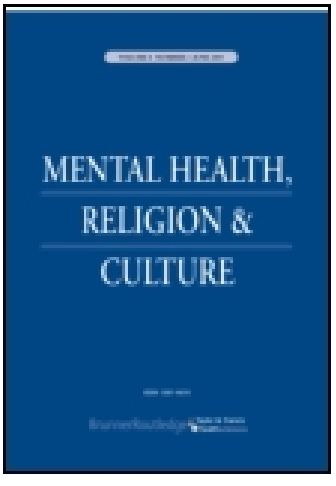

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Understanding and awareness of dementia in the Sikh community

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Previous literature confirms that older black minority ethnic populations are less likely than white populations to contact dementia services in the UK. However, it is unknown whether this is due to a higher or lower prevalence of dementia or due to different needs or coping strategies within these communities. The aim of this study was to explore the understanding and perceptions of dementia amongst Sikhs living in the UK. Six focus groups were involved with 28 Sikh participants who were recruited from Gurdware (Sikh places of worship). Data were analysed using constant comparative methodology. The themes reported in this paper include "awareness and interpretation of the characteristics of dementia", "multiple perspectives of the same symptoms" and "causes of dementia". The findings have been discussed in the context of existing research and provide an introductory insight into informing culturally appropriate interventions.

Keywords: dementia; religion; Sikh; South Asian; culture

Introduction

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" (Department of Health [DoH], 1989) document recognised that individuals from different cultural backgrounds 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.

Ethnic minorities and 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 white British 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 underutilise services in comparison with other groups.

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In an attempt to uncover possible reasons for the underutilisation 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 and 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, 44 of the 67 articles included in this review were originated from the USA, with African-Americans being the most frequently recruited ethnic population.

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, socio-economic 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). Insufficient consideration has been given to the possibility of intragroup diversity, with homogeneity within ethnic minorities being assumed instead (Uppal & Bonas, 2013). Variations in the history, culture and religion of groups can impact greatly on defining individual norms, values and experiences.

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. Similarly, Stuckey and Gwyer (2003) found that religion enabled participants to search for meaning in the face of dementia. A review by Regan, Bhattacharyya, Kevern, and Rana (2013) suggested that although religion assisted in positive coping it is likely to have impeded access to care for certain minority groups in comparison with the ethnic majority. Whilst the multidimensionality 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).

Sikhs

Sikhs form part of the global classification of "South Asians" as many originate from Punjab, India. Approximately 0.8% of the UK population is Sikh, making it the fourth largest religion in the UK (Census, 2011). Sikhism is a monotheistic religion and was founded in 1469 by the first Guru (teacher/enlightener), Guru Nanak Dev Ji with the Holy Scriptures of Sri Guru Granth Sahib Ji (1708) as the current living Guru.

Sikhs 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 Amritdhari (initiated) and Sehajdhari (uninitiated) Sikhs. An Amrtidhari is an individual who receives Amrit (nectar) and belongs to the order of Khalsa, a saint-soldier sect. They wear a uniform comprising of the 5 Ks – kesh (uncut hair), kanga (wooden comb), kara (iron bracelet), kachera (specific type of undergarment) and a kirpan (dagger). These symbols represent the ideals of Sikhism including honesty, equality, loyalty, meditating on God and helping others.

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 (Odutoye & Shah, 1999) or whether differences exist in the perceptions of the causes or symptoms or a general reticence to use health-care services within this community. The first Sikh migration occurred in the 1950s (Singh, Chadda, & Bance, 2007), meaning that these individuals are now likely to be reaching their 70s or 80s. Consequently, insights into the beliefs about dementia as held by the Sikh community may 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, Worth, Irshad, & Brown, 2009; Bowes & Wilkinson, 2003).

Aims

The aim of the proposed research was to recruit Sikh adults in the community in order to investigate their understanding and awareness of dementia, taking into account how their religious and cultural background may facilitate this understanding.

Methodology

Design

This was a qualitative study using a focus group methodology. 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).

Inclusion and exclusion criteria

All participants were over the age of 18 and 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. Participants identified themselves as Sikh.

