



Supporting people with epilepsy

Epilepsy Connections

Epilepsy, Culture and Religion:

Attitudes in Black Minority Ethnic Groups in Glasgow

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Experiences, Cultural Attitudes and Religious Beliefs on Epilepsy in BME communities in Glasgow

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Summary

The overarching purpose of this study was to explore ways of providing information and support to people with epilepsy and their families from the Black and Ethnic Minority (BME) communities in a culturally and religiously acceptable way. Members of BME backgrounds were underrepresented in use of support services offered at Epilepsy Connections. To investigate this, three main themes were explored in this soft research study modelled from the Bradford Study "South Asians and Epilepsy- health experiences, needs and beliefs in communities in Bradford" (5). The results from four focus groups and forty-two questionnaires completed by participants from the Pakistani, Indian, Chinese and African community groups in Glasgow are presented here.

A high level of knowledge and experiences of epilepsy existed within the different communities, particularly in the Pakistani and Indian groups. Epilepsy was not regarded as an infectious condition although people with epilepsy had had negative experiences suggesting the contrary. Although awareness was high in the Pakistani group, this group also had the most negative perceptions of epilepsy. All lifestyle factors were affected by epilepsy but most often problematic was the subject of marriage. Religious beliefs and supernatural associations with epilepsy emerged from the study.

These results suggest that volunteer befriending services that have an understanding of the individual's support needs with respect to their culture and religion and bilingual support workers may be the key to supporting people with epilepsy on a one to one basis. However, with developing confidence and independence, participation in support groups with bilingual workers may further increase confidence and reduce isolation. Furthering community education and raising awareness may bring about reduction of stigma and overcoming supernatural associations and other misconceptions about epilepsy.

1. Background

Epilepsy Connections was set up in April 2000 to provide information and support services to people living with epilepsy in the Greater Glasgow Health Board area.

Epilepsy Connections' overarching aim was to "promote full social inclusion of people living with epilepsy" and this encompassed BME communities.

Figures from the 2001 census analysis showed that over 4.5% (39,318 people) of the population living within the Greater Glasgow Health Board area were from BME communities (1) Ethnic Group Profile from the 2001 Census NHS Greater Glasgow Area, Greater Glasgow NHS Board (GGNHSB) Information Service. The largest community were Pakistani (2.1% of the Greater Glasgow population or 17,964 people) and the second largest were Chinese (0.6% or 4,912 people). Since April 2000 however, 11,115 asylum seekers have been dispersed to Glasgow (2001 census group data analysis data, Glasgow City Council, 2003), who have not all been included in the census therefore the BME population distribution may have changed significantly.

The impetus for this piece of work arose from the following observations:

- It became evident that people from BME communities had not accessed Epilepsy Connections' services since current service users did not reflect the ethnic make-up of the GGNHSB population
- After becoming aware of Glasgow's diverse population, Epilepsy Connections wished to offer their services to **all** people living with epilepsy regardless of race, colour or ethnic origin
- It is well documented that inequalities in health exist within the BME community. People from the BME community do not have the same access/uptake to health services and health information as the indigenous population
- The Race Relations (Amendment) Act 2000 places a legal obligation on all public bodies to provide services (including information) in a way that is fair and accessible to all.

2. Aim

The overall aim of the study was to identify the attitudes and beliefs towards epilepsy and to incorporate this into existing services to address the information and support needs of people with epilepsy in BME communities in Glasgow.

3. Objectives

This study hoped to:

- Identify the different BME Groups in Glasgow
- Establish links with different BME community organisations in Glasgow
- Identify and address epilepsy needs within a range of BME groups
- Identify cultural and religious attitudes towards epilepsy
- To improve services to people with epilepsy, their family and friends from BME communities
- To find out what kind of information and support BME community needs regarding epilepsy
- To provide services that take into account people's cultural and religious beliefs
- To identify which routes are best for the BME community to access information on epilepsy.

