignette with dementia symptoms) a housewife...Do you know what I mean, there’s not a great demand on her brain levels” (1L, 18-25 year old Amritdhari; L331 – L334).

One participant spoke about taking his grandfather to India and how a withdrawn and quiet man in England transformed into a sociable individual when in his hometown of India. It was suggested that the differences in lifestyles across countries impacted upon one's health and well-being.

“There’s definitely a change in his mentality, the way he deals with his surroundings just after his trip and I’ve seen that with my parents with a lot of people who have gone India, you know who aren’t feeling well and stuff” (1L, 26 – 40 year old Amritdhari; L211 – L213).

Stress in relation to difficult life experiences was believed to be a possible cause of dementia.

“When people go through a lot of hardships in their life and stuff and when they’re older they’re much more kind of degenerated” (2L, 18 – 25 year old Amritdhari; L307 – L309).

However one participant commented that some religious people don’t let stress exist in their lives. A perceived cause of stress was a wish to earn more money, have bigger houses etc.

“If you talk to Mahapurash [a well known religious person] from India...they go you never used to hear about stress related bimari [illness]... They were so free minded... It comes from all the additional maya [material wealth/money] that we want” (1L, 26 – 40 year old Amritdhari; L498 – 504).

5.3.3 Religious

Religious causes of dementia included the impact of ‘karam’ (act, action, deed, fate) on situations in life.

“She knows that it’s not just a chance thing it’s because she’s obviously done something to accumulate that sort of karam [act, action, deed, fate], that she deserves not deserves it in a mean way but like that she knows why she has it because of her karam [act, action, deed, fate]” (1L, 18 – 25 year old Amritdhari; L454 - L458).

Others believed that dementia symptoms might be a consequence of one’s inability to control the power of Paath (reading of religious text).

“Kai vele ih vi hunda ki thuse baala vi Paath karde ya [sometimes it happens if you read a lot of religious text] and don’t know how to sustain it fir kidha ohnu bahrthana ho janda ya [and then you don’t know how to use it]” (5D, 26 – 40 year old Amritdhari; L184 – L186).

5.3.4 Physical

The normal process of ageing was also considered a cause of dementia.

“When you get to a certain age your body function declines and obviously dementia is like a neurodegenerative disease. The neurons in your brain are being destroyed so when they are destroyed it’s difficult. So obviously its gonna impair your cognition of your brain, the way your brain works. So in

that sense it's mainly age related" (1D, 18 – 25 year old Sehajdhari; L271 – L274).

5.3.5 Biological - Genetic

The reason behind thinking that dementia could be genetically caused was described by one participant.

"I thought it was hereditary because when you go to the doctors and they ask you about questions, about have you got anyone in the family who has heart problems sort of dementia and others" (2D, 18 – 25 year old Sehajdhari; L424 – L426).

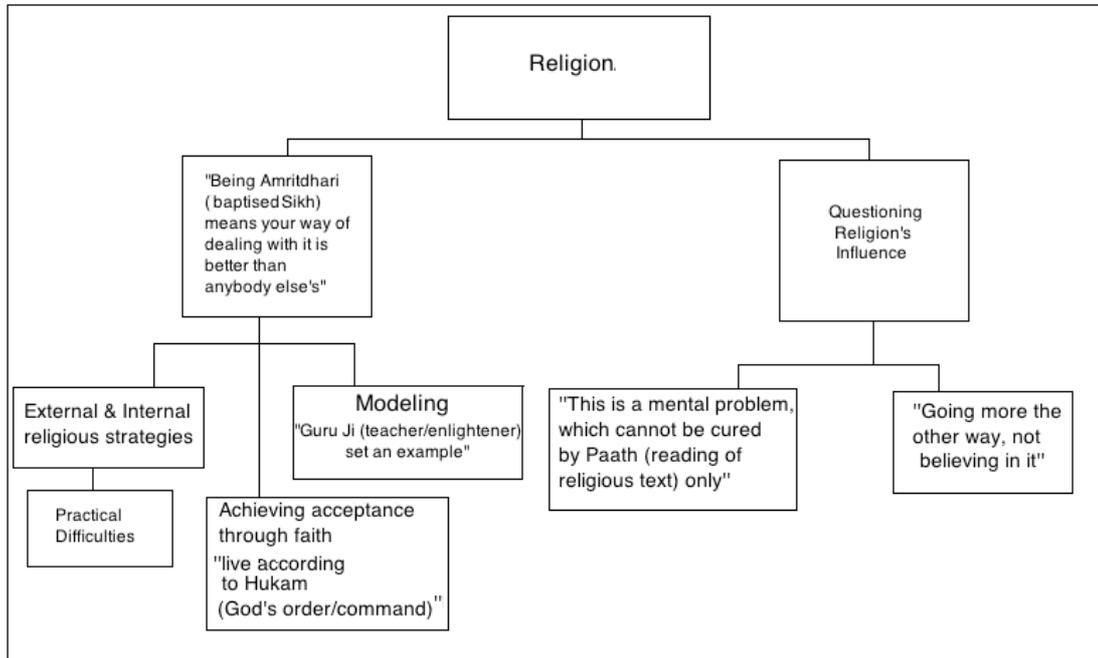
5.4 Coping

Much of the discourse surrounding the vignette focused on ways in which to manage with the dementia symptoms. There was strong theme of religious coping amongst most groups as well as recognising the importance of family in the coping process. Although religion was discussed to some extent in all of the groups, there were mixed views on how it could help. The influence of religion in the coping process was seen to be variable between family members and so was an important focus of the discussions given the collective method (i.e. involving the family) of decision making around care provision. Discussion around sources of support outside of the community and their role in the coping process was also covered.

5.4.1 Religion

Figure 3 shows the two categories arising within the sub-theme of 'religion', which are discussed below.

Figure 3. The categories within the sub-theme of ‘religion’ in coping.



5.4.1.1 *“Being Amritdhari (baptised Sikh) means your way of dealing with it is better than anybody else’s”*

The youngest age group (18 - 25 year olds) were often the most explicit in their assertion that being Amritdhari *“means your way of dealing with it is better than anybody else’s”* (3D, 18 – 25 year old Amritdhari; L442 - L443). Being Amritdhari (baptised Sikh) was viewed as a better, more virtuous lifestyle seen to promote positive consequences in all areas of an individual’s life in contrast to being Sehajdhari or non-Amritdhari (non-baptised Sikh).

“The level of what’s going to happen is the only thing you can control in terms of whether you decide to be, obviously to live a life of sin then the outcome is going to be worse than if you try and live a better life with Guru Ji

[teacher/enlightener] then the outcome is going to be slightly better” (1D, 18 - 25 year old Sehajdhari: L431 –L435).

The response above indicates that difficult life events are, in the main, out of one’s control, however choosing to be Amritdhari (baptised Sikh), which is within one’s power, can influence the outcome.

5.4.1.2 Achieving acceptance through faith; “live according to Hukam”

A number of participants reported that religion was able to help an individual understand and accept their difficulties, enabling them to “live according to Hukam (God’s order/command)”. Implicit trust in God’s actions made them more hopeful for a better outcome in the future.

“I think that’s what it comes back to, the fundamental thing about ja tha bhane’ch mahandi innit ke hukam’ch ya [if you live according to God’s order/command] you accept it. That this person was gonna be bimar [ill], when they get well they get well just straight like that when kirpa [grace, blessing from God] happens innit” (1L, 26 – 40 year old Amritdhari; L459 – L463).

Fundamental to accepting the situation was a ‘Chardi Kala’ attitude, with reduced focus on one’s difficulties.

“You don’t really make a big deal out of it. It’s kind of almost the Chardi Kala [to have a positive, buoyant and optimistic attitude to life and the future]

positive thinking thing that you don't think too much into it, you think it's all good" (2L, 18 – 25 year old Amritdhari; L515 – L517).

5.4.1.3 External and Internal Religious Coping Strategies

The use of external religious coping strategies such as speaking with religious people for advice to help cope with a dementia presentation arose from the Amritdhari (baptised Sikh) participants only.

"I think I can imagine her (woman in the vignette with the dementia symptoms) talking to her husband or maybe other Gursikhs [Sikhs devoted to the Guru] or her husband speaking to Mahapurakhs [well known religious people]" (1L, 18 – 25 year old Amritdhari; L108 – L110).

Only one Sehajdhari (non- baptised Sikh) participant added to this, offering a different conceptualisation of a religious coping strategy.

"Yoga is another form of meditation; sometimes people say it helps their eyesight and hearing. You never know it could help her memory as well" (1D, 18 – 25 year old Sehajdhari; L182 – L183).

There was a greater discourse on internal religious coping strategies such as Paath (reading of religious text) and individual meditation. These were reported to be protective, possibly reducing or even stabilising the dementia symptoms.

“There’s a thing in Bal Updesh [text aiding a person to learn Gurmukhi; the script used for writing the Punjabi language in the Sikh Holy Scriptures] erm...there’s erm like a whole paragraph where you have to say these words, really complicated words, well not complicated words but they’re like hard words to pronounce and you have to say it really really fast for thirty minutes every day in the morning and its meant to help your kind of memory” (2L, 18 – 25 year old Amritdhari; L591 – L596).

Others reported that it wasn’t the occupation of these internal strategies alone that would help but that a deeper, more meaningful connection to the strategy was required. When individuals failed to understand this, it was believed that their presentation could deteriorate.

“When people start doing Paath [reading of religious text] and then they start doing more Paath because they got more problems in their life but they’re actually not concentrating on Bani [short for Gurbani refers to various sections in the religious scriptures]... It’s actually making it worse, I think” (2D, 26 – 40 year old Amritdhari; L187 – L192).

5.4.1.4 Practical difficulties

Some participants spoke about potential complications in undertaking religious strategies whilst experiencing dementia symptoms, with memory difficulties having the greatest impact on one’s religious devotion.

“Like you can be married all your life and then get dementia and not even remember you’re married sort of thing...So even it could be the same way that she doesn’t remember that she took Amrit [ambrosial nectar given when you become baptised] that she even goes to the Gurdwara [Sikh place of worship]. It could be completely blanked for her” (2D, 18 - 25 year old Sehajdhari; L620 – L624).

Whilst many of these responses were from Sehajdhari (non-baptised Sikh) participants, only one Amritdhari (baptised Sikh) felt the same.

“She might forget that she like has faith in Maharaj [King, refers to God] or maybe that is she is like a really devout Sikh or whatever” (1L, 18 – 25 year old Amritdhari; L481 – L482).

5.4.1.5 Modelling “Guru Ji set an example”

Several participants described how all Sikhs have been gifted by the Gurus (teachers/enlighteners) with a resilient and distinctive set of characteristics that enable them to cope with difficult experiences such as the onset of dementia.

“The sets of values that Guru Ji [teacher/enlightener] has given us, if we followed those they’re designed in such a way, you know ten generations of Guru Ji you know developing this model effectively gives us a character set which is very, very strong. Being a Sikh, personally I’m a stronger person. I don’t know what percentage there are in the Sikh community {referring to

people with dementia}, maybe there's less because of this aspect" (1L, 26 – 40 year old Amritdhari; L915 - L929).

5.4.2 Questioning Religion's Influence

Responses from individuals who questioned the influence of religion included those who were doubtful that a mental problem could be cured by religion, with others believing that religiosity might decrease following the onset of dementia.

5.4.2.1 "This is a mental problem, which cannot be cured by Paath (reading of religious text) only"

There was a propensity amongst the older group of Sehajdharis (non-baptised Sikhs) to express their reservations when discussing how religion could help someone with a dementia presentation.

"Uhda apne community ch e belief ya bay thwanu Gurbani thwanu help kardi ya he na? Koi vi problem ya unhu overcome kar nu, paro ja sunaou, ja samjoua. Par menu ih nahi patha ja kidha dementia ch kis tara di help mil sakhdi ya religion de sabh na. [Well in our community there's a belief that Gurbani can help you, isn't it? It can help you overcome any problems, reading it, listening to it and understanding it. But I don't know what type of help religion can give for dementia]" (1D, 41 – 55 year old Sehajdhari; L341 – L347).

5.4.2.2 “Going more the other way, not believing in it”

Similarly the 18 – 25 year old Sehajdharis (non-baptised Sikhs) were the only group to report that religiosity might decrease following the onset of dementia symptoms.

“You might get a religious reaction, like some people they have like things happened and they tend to lose their religious beliefs” (4D, 18 – 25 year old Sehajdhari; L543 – L544).

Conversely one participant believed that religiosity would increase as a result of the dementia, but noted that this was more likely to occur in those who were already Amritdhari (baptised Sikhs).

“Personally Amritdharis (baptised Sikhs) that I know who have gone through something like big in their lives, their faith has just strengthened so much...but for the non-Amritdharis (non-baptised Sikhs) I don’t know it would affect them” (2D, 18 – 25 year old Sehajdhari; L647 – L651).

Interestingly, none of the participants from two of the 18 – 25 year old or 25 – 40 year old focus groups (who mainly consisted of Amritdharis; baptised Sikhs) contributed to these discussions.

5.4.3 Family

The importance of the family system in coping with a dementia presentation was universal throughout all the focus groups. Participants identified that caring for elderly relatives is a normal part of their culture, but that differences may exist in the way in which family members manage this presentation.

5.4.3.1 “Caring as a sense of responsibility”

Caring for elderly relatives was seen to be a part of the Punjabi culture and a normal responsibility for younger family members. Participants believed that just as the elders had cared for you as a child there would be a time when you would do the same for them.

“Obviously we owe them a lot and in that sense we should be able to look after them” (1D, 18 – 25 year old Sehajdhari; L581 – L582).

The responses from the oldest group of participants demonstrated that certain family members, specifically women were more likely to have this responsibility.

“Uhne nu ihde vi expect karaunge ke naih ghar ah ke fir je tho syana banda ya fir ohne di look after kar na. No hovai ja the hovai, ladies ko jadha expect kar de ya. (They expect you to come home and if there’s an elderly person then you should look after them aswell. If there is a daughter-in-law or a daughter, ladies are expected to do this)” (1D, 41 – 55 year old Sehajdhari; L537 – L544).

Sometimes this duty was seen to be too much for the women in the family yet because of the lack of knowledge of the support available it was felt that they would continue to struggle.

“Apne family chi h feeling ya je thwade family ch seva kare, syane vi ida soch diya. The apa vi ih try kardi ya, je jinni vi ho sakhda ke hunda. Par eh kise time ch too much hunda ye. Ine awareness ne heygaye kini help mil sakhdi ya, ja ki kar sakhde ya. [In our family you feel that you should do the selfless service of the elders. You try really hard to do as much as you can but sometimes it can get too much. There isn’t much awareness about how much help you can get or how you can get it]” (1D, 41 – 55 year old Sehajdhari; L488 – L496).

5.4.3.2 Differences in how family members deal with it

Participants displayed preconceived ideas about how Amritdhari (baptised Sikh) and Sehajdhari (non-baptised Sikh) family members in the vignette would manage with a relative who was presenting with dementia symptoms.

“It says here that they describe themselves as modern, the son and daughter-in-law. So they might consider going to the doctor, whereas the husband might consider going down more a religious route” (1D, 18 – 25 year old Sehajdhari; L169 – L171).

The vignette described the son and daughter-in-law as a ‘modern’ Sehajdhari (non-baptised Sikh) couple and some participants assumed from this that they would feel

less responsible for caring for their mother who was exhibiting the dementia symptoms.

“They’d look after the parents until a certain stage but they won’t be useful as in they wouldn’t see it as their responsibility to look after them” (3D, 18 – 25 year old Amritdhari; L622- L625).

The husband was seen as more likely to hold a positive attitude in caring for his wife, reinforced by principles of Sikhism.

