SOUTH ASIANS AND EPILEPSY
Understanding health experiences, needs and beliefs

Report

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# CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>i</td>
</tr>
<tr>
<td>EXECUTIVE SUMMARY</td>
<td>ii</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>CHAPTER ONE</td>
<td>17</td>
</tr>
<tr>
<td>Perceptions and experiences of epilepsy</td>
<td></td>
</tr>
<tr>
<td>CHAPTER TWO</td>
<td>37</td>
</tr>
<tr>
<td>Family support and impact on lifestyle</td>
<td></td>
</tr>
<tr>
<td>CHAPTER THREE</td>
<td>67</td>
</tr>
<tr>
<td>Conventional drugs and alternative therapies</td>
<td></td>
</tr>
<tr>
<td>CHAPTER FOUR</td>
<td>83</td>
</tr>
<tr>
<td>Experiences of service provision</td>
<td></td>
</tr>
<tr>
<td>CONCLUSIONS AND RECOMMENDATIONS</td>
<td>109</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>117</td>
</tr>
<tr>
<td>APPENDIX A</td>
<td>119</td>
</tr>
<tr>
<td>Steering and advisory groups membership</td>
<td></td>
</tr>
<tr>
<td>APPENDIX B</td>
<td>121</td>
</tr>
<tr>
<td>Breakdown of South Asians with epilepsy in Bradford</td>
<td></td>
</tr>
<tr>
<td>APPENDIX C</td>
<td>123</td>
</tr>
<tr>
<td>Invitation letter to patients</td>
<td></td>
</tr>
<tr>
<td>APPENDIX D</td>
<td>127</td>
</tr>
<tr>
<td>Information sheet</td>
<td></td>
</tr>
<tr>
<td>APPENDIX E</td>
<td>129</td>
</tr>
<tr>
<td>Topic guide</td>
<td></td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

We would like to thank all the people who we interviewed for their time and contribution. We are grateful to Ann Jacoby, Mark Busby, Nigel Hakin and other members of the Bradford Epilepsy Service, and to the members of the Research Steering Group for their enthusiastic support and commitment.
EXECUTIVE SUMMARY

This report presents the findings of a two-year qualitative study that examined experiences and understanding of epilepsy amongst South Asian communities in Bradford. The study also focused upon the role of families in providing support to persons with epilepsy, the use of traditional South Asian therapies, and views of service provision. The research was commissioned and funded by Epilepsy Action, and conducted by the Health Services Research Unit at St. Luke’s Hospital, Bradford NHS Trust. The study was undertaken to enable Epilepsy Action to develop more appropriate information and resource materials for individuals with epilepsy and their families. Recommendations have also been produced for practitioners and policy makers involved in planning and providing health care services.

AIMS

The main aim of the study was to examine the experiences of South Asians’ with epilepsy in relation to their health needs and beliefs and the role of health professionals in providing appropriate information and accessible services. The specific aims were:
- to examine the experiences of epilepsy, its management and impact on people’s lives;
- to explore the understanding of the illness, health and religious beliefs and the use of traditional South Asian therapies; and
- to understand access to health services, to identify barriers and to examine information available.

METHODS

Fieldwork for the study was conducted mainly in Bradford and partly in Leeds, both of which have sizeable South Asian populations. A sampling frame of persons with epilepsy over 18 years of age was compiled using data from the epilepsy register and hospital databases. The sample was divided by religious groupings (Muslims, Sikhs and Hindus). A total of 56 one-to-one interviews were undertaken with 30 people with epilepsy, 16 carers and 10 health professionals. In addition two focus groups were conducted with 16 people recruited from community centres. The framework approach was adopted to analyse the data.

FINDINGS

Perceptions of epilepsy

The most commonly used term for epilepsy - regardless of ethnic group – was the word mirgee, which means ‘fit’ but has a very negative connotation. Common explanations shared across all groups for having epilepsy were stress, family history, physical trauma, and previous health problems. Some Muslims believed epilepsy was caused by spirit possession and many attributed it to ‘the will of Allah’, whereas some Hindus and Sikhs believed sins committed in a past life caused the condition. Community members added other explanations like consanguineous marriages. Some respondents felt that people from the wider community shunned them due to fear of ‘catching’ epilepsy. Others mentioned that the wider community saw people with epilepsy as having some kind of disability and therefore as being in some way devalued.
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 expressed their concerns about not being able to fulfil 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 family. Over-protection was sometimes a main source of tension between people with epilepsy and their families. Some respondents had mixed feelings about the role (protectors and comforters) their families played. Others felt that their families were ashamed of having an ‘epileptic’ relative and mentioned isolation and exclusion even from family events.

Impact on lifestyle
Respondents’ concerns about the impact of epilepsy on their lifestyle were directly linked to whether epilepsy was a barrier for them in completing their education, in seeking employment, in finding a marriage partner, in having a ‘normal’ social life and in driving. Disruption of education was a particular problem for some respondents, whereas others felt that epilepsy had limited their choices of employment. Finding a suitable marriage partner was seen as a difficult process for many respondents. Some did not disclose their epilepsy to their partners until a seizure was witnessed. The impact of epilepsy upon people’s social lives differed according to the severity and risk of seizures. Some felt that they could not perform simple tasks like go to the corner shop, watch TV or read a book. However most respondents cited restrictions upon driving as having a major impact on their social lives.

Traditional South Asian therapies
More than half of the sample had sought help from traditional South Asian therapies usually as a second-line rather than an alternative to anti-epileptic drugs. All those who had used other therapies had experienced continued seizures, despite compliance with prescribed anti-epileptic drugs. Younger people in particular expressed considerable scepticism about the effectiveness of traditional South Asian treatments. They were usually persuaded by family or friends to use such therapies. Most respondents made use of two forms of traditional South Asian therapies: religious healing and herbal treatment. In most cases religious healing involved consultations with pirs (for Muslims) and gurus (for Hindus and Sikhs). Respondents were usually required to drink blessed water or recite from holy texts. Some Muslims were instructed to wear an amulet (taweez) containing verses from the Koran. Other respondents visited herbal practitioners (hakims) in the hope of finding alleviation or a cure for their epilepsy.

Service provision
Respondents raised four main issues concerning their experiences of service provision:

1. Lack of information - This was a common complaint voiced by the majority of respondents. The need for information increased when respondents 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 from the sample said they did provide explanations and information about epilepsy when requested to do so by patients, however, time restrictions during the consultation process left little
opportunity for deeper discussion. Health professionals believed educated people are more inquisitive about their condition. Respondents and health professionals agreed that epilepsy needs more attention from the mainstream media.

2. **Language barriers** - One-third of the respondents with epilepsy were not fluent in spoken English. There was very limited use of official interpreters in consultations. Usually family members took on this role. However, some people felt embarrassed at the idea of discussing personal problems through family members. Not all the carers interviewed were happy about interpreting; they admitted having difficulty in translating medical terminology. Health professionals expressed concerns about impartiality and confidentiality issues with such arrangements.

3. **Interaction with health professionals** – More than half of the respondents expressed dissatisfaction with their own (community) GPs. They believed their GPs lacked specific knowledge of epilepsy and were unable/unwilling to deal with sensitive issues. Most people, however, were satisfied with their specialist GPs and consultants. Epilepsy nurses were regarded as the most helpful health professionals due to their easy accessibility and holistic approach. They were considered essential in providing a further understanding of epilepsy and by reaching communities in a number of ways.

4. **Support groups** - A high number of respondents were open-minded about the idea of attending support groups but were faced with practical everyday issues like problems with 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. Other respondents felt that support groups were equally important for their families. However, not all respondents were keen on the idea of attending support groups. They did not want to be constantly reminded of their condition.

**CONCLUSIONS**

There is no one particular model of understanding epilepsy within any of the groups - Hindus, Muslims and Sikhs - that participated in the research. However, Muslims were more likely to regard it in fatalistic terms and Sikhs and Hindus to relate it to sins committed in a past life. Variations can be observed more within each group rather than between groups, pointing to the significance of individual features of gender, age, country of origin and level of education.

The fatalistic approach of many Muslims, in particular, did not prevent them from taking active steps to improve their condition.

Compliance with western medication was high. The main reason for stopping or reducing medication was fear of side-effects, for example harm to the foetus during pregnancy.

Optimum seizure control was the main goal for people with epilepsy and those who experienced seizures more often were more likely to turn to traditional South Asian therapies, particularly if western medication has proved ineffective in reducing seizures. Most respondents used both treatments simultaneously.
Many of our findings are generic to all groups with epilepsy regardless of ethnicity or religion. However this research has shown that the main issues of concern (stigma in relation to social life and employment) highlighted by studies 20-30 years ago are still present today.

No evidence of racism was found in patients’ experience of health services.

Respondents did have the perception that persons with epilepsy from white (English) communities faced less stigma and discrimination.

The support and encouragement of family members can have a dramatic impact upon the emotional state of people with epilepsy and can also influence the way in which they conduct their lives.

Epilepsy was often felt to be a highly stigmatising condition, which could affect the whole family. Of particular concern was the issue of marriageability.

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.

Four main issues regarding the provision of services for South Asians with epilepsy in Bradford were raised: lack of appropriate information and advice, language and communication barriers, interaction with health professionals and the potential merits of attending support groups.

The high levels of dissatisfaction with primary care irrespective of ethnicity of GP, reported should be a cause of concern, given its gate-keeping role in terms of access to secondary provision and the fact that many people receive the bulk, if not all, their epilepsy care through their GP.

**RECOMMENDATIONS**

- There should be an awareness of the belief systems of South Asian patients and a better understanding of the types of traditional South Asian treatments in common use.

- An information resource pack should be distributed at the time of diagnosis containing audio and videotapes, clearly written information on all aspects of epilepsy including treatment and side effects, and outlining further sources of support, information and advice.

- Information on epilepsy should take into account different South Asian languages, religions, cultures and lifestyles.

- Interpreters with more clinical knowledge of epilepsy should be present at consultations.

- Both people with epilepsy and health professionals identified the need for a South Asian liaison worker who can speak the language and has a deeper understanding of the culture.

- Support groups for people with epilepsy and their carers should be set up taking into account language, gender, location and childcare facilities.

- Community education is needed to help de-stigmatise epilepsy within South Asian populations.

- Information regarding employment rights legislated in the Disability Discrimination Act should be made available in South Asian languages.
• Information for health professionals outlining the main alternative South Asian therapies should be made available.

• Establishing an Epilepsy Register would equip local health providers with a valuable tool for monitoring access and equity of services for patients from minority ethnic groups.
INTRODUCTION

This report presents the findings of a two-year study that examined experiences and understanding of epilepsy amongst South Asian communities in Bradford. The study focused upon the role of families in providing support to people with epilepsy, the use of alternative therapies, experiences and views of service provision. The research was commissioned and funded by Epilepsy Action, and conducted by the Health Services Research Unit at St. Luke’s Hospital, Bradford NHS Trust. Fieldwork for the study was conducted mainly in Bradford and partly in Leeds, both of which have sizeable South Asian populations. The study was undertaken to enable Epilepsy Action to develop more appropriate information and resource materials for individuals with epilepsy and their families. Recommendations have also been produced for practitioners and policy makers involved in planning and providing health care services.

The report consists of six chapters. The introductory chapter provides a brief rationale for the research, including the data collection methods and sampling frame employed to conduct the study. Chapters 1, 2, 3 and 4 are empirical chapters based upon data collected from people with epilepsy, carers, service providers and community members. Wherever possible, the views of people with epilepsy and carers have been presented together rather than separately, as this helps to show the existence of similarities and differences in attitudes and levels of knowledge between the generations. It also helps to highlight the extent and manner in which cultural change is taking place. The final chapter provides a summary of the main conclusions and recommendations for policy makers and practitioners working in the field of epilepsy.

BACKGROUND

In 1999/2000 an epidemiological study (Wright et al, 2000) of the health needs of people with epilepsy was carried out in Bradford. Data from anti-epileptic prescribing in over 30 general practices, covering a population of 225,000 people, was used to identify people with epilepsy. Case notes and clinical review provided classification and aetiological details, demographic information, investigation and treatment information. The prevalence of just over 1% in the district was consistent with other national and European studies (Sander and
Shorvon, 1987). This Bradford database offered a unique resource from which to build more
detailed research into areas that include health beliefs and needs. Its existence in Bradford
provided advantages in that it offered essential background as well as a robust sampling
frame.

Around 24% percent of the population of Bradford is of South Asian background (people
who were born in or originate from the Indian subcontinent), predominantly Pakistani. In the
epidemiological study the prevalence of epilepsy in this population was found to be
significantly lower than that of the non-Asian population (Wright et al, 2000). The
standardised rate for all patients of Asian origin was 3.6/1000 compared to 7.8/1000 in the
rest of the population (OR 0.46; 95% CI 0.38, 0.57). The main risk factors for epilepsy
(cerebrovascular disease, pre and perinatal risk factors, CNS infections) are more common in
the Asian population, and it was therefore surprising that the prevalence should be so much
lower.

Epilepsy is primarily a clinical diagnosis. Where communication is poor between patient and
doctor, and the doctor fails to take an adequate history, then the diagnosis may be missed or
management and treatment options poorly understood. Cultural and linguistic barriers to
communication between members of minority ethnic groups and health service practitioners
have been well documented (Bhakta et al, 2000; Katbamna et al, 2000). Those most likely to
be disadvantaged, both as epilepsy sufferers and as carers, are women who are reliant on
intermediaries, usually family members or professional interpreters. It therefore seemed
possible that the low prevalence in the South Asian community may be due to problems with
communication and access to services.

The epidemiological study of epilepsy in Bradford provided extensive knowledge of local
health needs (Wright et al., 2000). It recommended that priority research areas should explore
the understanding, needs and health service experience of people with epilepsy from minority
ethnic groups.

**AIMS AND OBJECTIVES OF THE STUDY**
The main aim of this project was to facilitate appropriate support to South Asian people with
epilepsy and their families. It was intended that the information we collected through this
study would improve access to services and understanding about epilepsy and hence improve appropriateness of health services, treatment and awareness of epilepsy and its impact on people’s lives. The specific objectives were:

- to examine the experiences of epilepsy, its management and impact on peoples’ lives;
- to explore the understanding of the illness, health and religious beliefs and the use of alternative therapies;
- to understand access to health services, to identify barriers and to examine information available.

ADVISORY GROUPS
In the initial stages of the study an Epilepsy Project Steering Group (EPSG) was established to provide general guidance to the project (see Appendix A). Representatives from the Bradford NHS Trust, the voluntary/charity sector and academic staff working in the fields of ethnicity and health care as well as a representative of the funding organisation - Epilepsy Action - formed the EPSG. The group met to discuss sampling strategies, the topic guides used to gather data, and some of the preliminary findings from the study.

Additionally, a second advisory group (see Appendix A), formed by research professionals was established to discuss ongoing issues directly related to the management of the project. This Epilepsy Research Group (ERG) met on a monthly basis. Ethical approval for the study was obtained from the Local Research Ethics Committee (LREC).

BRADFORD EPILEPSY SERVICE
Bradford has a well-established community based epilepsy service, which runs outreach clinics from a number of locations throughout the city as well as undertaking visits to nursing and residential homes. The main purpose of the epilepsy clinic is to provide fast track consultations with newly diagnosed patients as well as monitoring patients who have had epilepsy for a period of time. Outreach clinics are held in easily accessible local health centres and usually include patients who may otherwise experience problems in attending hospital. The epilepsy service has been running for seven years and is headed by a full time consultant neurologist with a staff of four part-time specialist GPs as well as a specialist
epilepsy nurse and other support staff. The epilepsy service has a patient list of around 3,000 of which 139 were identified as belonging to a South Asian group.

METHODS

Since our aim was to explore people’s experiences, perceptions and attitudes towards epilepsy, we chose to undertake a qualitative approach. Individual in-depth interviews were conducted with a total of 56 people: 30 people with epilepsy, 16 family members (carers) and 10 health professionals. In addition two focus groups interviews were conducted with 16 members of the wider South Asian community in Bradford.

Samples

Preliminary discussions with staff from Bradford Epilepsy Service, local consultant neurologists and the advisory groups helped clarify the number and nature of persons with epilepsy we could expect to recruit to the study. We decided to focus upon persons with epilepsy over the age of 18. Our aim was to recruit a total of 30 respondents, 10 from each of the three main South Asian religious groups (Hindus, Sikhs and Muslims), including some non-English speakers. It was also decided to recruit a sample of 20 carers and 10 health professionals.

The first months of the project involved intensive reviewing of the Bradford Epilepsy Register, used as the sampling frame for the research. The intention was to draw samples from the register on the basis of ethnicity/religion. This presented two main problems, primarily due to outdated and sometimes inaccurate information. Firstly, a lack of recorded data on patients’ ethnicity meant that we had to identify South Asians from a long list of all persons with epilepsy in the Bradford area. We also had to identify which particular religious grouping South Asians belonged to by analysing their surnames. However, we found out that some South Asian names were recorded in the wrong order or mispelt. Second some information was either outdated or incomplete - for example, people changing addresses, not notifying change of GP, or no longer in the care of the Epilepsy Service.

It would have been impossible to overcome these problems without the assistance of the staff of the Bradford Epilepsy Service who took the time and trouble to contact GPs for an update
of South Asians patients’ records. In the end the register data showed a total of 139 South Asian adults with epilepsy in Bradford (see Appendix B for a detailed breakdown).

**Recruitment**

The recruitment process consisted of four stages (see Figure 1, p.7). The first stage involved combining different sources of information (Epilepsy Register, paper files from the Epilepsy Service and data from the Patient Administration System – PAS) to collect information about each persons, gender, general practitioner (GP), medication, address, telephone number and, where available, their fluency in English. In total we managed to compile these details for 17 Sikhs, 13 Hindus and 109 Muslims. These numbers reflected the latest Census figures for the South Asian population in Bradford when grouped by religion (see Table 2, p.8).

The second stage involved writing a letter (see Appendix C) in both English and the persons known or assumed first languages inviting them to take part in the study. The letter was accompanied by an information sheet, also in both languages (see Appendix D), explaining what the research was about, and a reply slip which enabled people with epilepsy to specify whether they wanted to take part in the research and, if so, preferred times for their interview. Those people who had been seen by the Epilepsy Service in the previous two years were sent letters providing a description of the project and a request to take part in the study. 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. All Sikhs (17) and Hindus (13) identified from the register were contacted. Muslims (due to large numbers - 109) were selected randomly to reach the desired quota (10 people).

A number of persons with epilepsy contacted the researcher to decline participation in the study. Some felt the research would be of no direct benefit to them. Others did not feel comfortable talking about their epilepsy and thought this might upset them and bring on a seizure (an issue that was highlighted by the literature review). On a few occasions, relatives, acting as ‘gatekeepers’, did not allow the researcher to establish contact with the person with epilepsy. Also a number of potential participants contacted turned out to have learning difficulties (which was not stated in the Register), and this forced us to exclude them from the sample following decisions taken by both advisory groups.
The third stage of recruitment involved telephoning those who had not returned their reply slips to find out whether they wished to be interviewed for the study. It was not possible to speak to all these individuals as some did not possess a phone or had a faulty line. These individuals were sent a reminder letter inviting them to participate in the study. In order to overcome the low response from some older female Muslims and their carers, a female Muslim South Asian freelance researcher (fluent in Urdu and Punjabi) was recruited.

The fourth and final stage involved boosting the numbers of Hindu and Sikh participants. Initially all persons with epilepsy from these groups were contacted. However, few agreed to take part while others had moved abroad. A few had moved to outlying areas of Bradford or to Leeds. We managed to find out their new addresses and wrote to them but did not receive any replies. The fact that relatively small populations of these communities resided in Bradford made our task more difficult. We took the problem to the advisory groups and it was decided that, in an effort to increase the sample of Sikhs and Hindus, it would be appropriate to contact a neurologist in Leeds and recruit additional participants from there. Despite our efforts, in the end only small numbers of Sikhs and Hindus showed interest in participating in the study.

CHARACTERISTICS OF SAMPLES

The South Asian population is heterogeneous in terms of ethnicity, religion and languages. The way in which we chose to subdivide the South Asian sample was based on pragmatic grounds. It was important to recognise diversity of experience in terms of epilepsy among the South Asian communities and one way of doing this could have been to focus on different ethnic groups: Pakistanis, Bangladeshis and Indians. Nazroo’s work (1997), however, shows that diversity is better understood on the basis of religious groupings (Hindus, Sikhs and Muslims) and he demonstrates that to a marked extent the differentials relate to systematic differences in socio-economic position between Muslims (relatively poor) and Hindus and Sikhs (relatively better-off). In addition, other studies have shown that both ethnicity and religion provide an important framework for understanding South Asians’ health behaviours and beliefs. Hence we chose to divide the sample into Muslim, Sikh and Hindu groups.
Figure 1: Process of recruiting people with epilepsy

1\textsuperscript{ST} STAGE

Identification of epilepsy patients by Bradford Epilepsy Register (139)

2\textsuperscript{ND} STAGE

Letters sent to patients (60)

- Negative response (10)
- Positive response (6)
- No response (44)

3\textsuperscript{RD} STAGE

Telephone call or reminder letter to Muslim’s (40)

- Negative response (5)
- Positive response (15)
- No response (20)

4\textsuperscript{TH} STAGE

Telephone call or reminder letter to Hindus and Sikhs + recruitment in Leeds (20)

- Negative response (1)
- Positive response (6)
- No response (10)
Religious groups and gender

As Table 1 shows, we managed to recruit sufficient numbers of Muslim participants but had difficulty finding Hindu and Sikh participants who fell within our inclusion criteria. We felt that this was due to the smaller population size of these two groups within the Bradford area (see Table 2).

Table 1: Persons with epilepsy sample

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hindus</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Muslims</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Sikhs</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>15</td>
<td>15</td>
</tr>
</tbody>
</table>

Table 2: Population by religion (Census 2001)

<table>
<thead>
<tr>
<th></th>
<th>Bradford</th>
<th>England &amp; Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hindus</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Muslims</td>
<td>16%</td>
<td>3%</td>
</tr>
<tr>
<td>Sikhs</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>

Age group

The sample consisted of both young and elderly persons with epilepsy. The youngest person to take part in the study was an 18 year-old Sikh woman and the oldest was a 68 year-old Hindu man. On the whole, the South Asian samples consisted of younger people in theirs 20s and 30s. The mean age for each group was 34 (Muslims), 51 (Hindus) and 33 (Sikhs).

Table 3: Persons with epilepsy age group

<table>
<thead>
<tr>
<th></th>
<th>Hindus</th>
<th>Muslims</th>
<th>Sikhs</th>
<th>TOTAL</th>
</tr>
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<tbody>
<tr>
<td>18-25</td>
<td>5</td>
<td>3</td>
<td>8</td>
<td></td>
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<tr>
<td>26-35</td>
<td>10</td>
<td>5</td>
<td>10</td>
<td></td>
</tr>
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<td>36-45</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>46-55</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>56-68</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</table>

Employment

In terms of employment profile, participant’s occupations ranged from warehouse operatives to teachers and senior managers. Notably a large number of Muslim females classified themselves as housewives although some of them had been previously employed. Half of the
Muslim men classified themselves as unemployed although at least one of these men was employed in an unofficial capacity. It was difficult to assign some respondents to particular categories, as their current status did not reflect their level of education or training. For example, one of our respondents was a trained doctor but was not practicing and another was a graduate in computing but was unemployed.

**Table 4: Persons with epilepsy occupation’s**

<table>
<thead>
<tr>
<th>Type of occupation</th>
<th>Hindus Female</th>
<th>Hindus Male</th>
<th>Muslims Female</th>
<th>Muslims Male</th>
<th>Sikhs Female</th>
<th>Sikhs Male</th>
<th>TOTAL</th>
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<td>Professional/Managerial</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
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<td>Skilled manual</td>
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<td>Unskilled manual</td>
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<td>Housewife</td>
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<td>Unemployed</td>
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<td><strong>TOTAL</strong></td>
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<td><strong>10</strong></td>
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<td><strong>4</strong></td>
<td><strong>2</strong></td>
<td><strong>30</strong></td>
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</tbody>
</table>

* Disabled

**Fluency in English**

As shown in Table 5, there was a good level of fluency in English amongst the South Asian samples. The majority of Muslim were interviewed in English, three preferred to be interviewed in Punjabi and five in Urdu. Only one person from each sample of Sikhs and Hindus could not speak English.

**Table 5: Languages spoken by persons with epilepsy**

<table>
<thead>
<tr>
<th></th>
<th>English</th>
<th>Urdu</th>
<th>Punjabi</th>
<th>Gujerati</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hindus</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muslims</td>
<td>12</td>
<td>5</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Sikhs</td>
<td>5</td>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

**Household composition**

Within the sample there was considerable variation in household structures across and within religious groups, as shown in Table 6. On the whole South Asians are more likely than other groups to live in larger households. However the size of South Asian families within the sample varied considerably. The majority of respondents, with the exception of one Sikh man, lived within families. Almost half the people within the Muslim group were sharing their household with their spouse and children. Hindus were much more likely than their Sikh
and Muslim counterparts to live in smaller households. A larger number of people within the Muslim group lived in extended families, usually consisting of a spouse, children, and the male spouse’s parents and siblings.

**Table 6: Persons with epilepsy household structure**

<table>
<thead>
<tr>
<th>Family composition</th>
<th>Hindus</th>
<th>Muslims</th>
<th>Sikhs</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse only</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Spouse + children</td>
<td>1</td>
<td>9</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Spouse + children + extended</td>
<td>1</td>
<td>6</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Spouse + extended</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Extended only</td>
<td></td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Parents + siblings</td>
<td>2</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Parents only</td>
<td></td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Siblings only</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Alone</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>4</td>
<td>20</td>
<td>6</td>
<td>30</td>
</tr>
</tbody>
</table>

**Health problems**

Medical histories of respondents varied considerably. Some people had suffered from frequently occurring seizures whilst others had experienced a few sporadic seizures. In terms of other health problems, two participants reported suffering from under-active thyroid and one from asthma. However, seven respondents claimed they had depression, a problem they believed was directly linked to their condition.

**Carers**

In recognition of the role of families in relation to people’s experience of epilepsy, we felt that it was important to supplement the views of the person with epilepsy with those of another family member. Hence, at the end of each interview, people were asked to choose someone who they felt cared for them during the epileptic seizures. The majority were able to suggest someone in their family whom we could interview. In 14 cases it was not possible to conduct an interview with another family member. Five participants could not identify anyone else in their family whom we could interview; two of these individuals, a Sikh man and a Sikh woman lived alone. Amongst those who were living with their families, six individuals did not feel that it was necessary to interview other family members. In addition, some carers themselves expressed a preference not to participate in the research; the
husbands of two Muslim women and one Hindu felt uneasy about discussing their spouses’ condition.

As Table 7 shows, in total 16 carers were interviewed. Amongst Hindus and Muslims spouses were identified as the main carers. A large proportion of the carers spoke English (Table 8). The non-English speakers were born outside the UK and emigrated to this country after their marriage. They felt more comfortable being interviewed in their own language.

**Table 7: Carers’ sample**

<table>
<thead>
<tr>
<th></th>
<th>Spouse</th>
<th>Sibling</th>
<th>Parent</th>
<th>Friend</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hindus</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Muslims</td>
<td>5</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Sikhs</td>
<td>2</td>
<td></td>
<td>1</td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

**Table 8: Languages spoken by carers**

<table>
<thead>
<tr>
<th></th>
<th>English</th>
<th>Urdu</th>
<th>Punjabi</th>
<th>Gujerati</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hindus</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muslims</td>
<td>7</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Sikhs</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The majority of interviews with carers were conducted separately from the person with epilepsy. Only four joint interviews were conducted. Joint interviews tended to be undertaken when both individuals lived in the same house and were both at home when the interviewer visited.

**INTERVIEWS**

Topic guides were used to facilitate the interviews (see Appendix E). Topic guides were informed by the literature review, views expressed by the advisory groups and preliminary discussions with persons with epilepsy and health professionals. The topic guides for persons with epilepsy and carers covered similar themes and explored issues including lay knowledge of epilepsy, continuity and change, health and religious beliefs, use of alternative therapies, interaction with health professionals and level of satisfaction with service provision.

Two interviewers conducted the interviews. The majority of interviews (51) were conducted by the male NHS Research Fellow who was fluent in Urdu and Punjabi; five interviews were
conducted by a female freelance researcher who was also fluent in Urdu and Punjabi. Before fieldwork began, meetings took place between the interviewers in order to discuss translation of the questions into the South Asian languages to be used. Efforts were made to ensure that words and phrases in the original topic guide retained the same meaning when translated into these languages.