Participants

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

Participants were recruited from Sikh Gurdware (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 displayed in Table 1. Of those that did not participate, 12 (30%) were aged 25 or under, 12 (30%) were between the ages of 26 and 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%)

Table 1. Demographic information of study participants and non-attendees[a].

Demographics	Frequency per cent (*N*, %) Participants (*N* = 28)	Non- participants (*N* = 40)
Age (year)		
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%

[a]Note: Note that individuals who signed the consent form but did not complete the demographic questionnaire are reported under "undisclosed".

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 (initiated Sikhs) and 13 (46%) were Sehajdharis (uninitiated Sikhs). In this study, there were six focus groups in total; three consisting of 18–25 year olds; two with 26–40 year olds and one with 41–55-year-old participants.

Procedure

Key people such as the presidents of the Sikh Gurdware (Sikh places of worship) and other prominent Sikh members of the community were approached in order to facilitate access to participants. Recruiting from minority ethnic religious groups can be challenging therefore multiple recruitment strategies were used (Mohammed, Jones, & Evans, 2008). All study literature was available in either English or Punjabi.

Individuals who were interested in taking part were given a consent form to sign after which they were asked to complete a demographic questionnaire that included information such as age, gender, language, education, marital status and ethnicity. Six focus groups took place in a quiet room in the Gurdwara and lasted between 37 minutes and an hour and four minutes. Groups consisted of between four and six 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 one researcher (GKU) was the only facilitator during these discussions it was felt that this number of participants was suitable.

All focus groups were audio-recorded. 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 (Figure 1). The vignette used in the current study was adapted from one that was devised in a previous study (La Fontaine, Ahuja, Bradbury, Phillips, & 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 was used to ensure that similar vignette-based discussions occurred throughout all groups.

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). Although this research 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 (Galdas & Kang, 2010).

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.

Figure 1. Dementia vignette.

Data collection occurred alongside data analysis so that previous focus group discussions were able to inform subsequent ones (Glaser, 1978). This process of data analysis also involved purposeful sampling of deviant cases, evident in the contradictory experiences arising alongside emerging themes (Strauss & Corbin, 1998).

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 co-authors (SB and HP). Regarding trustworthiness of the findings, quotes and verbatim extracts from the transcripts are included in the results to illustrate the themes that emerged. Peer review was also utilised as both co-authors simultaneously audited one of the transcripts.

As the focus group discussions occurred in English, Punjabi or both, one of the researchers (GKU) was responsible for the translation and transliteration of the Punjabi text in the transcripts into English. To ensure the validity of the translations, the researcher verified Punjabi words that arose in the groups 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.

Ethical approval

This research was approved by the School of Psychology Ethics Committee. Some ethical issues were noted to require consideration, specifically the sensitive nature of the discussions in the focus group. Participants would be signposted to discuss any concerns with their General Practitioner (GP).

Results

The themes that emerged in this research were grounded in the participant's words as is central to the method of constant comparison. Themes that arose included: "Awareness and Interpretation of the Characteristics of Dementia", "Multiple Perspectives of the Same Symptoms" and "Causes of Dementia". Figure 2 illustrates the main themes and their related sub-themes, each of which is explored in greater detail below.

It is important to note that the terms "Sehajdhari" and "non-Amritdhari" both mean "uninitiated Sikh". The original responses in transliterated Punjabi and their English translations are included in the quotations below.

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.

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.