4. Methodology

The 2001 Census for Scotland was used to collate information on the diversity of the BME communities in Glasgow.

A BME directory (Scottish Ethnic Minorities Directory, 2003), personal contacts and links, and a database compiled at Epilepsy Connections were used to identify different BME community organisations in Glasgow. A letter (Appendix 1) inviting organisations to participate in this research was sent to a total of 11 community organisations (Appendix 2). Nine of these organisations agreed to participate and nominated certain groups attending their centres, for either focus group research, or one to one interviews with the use of a questionnaire. Some of the organisations also requested presentations to raise awareness of epilepsy.

Four focus groups exploring the cultural attitudes and religious beliefs towards epilepsy were conducted. These were made up of:

- Seven Mandarin speaking Chinese women aged between 30 and 41 years who attended the Mother and Toddler group held at the Chinese Healthy Living Centre (CHLC)
- Eight Mandarin speaking Chinese women (who were well educated) and volunteered to participate in the focus group held at Epilepsy Connections' premises.
- Six Pakistani Muslim women who also volunteered to participate in the study at Epilepsy Connections. All were married, five of whom had children and four of whom had grandchildren.
- Six women, mostly from Africa, three from West Africa, 1 from Sierra Leone, 1 of Indian origin but who had lived in Africa and 1 from Russia. This focus group was held at Meridian (BME Women's Resource Centre) where the women usually attended for sewing classes or English language classes.

Appendix 3 contains the questioning route for the focus groups.

This study also used a semi-structured questionnaire where focus group work was not appropriate impractical or people were inhibited about speaking about their personal experiences on epilepsy. This worked particularly well with elderly people, people with epilepsy, relatives and carers of people with epilepsy who were otherwise reluctant to speak about their experiences in a group setting. The questionnaire can be found in Appendix 4.

5. Analysis of Focus Groups

5.1. Knowledge and experience of epilepsy

All participants (27 people) had heard of the condition of epilepsy across the three ethnic groups from each focus group study. Some people had more understanding of the condition than others and their knowledge of epilepsy varied considerably. e.g. one Pakistani woman was able to describe what happened in the brain during a seizure.

“Is it a mental block? The brain is not accepting what you want to do. All the cells in the brain stop working. Is it loss of consciousness? It’s all to do with the brain.”

A nurse from the Chinese volunteers group and a first aid worker from the African and others group could also describe epilepsy in more detail.

“...I am a nurse. Seizures are a result of over-activity of the brain- it’s not a bad evil thing”

One Chinese woman from the Mother and Toddler group perceived Epilepsy as

“ this people look like mental not right”

Another woman from the same group described a seizure as

“ they will fall down and sometime they are frothing at the mouth and jerking”

Eight people (West African, Pakistani and Chinese) related interesting anecdotes about seizures they had witnessed. Some related emotive personal experiences and how their lives had been affected and others described ways in which the individual having the seizure was given aid.

The word “fit” was used most often to describe a seizure. Tonic-clonic seizures were witnessed frequently and remembered vividly. These were commonly associated with epilepsy.

“ ...I only saw a guy in Pakistan. People said he had epilepsy (mirgee ka daura). He was shaky and unconscious, and there was this froth coming out of his mouth. Somebody took off their shoe and made him smell it, and he was ok after that. I have no idea what else happened”

Two different types of seizures were identified. One Chinese woman related:

“....This person was frothing at the mouth and her arms and legs were jerking....”

Additionally, another Chinese lady remarked on this:

“ This type of fit is violent. I have seen fits where the person only loses consciousness, just fell down- no jerking”

People participating in the focus groups were unable to identify the causes of epilepsy. Three people (1 Pakistani and 2 Chinese) thought it was an inherited condition. None of the participants believed that epilepsy was infectious. In fact, participants vehemently denied this.

5.2 Cultural and Religious Attitudes

5.2.1. Culture

To explore attitudes towards epilepsy, a series of pertinent questions were asked e.g. why is epilepsy not regarded the same as other health conditions like blood pressure and heart disease

“Epilepsy is a condition. It’s not within your control. You might have a disabled child or cancer which is not in your control. English people don’t mind about this, but Chinese people think this is important.”

