



# South Asians and epilepsy: Exploring health experiences, needs and beliefs of communities in the north of England

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## Summary

*Purpose:* To examine the beliefs and experiences of South Asians with epilepsy and the extent of provision of appropriate information and accessible services for them by health professionals.

*Methods:* Qualitative interviews with 30 South Asians with epilepsy, 16 carers and 10 health professionals. In addition, two focus groups were held with 16 South Asians without epilepsy recruited from community centers. The interview sample was divided by religious groupings (Hindus, Sikhs and Muslims). Fieldwork was conducted in Bradford and Leeds (England).

*Results:* Beliefs that epilepsy is caused by spirit possession (Muslims) or attributable to sins committed in a past life (Sikhs and Hindus) were reported as being widely held among South Asians living both in the UK and the Indian subcontinent, although few informants themselves subscribed to such views. Compliance with conventional medication was high; however, those who experienced seizures most often were most likely to turn to traditional South Asian therapies. Most informants used both treatments simultaneously. The main issues regarding the provision of services were: lack of appropriate information and advice; language and communication barriers; problems in interaction with health professionals. Also discussed were the potential merits of attending support groups. Greatest dissatisfaction was expressed in relation to primary care, whereas the highest praise was reserved for specialist epilepsy nurses.

*Conclusions:* Our findings show both similarities and differences between participants' experiences, where gender, age or other aspects of personal biography can be

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as important as religion, culture or country of origin. Furthermore, the impact of being diagnosed with epilepsy can be exacerbated by structural impediments to accessing information and appropriate services.

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## Introduction

People from minority ethnic groups in the UK are among the most socially and economically disadvantaged and those with the poorest health status.<sup>1–3</sup> In order to improve the nation's health, it is essential to understand the particular health needs and expectations of this diverse group of people and to plan appropriate and accessible health services with and for them.<sup>4,5</sup>

This paper presents the findings of a two-year qualitative study<sup>6</sup> that examined experiences and understanding of epilepsy amongst South Asian communities in Bradford and Leeds, neighbouring cities in the north of England. The study also explored the role of families in providing support for people with epilepsy, the use of traditional South Asian therapies, and views of service providers.

## Methodology

In addition to the hospital epilepsy service, Bradford has a community-based epilepsy service with a patient list of around 3000, headed by a full-time consultant neurologist with a staff of four part-time specialist GPs, a specialist epilepsy nurse and other support staff. Clinics in local health centres provide fast track consultations with newly diagnosed patients as well as monitoring patients who have had epilepsy for a period of time. An epilepsy register is maintained of all patients who have been referred to the community epilepsy service or who have been seen by the hospital epilepsy team. This provided the sampling frame. Information from the register was cross-checked with paper files from the hospital and community outreach epilepsy service; and the Patient Administration System (PAS)—a hospital database widely used throughout England and including patients diagnosed in hospital but currently in receipt of care from their GP only. Information was collected about each person's anti-epilepsy medication, gender, general practitioner (GP), address, telephone number and, where available, fluency in English. In total, these details were compiled for 17 Sikhs, 13 Hindus and 109 Muslims who met the inclusion criteria: over 18 years old; of South Asian origin; diagnosed as having epilepsy and receiving care for their epilepsy from the hospital, epilepsy service or GP; no identified and recorded learning disability. These numbers

reflect Census figures for the relative size of the South Asian population in Bradford when grouped by religion. Following Nazroo,<sup>7</sup> we adopted religious grouping (Hindu, Sikh, Muslim) as a robust framework for understanding diversity in relation to health rather than the more conventional ethnic divisions: Indians, Pakistanis and Bangladeshis. Nazroo<sup>7</sup> has shown that, to a marked extent, religious differences relate to systematic differences in socio-economic position between Muslims (relatively poor) and Hindus and Sikhs (relatively better-off).

All Sikhs (17) and Hindus (13) identified from the register were included. Muslims (109) were grouped according to five age bands (18–25, 26–35, 36–45, 46–55, and 56–68) and by gender. Ages ranged from 18 to 68. A quota sample was drawn to reflect the age and gender demographics of the 109. This was achieved by randomly selecting from the age/gender bands. Those people who had been seen by the local Epilepsy Service in the previous two years were sent letters, both in English and known or assumed first language, providing a description of the project, a request to take part in the study and a reply slip. Others, who had not contacted the Epilepsy Service for two years or more, were sent letters only after confirmation from their GPs that they were still taking medication for epilepsy. A number of people did not reply; others declined the invitation to take part. Reasons given included a belief that the research would be of no direct benefit to themselves and a discomfort about discussing epilepsy. Those who did not reply or who declined (66%) did not differ in terms of age banding or gender from those who accepted the invitation to be interviewed. The sample was self-selected in the sense that people chose whether or not to take part. Previous epidemiological work in the city<sup>8</sup> revealed that the level of service accessed is lower than that suggested by the population structure. This suggests that the Epilepsy Register may under-represent the actual number of people with epilepsy. Our sample may therefore be unrepresentative in that it did not include people who did not access services. Each person who agreed to participate was asked to nominate his or her main carer who was also asked to agree to an interview. In-depth interviews were undertaken with service users and health professionals. The views of the wider Muslim community (people who had had little or no direct experience of

epilepsy or of caring for someone with epilepsy) were sought through two focus groups recruited via local community centers located in areas of high prevalence of South Asians.