“I think like the husband, he’s Amritdhari [baptised Sikh] right so he’d do Paath [reading of religious text] right and he’d do seva [selfless service] cos he understands that but I’m assuming here that the non-Amritdhari [non-baptised Sikh] modern son and daughter-in-law don’t understand the concept of seva [selfless service] and Paath [reading of religious text] and so their first reaction would be oh put mom in a care home” (3L, 18 – 25 year old Amritdhari; L153- L158).

Although it was felt that differences were likely to exist between family members, in the end the pathway to care was dependent on the majority opinion in the family.

“So even if Sarbjit (woman in the vignette with dementia symptoms) and her husband do have really really strong faith it doesn’t necessarily mean they will take that option because the family decides” (3L, 26 – 40 year old Amritdhari; L776 – L780).

5.4.4 External Sources

The final sub-theme encompassed responses regarding how external sources such as General Practitioners (GPs) and others outside the Sikh community would aid coping.

5.4.4.1 General Practitioners

Many commented on their perceptions of a GP's role and their beliefs on how a GP's perspective compared to a Sikh's perspective.

Some participants viewed contact with a GP as valuable.

“I think maybe first get a trained specialist in this area, from out of the family that knows how to deal with someone with these kinds of problems” (1D, 18 – 25 year old Sehajdhari; L274 – L275).

Communicating with GPs was primarily linked to obtaining a diagnosis and medication, which participants had varying opinions on.

“To get the official diagnosis I think it will bring a certain peace of mind that you know what's causing it” (1D, 18 – 25 year old Sehajdhari; L546 – L548).

However others felt that a diagnosis might further exacerbate depressive feelings.

“Labelling someone like you’re saying I’ve gone mental, so she’ll be even more depressed I would say” (1D, 26 – 40 year old, Amritdhari; L490 – L491).

Furthermore, going to the GP and receiving medication was seen as futile given that there is no cure for dementia.

“Knowing a bit about this, like dementia doesn’t have a cure. So if you’re stuck with dementia there’s only so much the GP can do anyway even if you do go there” (1L, 18 -25 year old Amritdhari; L90 – L92).

A recurrent theme throughout these discussions was that diagnosis and medication were the only things that were offered by GPs, as they had little time to offer other forms of support.

“Provided by the GP anyway and you’re just a card, just a record and they’ll just administer medication and that’s all” (4L, 26 – 40 year old Amritdhari; L603 – L604).

5.4.4.1.1 Different Perspectives

Disparities in how dementia would be understood by Sikhs and GPs (who were viewed as non-Sikh) were evident in the discussions.

“The doctor’s gonna look at it in a different perspective, obviously from a medical perspective. We’re gonna look at it as a Gursikh [a Sikh devoted to

the Guru] as a spiritual and mental kinda” (1D, 18 – 25 year old Sehajdhari; L479 – L481).

It was felt that the two perspectives would be difficult to align.

“They’ll have their own understanding of the problem, either that will be from their cultural background or their scientific upbringing... Whichever one combination that they bring that’s going to be hugely disjointed say from an Amritdhari [baptised Sikh]” (1L, 26 – 40 year old Amritdhari; L635- L639).

However, a need for GPs to understand Amritdharis (baptised Sikhs) better and to recognise possible ways in which their religion could help was expressed.

“Even if the woman (in the vignette with the dementia symptoms) goes to the GP and tells her, he might not be even that well supported by telling her okay where can this woman’s faith be used to support her” (4D, 26- 40 year old Amritdhari; L546 – L548).

5.4.4.2 Other Sources of Support

The older participants identified difficulties in asking for help from outside one’s family or community.

“I think thora jai easy hunda ya relax hunda ya, je dementia je the problem ya, fir ohde lai apne religion ch apne culture ch bande nal gal kar sakhda ya.

Ohdele vi easy ho janda ya. Ik da fir pehla ch mathlab different culture ja bunda pehla nu ih worry honea ki is banda mere bare ki soch day a ja mere family bare ki osch ou ga. [I think its becomes a little easier, and more relaxed if you have dementia then you can talk to the person who has the same religion and culture. Even for them it is easier. I think there is another worry about different cultures, what the person is thinking about me, what they are thinking about my family]” (1D, 41 – 55 year old Sehajdhari; L576 – L583).

Furthermore, being able to communicate in one’s own language was deemed important in accessing support.

“If there’s an organisation to help you know, home care with Asian workers then that’s much better, so they can speak to them better, in their own language. They feel reassured, its better for them coming in” (2D, 41 – 55 year old Sehajdhari; L547 – L549).

6. Discussion

This section will discuss the four themes that arose from the data, in the context of previous research.

6.1 Awareness and Interpretation of the Characteristics of Dementia

The first theme identified existing knowledge, or lack thereof about dementia amongst the Sikh participants in this study, with many claiming they had never come across dementia previously. This precipitated an observation that there is a greater emphasis on physical illness. Fascinatingly, there was a belief that the presentation in

the vignette was temporary as the woman (with the dementia symptoms) was in good physical health. When visiting the GP, South Asians are often more likely to incorporate physical symptoms into their presentation in comparison with Caucasians (Nazroo et al., 2002). This demonstrates that if there is a view that good physical health denotes overall well being, Sikhs are unlikely to visit the GP. Sheikh and Furnham (2000) reported that the conceptual model by which patients understand their distress is predictive of both symptom presentation and help seeking.

Lack of knowledge regarding dementia is likely to contribute to barriers in accessing health and social care services (Meltzer et al., 2000). One of the traditional ways of managing was described as 'hiding it under the table' due to potential ramifications from family members as well as the community (Jutla & Moreland, 2009). It was felt that the community might blame family members for causing the dementia. A study by Mesquita (2001) demonstrated that emotions in collective cultures are likely to be linked to how behaviours reflect on others, whereas in individualistic cultures emotions relate to reflections on the self. Concealing the dementia presentation often progressed to hiding the person with dementia (Mackenzie, 2006). Jolley et al. (2009) found that stigma and shame were prominently associated with mental illness in Sikh elders. Similarly, South Asian males felt their memory problems threatened their position in the community hence felt more inclined to hide it (Lawrence, Samsi, Banerjee, Morgan & Murray, 2011).

Although there was a general unawareness of dementia, some participants were able to identify a few clinical features, most commonly memory loss and increased exposure to vulnerable situations. Many were surprised to learn that social withdrawal and functional impairments in every day activities could be an outcome

of dementia (Jutla & Moreland, 2009). In addition, it was exceptional for participants to identify the emotional impact of dementia. Gotlib and Hammen (2010) argued that although South Asians were able to recognise both somatic and psychological symptoms of illness, they were more likely to report distress in somatic terms as this had greater legitimacy in their community.

6.2 Multiple perspectives of the same symptoms

Four sub-themes arose from this theme demonstrating the variety of interpretations made by Sikh participants about the dementia symptoms in the vignette. Arguably the most fascinating interpretation of the dementia symptoms in the vignette was that it “describes a Gursikh (Sikh devoted to the Guru)”. Participants noted that behaviours such as getting up early, mumbling and caring less about appearance could be indicators that the woman (in the vignette) was being drawn closer to God. Conceptualising the presentation in this way may aid coping and even diffuse stigma, with the consequences being very different if the presentation was seen as dementia (Hinton, Franz, Yeo & Levkoff, 2005). However, some Amritdharis (baptised Sikhs) argued against the presentation being interpreted as an increase in piety, as clearer thinking and a focus on the present would be more appropriate than the symptoms in the vignette. Equally, viewing the symptoms as evidence of the normal process of ageing may make it easier to manage (Lawrence, Samsi, Banerjee, Morgan & Murray, 2011) though undoubtedly hindering access to services.

Interestingly participants expressed the view that if an individual exhibited severe forgetting (i.e. inability to recall family members) or violence as well as other symptoms mentioned in the vignette, this signified a serious problem. Given that these symptoms are more likely to occur in the later stages of dementia, Sikhs are

unlikely to contact services until the illness has escalated. Bowes and Wilkinson (2003) noted that South Asians would only contact services following the onset of a crisis and not before, in order to preserve the dignity and respect of the individual with dementia as well as the family.

Community perceptions were considered to be important in the final interpretation of symptoms in the dementia vignette. The oldest Sehjadhari (non-baptised Sikh) group expressed a belief that symptoms experienced by the Amritdhari (baptised Sikh) woman in the vignette may be due to wanting to live a non-religious lifestyle however feeling powerless to change due to perceived disapproval from the community. Stigmatisation and self-blame were found to exacerbate feelings of powerlessness in South Asian women (Abraham, 2000). Alternatively, these findings may signify a conflict between baptised and non-baptised Sikhs, where superiority is assumed in being Sehjadhari (non-baptised Sikh) whilst Amritdharis (baptised Sikhs) are perceived as repressed and discontent. In other literature this has been recorded as ‘culture conflict’ mainly evident between Western and Eastern cultures (Burr, 2002).

The emergence of this theme in the data, demonstrates that differences exist in the interpretation of the dementia symptoms by baptised and non-baptised Sikhs.

6.3 Cause of dementia

Dementia was believed to have several potential causes, including ‘it could happen to anyone’, social, religious, physical and biological factors. Sehjadhari (non-baptised Sikh) participants were likely to assert that dementia could happen to anyone regardless of piety, however Amritdharis (baptised Sikhs) disagreed with this. Similarly Cinnirelli and Lowenthal (1999) reported that some religious groups

believed depression was impossible in the truly religious individual. Existing reviews have reported the existence of a health-related gradient, with better health associated with greater religious involvement (Jarvis & Norcutt, 1987). George, Ellison and Larsen (2002) added that religion promoted good health practices, greater levels of social support and facilitated meaning making, noting however that greater understanding of the potential mediators in the health-religion relationship is needed.

Social factors comprised of increased isolation and experience of stressful life events. Participants described that reduced social activity resulted in fewer cognitive demands and therefore an increased possibility for dementia. Although it is unknown whether early signs of dementia cause social isolation or whether reduced sociability cause a greater risk of mental decline, James, Wilson, Barnes and Bennett (2011) carried out a longitudinal study over 12 years and reported that the more socially active adults experienced less cognitive decline. Furthermore, the country of residence was suggested to influence well-being, specifically that India offered a more inclusive and stress-free environment than the UK and that many Sikhs would go to India if they were feeling unwell. Chiu, Morrow, Ganesan and Clark (2005) interviewed South Asian women who moved to Canada from their small Indian villages and reported similar experiences of reduced social support and how this impacted on illness. Braun, Takamura and Mougeout (1996) suggested symptoms of dementia were aggravated by migration and exposure to a different culture although this was after symptoms had already surfaced. However if this is a commonly held belief in the Sikh community, individuals may primarily encourage relatives who are experiencing dementia symptoms to visit India consequently increasing the time between symptom onset and access to professional help.

One Amritdhari (baptised Sikh) spoke about stress as a concept of wanting more ‘maya’ (material wealth/money) and commented that stress rarely existed in the lives of ‘Mahapurakhs’ (well known religious people). Therefore those who develop dementia may be stigmatised for their gluttony and their failings to be appreciative of what they have (Hinton et al., 2000).

Religious causes of dementia included ‘karam’ (act, action, deed or fate) as well as an individual’s failure to control the power of the meditation. The impact of karma on South Asian’s illness cognitions has been well documented, with individuals believing that illness is a punishment for previous bad deeds (Ahmad, 2000; Zhan, 2004). The consequences of which may be two fold; encouraging less contact with Western health services whilst allowing for a reduced sense of blame and stigmatisation as it was destined to happen.

There was an appreciation that if the power obtained from religious practices such as Paath (reading of religious text) and Simran (meditation, constant remembrance of God) were not managed correctly they could manifest into symptoms of dementia. Research has investigated the positive effects of prayer on health; with little understanding of the intricacies of prayer (McCaffrey et al., 2004) and how these views differ across different religious communities.

Physical and biological factors such as normal ageing and genetics were also perceived to contribute to the onset of dementia (Neary & Mahoney, 2005). Ageing was identified as both a cause for dementia and a reason for viewing the dementia presentation as normal, demonstrating difficulties in differentiating the effects of normal ageing with the onset of dementia (La Fontaine et al., 2007). Moreover, given that poor diet, heavy alcohol use and lack of exercise have been widely reported in

South Asian communities (Loughlin, Maximova, Tan & Gray-Donald, 2007) and are known risk factors for the onset of dementia, Sikh participants in this study failed to acknowledge any of these as a cause of dementia.

6.4 Coping

The final theme explored ways in which participants would cope with the onset of dementia, individually and collectively within their families as well as perceptions about seeking external support. Amritdhari (baptised Sikh) participants believed that being religious offered a better ‘way of dealing with it’. This coincides with findings disclosed previously regarding the possible benefits of religious affiliation. Religious strategies included both internal and external activities such as Paath (reading of religious text) and speaking with Mahapurash (well known religious person). The use of religious strategies has been seen to promote coping in South Asian’s suffering from a mental illness (Hussain & Cochrane, 2003).

Unsurprisingly, only Amritdhari (baptised Sikh) participants contributed to this discussion on religious strategies and believed that sincere devotion to Paath (reading of religious text) was important in reducing one’s dementia symptoms. Abou-Saleh, Katona and Kumar (2011) reported that religious coping strategies were more likely to be mentioned by those who viewed religion as an integral and enduring part of their lives. One Sehajdhari (non-baptised Sikh) mentioned yoga might be useful in reducing the onset of illness, highlighting the varying definitions of religious practice within the Sikh Community.

Religion provided other benefits in coping, including acceptance of the situation and having faith that the difficulties being experienced were a part of ‘Hukam’ (God’s order/command). Participants commented that the outcome of the

situation was dependent on 'kirpa' (grace, blessing from God) with their role being to remain in 'Chardi Kala'. Being in 'Chardi Kala' within Sikhism is characterised by an individual's ability to have confidence, optimism, courage and resolute willingness to continue in the face of adversity. Research with individuals diagnosed with dementia has demonstrated similar findings, including an attitude of acceptance of both the good and the bad in life but an ability to laugh over it and being thankful to God for being alive (Katsuno, 2003; Mackinlay, 2001). However, thinking in this way could be harmful as it may lead to a sense of fatalism, believing that someone or something else is in control. This could result in feelings of guilt, self doubt and low self – esteem if 'kirpa' (grace, blessing from God) are not received (Kelleher & Islam, 1996). Not only that but if Sikhs believe religion alone can alleviate or cure illness, this may further prevent them from accessing services.

Being a Sikh in itself was seen as protective and an explanation of the possibility of reduced prevalence of dementia in this community. Participants described that God has bestowed Sikhs with robust characteristics, which aid them to cope with difficulties. Bandura (2003) claimed that having religious models could be a powerful way to inspire and motivate individuals to acquire new skills and behaviours to enhance coping. However this may be further prevent service access if the rhetoric within the Sikh community is that they should be able to manage.

In a similar manner, although caring for relatives was seen as the responsibility of the family, the oldest group indicated that the women alone were more likely to have this responsibility. Brijnath and Manderson (2011) demonstrated similar findings regarding the role of women when interviewing carers of those with dementia in India. Participants in the current study reported that competing demands on their time with work, looking after children and caring for an elderly relative was

sometimes very difficult to manage. These women claimed to want support but commented that this could lead to ridicule and criticism for not being able to manage alone. This concept of filial piety has been commonly found in Asian cultures (Dilworth-Anderson & Gibson, 2002; Turner, Christie & Haworth, 2005). Scattolan and Stoppard (1999) reported that women were more likely to use avoidant than active coping strategies as the latter was seen to have greater implications for their life. Decisions based on family or wider community's perceptions acted as a further barrier in accessing services (Baker, Miller, Dang, Yaangh & Hansen, 2010).