Attitudes towards people with epilepsy were explored to find out whether they are treated differently by their families and friends and others in their communities.

Here different groups were divided in their opinions. The African and Pakistani focus groups were relatively far more negative. They felt that there was more of a stigma attached to people with epilepsy and attitudes towards disability were on the whole quite negative. People said they felt frightened and uncomfortable although attitudes changed after education and first aid training was received.

“...oh yes, without a doubt, people look down on people with epilepsy”

“people are frightened. They don’t want to take them out because of the unpredictability of seizures- they could have a seizure anywhere at any time”

The Pakistani focus group comparatively felt there was more of a prejudice towards people with a disability.

“...if you see someone in a wheelchair, you always talk to the carer- you forget there is a **person** in the wheelchair. They feel so happy when a person speaks to them. I know. I am a carer for my husband. When I take my husband to my mum’s, people talk to me not to him. I used to say ‘talk to him’ so that he didn’t feel like a vegetable...so that he felt that he exists”

When asked about China’s ‘one child’ policy which stipulates that couples living in the cities should only have one child, one participant’s response was a political rather than cultural attitude.

“.....if child has epilepsy or is disabled, then government allows you to have another child”

One Chinese woman from the Mother and Toddler group said

“...people with epilepsy don’t want to discuss with other people about themselves, and don’t want to tell other people. They are usually isolated”

“People with epilepsy are very sensitive. Your meddling might upset them, and they might misunderstand your good intentions”

“.....if someone had epilepsy you would be careful of the way you spoke to them. You would be more sensitive towards them..”

In the African and Others group participants were very supportive. Again, they had very empathic attitudes even though they thought that cultural attitudes were not sympathetic ‘back home’.

“I did training” (in UK) “... Back home (West Africa) people believe epilepsy is infectious.they just leave the person, and they are frightened to go closer to the person. They think that if the fluid from their mouth touches you, you get infected. You wouldn't go close to them. Now I feel different”

This group showed mixed attitudes towards epilepsy and some other comments to emerge were:

“...people with epilepsy just like us...Sometimes they are more clever than us, but the difference is they have seizures”

“...people in Russia feel ok about people with epilepsy. The majority of people are ok about it. You can meet people who don't like disability...”

When questioned about epilepsy being infectious most members of each of the four groups said no. Some people reacted strongly and altruistically. Generally, everybody agreed that epilepsy was not infectious but it could be inherited.

“ No, God forbid, Allah mafee (may God have mercy), I wish our people would change their thinking. Even if somebody had leprosy, I would help that person.....maybe tomorrow I may need the help.....”

“ No, I didn't think I could get it. ...Everyone was in the church and everyone was feeling quite spiritual. God obligates you. He gives you the strength to do it. You don't mind if it's infectious or not. I needed to help.....I did feel frightened though”

Participants were asked what impact epilepsy had on lifestyle. How did epilepsy affect domestic duties, religious activities, work, making friends, and marriage.

The majority of participants felt that life was affected quite dramatically. One Pakistani woman connected the frequency of seizures and the seizure pattern to the quality of life. Another Pakistani woman thought seizures might be triggered by domestic circumstances, stresses of life, financial pressures. Another person noted that depression was more frequent in 'ill people' and people with epilepsy too.

“it depends on their pattern. They have a seizure and then it takes a few days to get back to normal, and then they are 'full of beans'. If they have frequent seizures, then life expenditure and social life will be very hard.”

One Chinese woman related an unfortunate incident where a baby was burned because a mother had had a seizure whilst she was cooking. This group agreed that people with epilepsy needed more education about avoiding dangers and considering safety issues.

