

# Religious beliefs about causes and treatment of epilepsy

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## ABSTRACT

### Background

It has been acknowledged that religious and complementary therapies are commonly used among South Asian communities in the UK. However, little is known about their religious beliefs in relation to epilepsy and the type of South Asian therapies that they use to treat the condition.

### Aim

To explore the influences of spiritual and religious beliefs on explanation of the cause of epilepsy, and the choice of treatment in people of South Asian origin who have epilepsy.

### Design of study

Qualitative study using interviews with patients, carers, health professionals, and focus groups of people from minority ethnic communities.

### Setting

Bradford and Leeds.

### Method

Semi-structured individual interviews with 20 Muslims, six Sikhs, and four Hindus with epilepsy; 16 nominated carers (family members, friends); 10 health professionals (specialist GPs, neurologists, specialist nurses, social workers, community GPs); and two focus groups with a total of 16 South Asians without epilepsy.

### Results

It was found that over half of responders attributed their illness to fate and the will of God, or as punishment for sins of a past life. Some patients had experienced prejudice from people who believed that their epilepsy was contagious. A strong network of traditional healers was found, providing a parallel system of health care in the UK and on the Indian subcontinent. People turned to religious/spiritual treatments in desperation for a cure, often under the influence of their families after the perceived failure of Western medicine. Such treatments were viewed as complementary rather than as an alternative to Western medication. Younger people in particular expressed considerable scepticism about the effectiveness of these traditional South Asian treatments.

### Conclusions

In this study's South Asian sample, patients commonly turned to traditional healers in search of better health. Health professionals should be aware of the belief systems of these patients and understand the types of treatments in common use. Although these treatments might potentially compete with Western health care, they are used as an adjunct rather than a substitute. Patients have a 'healthy' scepticism about the effectiveness of such treatments, and adherence to medical therapy does not appear to be affected.

### Keywords

beliefs; epilepsy; medicine, traditional; Southern Asia; spirituality.

## INTRODUCTION

There is a wide variety of influences on people's beliefs about illness and treatments, including culture and religion. Religious beliefs can exert positive influences on health by acting as a source of inspiration,<sup>1</sup> or negative influences when they are linked with guilt and punishment.<sup>2</sup> Religious beliefs can also engender a sense of fatalism, a belief that someone or something is in control.<sup>3</sup> This identification of an external locus of control can impact on health behaviour.<sup>4</sup>

Beliefs about health and illness affect people's decisions regarding their choice of treatments.<sup>5</sup> Religious and complementary therapies are commonly used among South Asian communities in the UK.<sup>6-8</sup> However, details about the type of therapies and how they are used in relation to conventional medicine are scarce; in particular, little is known about alternative treatments for epilepsy.

It is important that health professionals are aware of their patients' lay beliefs about illness and the alternative treatments that they may choose. This article reports findings about beliefs and their impact on the choice of spiritual and traditional therapies from a study exploring health beliefs and experiences of people of South Asian origin who have epilepsy.

## METHOD

This was a study of the health beliefs and experiences of people living in Bradford and Leeds, who are of South Asian origin and have epilepsy. Individual in-depth interviews were undertaken with 30 patients, 16

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carers and 10 health professionals. In addition, focus groups were conducted with 16 South Asians from local communities who did not have epilepsy.

The South Asian population is heterogeneous in terms of ethnicity, religions, and language. Religious grouping provides a robust framework for reflecting some of this diversity;<sup>9</sup> we chose to divide our sample into Muslim, Sikh, and Hindu patients.

A sampling frame of patients aged over 18 years who have epilepsy and live in Leeds and Bradford was compiled using data from epilepsy registers and hospital databases. Using recorded information on ethnicity and religion, together with an analysis of names, these were categorised into the three religious groups. The largest group was of Muslims (109), from which a random sample was selected. All patients from the Sikh (17) and Hindu (13) categories were invited to participate in the study. Patients were invited by letter and asked to indicate on a return slip whether or not they wished to take part.