Interviews were arranged with respondents at a time and venue that suited them. The majority of interviews were conducted in the participant’s own homes and lasted between 45 to 60 minutes. Given the potentially sensitive nature of some of the subjects included in the topic guide, we offered participants the option of being interviewed by someone of the same sex. Four females (three Muslims and one Sikh) and one female carer (Muslim) took this option. This arrangement was not always possible though, for example when the person with epilepsy and their carers were interviewed together.

Great care was taken to ensure that interviews remained confidential. Participants were assured that anonymity would be maintained. In the report, all of the individuals who were interviewed would be given pseudonyms relevant to their religion and gender. We also had to ensure that, when persons with epilepsy and carers were interviewed separately about the same range of issues, discussions remained confidential and did not damage the relationship between these family members. Both people with epilepsy and carers were also reassured that the information they provided would not be discussed with service providers. A total of 12 interviews with persons with epilepsy and their nominated carers had to be conducted in Urdu or Punjabi and then later translated into English by the interviewers. All of the interviews were transcribed in full.

**Health professional interviews**

Health professionals play an important role in the provision of culturally appropriate health care services. Having collated the views of people with epilepsy and carers towards practitioners, we were keen to contextualise these experiences within a broader picture of service provision. As one of the main aims of the study was to improve support for individuals with epilepsy, it was particularly important to examine how existing service provision within the fieldwork areas catered for the needs of people with epilepsy from diverse cultural backgrounds. Previous research on caring suggests that stereotypical attitudes
amongst health professionals, culturally inappropriate services, and linguistic barriers can often influence uptake of health services amongst minority ethnic groups and dilute the impact of advice provided by health professionals (Ahmad and Atkin, 1996; Atkin et al, 1999). We were keen therefore to explore the views of professionals about existing health care services particularly in relation to the provision of information and models of good practice. In addition we wanted to explore attitudes of service providers towards the role of families in providing support to persons with epilepsy, as well as their understanding of persons with epilepsy and their families’ information and support needs.

Interviews were conducted with individuals involved in delivering epilepsy services in Bradford. As Table 9 shows, in total 10 health professionals (consultant neurologists, specialist nurses, GPs and a social worker) were interviewed. The interviews with these different professionals provided us with useful contextual information that enabled us to gain a richer understanding of people patients’ and families’ experiences and perspectives.

### Table 9: Health professionals’ sample

<table>
<thead>
<tr>
<th>Role</th>
<th>Number of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community GPs (with many epilepsy patients)</td>
<td>2</td>
</tr>
<tr>
<td>Specialist GPs</td>
<td>2</td>
</tr>
<tr>
<td>Specialist epilepsy nurses</td>
<td>2</td>
</tr>
<tr>
<td>Consultant neurologists</td>
<td>3</td>
</tr>
<tr>
<td>Social worker</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>10</strong></td>
</tr>
</tbody>
</table>

### Focus groups

The focus group is a useful technique for exploring cultural values and beliefs about health and disease. It is particularly useful for research among different cultural groups. It can be used to examine not only what people think, but how they think and why they think in that way, their understanding and priorities (Bowling, 1997). Having interviewed people with epilepsy and their carers we felt we needed to pursue some issues in greater depth and decided to conduct focus groups with a sample of South Asian community members who had no direct connection with epilepsy.

Two focus groups were used, comprising eight members each, for group discussions lasting around one hour. One group was composed of men aged 30 - 65 and the other women aged 25-55. A facilitator with experience in South Asian community work was hired to conduct
the discussions. He was also responsible for recruiting participants at random from various classes held within community centres. An unstructured topic guide was used to stimulate and guide discussion. The discussions took place in a room within a local community centre, which was easily accessible to all focus group members. A comfortable environment was provided with light refreshments. The researcher was also present to make observational notes and tape-record the meetings.

**Table 10: Community members’ sample**

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housewife</td>
<td>Female</td>
<td>26</td>
</tr>
<tr>
<td>Teacher</td>
<td>Female</td>
<td>31</td>
</tr>
<tr>
<td>Housewife</td>
<td>Female</td>
<td>55</td>
</tr>
<tr>
<td>Housewife</td>
<td>Female</td>
<td>25</td>
</tr>
<tr>
<td>Scientist</td>
<td>Female</td>
<td>29</td>
</tr>
<tr>
<td>Housewife</td>
<td>Female</td>
<td>50</td>
</tr>
<tr>
<td>Housewife</td>
<td>Female</td>
<td>40</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>Female</td>
<td>30</td>
</tr>
<tr>
<td>Retired (Textile worker)</td>
<td>Male</td>
<td>65</td>
</tr>
<tr>
<td>Social worker</td>
<td>Male</td>
<td>38</td>
</tr>
<tr>
<td>Unemployed</td>
<td>Male</td>
<td>26</td>
</tr>
<tr>
<td>Teacher</td>
<td>Male</td>
<td>34</td>
</tr>
<tr>
<td>Student</td>
<td>Male</td>
<td>30</td>
</tr>
<tr>
<td>Engineer</td>
<td>Male</td>
<td>46</td>
</tr>
<tr>
<td>Unemployed</td>
<td>Male</td>
<td>52</td>
</tr>
<tr>
<td>Imam (Religious teacher)</td>
<td>Male</td>
<td>62</td>
</tr>
</tbody>
</table>

**Total number of participants: 16**

**ANALYSIS**

Interviews with persons with epilepsy, carers, service providers and community members were tape-recorded, translated if necessary, and fully transcribed. Each transcript was classified using a labelling system (see Table 11, p.15).

The framework approach devised by Ritchie and Spencer (1994) was employed to analyse the data. A coding frame was devised based upon the common themes and sub-themes running across the interviews. This coding frame was then applied to each transcript (people with epilepsy, carers and service providers) and relevant text was indexed in the transcript whenever a particular theme appeared. The next stage involved transferring this indexed data onto a grid.
The construction of a grid to analyse the data served two purposes. First it enabled us to focus upon the experiences and views of each individual and relate them to the themes we had identified. This was useful as it highlighted how, for example, peoples’ material circumstances and family structure impacted upon their understanding of epilepsy and their coping strategies. Second it enabled us to compare cases and identify similarities and differences between groups of people. Although we were interested in looking at how religion impacted upon people’s understanding and experience of epilepsy, we did not think that people’s religious status should be used as an explanatory variable in isolation from other aspects of their identity. It was felt that gender, age and social class were equally important factors, which needed to be taken into consideration. Using this approach helped us to identify commonalities in experience across groups. It also helped to highlight when religion made a difference to people’s understanding and experience of epilepsy in that the accounts of Hindu, Sikh and Muslim individuals have been juxtaposed to highlight similarities and differences between the groups.
SUMMARY

- This report is based upon a qualitative study that was undertaken to examine the experiences of people with epilepsy who are of South Asian origin in relation to their health needs and beliefs and the role of health professionals in providing appropriate information and accessible services.

- A sampling frame of persons with epilepsy over 18 years of age from Bradford and Leeds was compiled using data from epilepsy registers and hospital databases. The sample was divided into Muslims, Sikhs and Hindus.

- The largest group was of Muslims (109), where a random sample was selected. All persons from the Sikh (17) and Hindu (13) categories were invited to participate in the study. A total of 20 Muslims (10 male and 10 female), 6 Sikhs (2 male and 4 female) and 4 Hindus (3 male and 1 female) accepted the invitation.

- Individual in-depth interviews were undertaken with 30 persons with epilepsy, 16 carers and 10 health professionals. Semi-structured topic guides were used to facilitate the interviews. In addition two focus groups were conducted with 16 people (eight males and eight females) recruited from community centres. A topic guide was used to stimulate discussion.

- A male researcher conducted most of the interviews; a trained female researcher conducted five interviews at the request of participants. Interviews took place in people’s homes and lasted about one hour. Twelve of the interviews were conducted in Urdu or Punjabi. All interviews were tape-recorded, translated if required, and transcribed. A framework approach was adopted to analyse the data.
CHAPTER ONE
PERCEPTIONS AND EXPERIENCES OF EPILEPSY

This chapter examines the perceptions and experiences of individuals diagnosed with epilepsy and analyses how they and their families make sense of the condition. Overall our study shows that there is no one particular model of understanding epilepsy within any of the religious groups (Hindus, Muslims and Sikhs) that participated in the research. We observed more variations within each group than between groups, pointing to the significance of individual features of gender, age, country of origin, family history and social class.

WORDS USED TO DESCRIBE EPILEPSY

The linguistic diversity present in our sample provided us with a number of words or phrases used to describe epilepsy. We have mentioned earlier that many of our interviews were conducted in South Asian languages (Urdu, Punjabi) and for purposes of analysis were translated into English. Even though a large number of respondents spoke in English we found that they often reverted to terms or phrases in their mother tongue. It was not always possible to translate phrases from another language into English without losing the subjective meaning and in such instances we have remained true to the respondent’s words and tried to provide an approximate English equivalent.

We found within our sample quite a few different expressions or terms used to describe epilepsy. The terms used not only differed according to the respondent’s language and ethnicity but were also dependent upon other variables like social class, place of dwelling (urban/rural) and level of education.

While a number of people from the sample used the English word ‘epilepsy’ the majority of respondents (also) used terms from their own languages. The most commonly used phrase for epilepsy, regardless of ethnic group, was *mirgee*. However the interpretation of the meanings of *mirgee* differed within the sample. Some respondents described *mirgee* as a classic manifestation of a tonic clonic seizure:

*You know, when they seize up, you know, whatever connection clicks, whatever, so basically the same as two waves in your head, when they connect, that causes you to seize up. Seizing up, yes, is what you would call it (the word mirgee). To a lot of people it would be very, very scary and freaky. You’d probably think ‘the*
guy is dying or something’ the first time he's having it. That’s for starters and what happens to them is they just crunch up. Yes, he crunches up and he really, you know, like tensifies himself (Carer of a 26 year-old Muslim male).

Others, like 31 year-old Muslim female Rizia, were worried when they found they had mirgee because of the negative associations they felt were linked to the word:

In our language it’s really bad so I really didn’t know what it was, just knew it was really bad, crazy or something, I never imagined I’d get it.

One respondent, a Hindu carer who came from the Gujerat region of India, used the term ‘fit’ to describe epilepsy. Others used terms they had learned from their parents. Ranjeeta, a 48 year-old Sikh woman, used the term gussy, which she had heard from her parents and was told was widely used in the Punjab region of India where they had come from:

In Punjabi there’s an awful word, it’s called gussy and in Punjabi when you’ve got epilepsy its called gussy. And it’s a horrible word and it just means that you drop down like you’re dead when you’re having a fit.

PERCEPTIONS OF CAUSES OF EPILEPSY

An important aspect of perception of epilepsy, as of any chronic illness, relates to the notion of cause. In our study we felt it was important to gather different perspectives on people’s understanding of possible causes of epilepsy. For that we tried to explore the views of not only individuals with epilepsy and their families but also of lay community members who had little or no contact with persons with epilepsy. We thought that this would help to examine views and prejudices held at a societal level.

From the person with epilepsy and their carers’ perspective the common explanations for having epilepsy were stress, family history, physical trauma, previous health problems, unknown causes, fate, sins committed in a past life, and spiritual possession. The following sections discuss these perceptions in greater detail.

Stress

Stress was considered to be one of the major causes of epilepsy by many individuals. Almost half the sample of persons with epilepsy thought that stress had contributed to their condition. They talked about events in their lives that they felt had given rise to considerable worry and tension. For example, Amanroop, a 24 year Sikh woman, had a number of explanations or contributing factors that she thought could be responsible for causing her epilepsy. Amanroop
believed that her epilepsy was caused by a multitude of problems that she had stored up in her brain over time (a tumour, pregnancy and moving houses). Amanroop had been experiencing problems with a non-malignant tumour in her throat and thought that this may have had an effect on the veins leading to her brain becoming tight (constricted). The doctors had told her that they would be unable to remove the lump in her throat, which was causing her discomfort but was not life threatening, because she was pregnant. Although the baby was later born healthy, at the time this had led to Amanroop worrying excessively about the possible effects of the tumour on her baby. In addition, prior to her first seizure, Amanroop had moved into a new house that she was totally refurbishing. She felt under pressure to complete the house refurbishments on a tight budget, which meant having to do much of the work herself with the help of her husband. All these factors, combined, had led her to become run down, suffering from headaches and then having a seizure.

While some people spoke about accumulated stress over a period of time leading to their epilepsy, others pinpointed the exact event that led to their first seizure. Nagesh, a 68-year-old Hindu man, felt the reason for his epilepsy was due to the sudden shock of finding out that his 21 year-old son had been struck down by a mysterious illness, which had left him permanently paralysed from the waist down: “It (his first seizure) happened at work, after what happened to my son”.

Others thought that they had been living under stressful circumstances for a long period of time, which had resulted in an accumulation of pressure. Individuals who had been looking after ill members of the family for a prolonged period, those experiencing stressful family situations, and those dealing with work-related problems felt that this had had a negative impact upon their health. As 48 year-old Sikh female Ranjeeta explained:

It started in 1996... at the time ... I was managing a team of about ten social workers of the most difficult side of social work (child abuse)... and I was working very long hours... and after about a year I just had a grand mal fit while at work. The sort of work I'd been doing, the hours I'd been putting in, going to court, barristers, police, it’s quite intimidating work when you are trying to protect children...and I think when you have parents threatening you it’s very difficult, and...I accept now it was stress but I'd just done too much.
**Family history**

Muslims, in particular, identified having a family history of epilepsy as a possible reason for their condition. Asghar, a 43-year-old Muslim male, explained how he felt he was genetically more prone to epilepsy:

> You see, it’s in the family this problem; it’s in the family. My dad died because of this, he was walking and he fell and died because of this, my aunt has epilepsy too, she had cancer but her main problem was this, epilepsy.

Similarly Saima, a 26-year-old Muslim female, thought her epilepsy was also inherited:

> I think it’s in our family because I have a brother and he’s the same, and I have an auntie as well, so it’s in the family, definitely.

We also found that in some cases health professionals had told patients that the probable cause of their epilepsy was inheritance of particular genetic traits. This had led people to enquire about other family members in the UK or abroad who may have suffered from epilepsy. Some of these enquiries revealed that other members of the family may have had epilepsy but this was not openly discussed and was only known by the select few. In some cases those enquiring whether there was any past history of epilepsy within the family had met with silence or disapproval, especially from older family members. Other people, after investigating their family histories to try to make sense of their own condition, felt frustrated because they could not find any relative with epilepsy. As Akhtar, a 25 year old Muslim male, said:

> The hospital got to say sometimes it beens (is) running in your genes, through your blood, but like we’ve asked our uncles and everyone, mum and dad they say no one, we know of nobody.

A different patient, 40 year-old Hindu male Kumar, said that he had been at a higher risk of developing epilepsy due to a combination of family history and a traumatic birth:

> I was told when I was born, probably if you have had a bad birth, you could possibly pick up epilepsy from that. A late uncle had epilepsy in the family so that could have been linked. And me sister got it late as well…. It could be a bit of both (herititary and birth trauma) to be honest.
Previous knowledge of epilepsy

At the other extreme, some individuals with prior knowledge of epilepsy within the family or social network used the information they had about epilepsy to question health professionals about their diagnosis. This was the case of Khalida, a 56 year-old Muslim schoolteacher, who strongly challenged the specialist when he diagnosed her with epilepsy. Her disagreement stemmed from the fact that she had witnessed her brother having (tonic clonic) seizures 35 years ago and hers were ‘nothing like that’:

*I just jumped on him (the consultant); I just shouted at him, I said ‘how can you say I’m epileptic’? I didn’t mind, I didn’t mind this thing, but the thing is if it’s not there (the seizures) how can I think I’m epileptic, all those things they can come to me?*

One individual said he was able to tell immediately that his brother had suffered from a seizure, although he was still undergoing medical investigations. This was the case of Saleem, a 32-year-old Muslim male who had suffered from epilepsy from the age of 16. When he was 20 his younger brother Amjad, who was 13 at the time, experienced his first seizure during a family meal:

*He (the brother) was sitting down... eating and the fork kept dropping out of his hand. ...Dad started shouting ‘what you doing every morning, you don’t sleep at night or what?’ ...So next day... (Only) me and him are eating and I see... he did it again... (I) grabbed his head and... his eyeballs were turning, I knew it straight away. Fork shook... I grabbed him... I knew there was something wrong with him. I grabbed him and his eyeballs were turning, honestly his eyeballs were turning... I let him go. I told me mum, I said... its epilepsy, she said ‘how do you know? It’s not epilepsy!’ and three months later he had a fit, his first fit.*

Sara, a 34 year-old Muslim housewife, also felt that her family’s previous experiences of people with epilepsy (in Pakistan) helped them to identify her condition even before the health professionals:

*I think the family sussed it out straight away because, you know what it’s like, in certain illnesses they (the family) know straight away what it is, doesn’t matter how long (it takes to be diagnosed). There’re certain types (of illnesses - epilepsy, schizophrenia) that are obvious. Here the doctors take ages, they do tests and everything, then a good couple of years down the road they tell you what it is, but family (they) immediately found out, you know.*
Previous health problems
For many of the individuals within the sample, there was a strong belief that their epilepsy was a result of other health problems they had suffered at some point in life. Akhtar, a 23-year-old Muslim male from Bradford, thought his epilepsy was caused by the large doses of medication he had taken whilst suffering from childhood leukaemia. Safina, a 65-year-old grandmother from Bradford, felt that her epilepsy was a direct cause of her kidney transplant, which was undertaken more than five years before her first seizure. Two respondents believed they had developed epilepsy as a result of other health problems. One of them, Jogindar, a 42-year-old Sikh, who used to be a head teacher, said his epilepsy was a consequence of lesions caused by a brain haemorrhage. The other, 47-year-old Hamid, a specialist youth worker, said his epilepsy was “the result of a benign (brain) tumour on his lower left lobe that cannot be removed”. Where people were given a ‘medical’ cause for their epilepsy this was generally accepted but was not seen to necessarily negate belief in divine providence.

Unknown causes
For many respondents within the sample for whom the medical cause of their epilepsy was unknown, uncertainty had led them to speculate about probable causes. One such patient was 28-year-old Asifa, a Muslim housewife, who trained as a court interpreter before being diagnosed with epilepsy:

*I have no any idea what caused my epilepsy. I tried to find out myself, read about it, ask other people, ask the doctors. What I’ve been told is electrical activity in the brain, a certain part of the brain, and when electrical impulses get out of control or the nervous system, that’s what mostly triggers, it is when I’m upset or under stress or lack of sleep, over-tired, these kind of things. Sometimes, there have been times when it’s been none of these, it just comes for no reason, so I don’t know basically.*

Other respondents, particularly if they had been diagnosed at an early age, were very dismissive of explanations given to them by family members as to the probable cause of their epilepsy. Santosh, a 42-year-old Hindu male believed the cause of his epilepsy was unknown despite the fact that his wife, who was present at the time of the interview, offered a different explanation:

*I don’t know but my mother-in-law says when he was young that he used to bang his head a lot because of the headaches he suffered around the age of four. My mother-in-law thinks it’s because of that, but I don’t believe it is.*
Another participant, Banares, a 27-year-old Muslim who had no known cause for his condition challenged the specialist when he was told he was not displaying the ‘classic symptoms’ of epilepsy. Banares was very keen to have a positive diagnosis of epilepsy, as it would help to convince his suspecting parents that his problems were not related to illicit drug taking:

*As parents they think it’s something to do with drugs, illegal drugs that’s what they thought. Because they thought ‘how come 22, 23, 24 up to all that age he’d been alright and all of a sudden he’s gone to university’... So since then I thought to myself ‘it’s best if I get checked up, just to please my parents’, I said to Dr X ‘do a full check on me’. He was saying to me that there’s so many ways you can have fits again, blowing a bag and collapse and stuff and that’s what I got really annoyed. I wanted to know if I’m epileptic or not. I said ‘you’re supposed to be a specialist so tell me what process to take to find out if I’m epileptic’. And he told me ‘you need to do an EEG’. I said to him ‘it’s a waste of time coming to you for help; I’ll come to you after I’ve done my EEG’. I did all that showed him it and then I said ‘my GP has actually diagnosed me epileptic, I don’t know, what you think’? He goes ‘leave it with me’, so he read it and said ‘right, sit down’; I was diagnosed epileptic after that.*

**Fate**

For many individuals within our sample there was a strong belief that they had been fated to suffer from epilepsy. They felt that nothing could have stopped their condition from happening and found it difficult to identify any causal factors. The idea that it was God/Allah who was responsible for the condition was discussed by some. Take the example of Akhtar, a 25-year-old Muslim man, who had suffered from epilepsy from the age of seven:

*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.*

One Muslim female respondent, 31 year-old Razia, told us about illness presenting itself as an opportunity to help to expiate a person’s sins if they remained steadfast in adversity:

*In Islam, it says the more you feel ill the more your... what is it?... God will forgive you, whatever you say that person will get better. While you’re ill, say, my mum’s not feeling well and I say “please make my mum better”, plus when my bad things are going away cause I’m suffering. That’s what it says in Islam, so when I used to have a fit I used to think, “that hurt me”, I used to think, “at least God will listen to me and my bad things are going and good things are coming”.*
**Sins of a past life**

The belief in punishment for sins that may have been committed in a past life is part of the religious doctrines of Hinduism and Sikhism. Nevertheless, very few Sikhs or Hindus from the sample thought that this was the direct cause of their epilepsy. Bhupinder Kaur, a 46 year-old Sikh woman, told us:

> 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.

Sachdev, a 19-year-old Sikh man, who was diagnosed at the age of 12 had been told by his parents that his epilepsy was caused by sins he had committed in a past life:

> I remember them having 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. To me, it’s more a nonsense but to you, because you are older, you have more knowledge of this, of religion, and your views again are different from mine, but I don’t really believe in this sort of thing.

**Spiritual possession**

Widespread beliefs in spirit possession in one form or other are found in many religious and belief systems, such as Christianity, Judaism, Islam and voodooism (Paladin, 1995). Epilepsy fits well into this idea as a seizure can be seen as a clear manifestation of possession due to its unpredictable nature (Carrazana et al., 1999).

In our study, however, very few respondents thought that their epilepsy was caused by evil spirits (*jinn’s*), bewitching or spells that had been cast upon them. These beliefs were predominantly found in the Muslim sample, although we acknowledge the low numbers of Sikhs and Hindus we were able to recruit may not be typically representative of the wide spectrum of views present within these religious groupings. On the whole respondents who were born and bought up in the Indian subcontinent (Pakistan, India) were more likely to subscribe to such beliefs, as explained by the carer of 35 year-old Muslim male Iqbal:

> Magic, you know how it is in India, in Pakistan and Africa and everywhere, yes, we thought it was the outside job and he went to see a lot of priests, things, at first, he didn't know what it was.
Khalida, the 56 year-old Muslim schoolteacher, went on to explain the different attitudes of people from the Indian subcontinent towards those with epilepsy and how these affected her approach to disclosure:

*I never told any of my Pakistani colleagues that I’m epileptic. Not the people who came especially from Pakistan, they got funny ideas, not to those… The people who are educated here, they are okay, they are very nice. Not even to the educated one’s (from Pakistan) because they’ve got the same (negative) mentality, Pakistani people who are brought up over there (in Pakistan). I have got a head of department now, she’s young, she’s about 35 and I told her because she is head of my department plus she is very nice as well, she’s very, very nice, I told her because I got to tell her. She is Pakistani, she is Pakistani but she is been brought up here, she was born here. They have different mentality.*

Many respondents did say that the prevalence of beliefs in spirit possession was much greater in the Indian subcontinent than in the UK. The carer of 46 year-old BhupinderKaur, a Sikh female, gave us an example of the differing beliefs found within the same family living in two different countries:

*My nephew has it and they (the family in India) went ages without getting any medication for him, they said he's got this, he's got that, he's got some kind of spirit involved, the winds affected him, that he's got jinn (demons), but in our family we’ve never believed things like that, you see. My father, he came here as well, we did not have those beliefs. I mean the doctors gave us the medication, we will take that, there's no point in listening to other people and so much time went by and they never gave him (the nephew) any medication, so we don't believe in those things. My in laws family think that way, you see, my brother in-law doesn't give the boy any medication, doesn't seek any help because they said 'oh he's got something, he's got something, he's got some spirit, some spirit has possessed him’. The majority think that, yes, most of the people think that way. 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.*

Others felt such beliefs were determined by level of education and were more likely to be found amongst older people who were more superstitious by nature regardless of where they lived. As the husband of Asifa, a 28-year-old Muslim woman, pointed out:

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

One respondent 32 year-old Muslim male Saleem told us about his experiences as a child of spiritual possession within the family:
All right, there’s another thing now, they’re (religious healers) treating my mum as well, and people yeah and mum she has jinn (demons), yeah. We were small I don’t know if you can remember it (speaking to his cousin) yeah, you and me had a brother remember. Used to be asleep at night, dad used to be at work, she used to go into a fit grinding her teeth, pulling of the hair, you know in Pakistan you know these pir or whatever they showed another person out there this thing talked, yeah. (How the possession started) My nanni (grandmother) passed away, they were all round the bed and everyone was told to read kalma (prayers), my mum didn’t read Koran she was? She couldn’t read kalma (prayers) she was crying. And when my mum had it yeah, they got a pir Fakir (religious healer) and he talked to the jinn.

Mental illness

The distinctions between what constituted genuine mental illness as oppose to spiritual possession were blurred. The experiences of 24 year-old Muslim male Mohammed highlighted some of the contradictions:

My mother who’s got mental illness but that’s different (to epilepsy).She’s got sometimes like she’s normal and speaking but then sometimes she just starts talking like in different language and so she talks about other stuff and just ... she’s got a brother my real uncle, he is like mentally disabled as well so but she hasn’t got she doesn’t have fits or epileptic attacks. Yeah, I’ve seen her like that, she’s like a totally different person it’s like somebody with a personality disorder, like that she changed completely changes and normally she just speaks in her own language which is Hindko. Yeah Hindko but when she changes and goes into them moods it’s like she speaks in Urdu and normally she doesn’t speak or she can’t write in Urdu. (Seeking treatment) No not Pir (religious healers) but Hakims (herbal practitioners), Hakims she’s seen Hakims Yes they said she got like 3 Jinn’s on her, they talk through her body.

Some respondents like 29 year-old female Shanaz, who had been born and bought up in Pakistan, felt that younger people had a better understanding of epilepsy than older people:

The younger generation they tend to understand more about the 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 the children will catch it.

Sachdev, a 19-year-old Sikh male, also thought that younger people had a more open-minded attitude towards people with epilepsy:

I think the younger person, he’ll have more time to learn about it and progress from there, whereas older people, they’ll see themselves as “Is this what happens to me when I get to a certain age and will it happen to this person or that person”?
Conversely, 24 year-old Muslim male Mohammed thought that English people and older people from the South Asian communities had a better understanding of epilepsy:

> I think English people they understand epilepsy more better than a few Asians, like my dad, they know, older generation they know, yes, younger generation they don't know.

Others mentioned that older people were more fixed in their ways and believed in what they had been taught. Beliefs about spiritual possession were not limited to respondents from any particular social class or confined to those with limited education but were seen across the sample. For example, Sapna, a 53-year-old Hindu female from India, had qualified and practised as a doctor for 10 years before moving to the UK. In 1986 Sapna had her first seizure while preparing for her conversion exams to enable her to practice medicine in the UK. Although her understanding of the mechanics of epilepsy was comprehensive and she felt that the pressure she was under at the time was a major contributory factor, Sapna still believed that jinn’s (demons) were partly responsible:

> 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...

**Catching epilepsy**

Whilst none of our sample believed that epilepsy was contagious the idea of epilepsy as a transmittable disease (through everyday contact) was mentioned by a total of six respondents (five persons with epilepsy and one carer). Respondents felt that some people from the wider community shunned them due to fear of catching epilepsy. The experiences of 29 year-old Muslim female Shanaz highlighted such prejudices:

> Other people, sometimes you sense, they just keep away because they don’t want to get it (epilepsy), they think they might catch it. I mean, if that’s the case I just tend to back off those kinds of people. 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 and it’s not something that’s inherited otherwise my kids would have it. 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. In those kinds of situations I just tend to withdraw myself because I just don’t think it’s worth upsetting people.
Such sentiments were not confined to any one particular religious or ethnic group, as shown by the experience of 25 year-old Sikh female Amanroop:

*I haven't told anybody, nobody knows. Nobody knows that I've got it and they'd say, “Oh, you didn't tell us, did you?” Because I just can't stand them telling each other and talking and stuff about me. Yes, they do. They'll start “she's got epilepsy and all and I don't want to catch it and stuff”. Yes, they do, they do think it's contagious. Not through human contact, like shaking hands, like if I eat something off they won't eat with me. It happened at my brother’s engagement party. Here as well, not only in India, it’s our people here. That's why, you know, I don't want anything, I'm really afraid to go in to people because of what they would say if something happened.*

**Community perceptions**

Community members within the focus groups that we conducted identified a number of similar ‘causes’ for epilepsy. Genetic inheritance, birth trauma and spiritual possession were all common beliefs. Others presented more diverse views that they had heard about but did not necessarily believe. A 45 year-old Muslim man who had been told by elders that if a person sustained an injury as a result of being caught up in an earthquake conveyed one such view then they would become ‘epileptic’. Others thought that epilepsy or seizures were due to some kind of deficiency within the individual, which led to general weakness, although the group agreed that not all weak people were prone to epilepsy.