All groups had very many ideas about marriage. All groups felt that it was more difficult to get married if you had epilepsy. There was an element inbuilt into all three cultures (Pakistani, African and Indian) that the family was 'checked out' before marriage and if it was found out that the future spouse had epilepsy then the marriage proposal would be ended or an excuse found not to go through with the marriage.

It was asked whether it would be beneficial or detrimental to disclose epilepsy prior to marriage. Mixed opinions were expressed. In Muslim culture it is the normal practice to marry within the family. One woman was of the opinion that the future spouse should be told

“...if you marry within the family, it's ok because you would know your cousin well. You would know what he would want. You would want to be with him and accept his epilepsy. If you marry outside the family, the girl might not co-operate because she didn't know. If she knows beforehand she would build it in into her relationship.”

In the African group:

“I'll give you an example of a girl who had epilepsy back home (in Africa). Somebody proposed to marry her, and people at her college told the fiancé that she had epilepsy. When the girl opened up to the man about it he broke off the relationship”

“These days things are changing. Before in my country in Africa if you were going to marry, the two families would secretly investigate the other family to find out if there was any sickness or if there had been anyone who had gone to prison. They would want to know all that before the daughter was given into that family. It's not like here where you marry the person and **then** you meet the family (*all laugh*). So if you refuse them and tell them that this is the problem then they will never support you.”

When asked why it was so difficult to marry people with epilepsy, the response was that there was the chance that your children might inherit the condition and affect the future line of their family.

The Chinese group felt that marriage, education and work were heavily influenced by having epilepsy.

“Marriage is different. Employment is not a big problem. Why? Because if you marry a person with epilepsy you carry the burden for the rest of your life. That's why people don't tell others that they have epilepsy”

“Epilepsy in my eyes is not normal. People are different. People look at you with a different attitude. Its very difficult for people with epilepsy to get married because of the inheritance factor for children.....people don't want this passed onto their children”

The stigma of epilepsy was explored by asking why this was not discussed as readily as other conditions such as coronary heart disease, blood pressure, diabetes. Why did people not want to disclose their epilepsy?

Again, participants had mixed attitudes. Some people from the Chinese community thought that epilepsy wasn't a condition to hide. It was a condition like any other, however within the same group some people felt that it was a mental illness, which couldn't be cured like 'cancer'.

“I don't look down on people with epilepsy. I look down on a woman who sells her body and develops a sexual disease.... You can't control epilepsy”

Pakistani and Indian people felt it was an inherited weakness in the family line and this was an attitude to disability in general and would be passed down through the generations.

5.2.2. Religion

Participants mainly followed three religions in the focus groups. These were Buddhism, Islam and Christianity. No others were mentioned. Christians and Muslims strongly believed prayers and faith in God could heal people with epilepsy. Any illness, not just epilepsy was attributed to the will of God who people felt was ultimately in control. One Christian woman firmly believed that seizures could be controlled without medication if the person's faith was strong enough. Both groups felt that if the religious faith was strong enough these 'strong' people would be more likely to help others that were ill because of their firm belief.

“ only those who have sympathy or have faith in Allah will support ill people”

“ if faith is big, seizures can be controlled without medicine”

“ we believe strongly that prayers make you well. I thought what can I do...The answer was to make prayer. I believe strongly in the power of prayer”

These groups commonly mentioned superstitions associated with epilepsy. Possessions by demons, evil spirits, punishment for sins committed in past lives (Buddhist), black magic (Kala Jadoo). One West African woman related an incident she had witnessed in church of a woman taking what looked like a seizure but describing all manner of strange behaviour such as climbing walls and impossibly high jumps.

When questioned as to why these superstitions had arisen:

“ it's about the way you think and your mentality. It's not only uneducated people who say this, everybody does, and it spreads through the community.....”

The Muslim group said that the Pakistani community believed black magic could be performed on people, which could result in the person developing epilepsy. Also, people appeared to be in a trance, non-responsive and unaware of others during a seizure and this sparked off many misconceptions around epilepsy.