#### Characteristics of sample

A total of 20 Muslims (10 male and 10 female), six Sikhs (two male and four female) and four Hindus (three male and one female) accepted the invitation. The age range was 18–68 years, with 18 responders aged below 35 years. Five responders classified their occupation as professional/managerial, six as skilled or unskilled manual, nine as housewives, eight as retired or unemployed, and two as university students.

Each responder was asked to nominate their main carer. Fourteen responders preferred not to nominate a carer for interview. For the remaining 16 responders, eight of the carers nominated were spouses, three siblings, four parents, and one a friend.

#### Interviews and analysis

Wide-ranging topic guides were used, which included a section on health beliefs and practices in relation to epilepsy as well as questions about the impact of epilepsy on lifestyle and relationships, understanding of seizures, and treatment options. These were informed by a literature review, the research advisory group (which included representatives from local communities), and preliminary discussions with patients and health professionals. Most of the interviews were conducted by a male researcher, but five were undertaken by a trained female researcher at the request of patients. Interviews took place in the patients' or carers' homes and lasted roughly 1 hour. Twelve of the interviews were conducted in Urdu or Punjabi.

Two focus groups were held, consisting of eight males and eight females recruited from community

## How this fits in

Religion plays an important role for many individuals from South Asian minority ethnic groups in coping with, and understanding, their illness. Religious and traditional therapies are commonly used in South Asian communities. Little is known about how these traditional and religious forms of therapy are used in relation to conventional medicine. Although many people of South Asian origin attributed their illness to the will of God or saw it as punishment for sins of a past life, this did not necessarily lead to resignation or passivity in respect of their illness. There is a strong network of traditional South Asian healers providing a parallel system of health care in the UK and South Asia, which is invisible to the mainstream NHS. People often turned to spiritual and other traditional healing in desperation and as a result of family pressure, although some had doubts about its effectiveness. Religious and traditional therapies were used as an adjunct to, rather than a substitute for, conventional medical therapy.

centres. An unstructured topic guide was used to stimulate discussion.

All interviews were audiotaped, translated if required, and transcribed. A framework approach was adopted to analyse the data. A coding frame was applied to each transcript and relevant text was indexed whenever a particular theme appeared.<sup>10</sup> Indexed data were transferred to a grid to compare cases and identify similarities and differences.

## RESULTS

We found that many of our responders believed that they had been fated by God to suffer from epilepsy. This was particularly, but not exclusively, true for Muslim patients. The following comments were typical:

*'Well, everything comes from up there; everything's from Allah and the one who fixes it is Allah as well. You see that's our Muslim belief, what do you think? You see, the doctor's give you your medication but the cure comes from Allah ...'* (43-year-old Muslim male.)

*'If it's written for you, it's written for you, there's nothing you could do about it, can you? So when it comes to you, it comes to you, it's in God's hands, so there's nothing you can do about it.'* (25-year-old Muslim male.)

The belief that illness may be a punishment for sins committed in a past life is part of the doctrine of Hinduism and Sikhism. We found some evidence of this belief in our sample:

*'They do say that you have to repent in this life for sins that you've maybe committed in your previous life, but I don't know ... I mean illness is something*

*that's fated to happen to you in life. I don't know, I mean, I just can't understand that, I think I was just fated to have it.'* (46-year-old Sikh female.)

*'I remember them having a conversation with some guru of theirs and he was saying that in a previous life ... I'd killed a snake or something, that's why I'm epileptic ... That's kind of spooky, actually. But I don't really believe in this sort of thing.'* (19-year-old Sikh male.)

Epilepsy has been associated with spirit possession in many cultures.<sup>11</sup> Few of our responders gave credence to such beliefs; however, there was support for the belief of possession by spiritual beings (jinn) among some of our sample, particularly older Muslims and those born or brought up in the Indian subcontinent. A Sikh woman, for example, described how her nephew in India:

*'Went for ages without getting any medication ... [The family in India] said he's got this, he's got that, he's got some kind of spirit involved, the wind's affected, that he's got jinn [possession by spiritual beings]. But in our family we've never believed things like that you see. I think these beliefs are more prevalent in India. I think it's more in the villages really, you see, because people don't have that much knowledge in the villages.'* (46-year-old Sikh female.)