When discussing family involvement in care, participants perceived differences between how Amritdhari (baptised Sikh) and Sehajdhari (non-baptised Sikh) family members in the vignette would cope. Amritdhari (baptised Sikh) participants were more likely to posit that the Amritdhari (baptised Sikh) husband would care for his wife at home whilst the Sehajdhari (non-baptised Sikh) family members would access health services. This notion of personally caring for those around you corresponds with the concept of 'seva' (selfless service) in Sikhism, where individuals are encouraged to serve and attend to others with pure intentions, viewing it as a duty to society. Both the Amritdhari (baptised Sikh) and Sehajdhari (non-baptised Sikh) participants viewed the term 'modern' (as the son and daughter-in-law were described in the vignette) pessimistically, signifying a reduced sense of responsibility towards the elders in the family. Given that the son and daughter-in-law in the vignette were seen as more likely to contact the GP than the father/husband, communicating with the GP may implicitly suggest a desire for reduced involvement and delegating one's responsibility. Therefore the challenge for health professionals would be to re-frame this as getting more support for their family members rather than avoiding their duty.

The oldest group of Sehajdhari (non-baptised Sikh) participants expressed doubt and scepticism with regards to the importance of religion in dementia. They acknowledged that religion was important within the Sikh community however recognised the need for additional support. It may be noteworthy to mention that all the participants in this group were women; hence the need for support may be more representative of gender roles in the family system (Chiu, Morrow, Ganesan & Clark, 2005).

Similarly, many of the 18 – 24 year old Sehajdhari (non-baptised Sikh) participants claimed that levels of religiosity might lessen following the onset of dementia. However one participant asserted that religiosity would strengthen in those who were already Amritdhari (baptised Sikh). Croog and Levine (1972) demonstrated that following a heart attack, participants who had identified themselves as religious previous to the illness reported intensified beliefs about their religion a year later. These findings are in line with previous research, where individuals with greater religious commitments viewed religion as a source of support, community and belonging than those who were less religious (House, Landis & Umberson, 1988).

The final category to emerge focused on Sikh's views of external sources in coping, which included their perceptions of GPs as well as other sources. More Sehajdhari (non-baptised Sikh) participants felt it would be useful to involve a trained specialist in order to clarify the symptoms. However many Amritdharis (baptised Sikhs) had negative perceptions of GPs specifically that they were overly focused on diagnosis and medication and employed little time with their patients. This notion that GPs had insufficient time to talk with their patients seemed to be linked with caring less and has been illustrated in other research (Cinnerella &

Loewenthal, 1999). Subsequent research with South Asians about their help seeking behaviours discovered similar attitudes towards GPs (Gilbert, Gilbert & Sanghera, 2004).

Amritdhari (baptised Sikh) participants felt that differences in Sikhs and GPs frame of reference when considering dementia, its causes and treatment would prevent contact with GPs. However Sehajdharis (non-baptised Sikhs) identified differences in language and culture as preventative in getting help from services (Daker-White, Beattie, Gilliard & Means, 2002). It is likely that ethnic communities will vary in their language, attitudes to illness and help seeking behaviour, however health professionals often lack the confidence and competence to cope with cultural and religious differences (Jolley et al., 2009; MacCarthy, 1988). Furthermore visiting the GP was not deemed important because of the knowledge that a cure for dementia does not exist (Bowes & Wilkinson, 2003). Contrastingly, Jutla and Moreland (2009) interviewed South Asian carers for individuals with dementia and found that if they had known what dementia was they would have been more prompt in contacting services. However, the majority of the sample of 15 carers recruited in the study reported satisfaction with their GPs and service provision, hence more recent positive experiences may have shaped their previous preconceptions about GPs. It is also important to note that Sikh participant's believe they are unlikely to be understood by health care professionals, which may unknowingly result in a self fulfilling prophecy even when the situation is very different (Jussim, 1986).

7. Clinical Implications

The findings of the current study suggest that Sikhs have a lack of awareness of the symptoms of dementia and how it would present. Coupled with fear of blame

and stigmatisation from family members and the larger community this is likely to reinforce avoidant coping strategies. Amritdhari (baptised Sikh) participants believed that religion offered effective ways of coping, which may help in accepting the situation and maintaining 'Chardi Kala' (to have a positive, buoyant and optimistic attitude to life and the future). Notably families were seen to play a significant role in the decision-making and help seeking process. Perceptions of GPs as focused on the medical model of illness and therefore likely to hold conflicting views with Sikhs about dementia further prevent contact with services. Language and culture were identified as important factors in considering support outside of the community.

These findings demonstrate that there are significant barriers to help seeking in the Sikh community and may explain reduced Sikh presence in services. At a community level, greater outreach work is needed to provide prevention information, and education in order to inform Sikhs about dementia and about available services (Kaur, Jutla, Moreland & Read, 2010). However this study also highlights that the Sikh community is not homogenous in their perceptions about dementia, with differences exhibited between Amritdharis (baptised Sikhs) and Sehajdharis (non-baptised Sikhs).

Given that the majority of Sikhs in this study did not favour diagnosis and medication, it is important to explain that dementia is a holistic illness. Emphasis around assessment being about identifying the needs of the person with dementia, identifying their psychological and social needs as well (British Psychological Society, 2009) and not just about diagnosis is required. Healthcare professionals, particularly gatekeepers such as GPs, need to have a greater understanding of the Sikh community, notably Amritdharis (baptised Sikh) and Sehajdharis (non-baptised Sikhs) and how this may influence their explanatory models of illness (DoH, 2001).

Given the likelihood of GP consortia as outlined in the NHS White Paper, Equality and Excellence (DoH, 2010) the recognition and implementation of the findings in this study are of paramount importance.

Furthermore, there is a need for health professionals, regardless of whether they share the same religious traditions or interests, to promote a more inclusive discussion about cultural and religious coping strategies (Nadirshaw, 1992). Kitwood's (1997) research has been crucial in calling for recognition of the centrality of the person within person-centred care.

This study has highlighted the need for health professionals to understand the subjective experience of the Sikh person with dementia, acknowledging the relevance of the client's background as well as being mindful of their own assumptions about cultural and religious variations (Johnson & Nadirshaw, 1993). Health professionals are encouraged to offer a non-judgmental and accepting space for discussion, to enable Sikhs to demonstrate how their religious and cultural views may facilitate understanding of their illness and to work collaboratively in finding a common ground.

Furthermore family involvement in assessment and practice needs to be taken into account. Health professionals should be responsive in involving families in the process and in giving them accurate information about dementia, its progression and potential causes in order to reduce stigma. It may also be important for professionals to be aware of the family system (i.e. baptised/non-baptised Sikhs) and how this may determine access to services.

8. Study Limitations and Directions for Future Research

The present study was original in evidencing how Sikhs in the community conceptualise dementia. The literature review demonstrated a greater focus on South

Asian's views therefore the present study was novel in its focus on both Amritdhari (baptised Sikhs) and Sehajdhari (non-baptised Sikhs). However due to the small sample size as well as potential differences between participant and non-participant demographics, suggests that this may not be a complete picture of Sikh perceptions of dementia. Future research could build on these findings with greater recruitment of the older Sikh population.

Although only 4 individuals aged 41 – 55 years old took part in the study, 12 had initially consented but did not participate. This age group had the highest non-attendance after consent. Similarly although 4 individuals aged 56 or over had consented, all failed to attend the focus groups. The researcher noted that during recruitment although older Sikh adults wanted to learn more about the study they were hesitant to commit to the focus groups, suggesting reservations about sharing their opinions and perspectives with others. The researcher felt that had there been more time, individual interviews would have been offered as these age groups may be more likely to be caring for an elderly relative in the community.

A further strength of this study was the use of qualitative methodology allowing the researcher to investigate participant's attitudes and belief systems about dementia, something which quantitative measures are not particularly sensitive to. Moreover, the use of vignettes was seen as a useful method in developing rapport and enabling participants to feel at ease without having to refer to their own experiences (Hazel, 1995).

Throughout this study distinct differences were exhibited between baptised and non-baptised Sikhs. However as it has been difficult to corroborate these

findings given that this is the first study to have recruited both baptised and non-baptised Sikhs, further research in this area is encouraged.

The dissemination of this study will provide a valuable contribution to healthcare professionals' knowledge about the Sikh community.

9. Summary

In summary, this research adds to previously limited data on how British Sikhs understand and manage dementia in their community. This can inform service providers on how to develop more culturally sensitive services. In particular, it can point to areas where education on the nature of symptoms might allow families to recognise signs of the development of symptoms sooner. Services might seek to work with families, and be respectful and accommodating of religious beliefs and practices as useful aids to coping with dementia.

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Section D

Critical Appraisal

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by

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To the University of Leicester, School of Psychology, Clinical Section.

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1. Introduction

The following section outlines my reflections on issues that emerged from undertaking the current research. I explore reasons that guided my area of investigation as well as my choice of methodology. The content is based on notes written in my reflexive diary, where I have considered issues such as my position in the research as well as dynamics occurring during recruitment but also how this experience has impacted on my personal and professional development.

2. Choice of Research Topic

Qualitative researchers have a responsibility to make their relationship to the research material clear, in order to aid transparency and to think about the author's frame of reference (Madill, Jordan & Shirley, 2000). I am a trainee clinical psychologist and also a British Amritdhari (baptised Sikh). My experience previous to and during the course of training, my ethnic background and the fact that I am a trainee in Leicester, an area where the number of ethnic minorities is predicted to overtake the Caucasian population, have all influenced my interest in researching how the Sikh community conceptualises dementia.

It was during my initial clinical role as a support worker that I first came across dementia. I recall how the client with dementia was perceived as being 'away with the fairies' and 'he is always saying that' when he alleged to have been kidnapped, with little being done to help him adjust and cope with what was happening. On reflection, I wonder how much knowledge and awareness staff and relatives had about dementia and ways to manage this incurable illness. At the time and most likely up until training I would also have placed myself in the 'reduced

awareness' group believing that dementia equated most significantly to memory loss, thinking very little about the impact holistically.

I have always been interested in thinking about what resources people use when faced with difficult situations like illness. During my MSc thesis I undertook research on religious faith and coping with rheumatoid arthritis and was fascinated with one conclusion in particular, indicating a negative correlation between religious faith and active coping (Uppal, 2007). This encouraged me to consider the role that culture and religion may play in framing and managing adverse situations.

Having undertaken a preliminary review of the literature, I was surprised to learn that although there seemed to be a plethora of government documents (DoH, 2001, 2009; NICE, 2006) encouraging a person centred approach to care, there was a limited understanding of illness perceptions in ethnic minority communities (Nazroo, 1997; Rathod, Kingdon, Phiri & Gobbi, 2010). Furthermore when studies did include ethnic minorities, a reductionist approach (use of the term 'South Asian') was commonly utilised. Given my location in the UK, studying and working in Leicester and Derby, it seemed apt to utilise the diversity of these areas to research the current topic.

3. Choosing a methodology

Having previously employed quantitative methodology, my approach to research within the supportive environment of training was to use qualitative techniques as something new. However as mentioned in the previous chapter, I was acutely aware that the chosen methodology would primarily depend on the research question and how it could best be answered.

Furthermore, focus groups were chosen as a valuable and versatile way to access community attitudes and to facilitate discussion on sensitive topics such as

dementia (Farquhar, 1999). The idea of facilitating focus groups seemed a daunting one for me, having little experience in this previously. Discussions with my research supervisor, who has expertise in qualitative research and clinical supervisor, who offered me the opportunity to facilitate a one-off focus group at a day centre (as part of my older adult placement) made me feel more confident and better equipped when using this method for my research. The use of constant comparative methodology warranted a greater sense of credibility and validity to the findings as it provided a rigorous and well-established method of analysis.

4. Planning

For this thesis, my interest has always been on the topic of dementia, however I had initially submitted a proposal for peer review investigating the use of coping strategies in an ethnically diverse sample of people with early, mid and late stage dementia. Following peer review as well as discussions with my research supervisor, other research ideas were considered. This was due to the ethical implications in recruiting individuals with a diagnosis of dementia, as well as being mindful that given their stage of illness, interviews may not have provided sufficient material for analysis. A subsequent proposal involved interviewing carers, as it was thought that they could act as historians about the coping methods used by those they care for. However after speaking with my clinical supervisor who works with older adults in Derby, she reported that although the city's population is diverse, the number of individuals from ethnic minority communities who actually contact services is small. In the end, it was decided that one ethnic and religious community, the Sikh community would be approached to gain their views of dementia. Potential ethical issues were also identified and discussed with my supervisors following which ethical approval was sought from the School of Psychology Ethics Committee.

5. Recruitment

Having received ethical approval promptly and early on in the year, I spent time considering the recruitment phase of this research. Given the difficulties mentioned in previous research about recruiting from ethnic minority communities, I recognised the importance of starting this sooner rather than later (Ahmed, Hussain, & Vournas, 2001). First, I designed several posters in both English and Punjabi and sent them to friends and family to gain their feedback on issues of clarity. Several individuals felt that they did not know anything about dementia and believed this would be a barrier to participating. With this feedback the line ‘you do not need to know anything about dementia just be willing to talk about it’ was added to the recruitment poster.

Secondly I contacted Gurdwara (Sikh places of worship) in Leicester and Derby and attended the Sunday programme at every Gurdwara in both these areas in order to generate interest in participating in the study. This process was a steep learning curve and at times felt quite demoralising. During one occasion, a family were hosting a programme at the Gurdwara (Sikh place of worship). When approached, many individuals declined to participate and others seemed quite hostile at being asked. Finally a member of the family came up to me and enquired about the study, moreover, she informed me that their grandmother who had dementia had recently passed away. Given this information, attitudes of those approached made sense, however on reflection I felt that I couldn’t have anticipated this being the case. Nonetheless, this experience made me more mindful of potential issues in subsequent recruitment days.

Although Sikhs of all ages were interested, approached me and left their contact details, when reminders were sent out about a fixed date for the focus group

many did not attend. On the first Sunday I had arranged a focus group one person turned up with others failing to notify me of their absence. I wondered whether being from the same community as my participants meant that I wasn't taken as seriously as someone from a different ethnicity and/or religion. I also reflected whether this lack of presence might be an expression of not wanting to know about dementia because then the responsibility would be placed on them to identify this in their relatives. Following this I adapted my recruitment strategy slightly, in that as well as attending Sunday programmes at the different Gurdwara (Sikh places of worship), I attempted to contact pre-existing groups (i.e. youth Sikh groups, Punjabi classes). This ensured that individuals were already together and present at a certain time and place increasing the likelihood of attendance in the focus groups.

This process has made me recognise the inherent difficulties in organising focus groups and the realisation that using this methodology may have contributed to the nonattendance of those with more unusual views of dementia. On several occasions I was approached by members of the Sikh community who believed that dementia did not exist or was due to 'overuse of the mind' with one individual even disagreeing with the use of the label 'Sikh', however these individuals failed to turn up to any of the focus groups.

My initial and perhaps naive thoughts regarding recruitment in this population included the belief that my identity as a Sikh may encourage participation from the Sikh community, however this was not the case (Mirza, 1998). It is possible that some Sikh's were reticent due to their perceptions of anonymity, believing that I as a fellow Sikh would be more likely to know them and their families compared to if the researcher was Caucasian. Other research has been divided on the benefits of 'ethnic matching' with Sinclair et al. (2000) reporting that matching the investigator

and the population being studied enabled recruitment and retention. However Culley, Hudson and Van Rooij (2009) claim there is no robust evidence to indicate that ‘ethnic matching’ leads to more valid or reliable data. It may be that whilst I came across obstacles and difficulties during recruitment, these would have been even greater if I were of a different ethnicity/religion. Encouragingly I did manage to recruit 28 individuals, demonstrating that persistence and determination does pay off.

