

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

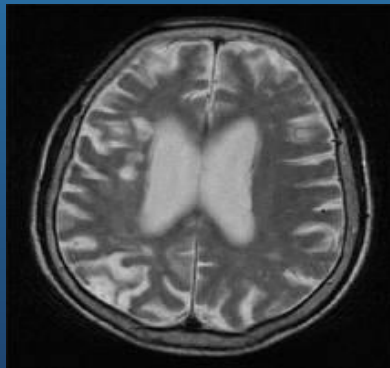
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Plan

- Background to the study
- Research aims
- Methodology
- Results - some of them!
- Discussion
- Clinical Implications
- Limitations

Background to the Study 1

- Progressive and irreversible degenerative deterioration.
- 850, 000 in the UK (Alzheimer's Research Trust, 2014).
- Assessment and person centred care (NICE guidelines, 2006).



Background to the the Study 2

- 25,000 in 2011 to 50,000 in 2026 (Alzheimer's Society).
- Second highest incidence (Barking & Dagenham NHS Trust, 2007).
- Dementia services are not meeting the standards for South Asians (Jolley, 2005; DoH, 2005).

Background to Study 3

- Lack of knowledge and understanding of dementia in South Asian communities (Patel et al. 1998).
- Who are South Asians?
- Religion and dementia (Mackinlay, 2001; Stuckey & Gwyther, 2003).
- Religious groups and beliefs about illness.

Background to Study 4

Why Sikhs?

- Derby (2.1%) & Leicester (4.2%).
- Sikh migration in 1950s
- Amritdharis (baptised Sikhs) and Sehajdharis (non-baptised Sikhs).
- ‘Chardi Kala’

‘Win the game of life, let your mind surrender and accept death’ (SGGS, Page 153)

Methodology 1

Design

- Focus groups (Kitzinger, 1995)

Participants

- Inclusion criteria
- 28 participants out of 68 agreed.
- 50% male, 50% female.
- 54% Amritdhari (baptised), 47% Sehajdhari (non-baptised).
- Participants Vs. Non-participants



Methodology 2

Procedure

- Leicester & Derby Gurdware (Sikh places of worship).
- 37 minutes - 64 minutes focus groups.
- 6 participants maximum.
- Focus group guide.
- Conversations in English & Punjabi.