Similarly, a 28-year-old Muslim woman commented:

*'I think they think it's something like an evil spirit, I would say that's the elders, no matter where they are.'*

Medical knowledge did not necessarily preclude belief in jinn, as the following comments from a Hindu woman, who had herself been medically trained, demonstrate:

*'This is one of these things, not like diabetes or coronary heart disease, it's one of the things that happened to me, maybe the jinn, jinn is a factor, I don't know. As far as I'm concerned, my knowledge [medical], I don't know anything ...'* (53-year-old Hindu female.)

Belief that epilepsy is a contagious disease was experienced by responders through the negative attitudes and actions of other community members, as a 29-year-old Muslim woman explained:

*'Other people, sometimes you sense, they just keep away because they don't want to get it*

*[epilepsy]. They think they might catch it. Sometimes you shake hands with other women if you're greeting them but they don't want to put their hand forward, they don't want to shake hands, so I just think "leave it". I mean, I know it's not an infectious condition. Our Asian women here, the elderly ones in particular, tend to think that if I mix with their children or sit with them, then, like I say, the children will catch it.'*

### **Traditional South Asian therapies**

We found that the use of traditional South Asian therapies (as outlined in Supplementary Appendix 1) was widespread in our sample, although in all cases it was a second-line treatment rather than an alternative to anti-epileptic drugs. However, as our sample was accessed through medical records, we have no knowledge of the extent to which people with epilepsy may have been using traditional therapies without being in contact with medical services.

Sixteen of the 30 people from our sample who had epilepsy had sought help from traditional South Asian healers. A common reason for using these therapies was desperation and each individual's hope that he or she might find a cure or effective treatment for their seizures:

*'I think it is desperation because, you know, you've been trying something for so long and it's not getting you anywhere, I suppose it is. I don't care as long as it helps me. Anything, I was willing to do anything. I'd try anything to cure the problem but the only answer was these tablets. No more.'* (42-year-old Hindu male.)

*'I was really tired, sick of it, nothing was helping and I'm suffering. I'll do anything to get better. They [amulets] helped me, I believe in it, they helped me, but I think the medication the doctor writes ... you should always go for the medication.'* (31-year-old Muslim female.)

*'[W]e must have tried nearly everything, anybody that said, you know, try this for epilepsy, it's like go an Islamic way going beyond it. It's like, you know, something you wouldn't do, you know. My family is quite religious and sometimes we actually went to this [Hindu healer]. There's nothing wrong with that but I suppose, you know, when you've got, your child, you're helpless, you don't know what to do, you run to everyone, you don't care who you're going to and what religion they are.'* (34-year-old Muslim female.)

All those who had used other therapies had experienced continued seizures, despite compliance

with medical regimens. Some people were persuaded to use them by family or friends, often when visiting India or Pakistan, while others looked for alternative treatments as they were suspicious about the effects of long-term antiepileptic drugs on their physical or mental health.

Most of our sample, irrespective of ethnicity, used some form of religious healing. For some, this was a personal prayer or recitation from religious texts in private, rather than seeking help from religious healers. Others undertook pilgrimages to places of worship in order to seek forgiveness for their sins and alleviation of their illness. Fourteen responders turned to religious healers, usually under pressure from their families or in an attempt to placate them, as illustrated in the following examples:

*'Pir came from Pakistan and he was 100 years old or something, came with a long white beard. He made me read something in Farsi. It's like Arabic, couldn't understand it, I read it, yeah. He said to me "Understand it?" I said "Alright". My dad read it and he said "I understand it", he gave me something, told my mum downstairs "It's like a sayaa [influence of a evil spirit] when he was born", he said "naraa [veins] in his head, which collapses".'* (32-year-old Muslim male.)