6. Focus groups

6.1 Vignettes

The data in this study was collected using focus groups with discussions in English, Punjabi or a mixture of both. Talks with my research supervisor about the structure of these focus groups led to the possibility of using a vignette. It was felt that a vignette would encourage greater participation in the discussion and may ‘depersonalise’ the discussion so that participants would not feel pressured to talk about their actual experiences unless they wanted to. However, the likelihood of over disclosure was considered, given that this opportunity to discuss dementia in their preferred language, in a group facilitated by someone of a similar ethnic background, might be seen as a rare event for some and that, as a consequence, people might be unguarded in their responses. This occurred on one occasion, where the participant was concerned about her father-in-law and had understood that if she came to the group she may be able to get some help for him. Although during recruitment I had tried to ensure that all participants were aware of the purpose of the focus groups, this is not always possible as some participants may have alternative motivations.

6.2 Power

Power relations are fluid processes, with power and powerlessness being experienced by the researcher as well as the participants (Grentz, 2005). At times I

felt particularly powerless, most noticeably during the recruitment phase of the study, feeling anxious that I wasn't going to recruit enough participants. It was also clear that power shifted towards potential participants demonstrated in their non-attendance. Throughout training I have developed a keen awareness of how my ethnicity may impact on clinical situations as well as conducting this research. Although I felt I had the advantage of sharing the same ethnicity with my participants, I wondered to what extent this insider perspective was helpful.

I reflected whether I was more likely to assume an understanding of the thoughts, feelings and experiences Sikh participant's expressed in the study. I also questioned whether in being 'ethnically matched' I missed opportunities to ask participants to expand on their responses and clarify their views (Simmel, 1921). I tried to address these by paying close attention to responses that surprised me or which were different to my own expectations and experiences. Similarly discussions of the transcripts during supervision helped to identify whether this was occurring and to prevent this in future groups. The process of data collection in parallel with analysis also helped to reduce the possibility of this happening, as emerging categories and concepts were presented in the next round of focus group discussions for further clarification.

Throughout the focus groups participants used Punjabi words that although translatable into English they failed to capture the emotional and cultural context comprehensively e.g. 'Ardas' as 'prayer' or 'Hukam' as 'God's order/command' do not do complete justice to the meaning of the original word. It is at times like this a degree of 'ethnic matching' may have helped in interpreting the data on a cultural level (Tang, 2002). In qualitative research, where the aim is to hear the individual's story and views, a shared vocabulary is essential. Lee (2001) reported that interviews

conducted in an individual's first language might help promote a sense of identity of what it means to be a member of that minority population.

It was also important for me to consider my appearance, specifically the fact that I wear a turban, indicating to participants that I am an Amritdhari (baptised Sikh). I reflected on what this may have meant to participants, on the one hand seeing it as a further level of congruity with the Amritdhari (baptised Sikh) participants whilst on the other hand a potential barrier for the Sehajdhari (non-baptised Sikh) participants. I wondered whether Sehajdhari (non-baptised Sikh) participants would be more likely to hold religious stereotypes about Amritdharis (baptised Sikhs), hence viewing me as distinct from them. Also I considered whether they would be less likely to disclose alternative, non-religious or even anti-religious views in the discussions. In reflecting on this before and during recruitment I took care in trying to respond neutrally and openly to participants in the discussion. Although when analysing the results, the extensive and contrasting responses from participants indicated that participants had felt able to speak openly and honestly about their thoughts and opinions. With the help of supervision and the use of continual reflection, the fluctuating dynamic of power in the research relationship has been considered throughout the stages of this study.

7. Data Analysis

Prior to training I felt quite unfamiliar and unknowledgeable about qualitative research, especially constant comparative analysis. Following teaching on the course, research supervision as well as reading book chapters and articles on this methodology I was able to feel more confident in why this method was appropriate and how I would use this approach in analysing the data.

Constant comparative methodology, although a core technique in grounded theory, differs when using it as a standalone method, in that a theory is not generated at the end (Glaser & Strauss, 1971). Central to grounded theorists is that the literature review should not be done prior to data collection (Glaser, 1978). However I felt that this was not practical as the previous literature enabled me to avoid replication by conducting new research and helped to develop the focus group topic guide. The previous literature was also advantageous in offering other methodological insights, such as the benefits of using a vignette in focus groups.

I also felt that constant comparative analysis reinforced the notion that themes should be grounded in participants' accounts. I learnt the importance of this after I attempted the analysis of my first focus group. Following research supervision I found that that the codes I had generated were not grounded enough in the data. Being explicitly attentive to this concept helped me in subsequent analyses.

Seeing myself as a novice qualitative researcher, I found the clear framework involved in constant comparative methodology helped me systematise the analysis process and increase the traceability of my themes (Boeije, 2002; Charmaz, 2006). In addition, as my analysis progressed differences began to emerge between participant responses hence the use of this methodology was further strengthened in its promotion of constant comparison and reflection of 'old' material with 'new'.

One of the biggest struggles I was faced with was considering what was most relevant to include in the study write up, whilst being attentive to the word count. I found research supervision and constantly referring back to the research aims helpful during this time.

8. Personal and Professional Development

Being able to choose my own research topic for this thesis and being genuinely interested in the findings has been central in maintaining my motivation since it's conception. One of the biggest things I will take away from this experience is that organisation and management of the workload is key in minimising the pressure you place on yourself and in maintaining a healthy work/life balance. Friends and family outside of the 'psychology world' have helped enormously in allowing me to gain perspective in acknowledging the thesis whilst recognising there is a world outside of it.

Although it has been difficult to juggle research commitments whilst driving over 120 miles to my clinical placement, I have learnt that I really enjoy both clinical and research work and that my ideal qualified role would incorporate both. Knowing that you have the opportunity to contribute to a new area in research has been particularly encouraging. I hope to publish and disseminate my findings widely staying true to my aims of giving the Sikh community an opportunity to be heard but also aligning with my beliefs that not publishing research is unethical.

9. Implications for Clinical Practice

Completing the thesis has strengthened my ability in facilitating focus groups with people of all ages, transcribing and analysing qualitative data and has continued to highlight the importance and value of person centred care. The latter has been increasingly important to hold onto given the likely impact of NHS reforms in the future.

This research has enabled me to appreciate how cultural and religious coping strategies can promote resilience but also recognise ways in which services can use this knowledge to cater to individual needs. However I also fervently believe that

although the provision of knowledge in making an informed choice is necessary, everyone has the right to make his or her own decisions about what they wish to do with that information.

Although this study focussed on the Sikh Community, I have reflected on the importance and relevance of these findings in other communities. During the recruitment phase I acknowledged some of the benefits in recruiting from a 'marginalised' community as an opportunity for their views and opinions to be expressed and for their difficulties in accessing services to be recognised. Furthermore this process has made me feel more confident about being an ambassador for Clinical Psychology and its role in mental health care. Undoubtedly these skills will be useful in a variety of roles and environments in the future.

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Section E

Appendices

Submitted April 2012

by

Gobinderjit Kaur Uppal

To the University of Leicester, School of Psychology, Clinical Section.

In partial fulfilment of the degree of

Doctorate in Clinical Psychology.

Appendix A

Guidelines for Mental Health, Religion & Culture Journal Preparation.

1. General guidelines

- Papers are accepted English. British English spelling and punctuation is preferred.
- A typical article may be between **5,000** and **10,000 words**. A short article for rapid publication will not exceed **2,000 words**. These limits include references, but not abstract or keywords, as these are for editorial and referees' reference only and will not get published. Papers that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; appendices (as appropriate); references; table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- Each paper should have between three and seven keywords.
- The title page should include the title of the paper, all the authors' full names, affiliations, postal addresses, telephone and fax numbers and email addresses. One author should be identified as the Corresponding Author at the bottom of the page. An abbreviated title should also be given, for running headlines within the article.
- Biographical notes on contributors are not required for this journal.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms should not be used.
- Authors must adhere to [SI units](#). Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.

2. Style guidelines

- Description of the Journal's [article style](#), [Quick guide](#)

- Description of the Journal's [reference style](http://www.tandf.co.uk/journals/journal.asp?issn=1367-4676&linktype=44), <http://www.tandf.co.uk/journals/journal.asp?issn=1367-4676&linktype=44>
- Manuscripts may be submitted in any standard format, including Word, PostScript and PDF. These files will be automatically converted into a PDF file for the review process.
- This journal does not accept Microsoft Word 2007 documents.
- Please use British spelling (e.g. colour, organise). Use double quotation marks with single within if needed.

If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

Word templates

[Word templates](#) are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact authortemplate@tandf.co.uk

3. Figures

We welcome figures sent electronically, but care and attention to these guidelines are essential as importing graphics packages can often be problematic.

- Illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Figure 3). Each figure should be numbered with Figure number (Arabic numerals).
- Figures must be saved separate to text. Please do not embed figures in the main document.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the paper (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).

- Figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly. Captions should include keys to symbols, and should make interpretation possible without reference to the text.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

4. Tables

Tables should be numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

5. Reproduction of copyright material

As an author, you are required to secure permission if you want to reproduce any figure, table, or extract from the text of another source. This applies to direct reproduction as well as "derivative reproduction" (where you have created a new figure or table which derives substantially from a copyrighted source). For further information and FAQs, please

see <http://journalauthors.tandf.co.uk/preparation/permission.asp>.

6. Informed consent

Manuscripts must include a statement that informed consent was obtained from human subjects. Authors should protect patient anonymity by avoiding the use of patients' names or initials, hospital number, or other identifying information.

7. Code of experimental ethics and practice and confidentiality

Contributors are required to follow the procedures in force in their countries which govern the ethics of work conducted with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

For human subjects or patients, describe their characteristics. For human participants in a research survey, secure the consent for data and other material - verbatim quotations from interviews, etc. - to be used. Specific permission for any facial photographs is required. A letter of consent must accompany any photographs in which the possibility of identification exists. It is not sufficient to cover the eyes to mask identity.

It is your responsibility to ensure that the confidentiality of patients is maintained. All clinical material used in your article must be disguised so that it is not recognisable by a third party. Where possible and appropriate, the permission of the patient should be obtained. Authors are invited to discuss these matters with the Editor if they wish.

8. Conflict of Interests

All authors of accepted articles will be required to complete a declaration of competing interests and/or financial support.

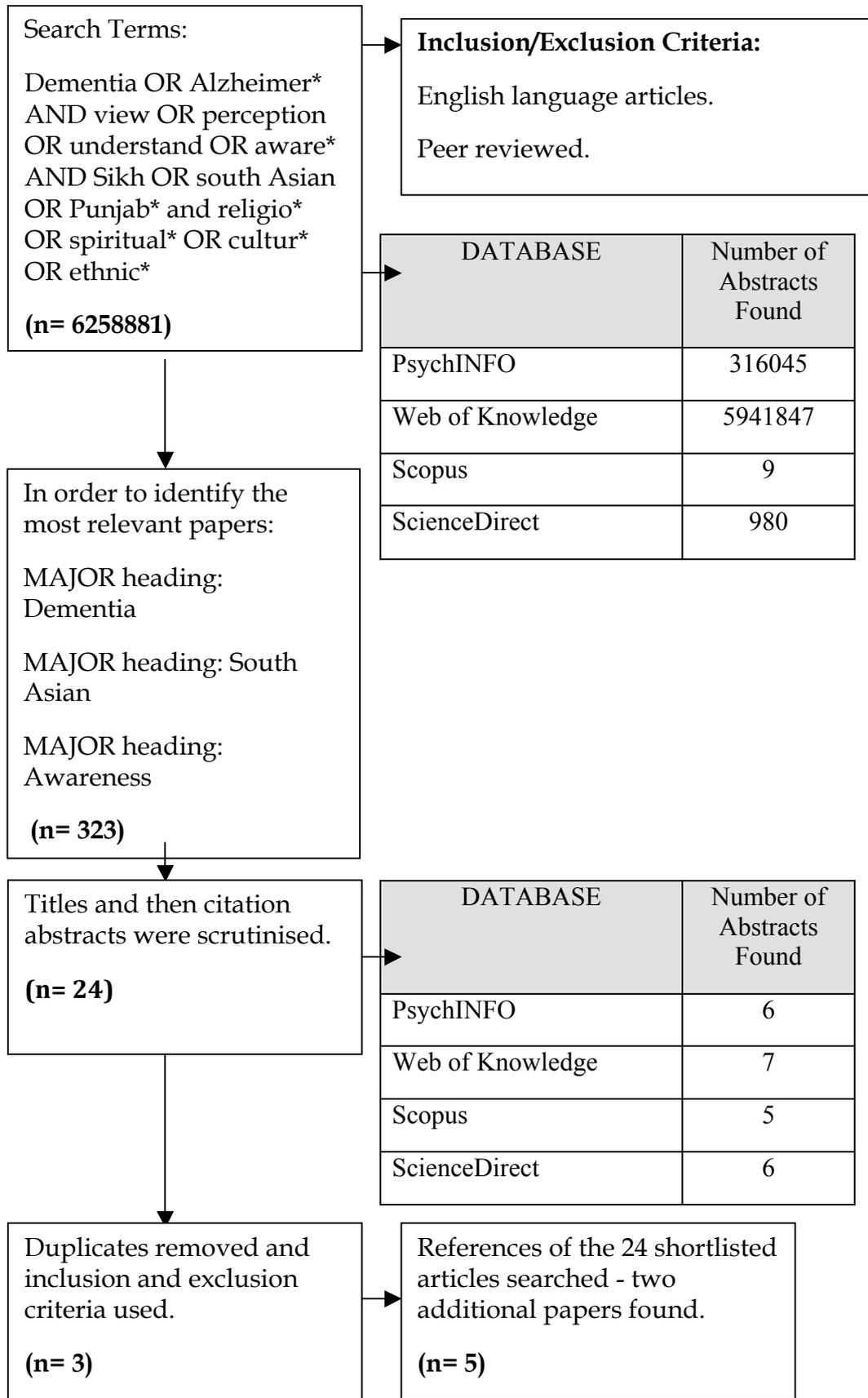
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Exceptions are made for Government employees whose policies require that copyright cannot be transferred to other parties. We ask that a signed statement to this effect is submitted when returning proofs for accepted papers.