Ethical approval was obtained from the Bradford Local Research Ethics Committee.

### Characteristics of the sample

A total of 20 Muslims (10 males and 10 females), 6 Sikhs (2 males and 4 females) and 4 Hindus (3 males and 1 female) agreed to take part in the study. They ranged in age from 18 to 68 years, with 18 informants being under 35 years. Five informants classified their occupation as professional/managerial, six as skilled or unskilled manual, nine as housewives, eight retired or unemployed. Twenty were only receiving treatment from their GP and 10 were registered with the hospital epilepsy service. The findings relate primarily to the Muslim sample. However, data from the Sikh and Hindu interviews have been included, as the views and experiences described do not diverge significantly from those of the Muslim sample. Fourteen informants preferred not to nominate a carer for interview. For the remaining 16 informants, 8 of the carers nominated were spouses, 3 siblings, 4 parents and 1 friend. The 10 health professionals who took part in the study comprised the consultant neurologist from the hospital service, the neurologist who heads the community epilepsy service, two specialist epilepsy nurses (one from the hospital and one from the community service), and two GP specialists who support the community service. In addition, interviews were conducted with three community GPs with a number of patients with epilepsy registered within their practice and a consultant neurologist from a neighboring town with a large South Asian population. The two focus groups involved eight men and eight women, respectively.

### Data collection and analysis

Informants were given a choice of male (H.I.) or female interviewer and interviews were conducted in the respondent's preferred language. Wide-ranging, semi-structured topic guides were used, which included a section on health beliefs and practices in relation to epilepsy as well as questions about impact of epilepsy on lifestyle and relationships, understanding of seizures and treatment options, formal and informal support. The topic guides 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 H.I., with five being undertaken, at the request of participants, by an experienced female South Asian researcher who was familiar with both the area and local population. Interviews took place in patients' or carers' homes and lasted an average of 1 h. Twelve were conducted in Urdu or Punjabi, the rest in English. The interviews with health professionals were undertaken in their places of work. The focus groups were conducted in Urdu in local community centres.

All interviews and the focus groups were audio taped, translated into English where required, and transcribed in full. Analysis followed the framework approach outlined by Ritchie and Spencer.<sup>9</sup> A coding frame, derived from preliminary readings of the transcripts, was applied to each transcript and relevant text indexed. Indexed data were transferred to a grid, specifying themes along one axis and (coded) respondent identities along the other. The range of responses could then be analysed by theme, whilst retaining the integrity of individual interview profiles.

### Findings

#### Perceptions of epilepsy

According to all informant groups (people with epilepsy, carers and focus groups), the belief that epilepsy is caused by spirit (*jinn*) possession is widespread amongst Muslims living in the UK as well as in the Indian subcontinent. Similarly, Sikh and Hindu informants reported that, amongst the Sikh and Hindu communities, epilepsy was widely held to be the result of sins committed in a past life. However, few people with epilepsy reported subscribing to these views themselves. In part, the likelihood of holding such beliefs may be explained by generational factors and length of residency in Britain, with older people and recent immigrants reported by informants to be most likely to hold to such beliefs. They may also reflect a different investment in, and knowledge of, epilepsy among those who have the condition compared with those who do not.

While not accepting spirit possession or past sins as causal explanations, people with epilepsy themselves, from all religious groups, tended to talk in fatalistic terms or to attribute their condition to 'the will of Allah'. Common explanations for having epilepsy, shared across all informant groups, were stress, family history, physical trauma, and previous health problems. Some people with epilepsy felt that others shunned them through fear of 'catching' epilepsy. Others, from both individual interviews and focus groups, mentioned that the wider community saw people with epilepsy as having a disability and

therefore as being in some way devalued. The most commonly used term for epilepsy, regardless of ethnic group, was the word *mirgee*, which means 'fit' but has a very negative connotation.

### Family support

Carers regarded epilepsy as a condition that made their relatives socially vulnerable. Some people with epilepsy tended to see their condition as a personal tragedy; others were concerned about not being able to fulfill expected family responsibilities. People with epilepsy frequently had to confront and negotiate barriers as well as engage with the negative attitudes about epilepsy held by their families. Over-protection was often a source of tension between informants and their families, especially for young women. Some had mixed feelings about the roles (protectors and comforters) their families played. Others felt that their families were ashamed of having an epileptic relative and mentioned isolation and exclusion from family events. The issue of future marriage prospects was often crucial, especially for young women.