*'People (pirs) came from Pakistan here and I went there once, I remember, in Bradford and he said, "I'm gonna do something". I don't know what they were doing...'* (39-year-old Muslim male.)

*'My parents sent this [taweez, amulet] from Pakistan. I had a couple sent a couple of years ago and they've been helping as well. Got it from [pir in Pakistan]. I think it does [work] but when I have these attacks I just have these doubts, again. I had these taweez; I had to wear them on my arm, one on each, one on my left and one on my right. Then after 2 or 3 years I was in that previous state when I used to keep on having fits again and again. I thought they weren't working so I just took them off, just stopped using them. Yeah, I told them [family] that I took them off but I have the arm ones.'*

[Asked if the family objected]: *'No, because I got some more taweez they said, "Here, wear these new ones". Wearing the taweez I think does help a lot, not me myself personally but my family think that's one of the reasons that's helped me a lot.'* (24-year-old Muslim male.)

Many of these consultations were with gurus (Hindus and Sikhs) or pirs (Muslims) visiting from the

Indian subcontinent, although some responders took advantage of trips abroad, when visiting family, to consult with local, well-known healers. Others consulted religious healers established in the UK, often affiliated to famous pirs from the Indian subcontinent. Most of the Muslim sample who had consulted with pirs were instructed to wear some kind of amulet containing verses from the Koran (*taweez*), usually around the neck or the arm. Others were required to drink blessed water or recite from holy texts:

*'I've had people giving me taweez, all sorts, I've been ... I don't know, people say different things, "You should do this, you should do that". I've tried everything. I was having it [seizures] and actually there was this lady who was giving me taweez and I went better for 1 year I didn't have a fit. This taweez and she put dam on water [blessed the water], she used to give me that.'* (31-year-old Muslim female.)

Five responders visited hakims (herbal practitioners) in the hope of finding a cure for their epilepsy. A number of hakims practised in the district, often advertising consultations or mail order treatments through newspapers for minority ethnic groups. However, the majority of people made use of hakims while on trips to visit relatives in India/Pakistan, primarily because of the difficulties of locating practitioners and the prohibitive costs involved in consulting locally in the UK. A 23-year-old Muslim man explained:

*'In this country people usually go to the doctor first, because it's free and the hakim charges money. In Pakistan, however, the hakim is cheaper than the doctor. Here, we pay for the hakim in pounds; over there [in Pakistan], we pay in rupees. I think the hakim's cure is better, the cure is from Allah and both are ways of accessing the cure.'*

Younger people, in particular, expressed considerable scepticism about the effectiveness of such healers. A 28-year-old Muslim woman, for example, said:

*'I also went to see the hakims, I tried everything, people that give like prayers to read, to get better, I went to see them. So what I did was I tried everything and sometimes I'd feel better, sometimes I wouldn't, but, I mean, they say it's kind of psychological as well. Well, you know you take it [herbal medication] for ... you take it and you don't have any fits for a week and then the next*

*week you'll have three and you think, what was the point of taking that, it hasn't made any difference.'*

Most of them were persuaded or coerced by their families into seeking this kind of treatment. Some were reluctant to follow instructions prescribed by healers as they were a little sceptical as to how much they would benefit.

*'We've been asking all those sorts of people but nobody can come up with any answer. They've tried their best, but if anybody does know ... but nothing. Well, they just said it comes from, some say it comes from the ancestors, old ancestors or somebody who's not a good psychic person or something. One of them, I overheard, will say that when I was born. Over in India, one or two of them did say that it could be to do with black magic, but I don't believe that stuff.'* (42-year-old Hindu male.)

*'Someone once suggested, I think it was in the family, you know, some pir sahib is really good, he will do some dua [recite prayers] or something ... but I don't really believe in that stuff. I mean, I'm sure there are many true people out there but they're difficult to find, aren't they?'* (28-year-old Muslim female.)