Appendix B

Literature Review Search Process - Identification of Papers



Appendix C

Data Extraction Pro-Forma

Article Number:		
Review Date:	Country of Study:	
Title:		
Author (s):		
Publication Date:		
Journal:		
Volume:	Number:	Pages:
Keywords/Definitions:		
Aims:		
Method:		
Sampling/Participants:		
Analysis Used:		
Results:		
Controls/Validity/Reliability:		
Conclusions:		
Extra Notes:		

Appendix D

Summary of the Studies included in the Literature Review

<i>Paper</i>	<i>Country & Participant demographics*</i>	<i>Type of Study & Methodology</i>	<i>Aim</i>	<i>Analysis</i>	<i>Results Summary</i>	<i>Reliability & Limitations</i>
1. Jolley et al. (2009)	<p>United Kingdom.</p> <p>Total sample size (n = 40), South Asians (n=10) included in the review as rest of the sample were either African-Caribbean (n=20) or South Asian carers (n=10). Age and gender not disclosed.</p> <p>South Asians recruited from religious and voluntary organisations in Wolverhampton.</p>	<p>Qualitative.</p> <p>Four discussion workshops with the use of vignettes.</p>	<p>To discuss ethnic elderly dementia care with community organisations to identify gaps in knowledge and services.</p>	<p>Summary of discussions.</p>	<p>Knowledge of dementia across all groups not only ethnic groups seemed to be scant. The need for educational material to be made available in different languages for those who have an individual suffering with dementia in their family. The importance of culturally appropriate care.</p>	<p>Elicited views from individuals from religious and voluntary organisations in the community however impact of religion never discussed explicitly. Only 10 individuals from the Asian community recruited. The number of males: females or age range of this sample unknown.</p>

<i>Paper</i>	<i>Country & Participant demographics*</i>	<i>Type of Study & Methodology</i>	<i>Aim</i>	<i>Analysis</i>	<i>Results Summary</i>	<i>Reliability & Limitations</i>
2. La Fontaine et al. (2007)	<p>United Kingdom.</p> <p>Total sample size (n = 49) all South Asian. Aged between 16 – 61 years old.</p> <p>Participants were from India or of Indian Origin.</p> <p>Recruited from cultural centres, arts and leisure centres, Sikh Gurdwara (places of worship), women’s groups and colleges.</p>	<p>Qualitative.</p> <p>Two focus groups to look at 1) views of ageing and age associated difficulties and 2) exploration and understanding of dementia. In the second focus group vignettes were used.</p>	<p>To explore the perceptions of ageing, dementia and age associated mental health difficulties amongst Punjabi Indian origin.</p>	<p>Thematic analysis.</p>	<p>No clear differences between different generations in perceptions of ageing. Ageing seen as negative, with people becoming increasingly worried as they got older. Stigma & ignorance were 2 themes identified when discussing mental health difficulties associated with ageing. Causes in the mild dementia vignette believed to be linked with physical health (diabetes) or was emotionally based (depression). The more severe dementia vignette elicited themes such as a ‘lack of love’ as a cause. Across all 3 vignettes participants discussed the need for self help, medication & family.</p>	<p>Included a minority group that has been noted to be difficult to recruit. Interesting use of vignettes from normal ageing to severe dementia to investigate community understanding. The sample included both Sikh and Hindu Indians however did not elicit the influence of the differences in religion/culture. Groups consisted of a wide variety of ages including 36 – 61 that may have inhibited some group member’s discussion.</p>

<i>Paper</i>	<i>Country & Participant demographics*</i>	<i>Type of Study & Methodology</i>	<i>Aim</i>	<i>Analysis</i>	<i>Results Summary</i>	<i>Reliability & Limitations</i>
3. Patel & Prince (2001)	<p>India.</p> <p>Total sample size (n = 88) with 37 South Asians.</p> <p>Aged between 50 - 89 years old.</p> <p>Participants were of Goan or Indian origin.</p> <p>Older people living in the community as well as those living in old age homes were recruited. Key informants including carers were also recruited from the community.</p>	<p>Qualitative.</p> <p>Focus group discussion with the use of vignettes.</p>	<p>To investigate the understanding and opinions of Goan people regarding the health experiences of older people with a focus on dementia and depression.</p>	<p>Constant comparison Methodology.</p>	<p>The term dementia was not mentioned in any of the focus groups as a cause of ill health in old age. Although on two occasions descriptions of a person with probable dementia were described. Dementia often seen as a normal feature of ageing. In addition dementia was seen as a lack of love from the child to the parent.</p>	<p>Study conducted in India. Religion/faith of participants not identified. Included health workers and older adults in the community however differences between the two and their conceptualisations of dementia were not identified.</p>

<i>Paper</i>	<i>Country & Participant demographics*</i>	<i>Type of Study & Methodology</i>	<i>Aim</i>	<i>Analysis</i>	<i>Results Summary</i>	<i>Reliability & Limitations</i>
4. Purandare Luthra, Swarbrick & Burns (2007)	<p>United Kingdom.</p> <p>Total sample size (n = 246) with 191 South Asians and 55 Caucasians. Mean age: Indian 72 years, Caucasian 78 years.</p> <p>Recruited from 3 day centres, 2 predominantly South Asian and 1 Caucasian in Manchester.</p>	<p>Quantitative.</p> <p>Dementia Knowledge Questionnaire (DKQ) was completed.</p>	<p>To examine knowledge of dementia in South Asian older people as compared with Caucasian older people.</p>	<p>SPSS. Fishers Exact test and Mann Whitney U-test.</p>	<p>Scores were significantly lower in Indian participants. Only 21% of Indians knew that dementia was a disease of the brain. Memory impairments were most commonly recognised as a symptom of dementia.</p>	<p>Short questionnaire whereas more information may have been elicited from either a longer questionnaire or qualitative follow up. Day centre managers were asked to hand the questionnaires out – may be differences across the day centre’s in those who refused and those who completed it however demographics unavailable. Those who completed it may have had dementia but not have had a diagnosis. South Asian groups mainly consisted of Gujarati individuals.</p>

<i>Paper</i>	<i>Country & Participant demographics*</i>	<i>Type of Study & Methodology</i>	<i>Aim</i>	<i>Analysis</i>	<i>Results Summary</i>	<i>Reliability & Limitations</i>
5. Turner, Christie & Haworth (2005)	<p>United Kingdom.</p> <p>Total sample size (n=192) with 96 South Asians aged between 58 and 85 years old.</p> <p>96 were South Asian (Indian, Pakistani or Sri Lankan) and 96 Caucasians.</p> <p>Caucasians were recruited from GPs only, whereas South Asians were recruited from 3 GPs and 2 South Asian Organisations.</p>	<p>Qualitative.</p> <p>Semi-structured individual interviews in either English or 4 Asian languages.</p>	<p>To discover whether differences exist in views about nature, causes and treatments for dementia and who participants believe should provide the care in South Asian and White older people.</p>	<p>IPA of the interviews.</p> <p>Quantitative analysis of frequency of themes.</p>	<p>South Asians had much less knowledge regarding dementia and were more likely to link it to the normal ageing process. Consequently they felt there were few treatments available. South Asians were more likely to look to family and friends to care for them.</p>	<p>South Asians were made up of Muslims or Hindus however impact of differing religions was not taken into account even though they recorded that South Asians were more likely to adhere to religious practices than Caucasians in this sample. Both groups (South Asians and Caucasians) were demographically different (i.e. level of education, whether they were married or not). Recruitment in 2 areas of London therefore may not be generalisable.</p>

*This review only includes South Asians in the community without a diagnosis of dementia & excludes carers for those with dementia

Appendix E

Demographic information of study participants & non-attendees*

Demographic Characteristics	Frequency Percent (N, %)	
	Participants (N = 28)	Non- participants (N = 40)
Age (yr)		
18 – 25	14, 50%	12, 30%
26 – 40	10, 36%	12, 30%
41 – 55	4, 14%	12, 30%
56 +	-	4, 10%
Location recruited		
Leicester	8, 29%	17, 42%
Derby	20, 71%	23, 58%
Gender		
Male	14, 50%	27, 67%
Female	14, 50%	13, 33%
Amritdhari (baptised Sikh)		
Yes	15, 54%	9, 22.5%
No	13, 46%	14, 33%
Undisclosed	-	17, 42.5%
Country of Birth		
UK	20, 71%	12, 30%
India	7, 25%	11, 27.5%
Canada	1, 4%	-
Undisclosed	-	17, 42.5%
Marital Status		
Single	16, 57%	10, 25%
Married	12, 43%	12, 30%
Widowed	-	1, 2.5%
Undisclosed	-	17, 42.5%
Ethnicity		
Indian	11, 39%	13, 32.5%
Other-Sikh	17, 61%	10, 25%
Undisclosed	-	17, 42.5%
Primary language		
English	15, 54%	9, 22.5%
Punjabi	8, 28%	11, 28%
Both	5, 18%	3, 7%
Undisclosed	-	17, 42.5%
Level of Education		
Secondary school	5, 18%	7, 17.5%
College	6, 21%	7, 17.5%
HND	1, 4%	-
Vocational	-	1, 2.5%
Bachelor's degree	13, 46%	6, 15%
Master's degree	3, 11%	2, 5%

Undisclosed	-	17, 42.5%
Others in household		
Parents	6, 20%	-
Parents & siblings	7, 25%	7, 17.5%
Children	1, 4%	2, 5%
Children & siblings	1, 4%	-
Spouse & children	7, 25%	9, 22.5%
Spouse	1, 4%	2, 5%
Spouse & parents	2, 7%	-
Spouse, parents & Children	-	1, 2.5%
Whole family	1, 4%	-
Non-family	2, 7%	-
Alone	-	1, 2.5%
Other	-	1, 2.5%
Undisclosed	-	17, 42.5%

* Note that individuals who signed the consent form but did not complete the demographic questionnaire are reported under ‘undisclosed’.

Appendix F

Trainee's statement of Epistemological Position

Different qualitative methodologies take different epistemological positions regarding the kind of knowledge that is produced, the assumptions made about the world and role of the researcher in the process (Willig, 2008). In the current study the trainee's choice of epistemological perspective is described as a contextual constructionist. This position is often relevant when the researcher is investigating cultural meanings (Giorgi, 1995).

'Studies conducted from within a contextual constructionist epistemology would be expected to show the relationship between accounts and the contexts within which they have been produced. That is, accounts need to be demonstrably grounded in the (e.g. situational, personal, cultural, social etc.) conditions within which they were produced. This applies to both participants' accounts (e.g. of their experiences, of their thoughts and feelings) and researchers' accounts (e.g. their analysis and interpretation of the data)'.

(Willig, 2001, p. 146).

Similarly, Pidgeon and Henwood (1997) identified that the researcher and the participant are not objective beings. Contextual analysis accepts this and understands that a common cultural understanding between researcher and participant may be a useful resource during analysis. This has been particularly true in some of the focus groups in the current study where Punjabi terms that are not so easily translated into English have been used. Furthermore grounding results in participant accounts was integral in clearly and logically demonstrating how the data was analysed (Madill, Jordan & Shirley, 2000). The trainee also recognised the

importance of presenting a complete picture of the data by including contrasting and diverse perspectives, in line with the contextualist approach to triangulation (Tinsley 1992). Moreover, the researcher felt more inclined towards a relativist stance, which takes into account the researcher's interpretations and constructions of the data, maintaining that results will vary according to the context in which data are analysed (Willig, 2008).

Contextual constructionism has been discussed in comparison to other epistemologies including radical constructionism and realism in Madill et al.'s (2000) paper. Whereas contextual constructionism is concerned with understanding the situation from the participants view point, realism focuses on accurately describing what is going on and therefore objectivity and reliability of that knowledge has to be considered. Triangulation is often used to confirm these findings, with the converging of the difference in perspectives representing 'reality'. Furthermore, critical realism is concerned with how the discourse relates to social and institutional structures, believing there is a reality outside of our thinking. In comparison, radical constructionist epistemology believes that knowledge is constructed and not found and in this way there is no 'truth' as knowledge is a reflection of the system that you are based in.

Constant comparative methodology may also be applied within a contextual constructionist epistemology, a critical tool in Grounded Theory. This methodology was chosen as the study was concerned with developing an in-depth understanding of Sikh's perceptions of dementia grounded in their responses rather than developing an explanatory theory that would be generalised to the Sikh community (Starks & Trinidad, 2007). Furthermore, the use of the dementia vignette in the

current study, in order to depersonalise discussion around a potentially sensitive topic such as dementia did not conform to principles of grounded theory.

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Appendix G

Study Information Sheet (English & Punjabi)



University of Leicester

**CONFIDENTIAL
INFORMATION SHEET**

Sikhs and Dementia

Investigators:	Gobinderjit Uppal
Supervised by:	Dr Sheila Bonas Dr Helen Philpott
Contact details:	104 Regent Road, Leicester, LE1 7LT. 0116 223 1648

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Research looking at the Sikh community is limited. The proposed study aims to look at Sikh adults living in the community in order to investigate their understanding of dementia and how their religious/spiritual and cultural background facilitates this understanding. We would like to find out your views on dementia. The information you give us will then be used to inform future NHS services and care provision so that they are able to provide care that recognises cultural, religious and spiritual identity.

Why have I been chosen?

You are being asked to take part in this study because you are an adult in the Sikh Community and we value your opinions.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form and complete a demographic information sheet. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What is involved in the study?

If you agree to take part in this study a researcher will ask you to confirm your availability on given dates. On this day, you will be asked to attend a focus group discussion consisting of no more than 9 other people. This will last no longer than an hour (approximately) and will be conducted in a location near you.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for people participating in this study, it is hoped that this research will contribute to improving mental health professionals' knowledge and understanding of the Sikh Community as well as the provision of care provided to those in contact with dementia services in the future.

Confidentiality of records.

All the information we obtain will be strictly confidential. The chief investigator will be responsible for security and access to the data. Only the study investigator (named above) will have access to the data. The information collected during the study, will be securely stored and analysed confidentially on a computer. No identifiers on the data held by computer will enable a third party to link the data to you. A study ID number will be assigned to you and this will appear on all data. All data will be kept strictly confidential and secured under lock and key. The data will be stored for 2 years after the study has been completed. The results of this study may be published in journals or presented at conferences; however, no personal details will be revealed. A report of the findings of the research will be sent to all interested participants.

Ethics Committee Review

All proposals for research using human participants are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the University of Leicester, School of Psychology Ethics Board.

Thank you for taking the time to read this. If you decide to take part you will be given a copy of this information sheet and a signed consent form to keep.



**CONFIDENTIAL
INFORMATION SHEET**

ਸਿੱਖ ਅਤੇ ਡਿਮੈਂਸ਼ੀਆ (dementia)

ਪੁੱਛ ਪੜਤਾਲ ਕਰਤਾ:	ਗੋਬਿੰਦਰਜੀਤ ਉਪੱਲ
ਸੁਪਰਵਾਈਜ਼ਰ:	Dr Sheila Bonas Dr Helen Philpott
ਸੰਪਰਕ ਵੇਰਵਾ:	104 Regent Road, Leicester, LE1 7LT. 0116 223 1648

ਆਪ ਨੂੰ ਰਿਸਰਚ ਸਭਦੀ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਦਾ ਦਿੱਤਾ ਜਾਂਦਾ ਹੈ | ਫੈਸਲਾ ਕਰਨ ਤੋਂ ਪਹਿਲਾਂ ਇਹ ਸਮਝਣਾ ਬਹੁਤ ਜ਼ਰੂਰੀ ਹੈ ਕਿ ਇਹ ਰਿਸਰਚ ਕਿਉਂ ਕੀਤੀ ਜਾ ਰਹੀ ਹੈ | ਇਸ ਵਿੱਚ ਕੀ ਕੁਝ ਆਉਂਦਾ ਹੈ ?

ਕ੍ਰਿਪਾ ਕਰਕੇ ਹੇਠ ਲਿਖੀ ਜਾਣਕਾਰੀ ਚੰਗੀ ਤਰਾਂ ਪੜ੍ਹ ਲਵੋ ਅਤੇ ਜੇਕਰ ਚਾਹੋ ਤਾਂ ਦੂਜਿਆਂ ਨਾਲ ਵੀ ਵਿਚਾਰ ਵਿਦਾਂਦਰਾ ਕਰ ਲਵੋ | ਜੇਕਰ ਕੁਝ ਸ਼ਪਸੱਟ ਨਹੀਂ ਜਾਂ ਹੋਰ ਜਾਣਕਾਰੀ ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਸਾਡੇ ਨਾਲ ਗੱਲ ਬਾਤ ਕਰ ਸਕਦੇ ਹੋ | ਇਸ ਰਿਸਰਚ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣਾ ਹੈ ਜਾਂ ਨਹੀਂ ਇਸ ਬਾਰੇ ਚੰਗੀ ਤਰਾਂ ਸੋਚ ਲਵੋ |

ਇਸ ਸਟੱਡੀ ਦਾ ਉਦੇਸ਼ ਕੀ ਹੈ ?