Some members of the women’s focus group thought that consanguineous marriages were a major causal factor within the Muslim community. Others counteracted this argument by pointing out that although low numbers of consanguineous marriages took place within the Sikh, Hindu and white communities, epilepsy was still common within these groups. The view that within the Indian subcontinent whole villages were intermarried yet did not display significant numbers of people with epilepsy was given as further proof that consanguineous marriages played a minimal role.

One of the focus group interviewees, a 30-year-old Muslim woman, whose father-in-law in Pakistan suffered from epilepsy, recounted a story she was told about the causes. His epilepsy, according to the learned elders within the village, was related to an excessive intake of salt when he was a young boy. The salt had caused some kind of chemical imbalance within his body that had lain dormant for many years but had been triggered by the trauma caused by the sudden death of a family member.
The women’s focus group had more experience of encountering people with epilepsy especially those respondents who had been raised or had spent extended periods of time in Pakistan. The opinion of two respondents was that *jinn’s* (demons) could possibly play a part in causing epilepsy. Others strongly disagreed with these opinions and told us that possession by the *jinn’s* (demons) had become an excuse in Pakistan to encompass all forms of mental illness. This was felt to be detrimental to people suffering mental illness, as they were often not referred to appropriate professionals (doctors, psychiatrists) for treatable conditions but were taken to pirs (religious healers) who benefited (financially) from propagating the myths of possession.

One elderly male focus group member mentioned that he had been bought up to believe that epilepsy could be caused through injuries as a result of a fall specifically caused by an earthquake. The younger respondents were surprised to hear this although some of the older ones agreed that it could be true.

Community members also mentioned commonly held beliefs from Pakistan about what to do in case someone has a seizure. A member from the women’s group explained that a black cloth without any embroidery should be “thrown” on the person’s face. She strongly stressed the fact that the cloth should be *black* and *without any embroidery*. A member from the men’s group recalled an incident in his youth in Pakistan. He was playing outside with other children when they witnessed a street seller having a seizure. Someone came, took the one of shoes off and made the seller sniff the inside of the shoe. He said he knew the person would get better sooner or later anyway but this was a common belief and practice in Pakistan even nowadays. Another member said that he was told that people with epilepsy should not go near still water because seeing one’s reflection in the in the water could trigger seizures.

**DISABILITY AND EPILEPSY**

Over a third of respondents from all religious groups within our sample of people with epilepsy and their carers felt the perceptions of the wider community towards persons with epilepsy were very similar to the negative attitudes displayed towards people with other disabilities. The term disability in this context was perceived as referring to persons with visible infirmities. Members of our sample disliked this kind of association:
I don’t know, I don’t know, it’s like..., I don’t know, what really pisses me off is people take it like it’s a disability (24 year-old Muslim male Banares).

I’ve got epilepsy and it’s a disability, yes, they call me names, you know, like my brothers and sisters, they call me names and, you know, sometimes I get mad, yes, I get frustrated with them, you know, and I start lashing out (23 year-old Muslim male Mohammed).

One respondent, 31 year-old Muslim female Farhana, considered the issue of disclosure to potential employers in terms of a sliding scale:

Well, I think that some people... it is classed as a disability, you know, if you went to work in a college or something, if you were epileptic, I think they’d put you down, it depends on... how severe it is as well because I know someone whose... well, someone's son who's got it and when he tries for jobs he puts down that he is. I suppose it depends on how bad it is as well and whether you think it stops you from doing things as well. Some people have them quite often; some people don't, so it depends.

A comprehensive and lucid account regarding the term disability in the context of community perceptions, partners’ attitude and seeking employment was provided by 40 year-old Hindu male Kumar:

I don’t think it’s a disability, to be honest. You probably might not find it with other people but for me I don’t class it as a disability. I don’t think (it has stopped me from doing anything) but disability was years ago and I think any person with a disability was seen as more than anything else an outcast. My wife did when she first... well, she did really, but she didn’t know about it, Asian families probably don’t tell people, they (community) think it’s a disability more than anything else. I’ve been to job interviews where I’ve mentioned this because I have to mention it and they’ve said “no, we can’t” (give you a job) It’s made me more determined to be honest, to do better. That’s just to say I’m sorry more than anything else but like job interviews they don’t see this person as a person, it’s just a disability more than anything else. Yeah, that’s why they took me on, yeah, but I’ve had a few problems since and I’ve stood up for myself and they’ve actually said... and I know the rights, that you cannot discriminate against disability. You know, we... my prime example is Sainsbury’s, they’ve got a head office, they must know about disabilities, and they’ve got personnel people who don’t take it in consideration. If I’ve got headaches at home they only see it as headache, they don’t see the underlying cause. If I go to work I might get... people are different, you know, if I had headache or something like that, then they probably would see and then they would benefit but when you don’t see something, that’s a disability, then they won’t know.
Others, like 39 year-old Muslim male Yaqoob, were determined to stress that although he suffered from seizures on a regular basis resulting in falling and receiving injuries he was not disabled:

*Because if I’m walking, okay, I’m not saying “I’m disabled” by walk or can’t get up, can’t do anything I’m fit by walking. But the main problem is if I’m walking when I have a fit I drop down, whether it’s on a road or I’m walking in a pavement or inside a home.*

Saima, a 26 year-old Muslim female, felt that the wider community only categorised persons with epilepsy as disabled depending on the frequency of their seizures and the impact (disruption) in their daily lives:

*I think it’s some kind of problem in the head, I don’t think it’s a kind of disability because it’s not affecting my life directly, it’s doesn’t make any… it’s okay.*

The views of carers from our sample regarding the intertwined relationship of epilepsy and disability helped to further our understanding of community perceptions and prejudices. In total five carers mentioned that the wider community saw people with epilepsy as having some kind of disability. The carer of 56 year-old Muslim female Khalida gave an example of attitudes within the South Asian community towards people with epilepsy in comparison to more common conditions like heart disease or diabetes:

*I think they got bad… this disease got bad reputation in our community. If you got epilepsy, you know, you’re not normal person. That’s what I think, that’s what people say, mean any disease is a disease it different way coming out, you know. Oh, yeah, the way that people see heart... you can have a heart attack “oh, you had a heart attack” but if you’ve got epilepsy, there is something... how can I put it... abnormal. It’s like... disabled person, yeah, because heart attack... you don’t call yourself disabled but if you’ve got epilepsy people say, “Oh, something wrong with him, might be catching”. So, I don’t know, everywhere (there is a) different way of explaining things.*

One respondent from our sample, 18 year-old Sikh female Saroop, as well as having epilepsy had cerebral palsy, which affected the use of one of her arms. Saroop’s carer (her mother) told us at great length about the negative attitudes her daughter faced within the extended family and the wider community towards both her physical disability and her epilepsy:

*Don't mention fits or disability to other Asians. Yes, you only have to be, say, a disabled child or something, they think, you know, they sort of outcast... which is to me, I mean to me, they're still people. I mean, we're perfect now but you don't know what's going to happen in five/ten minutes... something can happen to us, so, I mean, to me... it's like she says... one minute she wants to get*
married and the other minute she says... and I feel that I've had a word with my husband, I say how can I explain it to her, our people so cruel that they would probably turn around and say “she's disabled who wants to marry her?” Her grandma's already told her, anyway. She was watching Indian movie once and a wedding scene came and she started crying and I said “what's the matter with you?” “Grandma says nobody is going to marry me because... “I said, what?” she says,” Yes, grandma said to me ‘nobody going to marry you because you like this’...” I said “just ignore mama, don't listen to her!” But like I said, I say to myself “Asian people are cruel when it comes to disabilities”. I mean, they sort of... like I said, we're outcasts even in the family, they sort of try to ignore that person. They might be saying about 10% who thinks “oh, they are children and this and that”.

Saroop’s mother went on to tell us about the difference in attitudes within white communities towards persons with disabilities, while emphasising that prejudiced views were widely held across all South Asian groups:

*I think they (white community) are different. You see so many people who are disabled, and a normal person they're married to a disabled person. I mean, I said to her “can you imagine it in an Asian person?”. You know, perfect man never say, “I want to marry that girl” or a man who you know a bit... It's just an example, suppose I'm perfect and I see this man and he's disabled, “oh, I don't want to marry him”, I want like... girls do I want a nice house, but you never hear, I'm in love with so and so, does it matter if she, because this thing doesn't work, you never know what's forward, because you be perfect married and something can happen. Try explaining that to Asians. I think there is (prejudice) especially, yes, all Asian community, they are all the same. It's the same in India, Kenya, wherever. Why don't you just leave the person alone? I haven't said anything to Saroop... that, you know, Asians, I've only said other Asians are a bit cruel when it comes to disabilities and epilepsy. No, I think they're still the same. Where disabilities concerned, they're the same.*

**Positive aspects**

Surprisingly three respondents outlined the positive way that the experience of epilepsy had made them more sensitive, strong-willed, and more understanding of others with disabilities. Ranjeeta, a 48 year-old Sikh female, told us how being diagnosed with epilepsy had changed her attitude:

*It's made me more understanding of how other people might feel when they're disabled, in some way, and how inadequate people could feel, and having that empathy to understand and support others in similar situations.*

Others, like 32 year-old Muslim male Saleem, felt more empathy towards people with physical disabilities and found the general (negative) attitude of the public was due to ignorance:
Some people are ignorant in general, yeah, but there’s another thing, now I’ve got epilepsy. For instance, I’m swimming, yeah, you get these kids on Thursdays, with disabilities, they bring them in to swim, there be 10-12 of ‘em, they’ve got that down syndrome... And you’re swimming, you carry on swimming, they’re using the pool, so what do they do, a lot of people, they were in the fast lane, six/seven people that were swimming there, they just move over, they don’t even see ‘em. Why are they being so ignorant, there’s already four people swimming in the fast lane, you don’t need to move, it’s the same water, it’s going to go... there’s only a rope... rope. Very, very ignorant and I can... I’d rather sit with people with disabilities, I feel nice, feel good, than sit with Mr Rambo, Mr Perfect, you know, I’d smack ‘em in. So I can go, my heart goes out to people blind, with disabilities or whatever, I can sit with ‘em, communicate with ‘em, man, really well, I understand ‘em. Yeah, definite, because I wanna you know the next person suffering from epilepsy... you can, I suppose, you can talk to ‘em easy, you can talk; you’re not the only one cripple... I’m a cripple as well, you know.

Farhana, a 31 year-old Muslim female, felt that her condition had made her into a stronger and more independent person:

Well, it does make you stronger and it makes you see who’s there for you, if you’re ill... its like, it's a lesson for you and it’s a lesson for others as well, who are nearby, who really care for you, and they aren't going to be there when your ill or they're going to just leave you and suffer. So, it does... it makes you really strong, basically.
SUMMARY

- Overall our study shows that there is no one particular model of understanding epilepsy within any of the groups - Hindus, Muslims and Sikhs - that participated in the research. Variations can be observed more within each group rather than between groups, pointing to the significance of individual features of gender, age, country of origin and level of education.

Words used to described epilepsy

- The terms used by our sample to describe epilepsy differed not only according to the respondent’s language and ethnicity but also depending on place of dwelling (urban/rural) and level of education.

- While a high number of people from the sample used the English word ‘epilepsy’ the majority of respondents also used terms from their own languages. The most commonly used term for epilepsy - regardless of ethnic group – was the Urdu word *mirgee*, which literally means ‘fit’ but with a very negative connotation.

- However, one Sikh female used the word *gussy*, which she heard her parents use who came from the Punjab region in India. One Hindu carer used the term ‘fit’ to describe her husband’s epilepsy.

Perceptions of causes of epilepsy

- Almost half of our sample of people with epilepsy thought that stress had caused their condition. They all remembered stressful events in their lives that they felt triggered their epilepsy.

- Muslim epilepsy sufferers were much more likely than their Hindu and Sikh counterparts to consider family history as having a bearing upon the onset of their condition.

- For some individuals within the sample there was a strong belief that their epilepsy was a direct result of other health problems (leukaemia, kidney transplant, brain haemorrhage) they had suffered at some point in life. For others the cause of their epilepsy was unknown.

- Muslim respondents were more likely to say that they were fated, destined by God to suffer from epilepsy than their Sikh and Hindu counterparts. These particular individuals felt that nothing could have avoided their condition from happening.

- Very few Sikhs and Hindus from the sample thought that their epilepsy was a punishment for sins that may have been committed in a past life, although this is part of the religious doctrines of Hinduism and Sikhism.

- A few respondents – typically older people and those who were born and brought up in the Indian subcontinent - were more likely to believe that their epilepsy was caused by spiritual beings (jinns). Beliefs about spiritual possession were not limited to respondents with limited education but were seen across the sample.
Community views

- Five epilepsy sufferers and one carer - from different ethnic groups - felt that some people from the wider community shunned them due to fear of catching epilepsy.

- Community members (from the focus groups) perceptions of causes of epilepsy ranged from genetic inheritance to birth trauma and spiritual possession. Others thought that epilepsy or seizures were due to some kind of deficiency within the individual. One person believed their relatives epilepsy was caused by an excessive intake of salt during childhood that had caused a chemical imbalance in the body. This had lay dormant for many years but was finally triggered by some sort of trauma.

- Some members of the women’s focus group believed that consanguineous marriages were a major causal factor for epilepsy within the Muslim community. Others counteracted this argument by pointing out that within the Indian subcontinent whole villages were intermarried and yet did not display significant numbers of people with epilepsy. Also they pointed out that low numbers of consanguineous marriages took place within the Sikh, Hindu and white communities and epilepsy was still common within these groups.

- Two respondents believed that spiritual beings could play a part in causing epilepsy. Others strongly disagreed counter-arguing that possession by spiritual beings had become an excuse in Pakistan to encompass all forms of mental illness.

- One elderly member of the male focus group mentioned that he had been brought up to believe that epilepsy could be a result of a fall specifically caused by an earthquake.

Disability and epilepsy

- Eleven persons with epilepsy from different ethnic groups felt the perceptions of the wider community towards persons with epilepsy were very similar to the negative attitudes displayed towards people with other disabilities. The term disability in this context was perceived as referring to persons with visible infirmities. Members of the sample disliked this kind of association.

- In total five carers mentioned that the wider community saw people with epilepsy as having some kind of disability.

- Some respondents felt that the wider community categorised persons with epilepsy as disabled depending on the frequency of their seizures and the level of disruption in their daily lives.

- One carer complained about the difference in attitudes within white communities towards persons with disabilities, while emphasising that prejudiced views were widely held across all South Asian groups.

- Three persons with epilepsy outlined the positive way that the experience of epilepsy had made them more sensitive, strong-willed, and more understanding of others with disabilities.
CHAPTER TWO
FAMILY SUPPORT AND IMPACT ON LIFESTYLE

The support and encouragement of family members can have a dramatic impact upon the emotional state of people with epilepsy and can also influence the way in which they conduct their lives. The willingness of other individuals to support them in coping with epilepsy will be influenced by their own attitudes towards the disease and the motivation they possess towards encouraging people to live a ‘normal’ life. More generally, cultural and gendered expectations about care-giving may mean that there are differing levels of involvement from parents, spouses, children, siblings and extended family members towards encouraging people with epilepsy to get on with their lives.

Given the importance of family support and social network for South Asian people, this chapter examines how people with epilepsy are influenced by family members in making decisions that may impact on their lifestyle and general well-being. It considers the efforts of parents, spouses, and children as well as their siblings and wider kin network in helping them to cope with their condition. It also assesses how family members’ perceptions of epilepsy may impact on people’s choices in relation to education, employment, marriage and social life.

COPING WITH EPILEPSY

Families can play a vital role in the understanding, treatment and long-term management of chronic illnesses, including epilepsy. People with epilepsy suffer varying degrees of stigma, which can also extend to the family. Indeed much of the stigma felt by those with epilepsy is often learned not from society at large but has been taught to them by the (negative) attitudes of their own families. Having epilepsy has social and psychological consequences for families and impact on intra-familial relationships. Many family members expressed frustration, anxiety, helplessness, as well as a sense of unfairness and occasional resentment as common responses to their relative’s condition and its practical and social meaning. More generally, family members regarded epilepsy as a condition that made their relatives socially vulnerable. As the carer of Sachdev (a 19 year-old Sikh male) pointed out:

*I think socially its disabling him a lot, he doesn't really go out, he can't really afford to drink in terms of the impact of the medicine, he doesn't have many*
people he can go and see, he's taken a year out of college because I think to an extent that was causing him problems and stress and he had fits at college a number of times and both travelling there and at college as well, so physically he's very disabling. I think he could do more and be less molly coddling, that could be done, but in terms of the options he presents himself with, I don't really know what he would be doing, he would be dossing about college again and he wouldn't be taking it seriously.

Many people shared and seemed to have internalised their families’ negative views. They often accepted their relatives’ views about their vulnerability and tended to see their condition as a personal tragedy. This feeling was particularly strong among those with an earlier diagnosis of epilepsy, like Sara, a 34 year-old Muslim female, who said:

They were feeling helpless, obviously, because they can’t do anything. Their reaction made me think it was something serious because they said I couldn’t go out and do stuff my brothers or sisters do. I began to think like that as well kind of feeling sorry for myself.

Others like 48 year-old Ranjeeta, a professional Sikh woman who was diagnosed with epilepsy only five years ago, also had to contend with negative familial attitudes:

I used to be ashamed of it at first. Sometimes these things in Asian families they're not spoke about because people might feel your inadequate, although my parents, I'd like to think particularly dad, who was a lot more forward thinking than that, he would say, “so what, what does it matter, you're my daughter, you know they can think what they like but I don't hide it anymore”.

Respondents had frequently to confront and negotiate barriers as well as engage with the negative attitudes about epilepsy held by their family. Shazad, a 23 year-old Muslim male, felt that his family was ashamed of having an ‘epileptic’ relative and that his epilepsy was a source of ridicule for his siblings:

I've got epilepsy and it’s a disability, yes, they call me names, you know, like my brothers and sisters, they call me names and I get mad, I get frustrated with them and I start lashing out.

Some young people believed that their parents treated their siblings more favourably, giving them greater freedom, as explained by 24 year-old Muslim male Mohammed:

I think they (the family) do a lot of worrying, like compared to my brother, he goes out more, has more freedom, has more friends but me, actually I don’t go out a lot and it’s hard for me to make friends as well.
Although most people had their epilepsy under control, some respondents expressed their concerns about not being able to fulfil expected family responsibilities. Some people felt their condition could compromise their role as wife or husband. Several resented not being able to help with normal domestic responsibilities, such as cooking and driving. Men worried about their role as ‘bread-winners’; women about their role as ‘mothers’. Some respondents felt they were unable to fulfil the normal expectations of a wife, husband or parent. For example 28 year-old Muslim female Shanaz explained about the way her epilepsy affected the whole family even to the extent that it stopped her husband from working:

My father in-law doesn’t work and my mother in-law she’s disabled, so he looks after her and my mother in-law she just sits, sits at home when I’m doing my housework and things. She just keeps an eye on me; she’s keeps watching over what I’m doing making sure I’m okay. There’s been occasions where I’m like, I’ve been ironing and I’ve injured myself or when I’ve been making milk for my baby I’ve injured myself as well, so my mother in-law always watching over me. My husband he takes a lot of care of me and he often looks after the children for me. Like my husband he’ll kind of stay awake during the night to make sure I’m okay so during the day he gets tired so he goes to sleep and he can’t work because of that.

Asghar, a 43 year-old Muslim male, felt angry and bitter about not being able to fulfil his role as a provider for his family:

I used to have a shop, my own business, when I first came here but then I had to sell it off. My heart’s kind of broken, isn’t it? If I don’t have my house, what kind of plans could I make for the future? If I got well today and Allah was merciful to me then who doesn’t want to work and raise money for the family?

Housewives with responsibilities for children, partners and extended family obligations like 34 year-old Sara and 31-year -old Razia both Muslim females told us that they just could not afford to let epilepsy get in the way:

Sara:
If I have a fit now or if during my married life it’s like putting a stop isn’t it because I haven’t got time to stop in life for anything right now because I’ve got a family in the house, I just can’t do it, it would be stopping me from my duties.

Razia:
I think to myself I’ve got a son I’ve got more responsibilities I don’t have time to think that I’ve got epilepsy so if I jerk I just ignore it whereas before if I used to jerk I used to sit down I’d say everybody quiet you know I’m gonna have a fit let me lie down or I’m scared or this and that, I think that’s what helped is my son. Before I used to think I’m gonna have a fit but now I’m so occupied that I don’t realise.
Mothers with epilepsy felt it was unfair for their children to have to deal with the condition. Either through experiencing seizures, which understandably caused distress or through injuries unintentionally inflicted upon them by their mothers:

*A couple of times I’ve been feeding my baby daughter and I’ve had a fit whilst feeding her and she’s fallen on the floor and hurt herself. So I’ve had to take her to the doctor. And it really upsets me when that’s happened because it’s my condition and I don’t want it to affect my children* (28 year-old Muslim female Shanaz).

*Something that really scared me when the baby was small as well. I mean very small because now that it’s tougher and that time they’re so delicate and if I have a fit while they’re feeding or if I dropped him, what’s going to happen?* (28 year-old Muslim female Asifa).

The pressures of living with epilepsy while working and raising a young family led to one respondent, 46-year-old Sikh woman Bhupinder, taking the decision not to have any more children:

*I decided not to have another child. My husband’s sister was saying “you should have another baby”, we want a boy but I’m happy with my two girls, really. I thought “well, if I have a son, what’s the point if I’m not going to be able to look after him”? My husband, he was of the same opinion, as well. He said “what’s the point in having more children if you’re not well enough to look after them”?*

Others, like 27-year-old Muslim male Banares, had a particular dislike of being dependant on other family members:

*The only thing that concerns me is when I get older, and my children and stuff, obviously my parents aren’t going to be for the rest of my life are they, there’s a point where I’ll have to go and earn a living for myself and my family, you know, how am I going to support them? That’s what really worries me, apart from that nothing really, I’ve got lovely brothers who support me when they can financially and physically if I need anything and I can’t ask much more from my sisters and parents. We’ve got a lovely family it’s just that they think they should take responsibility for me all the time but I need to stand on my own two feet.*

However family members (especially female carers) too felt burdened at times when caring for the person with epilepsy in addition to looking after the children and the house. One respondent – the wife/carer of 43-year-old Muslim male Asghar outlined the invaluable help of her own family:

*He’s not obviously working; well going out has stopped a lot, yeah. Problem of epilepsy is I don’t let him out a lot, he can’t shop, my brother does all that,*
everything for me. My youngest sister comes most and helps me, yeah, she helps me a lot and all, and she does a lot. Without my family I don’t know what I would do.

Over-protection was sometimes a main source of tension between people with epilepsy and their families, reflecting many of the difficulties outlined above. Parents, especially, felt the need to protect their child from risk and danger. Generally, younger people and women were more likely to be over-protected by family members. This was the case of 19 year-old Sachdev, a Sikh male, who said:

My family are more over-protective than they were. If I were to come home Saturday later than I do, then they’d ring me or something, or if I’m with friends they’d ring them, ask where I am and am I OK?

Thirty-four year-old Muslim housewife Sara felt that she became the main focus of her family after she was diagnosed with epilepsy at a young age:

Being a girl was a big problem, you’re probably aware of that because being an Asian that’s a very big problem, you know, it just stops you in path, doesn’t it? They just stop thinking about anything else and, that’s it, you know, I was the main focus in the family, I was the centre of attention of everything.

Others like 31 year-old Muslim female Razia told us about her mum’s over protective behaviour even on her wedding day, recognising her mothers concerns about the potential embarrassment to the family of her having a seizure on such an important day in front of relatives and guests:

When I got married as well my mum used to say don’t meet her, don’t meet her (to friends and relatives), she’s going to have a fit, she’s gonna have a fit, she’s really thingy, my mum’s very protective over me, over protective I can say.

Others felt that their families treated them differently but in a positive way; they were taken care of and lavished with attention and love more than other siblings. Twenty-four year old Muslim male Mohammed gave us his views:

My family treat me more… better, try not to treat me bad, try to treat me more good, or, what’s the word I’m looking for, try to take more care of me because I’ve got this condition, try to look after me.

The same happened to 56 year-old Muslim female Khalida who told us:

It’s only my brothers and my mother and father. They knew that I’m epileptic, they love me, they adore me.
Some participants had mixed feelings about the role their families played. They recognised that there were times when the family took on the role of ‘protectors’ and ‘comforters’, ensuring they were injury-free during a seizure. Other times, however, the family was seen as too restrictive and over-protective. Saima, a 26 year-old Muslim female, gave her account:

They never ever let me go alone. My father used to say, “Go with your sister”. They always carry whatever I buy, the shopping. And they are always with me; no matter if I go for 10 minutes, 1 hour or 2 hours... Wherever I go, they are always with me.

Others felt that their families either withheld or filtered information they thought might upset or worry them and potentially trigger a seizure. For example, Santosh, a 41-year-old Hindu male, told us:

I’m treated just the same, just the same as everybody else (in the family), but it’s the odd bits and bats, which get left behind, which I get to know later on. Sorting out, yes, they (family) don’t want to overload my brain about it, get things worried about it.

One respondent, 31 year-old Razia, felt patronised about not being told of the death of her aunt:

They won’t tell me, if something’s happened that’s bad, they just say ‘it’s nothing’. Every time they said ‘don’t tell her’ and I always used to guess there was something going on. There’s also my family, what they do, like if somebody dies, like my aunty died, they kept saying ‘don’t let her know because she’s gonna have a fit’. They wouldn’t tell me, they said not to tell me, what did they think? They never thought I would find out, eventually I did.

The feeling that family restrictions were imposed rather than negotiated made them all more difficult to accept, although most people would not challenge those restrictions, as they feared upsetting their relatives.

The negative views of epilepsy can be compounded by the negative experience of broader social relationships. 29 year-old Muslim female Shanaz, remarked:

People in our neighbourhood here they will kind of say “she doesn’t even have her mum and dad here (in the UK) to look after her and she has epilepsy” and, you know, I do feel it when they say things like that.

Sachdev, a 19 year-old Sikh male told us about his experiences of having a seizure in the street and the subsequent (negative) reaction of family friends and neighbours:
My parents’ friends, they think: “Oh, their son’s ill, he’s really not well so how do we treat him? When we see him on the street or something do we just be ‘Hello, how are you?’ or just ‘How’s your medication coming along?’” I remember having a fit one time, just at the bottom of the street, and one of their friends had to ring for an ambulance and when an ambulance came, some of the residents they came out to the house to see what was happening. As I walked down the street, later on, after I’d recovered, I saw these people and they sort of looked at me in a different way than they would have normally, thinking “this is the bloke that had that fit”, so their view changed slightly. They (neighbours) don’t really have an understanding of what it is. Some do, some don’t. There’s this one bloke that walks up and down the street sometimes and when he sees me on the street, looks at me in a slightly different way and he was the actual bloke that my parents got to phone for an ambulance but, again, he’s... traditional, he doesn’t really know much about it.

Social networks are important in confirming South Asians’ sense of being a member of a wider group in which they can identify themselves in terms of culture and religion. Epilepsy, however, can help to restrict the opportunities for such encounters and contribute to create a sense of isolation. Social isolation was a particular concern for some respondents who described themselves as having few or no friendships beyond family life. This was the case of 31 year-old Muslim female called Razia:

_I was very out going, I was into music and I used to be really out going, I used to enjoy myself, I was that type. Once I had epilepsy I used to be worried and scared somebody might see me, so I used to stay in then, so I never used to go out in case somebody saw me. If I had a fit outside I used to always worry. Say I go to the shop and I had a fit what would people think “what’s wrong with her”? So I used to stay in all the time, worry about it._

Other respondents mentioned isolation even within their families as they were excluded from certain events. Farhana, a 31 year-old Muslim female told us:

_All my relatives, you know a group of them, they all go swimming every Tuesday in Bradford and they tell me about it and I'm there thinking, “I can't go”. Well, I probably can go, probably me thinking I can't go because I was pregnant, you know, my health isn't 100% so I don't think them lot (the family) would be pleased if I went and I had a fit there._

Others like 25 year-old Sikh female Amanroop felt self-conscious at the risk of having a seizure:

_Even now I'm afraid to go out. My brother was wedded and I'm afraid to go because if it happens to me, all the people are going to be looking at me and thinking “oh, there’s something wrong with her”._
South Asians and Epilepsy

Mohammed, a 24 year-old Muslim male, told us about the way his friends had treated him when he had a seizure in college:

At college I used to have a couple of friends who used to bring me water when I used to have an attack, but most of my friends used to keep distance because they didn’t like the idea of someone having epilepsy. Could have been frightened, mainly.