5.3 Culturally/Religiously Sensitive Support Services

The Muslim group thought that people with epilepsy should have a support network from within their own community. This group suggested 'befriender' type activities where both parties could watch films and videos, reading from the holy Quran, talking about religion, play traditional games like Ludo and Caremboard, cards, entertain them and give them company.

All four groups suggested befriending of the person and offered support within their community. It was suggested by the Muslim/Pakistani group that it would be easier to have someone from the same background that would understand the barriers and culture and language. The kind of support suggested including emotional support and reducing isolation.

“ be a good friend to them, listen to them and talk to them”

Support to go out shopping, play games, learn the Quran and be taken to church. Regularly visit them to combat loneliness.

All groups felt that education was vitally important, like giving out information leaflets, having more “awareness raising” events in community organisations where people commonly meet, ensuring information leaflets were accessible. One woman from the Muslim group suggested

“...have leaflets widely available in post offices, banks and other health places. Pharmacies are very important because people go to pick up their medication all the time. Write a poster to say you have this service, and if I needed help I would know where to go. Advertise all this.”

The focus groups highlighted the importance of building in cultural and religious values in future activities. Befriending activities and raising awareness of epilepsy were the main suggestions.

6. Analysis of Questionnaires

A total of 42 questionnaires were completed. The Outreach and Liaison Worker at Epilepsy Connections working with the Chinese community translated the questionnaire into Chinese to facilitate administration and to overcome English language difficulties. Some of the questionnaires therefore were self-completed however, in some cases, the Multicultural Outreach and Liaison Workers used the questionnaires as the basis for semi structured ‘interviews’.

The participants were asked to select a category to identify background in order to assess whether or not they had any previous knowledge or awareness of epilepsy. Figure 1 below shows 27 of the people interviewed belonged to the ‘other’ category. As has already been outlined, the research aim was to identify the level of awareness and the provision of culturally acceptable services therefore members of the community and not necessarily those with epilepsy were included in the interview. The existing client database at Epilepsy Connections has, to date, only a very small number of people with epilepsy from a BME background and access through medical records has been denied. Therefore, a start has been made to raise awareness and give information on how to access epilepsy support services within the community. Relevant and culturally acceptable services are being developed by consultation with a small representative number of individuals and community groups to find out what relevant services should encompass.

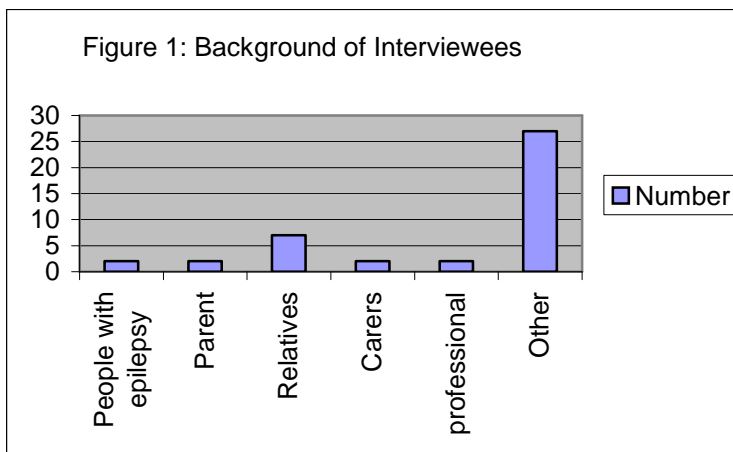
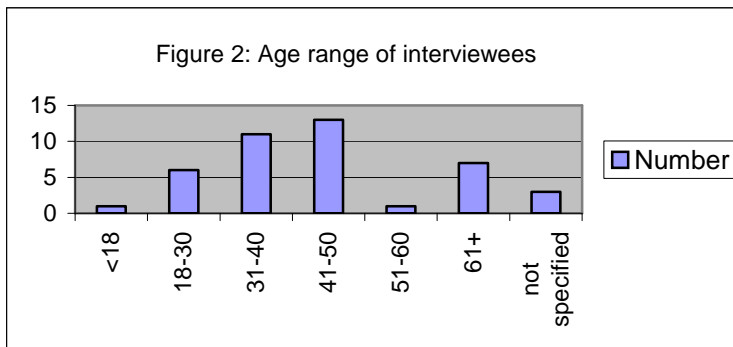