ਸਿੱਖ ਕਮਿਊਨਿਟੀ ਵਿੱਚ ਇਸ ਬਿਮਾਰੀ ਡਿਮੈਂਸ਼ੀਆ (dementia) ਬਾਰੇ ਰਿਸਰਚ ਬਹੁਤ ਘੱਟ ਹੈ |

ਇਸ ਸਟੱਡੀ ਦਾ ਮਕਸਦ ਸਿੱਖ ਲੋਕਾਂ ਕੋਲੋਂ ਇਸ ਬਿਮਾਰੀ ਬਾਰੇ ਪੁੱਛ ਪੜਤਾਲ ਕਰਨਾ ਕਿ ਉਹ ਇਸ ਡਿਮੈਂਸ਼ੀਆ (dementia) ਬਾਰੇ ਕੀ ਜਾਣਦੇ ਹਨ | ਉਨ੍ਹਾਂ ਦੇ ਧਾਰਮਿਕ, ਅਧਿਆਤਮਿਕ ਅਤੇ ਸਾਹਿਤਕ ਕਲਚਰਲ ਪਿਛੋਕੜ ਇਸ ਡਿਮੈਂਸ਼ੀਆ (dementia) ਨੂੰ ਕਿਵੇਂ ਸਮਝਦਾ ਹੈ | ਜੋ ਜਾਣਕਾਰੀ ਆਪ ਦਿਉਗੇ ਇਸ ਨੂੰ ਭਵਿੱਖ ਵਿੱਚ ਨੈਸ਼ਨਲ ਹੈਲਥ ਸਰਵਿਸ (NHS) ਨੂੰ ਦੱਸਣ ਲਈ ਵਰਤੀ ਅਤੇ ਦੇਖ ਭਾਲ ਲਈ ਜਾਵੇਗੀ | NHS ਸਿੱਖਾਂ ਦੀਆਂ ਧਾਰਮਿਕ ਅਧਿਆਤਮਿਕ ਅਤੇ ਕਲਚਰਲ ਪਛਾਣ ਸਮਝ ਕੇ ਸਿੱਖਾਂ ਨੂੰ ਕੇਅਰ ਦੇਣ ਸਮਰਥ ਹੋ ਸਕੇਗੀ |

ਮੈਨੂੰ ਕਿਉਂ ਚੁਣਿਆ ਗਿਆ ਹੈ ?

ਤਹਾਨੂੰ ਇਸ ਸਟੱਡੀ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਇਸ ਕਰਕੇ ਚੁਣਿਆ ਗਿਆ ਹੈ ਕਿਉਂਕੇ ਆਪ ਸਿੱਖ ਕਮਿਊਨਿਟੀ ਨਾਲ ਸੰਬੰਧ ਰੱਖਦੇ ਹੋ ਅਸੀਂ ਆਪ ਦੇ ਵਿਚਾਰਾਂ ਦੀ ਵੀ ਕਰਦੇ ਹਾਂ |

ਕੀ ਮੈਨੂੰ ਇਸ ਵਿੱਚ ਜ਼ਰੂਰੀ ਹਿੱਸਾ ਲੈਣਾ ਪੈਣਾ ਹੈ ?

ਇਹ ਆਪਦੀ ਮਰਜ਼ੀ ਹੈ ਕਿ ਆਪ ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਜਾਂ ਨਹੀਂ |

ਜੇਕਰ ਆਪ ਹਿੱਸਾ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਆਪ ਨੂੰ ਜਾਣਕਾਰੀ ਸ਼ੀਟ ਰੱਖਣ ਲਈ ਅਤੇ ਇਜ਼ਾਜ਼ਤ (consent) ਫਾਰਮ ਤੇ ਦਸਤਖਤ ਕਰਨ ਲਈ ਦਿੱਤਾ ਜਾਵੇਗਾ | ਜੇਕਰ ਆਪ ਨੇ ਹਿੱਸਾ ਲੈਣ ਲਈ ਫੈਸਲਾ ਕੀਤਾ ਹੈ ਫਿਰ ਵੀ ਆਪ ਕਿਸੇ ਸਮੇਂ ਇਸ ਸਟੱਡੀ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣੋਂ ਇਨਕਾਰ ਕਰ ਸਕਦੇ ਹੋ | ਆਪ ਨੂੰ ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਨਾ ਲੈਣ ਲਈ ਕੋਈ ਕਾਰਣ ਨਹੀਂ ਪ੍ਰਦਿੱਤਾ ਜਾਵੇਗਾ |

ਇਸ ਸਟੱਡੀ ਵਿੱਚ ਕੀ ਕੁਝ ਆਉਂਦਾ ਹੈ?

ਜੇਕਰ ਆਪ ਇਸ ਸਟੱਡੀ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹੁੰਦੇ ਹੋ ਤਾਂ ਰਿਸਰਚਰ ਆਪ ਨੂੰ ਪੁੱਛੇਗਾ

ਕਿ ਆਪ ਕੋਲ ਕਦੋਂ ਸਮਾਂ ਹੈ | ਫਿਰ ਇਸ ਦਿਨ ਆਪ ਨੂੰ ਮੈਂਬਰਾਂ ਨਾਲ ਦਾ ਵਿਚਾਰ ਵਿਟਾਂਦਰੇ ਵਾਲਾ ਗਰੁੱਪ ਵਿੱਚ ਹਾਜ਼ਰ ਹੋਵੋਗੇ | ਇਹ ਵਿਚਾਰ ਵਿਦਾਂਦਰਾ ਇੱਕ ਘੰਟਾ ਲਗ ਭਗ ਚੱਲੇਗਾ | ਇਹ ਤੁਹਾਡੇ ਨਜ਼ਦੀਕ ਏਰੀਆ ਵਿੱਚ ਹੀ ਹੋਵੇਗਾ |

ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਦੇ ਕੀ ਫਾਇਦੇ (benefits) ਹਨ?

ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਦੇ ਇਸ ਸਮੇਂ ਤਾਂ ਕੋਈ ਫਾਇਦਾ ਨਹੀਂ ਪਰ ਇਹ ਉਮੀਦ ਕੀਤੀ ਜਾਂਦੀ ਹੈ ਕਿ ਇਸ ਨਾਲ ਦਿਮਾਗੀ ਸਿਹਤ ਸੁਧਾਰਨ ਪ੍ਰੋਫੈਸ਼ਨਲਾਂ ਦੇ ਗਿਆਨ ਵਿੱਚ ਵਾਧਾ ਅਤੇ ਸਿੱਖ ਕਮਿਊਨਿਟੀ ਨੂੰ ਸਮਝਣ ਵਿੱਚ ਅਤੇ ਡਿਮੈਂਸ਼ੀਆ (dementia) ਵਾਲੇ ਲੋਕਾਂ ਦੀ ਦੇਖ ਭਾਲ ਦੀ ਸੇਵਾ ਸੁਧਾਰਨ ਵਿੱਚ ਯੋਗਦਾਨ ਪਾਇਆ ਜਾ ਸਕੇਗਾ |

ਰਿਕਾਰਡਾਂ ਦੀ ਗੁਪਤਤਾ (Confidentiality of Records)

ਜੇ ਵੀ ਜਾਣਕਾਰੀ ਆਪ ਦਿਉਗੇ ਉਹ ਗੁਪਤ ਰੱਖੀ ਜਾਵੇਗੀ | ਮੁੱਖ ਪੜਤਾਲ ਕਰਤਾ ਸਕਿਊਰਿਟੀ ਅਤੇ ਜਾਣਕਾਰੀ ਬਾਰੇ ਜੁੰਮੇਵਾਰ ਹੋਵੇਗਾ | ਸਿਰਫ ਰਿਸਰਚਰ ਕਲੋ ਹੀ ਇਹ ਜਾਣਕਾਰੀ ਪੁੱਛੇ ਹੋਵੇਗੀ | ਇਕੱਠੀ ਕੀਤੀ ਜਾਣਕਾਰੀ ਸਾਂਭ ਕੇ ਰੱਖੀ ਜਾਵੇਗੀ | ਇਸ ਜਾਣਕਾਰੀ ਬਾਰੇ ਤੀਜੇ ਇਨਸਾਨ ਨੂੰ ਕੋਈ ਗਿਆਨ ਨਹੀਂ ਹੋਵੇਗਾ | ਆਪ ਦੀ ਜਾਣਕਾਰੀ ਤੇ ਸ਼ਨਾਖਤੀ ਨੰਬਰ ਲੱਗਾ ਹੋਵੇਗਾ | ਇਹ ਜਾਣਕਾਰੀ ਸਾਂਭ ਕੇ ਜਿੰਦਰੇ ਲੱਗੇ ਵਾਲੀ ਜਗਾ ਰੱਖੀ ਜਾਵੇਗੀ | ਇਹ ਸਾਰੀ ਜਾਣਕਾਰੀ ਦੋ ਸਾਲ ਲਈ ਰੱਖੀ ਜਾਵੇਗੀ | ਇਸ ਸਟੱਡੀ ਦੇ ਰਿਜ਼ਲਟ ਜਰਨਲ ਵਿੱਚ ਜਾਂ ਕਨਫਰੰਸਾਂ ਵਿੱਚ ਪੇਸ਼ ਕੀਤੇ ਜਾ ਸਕਦੇ ਹਨ | ਕਿਸੇਦੀਵੀ ਨਿੱਜੀ ਵੇਰਵਾ ਨਾਂ, ਪਤਾ ਆਦਿਕ ਨਹੀਂ ਦਿੱਤਾ ਜਾਵੇਗਾ | ਇਸ ਰਿਸਰਚ ਦੇ ਨਤੀਜੇ, ਸਾਰੇ ਲੋਕਾਂ ਜਿਨ੍ਹਾਂ ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲਿਆ ਹੈ ਨੂੰ ਭੇਜੇ ਜਾਣਗੇ |

ਨੈਤਿਕਤਾ ਕਮੇਟੀ ਰੀਵਿਊ (Ethics Committee Review)

ਇਸ ਰਿਸਰਚ ਵਿੱਚ ਮਨੁੱਖੀ ਹਿੱਸਾ ਲੈਣ ਵਾਲੇ ਅਗਲੀ ਕਾਰਵਾਈ ਤੋਂ ਪਹਿਲਾਂ ਨੈਤਿਕ ਕਮੇਟੀ ਹਾਹੀਂ ਰੀਵਿਊ ਕੀਤੇ ਜਾਂਦੇ ਹਨ | ਇਸ ਬਾਰੇ ਲਿਸਟਰ ਯੂਨੀਵਰਸਿਟੀ ਸਕੂਲ ਆਫ ਸਾਈਕਾਲੋਜੀ ਐਥਿਕਸ ਬੋਰਡ ਰਾਹੀਂ ਰੀਵਿਊ ਕੀਤਾ ਗਿਆ ਹੈ |

ਇਸ ਨੂੰ ਪੜਨ ਲਈ ਆਪ ਦੀ ਬੜੀ ਮੇਹਰਬਾਨੀ | ਜੇਕਰ ਆਪ ਪਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਆਪ ਨੂੰ ਇਸ ਜਾਣਕਾਰੀ ਦੀ ਸ਼ਟਿ ਦਿੱਤੀ ਜਾਵੇਗੀ ਅਤੇ ਸਹਿਮਤੀ ਦਾ ਫਾਰਮ ਦਸਤਖਤ ਕਰਕੇ ਰੱਖਣ ਲਈ ਦਿੱਤਾ ਜਾਵੇਗਾ |

Appendix H

Recruitment Posters (English & Punjabi)



University of Leicester

VOLUNTEERS NEEDED FOR RESEARCH ON SIKHS' VIEWS OF DEMENTIA

We are looking for volunteers to take part in a group discussion. **You do not need to know anything about dementia just be willing to discuss issues around it.** As a participant, you will be asked your views of dementia and how your religion/spirituality influences these views. The discussion will take approximately one hour.

The information you give us will be used to inform future NHS services and care provision.

If you are interested please pick up an information sheet below and **email/ring me if you would like to take part** or have any questions or queries gku1@le.ac.uk

Thank you!

This study has been reviewed by, and received ethics clearance through, Psychology Ethics Committee, University of Leicester.



University of Leicester

ਬਿਮਾਰੀ ਜਿਹੜੀ ਤੁਹਾਡੀ ਯਾਦਾਸ਼ਤ, ਧਿਆਨ ਅਤੇ ਬੋਲੀ ਤੇ ਅਸਰ ਪਾਉਂਦੀ ਹੈ (ਧਣਮਣਟਓ) ਬਾਰੇ ਸਿੱਖਾਂ ਦੇ ਵਿਚਾਰ ਜਾਨਣ ਲਈ ਵਲੰਟੀਅਰਾਂ ਦੀ ਲੋੜ ਹੈ ॥

ਗਰੁਪ ਵਿਚ ਵਿਚਾਰ ਵਿਟਾਂਦਰਾ ਕਰਨ ਲਈ ਅਸੀਂ ਵਲੰਟੀਅਰ ਦੀ ਭਾਲ ਵਿਚ ਹਾਂ ॥ ਵਲੰਟੀਅਰ ਦੇ ਤੌਰ ਤੇ ਆਪ ਕੋਲੋਂ ਬਿਮਾਰੀ ਜਿਹੜੀ ਤੁਹਾਡੀ ਯਾਦਾਸ਼ਤ, ਧਿਆਨ ਅਤੇ ਬੋਲੀ ਤੇ ਅਸਰ ਪਾਉਂਦੀ ਹੈ (ਧਣਮਣਟਓ) ਬਾਰੇ ਸਵਾਲ ਪੁਛੇ ਜਾਣਗੇ ॥ ਤੁਹਾਡਾ ਧਰਮ ਇਨ੍ਹਾਂ ਖਿਆਲਾਂ ਤੇ ਕਿਵੇਂ ਪ੍ਰਭਾਵ ਪਾਉਂਦਾ ਹੈ? ਇਸ ਗੱਲ ਬਾਤ ਨੂੰ ਇੱਕ ਘੰਟੇ ਦਾ ਸਮਾਂ ਲੱਗ ਸਕਦਾ ਹੈ ॥

ਜੇਕਰ ਆਪ ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਦੇ ਚਾਹਵਾਨ ਹੋ ਤਾਂ ਹੇਠ ਲਿਖੇ ਸਵਾਲ ਪੜ੍ਹੋ ॥ ਹੋਰ ਜਾਣਕਾਰੀ ਲਈ ਹੇਠ ਲਿਖੀ ਈਮੇਲ ਤੇ ਸੰਪਰਕ ਕਰ ਸਕਦੇ ਹੋ gku1@le.ac.uk

ਧੰਨਵਾਦ!

This study has been reviewed by, and received ethics clearance through, Psychology Ethics Committee, University of Leicester.