Some respondents, like 42 year-old Sikh male Jogindar, mentioned the sense of guilt that both family and friends felt about his epilepsy:

I can honestly say that I think my family and friends feel a sense of guilt about my illness because they feel powerless to help, you know, powerless... and powerless to stop my fitting. I think it’s more disturbing to them than it is for me and the effect on my family and friends of my illness is profound.

Similarly, 29 year-old Shanaz felt that her epilepsy had led to her feeling self conscious and inferior:

I do feel low; I do have an inferiority complex, actually. Well, my epilepsy is disruptive for other people and I just think, well, even when I have a fit that people, once I have recovered, they just look in my direction and I don’t like it.

However, the picture is not all negative. Other respondents like Muslim males Banares (27) and 25 year-old Amjad told us that their friends had become a source of social support:

Banares:
Friends, I tell them I’m epileptic, they know anyway, they’re always on the lookout, they always look at me, how I am. If I’m with friends who are not (religious), I don’t mean to be bad or anything, people who are not in deen (into religion) they just chill out, they’re not really bothered (to help). If I’m walking with them, they wouldn’t bother, I’d tell them first I’m epileptic, cause I’ve got a lot of friends who are not (religious), not but I don’t hang around with them much.

Amjad:
Some of them, they don’t know what it is like you said, they don’t know what it is, you have to tell them or you have a blank out, you shake and you have coming out and everything. The last time I had a fit before I went to Pakistan that was just after? All my hands and everything, knuckles and everything were scraped, do you know the concrete, the floor I fell on, it was a concrete floor it was just up the road that, my hand like that my other mate went somewhere in the car to go get something. There was lads standing round me, this gorah (white person) Pete and I had a fit, they already knew it was a fit. They you know when I had it they were got scared they were in emotional shock, they even say to me this day we got so scared they just froze and just called the what do you call it the ambulance. My other mates some of them they just keep a
hold of me like they say this and that ah somebody else, they know how to precautions. So basically I always hang around with someone who knows.

The wider community, particularly neighbours, sometimes demonstrated ambivalent attitudes towards people with epilepsy. They felt it was their neighbourly duty to assist in case someone has a seizure outside their house. Yet the same people, in other social situations, could manifest feelings of abhorrence towards a person with epilepsy. This was well explained by Shanaz, a 29 year-old Muslim woman:

Family, they give me a lot of support, but other people... sometimes you sense they’re... they just keep away because they don’t want to get it (epilepsy), they think they might catch it. If that’s the case, I just tend to back off those kinds of people. 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 and it’s not something that’s inherited otherwise my kids would have it. Even though I’ve fallen so many times whilst I’ve been in the garden and because of the women who live in the neighbourhood know that I’ve got epilepsy they run and kind of pick me up and take me inside.

One respondent, 39 year-old Muslim male Yaqoob felt that people with epilepsy were devalued by society at large irrelevant of the particular ethnic group they belonged to:

They (community) think it’s no good, if anybody has epilepsy you have no value. Whatever it is, epileptic people have no respect at all. I’ve seen the English community as well, they saw the girl was crying and she said I’m having fits outside, I’m scared and people are making fun out of me.

DISCLOSING EPILEPSY

People with epilepsy choose to conceal or reveal their condition depending on other people’s perceived or actual attitudes towards their illness. The severity of epilepsy was found to be a key factor, as the likelihood of having a seizure in front of others seemed to be a major reason for revealing. Information control in order to reduce or manage stigma associated with a condition like epilepsy was practiced by a number of respondents. Shanaz a 29 year-old Muslim female who suffered from frequent seizures decided to adopt a very open attitude and chose to disclose her epilepsy, as she feared she would need help in case of a seizure outside her home:

If I’m meeting a new person I do tend to introduce the subject in some way so they get to know I’ve got epilepsy. I tell them myself, you know, if I’m in a group of people, I’ll tell them. Or if I go into a shop and I’ll say to the shopkeeper “look I’ve got epilepsy and if I do have a fit can you put me to a side”? And I explain to them, I stress that it won’t be, it won’t affect them in any way me
having epilepsy. You know, because in the inside of my mouth it all gets cut whilst having a fit, so I say to them “can you please help me if I do have a fit”? Others, like 28 year-old Muslim female Asifa who had been diagnosed with epilepsy from a young age, revealed her changing attitudes over time about disclosing her epilepsy to others:

To tell you the truth, at the beginning, especially in Asian cultures, you don’t want to discuss it with your friends or anything. I didn’t tell anyone about it, that it had happened. It’s just that, you know, because I had heard of someone who had it before I had it, friends talking “Oh, have you heard ... they have fits or something and this happens and that happens and, although I know that at that time mine wasn’t so bad, the fits have gone worse now, the way they affect me and the fit itself, it’s worse now, it’s more severe and at that time there was a few jerks during my sleep, stiffening of the body, a bit of frothing but now it’s, you know, it’s more severe and even though it wasn’t that bad, I just, you know, didn’t know what they would assume. Not confidant enough to say. A lot of people do see it as a mental disease. I think that’s the reason why I didn’t want to tell anyone as well because they would think there was something wrong with me. A lot of people don’t think it’s physical. They think it’s a... as they say in Urdu “dimagh key karabi” (something wrong with the brain) ... dramatic.... Now I know I am much better with it. Now and then, when someone asks, “Why don’t you work?” “Why not?” I just tell them basically. I think I’m more confident about it now.

One respondent, 23 year-old Mohammed, who was also hard of hearing, feared becoming a source of ridicule amongst his friends if they found out about his epilepsy:

I don’t tell anyone, I keep it in the family because they might laugh at me, make jokes and stuff.

A number of factors were taken into consideration before respondents decided on whether to disclose or conceal their epilepsy. Decisions were made after weighing up the quality of relationships, likelihood of the person finding out and experience of other’s reaction upon telling them. For example Khalida, a 56 year-old Muslim female, preferred to conceal her epilepsy from the wider community and even from close relatives, as she feared this would lead them to treat her and her family differently:

Maybe people they won’t come to my house or they like, you know, family business, they won’t do that with me, I don’t know what is going to happen. So it’s better to keep your mouth shut. I think most of the people in my family they don’t know because they don’t understand nerve disorder or thing like that, they think it’s “jinn” because it comes suddenly and then goes, it’s not there all the time.
However, Khalida disclosed her condition to a select few colleagues from work that she believed she could trust:

*If I keep on telling everybody then I’m going to hear their response as well, isn’t it? And that’s too painful, the response of people, it’s very, very painful...When I had the fit (at work) after I rang him (the head teacher) he was very nice, I said “Keith, this is what happened, I think I’m epileptic” and I had to tell them because I was on medication as well and since then whoever was head of my department, head of languages - not head of my Urdu department, I didn’t tell that person because, I told you, he was... he did PhD, he was very educated person but he was Urdu speaking (Pakistani) as well, but one day we were all sitting (in the staff room), they didn’t know I’m epileptic and he (the Asian teacher) said that a girl had a epileptic fit in his class and that they should have “jooti sunga ho” (made her smell the shoe) and I didn’t like it.*

Kulsoom explained to us that in the Indian subcontinent it was a common practice to take off one's shoe and make the person experiencing a seizure smell it as this would help them to come out of their seizure.

Selective disclosure was also practised by a number of our respondents. Decisions about whom they told and how they introduced the subject of epilepsy were carefully considered, as 48 year-old Sikh female Ranjeeta told us:

*They can think what they like but I don’t hide it anymore, I don't go round telling everyone but if it comes into the conversation like, how they say, well, “why don’t you drive”? a lot of people say that, well, it’s because I have epilepsy and that’s often the way in. For me there’s two sorts of people, my friends and family, who want to know more because they're concerned, and those people that just say “oh, right”... and become embarrassed and move on to the next subject, so I'm not really frightened of people’s responses anymore.*

Mohammed Ishtiaq, a 24 year-old Muslim male, decided not to tell a particular work colleague because of a conversation he overheard:

*Once one of the staff, when I just started (work), didn’t know I had epilepsy and said, “Oh, I knew this person who was a customer who had epilepsy and he fainted and it was right horrible” and she didn’t know I had epilepsy. And the way she was talking about epilepsy, I was surprised that not a lot of people know about epilepsy when I tell them I’ve got epilepsy, but this person knew about epilepsy and she was saying it’s quite bad so I didn’t tell her I had epilepsy as well.*
IMPACT ON LIFESTYLE

The impact that epilepsy has on people’s lives is perhaps greater than many other chronic conditions due to the unpredictability of seizures and the associated stigma attached to it. People’s concerns about the effects of epilepsy on their everyday lives were directly linked to whether epilepsy was a barrier for them in completing their education, in seeking employment, in finding a marriage partner, in having a ‘normal’ social life and in driving.

Education

Disruption of their education was a particular problem for some respondents, irrespective of gender and ethnicity. Santosh a 42 year-old Hindu male, gave an account of how epilepsy affected his schooling days and the subsequent impact this had on his future prospects:

It’s affected school a fair bit but, again, nobody wasn’t bothered that much, nobody wants to know. They know that I’ve got it but they never took too much into consideration. It stopped me doing quite a few things...my personal hobby, I did want to learn more but I can’t educate myself. Learn, some jobs, better educated, at my time when I was 16 there was more jobs available, better jobs available but none of them I can’t do.

Some people said they felt undervalued because of their epilepsy, with teachers considering them to be inferior to their peers. Thirty-two year-old Saleem, a Muslim male, remarked:

Before I was so bright at school, but when it came to my exams, 15-16, it just went. I tried in college as well, studying, we used to read, at the end of they used to ask questions and everyone was all right, except me. I couldn't think, even my mates said, “You know, teachers in college are ignorant”. But, at that time, I couldn't figure it out. They'd shout at me and they'd make me nervous, it'd just goes, it (mind) just blanks.

Other respondents felt their epilepsy gave their parents a perfect excuse to withdraw them from the schooling system. Sara, a 34 year-old Muslim female, was one of them:

When it first happened, when it happened in school, the first thing I wasn’t allowed to do was physical education. You know, my parents didn’t like that. I hurt myself a couple of times and, you know, parents just stopped sending me to school. I’ll be honest with you, at that time, even if I’d wanted to do something I wouldn’t have been able to do it, so it came on at a time and it gave my parents an excuse to take me away from school anyway. Twenty years going back... for an Asian girl, it wasn’t common, you know... these things weren’t allowed, especially when your parents were religious. They wouldn’t allow these things, and education wasn’t important to them, you know, they just didn’t see it so.
Prolonged absences from school led to one respondent, a 19-year-old Sikh male, being unable to make friends from amongst his peer group, which resulted in a lack of confidence and isolation:

*I have lost confidence in myself as a person because after I missed the whole year of school I didn’t have much communication with other people, just a couple of my friends and again that was just around in the garden or something, so it stopped me from going out and making other friends and getting to know people in different ways and things.*

The disruptions that were faced by younger people throughout their school life were not confined to those living in the UK. A 28-year-old Muslim female, Shanaz, told us about her experiences of schooling in Pakistan:

*I went to primary school and then my parents thought it better that I didn’t go to school because I kept having fits on the way to school, so they withdrew me from school. But I really enjoyed studying so then I went back to school and completed my metric examination, and after my matriculation exams I stopped attending school because my fits got worse. When I was little I kind of could sense when the fits were going to happen, but as I got older I’d have complete blackouts so it was more difficult for me to know when they were going to happen. That’s why I wasn’t able to study further after my metric exam.*

By contrast, some respondents had a normal school life, despite having occasional disruptions to their studies. However, one respondent, a 24-year-old Mohammed Ishtiaq, told us about the family pressures he faced, even though he was an adult, in deciding which universities to apply to:

*I could have gone to uni in another town, like Manchester or York or somewhere, but because I’ve got this condition my family said “we don’t want you to go to another town, if you go there, and if you have a fit or something, and if you live in a rent house somewhere, you’ll have nobody to take care of you. Stay in Bradford and stay with us”. My grandparents said, “ live with us and we will be taking care of you”.*

**Employment**

Respondents felt there was little formal support to help people with epilepsy to enter the labour market and many employers held negative and damaging views. This was highlighted with the experiences of two Muslim brothers’, 31-year-old Saleem and 25-year-old Amjad, entries into the labour market:

**Saleem:**

Twelve years ago I went for an interview, it was at Northern Bakeries. When it started off (the owner) was a young man and everything was like school, he said “Epilepsy”? You know, when he said it like that, “epilepsy”? And me not
knowing and I said, “I’m alright now”, he said, “It’ll never go away, what’s up with you”? And then his tone changed and as soon as he tone changed, I was a kid, I just walked off. That interview, him treating me like dirt, you know, him finding out I had epilepsy, I’ll give him epilepsy, you know.

**Amjad:**
With the epilepsy, I’ve been turned down by so many places, so I can’t be asked. Wherever I try I know what they’ll say. I’ve tried Morrisons, I’ve tried wherever, you know, they tell you straight away, once you send the application form, you have epilepsy written there, don’t you? It says “any medication or medical”, so you write “epilepsy”, so you don’t get a reply... Yeah because I could turn around and say you’re not giving me a job because of my epilepsy, it might be because of my qualifications or whatever might have a criminal record or might be this, might be that but God knows how I see it bloody epilepsy. Who wants to employ anybody with epilepsy?

Unable to secure employment within the mainstream labour market led to Amjad taking work as a taxi radio operator at a friends company:

> I’m still sitting there, 25, operating there, getting paid £100 to do so many hours, and that’s not even £1 or £2 an hour, and that’s how basically we get by. But at the end of the day you’ve got no choice because you can’t live off dole... it’s not enough to feed you, if you want a family and everything, these days to wear a pair of decent trainers, gold and everything you know what it’s like...

Although Amjad felt a sense of exploitation through working long hours for low pay he was appreciative of the help he received at work, especially as he was experiencing seizures on a daily basis:

> Twice in a day yeah (seizures), my brothers seen me twice in a day at taxi office you know where the benches are, where we had the weights room we used to have a bed there. When I used to have a fit on a chair or something they used to lay me out on the bed. Once they lied me on the bed, I had another one there. Where else would they do that?

Interestingly, 42 year-old Hindu male Santosh recalled very similar experiences 26 years earlier when he was looking for employment:

> Everywhere I go, even at that time when I was 16 when I left school, every employer I went to, one or two did decide to give me a job but then I had to declare it that I had got this problem. Oh no, no, no, I don’t want to know about you then. I don’t want to know you. As simple as that, straight out. Oh they know about it (epilepsy) but they don’t want to explain nothing, they don’t want to know, simple.
Those who were employed described various problems faced at the workplace, including a lack of support from bosses and colleagues, teasing, unwelcome comments and a covert suspicion that they were unable to do the job properly because they had some sort of mental illness. This was experienced by 42 year-old Sikh male Jogindar, who worked as a clerk:

*It’s difficult at work sometimes as some colleagues are not altogether at ease with my condition. I am sure they think I only got this job because I have epilepsy. Once I overheard some hurtful comments.*

However not everyone experienced hostilities or negative attitudes at work. Kumar, a 40 year-old Hindu male, told us:

*I actually used to work with two people who had epilepsy at work. One of them, Steven, he used to have it regular, probably every other month, but he seemed to work with it. And also an ex-manager had it for years, so they were understanding about it.*

Others who were diagnosed as adults with epilepsy told us about the profound impact it had on their careers. Sapna a 53 year-old Hindu female who had trained as a medical doctor in India and was in the process of revising for conversion exams to enable her to practice medicine in the UK when she had her first seizure, became very upset when she told us her story:

*I was severely wanted to work as a doctor. It was my aim, not the money, I wanted to serve. Even now I think if my children finish their education, if they stand on their own, I wanted to go to put them out there to work, but the hospital, it is my aim, it is what I studied, I wanted to work. I don't feel like it now, it is too late, even if I passed and I get over the difficulty, who is going to give me the job? At my age, who will take me, officially, yes, they will ask for the history, what health problems. As soon as they know I got epilepsy, which consultant will give me job? Nobody will give me the job. They will say, “It’s too late”. That’s why I gave up. I know I can't, it’s not worth trying, exam fees and studying up and down, it’s not worth for me.*

Other respondents felt that having a long-term condition like epilepsy had limited their choices of careers. One respondent, 24 year-old Muslim male, Mohammed who was taking a gap year from university told us:

*Work wise I think it has limited my ambitions. What I can do? Like computing, I think that it’s one of my hobbies and it’s a thing I can easily take, I can tell how to run a program, how to set everything up, it’s easy for me but if I was to be like a doctor or engineer or something, it’s be quite hard for me because remembering different types of information is quite hard for me.*
Similarly, Asifa, a 28 year-old Muslim female, who had trained as a court interpreter, was also unable to follow her chosen career:

*It’s the same problem again with the interpreting work. I would like to... because it is interesting, in court and things like that, I did it in law, it was for court rooms and, I mean, I would like to do it, but that’s the same thing again, you know, what happens if I have a fit there? It’s the same, it’s just leaves nothing really. I don’t know what I can do.*

Others, like 48 year-old Ranjeeta (Sikh female) and 47 year-old Hamid (Muslim male), had to take time away from work or cutback their hours, which had financial repercussions and affected their families:

*In my professional career I dropped so many things, which I had worked so hard for... I’d dropped them... I’d come out altogether, which in itself, although you give it up, it does have it’s little mark where it left, you know, gosh, where you could have been. I’m not boasting but I was involved in all sorts of stuff for the European Youth Conferences and Youth Commissions and so. Also I was Board of Directors for the Princes Trust Business and advisor to Prince Charles so, which for a number of years and I just couldn’t carry that responsibility for too long because it was too much.*

Only two people mentioned that any consideration was given to them on account of their epilepsy. 32 year-old Muslim male Saleem told us that having epilepsy could sometimes be advantageous in the workplace:

*You have your advantages as well, I’ll tell you, epilepsy you have your advantages. But everyone’s not the same, there are people you tell like I was working in a factory yeah, you’ve got epilepsy everyone used to say... - it’s a racist place this I worked there. On top it was all dirty work, you know, grassing crumbing and everything, it was all dirty, honestly, they used to say to me “you don’t climb up (on the high machines), do whatever you want on the downstairs, make yourself look busy”.*

Another respondent 42 year-old Hindu male Santosh felt valued and respected at work both by fellow colleagues and managers:

*People at work they do respect me more than some others. Because the way I think about that is that certain jobs when my supervisor comes around, he won’t give it to anybody else. Complicated jobs he brings round to me. Just the normal thing that we do every day, he’ll leave it to the others in my section, but anything complicated, bits of this and bits of that he bring round to me.*

Disclosing epilepsy in the workplace was difficult for respondents, 46 year-old Sikh female Bhupinder, decided not to immediately disclose her epilepsy to her employers but was pleasantly surprised at the attitude of her line manager when he found out:
I had to tell them (the managers) because on my sick notes it’s written the reason why I have to take time off from work. So that’s how they found out. Sometimes when I was at work I used to get headaches and I’d feel dizzy so I’d have to come home from work, you know, they’d drop me off at home. My manager, his sister, she's got epilepsy as well, she’s got the same thing, so that’s why he used to drop me off when I was feeling like that. I haven't really needed to (tell work colleagues), the only thing is that I get headaches at work, I tell them that and, I mean, they don’t know why I get them, they don’t know anything about my epilepsy.

The issues around securing employment were far from straightforward for some respondents like 27 year-old Muslim male Banares. Faced with difficulties in the employment market which he was challenging Banares was also fighting the family to assert his right to independence:

I think you should support your own family. Both of us are married now, me and my older brother, and our father has always told us to go ahead and support your own family. Now I’m 27, it’s about time I did start working and did start taking care of my own family. I’ve sent off a lot of CVs, my doctor she said “I’m telling you not to work but if you want to work it’s up to you, send CVs off but make sure you write you’re epileptic in there, okay”? I said “no problem”, so I wrote in them “I’m epileptic” and send (them) off. Straight away I thought “when I go there I’ll be abnormal and everybody will know”. When I got my replies back, then my parents found out, it was okay, my parents thought… my whole family, my brothers, everyone… no one knew that I was applying for a job. I told my father “look, I’ve been applying for jobs and I’ve told them I’m epileptic and a couple of companies said yeah, they’ll take me on”. My dad got really annoyed, he said this and that, “what happens if you have a fit, who’s gonna take care of you? The gorrah (white people) they’re like this and that”, so I sat down with my older brother and said to him “look, this is the situation, I can’t stay on income support all my life, I want to save some money and, you know, buy my own house” and he goes to me “just forget it, forget work, don’t worry about it, we’ll buy you a house”.

Marriage

The concept of family and retention of cultural values and religious beliefs are central to South Asian communities – irrespective of ethnicity. Marriage is looked upon as the union of two families rather than the union of two people. Finding a suitable marriage partner was a common worry for single respondents and their families. Sara a 34 year-old Muslim housewife, gave her account:

The first thing they (family) start thinking about is “oh, we won’t be able to get her married off”, that’s the first hurdle that comes straight. It’s one of those things that have, we still have I think like that as well, it’s the first thing “oh, God, nobody wants to marry you”, you know, they (community) categorise you
like disabled really. I suppose if I was back home (Pakistan), I don’t know what would have happened. Because the people, relatives, they’ll say “we don’t want to marry, we don’t want a daughter-in-law, we don’t want to marry someone who can’t even look after herself”.

Two Muslim male respondents (39 year-old Yaqoob and 24 year old, Mohammed) experienced similar difficulties in finding marriage partners although the age difference between them was 15 years:

Mohammed:
That’s big problem for the epileptic people. Yeah, there were big problems in my family, nobody agreed to give me a girl to marry. Nobody, even my own uncle, they wasn’t ready to give me their daughter cause I’m epileptic.

Yaqoob:
I had a problem, I went to Pakistan, my mum took me Pakistan and went there and my wife’s dad said” It’s okay we agreed to give her to you”.

The feelings of rejection were more acute when they came from within the family as Mohammed, a 24 year-old Muslim male, told us:

Most of them are okay about it, apart from one uncle, he talks about ‘rishtas’ (marriage proposals), he’ll give his daughter to my little brother to get married but not to me. And my grandparents and my dad ask him “Why is that”? He said “Because he’s got this condition (epilepsy)”. Yeah, I felt upset about that, said “Oh, no, how could he just say that”? Yeah, he’s the only one, rest of them try to feel sorry for me, not really sorry but try to like keep a positive... or don’t show me any signs of it. He’s the only relative, my uncle, who is like that.

Some families preferred not to disclose the epilepsy before the marriage took place. This happened to around six or our respondents, who had not told future partners about their epilepsy. One such case was that of 29 year-old Muslim female Shanaz as she recalled the time when her in-laws found out about her epilepsy:

At the beginning when I came they (in-laws) didn’t know about epilepsy, they didn’t know anyone who had epilepsy, they didn’t know anything about how to respond to when I had an attack, but now, since I’ve been living with them, they’ve grown to learn what they should do. When I came here and they saw how I had fits they didn’t mind at all, that’s something that I think they had a lot of courage to be able to deal with it.

One Hindu respondent 40 year-old Kumar felt that although his wife was not told about his epilepsy before coming over from India for their marriage, when she eventually did find out it was not a big issue:
She does know now, probably should have told her before we got married, but at the time it wasn’t an issue with me. Cause I didn’t have a lot of fits, we’ve been married for 13 years, didn’t have a lot of fits, so I don’t think it was an issue but she seen me once, that’s it. Of course she was shocked, she didn’t know what to do, but that was it, then mum must have told her, she was all right, basically.

However Kumar’s wife (in a separate interview) became quite upset when she told us the story about finding out her husband had epilepsy:

I was really shocked when I found out, you know, they didn’t tell me that he got this sort of problem, you know. I didn’t know at all then when I got married. He didn’t tell me, but he was taking medicine, I was wondering why he takes medicine regularly because when ever I asked, “Oh, it’s just for headache”, you know, he was taking medicines and sometimes I was wondering what sort of headache is that it never goes. It was either headache or stomachache. Then when I was expecting my first child he was just sleeping on the settee and all of a sudden he started shaking, you know. I was pregnant and I was on my own, he was sleeping. I was quite shocked what happened to him, shaking like that and then there was, what do you call it? Froth started coming out of his mouth. Then I tried to open his mouth, in the end I didn't know what to do because my mother-in-law she was at work so was my father-in-law, yes, then I ran to next door, the neighbours, I mentioned the problem and he knows something I don't know. “What's wrong with him?”. Then he went and we dialled for an ambulance, we went to hospital, I was like crying, really shocked, and I didn't know what to do and what happened with him. Then he told me “Sometimes it happens, you know” and his mother told me as well.

Mrs Kumar went on to tell us about the feelings of helplessness and isolation she felt at the time, especially due to the lack of any social support network:

I’ve got a few friends but you can’t - with your friends - share your personal feelings. It’s not same like your own brothers, sister or that. Very bad, you can’t talk about to your own husband, to anybody, you know - you are Asian yourself (the interviewer) and you know - otherwise they think “Oh, she's talking about her husband”.

Mrs Kumar continued by explaining the difficulties she had encountered in explaining to her own family in India that her husband suffered from epilepsy:

I told them (her family) when I went over there (to India), I told them because I thought if I write them a letter they might be worried. All my relatives, you know, they think, generally they think they're not like normal people. I mean they are normal, like there's something wrong them. I think Government you know, Government they should do something, you know. Like he was epileptic, I didn't know why it came up closed, you know. I mean, you should have every right to know everything (before you agree to marry someone and come over to this country).
The wife of one Hindu patient (42 year-old Santosh) told us about her shock and surprise when she found out that her husband suffered from epilepsy and her own families sense of feeling cheated:

> When we got married I didn’t know and nothing happened for a few months and then he had a fit and it all came out that he suffers from ‘mirgi’ (epilepsy). I was shocked and I was worried that I have got married to someone who is not normal...somebody who has this problem... My family felt his family should have told us at the outset... My family were not very happy and I even considered divorcing him for a while but I was pregnant, so what could I do? But my family was really angry. But I think its ‘kismet’ (fate) and I’ve coped with it for so long, at first, the first five or six years were hard but then I got used to it. When we make decisions we have to live with the consequences...he’s not all that bad as he wouldn’t have been able to father two children if he was...

The experiences of those who were already married showed the importance of having a partner who could offer support and care. Sapna, a 53 year old Hindu female, who was finding it difficult to come to terms with her epilepsy was grateful she had an understanding and concerned partner, as she explained:

> My husband supports me, he always does, he'll say “Take the tablet properly, you calm down, don’t worry about anything”. He always supports me in that respect but I am the victim, I have to suffer whatever anybody can tell, I feel why has it come to me?

Finding a suitable marriage partner was seen as a difficult process for many South Asian people, however having a long-term unpredictable condition like epilepsy further exacerbated the situation. The narrative of 28 year-old Muslim female Asifa highlighted the key role of the wider family in deciding the potential suitability of a candidate and the impact of epilepsy on the whole process:

> You know what it’s like in our culture, it’s so difficult for girls to find a marriage partner. I know many girls who are nice and they have someone in mind and the boy likes them and they like the boy but the families (boys’ family) won’t agree to it. That’s ignorance. I know of a few marriages that have broken up because the epilepsy was hidden at the time of the ‘rishta’ (engagement) and when they found out they ended the marriage.

Some carers of younger respondents from the sample had concerns about their relatives not being able to form relationships with members of the opposite sex. As 19 year-old (Sikh male) Sachdev’s brother told us:

> I think in terms of the way he should be, in terms of social achievement and development, people he should be meeting and interacting with, and I think that
his sexuality is now beginning to raise its head in terms of not having a relationship with anyone and that kind of thing. Not being, not going out sufficiently to be able to meet anyone as well (carer).

One respondent 28 year-old Muslim female Shanaz even gave her in-laws (not her husband) the option to divorce if they were unhappy with the fact she suffered from epilepsy:

> When they saw it (seizure) I gave, when they saw me having a fit I explained everything to them and I gave them the option of, you know, I explained what my condition was. And at that stage I didn’t have any children so I gave them the option of saying, well, if you’re not happy about it we can divorce, if you want, but they didn’t, he (husband) didn’t want to. My in-laws say “We’re happy with it”, I explained everything to them and they said it wasn’t a problem.

**Social life**

The impact of epilepsy upon respondent’s social lives differed according to the severity and risk of seizures and social class – irrespective of ethnicity. Those who suffered severe seizures were more prone to have some social life restrictions imposed upon them not necessarily by their condition but by their families. For example, 19 year-old Sikh male, Sachdev complained about his families’ over-protection:

> My family are more over-protective than they were. I did because I realised that there are certain things that I can’t do and my friends they go clubbing and things and I know that I can’t go. I can go clubbing but not for as long a period of time as they do.