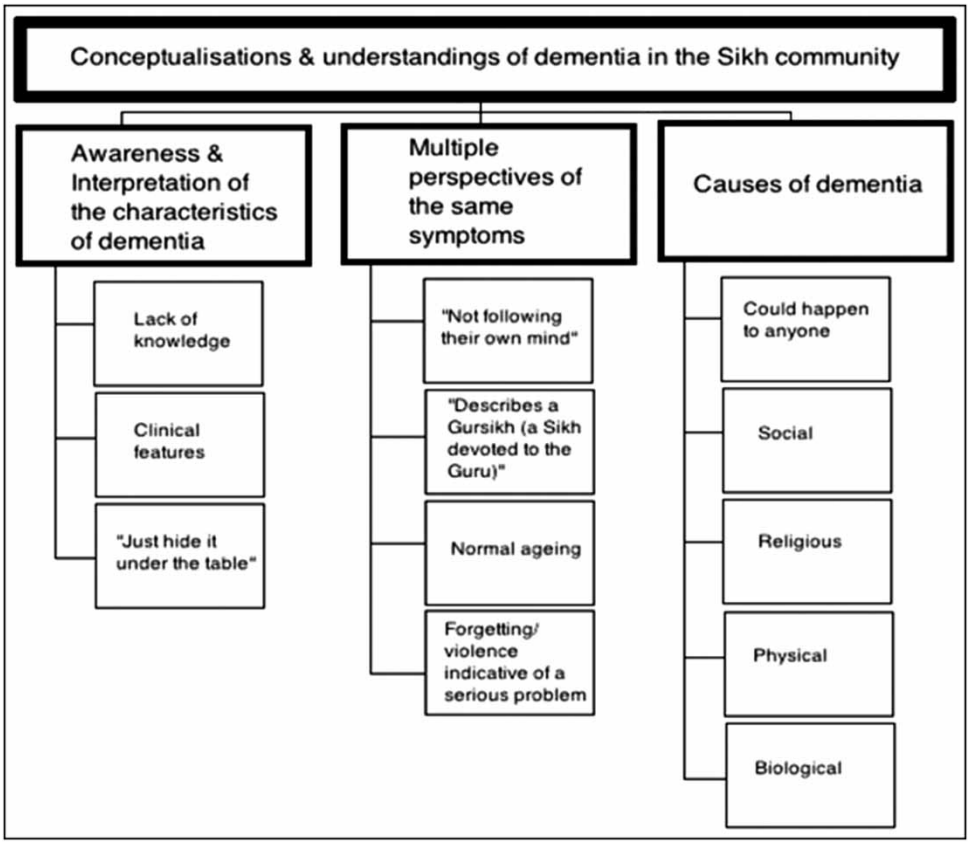

Figure 2. The themes that emerged from the focus group discussions.

> I've never really come across dementia, never really thought about it. I don't really know much about it. (18–25-year-old Amritdhari)

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. (18–25-year-old Amritdhari)

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. (41–55-year-old Sehajdhari)

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 and 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. (18–25-year-old Amritdhari)

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 and 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. (18–25-year-old Sehajdhari)

> 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]. (41–55-year-old Sehajdhari)

"Not talking about certain things just hide it under the table"

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

> 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. (18–25-year-old Sehajdhari)

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.

> 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]. (26–40-year-old Amritdhari)

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 joungay ki patha fir [If I tell them they may kick me out, then what]. (26–40-year-old Amritdhari)

Multiple perspectives of the same symptoms

This second theme emerged as participants made sense of the dementia vignette. Themes depicted different possible explanations for the presentation including, "not following their own mind", "describes a Gursikh (a Sikh devoted to the Guru)", "normal ageing" and "forgetting/violence as indicative of a serious problem".

"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. They believed that the woman in the vignette did not follow her own mind in becoming Amritdhari (initiated 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]. (41–55-year-old Sehjadhari)

"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. (26–40-year-old Amritdhari)

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. (26–40-year-old Amritdhari)

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. (18–25-year-old Sehajdhari)

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. (18–25-year-old Sehajdhari)

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. (18–25-year-old Sehajdhari)

Maybe if violence came into it or something I would start thinking something else. (18–25-year old Amritdhari)

Causes of dementia

Potential causes for the onset of dementia were grouped into four sub-themes as displayed in Figure 3.