### Impact on lifestyle

Disruption of education and perceived prejudice on the part of teachers were major issues for some informants. One person reported that epilepsy had given her parents an excuse for excluding her from formal education. Others felt that epilepsy had limited their choices of employment. Finding a suitable marriage partner was a difficult process for many. Some did not disclose their epilepsy until their partners had witnessed a seizure. The impact of epilepsy upon people's social lives differed according to the severity and risk of seizures. Some people felt that they could not perform even simple tasks, like going to the corner shop, watching TV or reading a book. Many informants cited disqualification from driving as the most significant restriction to their social and economic lives.

### Concordance and use of traditional South Asian therapies

Optimum seizure control was the primary goal for people with epilepsy. Concordance with Western medication was high. The main reason for stopping or reducing medication was fear of side effects, for example, harm to the fetus during pregnancy. However, more than half of the sample had also sought help from traditional South Asian therapies. Those who experienced seizures most often were most likely to turn to traditional South Asian therapies, particularly if Western medication had proved ineffective in sufficiently reducing seizures. Most people had used both treatments simultaneously. Bradford

supports a well-established network of South Asian therapists and many people retained close links with Pakistan and India and would often consult traditional therapists during visits to relatives.

Informants made use of two main forms of traditional South Asian therapies: religious healing and herbal treatment. In most cases, religious healing involved consultations with *pirs* (for Muslims) or *gurus* (for Hindus and Sikhs). Informants were usually required to drink blessed water or recite from holy texts. Some Muslims were instructed to wear a *taweez* (amulet) containing verses from the Koran. Some people visited *hakims* (herbal practitioners) in the hope of finding alleviation or a cure for their epilepsy. Younger people, in particular, expressed considerable skepticism about the effectiveness of traditional South Asian treatments but were often persuaded or coerced to try them by family or friends, often on trips to India or Pakistan.

### Service provision

Informants raised four main issues concerning their experiences of service provision:

1. Lack of information—This was a complaint voiced by the majority of people with epilepsy and their carers. The need for information increased when informants were faced with life-changing events such as puberty, pregnancy or menopause. Those diagnosed at a young age and whose parents could not communicate in English were further disadvantaged. Most health professionals who were interviewed said they did provide explanations and information about epilepsy when requested to do so by patients; however, time restrictions during the consultation left little opportunity for deeper discussion. Health professionals believed that educated people were more inquisitive about their condition. All informant groups agreed that epilepsy needs more attention from the mainstream media.
2. Language barriers—One-third of informants with epilepsy were not fluent in spoken English, yet there was very limited use of official interpreters in consultations, family members usually taking on this role. However, some people felt embarrassed discussing personal problems through family members. Conversely, not all the carers interviewed were happy about interpreting and admitted to having difficulty in translating medical terminology. Health professionals expressed concerns about issues of impartiality and confidentiality and referred to an urgent need to recruit South Asian staff to the epilepsy service.
3. Interaction with health professionals—More than half of those with epilepsy expressed dissatisfac-

tion with their own GPs, many of whom were South Asian themselves. Informants believed their GPs lacked specific knowledge of epilepsy and were unable or unwilling to deal with sensitive issues. Most people, however, were satisfied with specialist GPs and consultants. Epilepsy nurses were regarded as the most helpful health professionals, owing to their easy accessibility and holistic approach. They were considered essential in providing a more comprehensive understanding of epilepsy for both patients and their families by undertaking home visits and taking part in community events.

4. Support groups—Most people with epilepsy were open-minded about the idea of attending support groups but were faced with practical problems over childcare or transport. Some were more concerned about the language the group would be conducted in or whether the group would be mixed or single gendered. Others felt that support groups would be of equal value for their families. However, not all informants were keen on the idea of attending support groups, which they saw as a potential reminder of their condition.

## Discussion

Many of the issues raised reiterate findings of previous studies conducted in different national contexts and among different ethnic populations.<sup>10–14</sup> Issues highlighted include social stigmatisation, difficulties finding a marriage partner, difficulties of disclosure, and discrimination in education and employment. Epilepsy was often felt to be a highly stigmatising condition that could affect the whole family. Most families, however, were reported to be very supportive, although there was often a fine line between what was experienced as supportive and what was experienced as overprotective.