One respondent 25 year-old Muslim male Amjad, told us about feelings of exclusion as he was unable to take part in social events with his friends:

> I go out with my mates, sometimes. They can get into places that how I won’t be able to get in because of my epilepsy, do you get me? Sometimes nightclubs, they all go out night clubbing and everything. Some of them throw little pills, ecstasy pills, I know you’re not allowed to take them but they take for the fun of it or they take a bit of whiz or something or they’ll have a drink. I’ve stopped all that cause you can’t do it no more because of the epilepsy. I wanted to do swimming like my brother does, he’s all right. But imagine I went swimming I had a fit, and imagine he was a bit hard at me, I did have a fit and you could die before he could get, before the guy could save me, pull me out of the water, anything could happen. Sometimes I wanted to go somewhere with my mates, once on a holiday, not a holiday, but, you know, like camping sites, but I couldn’t go with them because they were going to do canoeing and rock climbing and everything like that. I couldn’t go with them I had to say no because it’s dangerous for me. Sometimes, even these days, when I’m climbing over a wall like that and I start walking like that I can’t do it no more, I get
scared. Clubbing, that’s all young life in it? The way our young life, the way we all go, something you see you can’t go.

Others like 31 year-old Muslim female Razia felt upset, but recognised the potential dangers when she was told by health professionals not to undertake some hobbies that might cause her harm:

*He explained to me that it’s like a seizure and a lot of people suffer from epilepsy and I shouldn’t do some things. That I’m allowed to not like sew or drive and I should take my medication not stop my medication. I really liked to sew. I can’t like sew clothes, some people do with machinery that can be dangerous.*

Similarly 42 year-old Hindu male Santosh, told us about the wider ramifications of having a condition like epilepsy and its impact upon special events:

*Anything I want to do, whatever I’m interested in I can’t do. I will give you one example. Last year I was on holiday, certain rides I can’t go on, like the roller coasters. I was at Florida, USA. They’ve got a big 40-storey high building. They take you up there and then they let go, straight down and sometimes they do say that if you’ve got problem like this or heart disease or something, don’t bother going on, so just think how much I’m missing. I spent all that money going in and how much have I missed. Well, they (the family) were all just sorry, that’s all. They enjoyed it so I said, “You enjoy yourselves.” So there are many places I go I can’t go in, some rides I definitely can’t go in.*

Other respondents told us about the profound impact of epilepsy upon their social lives from going out alone to doing everyday things like watching TV or reading a book. One respondent 28 year-old Muslim female Shanaz felt particularly dis-advantaged, as she was unable to fulfil expected social obligations:

*I can’t watch certain things, I mean like the TV, if there’s a film on and someone’s being badly treated or there’s injustices happening. I’ll have, whilst watching it, I’ll have a fit, it really effects me. This is a big problem for me, you know, when women come to visit my mother-in-law, they sit and chat and talk about their family situation and problems they might be having with their daughters or daughters-in-law. That I find it really difficult to listen, it really affects me, so I excuse myself and my mother-in-law explains to them that I find it really difficult to listen to things like that that could be upsetting to me, so that’s a big problem for me. You know, it’s just like when you pour Coke into a glass and all the froth builds up, it’s like that for me. If someone tells me something or something happens, I get so wound up about it unnecessarily; it might be over such a small thing.*
Forty-eight year old Sikh female Ranjeeta who was an avid reader told us about the effects of epilepsy upon one of her favourite hobbies:

*I can read no more than a couple of pages and then I have to put the book down. (Before) I could read quite a lot more and more importantly retain it, now I could read two pages and tomorrow forget more or less what I read, where as before I could retain things and recall much quicker.*

Some participants, particularly Muslim women, believed that their families used epilepsy as an excuse to exercise social control upon them. 31 year-old Muslim female Razia, gave an account of her experience:

*Once I had epilepsy the family used to be worried and scared somebody might see me, so I used to stay in. I never used to go out in case somebody used to saw me, if I had a fit outside they used to always worry. Say I go to the shop and I had a fit what would people think that what’s wrong with her, so I used to stay in all the time, worry about it.*

Other respondents did not have permission to disclose their epilepsy to friends and were sometimes excluded from events on account of their epilepsy. This was a cause of embarrassment at school for 31 year-old Muslim female Razia:

*When I was at school I wanted to do swimming, I was into swimming but I was epileptic I couldn’t do swimming. I used to feel embarrassed cause the other girls. I was in a girls’ school and the other girls used to go swimming and they used to look at me and go “Look at her, she can’t do swimming”. Some girls used to say “You get away with it”, some girls used to look at me and think “Why can’t you do swimming”? I didn’t tell them (about her epilepsy) cause my mum told me to keep quiet about it.*

Others felt that they did not have independence to do simple tasks, like going alone to the corner shop to buy some milk. For example, Asifa a 28 year-old Muslim housewife told us:

*Sometimes I pop out to the shop, just the corner shop, but always someone with me. Most of the time my husband or my mum, my neighbour, my sister, you know, I can go out with people who know about it, someone there with you, so, it does stop me going out alone.*
Driving
The single most important issue cited by most people concerned restrictions upon driving. Overall 17 people from our sample mentioned the significance of not being permitted to drive and the consequences this had on their lives. On the whole younger people felt a greater sense of loss at not being able to drive. The example of 19 year-old Sikh male, Sachdev and 25 year-old Muslim male, Amjad encapsulate the psychological and practical implications for young people:

Sachdev:
Now my friends drive, you know, something I’d just like to do, I’d like to learn how to drive but I can’t.

Amjad:
Half of the things what you want out there, you’re not a part of it, you can’t achieve it because you always get knocked back. Epilepsy - that’s the way how I see it. Diving’s a big thing, these days to get around you need a car, the world basically is on about cars, people like fast motors. Who likes paying £4 or £5 for a taxi fare just to go down town, or you wait outside a bus stop all day or sometimes at night you have to go places. I feel like doing something through my life and I’m 25 now and I see all my mates around me. And I’ve seen the younger generation growing up who used to be little, my little cousin brother ant things, my little mate who are just growing up, they’ve got so much, nice cars and, not only with the nice cars with a car you can get a job. Like when I was in Pakistan weren’t allowed to drive no motorbike, you know, people love driving motorbikes there and we had four motorbikes in the bloody yard! I couldn’t sit on a motorbike there, not allowed to ride a motorbike.

However the feelings of those respondents who were in the process of learning to drive or had driven previous to their diagnosis also conveyed a sense of disruption or loss of independence:

I've driven for almost twenty years, since I was eighteen, nineteen and I think that has been one of the hardest things in that my independence is taken away, I have to rely on taxi's, friends, I can't just pop into the car and go off where I want and I think that’s been very, very difficult for me. I get to six months and I think this is wonderful I can start thinking I'm going to get that sort of car, another six months and I get my licence back and then I have a seizure and I have to start counting again from day one, so that's been difficult (48 year-old Sikh female Ranjeeta).

Two Hindu male respondents 42 year-old Santosh and 40 year-old Kumar talked about the years they had missed out while friends and family enjoyed the independence that driving bought:
Santosh:
It’s only just recently … driving licence … I didn’t have one till recently. All them years I’ve wasted. Is it 18 when you get a driving licence? Yes, 17, 18? I’ve only just got one now, about a year ago. So all my friends went through the driving phase. They’re all more happy.

Kumar:
Now hopefully I’ll learn to drive. I’ve always said to myself I’ll just make sure I don’t have another (seizure), probably my fault as well that possibly I need to say look I’m quite, I haven’t had one for years and probably won’t have another one for years so lets go do driving. That’s just to say I’m sorry more than anything else.

Others had lost the will and motivation to drive even when their seizures were under control:

I was learning to drive, I took about three or four lessons and then, you know, because I had to go abroad I just stopped it and I would have thought if I came back, I would have started learning but when I started having these fits I just lost heart then (Muslim Female Farhana, 31).

I’m not driving, I don’t, at first I didn’t get it so they gave me the licence but I don’t feel like, I don’t feel, I’ve no interest that I want to drive. My husband says “If you want to learn you can” but the enthusiasm has gone (Hindu female Sapna, 53).

One respondent (56 year-old Muslim schoolteacher Khalida) told us about the direct affect of not being able to drive had on her career:

If I apply for something (promotion), for more points then I need to know the driving, isn’t it? If I’m head of department, if I’m doing some work in pastoral there, you should have the driving. It’s important for you to do the driving, and how can you apply for that job if you can’t drive? I can’t take my husband everywhere with me.

Some respondents (three young Muslim men) were tempted to continue driving even after they had been told about the dangers involved but decided not to:

Driving the biggest thing that really annoys me. Yeah, I was driving, I was taking lessons and then when Dr XXX said “Because of you being epileptic you got to tell DVLA. I haven’t told them. Best leave it, never know, if you’ve got family and that in the car could be dangerous (27 year-old Muslim male Banares).

I was driving, haven’t taken a test, I was told you can’t get a driving licence if you have an epileptic condition cause if your on the road and if you have a fit on the road you could kill yourself and other people as well, so stopped (24 year-old Muslim male Mohammed).
SUMMARY

- Our study reveals that the support and encouragement of family members can have a dramatic impact upon the emotional state of people with epilepsy and can also influence the way in which they conduct their lives.

Coping with epilepsy

- Carers regarded epilepsy as a condition that made their relatives socially vulnerable. Many expressed frustration, anxiety, helplessness, as well as a sense of unfairness and occasional resentment as common responses to their relative’s condition and its practical and social meaning.

- Few persons with epilepsy shared and seemed to have internalised their families’ negative views. They often accepted their relatives’ views about their vulnerability and tended to see their condition as a personal tragedy. This feeling was particularly strong among those with an earlier diagnosis of epilepsy.

- People with epilepsy had to frequently confront and negotiate barriers as well as engage with the negative attitudes about epilepsy held by their family. One person felt that his family was ashamed for having an ‘epileptic’ relative and that his epilepsy was a source of ridicule for his siblings.

- Although most respondents from the sample had their epilepsy under control, some respondents expressed their concerns about not being able to fulfil expected family responsibilities. Some people felt their condition could compromise their role as wife or husband. Several resented not being able to help with normal domestic responsibilities, such as cooking and driving. Men worried about their role as ‘bread-winners’; women about their role as ‘mothers’. Some respondents felt they were unable to fulfil the normal expectations of a wife, husband or parent.

- Over-protection was sometimes a main source of tension between the individual with epilepsy and their families, reflecting many of the difficulties outlined above. Parents, especially, felt the need to protect their child from risk and danger. Younger people with epilepsy – particularly females - were more likely to be over-protected by family members. Some believed that their parents treated their siblings more favourably, giving them greater freedom. Others felt that their families treated them differently but in a positive way; they were taken care of and lavished with attention and love more than other siblings.

- Some respondents had mixed feelings about the role their families played. They recognised that there were times when the family took on the role of ‘protectors’ and ‘comforters’, ensuring they were injury-free during a seizure. Other times, however, the family was seen as too restrictive and over-protective. A number of people complained that their families either withheld or filtered information they thought might upset or worry them and potentially trigger a seizure.
The feeling that family restrictions were imposed rather than negotiated made them all more difficult to accept, although most respondents would not challenge those restrictions, as they feared upsetting their relatives.

Social isolation was a particular concern for some respondents who described themselves as having few or no friendships beyond family life. Other respondents mentioned isolation even within their families as they were excluded from certain events.

The wider community - particularly neighbours - sometimes-demonstrated ambivalent attitudes towards people with epilepsy. They felt it was their neighbourly duty to assist in case someone has a seizure outside their house. Yet the same people, in other social situations, could manifest feelings of abhorrence towards a person with epilepsy.

**Disclosing epilepsy**

A number of factors were taken into consideration before respondents decided on whether to disclose or conceal their epilepsy. Decisions were made after weighing up the quality of relationships, likelihood of the person finding out and experience of others reaction upon telling them. Some respondents preferred to conceal their epilepsy from the wider community and even from close relatives, as they feared this would lead people to treat them and their family differently.

Selective disclosure was also practised by a number of our respondents. Decisions about whom they told and how they introduced the subject of epilepsy were carefully considered. The severity of epilepsy was found to be a key factor, as the likelihood of having a seizure in front of others seemed to be a major reason for revealing. Information control in order to reduce or manage stigma associated with epilepsy was practiced by a number of respondents.

However, some respondents who suffered from frequent seizures decided to adopt a very open attitude and chose to disclose their epilepsy, as they feared they would need help in case of a seizure outside their home.

**Impact on lifestyle**

Disruption of their education was a particular problem for some respondents, irrespective of gender, ethnicity and country of birth. Respondents explained how epilepsy affected their schooling days and the subsequent impact this had on their future prospects.

Some female Muslims, in particular, felt their epilepsy gave their parents a perfect excuse to withdraw them from the schooling system.

Prolonged absences from school made one Sikh male unable to make friends from amongst his peer group, which resulted in a lack of confidence and isolation.

Another male respondent told us about the family pressures he faced, even though he was an adult, in deciding which universities to apply to due to distance from home.
• By contrast, some respondents had a normal school life, despite having occasional disruptions to their studies.

Impact on employment
• The issues around securing employment were far from straightforward for some respondents. Faced with difficulties in the employment market which they were challenging they were also fighting the family to assert their right to independence.

• Respondents felt there was little formal support to help people with epilepsy to enter the labour market and many employers held negative and damaging views about the condition.

• Those that were employed described various problems faced at the workplace, including a lack of support from bosses and colleagues, teasing, unwelcome comments and a covert suspicion that they were unable to do the job properly because they had some sort of mental illness.

• Some respondents felt that having a long-term condition like epilepsy had limited their choices of careers. Others who were diagnosed as adults with epilepsy complained about the profound impact it had on their careers.

Impact on marriage/relationships
• Finding a suitable marriage partner was seen as a difficult process for many South Asian people, however having a long-term unpredictable condition like epilepsy further exacerbated the situation. For South Asians marriage is looked upon as the union of two families rather than the union of two people.

• The narrative of some Muslim females highlighted the key role of the wider family in deciding the potential suitability of candidates and the impact of epilepsy on the whole process.

• Six respondents – following their families’ instructions – did not disclose their epilepsy to their future partners before the marriage took place or even later. They only disclosed their condition after the partners witnessed a seizure for the first time.

• Some respondents’ spouses – from all ethnic groups – described their shock and surprise when they found out that their partners suffered from epilepsy and how their own families felt cheated.

Impact on social life
• The impact of epilepsy upon peoples social lives differed according to the severity and risk of seizures – irrespective of ethnicity. Those who suffered severe seizures were more prone to have some social life restrictions imposed upon them not necessarily by their condition but by their families.

• Five respondents told us about the profound impact of epilepsy upon their social lives from going out alone to doing everyday things like watching TV or reading a book.
• Other respondents did not have permission to disclose their epilepsy to friends and were sometimes excluded from events on account of their epilepsy. Others felt that they did not have independence to do simple tasks, like going alone to the corner shop to buy some milk.

• Some people, particularly Muslim women, believed that their families used epilepsy as an excuse to exercise social control upon them.

**Impact on driving**

• However, the single most important issue cited by most epilepsy sufferers concerned restrictions upon driving. Overall 17 people from our sample mentioned the significance of not being permitted to drive and the consequences this had on their lives. On the whole younger respondents felt a greater sense of loss at not being able to drive.

• Others had lost the will and motivation to drive even when their seizures were under control.

• Three young Muslim men were tempted to continue driving even after they had been told about the dangers involved but later decided not to.

• Respondents who were in the process of learning to drive or had driven previous to their diagnosis also conveyed a sense of disruption or loss of independence.
CHAPTER THREE
CONVENTIONAL DRUGS AND ALTERNATIVE THERAPIES

This chapter reports upon respondents’ perceptions of the use of conventional western medication for epilepsy and the use of alternatives therapies. It examines users experiences of anti-epilepsy drugs and any side effects that they may have encountered. Also it focuses upon the reasons why individuals decided to turn to alternative therapies and the wide range of treatments used within the sample.

TAKING MEDICATION
Compliance with medication regimes is essential for controlling seizures and establishing long-term and sustainable management of epilepsy. Amongst all participants there was a high level of adherence to the medication that had been prescribed to them for their epilepsy. Although not all were clear about the function of their medicines, most people were happy with the dosage they had been prescribed and generally felt that taking medication reduced their chances of having a seizure. However, these sentiments were not shared by everyone, particularly amongst those individuals who were still experiencing seizures.

Some individuals were also unhappy about the side effects experienced from taking their prescribed medication. A considerable number complained of headaches, loss of short-term memory, stomach problems and general tiredness. Some of these problems were thought to be related to the long-term use of medication and it was perceived as a consequence of accumulated toxicity upon the body. Saleem, a 32-year-old Muslim man, said:

It is a drug... It makes your eyes funny; people think you’re constantly on drugs. It is a drug, though it is a drug people understand, it is a drug.

Optimum seizure control was the main goal for respondents and those who experienced seizures more often were more likely not to adhere to prescribed medical regimens. Within the sample many respondents either tweaked the doses in a bid to decrease the frequency of their seizures or took breaks from their medication. For example, 25-year-old Amjad, a Muslim male, felt that adhering strictly to his medication made little difference to his seizures:

They (the medication) used to cause them (the seizures). I never used to believe it, I’d think... come on... you’ve had it (the seizures) for so long, for so long you
give hope in it (the medication), you don’t care no more. So at times you used to think sack it (the medication), I’m going to have another fit again. Sometimes I might not have a fit I might take my tablet, I will have a fit if I’m still taking my tablet but if I miss a tablet I’m still gonna have a fit. If I miss the tablet I might not have a fit, you don’t know, it’s one of these things, it’ll just come up, it just comes from nowhere. But now I’m just, you know, cautious, I just try and go with it (the medication) to see like if it is (working).

Others, who were totally seizure free or experiencing very few seizures, strictly adhered to their prescribed medication and even opposed suggested changes by health professionals. For example, 68 year-old Hindu male Nagesh, who had not experienced any seizures for some time was recommended by the specialist to reduce his intake of tablets from three to two. Nagesh duly obliged and within a few weeks suffered a seizure. Straight away he returned to his original dose of three tablets and has ever since resisted any suggested changes. Even though this incident took place many years ago, and newer, more effective tablets have been introduced, Nagesh refused to attend clinic appointments because of this incident.

Some respondents went through periods of their life when they had to make difficult decisions about taking medication. One such time was when two of the respondents were pregnant and they had to make a difficult decision on whether they should keep taking the medication while knowing the potential harm it may cause to their unborn babies or, conversely, risk having seizures and harming the baby through injuries from potential falls. Asifa, a 28-year-old Muslim mother of three, who had epilepsy since the age of 12, faced such a dilemma with her third and most difficult pregnancy:

I did that – no one knew about it (that she stopped taking her medication). That was during the pregnancy. I was scared that they’d have some effect on the baby...Actually, the fits had got bad in the first place ... I was having cluster fits and the medication was put up and up and up. I was pregnant, I was really scared that there would be some effect on the baby because of the tablets and I was very uncomfortable taking so many – you know - three in a morning, three at night... I wasn’t happy about it at all and then, you know, I think it was about for a week I just thought: I’m having the fits anyway, I’ll have them but at least I won’t be taking the tablets; the tablets won’t be doing anything to the baby even if the fits are, so it’s not changing...I don’t know whether it was that week or whatever, I was quite bad that week and I thought to myself, it’s not sensible, you know; I was just so emotional at that time but then I went back on the tablets, so that was very briefly, for about a week or something like that.

Some respondents, particularly if they had been diagnosed at a young age, went through a rebellious period in their adolescence and stopped taking tablets. This was a common
phenomenon experienced by young people from all ethnic groups and has been identified in other long-term conditions, like diabetes and thalassemia. For example, Razia, a 31-year-old Muslim woman who had been diagnosed with epilepsy since the age of 12, recalled:

*When I was at that age 15 I used to (take medication). It wasn’t that I never understood properly, like if I had a headache you take a tablet, it goes away. I used to take the medication but I still used to have fits, so, in my head, I used to think what’s the point of eating tablets? So I stopped eating tablets.*

Respondents found it difficult to recognise the problems they were facing were not necessarily linked to side affects of medication or even epilepsy related. For example, Ranjeeta, a 48-year-old Sikh female social worker, was feeling lethargic and thought this was exclusively caused by her medication. She later confirmed that she was going through menopausal changes but was not taking hormone replacement therapy and admitted this could have been a more likely cause of her lethargy.

Two respondents felt that long-term use of a particular anti-epilepsy drug had left them with impotence. Although one of them had fathered a child he felt his wife had problems conceiving because of the “watery consistency of his sperm”. Others found that the tablets they were taking for their epilepsy had made them gain weight and really slowed them down to the point where they were often feeling tired and drowsy. Khalida, a 57-year-old Muslim schoolteacher, spoke about the effects of feeling drowsy on her work:

*You are not a normal person...If there was a school meeting for teachers... I used to sleep in meetings all the time. The minute I sat, if I had a free lesson I sit in staff room, the minute I sit, after two or three minutes, I used to go to sleep. If I’m checking exercise books in my free lesson I won’t be able to check one full exercise book, I used to sleep. If I was sitting here I used to sleep, now I can sit for a while but before that I used to be sleepy.*

One respondent, 43 year-old Muslim male Asghar, eloquently told us his views about illness and its cure:

*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 doctors give you your medication but the cure comes from Allah, you see, they can take the glory and say “okay, the patient came to me, I gave him medication and I fixed him” but this is for those who think, and people who consider but people don’t have time to think anymore.*
USING ALTERNATIVE THERAPIES

The use of what is termed as ‘alternative therapies’ has been found to be widespread amongst South Asian communities in the UK (Bhopal 1986, Sharma 1990, Fernando 1989; 2002). Alternative therapies refer to any form of practice that is outside the realms of conventional western medicine and include religious healers, hakims (herbal practitioners) and Chinese practitioners. The alternative therapist adopts a more holistic view and seeks to address the mental, emotional, spiritual aspects of a person in addition to physical symptoms. Many South Asians prefer the holistic approach as it fits into their beliefs about well-being linked to more than the absence of disease and encompasses anxieties and other difficulties that may be impacting on their general well-being. The family and to some extent the community are seen as an intrinsic part of the treatment process, which differs from western notions of individuality and patient confidentiality (Kakar 1982).

Often alternative therapies are used when western medication has proved ineffective in curing a problem or relieving symptoms. Although some practitioners of alternative therapies insist on their patients abandoning any conventional medicine they may have been prescribed there is evidence that both conventional and alternative are used simultaneously. For example, epilepsy sufferers may visit religious healers for prayers or amulets while taking anti-epilepsy drugs at the same time.

Our research found that the widespread use of alternative therapies was not necessarily or even primarily related to belief in its efficacy. Respondents turned to alternatives for a number of reasons. Some were persuaded by significant others like family or friends or distant relatives while others were suspicious of the effects on their bodies and minds of long-term use of anti-epilepsy medication. However one commonality between all respondents who had tried alternative therapies, regardless of age or ethnicity, was their desire/desperation for a cure or reduction in seizures that conventional medication had so far proven unable to provide. As 42 year-old Hindu male Santosh told us:

*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.*
Others, like 31 year-old Muslim female Razia, had made extensive use of *taweez* (amulets) but still relied on her tablets:

> 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.

One respondent, 34 year-old Muslim female Sara, told us that belief in the efficacy of any alternative therapy was essential for it to be effective:

> *Hakim, taweez (amulets) and things like that, I think you’ve got to have a very strong belief for these things to work. Yeah, because they don’t just work, it’s no good trying something. It’s not the cure, I believe, you’re a Muslim yourself, aren’t you?, but cure isn’t actually in the medication, it’s the belief you’ve got, in that thing that it works. And it does work, if you believe in something.*

Similarly 25 year-old Amjad felt that religious adherence was an essential factor in curing epilepsy and gave us the example of a relative who had been cured of her epilepsy primarily because she was deeply religious and prayed regularly and stayed away from sinful activities:

> *She’s alright (relative who had been cured), but you know what it is with us lot, we’re fucked as well in a way, we fuck it, whatever you do, that stupid thing here and there, you get me? (Undertake sinful acts) We’re not that religious, not that down to the bone.*

In our study most respondents made use of mainly three forms of alternative therapies: religious healing, *hakims* (herbal practitioners) and Chinese medicine. Below we address in greater detail their experiences and perceptions of these therapies.

**Religious healing**

Religious healing is practised at a number of levels: individually, in groups or by religious healers. At the individual level, a person who is suffering from an illness may say prayers, recite religious texts or drink holy water. They may even fast for periods of time or carry out a pilgrimage to places of worship in order to atone for their sins and ask for forgiveness and alleviation of their illness. At a communal level, prayers may be said at places of worship or money given to charitable causes as a way of seeking the favour of God.

Alternatively, a religious healer may be consulted for a number of illnesses/problems, which may or may not be perceived to have a spiritual element (epilepsy, mental illness). Some
Muslims refer to such healers as *pirs*, men who are thought to be closer to Allah because of their piety and wisdom (Kakar, 1982). The *pirs* are thought to adopt the role of a mediator between the people and Allah. They are regarded as being *walliyes* (friends) of Allah and have reached this exalted position either through birthright (lineage) or by a lifetime of devotional acts.

*Pirs* offer a number of treatments dependent upon the problem. Amulets (*taweez*) containing verses from the Koran are often given for a number of problems both minor and major. For example, *taweez* may be prescribed for people seeking employment, trying to conceive children or seeking relief from headaches. Amulets are usually worn next to the body (around the neck or on the arm) and act as a defence against evil spirits or the evil eye (*buri nazaar*). Other types of amulets are dipped in water and then the blessed water is drunk.

When the problem is thought to be spiritual, for example the patient complains about hearing voices or losing control of their body (clonic tonic seizure), the *pir* may diagnose the person as being possessed by evil spirits or demons (*jinn*) and the only way to alleviate the problem would be through exorcism. Only specialist *pirs* have the specific knowledge to perform exorcisms and it must be stressed that they are rarely carried out.

*Pirs* from the UK are often affiliated to famous *pirs* throughout India/Pakistan. Sometimes these senior *pirs* are invited to the UK and travel from city to city providing religious healing. While most *pirs* do not levy a charge for their services they do expect some type of payment in kind. The amount is often up to the individual and may be paid in cash, jewellery. Others ask for donations for a mosque or other places in India/Pakistan that may be in need of charity.

Most respondents – irrespective of ethnicity - made use of some form of religious healing. Take the example of Saleem a 32 year-old Muslim male who told us about a conversation he had as a teenager ago with a *pir*:

*Pir Shah came from Pakistan and he was 100 year 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 naïfs, told my mum downstairs “it’s like a sayaa (influence of a spirit) when he was born”, he said “naraa (veins) in his head which collapses”. Me and dad went to Dr
xxx a few months later he showed us a circuit board, he said these wires touch and connect. Afterwards when we came back home dad said “Allah ne bandyi” (Pir was a person close to God and not everyone is blessed with these powers), you know, he said “not everyone has that”.

Thirty-nine year-old Muslim male Yaqoob told us about his family’s efforts to persuade him to see a pir as they were convinced his epilepsy was related to jinn possession:

Most people think like that they are jinns and want to give you taweez or something like that. Pir, my mum forced me sometimes saying “You have to go you try it there, what’s going on, what you gonna lose there if you go there” and I had to accept those things. My family try, they took me to the pir everywhere, to a priest, I don’t know what they were but they took me there as well and they gave me something to drink. I tried, I think it didn’t work, it’s a disease, it’s not ghost it’s a disease, it’s not a ghost giving me trouble, if it’s a ghost it could kill me a long time ago. People (pirs) came from Pakistan here and I went there once, I remember, in Bradford 3 and he said bring a black goats head. Then “I’m (pir) gonna do something”, I don’t know what they were doing and “I’ll do this and I’ll do that” (cure him from epilepsy). But we couldn’t find a goat’s head here.

Others, like Banares, a 27 year-old Muslim male, and Khalida, a 57-year-old Muslim female, were also coerced by their families on visits to Pakistan into trying religious healing:

**Khalida:**
My mum she used to be upset “why my kids they got this problem, everybody else is okay, what have I done?” She took me to a pir as well. It was in Pakistan, the pir, I don’t know what he did and after that he said “can you open your mouth?”, and I said “why?” because he wanted to spit in my mouth, I said “no, I won’t”, my mother said “you must obey”. I said “I don’t think so”. Yeah, it’s our people, they believe in these things, I don’t believe, I don’t know why I’m like that, I don’t believe in these things. I don’t believe in pir, okay, you respect them because maybe they know bit more than you, I am a pir as well, I’m God’s human being, why won’t he listen to me, why should I go to another person to tell my problems, you pray to God, why can’t I pray myself? I have tried many things, it works, all of them, it works.