Appendix I

Participant Consent Form (English & Punjabi)



**CONFIDENTIAL
CONSENT FORM**

Sikhs and Dementia

Investigators: Gobinderjit Uppal
Supervised by: Dr Sheila Bonas
Dr Helen Philpott
Contact details: 104 Regent Road,
Leicester,
LE1 7LT.
0116 223 1648

Please read the following statements and initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

4. I understand that all data will be kept strictly confidential to this research.

5. I agree to take part in the above study.

Signed _____ Date _____

Full Name in Block Letters _____

Signed (Investigator) _____ Date _____

Full Name in Block Letters _____



**CONFIDENTIAL
CONSENT FORM**

ਸਿੱਖ ਅਤੇ ਡਮਿੰਸ਼ੀਆ (dementia)

ਪੁੱਛ ਪੜਤਾਲ ਕਰਤਾ: ਗੋਬਿੰਦਰਜੀਤ ਉਪੱਲ
ਸੁਪਰਵਾਈਜ਼ਰ: Dr Sheila Bonas
Dr Helen Philpott
ਸੰਪਰਕ ਵੇਰਵਾ: 104 Regent Road,
Leicester,
LE1 7LT.
0116 223 1648

ਕਿਰਪਾ ਕਰਕੇ ਹੇਠ ਲਿਖੀਆਂ ਗੱਲਾਂ ਪੜ੍ਹੋ ਤੇ ਬਕਸੇ ਵਿੱਚ ਆਪਣਾ ਨਾਂ ਪਾਉ

1. ਮੈਂ ਤਸਦੀਕ ਕਰਦਾ/ਕਰਦੀ ਹਾਂ ਕਿ ਉਪਰ ਲਿੱਖੇ ਬਾਰੇ ਜਾਣਕਾਰੀ ਸ਼ੀਟ ਪੜ੍ਹੀ ਹੈ ਅਤੇ ਸਮਝਦਾ ਹੈ ਅਤੇ ਸਵਾਲ ਪੁੱਛਣ ਦਾ ਮੌਕਾ ਮਿਲਿਆ ਸੀ |
2. ਮੈਂ ਇਹ ਤਸਦੀਕ ਕਰਦਾ/ਕਰਦੀ ਹਾਂ ਕਿ ਮੇਰੇ ਕੋਲ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਸ਼ਾਮਲ ਹੋਣ ਲਈ ਜਾਂ ਨਾ ਹੋਣ ਲਈ ਫੈਸਲਾ ਕਰਨ ਲਈ ਕਾਫੀ ਸਮਾਂ ਸੀ |
3. ਮੈਂ ਸਮਝਦਾ ਹਾਂ ਕਿ ਮੇਰਾ ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣਾ ਵਲੰਟੀਅਰ ਹੈ, ਮੈਨੂੰ ਪੂਰੀ ਅਜ਼ਾਦੀ ਹੈ ਕਿ ਮੈਂ ਕਿਸੇ ਸਮੇਂ ਬਗੈਰ ਕਾਰਣ ਦਿੱਤਿਆ ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਤੋਂ ਇਨਕਾਰ ਕਰ ਸਕਦਾ ਹਾਂ |
4. ਮੈਨੂੰ ਪਤਾ ਹੈ ਕਿ ਸਾਰੀ ਜਾਣਕਾਰੀ ਗੁਪਤ ਰੱਖੀ ਜਾਵੇਗੀ |
5. ਮੈਂ ਇਸ ਰਿਸਰਚ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤੀ ਪ੍ਰਗਟਾਉਂਦਾ ਹਾਂ |

ਦਸਤਖਤ: _____ ਮਿਤੀ: _____

ਪੂਰਾ ਨਾਂ (ਵੱਡੇ ਅੱਖਰਾਂ ਵਿੱਚ): _____

ਦਸਤਖਤ (investigator): _____ ਮਿਤੀ: _____

ਪੂਰਾ ਨਾਂ (ਵੱਡੇ ਅੱਖਰਾਂ ਵਿੱਚ): _____

Appendix J

Demographic Questionnaire (English & Punjabi)

Demographic Questionnaire – English

What is your age?

- 25 or under
- 26-40
- 41- 55
- 56 or older

What is your gender?

- Female
- Male

Are you

- Amritdhari Sikh
- Sehajdhari Sikh
- Other (please state)

What is your country of birth?

- United Kingdom
- Other (please state)

What is your current marital status?

- Divorced
- Living with another

- Married
- Separated
- Single
- Widowed
- Would rather not say

To which of the following ethnic groups would you say you belong to?

- White
- Black Caribbean
- Black African
- Indian
- Pakistani
- Bangladeshi
- Other (please state)

What is your primary language?

- Punjabi
- English
- Other

What is the highest level of education you have completed?

- Secondary School
- Vocational/technical school (2 year)
- College
- Bachelor's degree
- Master's degree
- Doctoral degree
- Professional degree
- Other

Which of the following best describes the setting in which you live?

- Private residence
- Partially supported living (retirement village)
- Fully supported living (hostel)
- Other

Who else lives in your household?

- No one else
- Spouse/partner
- Parents
- Children
- Brothers/Sisters
- Other relatives
- Non-family members

Thank you for taking the time to complete this questionnaire!

Demographic Questionnaire – Punjabi

ਆਪ ਦੀ ਉਮਰ (age) ਕੀ ਹੈ?

- 25 ਸਾਲ ਜਾਂ ਘੱਟ
- 26 – 40
- 41- 55
- 56 ਜਾਂ ਇਸ ਤੋਂ ਉੱਪਰ

ਆਪ ਦਾ ਲਿੰਗ ਕੀ ਹੈ?

- ਇਸਤਰੀ
- ਮਰਦ

ਕਿਸੇ ਇੱਕ ਤੇ ਟਿਕ ਲਾਵੋ (please tick one)?

- ਅੰਮ੍ਰਿਧਾਰੀ
- ਸਹਿਜਧਾਰੀ
- ਹੋਰ (other)

ਤੁਸੀਂ ਕਿਸ ਮੁਲਕ ਵਿੱਚ ਜਨਮੇ ਸੀ?

- ਯੂਕੇ
- ਹੋਰ (other)

ਆਪ ਦੀ ਵਿਆਹ ਦੀ ਅਵੱਸਥਾ ਕੀ ਹੈ (current marital status)?

- ਤਲਾਕਸ਼ੁਦਾ

- ਹੋਰ ਕਿਸੇ ਨਾਲ ਰਹਿ ਰਿਹਾ
- ਵਿਆਹਿਆ ਹੋਇਆ
- ਇੱਕਲਾ / ਅਣਵਿਆਹਿਆ
- ਘਰ ਵਾਲੀ / ਘਰ ਵਾਲਾ ਗੁਜਰ ਚੱਕਾ
- ਕੁਝ ਨਹੀਂ ਕਹਿਣਾ

ਕਿਸੇ ਇੱਕ ਤੇ ਟਿਕ ਲਾਵੋ (please tick one)?

- ਗੋਰਾ
- ਕਾਲਾ / ਕੈਰੀਬਿਅਨ
- ਕਾਲਾ ਅਫਰੀਕਨ
- ਇੰਡੀਅਨ
- ਪਾਕਿਸਤਾਨੀ
- ਬੰਗਲਾਦੇਸ਼ੀ
- ਹੋਰ

ਆਪ ਦੀ ਮੁਢਲੀ ਜੁਬਾਨ ਕਿਹੜੀ ਹੈ?

- ਪੰਜਾਬੀ
- ਅੰਗਰੇਜ਼ੀ
- ਹੋਰ

ਆਪ ਕਿੰਨੇ ਪੜ੍ਹੇ ਹੋ?

- ਹਾਈ ਸਕੂਲ
- ਤਕਨੀਕਲ ਸਕੂਲ
- ਕੁਝ ਕਾਲਜ

- ਡਿਗਰੀ
- ਮਾਸਟਰ ਡਿਗਰੀ
- ਡਾਕਟਰਲ ਡਿਗਰੀ
- ਪ੍ਰੋਫੈਸਨਲ ਡਿਗਰੀ
- ਹੋਰ

ਆਪ ਕਿਹੋ ਜਿਹੇ ਘਰ ਵਿੱਚ ਰਹਿੰਦੇ ਹੋ?

- ਪ੍ਰਾਈਵੇਟ ਰਿਹਾਇਸ਼ (private)
- ਰਿਟਾਇਰਮੈਂਟ ਪਿੰਡ (retirement village)
- ਹੋਸਟਲ (hostel)
- ਹੋਰ

ਆਪ ਦੇ ਘਰ ਵਿੱਚ ਹੋਰ ਕੌਣ ਰਹਿੰਦਾ ਹੈ?

- ਕੋਈ ਵੀ ਨਹੀਂ
- ਘਰ ਵਾਲੀ / ਵਾਲਾ ਜਾਂ ਪਾਰਟਨਰ
- ਬੱਚੇ
- ਭਰਾ / ਭੈਣ
- ਦੂਸਰੇ ਰਿਸਤੇਦਾਰ
- ਨੌਨ ਫੈਮਲੀ ਮੈਂਬਰ

ਇਹ ਫਾਰਮ ਭਰਨ ਲਈ ਸਮਾਂ ਲਾਉਣ ਵਿੱਚ ਆਪ ਦੀ ਬੜੀ ਮੇਹਰਬਾਨੀ!

Appendix K

Introduction to Focus Group Discussions

Good afternoon and welcome. Thanks for taking the time to join this discussion on Sikh individuals' understanding and awareness of dementia. My name is Gobinderjit Uppal and I work for the NHS as a trainee clinical psychologist.

You were invited because you are all Sikh adults living in Leicester/Derby and I'd like to hear your views. There are no right and wrong answers and people will have different points of view. Please feel free to share your point of view even if it differs from what others have said. The discussion today is not about reaching a consensus but about understanding everyone's views.

I will be recording the session, as I don't want to miss any of your comments. No names will be included in the write-up. Your comments are confidential.

I'm interested in hearing from each of you but there will be times where I may have to move the discussion on due to the limited time we have today and I hope you understand this.

If you have a mobile please put it on quiet mode.

Any questions before we begin?

I'm going to give each of you a scenario to read and then we're going to get your thoughts on what you think is happening here.

Appendix L

Dementia Vignette for Focus Groups (English & Punjabi)

Dementia Vignette – English

Sarbjit Kaur is an Amritdhari woman who lives with her Amritdhari husband and Sehajdhari (non- Amritdhari) son and daughter-in-law who describe themselves as ‘modern’. She is in reasonably good physical health.

For the past 3–4 years, her family has noticed that she is becoming more and more withdrawn, inactive, careless about her appearance and has become very forgetful, often not recognising close family members. However, she does remember details of her younger days and can spend hours talking about the events of her youth, even though she frequently forgets things that have happened yesterday.

She does not go out now and spends most of her time in her room seeming to be doing nothing in particular. The family have noticed that when she is left on her own, she mutters and mumbles to herself. When asked what she is talking about she does not reply.

She sometimes wakes up at odd hours of the night and starts getting ready for the day, insisting that it is morning. Her family has a hard job persuading her to get back to bed at these times.

Dementia Vignette - Punjabi

ਸਰਬਜੀਤ ਕੌਰ ਇਕ ਅੰਮ੍ਰਿਤਧਾਰੀ ਔਰਤ ਹੈ ਜੋ ਅਪਣੇ ਪਤੀ ਪੁੱਤਰ ਤੇ ਨੂੰਹ ਨਾਲ ਰਹਿੰਦੀ ਹੈ। ਉਸਦੀ ਸਰੀਰ ਦੀ ਸਿਹਤ ਕਾਫੀ ਚੰਗੀ ਹੈ। ਪਿਛਲੇ ੩ - ੪ ਸਾਲਾਂ ਤੋਂ ਉਸਦੇ ਪ੍ਰਵਾਰ ਦੇ ਧਿਆਨ ਵਿੱਚ ਆਇਆ ਹੈ ਕਿ ਉਹ ਆਪਣੀ ਸ਼ਕਲ ਬਾਰੇ ਕੋਈ ਧਿਆਨ ਨਹੀਂ ਦਿੰਦੀ ਤੇ ਉਹ ਅੱਗੇ ਨਾਲੋਂ ਘੱਟ ਕੰਮ ਕਾਰ ਕਰਦੀ ਹੈ। ਉਸਦਾ ਚੇਤਾ ਵੀ ਬਹੁਤ ਮਾੜਾ ਹੋ ਗਿਆ ਹੈ। ਉਹ ਕਦੀ ਕਦੀ ਪ੍ਰੀਵਾਰ ਦੇ ਮੈਂਬਰਾਂ ਨੂੰ ਪਛਾਣਦੀ ਨਹੀਂ। ਫਿਰ ਵੀ ਉਹ ਆਪਣੇ ਜਵਾਨੀ ਦੇ ਦਿਨਾਂ ਦੀਆਂ ਬਹੁਤ ਗੱਲਾਂ ਕਰਦੀ ਹ ਅਤੇ ਘੰਟਿਆ ਬੱਧੀ ਇਸ ਬਾਰੇ ਗੱਲਾਂ ਕਰਦੀ ਰਹਿੰਦੀ ਹੈ। ਪਰ ਉਸ ਨੂੰ ਕੱਲ੍ਹ ਹੋਈਆਂ ਗੱਲਾਂ ਦਾ ਚੇਤਾ ਭੁੱਲ ਜਾਂਦਾ ਹੈ।

ਉਹ ਹੁਣ ਘਰੋਂ ਬਾਹਰ ਨਹੀਂ ਜਾਂਦੀ। ਸਾਰਾ ਦਿਨ ਆਪਣੇ ਕਮਰੇ ਵਿੱਚ ਬੈਠੀ ਰਹਿੰਦੀ ਹੈ। ਪ੍ਰਵਾਰ ਦੇ ਧਿਆਨ ਵਿੱਚ ਆਇਆ ਹੈ ਕਿ ਜਦ ਉਹ ਇਕੱਲੀ ਬੈਠੀ ਹੁੰਦੀ ਹੈ ਤਾਂ ਅਪਣੇ ਆਪ ਹੀ ਮੂੰਹ ਵਿੱਚ ਗੱਲਾਂ ਕਰਦੀ ਰਹਿੰਦੀ ਹੈ। ਜਦੋਂ ਉਸਨੂੰ ਪੁੱਛਿਆ ਜਾਂਦਾ ਹੈ ਕਿ ਉਹ ਕੀ ਗੱਲਾਂ ਕਰਦੀ ਹੈ ਤਾਂ ਕੋਈ ਜਵਾਬ ਨਹੀਂ ਦਿੰਦੀ।

ਕਦੀ ਕਦੀ ਉਹ ਅਜੀਬ ਸਮੇਂ ਰਾਤ ਨੂੰ ਇਹ ਸਮਝਦਿਆਂ ਉਠ ਪੈਂਦੀ ਹੈ ਕਿ ਦਿਨ ਚੜ੍ਹ ਗਿਆ ਹੈ ਅਤੇ ਤਿਆਰ ਹੋਣ ਲੱਗ ਪੈਂਦੀ ਹੈ। ਉਸਦਾ ਪ੍ਰਵਾਰ ਉਸਨੂੰ ਦੁਆਰਾ ਸੌਣ ਲਈ ਮਨਾਉਣ ਵਿੱਚ ਮਸ਼ਕਿਲ ਸਮਝਦਾ ਹੈ।

Appendix M

Focus Group discussion guide

I would like to ask you about the family in the story - there are no right or wrong answers, please just say what you think

Can you tell me what you think some of the problems are for this family?
(Anything else? Was that new to anyone?)

Do you think these problems are unusual, or are they often found in families?

What do you think they might do to help solve the problems? (Anything else?
Was that new to anyone?)

Who could they talk to for advice? (Anything else? Was that new to anyone?)

What sort of help might be available for them? (Anything else? Was that new to anyone?)

If you were asked to write an end to this story, what do you think they would actually do in order to manage looking after Sarbjit?

Why do you think they would do that? Why do you think they wouldn't do some of the things that you said might help?

Doctors would describe Sarbjit as having the illness dementia -I would like to know what you know about dementia. Lots of people don't know much about this illness, so it is really helpful if you tell me when some of the things that come up are new to you.

Can you tell me how you would know if someone had dementia? (Anything else?
Was that new to anyone?)

What do you think causes dementia? (Anything else? Was that new to anyone?)

What sorts of people get dementia? (Anything else? Was that new to anyone?)

If her GP had told Sarbjit she had dementia, what do you think that would mean to Sarbjit? (What might she think? How would she feel? What would she do?)

And what would it mean to her family? (What might they think? How would they feel? What would they do?)

What do you think the GP would do to help Sarbjit (Anything else? Was that new to anyone?)

What do you think that doctors or other health and social care services should offer to families like Sarjit's? (Anything else?)

Sarbjit and her family are Sikhs.

Do you think that being a Sikh would affect how Sarbjit experiences her condition? (What would she think, feel, do? Why? How?)

Do you think that being Sikh would affect how her family look after her? (What would they think, feel, do? Why? How?)

Do you think there would be any differences in the way her husband would look after her compared to her son and daughter-in-law? (Why? How?)

Do you think that the nature of dementia as an illness raise any particular issues for Sikhs? (What? Why?)

Do you think that being Sikh would affect how they cope with the problems that arise from Sarbjit's condition (Why? How?)