"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, 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. (18–25-year-old Sehajdhari)

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

The ones with the higher level they probably wouldn't be in there anyway. (26–40-year-old Amritdhari)

Social

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

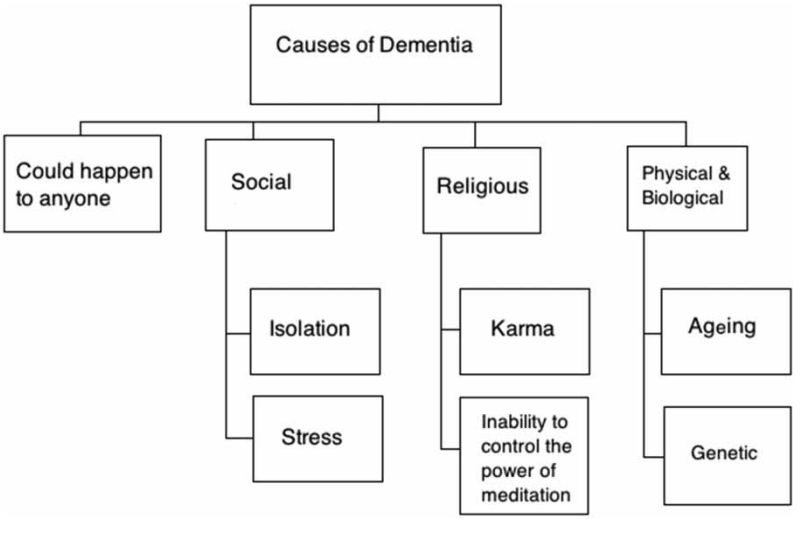

Figure 3. Causes of dementia as identified by Sikh participants.

> 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. (26–40-year-old Amritdhari)

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. (18–25-year-old Amritdhari)

However, one participant commented that some religious people do not let stress exist in their lives. A perceived cause of stress was a wish to earn more money, to own a bigger house, 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. (26–40-year-old Amritdhari)

Religious

Religious causes of dementia included the impact of "karam" (act, action, deed and 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]. (18–25-year-old Amritdhari)

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]. (26–40-year-old Amritdhari)

Physical and biological

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

> When you get to a certain age your body function declines and obviously dementia is like a neurodegenerative disease … So obviously its gonna impair your cognition of your brain, the way your brain works. So in that sense it's mainly age related. (18–25-year-old Sehajdhari)

Discussion

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

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 in the

community. Fascinatingly, there was a belief that the presentation in the vignette was temporary as the woman (with 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 white British populations (Nazroo, Fenton, Karlsen, & O'Connor, 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 everyday 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.

Multiple perspectives of the same symptoms

There were a variety of interpretations made by Sikh participants about the dementia symptoms in the vignette. Arguably the most interesting 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 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 et al., 2011) though undoubtedly hinders 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, 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. The oldest Sehjadhari group expressed a belief that symptoms experienced by the Amritdhari 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 initiated and uninitiated Sikhs, where Amritdharis are perceived as repressed and discontent.

Causes of dementia

Dementia was believed to have several potential causes, including "it could happen to anyone", social, religious, physical and biological factors. Sehajdhari participants were likely to assert that dementia could happen to anyone regardless of piety; however, Amritdharis disagreed with this. Similarly, Cinnirella and Loewenthal (1999) reported that some religious groups believed depression was impossible in the truly religious individual. George, Ellison and Larson (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 that participants in this study believed contributed to a dementia presentation comprised of increased isolation and experiences of stressful life events. Country of residence was also 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 greater experience of illness. Braun, Takamura, and Mougeot (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 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.

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 twofold; encouraging less contact with Western health services whilst allowing for a reduced sense of blame and stigmatisation as it was destined to happen.

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). Although poor diet, heavy alcohol use and lack of exercise have been widely reported as known risk factors for the onset of dementia in South Asian communities

(O'Loughlin, Maximova, Tan, & Gray-Donald, 2007) participants did not acknowledge any of these as potential causes of dementia.

Limitations and directions for future research

The present study was original in evidencing how Sikhs in the community conceptualise dementia and its focus on both Amritdhari and Sehajdhari. However, 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. Although only four individuals aged 41 and older old took part in the study, 16 had initially consented but failed to attend the focus groups. It may be useful to consider alternative methods of recruitment and participation to engage this age group.

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. Barriers to help seeking in the Sikh community may explain reduced Sikh presence in health-care services. Greater outreach work is needed to provide prevention information and education in order to inform Sikhs about dementia and available services (Kaur, Jutlla, Moreland, & Read, 2010). However, this study also highlights that the Sikh community is not homogenous in their perceptions about dementia, with differences exhibited between Amritdhari and Sehajdhari Sikhs.

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