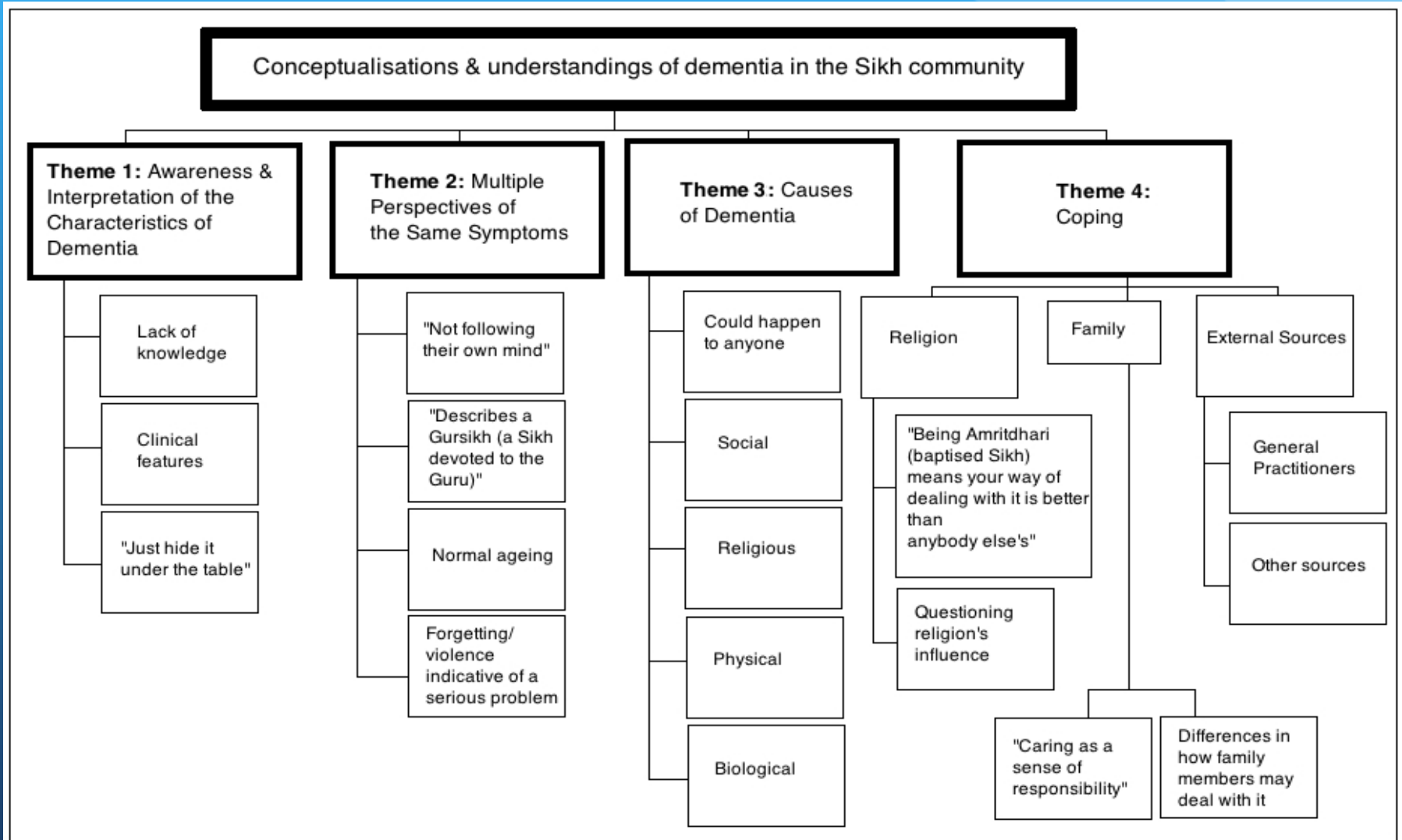
Methodology 4

Sarbjit Kaur is an Amritdhari (baptised Sikh) woman who lives with her Amritdhari husband and Sehajdhari (non- baptised Sikh) 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For the past 3-4 years, her family has noticed that she is becoming more and more withdrawn, inactive, careless about her appearance and has become very forgetful, often not recognizing close family members.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.

Results



Results Theme 1 - Multiple Perspectives of the Same Symptoms

- “Not following their own mind”.
- “Describes a Gursikh (a Sikh of the Guru)”.
- Normal ageing
- Violence/forgetting indicative of a serious problem.

Results - Multiple Perspectives of the Same Symptoms

“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 Sehajdhari).

Results - Multiple Perspectives of the Same Symptoms

“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.... they see it as pointless as they seek a higher meaning in life”

(26 - 40 year old Amritdhari).

Results - Multiple Perspectives of the Same Symptoms

“My grandma she’s very, she remembers a lot of er things from say years ago...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).

Results - Multiple Perspectives of the Same Symptoms

“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”