This is what Sarbjit could actually be offered by health and social care services in this area:

- Medication from her psychiatrist.
- Further assessment from Clinical Psychology – memory strategies, ways of managing and coping with changes.
- Carers assessment by Social Services which may mean more support allocated for her care including respite care, monetary allowance.
- Needs assessment by Social Services that may lead to day centre placement for Sarbjit.
- Support from organisations in the area for both Sarbjit and her family such as Alzheimer's Society, Carer's groups.

Which of these services would Sarbjit and her family be likely to actually use? Why/why not?

What sort of additional services would help Sarbjit and her family that take into account their beliefs and values as Sikhs? (anything else? what could GPs do, what could other health services do? what could the community do?)

Appendix N
Example of Line-by-Line Coding

G: Why do you think that is, why do you think there's this kind of, you mentioned it before about people knowing outside of the family. Why do you think people don't speak up about it?

P1: I think they think that...

Negative community perceptions

P2: Other people sort of look down on it.

P1: Yeah that they don't take care of her or it was their problem, or they created it or it might be its not got nothing to do with them. They just feel like they let her down and erm if she's got a serious, you know any problems that it will just look bad on their family.

Blame on the family for dementia

Stigma by family association

P2: Yeah it's a lot about pride...appearances in the community.

Community perceptions matter

P1: Its because no-one has an understanding of why you get it, its to do with you you know your own body. But they sometimes believe that other people create mental illnesses or there's issues in the house that has made her this way.

Lack of understanding. Blame

P2: Yeah I think that's the first thing, like oh what have they done to her? That sort of thing, like they must have been neglecting her for her to sort of breakdown.

Lack of understanding exacerbates misunderstandings that other people are to blame for dementia onset

P1: They don't really talk about it, its one of those things that she's just got memory issues but they've never openly said dementia. Cos erm the daughter of the family, she's younger she talks about it more openly, she's not embarrassed. She's in the medical field and she understands that its something that, not what the family has brought on to her.

Difficulties are not spoken about

Appendix O

Example of a Theoretical Memo

Religion as a better way of coping

‘If they’re Amritdhari they can probably handle it probably better’

- Amritdharis can deal with it better than Sehajdharis based on meditation, prayer, getting advice from religious people. The groups so far have been majority Amritdhari participants, would the same be spoken about with a group of Sehajdhari? What would they use to cope?

However benefits reaped from religion depend on:

Belief in ‘Hukam’ and ‘Karam’. ‘It depends on how strong her Sikhi is’.

- So there seems to be a belief that religion can help but within that it depends on how strongly you believe in it and how much you acknowledge the causes (i.e. Karam – past deeds/actions). Implying that if you recognise a reason for this happening to you then it makes it easier to cope with dementia?

Emerging discussion about the practicalities of carrying out religious practices when someone has dementia – ‘if memory is poor how can someone recall that they need to do their Paath (prayers)’.

⇒ So what is being said here is that religious coping strategies help (religious) people deal with dementia better. However a caveat to this is that belief in religion and the use of these strategies are paramount in effective coping. Further data needed to look more closely at coping strategies.

Appendix P

Reflexive Diary Excerpt

23rd July 2011

“The fact that I am an Amritdhari felt very present today with both groups consisting of participants who are Sehajdhari. I felt as if I asked Sikh related questions with more hesitation such as ‘how does being a Sikh affect Sarbjit’. Reflecting back on this I think I was acutely aware of the presence of possible preconceptions they may have had about religion and ‘religious people’. Also I didn’t want participants to submit to demand characteristics of what they believe they should say in response to Sikh related questions just because an Amritdhari has asked them.

Interestingly how Sikhism was spoken about in these groups was very different to the other focus groups – one person mentioned yoga whilst in the older group the women saw that religion was useful but with medication as well. In the latter group the participants were very questioning of religion and even said that although it is recognised in the community as being used by Sikhs, they wondered how much it really could help. I wonder whether their beliefs in medication are much stronger than come across in the group and whether they commented they could see the use of religion because of my ‘religious status’. I think that I was surprised to hear about was one of the older participants reporting that the dementia presentation may have been due to the fact that the woman did not want to be Amritdhari any more and felt trapped. That’s so interesting and I’ve never thought about it like that. It seems really interesting how Sehajdhari see being Amritdhari like a punishment. I suppose this makes me think that they felt comfortable enough to voice their true opinions about religion, it’s been really insightful and I wonder if this is a commonly held belief? If I had more time this would be the group to recruit in the future.

I also found that as the group members in the older group used a combination of English and Punjabi sometimes it was difficult for me to hold onto what they were saying and reflect it back to them in a way that was understandable. It seems my Punjabi brain has a very different style to my English brain”.

Appendix Q

Glossary of Punjabi Terms* used in the Study

Word used in focus groups	Dictionary Definition
Abhiyaas	To meditate, when there is a constant effort to tune the mind so that it can remain in the constant remembrance and contemplation of the Brahm.
Amrit	Literally translated as "nectar." It is composed of water and sugar and is stirred with a double-edged sword while prayers are spoken. Initiation into Sikhism involves drinking this ambrosial nectar.
Amritdhari	Refers to a Sikh who has been initiated or baptised as a Khalsa by taking "amrit" or "nectar" . "Dhari" mean "practitioner" or "endowed with" (lit. having taken). So an Amritdhari is one who has received baptismal vows of the Khalsa initiated by Guru Gobind Singh Ji (10 th Guru of the Sikhs).
Amritvela	Literally means the "ambrosial period". Amrit Vela is usually ascribed as anytime between 2am-6am.
Anand	Joy, happiness, pleasure.
Ardaas	Meaning a request, a supplication, a prayer, a petition or an address to a superior authority. It is a Sikh prayer that is done before performing or after undertaking any significant task; after reciting the daily Banis (prayers). The prayer is a plea to God to support and help the devotee with whatever he or she is about to undertake or has done.
Avastha	Spiritual state.
Avguns	Bad qualities that an individual may possess.
Bachan	An agreement or promise.
Bal Updesh	Literally translated as 'mighty one who preaches'. Step by step guide in learning Gurmukhi.
Bani	Short for Gurbani is the term used by Sikhs to refer to various sections of the Holy Text that appears in their several Holy Scriptures.
Bezurg	The elderly.
Bhaji	Respectful term for brother.
Bhenji	Respectful term for sister.
Bibi	Older woman.

Word used in focus groups	Dictionary Definition
Bimaari	Illness.
Brahmgiani	An illuminated Soul, a man who has realized God. One who has attained to the stage of having 'knowledge' or rather wisdom of God.
Char Sahibzaade	The word " <i>Sahibzaada</i> " means "son" in Punjabi and is a term commonly used to refer to the 4 sons of Guru Gobind Singh Ji (10 th Guru). Martyred at 6, 9, 14 and 18. The martyrdom of the four Sahibzaade is an important part of Sikh history and the occasion of their martyrdom is remembered and commemorated both with great vigor and acute sadness, by large numbers of Sikhs, every year in December.
Charana	'Charan' translates as feet but to touch another's feet is to be humble.
Chardi Kala	Means a "positive, buoyant and optimistic" attitude to life and the future. To remain in high spirits.
Chubban parash	Spicy powder in India that is good for digestion.
Damak	Mind.
Degh	The word "degh" means "large cooking pot" or "cauldron" or an "offering".
Dharam	Religion, righteousness, duty, virtue, merit, honesty, sect, justice, characteristics, faith.
Dukh	Pain.
Eshwar	Almighty God.
Gian	Wisdom.
Giani	Someone learned in the Sikh religion or knowledgeable in "Dharam" or "path of righteousness". The word Gian in Punjabi means Knowledge. So a "Giani" is someone who has spiritual and religious knowledge and can help the congregation in understanding of the Holy Scriptures.
Gore	Caucasians/White people.

Word used in focus groups	Dictionary Definition
Granthi	A ceremonial reader of the Guru Granth Sahib. Duties include arranging daily religious services, reading from the Sikh scripture, maintaining the gurdwara premises, and teaching and advising community members. A granthi is not equivalent to a minister as there are no such religious intermediaries in the Sikh religious tradition.
Gun	Good qualities/merits/virtues.
Gurbani	The revealed wisdom of the Sikh Gurus in their own words, found in the Guru Granth Sahib.
Gurdwara Sahibs	Translated as Guru's portal/ abode / House or Door. The word can be split into two: "Gur" or "Guru" referring to their Guru, Guru Granth Sahib i.e. Gurbani / Vaheguru / the word Shabad and "duwara" meaning "Door" of the "House".
Gurmukhi	Translated as "from the mouth of the Guru". Script for writing the Punjabi language, used in the Guru Granth Sahib (Sikh Holy Scriptures).
Gursikh	A Sikh devoted to the Guru.
Guru	A Guru is a teacher or enlightener who brings his followers (devotees) from darkness to light.
Guru Ghar	Literally translated "Home of the Guru". Any building or room dedicated to housing the devotional songs of the Guru for the purpose of spiritual practice;
Guru Gobind Singh Ji	The tenth and last living prophet of the Sikhs, he passed the guruship onto the Sikh scripture, the Guru Granth Sahib. Guru Gobind Singh Ji founded the order of the Khalsa during Vaisakhi 1699.
Guru Granth Sahib Ji	The Sikh scripture, written in poetry organized in 31 sections, with each section corresponding to a particular melodic scale, or raag. It includes the poetry of six Sikh Gurus, and 36 other saints, including Muslims and Hindus. It is 1430 pages long and is the embodiment of the spiritual knowledge and authority of all the Gurus. The words from the Guru Granth Sahib are the central focus at all Sikh Gurdwaras (Sikh places of worship).

Word used in focus groups	Dictionary Definition
Hukam	God's order/command. A decree by a high authority. Can also refer to a passage from the Guru Granth Sahib, selected by randomly opening the Sikh scripture during a daily ceremony. The passage is considered by Sikhs as the divine "command of the Guru" for the day.
Hunna	Slang term for yes.
Ishnaan	The act of washing/bathing.
Jap Ji Sahibs	Japji Sahib is the first sacred composition found in the main Sikh holy scripture called the Guru Granth Sahib. The word 'Jap' means to 'recite'/'to 'chant'/'to stay focused onto'. 'Ji' is a word that is used to show respect as is the word 'Sahib'.
Kabir Ji	A muslim devotee who contributed to the writings in Sri Guru Granth Sahib Ji.
Kant	Off by heart.
Karam	Act, action, deed, fate. It is a Sanskrit word and a concept of eastern religions meaning action, effect, destiny.
Katha	Verbal explanation of Sikh scriptures. Katha is the verbal explanation/discourse of Gurbani (the utterings of the Guru's).
Kirpa	Grace, kindness, blessing, mercy.
Kuprey	Clothes.
Maharaj /a	King/emperor (often used when referring to God).
Maharpurash/Mahapurakh	A well known religious person.
Mastane	Carefree, unbothered by the outside world.
Mata	Respectful word for older woman/grandmother. Mata translates as 'mother'.
Maya	Material wealth/money.
Mushkal	Difficult.
Naam	The need to remember God by repeating and focusing your mind on His name.

Word used in focus groups	Dictionary Definition
Naam Simran	Remembering God's name through meditation. This is a seminal form of worship for Sikhs. The continual remembrance of Naam.
Nana	Grandfather.
Nani	Grandmother.
Nitnem	Means "Daily routine or habit". Nitnem is a collaboration of different banis that were designated to be read by Sikhs every day. The Nitnem bani's usually include 5 bani's (prayers).
Paath	From the Sanskrit "patha" which means reading or recitation, is in the religious context, reading or recitation of the holy texts and refers to the recitation of Gurbani.
Pagal	Crazy, mad.
Pangtheya	Stanzas/sections of the scriptures.
Pyaar	Love.
Raam	Almighty God.
Rogue	Disease.
Roti/Rotia	Chapatti.
Sakhia	True stories.
Salok Mahela 9	Verses written by the 9 th Guru said to have been compiled before his martyrdom. The message of the slokas is fundamentally the same as that of the rest of the Sikh Scripture. Here, as everywhere else in the Guru Granth Sahib, the stress is on remembrance and contemplation of God and recitation of naam, i.e. God's Name.
Sangat	Congregation of the spiritual.
Santhya	The study of correct pronunciation and meaning of religious scriptures.
Sat Sri Akaal	A common Punjabi greeting, meaning "God is True and Timeless."

Word used in focus groups	Dictionary Definition
Sehajdhari	Like other Sikhs, the Sahajdharis believe in the Ten Gurus and in the Guru Granth Sahib, though they exempt themselves from obligations such as not cutting their hair, not eating meat as they have not received 'amrit' and are therefore not baptised.
Seva	Community service. A central aspect of Sikh theology; Selfless service, which is believed to bring one closer to God.
Shaheed	Martyr.
Sikhi	Sikhism in Punjabi is called 'Sikhi'.
Simran	Meditation, constant remembrance of God – Practicing the presence of God.
Sukhmani Sahib	'Peace in your mind/consoler of the mind' prayer signifying the soothing effect it has on the reader. Written by the 5 th Guru. Sukh literally means peace or comfort and mani means mind or heart.
Syana	Older, wiser person.
Tuks	Verses in the Holy Scriptures.
Vaheguru	Literally "the wonderful Lord". God.
Yakeen	Belief.

*The words in this glossary may not occur in the quotes used in the results but were present in the transcripts.

Appendix R

Ethics Committee Approval Letter

To: **GOBINDERJIT UPPAL**

Subject: Ethical Application Ref: **gku1-820d**

(Please quote this ref on all correspondence)

10/12/2010 14:41:12

Psychology

Project Title: Sikhs and Dementia: cultural, religious and spiritual constructions in this minority population.

Thank you for submitting your application, which has been considered.

This study has been given ethical approval, subject to any conditions quoted in the attached notes.

Any significant departure from the programme of research as outlined in the application for research ethics approval (such as changes in methodological approach, large delays in commencement of research, additional forms of data collection or major expansions in sample size) must be reported to your Departmental Research Ethics Officer.

Approval is given on the understanding that the University Research Ethics Code of Practice and other research ethics guidelines and protocols will be compiled with

- <http://www2.le.ac.uk/institution/committees/research-ethics/code-of-practice>
- <http://www.le.ac.uk/safety/>

The following is a record of correspondence notes from your application **gku1-820d**. Please ensure that any proviso notes have been adhered to :-

Dec 10 2010 11:25AM Dear Gobinderjit,

Your proposal has been reviewed by the School of Psychology Research Ethics Committee. The Committee recommended approving your application, subject to one area of clarification. Can you please explain how you will ensure that you have the appropriate permission or consent to recruit participants within the Sikh Gurdware?

Best wishes,
Melanie

Dec 10 2010 11:38AM Hi Dr Takarangi,

Thank you for reviewing my ethics application. In response to your note below, I have already informally approached the Presidents of several Gurdware in Leicester and Derby to inform them of the study and to check whether they would be happy for me to recruit from their respective Gurdware, consequently allowing me to advertise recruitment for my study. The individuals I have approached have supported the research and were more than willing and have given me a number of different groups/classes i.e. Punjabi

Appendix S

Research Chronology

Draft proposal submitted for Peer Review	September 2010
Revised proposal submitted to Research Ethics Committee.....	November 2010
Ethical approval received	December 2010
Participant recruitment	February - July 2011
Focus group 1 conducted.....	15 th April 2011
Focus group 2 conducted.....	24 th April 2011
Focus group 3 conducted.....	1 st May 2011
Focus group 4 conducted.....	15 th May 2011
Focus group 5 conducted.....	23 rd July 2011
Focus group 6 conducted.....	23 rd July 2011
Transcription and analysis completed.....	January 2012
Thesis write up.....	January - April 2012
Hand in of thesis.....	April 2012
Examination of Thesis by Viva	July 2012
Editing for journal and submission.....	Summer 2012