## Fatalism

Many informants spoke of epilepsy in fatalistic terms. A common assumption among health professionals is that religious fatalism leads to passivity, guilt and resignation. Individuals who perceive that their health is under the control of powerful others may construct an external health locus of control; and this may have detrimental effects on their willingness to adopt behaviour that is health promoting.<sup>15,16</sup> However, this assumption was not borne out by our findings, as the fatalistic attitudes adopted, especially by Muslims, did not appear to prevent people from taking active steps to improve their condition. Although religious beliefs influ-

enced the ways in which some people interpreted their experiences, their attitudes were complex and varied and did not necessarily result in passivity or failure to access services.<sup>17,18</sup>

## Use of South Asian therapies

Traditional therapies were used in conjunction with, rather than in place of, prescribed medication. The prevalence of their use reflects alternative belief systems but is also shaped by relative costs and accessibility. In Britain, medical services are accessible and free at the point of delivery, whereas traditional therapists usually charge for their services or expect a donation. On the Indian subcontinent, the reverse holds, especially in rural areas where medical services are scarce and expensive compared with traditional therapists who are easily accessible and affordable. The pattern of usage is correspondingly heavily skewed in favour of traditional approaches.<sup>19</sup>

## Service issues

The main issues of concern for informants related to primary care provision, even though this is where religious, ethnic, cultural and language affinity with service providers was greatest. By contrast, informants expressed greater satisfaction with secondary care provision. However, lack of overt prejudice on the part of staff did not mean that people from South Asian backgrounds were not disadvantaged. For people with poor English, inadequate language support was a major structural weakness of service provision, which not only impeded access to and utilisation of services but their understanding of their condition and of service structures and their approaches to management and control.<sup>20,21</sup>

## Information and advice

Lack of appropriate information and advice can be partially addressed by providing better language support. However, employing more interpreters is not the whole solution as there are issues relating to differences in education and background between interpreters and patients, as well as concerns around confidentiality and impartiality.<sup>22</sup>

The issue of how to provide information and advice, moreover, was not simply one of language difficulties: it was also mentioned by fluent English speakers. There is a need to reassess the whole process of how information is delivered: when, where and by whom it is provided seem to be as important as the message itself.<sup>23</sup> Improving communication is a complex challenge that has to

acknowledge not only language but also beliefs, values, cultural/ethnic background, gender, age and social class as factors when devising strategies. Studies in chronic illness and disability within South Asian communities highlight the central significance of communication in service provision for both patients and their families.<sup>24</sup>

### Interaction with health professionals

Informants highlighted the central role played by specialist epilepsy nurses (SENs). Among their most valued qualities were the ability to gain the confidence of people with epilepsy by conversing on a more personal and informal level; acting as a link between other health professionals and patients; proactively engaging with patients and exploring issues of concern that they may not have had opportunity to raise with consultants. It may be that some of the characteristics and skills of SENs could be incorporated into the approaches of other service providers.

High levels of dissatisfaction with general practitioners amongst South Asians have been noted elsewhere<sup>25</sup> and should be a cause of concern, given their gate-keeping role in terms of access to secondary care provision and the fact that many people receive most, if not all, their epilepsy care through their GP.

### Conclusion

This study has presented a range of views, perceptions, beliefs and experiences of South Asian people with epilepsy, carers, members of the wider communities and health professionals. Although the sample size is small, it is consistent with the use of a qualitative methodology. People's perceptions and experiences of epilepsy and treatment, as well as their needs and interaction with health professionals across sectors of care vary over time and cannot be predefined for any ethnic group. Access to appropriate services allows people to make informed choices in relation to their needs at a particular time. Personal and social factors—ethnicity, gender, age, social class, personal circumstances—influence the need for and access to services. Our findings show both similarities and differences between participants' experiences, where gender, age and other aspects of personal biography can be as important as religion, culture or country of origin. In many ways, it was the similarity of our findings to those of other studies that was most notable.

The most significant divergence related to religious and spiritual beliefs. Epilepsy was interpreted within both a medical and spiritual frame of reference. Tensions between the two were exposed in

differing explanations of cause, with few informants subscribing to the views of many of those around them, and in differing approaches to treatment and beliefs in the possibility of cure. Younger people, especially, were likely to be skeptical about the efficacy of traditional remedies, in particular the promise of a cure; however, inadequate control through anti-epileptic drugs meant they were often willing to try alternatives. Health professionals need to be aware of the religious and spiritual dimensions to people's lives and how these influence people's understanding and management of their condition. They also need to be alert to the various alternative treatments to which their patients may have recourse.

Our research revealed the dense network of familial and social relations (often spanning continents) in which people are enmeshed and which characterise the South Asian communities from which our informants were drawn. People did not act independently but were heavily influenced by the beliefs, opinions and actions of those around them. Health professionals need to view their patients not from the perspective of isolated, autonomous individuals but from the perspective of their positions and roles within their families and communities.

In terms of service provision, the main issues identified in the study related to inadequacies within primary care, insufficient language support and insufficient attention to people's information needs.

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