**Banares:**
I don’t know, I’ve been to Pakistan with them (family) once to go to these pirs and stuff, you know, just give you something, wipe your head or something, I don’t know. I believe in it but I don’t want it, I don’t want it. Because it’s something my older brother told me totally against, older brother totally against, cause we’ve seen round this area the bad effects of taweez. Obviously, you get good taweez you get bad, but whatever God plans he’s the best of all plans and I can’t, can’t go to someone and say give me a taweez and make me feel better, if I’m going to get better then God will make me better. (I went) just to please them (parents) really, they were saying that, not only my parents it was
Some respondents went along to see religious healers through desperation although they were highly sceptical. This was the case of 42 year-old Hindu male Santosh:

*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.*

Others, like 28 year-old Asifa, a Muslim female, refused outright to see a religious healer even though her family insisted:

*Someone once suggested, I think it was in the family, you know, some peer 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? So, most of them are just quacks basically, so… I don’t believe in that stuff…*

One respondent, 24 year-old Muslim male Mohammed, agreed reluctantly to wear a *taweez* (amulet) that had been specifically bought over from Pakistan for him:

*My parents sent this one from Pakistan. I had a couple sent a couple of years ago and they’ve been helping as well. Got it from Mullana Kari Saab (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, I used to wear them but don’t try to take them off even if your having a bath, but it used to completely get wet and at night time when I was sleeping I couldn’t sleep on one side, they used to get pressured. Then after two or three 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.*

Respondents that were diagnosed at a young age were unable to exercise any degree of choice in whether they wanted to seek any kind of alternative treatment. Such decisions were based on parents own views of illness or influenced by significant others (friends and family) experiences. The example of 34 year-old Muslim female Sara highlights the dilemmas of seeking alternative therapies even though they may be in contradiction to one’s beliefs:
South Asians and Epilepsy

My mother, we 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. 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.

On the whole those respondents who had used some form of religious healing involving taweez (amulets) had obtained them through male pirs. However, two Muslim female respondents (34 Year-old Sara and 31 year-old Razia) told us about their interactions with female religious healers:

Razia:
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 one year I didn’t have a fit. This taweez and she put dam on water (blessed the water), she used to give me that. She used to give me seven taweez for a week, so I used to have one taweez everyday and the water I can drink it whenever I want. I was taking me medication, but I went to that woman for a year and I didn’t have no fits and then I started getting it.

Sara:
I mean there was actually a time when we were living in Birmingham when we came to see a lady in Leeds. I think she was quite popular for giving, you’re going to laugh at this, lemon and drinking it in water. I used to... God, I went... oh, it’s horrible, I had to drink lemon juice every morning, it’s horrible for a long, long time. It didn’t cure it, it’s just one of those things that someone told my mum that try this out. You must try other things as well. They must have taken me to like I said they tried a few but this particular Indian lady I just remember because of the lemons, they were awful I had to sometimes they mention them for dieting now and I thought “God don’t mention them, lemons”. I just couldn’t do it, drinking that awful thing in hot water as well well, luke-warm water first thing before breakfast.

One respondent, 25 year-old Muslim male Amjad, had been given a taweez (amulet) by a pir who came to visit him at home but refused to wear it:

I went to this... we’ve got this other one who goes to your house Bakriar-e-Pir, 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.

Amjad continued to tell us about a relative who had been cured from epilepsy by visiting a pir in Pakistan and the hurt he felt when relatives did not even offer him this source of help:
I’ll tell you something, I know someone who has who has stopped taking their medication, I don’t know if my brother told you yesterday. You know my brother in-law’s wife, her sister, she’s from Bradford 3, about 29-30, same age as my brother, she’s an epileptic ... She stopped her medication, prays and everything, she’s alright. Inshallah (by the will of Allah) she does all right, she’s all right, good for her. Then they go again she’s been to these pirs, fakirs whatever you want to call them, one in Pakistan that helped her, she’s been to see all of them, but half of them are conmen, you know that, they go round taking money off you. It’s like I told you, the only thing my aunty and these lot were fussed they said to me is that they tell you the only thing they can do for you, the best thing they can do is talk to you. Talk I’ve heard talking too much? Its never going to do anything for me, why didn’t they take me to that guy who went with my sister in-law, my brother’s sister in law, this was from my brother’s side, when she went to, what I was telling you, to that mazaar (shrine), she went, if there is someone why didn’t they take me there? I stayed in Pakistan six months, six months, isn’t that a long time? Travelled from Faisalabad to Mirpur and I used to go to Mirpur nearly every couple of months or two, I used to stay there bloody a week or two, so they could have introduced me to that guy, took me round in it. But they didn’t, nobody ever did ought for me, I don’t be arsed, I don’t ask nobody for no favours.

Six Muslims (five females and one male) mentioned that they recited the Koran or made prayers as oppose to going to pirs:

**Asifa:**
I do believe in dua (pray to Allah) itself, reading to yourself or pray or Koran, reading and praying – that’s different, but no alternatives never been... It helps. I think it makes you, well I feel that when I, if I pray to myself, for example, before going to bed or in the morning, and I do believe that it helps in a way, it keeps me calm.

**Farhana:**
In the Koran I was reading a couple of weeks back, it tells you in, there's notes about this epilepsy, there's quite a bit about people who are epileptic what they should read, its in the Koran. Well I think praying is really important, I think if you do pray it’s really good, it just makes you feel better and it makes you closer to Allah, so you feel better.

**Hakims**
The word *hakim* is derived from *hikmat*, meaning one who possesses knowledge and is wise. The practice has its basis in Greek medicine and uses Hippocrates theory of the four humours (blood, phlegm, black and yellow bile). Any imbalance in these causes ill health and it is the *hakim’s* role to help to regain the body’s original state by a combination of medication and abstinence (Rack 1982).
The **hakim’s** method of treating patients involves taking a comprehensive case/lifestyle history including asking questions about sleep patterns, diet, exercise and any worries a person may be experiencing supported by a number of diagnostic checks. These include examination of the pulse, observation of the tongue and/or examination of urine and stools. Treatment regimens usually include a combination of medication (*dawaa*) and abstinence (*parhez*) from foods that are thought to either prolong or aggravate the problem.

Although little research is available on the use of hakims in the UK there is evidence (Ahmad 1992) that **hakims** both resident and visiting from the Indian sub-continent are widely consulted. Aslam and et al. (1992) found that up to four or five hakims where in full time practice in cities like Bradford and a number of others were engaged in part-time/ unpaid practice. *Hakims* resident in other cities advertise in minority ethnic newspapers and offer mail order treatments. Although **hakims** have been incorporated into health systems in other countries the chances of this happening in the UK are still remote (Ahmad 1992).

Our study showed that some respondents visited **hakims** in the hope of finding a cure for their epilepsy. The majority of people made use of **hakims** while on trips to visit relatives in India/Pakistan, primarily due to the prohibitive costs involved, as the carer (father) of 23 year-old Muslim male Shazad 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.*

Forty-two year old Hindu male Santosh visited hakims both her in the UK and on visits to India:

*Been to see the hakims, been to see them. Drink, yes that’s what they gave me (blessed water), but that doesn’t help. Somebody’s come up with saying a few words of their own… I don’t know what he said actually. I don’t understand them. Then he’s been round to say some things but then that’s about it. You can’t exactly give me anything to drink more than the water.*

Twenty-eight year old Muslim female Shanaz had tried herbal remedies prescribed by hakims but felt they were of limited benefit:

*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 (hakims prescribed 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.

One Muslim male respondent, 39 year-old Yaqoob, felt that the hakims he had consulted in Pakistan were out to cheat him, especially if they knew he was from England:

I went to hakim many times, he gave me something, I don’t know what it was, some powder, it was normal powder. They charge you a lot, family take me there to the hakim, don’t know what they call them, they got beard, these guys, sitting doing this, ask “what’s your problem?” and I’ll tell and they say “okay, I’ll do this and this for you”. (Laughing) They can look and they can scan your brain and they gonna find out you’re a Pakistani or you’re British and then they gonna give you powder and earn some money from you.

Twenty-four year-old Muslim male Mohammed who had his first seizure in Pakistan and subsequently moved to the UK to seek treatment told us about his experiences of visiting hakims in Pakistan:

Mainly they given me taweez and I’ve got some medicine, some liquid medicine from the hakim in Pakistan. The liquid one, it was and they said I was to take it twice a day, it was like taking bleach, I didn’t like it. I don’t think it did help me at all. He said an Asian name for epilepsy, ‘mirgee’, have you heard that? He said I’ve got that. Says your brain just stops functioning and then just starts again.

Chinese medicine
In Chinese medicine diagnostic information is gathered by four examinations: looking, listening, asking and touching. Most important examinations are based on checking the patient’s tongue (colour and coating) and wrist pulse rate, both of which are believed to reflect the overall condition of the patient’s internal organs. Present and past medical conditions and lifestyle are also investigated. Practitioners recommend a course of treatment to heal the problem according to the principles of Chinese medicine, which involves the prescription of herbs imported from China occasionally combined with other alternative therapies, such as acupuncture and massage. All activities are under control of the code of practice of the professional body, the General Council of Traditional Chinese Medicine (GCTCM).
In our study only one patient made use of Chinese medicine for epilepsy with very little improvement to her health. The carer of 46 year-old Sikh female Bhupinder told us:

Well, she has had Chinese medication. It was the needles that they put it in the head. The Chinese doctors only put the needle, the needle treatment (acupuncture) once. She didn’t feel very well afterwards, she wasn’t much better than now.

Fifty-three year old Hindu female Sapna (a trained doctor) expressed scepticism about Chinese medicine:

This is only... like a wave... the brain waves, sometimes the brain won’t answer that’s why it is happening and why, how acupuncture will help? Why will acupuncture help me?

Another respondent, 34 year-old Muslim female Sara, spoke positively of the benefits of using Chinese therapies although she had no personal experience of using them:

I suppose there is (advantages in using alternatives) because, I’ll give you an example, my husband’s niece, she’s on medication from her and she was suffering from asthma, and other things as well because you know just recently they took her to a Chinese it was herbal medicine. And that actually cured her asthma, so I think they can’t... I think obviously things do work, like I said it’s the belief as well, it’s what you believe in as well.

Other alternative therapies

One respondent, 19 year-old Sikh male Sachdev was quite unique in our sample, as he had tried a number of conventional and holistic therapies including psychotherapy, hypnotherapy, reiki massage and aromatherapy. Although the interviewee had mixed views about the benefits associated with using alternatives he was positively against trying any kind of religious healing:

They (parents) have tried to but I just know I don’t want to see any of these people (religious healers). No, because again it’s just superstition of things that I wouldn’t want to see someone who just does whatever it is he does and just makes me do this, or says I have to do this. I’d rather do it my own way. I did use aromatherapy. That helped with sleeping and relaxing me and I tried reiki as well. I’m not sure how it works because the guy (reiki therapist) that does it, he places his hands on your body rather than touching your body, it’s slightly above the body and I’m not sure how that works but it does make you feel refreshed and it makes you look more refreshed than you have been before you did. Reiki was through my brother, so through him and aromatherapy, his partner, she has books and things on it so I just borrowed a book and read that, how it helps some people in different ways and how it’s relaxing so I just tried it to see how it would help me. Changes, no, I’m not really sure, it’s just trying different things to become stress-free and just trying a different diet and just
things like that really. I’ve tried some things like how to become stress-free and things but I don’t feel it really works.

Similarly desperation bought on by the use of ineffective (conventional) medication led to 46 year-old Bhupinder visiting a private clinic:

I wanted to get it treated so I went to this private clinic and it was in Heckmondwyke, I had treatment there for one year and I was completely free of my fits during that time, I mean I really have felt that I'd recovered. It did cost me, it costed us about £5,000/£6,000 but I was really happy with the treatment.

Others, like 42 year-old Hindu male Santosh, regularly relied on home made herbal remedies that helped to alleviate common illnesses like colds or indigestion but felt they were powerless against epilepsy:

Well, say you’ve got something like a cough problem, where your local chemist can’t give you much, some things are explained in the books or in the papers which do work; some remedies which we can brew up ourselves, make up ourselves, simple, and it may be more effective than what you get at the chemist. Something let’s say, which has just come up, and then suddenly you’re not getting enough sleep or something like that. May calm things down. There’s a certain cough I come up with once a year. It lasts about three or four weeks, can’t get shut of it. Just can’t get shut of it. Then my mum makes things up and then try this, try that and eventually it calms down but if I go and see my GP, I don’t think they’ll want to know; it’s a waste of time again.
SUMMARY

- Optimum seizure control was the main goal for people with epilepsy and those who experienced seizures more often were more likely to turn to alternative therapies, particularly if western medication has proved ineffective in reducing seizures. There is evidence from our study that both conventional and alternative treatments were used simultaneously by most South Asian persons with epilepsy.

Taking medication

- Amongst most people with epilepsy – irrespective of ethnicity, gender, age and level of education - there was a high level of adherence to the anti-epilepsy drugs that had been prescribed to them. The majority of respondents were happy with the dosage they had been prescribed and generally felt that taking medication reduced their chances of having a seizure.

- Many respondents, however, admitted either having tweaked the doses in a bid to decrease the frequency of their seizures or taken breaks from their anti-epilepsy drugs without consent from their doctors.

- Respondents who had been diagnosed at a young age – irrespective of ethnicity and gender – admitted going through a rebellious period in their adolescence when they stopped taking tablets for a while.

- Others, who were seizure-free or experiencing very few seizures, strictly adhered to their prescribed dosage of anti-epilepsy drugs and even opposed changes suggested by health professionals.

- A considerable number of participants complained about the side effects of anti-epilepsy drugs, such as headache, loss of short-term memory, stomach problems and general tiredness. Two respondents felt that long-term use of a particular anti-epilepsy drug had left them sexually impotent. Others found that the medication had made them gain weight and often feeling tired and drowsy.

Using alternative therapies

- Sixteen people from our sample of 30 had sought help from traditional South Asian therapists usually as a second-line rather than an alternative to anti-epileptic drugs. All those who had used other therapies had experienced continued seizures, despite compliance with medical regimens.

- Some people were persuaded to use alternative therapies by family or friends, while others were suspicious about the effects of long-term anti-epileptic drugs on their physical or mental health. Respondents who were diagnosed at a young age were unable to exercise any degree of choice in whether they wanted to seek alternative treatment. Such decisions were based on parents’ views.

- Most respondents from our sample made use of mainly two forms of traditional South Asian therapies: religious healing and herbal treatment. However, one middle-aged
Sikh female made use of Chinese medicine and one young Sikh male tried psychotherapy, hypnotherapy, reiki massage and aromatherapy.

- Most respondents – irrespective of ethnicity - made use of some form of religious healing. For some, this was a personal prayer or recitation from religious texts in private. For others, religious healing was practised by undertaking a pilgrimage to places of worship in order to seek alleviation of their illness. However, fourteen respondents turned to religious healers.

- Younger people in particular expressed considerable scepticism about the effectiveness – and sometimes honesty - of such healers. 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, while others simply refused to see them. However, one respondent felt betrayed when relatives did not offer him this source of help.

- Many of these consultations were with gurus (for Hindus and Sikhs) and pirs (for Muslims) visiting from the Indian subcontinent, though some respondents took advantage of trips abroad, when visiting family, to consult with local well-known healers. A number of people had consultations with religious healers established in the UK, often affiliated to famous healers from the subcontinent.

- Most of the Muslim sample who had consulted with pirs were instructed to wear some kind of amulet (taweez) containing verses from the Koran, usually around the neck or the arm. People from all three religious groups were required to drink blessed water or recite from holy texts.

- Five respondents visited herbal practitioners (hakims) in the hope of finding a cure for their epilepsy. A number of hakims practiced in the district, often advertising consultations or mail order treatments through minority ethnic newspapers. 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.
CHAPTER FOUR

EXPERIENCES OF SERVICE PROVISION

This is the final empirical chapter of this report and focuses upon respondents’ perceptions and experiences of the delivery of health services. Having discussed the role of families in providing support in the previous chapter, this chapter examines the nature and quality of support that was provided to persons with epilepsy and carers by health professionals (community GPs, specialist GPs and nurses, consultant neurologists, social workers, among others) involved in the delivery of epilepsy services. It also examines some of the potential barriers to the uptake of health care services.

PROVISION OF INFORMATION AND ADVICE

Lack of information was a common complaint voiced by a number of respondents from our sample. The information void started at the point of diagnosis and continued throughout the life course of the condition and was not necessarily confined to those who had difficulties in speaking English. For example, 31 year-old Muslim female Farhana, who had been born and brought up in Bradford, told us:

_I asked them (health professionals) but they just... in my notes they just started writing epilepsy, like this person is epileptic and I'm thinking you know, what does that mean? And then I started reading books myself about epilepsy, but it still didn't make sense to me._

Other respondents, like 46 year-old Sikh female Bhupinder, who spoke little English, could not fully comprehend the magnitude of the diagnosis of epilepsy until she went home and read about it in a book:

_The doctor didn't say anything. My whole family was with me but he didn't say anything. I mean, they probably told my family members but no one told me why it happened. When I was diagnosed as having epilepsy, when they first told me, I didn't even know what the meaning of it was. I didn't know what the word was in Punjabi, so, you know, I like reading, so I got some books out and I checked out what it meant. Then I found out that it was actually, what the word was for it in Punjabi then it clicked with me what it was because I've come across people and children in India that had epilepsy. I had to find out for myself and when I did it actually frightened me because I thought this is the kind of condition where, you know, it stays with you all your life. You can't get rid of it, it's incurable. I was really shocked because in India the older generation they say that it's a really terrible disease, you know, the fact that you can just fall down and have an attack and you don't really have any warning_
signs for it, but, I mean, luckily, you know, it hasn't happened to me, I don't have fits like that but I can't say anything about the future.

Those respondents who had been diagnosed at a young age and whose parents could not communicate in English were further disadvantaged. Take the example of 34 year-old Sara whose parents could not speak English and had no explanation/information in their own language about epilepsy when their daughter was diagnosed 20 years ago:

I could have done at the time, probably, but I think I could have done with some kind of help or, you know, information at the time, especially for my parents. At the beginning some kind of support. If somebody had guided them (parents), you know as regarding my education and everything, it’s like everything just went down hill, they had nowhere to turn to, they couldn’t, you know, that’s it I suffered an illness that’s it for them, you know, nobody (helped).

In such cases young people especially were left in the difficult position of coming to terms with their epilepsy while at the same time educating parents about the condition. The example of 19 year-old Sikh male Sachdev highlights such complexities:

When I was younger, I was told I am epileptic. Now, what does that mean? I need someone to explain it to me, as the way someone would for my age. Because I wasn’t given any leaflets or anything about it and I was told ‘epileptic’, I looked that up in the dictionary and it’s something to do with the nervous system. Now I have no idea what this is. If somebody explained it to me better, I would have more knowledge of it. If someone could communicate with my parents as well and explain to them what it is and what you need to do and just things that I know that they should know. It was very difficult for the family (parents). I tried explaining to them what it is, but I couldn’t do it, and my brother, I had conversations with him, and the doctor did, but it’s just really explaining to them because they’ve never seen anything or even heard of it before and if you were to ask them now, “what is epilepsy?” – they’d just probably say “you go unconscious and you twitch” and this is what happens but whereas it goes in medical research things, they have no idea of what it does. I did try a great deal to explain to them because I knew they wouldn’t understand what it was. I’m saying just talking to them about it really because they thought I was really ill at the time and this is what I should do, this is what I shouldn’t do ... Well, whereas my parents, I think they would need an interpreter or perhaps a leaflet or something, a booklet that was written in Punjabi or something for my parents to read.

Even professionals with a good understanding of the aetiology of epilepsy, like 47 year-old Sikh female Ranjeeta (who had worked as a nurse), felt that she needed information and reassurance at the point of diagnosis:

I remember, despite being a professional, being very frightened because it’s something that’s out of your control, isn’t it? It can happen anywhere and
South Asians and Epilepsy

anytime and you have no control over it and that makes you very vulnerable and very afraid. So, I think to at the very beginning to have some sort of idea even in another language what epilepsy is, what causes it, because in those vulnerable days you thinking “well, is it something I've done or is it about me?” and I think this sort of information, what is epilepsy, how its caused, the impact it has on your brain, and things like that from the very early stages to get a bit of a grip of what this is, that's lovely if it can be done in different languages.

Another professional respondent (47 year-old Muslim male Hamid) who undertook counselling as part of his work felt that the way he was informed about his diagnosis was a little clinical:

It may have been explained but the shock of it I think put the barriers to what was being said, and it was said in a very clinical way, you know, rather than in a sympathetic way, which you've got to try and understand. I mean, I took time out later to try and understand, you know. They are professionals, they've got to deal with it in their professional manner and their professional way. I do my job, I take a slightly different line to what I do but that's my profession. So, you know, after a few months I said “fine, yeah, they were not hiding anything, they were just saying it in a very clinical manner”. For them mine’s only a minor issue not a major issue, they've dealt with some serious stuff, so me to them is nothing but for me that was like a major thing as an individual. So that's all it was, I had to try to come terms with that myself and I thought they could have been a little bit nicer but it wasn’t the case at that time. Or I felt that wasn’t the case, maybe they had been... but as soon as I was told I went fuck and I went blank, you know.

Respondents and their families felt overwhelmed at the initial diagnosis of epilepsy and needed time to come to terms with their condition. A total of four respondents regardless of education and language skills mentioned the need for easily understandable written information at the time of their diagnosis. For example 31 year-old female Muslim respondent Razia felt that the initial diagnosis and the effects of epilepsy could have been explained more comprehensively:

I think the hospitals should do more. I think they should sit down, explain to you everything, explain to your husband as well, when you’re both together, to say “this is what you should do”, explain more about it, show leaflets and tell them what it is. When I went to hospital, they just said to me “you’re epileptic and you’re going to have fits”.

Although participants complained about lack of information, our study showed that a number of health professionals, while under severe time constraints, did make efforts to provide explanations and information about epilepsy when requested to do so by patients. This was predominantly delivered through leaflets or short explanations at the time of diagnosis.
However due to the nature of the consultation process and the limited time available, discussions typically centred around immediate medical issues (for example changes in medication) leaving very little or no time for either the patient to seek information or for the doctor to explore the need for and convey specific information. The experiences of one consultant highlighted some of the difficulties faced by patients in a consultation:

*I’m sure they don’t (ask questions because of lack of time). But obviously any questions and you’ll answer it. I think people in front of doctors in that situation are likely to ... they could have a list of things and they’ll just look in their pocket or they’ll say No. That’s not just Asian patients, that’s non-Asian patients as well. I think we all do that when you go to see a doctor, I mean, even myself you go with the kids and you sit there, it’s the environment, you don’t necessarily get off all your chest, I think you come out and if you’ve got half of it off your chest then you feel you’ve done quite well. And, likewise, if you remembered half of what’s been said to you as well, then you’ve done quite well, haven’t you?*

Some participants expressed their need to find out more information and obtain greater support and reassurance during specific periods of their lives. Information needs increased at times of crisis or when respondents were faced with life changing events like puberty or pregnancy, as 28 year-old Muslim female Asifa told us:

*I think most of the answers I’ve got is by trying myself actually. No one has answered my questions for me. I’ve had to read about it or ask more myself. Every time there is something in this pregnancy, in the first pregnancy, I mean I was having fits then as well, not this bad and then when I got pregnant that time, after the babies, when they were born, about the medication, everything, I mean, I need to go to ask people about it, but I don’t think there’s enough information available. I don’t know how many times I rang the NHS Help line during this pregnancy asking, you know, this has happened, what do you think I should do, what do you think the effects will be, and they say the epilepsy nurse is Mr xxx.*

Faced with a situation of not knowing enough about their condition respondents employed resourceful means of seeking information. Some respondents read books from the library or leaflets and watched any TV programmes that were even remotely linked to epilepsy, as explained by, 24 Muslim male Mohammed and 31 Muslim female Razia:

**Mohammed:**
*I haven’t read a lot, but I’ve seen mainly on documentaries, like Open University programmes, and people who have got epilepsy, and leaflets and also when I was doing my first aid course. The nurse said... she was saying at college the people with epilepsy they... this, the reason they have cause the nerves going to the brain, they stop functioning for two or three minutes, because blood clots go to get too much information to go in and out of the brain but it gets. Instead of destroying the extra information, eh... it just keeps it*
there, then the brain just goes... blanks out for a couple of minutes and then comes... recovers again. That's why it goes into the seizure.

**Razia:**

*What I do, like if I go to hospital or doctor or something, I find leaflets, I get leaflets or go into the library and get books on it. I’ve done that. That helps a lot, I’ve learnt a lot about it, yeah.*

Other non English-speaking respondents like 46 year-old Sikh female Bhupinder, obtained information about epilepsy through her children:

*They (health professionals) should provide information and I think if they had things, if things were shown on TV that would be good as well. My children used to bring me things to read, you know, they got me books so I could look through them. Well, they used to bring me things in English and then we, you know, we get a Punjabi newspaper where they talk about health issues and there used to be things in that about it.*

Five respondents from the sample told us they obtained information about epilepsy by proactively discussing their condition with medically qualified people either from within their own family or from the wider social network. For example, 46 year-old Sikh female Bhupinder told us that her understanding of epilepsy considerably improved after a visit to India:

*I went to India and I had my sister-in-law there - she's a doctor - and she... they have a hospital there and she said that there were so many types of epilepsy, you know, they must know about the different types and I told her that I tend to get fits at night I said I never have them during the day. She explained a lot to me and helped me to understand about the type of epilepsy I had. No one here had done that.*

Similarly 31 year–old Muslim female Razia gained an understanding of her condition after she asked a visiting relative about the causes of her seizures:

*They didn’t exactly explain to me what really happens. My uncle’s son, he’s a pharmacist, so I just asked him generally, I said, “What happens when you’re epileptic?” And he told me it’s to do with my nervous system. He’s the one who told me what it was cause. I never knew I was epileptic. You have a fit and something in my brain that’s what I thought it was, but he explained it to me. He goes “this is what it is”, so I think in the hospital they should explain more.*

One respondent, 47 year-old Sikh female Ranjeeta, was grateful for the explanation and reassurance provided by a friend who was a doctor:

*I've got a friend who's a doctor, he was very helpful in the beginning but he probably helped me more than anyone to understand it because I thought it was*
something that's going to stigmatise me for life and he kept saying it's not an illness, it's a condition, it's a condition, don't think you're ill, you know, something's gone wrong, yes, you have no control over it, it's not your fault.

However four respondents mentioned that having too much information about epilepsy could be detrimental to the management of their condition as it could lead to excessive worry and perhaps even bring on seizures. For example, 47 year-old Muslim male Hamid told us:

_Sometimes I think if I have too much information I might frighten myself and it’s just a bit of a balance between knowing too much and knowing just enough, which keeps you going. Because I don’t feel frightened as such and if I started feeling frightened and petrified and, I don’t know, blaming myself, then I think I would need that additional direction and information, but I don’t know... maybe a little bit more information, exactly what it is and what it does, essentially._

Those respondents, like 28 year-old Muslim female Shanaz, who experienced frequent seizures did not want to do anything that they felt would lead to undue stress and cause more seizures:

_I don't go overboard or I don't make a great effort to find out, if I learn too much about it, that it's just going to cause me anxiety about it, you know, I'm probably going to have more fits._

According to the views of health professionals the difficulties encountered by patients in seeking or managing information were not exclusively dependent upon their ethnicity but were highly influenced by levels of education and social class. Patients that were educated were more likely to know how to seek information from sources like the Internet and were generally more inquisitive about their condition, as a consultant pointed out:

_I think the educated people, even though people share the same religion and the same values or whatever, the patients that are more educated will have more access to the Internet, the information and this and that, trying to find out and whatever by nature of their background of course._

Although our sample contained a number of professionals and students with relatively easy access to the Internet only one respondent 26 year old Muslim housewife Saima used this resource to find information:

_With the Internet I learned a lot about the type of epilepsy I had and about different treatments._
A (white) community GP told us his views about working with a predominantly poorly educated population in an inner city practice:

In this practice area we're not dealing overall with a well educated group of people and they don't seem to do a lot of questioning and that's not just Epilepsy, it seems to be everything. I can imagine if I was working in some of the nicer, posher parts, people would be coming to me with their Internet sort of print outs. I mean it happens occasionally but not very often.