Figure 2 below shows the age distribution of interviewees. Twenty-four people interviewed were between the ages of 31-50. This accounted for 57% of all people interviewed. Seven individuals were in the over 60's category. This was because an elderly day care centre servicing the BME elderly population in Glasgow was chosen for some of the interviews. Incidentally, service users were so interested in the condition of epilepsy that they asked for a presentation about epilepsy at the centre. Four people with epilepsy from BME backgrounds were identified from the Epilepsy Connections database and were approached with the option to be interviewed. Two accepted and one declined. One individual had a learning disability therefore his relative who cared for him was interviewed in his stead.



Twenty-two interviews were done with members of the Chinese community and 12 from the Pakistani community (Table 1). Clearly these numbers are small and not representative of the make-up of BME communities in Glasgow nonetheless they are an initial exploration of the views of people on Epilepsy from BME communities.

Table 1: Ethnic Background of Interviewees

Ethnicity	Number
Chinese	22
Pakistani	12
Indian	6
Malaysian	1
Afghanistani	1
Total	42

As with focus groups three main themes were explored. These were: knowledge and experiences of epilepsy; cultural and religious beliefs; support services that are culturally and religiously sensitive.

6.1. Knowledge of Epilepsy:

34/42 people had heard of epilepsy. Six people (all Chinese) hadn't heard of epilepsy before. Two people didn't answer the question.

When asked to describe epilepsy, the majority of respondents associated seizure activity with epilepsy. Three people from the others category associated epilepsy with a malfunction of cells in Experiences, Cultural Attitudes and Religious Beliefs on Epilepsy in BME communities in Glasgow

the brain which led to 'temporary fits and blackouts'. The transient nature of seizures was recognised and obvious signs of seizure activity like loss of consciousness, frothing at the mouth, jerking, dizziness etc. were also described. Interestingly, two people mentioned contracting epilepsy from fire or water.

Photosensitivity was described as the most common cause of epilepsy however three people ascribed malfunction of the brain to the cause of seizures. Seizure triggers were also mentioned such as flashes of light, strobe lights, insomnia, the sun's rays, water currents, fire and one person remarked on the lack of oxygen in the brain

"...have a deficit in their body. If the sun's rays are absorbed by the eyes the person becomes unconscious. Person froths at the mouth. The sun's rays trigger seizure"

Treatment: overwhelmingly, medical treatment with drugs, tablets and capsules. A couple of people said they didn't know. Alternative treatment therapies included treatment by Traditional Chinese Medicine, treatment by prayers, treatment by traditional herbal remedies.

"if you do Hakimi illaj (homeopathic treatment), 'mazon' is a strengthening formula-it looks like a jam" "medical treatment is not popular...desi diwaie (traditional medicines) give you herbs to strengthen your brain and reduce seizures"

Three members of Indian and Pakistani background mentioned the practice of making those who were undergoing a seizure sniff a leather shoe that was reputed to bring the person round. However, one parent of a person with epilepsy remarked:

" medicines- tegretol, prayers can also help. There is this thing about sniffing a shoe but I think that is degrading and has no effect"

One individual (relative of person with epilepsy) remarked on changing lifestyles to avoid triggers

"..treated with medicines and also change of lifestyle such as sleeping early"

When asked if epilepsy could be cured, 26 respondents said no, nine said yes, six said they didn't know and one didn't answer the question.

6.2. Perceived Attitudes to Epilepsy in the Community

Table 2 shows the results of the perceptions of epilepsy for each Ethnic group. Results varied substantially, with members of the Chinese community generally having the most positive perceptions of people with epilepsy regarding them as 'the same as everyone else and that they could lead normal lives'. Conversely, the Pakistani group had the most negative perceptions. People from an Indian background had mostly negative but some positive perceptions too. Both of the people with epilepsy thought the community had negative perceptions. One woman (Pakistani) said:

" I don't go to Albert Drive, I don't like going, people look down on me, they talk about me...."

