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

Hanif Ismail[a,*], **John Wright**[a], **Penny Rhodes**[a], **Neil Small**[b], **Ann Jacoby**[c]

[a] *Health Services Research Unit, Bradford Teaching Hospitals NHS Trust, St Lukes Hospital, Extension Block C, West Yorkshire, Bradford BD5 0NA, UK*
[b] *School of Health Studies, University of Bradford, UK*
[c] *Division of Public Health, University of Liverpool, UK*

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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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* Corresponding author. Tel.: +44 1274 365116.
E-mail address: hanif.ismail@bradfordhospitals.nhs.uk (H. Ismail).

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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.

Introduction

People from minority ethnic groups in the UK are among the most socially and economically disadvantaged and those with the poorest health status.[1–3] 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.[4,5]

This paper presents the findings of a two-year qualitative study[6] 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,[7] 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[7] 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 to 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[8] 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