A number of respondents felt that epilepsy was a marginalized condition in comparison to more common high profile illnesses like cancer or heart disease. The problems around obtaining epilepsy specific information through informal channels like TV and radio programmes was partly attributed to the non-popularity of epilepsy within the mainstream media. Twenty-eight year old Muslim female Asifa eloquently explained:

It's strange, isn't it? I don't think there's enough attention given to epilepsy and epileptic people. For example, kidney problems, symptoms for heart trouble, there're leaflets everywhere, you know, there's this and that. Just leaflets, booklets about certain symptoms to watch out for, watch your diet, watch this and whether they can lead to diabetes and if you're diabetic, you've these symptoms and if you have, if your cholesterol's high, this and for cancer, it'll be that but for epilepsy, there's nothing really. It doesn't tell you how to cope with it. I think there should be more advice on how to cope with it, how to stay calm after you've had a fit or what to think basically. Everybody deals with it in their way but these people should be told if it's there and if it's not something they can give you - a tablet - for and it'll go away. It isn’t, really. You take tablets but it doesn't go away and if it's going to happen, it still happens. Every time you open a normal magazine - 'Take a Break' - or things like that, a normal magazine, there's plenty of articles on “I fought for my life with cancer” and this and that but there's nothing in normal everyday life for epilepsy. There isn't. I don't think there is. I think if people knew about it, they'd be calmer about it.

Twenty-seven year-old Muslim male Banares felt epilepsy was very much a second rated illness and that resources were targeted towards more highly rated common illnesses:

I don't know, but if a person does suffer from epilepsy you should... I don't know, there should be something for that person like a pack or something, cause, for example, if I suffered from cancer or Aids, whatever a common disease, you'd get a pack, wouldn't you? I reckon epilepsy, because not many people have it, it's kind of like second division and maybe it doesn't get money and it all goes to the premier league like heart disease and that.
Health professionals also felt that epilepsy was a marginalized condition and did not have the recognition or priority that other conditions like heart disease or cancer commanded.

*From a general practice point of view I think epilepsy's never had a particularly high profile because obviously at the moment it's all cardiovascular work and that sort of thing and cancer so it's probably not high on the list of generally of people's priorities. Also we are told to prioritise these conditions by the government through the setting of targets.*

However, once again, the central issue of providing information in the appropriate languages featured prominently. Those respondents that spoke little or no English expressed a need for non-technical information in their own languages. For example, 28 year-old Muslim female Shanaz told us about the advantages of having information in her own language:

*It’s better if it’s in Urdu then I can read it myself and not bother my husband to explain it all to me.*

While for others written information in any language was inappropriate, as they were unable to read or felt that a one-to-one verbal communication would be more beneficial:

*Safina* (65 year-old Muslim female):
*I need to know why does epilepsy happen to people, I mean, that’s something that really concerns me; I want to know more about that. I want to know more but someone has to explain it to me in my own language because I prefer that to reading some leaflets. It’s not that I can’t read but I prefer talking to someone, it helps me to understand better.*

**LANGUAGE AND COMMUNICATION BARRIERS**

One-third of the South Asians with epilepsy in this study were not fluent in spoken English. Language barriers were identified as a major problem by health professionals caring for non-English speaking epilepsy patients. It was felt that communication was hindered by the fact that there was no common language for patients to ask questions and discuss their concerns. For some health professionals, language barriers prevented them from providing non-English speaking patients with a fundamental understanding of their condition. As one specialist GP told us:

*The language barrier is a problem, of course, and I'm not sure even with an interpreter that some of the terms that I use actually necessarily have a direct translation into the South Asian languages. So it is sometimes difficult to explain to patients what's going on when they're having a seizure if the language... Because it's hard enough when English spoken is the first language of both me and the patient, but if the patient's first language isn't English, trying to get that across can be difficult and I always often wonder if some of the South Asian patients go away not quite understanding what I wanted them to*
understand about it. Yes, it’s a problem but I think its not just language, I wonder, and you may know that better than I, whether it’s language and sort of culture as well, whether some of the terms that we use medically don’t translate directly.

The use of community interpreters was also problematic primarily due to issues of confidentiality, as one specialist GP pointed out:

It’s very, very difficult and there’s a confidentiality issue, which always worries me... But I think that’s a problem working as a doctor in Bradford. It’s not just epilepsy, you are going to see patients who don’t speak any English at all, yet you’ve got to do your best to deliver a service to them... And we’re not resourced, certainly in primary care, to have interpreters in the consulting room, which is the ideal isn’t it? Ideally an interpreter who doesn’t know the family... And that’s my other problem with interpreters in Bradford, that often the communities are very close knit and I’ve often been pretty damn sure that the interpreter actually knows this family or somebody from this family and then that’s no better than having a relative there. You really need somebody who doesn’t know the family, who can interpret impartially, but the resource is not there, not in primary care, so what you do in primary care is do your best and you do rely on relatives to translate.

All non-English speaking persons were accompanied by other family members when health professionals examined them. There was very limited use made of interpreters. This proved most problematic when there were no English-speaking adults within a family. For example, the wife of 68 year-old Hindu male Nagesh, was keen to know what she should do in case her husband had seizures at home but was not able to discuss this with anyone. Only two participants were provided with information through an interpreter. Twenty-eight year old Muslim female Shanaz told us about her experiences:

Sometimes I go with my husband, he interprets for me, and sometimes when I go where the reception desk is, where you give your letter in, I inform them I need an interpreter, so they sort something out. Well, you know, I’m glad she’s (the interpreter) there but I just don’t know when I’m telling her things whether she’s accurately then passing on that information to the consultant or not, there’s no way of me checking.

A specialist epilepsy nurse had also encountered similar problems with family members acting as interpreters and told us about a particular incident:

We had a case of a young man that came six months ago, he was in my group and he came with his brother-in-law, recently arrived from Pakistan. This young man, say six months ago, he's got married and came over here to his wife, she spoke English but didn't want to come to clinics, so the brother-in-law had come along and the registrar said “oh, do you mind coming through and
just chatting to these two men for a moment?" So, I went through and she said “I’m not quite sure about this story that his brother in law’s telling me, do you mind listening?” and he was saying that this guy had had these dos in Pakistan, he’s had a motor cycle accident which had resulted in the epilepsy, he was still having fits, this tale went on and this poor young man was sat there with his head down looking very, very miserable, so I said “well, I want to know what he thinks, can you ask him to tell me through you how he’s feeling?” So, this torrent of the Pakistani language, what's it called? – Punjabi - came out and then the guy said something like “oh, he's not very happy”, so, I said “he must have said more than that to you” and he said “well, yes, you know, he went like this”, and so I sought out one of the members of the staff who used to have a young Pakistani girl working here and I said “would you mind coming through translating?” which she did, and the difference in this guy as soon as she started talking to him, he suddenly sat back and here was somebody that could tell his tale and we found out more about his symptoms through her than we had through the brother-in-law. I’m not suggesting that this happens every time, but what I am suggesting is that it happens a lot and I know from other specialist nurses and other doctors in various other areas that this is a major concern. If you have a family member translating for you they will not always get the bones of the story, if you like, you know, because they… perhaps the medical terminology isn't quite understood, you know, and one thing and another, so, again it’s quite a barrier, isn't it?

The availability of interpreters was also problematic as they had been booked well in advance and were difficult to access especially when patients who may be suffering a crisis turned up at short notice. One nurse remarked on the shortage of interpreters:

We don't always have the opportunity here to have interpreters ...they're mainly used on women and children. So, you can book them to come to clinic, and we do in advance if we know they're needed, but I wish sometimes I could speak Urdu, Punjabi.

In the majority of cases, patients themselves expressed a preference for their own family members to interpret, as they felt that the presence of close relatives provided them with a source of emotional support. It was usually the spouse, parents or siblings who took on this role. Using family members as interpreters offered both advantages and disadvantages. Some family members took on this responsibility voluntarily as they felt that interpreters would not be able to translate information accurately to the patient. Instead, it was felt that family members were more likely to present information more sensitively using vocabulary that the patient would understand. However, the disadvantages of using relatives was stressed by the experiences once again of 28 year-old Muslim female Shanaz, who was usually accompanied to hospital visits by her husband:
Usually my husband (goes with me) or if he’s not available, then either my brother-in-law or my sister-in-law. Well, you have to talk to the doctor in English and I don’t like to burden my husband all the time by telling him all my problems, so I just think maybe I’d better keep it to myself and not make a fuss about it.

Health professionals also felt that gender could be a significant variable in communication with South Asian patients. A specialist GP told us about his experiences of male members of the family undertaking the role of translator:

*I think that the language thing is more (problematic). I think there are... - and again its anecdotal, you may have stats to prove or disprove - but I think that fewer of the female Asian patients speak English well compared to the male patients, because I think often a female patient will come and they will have a male interpreter with them who is family, who does speak English, but they themselves don't, but it's only an extension, the language barrier, I don't think that, I've not felt anything specific about female patients beyond the fact that they're probably less often speak English. It is an issue, isn't it? Yes, and I do wonder whether what I say, I can sometimes say a lot and what would be passed over to the patient will be something very short and then a very short answer will come back and I don't know if everything, I'm pretty convinced everything I've said hasn't gone over in that sentence, and sometimes vice-versa. I'll say something very simple and it will seem to become very complex in the interpretation and without understanding what's been said I can't have a clue what's passing over.*

A community GP speaking on the topic gave us his opinion of the dynamics involved when spouses translated for each other:

*Quite often are quite often it’s only one member of the family that speaks any decent English and that can either be the husband, who does all the talking for his wife, and that seems to work fairly well. When it's the other way round, when we have an English Asian sort of speak who has married somebody from Pakistan who comes over and doesn't speak any English then that seems to be a sort of conflict, not just, not talking about epilepsy specifically, I'm not just talking about consultations and I think maybe the man feels his positions being usurped and he's playing second fiddle to his wife.*

However health professionals did recognise the difficulties involved for women from a South Asian background in discussing personal issues like contraception or pregnancy through an interpreter or family member:

*Asking about contraception and about variance with periods, about the fact that some of the drugs we use can upset the periods, particularly Epilim, discussing plans for future conception, pre-conceptual care they had through language barriers, you say probably particularly through a male interpreter to a female patient because I think the female South Asian patients find it difficult enough to
talk about things, like gynaecological issues, to male doctors anyway, if they have a choice they would more often than the Caucasian population choose a female doctor. I think most females prefer female doctor for those sort of discussions but that thing is much greater I think amongst the South Asian population.

Others, like 46 year-old Sikh female Bhupinder, had to rely on extended family to interpret, which caused problems, as she felt embarrassed at the idea of discussing personal problems with her young nephew or niece:

At that time I couldn’t really speak English, you know, now I can get by, but then I wasn’t able to communicate in English, my children were young at that age, my husband had come from India. It was mainly my sisters, my brothers, nephews and nieces that used to ask about it. I sometimes couldn’t tell them things, you know, that I wanted to know about from the doctors, like personal things, like women problems. If I had been able to speak English I could have spoken directly about things. I would have been able to ask, you know, what happens, what had happened to me, why it’s happened, you know, I would have been... I wanted a clearer explanation about this thing. But, you know, the kids used to ask on my behalf all the questions I wanted to clarify.

Interestingly, not all the carers we interviewed were happy about interpreting. Some family members had found the situation highly emotional and had difficulty digesting the explanations they were being given about their relative’s condition while continuously interpreting this information to them at the same time. Some also admitted that they were unable to translate the information they were given as accurately and in as much depth as was needed. It was particularly difficult to translate medical terminology with which carers were unfamiliar.

Health professionals shared similar concerns about family members undertaking the role of interpreters. A commonly held view was that family members did not undertake the responsibilities of an interpreter in a professional manner. Health professionals felt that in their role as interpreters, carers did not necessarily speak on behalf of the patient. Rather, they were more likely to use the opportunity to present their own concerns and views. This made it difficult to assess the impact of the epilepsy upon patients. A consultant reflected upon this problem:

It’s difficult if they bring someone, but the difficulty is if they bring somebody along with them that’s informed consent really that they want, they’re happy to do dealings through them. It’s not entirely satisfactory. To be honest, it’s not entirely satisfactory to do it through an interpreter either, but on occasions I do
use the interpreter rather than the person they’ve brought along with them. Sometimes I’m not entirely happy when it’s particularly an Asian woman who brings her husband as an interpreter. Perhaps that’s an unproven view, it’s just sometimes, I’m not sure what’s happening in that situation, whether the tale I’m getting is the tale that he wants to give me rather than the tale that you’re getting from the patient. And I do occasionally use an interpreter to bypass that.

An Asian community GP who had no major problems in communicating directly with his patients expressed concerns about confidentiality when patients came into consultations with relatives:

Many times somebody else come and ask, what is wrong with him, you not supposed to tell really, you know. It is very difficult, you know, somehow they talk, they talk too much in community, they miss a confidence and it doesn't remain in confidence, yes, in Asian societies. So, it is difficult, when we don't tell, somebody else tells. Not from them, maybe not at the start, but, you know, normal talk, one person tells another, so it just spreads.

Health professionals felt that a more effective way of communicating would be for interpreters with more clinical knowledge of epilepsy to be present alongside family members. Some felt that interpreters played a more objective role than family members and were in a better position to help provide more accurate information about the patient’s condition. It was also noted that patients tended to ask more questions when interpreters were used.

INTERACTION BETWEEN PATIENTS AND GPs

A number of respondents from both our sample and focus groups expressed general dissatisfaction with their Asian GPs. The total number of respondents registered with Asian GPs was 25 (out of 30). Notably a high number of these (19) were dissatisfied with their GPs. The motivation for registering with Asian GPs was dependent on a number of factors. For example, respondents with limited English were keen to register with someone they could easily communicate with and who understood their cultural background. While for others accessing surgeries close to their homes (within walking distance) was seen as a priority.

One patient, 31 year-old Muslim female Razia, told us about her turbulent relationship with her GP especially after she had become pregnant contrary to his advice:

I’m not that happy with my GP. It’s because... I don’t know... It’s... Well, he was against me getting pregnant. He said to me... He said some hurtful things
to me like... He said to me... For example, he goes... I went one day, he goes to me “Animals have got no brains, animals haven’t got brains, you’ve got to no brains either”. When I got pregnant I was really happy because I imagined I’d never have kids because of my epilepsy, I thought... Plus I was scared if I have a child maybe he might have it. I know what it feels like and I don’t want my child to have it. But when I got pregnant I was really happy. Then thought “alright”, you know, it was really good after seven years. So I went to the GP and this is what he said to me. I was really shocked and taken aback and when my son was born, maybe he was saying it because of my illness, that it’s going to get worse and worse, you should have thought about it, but I was okay when he was born and I’m alright now. But sometimes when I’m worried about my son, when I go to see him, he sort of says and remarks “you’re supposed to look after him, give him this (medication) and come back”. What happened once was I went to see the doctor because (the son) was ill. He (the doctor) gave some medication. That night my cousin came, she’s got five children and he (the son) was crying, he had a reaction and she said to me “it’s best if you call a doctor to come home and see him”. So I called a doctor home and that doctor looked at the medicine my doctor gave and he said, “it’s all right, keep giving it”. The next day, when I went to the doctor to tell the doctor, you know, they give you a slip saying you needed to see a doctor, I gave him that and he started shouting at me: “She cost me £40!” Then he went inside the waiting room, it was packed, and he shouted at me there, in front of... there... my health visitor was there and he shouted at my health visitor. He got my file and said, “Look at her, look how stupid she is, she called a doctor home and he didn’t do nothing and I’ve got to pay £40!” And he went inside to the receptionists and he told them, and from that time... Sometimes he’s really nice, sometimes he’s, you know, a bit moody.

Similarly, 39 year-old Muslim male Yaqoob, whose wife was having trouble conceiving due to his low sperm count, had been told by his GP not to marry because of the risk of subsequently passing epilepsy onto any children he may father:

My doctor (GP) told me and told my dad “Don’t marry him off. If he’s married he’s gonna have a kid, they gonna have epilepsy as well”.

Complaints were however not confined to GPs from any particular ethnic group and covered a wide range of issues from neglect of the duty of care that was seen as an entitlement of patients to lack of GP’s knowledge about all aspects of epilepsy. Lack of time was also a common complaint, as 41 year-old Hindu male Kumar remarked:

The old one (doctor) when I was in Shipley he was very good actually, very good, one of the old style doctors who talked to people. This one (the new doctor) seems to want to be in and out, he’s not one to stand up. I think they probably need more time than anything else, I think they are pretty busy.
Another respondent, 24 year-old Muslim male Mohammed, who had been initially diagnosed in Pakistan but had subsequently moved to the UK, felt his English GP was wrong to say that his epilepsy was untreatable:

They (in Pakistan) did try to explain what could be, but I’m not exactly sure what they said at the time, but when I came here the doctors explained it properly. My GP once he said “It’s untreatable”. He said like that, but I don’t think that’s fair thing for him to say to a patient, you can’t treat it and you have to deal with it. Here, my GP, a while ago, when I used to have these fits again and again, I used to have them nearly two or three times a week, this was about five years ago and he used to call the doctor and he used to say “Ah, you have to keep on taking your tablets and there’s nothing that we can deal with”. He’s a gora (English) doctor, and he said that but I don’t think he should have said that. He should have said “We can help you, we can try and keep you on medicine” but I don’t think he should have said, “Oh, it’s something you’ve got and you have to deal with it”.

Other respondent’s spoke of the positive relationship they had with their GPs and other health professionals who they felt were caring and helped to reassure them in difficult times. Muslim male Hamid (47) told us:

My GP has been ultra supportive, they know I’m not coming to sort of tell lies or anything like that, they know I only come when I need to come. I’m with a local practice and they are ultra supportive to me, they’ll do anything I need, they’ve never let me down. And likewise the consultant has been absolutely brilliant, he’s given me extra time when I say “Can I see you in so many months rather than so many months?” He’ll say “No problem, sort it out”. And likewise Mr Ross, at LGI, he’s been absolutely brilliant, so, you know, I really can’t say I’m disheartened with anybody or anything, I suppose I currently know I’m reasonably pleased by that.

Twenty-eight year old Muslim female Asifa who had experienced many difficulties throughout her pregnancy remarked at the changing relationship with her GP:

I think it’s better now. I didn’t feel really comfortable talking to him at first, but he seems quite friendly now. Maybe it was me that needed time to open up. Yes, but he’s much better now. Maybe I’ve been through the worst, I don’t think it can get any worse. I’m feeling more confident about it.

SPECIALIST EPILEPSY NURSES

Some of the health professionals we had spoken to had been practicing for a number of years and had built up extensive experience and rapport with patients from South Asian communities. Such professionals were able to access views and beliefs of patients that would
otherwise be kept hidden. The ability of epilepsy nurses in gaining the confidence of patients was impressive, as shown in the account of one of them:

If there is a cause, you know, you can say you had as this young guy did, a motorcycle accident, you bash your brain and this is why you've got epilepsy, that's fine. But the ones that are really the worried ones are the ones that there's nothing wrong with their brain, so, then, you start to think do they feel they're cursed? Do they feel in some way God's put his finger on you and said, “right, you can have that”? The majority of them don't. The young ones don't. It is a medical condition. You need to go to hospital and you need to get some tablets and you'll be fine. It's the older generation, which I think would be true in most communities. One of my group, he must be 68 now; he'd been cursed, definitely. I said, "Why do you think that?" A few generations ago his family stole some land from another family in Pakistan and that was when they were cursed and, as it happened, in my group there were family members from this extended family. This man had epilepsy, his sister had epilepsy, his mother had epilepsy, cousin had epilepsy, cousin’s sister had epilepsy, cousin’s sister drowned in the bath, cousins had then married again and as a younger cousin there he had epilepsy, so, obviously a genetic cause, but not for them, particularly his sister dying, you know, that was dreadful. So, I said “Well, why don't you get the curse removed” In England we would just go along to the church and pray and can you do something similar?" And he said “Because it costs a lot of money to go back to Pakistan to find this family to have the curse removed”. So I find that very, very sad and we did try to explain to them that because so many family members had it, there was a strong chance it was genetic.

Another young man, a couple of years back, came to see me, a young man, maybe mid-thirties, came along, suddenly, burst into tears and I said “Oh, you know, have I said something to offend you, upset you”? “No, no”, he said “But can you tell me something? Why I've got epilepsy”? So, I said “Well, according to your notes we're not really sure, but what we do think is that somewhere back in your family, someone had epilepsy and they've passed it on to you”, which is the simplest way of describing it, and he said “Oh, well, my parents tell me that when we went back to Pakistan, when I was very small, I urinated on some holy ground and therefore that's why I had epilepsy” and he was utterly convinced about that and I said “Well, that isn't true”, but that man had reached 35 absolutely convinced that was true. There are spirits that are on that land and if you do anything on that land that upsets them, they will then come out and take your soul and use it in someway for their purposes. This was his idea, that he had disturbed these forces on this particular land by urinating on the land.

Specialist nurses were seen to provide an essential link between health professionals (GPs and consultants) and patients by fostering understanding of epilepsy through regular contact and provision of information. An example of the wide repertoire of skills employed by specialist nurses was given to us through the following account:
I’ll do anything that’s ethical but we run clinics ever Thursday afternoon to which everybody in that area comes. The clinics are all area based. We do a clinic, and we do a neurology service here for people with learning disabilities. So, I work in a clinic alongside the doctors and the neurologist, although plainly I can’t diagnose epilepsy or start treatments but I can do minor alterations and maintenance and deal with any problems that arise. I also go and see people at home and in their day services if they have learning disability or in the hostels for people with learning disability, because 50% of my work approximately is people with learning disability and 50% is the rest of the population. I do a great deal of education about epilepsy and training about epilepsy and training for the giving of medication particularly rectal diazepam. I also liaise with GPs, liaise with anyone who has an interest in epilepsy. I’m available on the telephone pretty much on a 24 basis and will deal with calls as they come up either over the phone or I’ll do home-visits if necessary. So my job is basically to offer technical advice and reassurance and education but people like the reassurance most of all. Even competent people, like a nurse I went to see, who had been caring for her sister for the last forty years. And she was very, very competent but it was the fact that she had someone there to refer back to that she really liked, the idea of, and that seems to be my job. I think a nurse provides a human face of the service, if you like. I think that once people see a nurse and once I go and see people and I have a visit with them and spend an hour chatting to them I think they’re more likely to use the service to then. Because it just presents a human face rather than a chunk of bureaucracy.

The holistic approach undertaken by specialist epilepsy nurses helped to unlock patients and carers views that would be almost impossible to reach by other health professionals, as one consultant remarked:

I think that patients aren’t entirely open with doctors. No, I don’t think they are. I think patients do hide information from doctors. Perhaps the information that’s a bit more on a personal level, and emotional information, things like that, I think they hide from doctors. I don’t think that’s personal to me. I’m certain they do it to me but I don’t think it’s a personal thing. I think they do that to doctors in general. I think a patient is much more likely, sometimes, to come along and where things aren’t going well, they’ll come and tell you that things aren’t going well but if they’re not quite as good, I think they’re quite likely to walk into a consulting room with a doctor in front of them and say yes, they’re OK, whereas if you put them in front of somebody else, perhaps non-doctorish, then I think they might be prepared to open up about one or two other issues.

Epilepsy nurses to a certain degree transcended barriers of language by reaching out to South Asian communities in a number of ways. Home visits were regularly undertaken, small-scale research projects at the local level to ascertain user needs as well as organisation of community events in collaboration with local people/service providers all helped to further
understanding of epilepsy. However much the specialist nurses had achieved with their work with South Asian patients they too felt that ultimately there was a need for an Asian liaison worker who could speak the language and had a deeper understanding of the culture. A good example of cultural, as oppose to linguistic misunderstanding, was given to us by one of the epilepsy nurses:

_The language barrier doesn't help at all. It was very disturbing for me, very sad that these ladies that I've known for years now were saying to me “yes, we understand what you're telling us about epilepsy, thank you very much for telling me all about it, and we've been to see you in your clinic, and you've told us all about the drugs that will harm the baby, and that we must take folic acid and keep you informed, but we don't really understand what you're talking about”. You think, “oh, that’s awful”, don't you? You have this condition, you go home and this nurse at the hospital is saying to you “well, this is best and this is that” and go on through diagrams but what she really needed and they both asked for is written information in Urdu or whatever so that they can then go through it when they get home with their families. We had leaflets and they're very vivid leaflets in Punjabi, Urdu and another might have been Bengali; three languages that were done through the BA branch there. They explained all the safety issues surrounding epilepsy, driving, safety in the home, one thing and another, how to look after somebody having a fit, what was a fit and these weren't taken up. They produced thousands of them and I got in contact with them, it must be four years ago for one reason or another, and explained they had this literature, would I like some, fabulous, left it out in clinic but it was never picked up, never, so I used to say to the Asian people that I saw “please take one of these”, “oh, thank you very much”, then I asked one of them why she hadn't picked it up anyway which was the obvious thing to do and she said “Because that’s not polite. You must give it to me, if you give it to me and say 'please take that', I will take it with me but I'm not just taking something”, where English people, well the other ones just... You know, that was a shame, what I try to do now is look round the web sites and other information areas for information in the different languages which is how I came across that web site. I've been in with a group that for two years now and Xxxxx was initially in the group and he then just got fed up, I must admit, I got really fed up with them in the end. We met about two years ago with the British Epilepsy Association, the NSE representative and various specialists nurses, we set out a questionnaire to all the nurses in ESNA asking them for what information would be best in their particular areas and it came back that Urdu was the one language they thought would be most of use, to have literature in all whatever. Xxxxx and I wanted audio cassettes because we had £1,000 given us from some Asian businessmen in Bradford to produce some literature for the Asian community so we were homing in on this, we thought this was excellent rather than leaflets in Urdu that they might not read or appreciate but we were shouted down and they produced this information in Urdu, in the written format and it was piloted and there was lots of things wrong with it._
Other health professionals also recognised and valued the work undertaken by epilepsy nurses:

*I think the key factor is the correct classification of epilepsy syndrome, the correct diagnosis and discussing therapy with the patients, discussing the side effects profile, discussing all issues of epilepsy, talking to the patient what the issues are, career choices, driving or whatever and then emphasising the self importance of drug compliance, what else. These are the points and from the patients point of view correct education, patient education, patients need to know what epilepsy’s all about, its not enough just to lay it to the patient when in a first world country patients are not doctors and you just don't assume that they know, give them literature handouts and whatever. In this regard the nurse specialist is very important because she can expand on issues that you have not had time to discuss in the very short out patient visit.*

Although specialist nurses had a heavy workload they were more accessible than other professionals (often giving out their mobile numbers) especially in times of need when patients needed advice, information or reassurance. The easily approachable friendly disposition of epilepsy nurses was greatly appreciated by patients like 28 year-old Muslim female Asifa:

*It’s been quite a while I haven’t been in touch with him (the nurse), four or five months now, but I used to ring him as well. He came round once. He’s very nice, you know. It was his idea; he actually offered to come round. He said “would you it be better if I came round? Would you feel more comfortable talking about it?” and I think that was after I’d had the baby and I was feeling quite low at that time. That really helped me.*

**SUPPORT GROUPS**

We asked our interviewees if they would consider joining support groups and were surprised at the overall (enthusiastic) response we encountered. For example 32 year-old Muslim male Saleem told us his motivation for attending such a meeting would be to discuss issues with people he felt he had something in common:

*For us, like I was thinking, like I asked you earlier on, you know if there were groups of people, you know, if they could meet every what Wednesday or Tuesday, say once a week, for a bit of coffee, sit around. Yeah, definite (would attend meetings), because I wanna you know the next person suffering from epilepsy I suppose you can talk to them easy, you can talk, you’re not the only one cripple, I’m a cripple as well, you know. You know, some people think in their mind, I used to think that way.*
Respondents who had previously encountered support groups either through their own work or knew of others who had a positive experience were more likely to support the idea:

Ranjeeta (47 year old Sikh female):
That’s something I’ve always felt keenly about, perhaps because as a professional I’ve been part of group work meetings and I just know how helpful they can be even if you just sit there and listen, but don’t actually say anything. You’re actually with people who are in similar situations, going through similar problems and I think they’re very, very useful.

Other respondents, like 19 year-old Sikh male Sachdev and 31 year-old Muslim female Farhana, felt that support groups were necessary not only for the individual with epilepsy but were equally important for their families:

Sachdev:
I think I would, yes (attend group meetings) to see how they’ve (other people with epilepsy) coped with it and how they feel about it. Perhaps, rather than me they (parents) have to go to a meeting if they were persuaded to do so rather than by some family member, perhaps by their GP or someone, if he suggested they go and see what they have to say, that would be helpful.

Farhana:
I think they should have support groups and they should, I think they should I don't know about English families but I know that a lot of Asian families don't know anything about Epilepsy and I think that people you know like families who have somebody Epileptic they should be going on some kind of a course or something to say this is what you do.

Not all respondents were keen on the idea of attending support groups, some respondents like 24 year-old Muslim male Akhtar and 53 year-old Hindu female Sapna had other (personal) reasons for not wanting to attend meetings:

Akhtar:
You are very lucky right because I would not talk to people in a group like I am talking to you, seriously, wouldn’t like to go to a group.