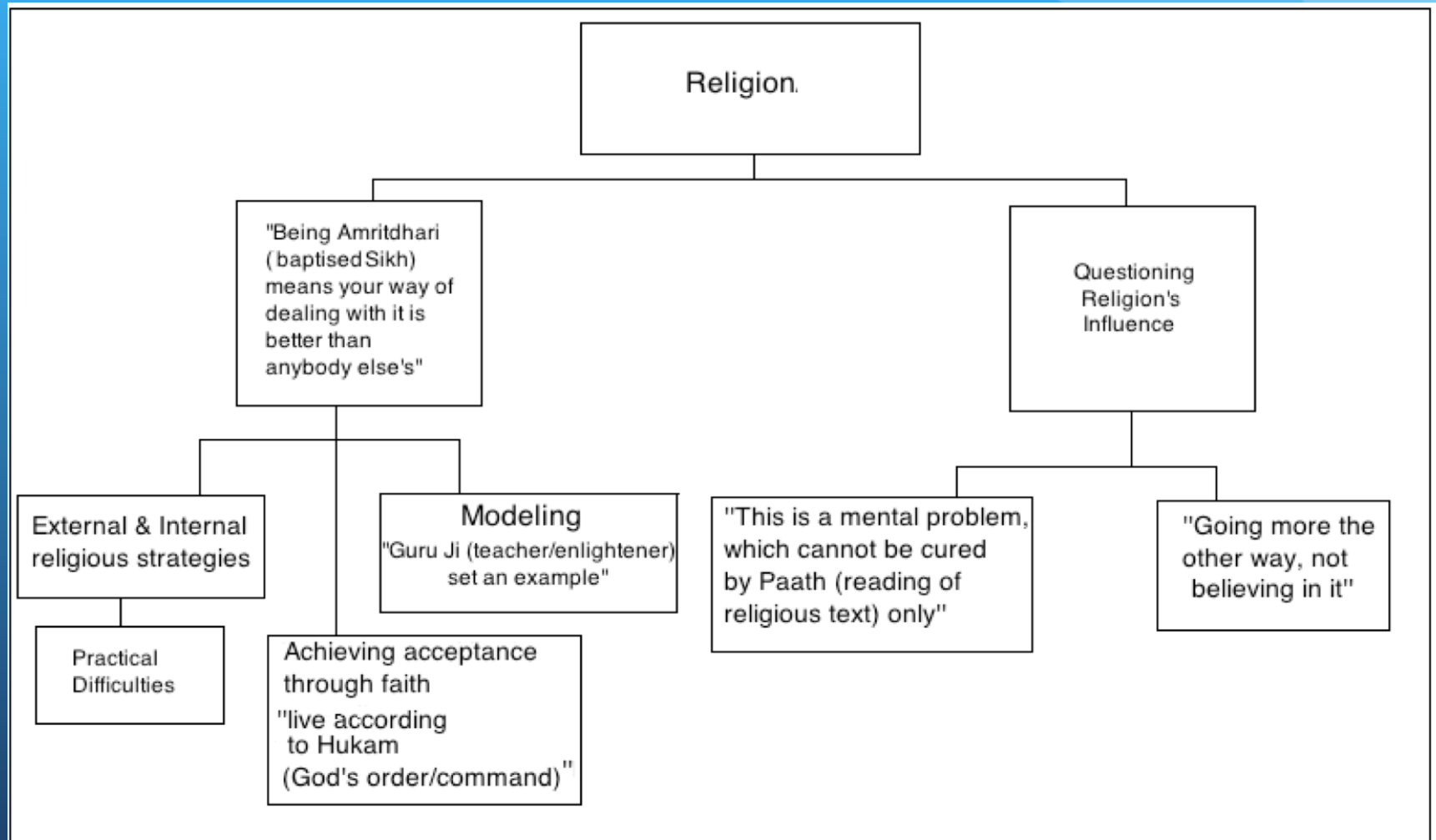
(18 - 25 year old Amritdhari).

Results Theme 2- Coping

- Managing with the dementia symptoms.
- Strong theme of religious coping
- Importance of family in the coping process.
- Sources of support outside of the community and their role in the coping process.



Results - Religious Coping



Results - Religious Coping

“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”

(18 - 25 year old Amritdhari).

Results - Religious Coping

“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”

(26 - 40 year old Amritdhari).

Results - Religious Coping

“The sets of values that Guru Ji [teacher/enlightener] has given us...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”

(26 -40 year old Amritdhari).

Results - Religious Coping

“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”

(41 - 55 year old Sehajdhari).

Results - Coping within Families

“Obviously we owe them a lot and in that sense we should be able to look after them”

(18 - 25 year old Sehajdhari).

“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”

(41 - 55 year old Sehajdhari).

Results - Coping within Families

“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] ...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”

(18 - 25 year old Amritdhari).

Results - External Sources of Coping

“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”

(18 -25 year old Amritdhari).

“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”

(18 - 25 year old Sehajdhari).

Discussion

- Increased piety - aid coping and even diffuse stigma (Hinton, Franz, Yeo & Levkoff, 2005).
- Normal process of ageing may make it easier to manage (Lawrence et al., 2011)
- Violence and severe forgetting as a problem (Bowes & Wilkinson, 2003).
- Differences between baptised and non-baptised Sikhs in interpreting the 'dementia' symptoms.

Discussion

- Differences between baptised and non-baptised Sikhs in coping.
- Acceptance of the situation 'Hukam' (God's order/command) and 'Kirpa' (grace, blessing from God).
- Being a Sikh seen as protective (Bandura, 2003).



Discussion

- Barriers to help seeking for women (Scattalon & Stoppard, 1999).
- Contacting a GP more likely to be done by 'modern' family members.
- Perceptions about GPs 'less caring' (Gilbert et al., 2004).
- Non-baptised Sikhs - culture/language differences.
- Baptised Sikhs -religious differences.

Clinical Implications

- Several barriers to help seeking/access to services.
- Outreach work at a community level.
- Sikhs are not a homogenous group.
- Holistic nature of dementia treatment.
- HCP's to promote discussion around culture & religion.
- Families involvement in care.
- www.sikhyourmind.com



**sikh
your
mind.**

Strengths & Limitations

- Novel.
- Small sample size.
- 4 older Sikhs, although 12 had initially consented.
- Participant Vs. Non-participants.

Summary

- Previously limited data on how British Sikhs understand and manage dementia in their community.
- Education on the nature of symptoms might allow families to recognise signs of the development of symptoms sooner.