*'I went to this ... we've got this other one who goes to your house Pir Sahib, they call him. That's what our lot believe in; he's all right, he gives taweez [amulets] and reads [recites from the Koran], still our faith. I've never worn them [taweez], don't believe in them.'* (25-year-old Muslim male.)

Five responders, however, did report improvements to their condition. It is possible that such 'improvements' coincided with periods of stability that were seizure-free, although some responders explained this in terms of the power of belief and the calming influence of recitation and prayer in reducing the stress that could provoke seizures.

There was very little overlap with more mainstream complementary therapies used by the white population:<sup>12</sup> only two people reported using a non-South Asian alternative — Reiki and a Chinese herbalist.

## DISCUSSION

### *Summary of main findings*

The study describes the influence of religion and religious and traditional treatments in a sample of patients drawn from South Asian communities in Bradford and Leeds. This is an area where there has been little empirical research.

The study benefited from a robust sampling strategy

and a considerable amount of fieldwork with 56 interviews and two focus groups. Our sample included patients from a range of different religions, socioeconomic backgrounds and ages in an attempt to capture the diversity of views and beliefs. We also interviewed carers and professionals. It should be noted, however, that our study sample was recruited from medical record data; hence, those who did not seek treatment from health professionals, and perhaps used traditional therapies as a first-line treatment, would not have been included.

A weakness of the study is the over-representation of Muslims in the sample, reflecting the local population. In addition, the sample was limited to patients and carers from one geographical area in the UK. However, we have no reason to doubt that the findings are likely to be applicable to South Asian communities elsewhere in the UK. The focus of the study was people with epilepsy and it may be that the findings about influence of religion are unique to this illness. However, we believe that our results are likely to be relevant to beliefs about the causes of, and treatments for, other illnesses and conditions for which Western medicine cannot offer a cure or can offer only limited help.

### *Beliefs about illness*

Among our responders, we found that fatalistic beliefs about health were common. Such fatalism has been described in many cultures.<sup>13</sup> It has been found to be more widespread in South Asian communities, with a potentially detrimental effect on health status.<sup>14</sup>

Belief in the will of God (Qadr Allah) is a particularly strong feature of the Muslim religion.<sup>15</sup> However, our data suggest that to assume this equates with fatalism and a passive attitude towards illness and health is oversimplistic. Belief in the overarching power of a supreme being did not prevent people from searching for proximate causes for their illness, or from taking active steps to alleviate their symptoms or seek a cure.

### *Spiritual and traditional treatments*

We found that there was a strong network of traditional South Asian healers being used both in Bradford and on the Indian subcontinent. This network provides a parallel system of health care that is 'invisible' to the mainstream NHS. In the UK context, people's first recourse was to Western medicine, which is free at the point of delivery. Often, the failure of Western medicine to offer a cure or adequate improvement to their condition prompted people to turn elsewhere for help. In South Asia, however, where issues of accessibility to, and affordability of, Western medicine assume greater importance, especially in rural areas, people are probably more likely to turn to indigenous alternatives as their first, or only, resort.

Complementary medicine is known to be popular in the UK. A recent survey highlighted that up to 33% of the population have used complementary therapies at some point,<sup>12</sup> usually for the treatment of long-term chronic conditions for which conventional medicine has failed to provide an acceptable remedy. However, these complementary therapies predominantly involve the use of physical or homeopathic treatments as opposed to spiritual interventions.<sup>12</sup>

The family and wider social network was a major influence on the use of traditional South Asian therapies. The existence of lay referral systems is well known,<sup>16</sup> and previous research has described the significance of kinship networks in South Asian communities.<sup>17</sup> Our study demonstrates the importance of family and kinship networks in the use of traditional South Asian therapies.