Sapna:
I don't want to tell everybody; even now most of the people I know don’t know about that, I try not to broadcast it for everybody to know I got this.

Other respondents, like 24 year-old Mohammed and 56 year-old Khalida (both Muslims), felt shy or uneasy at revealing their own private thoughts to a group of strangers:
Mohammed:
To other people, like similar to yourself (the interviewer) I could explain it to them, but to mere strangers, I don’t think I could.

Khalida:
Very shy person if it’s a general meeting somewhere if I have to stand up or speak or say something, if I know all the people personally then I might be open, but unknown people I feel nervous.

While those respondents who suffered from frequent seizures, like 28 year-old Muslim female Shanaz, did not want to take any steps that would increase her anxiety and risk more seizures:

Well, you know, I prefer not to talk about my illness because it makes me feel worse, I think it’s better for me to like remain quiet.

Some respondents, like 42 year-old Hindu male Santosh, just did not want to be constantly reminded of their condition:

No, I wouldn’t be interested, no. Because actually, I think, the less you remind them (persons with epilepsy) the better.

Similarly, 47 year-old Muslim male Hamid, who had previously organised and ran support groups, mentioned the importance of group dynamics and the beneficial effects of taking part in a group with a positive attitude:

I wouldn’t mind that because discussing issues, it’s fine, it’s fine but at the same time I, you know, try to be very, very constructive about the whole situation of mine. Sometimes I do have this slight vision of people that they may... - I could be totally wrong here - but they could bring a lot of negative and not everybody tries to be as positive in life. And if you start hearing too much negative I may start taking on board some of the negatives, which may not be beneficial to me. But if it was a group, which was a positive thinking group, then I would be more than happy, more than happy to be involved in discussions.

A number of respondents were open minded about the idea of attending support groups but were faced with practical everyday issues like problems with childcare or transport. Others were more concerned about the language the group would be conducted in or whether the group would be mixed or single gender, as 46 year-old Sikh female Bhupinder pointed out:

I think they (support groups) are a good idea because it does give an opportunity for people to discuss their problems. Well, I don't mind, you know, I don't mind, a mixed group. I know that some women do mind mixed groups, they prefer women only so they can talk about things. For some of our Asians it’s still the culture. Whatever people feel more comfortable with. Some women
can't speak English and so it would be difficult for them to attend a group where just English is spoken.

One respondent, 28 year-old Muslim female Asifa, felt that although attending a support group would not help her to cope any better personally, perhaps she could pass on her knowledge about living with epilepsy and help others:

I don’t really think it would be very helpful for me. It wouldn’t help me cope better, anyway, I don’t think so. It would be nice to try and see what other people, how it affects other people but it wouldn’t help me personally, I don’t think so, but it’s fine, I would like to see what it’s like, yes.

A community GP told us that in his experience patients would only attend a meeting if an incentive were provided:

Talking to them in their own language may have a better effect and maybe temptation to come some sort of snacks or something like that, make them to come or something like this. Yes, yes they've got a conception where they gain something they tend to come, when they don't gain anything they don't, they don't bother. Incentive to provide, we do find similar things like Diabetes Clinic there is a good attendance and Asthma Clinic there's not a good attendance because they don't gain anything.
SUMMARY

- Respondents from our sample raised four main issues regarding the provision of services for South Asians with epilepsy in Bradford: lack of appropriate information and advice, language and communication barriers, interaction with health professionals and the potential merits of attending support groups.

Provision of information and advice

- Lack of information was a common complaint voiced by the majority of respondents, regardless of ethnicity, gender, age, level of education and language skills. The information void started at the point of diagnosis and continued throughout the life course of the condition. Respondents and their families felt overwhelmed at the initial diagnosis of epilepsy and felt they needed more time and further explanations (verbal or written) to help them to come to terms with the condition.

- Those respondents who had been diagnosed at a young age and whose parents could not communicate in English were further disadvantaged. In such cases young people were left in the difficult position of coming to terms with their epilepsy while at the same time educating parents about the condition.

- For young and female respondents information needs increased at times when they were faced with life changing events such as puberty, pregnancy or menopause.

- Most respondents employed alternative means of seeking further information for their condition, such as reading books from public libraries, watching TV programmes even remotely linked to epilepsy, and discussing their condition with medically qualified people either from within their own family or from the wider social network. Only one respondent searched the Internet for information on epilepsy.

- The issue of providing information in the appropriate languages featured prominently amongst respondents. Those who spoke little or no English expressed a need for non-technical information in their own languages, while for others written information in any language was inappropriate, as they were unable to read or felt that a one-to-one verbal communication would be more beneficial.

- However, four respondents mentioned that having too much information about epilepsy could be detrimental to the management of their condition as it could lead to excessive worry and perhaps even bring on seizures.

- Although persons with epilepsy and their carers complained about lack of information, most health professionals from our sample said they did provide explanations and information about epilepsy when requested to do so by patients. This was predominantly delivered through leaflets or short explanations at the time of diagnosis. However, due to the nature of the consultation process and the limited time available, discussions typically centred around immediate medical issues leaving very little or no time for either the patient to seek information or for the doctors to explore the need for and convey specific explanations.
Health professional’s felt that the difficulties encountered by patients in seeking or managing information were not exclusively dependent upon their ethnicity but directly linked to their level of education. Educated patients were generally more inquisitive about their condition and also more likely to know how to seek information from other sources like the Internet.

A number of respondents felt that epilepsy was a marginalized condition in comparison to more common high profile illnesses, such as cancer or heart disease. The problems around obtaining specific information through informal channels, such as TV and radio programmes, were partly attributed to the non-popularity of epilepsy within the mainstream media. Health professionals also felt that epilepsy was a marginalized condition and did not have the recognition or priority that other conditions commanded.

### Language and communication barriers

- Language barriers were identified as a major problem by health professionals caring for non-English speaking South Asians. One-third of the respondents with epilepsy were not fluent in spoken English. It was felt that communication was hindered by the fact that there was no common language to ask questions and discuss their concerns. For some health professionals, language barriers prevented them from providing non-English speaking patients with a fundamental understanding of their condition.

- There was very limited use of official interpreters in consultations. In the majority of cases, persons with epilepsy themselves expressed a preference for their own family members to interpret, as they felt that the presence of close relatives provided them with a source of emotional support. It was usually the spouse, siblings, children or members of the extended family who took on this role.

- According to respondents using family members as interpreters offered both advantages and disadvantages. Some people with epilepsy felt that family members would be more able to translate information accurately and more sensitively to them, using vocabulary that they would understand. Others, however, felt embarrassed at the idea of discussing personal problems with health professionals having their spouses, young children or members of the extended family as interpreters.

- Not all the carers interviewed were happy about interpreting. Some family members had found the situation highly emotional and had difficulty digesting the explanations they were being given about their relative’s condition while continuously interpreting this information to them at the same time. Some also admitted that they were unable to translate the information they were given as accurately and in as much depth as was needed. It was particularly difficult to translate medical terminology with which carers were unfamiliar.

- Health professionals shared concerns about family members undertaking the role of interpreters. A commonly held view was that family members did not undertake the responsibilities of an interpreter in a professional manner. Health professionals felt that in their role as interpreter carers did not necessarily speak on behalf of the patient.
Rather, they were more likely to use the opportunity to present their own concerns and views. This made it difficult to assess the impact of the epilepsy upon patients.

- Health professionals also felt that the gender and age of family members acting as interpreters could mean significant difficulties in communication, particularly in the discussion of personal issues such as contraception, pregnancy or impotence. Also they expressed concerns about confidentiality issues when relatives came along into consultations.

- Health professionals believed that a more effective way of communicating would be for interpreters with more clinical knowledge of epilepsy to be present alongside family members. Some felt that interpreters played a more objective role than family members and were in a better position to help provide more accurate information about the patient’s condition. It was also noted that patients tended to ask more questions when interpreters were used.

- However, health professionals said the availability of interpreters was problematic as they had been booked well in advance and were difficult to access especially when patients who may be suffering a crisis turned up at short notice. The use of community interpreters as an alternative was not seen as ideal due to issues of confidentiality.

**Interaction with health professionals**

- Twenty-five people with epilepsy from the sample were registered with South Asian community GPs. Nineteen of them expressed general dissatisfaction with their GPs. Their main complaints were: neglect of the duty of care (that was seen as an basic right), lack of knowledge about all aspects of epilepsy, lack of time to listen to patients’ concerns, and lack of ability to deal with sensitive issues. However, some of these complaints were not confined to GPs from any particular ethnic group.

- Most respondents expressed satisfaction with their specialist GPs and consultants. They particularly stressed the positive relationship they had with their specialist epilepsy nurses who they felt were caring and helped to reassure them in difficult times.

- Epilepsy nurses showed an impressive ability in gaining the confidence of patients. They were seen to provide an essential link between health professionals (GPs and consultants) and patients by fostering understanding of epilepsy through regular contact and provision of information. The holistic approach undertaken by specialist epilepsy nurses helped to unlock patients and carers views that would be almost impossible to reach by other health professionals.

- Although specialist nurses had a heavy workload they were more accessible than other professionals (often giving out their mobile numbers) especially in times of need when patients needed advice, information or reassurance.

- Epilepsy nurses to a certain degree transcended barriers of language by reaching out to South Asian communities in a number of ways. Home visits were regularly undertaken, small-scale research projects at the local level to ascertain user needs as
well as organisation of community events in collaboration with local people/service providers all helped to further understanding of epilepsy. However much the specialist nurses had achieved with their work with South Asians they too felt that ultimately there was a need for an Asian liaison worker who could speak the language and had a deeper understanding of the culture.

**Attending support groups**

- At the time of the study there was no support groups available for South Asian people with epilepsy in Bradford.

- A high number of respondents were open minded about the idea of attending support groups but were faced with practical everyday issues like problems with 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.

- Other respondents felt that support groups were necessary not only for the individual with epilepsy but were equally important for their families.

- However, not all respondents were keen on the idea of attending support groups. Those who suffered from frequent seizures did not want to take any steps that would increase their anxiety and risk more seizures. Others just did not want to be constantly reminded of their condition. And some felt shy or uneasy at revealing their own private thoughts to a group of strangers.

- One South Asian community GP believed that people with epilepsy from the South Asian communities would be more willing to attend support group meetings if some refreshments and transport were made available.
CONCLUSIONS AND RECOMMENDATIONS

This report 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. 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.

There is little evidence within our study to support the widespread assumption that epilepsy services in Bradford might be under-utilised by South Asians largely due to cultural barriers. On the contrary, our findings reveal that the impact of being diagnosed with epilepsy can be exacerbated by structural impediments to accessing information and culturally appropriate services.

The richness of our findings owes much to the reflexive and inclusive methods we employed. The multi-disciplinary nature of the advisory groups provided a range of perspectives on the study questions; our respective contacts and skills facilitated the fieldwork process. Our approach facilitated gathering data from multiple sources – people with epilepsy, carers, community members and health professionals. Our methods of data collection enabled us to present thematic analysis without losing sight of the complexity of individual experiences, the importance of biographies and social interactions (between persons with epilepsy and carers; between people with epilepsy, their families and health professionals) and the role of professional cultures and services contexts.

Our findings show both similarities and differences between participants’ experiences, where social class, gender, age or other aspects of personal biography can be as important as religion, culture or country of origin. Our findings demonstrate the connectedness of human experience across, and diversity within ethnic, religious and social groups.
There is now a need finally to provide a concise outline of key conclusions and recommendations arising out of these various sections but without seeking to provide detailed justification at this point.

Models/conceptions of epilepsy

One important finding to emerge from the study was that there is no one particular model of understanding epilepsy within any of the groups - Hindus, Muslims and Sikhs - that participated in the research. Variations can be observed more within each group rather than between groups, pointing to the significance of individual features of gender, age, country of origin and level of education. This reinforces Nazroo’s (2001) argument that most epidemiological data relies on a crude approach to allocating people to ethnic groups – for example by country of birth or by broad geographic area, e.g. South Asians, and that there is a tendency to assume shared cultural and genetic factors within these groups. This not only produces data that are not useful but policy responses that are crude.

Fatalism

Muslims were more likely to regard epilepsy in more fatalistic terms whereas Sikhs and Hindus who were more likely to relate it to sins committed in a past life. A common belief among health professionals is that religious fatalism leads to passivity and resignation. Individuals who perceive that their health is under the control of powerful others may construct an external health locus of control with detrimental effects on health and behaviours through guilt and resignation (Alder, 1995). However, this was not borne out by our findings, as the fatalistic attitudes adopted particularly by Muslims did not prevent them from taking active steps to improve their condition. Although religious beliefs influenced 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 (Cf. Bywaters et al, 2003; Ahmad et al, 2000).
Compliance with AEDs and use of traditional South Asian therapies

Compliance with Western medication was high. The main reason for stopping or reducing medication was fear of side-effects, for example, harm to the foetus during pregnancy.

Optimum seizure control was the main goal for people with epilepsy and those who experienced seizures more often were more likely to turn to traditional South Asian therapies, particularly if Western medication had proved ineffective in reducing seizures. Most respondents had used both treatments simultaneously.

Alternative belief systems only partially explained the use of traditional therapies: opportunity and access were also important factors. In Britain, medical services are easily accessible and free at the point of delivery, whereas traditional therapists usually charge for their services or expect a donation. In the Indian subcontinent especially in rural areas, medical services are scarce and expensive compared with traditional therapists who are easily accessible and affordable.

Similarities/generic issues

More striking than the differences were the similarities in experience between the different groups. Many of our findings are generic to all groups with epilepsy, regardless of ethnicity or religion. This research has shown that many of the issues of concern raised by respondents reiterated findings of other studies (Temkin, 1945; Scambler and Hopkins, 1977; 1988; Aziz et al, 1997; Chung et al, 1995; Scambler, 1984). Issues highlighted included 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, which 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.
Respondents raised concerns that attitudes towards epilepsy in particular and disability in general were generally more negative in South Asian communities particularly among older people and those who have been brought up and spent most time in the Indian sub-continent.

Notably many respondents were at great pains to disassociate themselves from the label of disability and did not perceive themselves to be disabled. Conceptions of disability were found to be much less broad and inclusive than official definitions, under the Disability Discrimination Act (DDA), for example. Disability was seen to refer to people with visible physical impairments and, for this reason, people with epilepsy felt able to exclude themselves from the category of disabled people.

**Service issues**

The study found little evidence of the double oppression or double jeopardy of the combined effects of racism and disability discussed by other commentators (Stewart, 1984; Vernon, 1997).

However, people with poor English did encounter additional problems in accessing appropriate services and information. For these people, inadequate language support was a major structural weakness of service provision, which not only impeded access to and utilisation of services but also impacted on their understanding of their condition and their approaches to management and control. They were further disadvantaged by cultural differences and lack of familiarity with service structures (Mir and Tovey, 2003).

One-third of the respondents with epilepsy were not fluent in spoken English. There was very limited use of official interpreters in consultations. Usually family members took on this role. However, some people felt embarrassed at the idea of discussing personal problems through family members. Not all the carers interviewed were happy about interpreting; they admitted having difficulty in translating medical terminology. Health professionals expressed concerns about impartiality and confidentiality issues with such arrangements. This reflects findings in a number of studies (Rhodes and Nocon, 2000).
Other issues relating to service provision included lack of appropriate information and advice, interaction with health professionals, and the potential merits of attending support groups.

**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 (Rhodes and Nocon, 2000).

Lack of appropriate information and advice was not just an issue of poor English competence as it was also mentioned by fluent English speakers. Therefore, there is a need to reassess the whole process of how information is delivered, who is providing the information and where this information is provided seem to be as important as the message itself (Bhakta et al., 2000).

Communication is complex processes in which not only language but also beliefs, values, and cultural/ethnic background, gender, age and social class all play a part. 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 (Ahmad et al., 2000).

**Interaction with health professionals**

Respondents highlighted the central role played by specialist epilepsy nurses (SENs) among their most valued qualities were: ability to gain the confidence of people with epilepsy and converse on a more personal and informal level; facilitating the communication process; 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 characteristics and skills of SENs could be adopted by/incorporated into approaches of other service providers.
The high levels of dissatisfaction with primary care reported, irrespective of ethnicity of GP, should be a cause of concern, given its gate-keeping role in terms of access to secondary provision and the fact that many people receive the bulk, if not all, their epilepsy care through their GP. By contrast respondents expressed satisfaction with secondary care services.

**Support groups**

A number of respondents expressed the need for a support group for people with epilepsy and their carers. However past attempts to set up such groups in Bradford have been unsustainable. Support groups in other areas have proved more likely to be successful if they have had some form of additional outside input, e.g. help with premises, facilitation and funding (Lindsay, 1997; Wilson, 1994). It is unrealistic to expect groups to survive on the hard work and enthusiasm of one or two individuals and, perhaps, not surprising that previous attempts to set up groups have been short-lived.

**Recommendations**

- There should be an awareness of the belief systems of South Asians and a better understanding of the types of traditional South Asian treatments in common use.

- An information resource pack should be distributed at the time of diagnosis containing audio and videotapes, clearly written information on all aspects of epilepsy including treatment and side effects, and outlining further sources of support, information and advice.

- Information on epilepsy should take into account different South Asian languages, religions, cultures and lifestyles.

- Interpreters with more clinical knowledge of epilepsy should be present at consultations.

- Both people with epilepsy and health professionals identified the need for a South Asian liaison worker who can speak the language and has a deeper understanding of the culture.
- South Asians and Epilepsy

- Support groups for people with epilepsy and their carers should be set up taking into account language, gender, location and childcare facilities.

- Community education is needed to help de-stigmatise epilepsy within South Asian populations.

- Information regarding employment rights legislated in the Disability Discrimination Act should be made available in South Asian languages.

- Information for health professionals outlining the main alternative South Asian therapies should be made available.

- Establishing an Epilepsy Register would equip local health providers with a valuable tool for monitoring access and equity of services for patients from minority ethnic groups.
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APPENDIX A – LIST OF STEERING GROUP MEMBERS

Members of the **Epilepsy Project Steering Group** were:

Ms Veena Bahl (Advisor on Ethnic Minority Health, NHS Equality Strategy Unit, Dept of Health)

Dr Nigel Hakin (Consultant Neurologist, Bradford Epilepsy Service)

Dr Mark Busby (Consultant Neurologist, Bradford Hospitals NHS Trust)

Professor Ann Jacoby (University of Liverpool and Epilepsy Action)

Mr Dilshad Khan (Director of Equality and Diversity, Bradford Hospitals NHS Trust)

Dr Ingram Wright (University of Sheffield and Epilepsy Action)

Members of the **Epilepsy Research Group** were:

John Wright (Director of Research and Development, Bradford Hospitals NHS Trust)

Professor Neil Small (Professor of Community and Primary Care, University of Bradford)

Dr Penny Rhodes (Research Fellow, Bradford Hospitals NHS Trust)
APPENDIX B

Breakdown of South Asians with epilepsy in Bradford

Muslim M 64
Muslim F 45
Sikh M 12
Sikh F 5
Hindu M 8
Hindu F 5

No of Patients
APPENDIX C – INVITATION LETTER TO PATIENTS

23rd Jan 2002

Mr ............
Bradford

Dear Mr ........

I would like to invite you to take part in a research project about people with epilepsy. The neurologists at your local hospital are undertaking this project with researchers from the Bradford Royal Infirmary. The aim of this project is to find out about the needs and health beliefs of people, like yourself, who have epilepsy or who have had epilepsy in the past; we are also looking at how family members can better support people with epilepsy. The enclosed information sheet tells you more about our work.

I am writing to ask whether you would be willing to take part in this research. It will help us to plan better local and national health services for people with epilepsy. It will also give you the chance to express your views about the kind of advice/assistance that you have received from doctors and family members. This will help to identify what kind of information and support is most useful for people like you.

If you do decide to take part in this study, you can be assured that whatever you say will be treated in strictest confidence. Nothing you say will be passed on to anyone else. If you decide that you do not wish to take part in the research, your treatment will not be affected in any way.

I would be grateful if you could complete the attached sheet and return it in the enclosed prepaid envelope as soon as possible.

If I do not hear from you, Hanif Ismail (Research Fellow) will be in touch with you to find out whether or not you will take part. In the meantime if you have any questions about the research, do not hesitate to contact Hanif at the Bradford Royal Infirmary on 01274 364474.

Thank you for your help.

Yours sincerely

DR JOHN WRIGHT
Associate Medical Director/
Consultant in Clinical Epidemiology and Public Health
EPILEPSY RESEARCH

Please tick appropriate box(es)

I would like to take part in this study

I would like to find out more about this study

Preferred day/time for a researcher to contact you

I do not wish to take part in this study

Name: Mr
Address: Bradford

Tel No: 

(Please complete this form and return in the stamped addressed envelope)
What’s it all about?
We are inviting you to take part in a research study, which is looking at attitudes and beliefs around epilepsy: how epilepsy affects your life and what you think about the services you receive. This information will help to identify the needs of people who have epilepsy and ways in which services can be improved. We need to talk to people with epilepsy and their families. As part of this study we are arranging to speak to a number of people in Bradford who have epilepsy.

What will be involved?
We would like to talk to you about your experience as a person with epilepsy. We would like to ask you about your understanding of the disease and your views about the role of medicines and the ways epilepsy affects your life. We would also like to know about the kind of information given to you by those working in the NHS and the ways in which your family is helping you. More generally, we are interested in your ideas about how to improve services. As part of our work, we would also like to talk to other family members. We will ask them similar questions to those we ask you. We will, however, not contact any family member without first asking you. If you decide that you do not wish to take part in the research, you can be assured that your treatment, now or in the future, will not be affected in any way.

When and where will the interviews take place?
We would like to talk to you in your home, or any other place you choose, at a time that suits you. You can talk to a man or a woman, in a language of your choice. Your interview will last about 45 minutes. If you agree, the interview will be tape-recorded. This will help us remember exactly what you say. Only we will listen to the tape and it will be destroyed later. You may pull out at any time or choose not to answer certain questions.

Will anyone else find out what I say?
What you say will not be passed on to anyone else. Your name and the information you give us will remain confidential. We will not tell any other family member anything you say to us. Nor will we discuss your views with your GP or any other health professionals with whom you have had contact. Our report will not use any names of people we have interviewed.

Who are we?
Dr John Wright (Consultant in Public Health) and Hanif Ismail (Research Fellow) are carrying out the study. We work for the Bradford Hospitals NHS Trust. Epilepsy Action, a major national charity, is funding this research and will develop the information and other
materials for people with epilepsy and their families. If you would like to know more you can contact Hanif Ismail on 01274 382413.

You can also write to him at Bradford Royal Infirmary, Duckworth Lane, Bradford, BD9 6RJ or email hanif.ismail@bradfordhospitals.nhs.uk
APPENDIX E – TOPIC GUIDE

INTRODUCTION
Introduce yourself, provide information about research aims
Remind of importance of their role, confidentiality
Explain structure/duration of interview
Gain consent to use tape recorder
Establish ground rules

PERSONAL INFORMATION
I’d just like to start off by asking you a bit about yourself.

[Prompt, if needed]:
  Marital status
  Occupation/education level/type of housing/access to transport
  Household composition - number of children-education/employment details/others in household
  Family situation-relatives within the same city and within UK (physical and emotional proximity)
  Hobbies/interests
  Ethnicity, religion
  Languages spoken/read
  Length of time living in this country

UNDERSTANDING OF EPILEPSY
I’d like to start off by asking you a few questions about your condition.

- What do you think is wrong with you?
- What do you think caused your epilepsy?
  {Probe}
    Genetic Other
    - How long have you had epilepsy/when was it diagnosed?
    - Tell me the story of you epilepsy/before it was diagnosed?
    - Who diagnosed you? What did they say?
    - How did/how has being told you have epilepsy changed your life/identity?
- Have you had/do you have any other health problems?
  {Probe}
    Weight problems
    Diabetes
    Heart condition
    Other conditions that make it hard to get around limit mobility/ create dependence/necessitate special diet
High blood pressure
Breathing problems
Mental health problems
Importance compared to epilepsy

- Do you know anybody else with a similar condition?
  [Probe]
  Who?
  How similar/different from own experience?
  Known before/after own condition?

- Does anyone in your family have epilepsy?

- Do you/people see epilepsy as a physical/mental disease?
- How did being told you had epilepsy change your life/identity?

IMPACT OF EPILEPSY ON LIFESTYLE AND RELATIONSHIPS
Now I want to talk to you about how you are coping with your condition and how it has affected your life.

- Do your family/friends ever treat you differently because of your epilepsy?

- What do other people in your family/community think?
  [Probe]
  Stigma
  Ignorance
  Pity
  Fear
  Sympathy
  Support

  Have you told anyone outside your family about your epilepsy?
  IF ‘Yes’, why, who, under what circumstances etc?

- Does epilepsy prevent you from doing anything? [Probe]
  Socialising
  Domestic responsibilities
  Hobbies
  Religious activities
  Driving
  Other

  If working? Do people at work know you have epilepsy?
  If yes what is their reaction?
  If no- what would happen if they knew?
• Do you think epilepsy is a barrier to:
[Probe]
  Making friends
  Getting a job
  Following your chosen career
  Finding a marriage partner

• Do you ever feel down/depressed because of epilepsy?

• Are there any times when you feel low?
[Probe]
  When?
  Why?
  How often?
  Do you ever talk to people about how you feel?

• If you are feeling low, what makes things better?
[Probe]
  Things you can do
  Things others can do

• Is there anything your family say or do (about epilepsy) that upsets you?
[Probe]
  Over protectiveness
  Monitoring
  Not supporting you
  Undue criticism
  Other

• Do you talk about your illness with other family members?
[Probe]
  Perceived causes

• Do you talk about it with other people?
  Why/why not?

• What would make it easy/easier for you to cope with your condition?
[Probe]
  More family support
  Religion
  Material resources
  Health professionals

• Why would this make it easier?

• Does your religion say anything about epilepsy/ illness in general?
Why do you think this happened to you?
[Probe]
Test of faith
Punishment

UNDERSTANDING OF SEIZURES

• Can you remember how you felt when you had your first seizure?
[Probe]
If Yes
What was your reaction the first time it happened?
How did you feel?
What did your family do?
Did you call an ambulance/take ………to the GP/go to the peer/hakim?

• How often do you have seizures now?

• Have they got worse/better/no change?

• What do you/your family do when seizures happen now?

• Do you think anything in particular can trigger a seizure?
[Probe]
Stress
Tiredness
Feeling nervous
Anything else?

• Are you frightened/concerned about having a seizure outside the house?
[Probe]
Concerned other people might find out
Concerned that you may injure yourself

UNDERSTANDING OF TREATMENT/SERVICE PROVISION
Now I am going to talk to you about your experience of health services and the kind of treatment that you may have been given

• Do you/have you needed anyone to interpret for you?
[Probe]
Who?
How often?
Why that person?
When you visit the GP/Hospital or both?

• Have you ever used an official interpreter?
[Probe]
Any problems?
- South Asians and Epilepsy

- Have you ever had to manage without an interpreter?

- How is your health now?
  [If person has other illnesses, then explore their feelings towards these in relation to concerns about epilepsy]

- Which medicines are you taking for your epilepsy?
  [Probe]
  Compliance (especially changes in dosage/any breaks)
  Perceived benefits
  Side effects

- Would you stop taking medication if your seizures stopped completely?

- What do you think would happen if you stopped taking your medication?

- Do you think there is a cure for epilepsy?

- Who would you contact if you experienced any problems now?
  [Probe]
  GP
  Specialist nurse
  Consultant
  Why?

- Have you sought any alternative/traditional therapies?
  [Probe]
  Hakim
  Acupuncturist
  Peer (religious)
  Why/why not?
  Are there any advantages/disadvantages in using different approaches?

- Were you advised to make changes to your life?
  [Probe]
  By whom?

- What kind of advice have you been given?
  [Probe]
  Exercise
  Diet
  Relaxation
  Sex
  Support groups
  Verbal/written/audio/combination
  One off sessions/series of meetings
  Level of agreement/perceived usefulness
Were you happy with the way in which you were provided with this information? [Probe]

Appropriateness of advice/person giving advice
Use of interpreters
Understanding of terms used
Coverage of subjects
Appropriateness to own needs/lifestyles

Are there any other subjects about which you needed more information? [Probe]

Which?
Why were these subjects not discussed?

Do you have any suggestions as to how we could provide information to people with epilepsy? [Probe]

Radio/TV?

Would you attend group meetings to discuss issues around epilepsy?

LOOKING AHEAD
Finally, I would like to ask briefly about your future plans

Do you feel you can get better/achieve better control?

Which things do you think will help you to get better? [Probe]

Compliance with medication
Improved health care services
Family support
Better living circumstances
Prayer

What are your plans for the future?

Are there any questions you thought I would ask which I have not asked?

Is there anything else you would like me to know?

[Thank interviewee and ask about the possibility of interviewing a family member]