The other lady of Indian origins said:

" they thought I was going to give them it, they wouldn't come near me"

Table 2: Perceptions of Epilepsy

Ethnic Group	Perceptions of Epilepsy			
	Positive	Negative	Both	Not known
Chinese	15	4	2	1
Indian	0	4	2	0
Pakistani	0	10	0	2
Afghanistani	0	1	0	0
Malaysian	0	1	0	0
Total	15	20	4	3

In both cases feelings of isolation and being ostracised by the community were apparent. One person with epilepsy just didn't go to areas where she thought there were high numbers of people from the Pakistani community

“ I don't mind going to town but I never go out where there are a lot of people from the community”

Some of the negative perceptions were feelings of fear, being uncomfortable talking to the person, having superstitious beliefs (for example that the person having a seizure was possessed), avoidance, madness, panic, not knowing what to do, not understanding what was happening. There was also a feeling that people with epilepsy were given lesser importance and not treated with respect. People who said they had both positive and negative perceptions generally felt that although they were frightened they felt sympathetic and wanted to help that person.

There was a sense that ignorance of epilepsy stimulated the negativity.

One person commented

“ White people aren't frightened. Our people are frightened that they will catch this....”

“...because we have very little knowledge of epilepsy and they find it very difficult to deal with it or understand it....”

6.3. Epilepsy and lifestyle

Next, participants were asked about the impact of having epilepsy on an individual's lifestyle. The two issues that seemed most important in all communities were employment and marriage. Chinese community thought that chances of employment were most affected. A number of individuals from Pakistani and Indian backgrounds thought that epilepsy had a huge impact on all aspects of life- stops you getting jobs, a good marriage, a good education and leads to an isolated social life. People felt that life would be compromised because of personal safety considerations and the hazards of having a seizure in public and private life. However, the majority of respondents cited marriage as the single most important issue that was affected by having epilepsy.

People with epilepsy related personal experiences mentioning a poor education, isolated social life, poor employment record due to memory problems, problems in married life and reduced independence.

A woman completing the questionnaire related another incident. She disclosed that a very affluent Pakistani family whom she went to visit in Pakistan (where the patriarch of the family had a prominent public position) concealed one of his daughters who had epilepsy from the rest of his social circle and kept her locked in a small building at the bottom of his large garden. When asked why he had done this, the answer was “so that my other daughters have the chance of marrying good men”

6.4. Experiences and Expectations from Epilepsy services

Participants were asked which services they would access if they were required to get information and support either for themselves or for someone with epilepsy. A choice of services was presented and participants were asked to tick as many as they wished. The results are shown in Table 3.

Table 3: Services participants would use to get information and support for Epilepsy

Service	Ethnic Group					Total
	Chinese (22)	Pakistani (10)	Indian (6)	Afghanistani (1)	Malaysian (1)	
GP	17	8	5	1	1	32
Hospital	11	8	1	1		21
Pharmacy		2				2
Social Work	5	2		1		8
District nurse		2				2
Epilepsy Specialist Services	16	5	2			23
Occupational Therapy	10	2				12
Helplines	2	3		1		6
Community nurse	4					4
Voluntary Sector			1	1		2
Internet	1	1				2
Mental health services	2			1		3
Other		1(day care centre)		1 (refugee council)		2

Not surprisingly, GP services appeared to be the first port of call for any medical or information support services across all ethnic groups. Half of the participants would use hospital services. Epilepsy specialist services were also similar to hospital services in that about half of the participants interviewed would use them. However, it was unclear whether these were taken to mean Epilepsy specialist clinics based within hospitals or information and service providing voluntary organisations that dealt with epilepsy. Interestingly, social work and occupational therapy

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were frequently mentioned as services that would be used to access information and support services notably by the Chinese community and also to a lesser degree, by the Pakistani community. Helplines giving information were considered useful particularly by the Pakistani group. The Chinese group considered approaching community nurses for information whereas the Pakistani group would rather approach district nurses especially if the person with epilepsy also had a learning disability. Mental health services were also a place where information on epilepsy would be sought.