Although the pursuit of religious and other South Asian traditional treatments was common, there was considerable scepticism about their effectiveness, particularly among younger patients who were more likely to have been born and raised in the UK. This may reflect a shifting balance of belief in the effectiveness of Western versus South Asian traditional treatments. It also highlights the conflict between traditional cultural beliefs and the inevitable assimilation of normative values in immigrant populations.<sup>8,18</sup> In addition, it is unlikely that there would be any placebo effect of spiritual healing on the sudden episodic nature of epilepsy and so any initial faith in a cure might soon disappear. A placebo effect may be more noticeable for other chronic diseases. Traditional therapies, however, offered hope that Western medicine was unable to provide, and part of their appeal may lie in their perception as short-term solutions without the toxicity and side effects of conventional medicine. Although probably not effective at reducing seizures, these traditional therapies may be effective in other dimensions of health such as psychological coping and stress reduction.

### Implications for practice

Health professionals should be aware of the belief systems of people they see from South Asian communities, and acknowledge and respect their convictions. People of South Asian origin may commonly turn to religious and other healers. Clinicians working with people of South Asian origin should have some understanding of the main South Asian therapies, such as those practised by *pirs/gurus*, and *hakims*, just as they have of more mainstream complementary therapies, such as acupuncture and homeopathy. Although traditional South Asian therapies could be regarded as potential competitors with Western health care, in our study they were used as an adjunct to conventional

medicine rather than a substitute. Participants appeared to have a 'healthy' scepticism about their effectiveness, and clinicians should be reassured that their use does not appear to reduce adherence to medical therapy.

### Supplementary information

Additional information accompanies this article at <http://www.rcgp.org.uk/journal/index.asp>

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### Competing interests

None

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### REFERENCES

- Walsh F. *Strengthening family resilience*. New York: The Guildford Press, 1998.
- Ahmad WIU. *Ethnicity, disability and chronic illness*. Buckingham: Open University Press, 2000.
- Kelleher D, Islam S. 'How should I live?' Bangladeshi people and non-insulin-dependent diabetes. In: Kelleher D and Hillier S (eds). *Researching cultural differences in health*. London and New York: Routledge, 1996: 220–238.
- Rotter JB. Generalized expectancies for internal versus external control of reinforcement. *J Consult Clin Psychol* 1966; **43**: 56–57.
- Helman CG. *Culture, health and illness* (4th edn). Oxford: Butterworth-Heinemann, 2000.
- Ahmad WIU. The maligned healer: the 'hakim' and western medicine. *New Community* 1992; **18**: 521–536.
- Quereshi B. British Asians and alternative medicine. In: McAvoy BR, Donaldson LJ (eds). *Health care for Asians*. Oxford: Oxford Medical Publications, 1990: 93–116.
- Bhopal RS. The inter-relationship of folk, traditional and Western medicine within an Asian community in Britain. *Soc Sci Med* 1986; **22**: 99–105.
- Nazroo JY. *The health of Britain's ethnic minorities: findings from a national survey*. London: Policy Studies Institute, 1997.
- Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R (eds). *Analyzing qualitative data*. London: Routledge, 1984: 173–194.
- Carrazana E, de Toledo J, Tatum W, et al. Epilepsy and religious experiences: voodoo possession. *Epilepsia* 1999; **40**: 239–241.
- Zollman C, Vickers A. ABC of complementary medicine. Users and practitioners of complementary medicine. *BMJ* 1999; **319**: 836–838.
- Davison C, Frankel S, Davey Smith G. The limits of lifestyle: reassessing 'fatalism' in the popular culture of illness prevention. *Soc Sci Med* 1992; **34**: 675–685.
- Howlett B, Ahmad W, Murray R. An exploration of white, Asian and Afro-Caribbean peoples' concepts of health and illness causation. *New Community* 1992; **18**: 281–292.
- Katbamna S, Bhakta P, Parker G. Perceptions of disability and care giving relationships in South Asian communities. In: Ahmad W (ed). *Ethnicity, disability and chronic illness*. Buckingham: Open University Press, 2000: 12–27.
- Friedson E. *Profession of medicine*. New York: Dodd, Mead, 1970.
- Ballard R. *Desh Pardesh: the South Asian presence in Britain*. London: Hurst, 1994.
- Modood T, Beishon S, Virdee, S. *Changing ethnic identities*. London: Policy Studies Institute, 1994.