Pharmacies, Internet and the voluntary sector were less obvious choices. Interestingly, of the two participants who ticked the voluntary sector for information, one was a person with epilepsy and the other was a carer of a person with epilepsy who both mentioned the positive experiences they had had.

“ In Quarriers, I felt like a normal person. Hospitals treat you like a disabled person...”

“ we are asylum seekers so its difficult to get services...charity organisations helped us”

Other agencies mentioned were day care centres which may have been run by voluntary organisations) and a refugee council organisation where people seeking asylum trusted them enough to get advocacy services.

Table 4: Cultural and Religious needs and Epilepsy Services

Ethnic Group	Culturally appropriate Services Required		
	Yes	No	Don't Know
Chinese	6	2	14
Pakistani	9	2	1
Indian	5	0	1
Afghanistani	1	0	0
Malaysian	1	0	0

About 64% of the Chinese group answered “don't know” to this question, 6 people (27%) answered “yes” however no record is available as to what these culturally appropriate services might be. All other groups were in favour of culturally appropriate services. When asked what these might be the Chinese groups requested more information about epilepsy be made available and support should be provided through peoples love and special help. It still remained unclear how these services would be culturally different from those already provided.

The Pakistani (75%) and the Indian groups (83%) were much more definite about the availability of culturally sensitive services. When asked how current services could be made culturally sensitive some ideas were to have specific activity groups to reduce isolation; people with epilepsy if isolated needed the support of their own culture own people so that the person would be familiar and comfortable, religious and cultural activities for children with epilepsy from the BME communities so that they could learn a little about their own ideals and values, opinions for the need for a lady doctor for Muslim girls whereas others didn't think there was a need for gender specific services

“ a doctor is a doctor-male or female. We don't need gender specific services”

“ religion puts boundaries round a person. These need to be respected e.g. women only workers etc.”

“people are different. They have different beliefs and faiths-these need to be respected when a service is provided”

The need to educate people and preserve a person’s dignity during a seizure, giving information bilingually.

Participants were asked to choose from a list of barriers to using services, which they felt were important in accessing services. Table 5 shows the results.

Table 5: Barriers to using voluntary sector services

Barrier	Ethnic Group				
	Chinese	Indian	Pakistani	Afghanistani	Malaysian
Stigma	6	3	9		1
Language	7	5	10		1
Racism	4	0	0		
Cultural/Religious Beliefs	2	2	3		
Confidentiality	16	0	2		
Fear of meeting someone you knew	2	2	4		
Male workers	0	1	2		
Cultural background of workers	0	0	0		
Others	0	0	1	1	

Participants thought that the stigma of epilepsy and language were important barriers in the use of epilepsy support services. Breach of confidentiality was a major issue in the Chinese group but not as important for the Pakistani and Indian group. A few people said there was a lack of knowledge and general ignorance about the support services available for people with epilepsy and their families.

Participants were then asked which epilepsy support services should be provided to help people with epilepsy in order to identify and target for improvement in the future. The results are shown in Table 6.

Table 6: Support Services, which would help people with Epilepsy from BME backgrounds

Support Service	Ethnic Group				
	Chinese (22)	Pakistani (12)	Indian (6)	Malaysian (1)	Afghanistani (1)
Information about Epilepsy	17	11	6	1	1
Listening Ear Support	7	5	2	0	0
Safety during seizures	6	3	1	0	0
First Aid for Seizures	9	8	1	0	0
Advocacy	9	2	2	0	0
Befriending	12	3	2	0	0
Parents/Women's/Art Group	11	7	3	0	0
Computer Training	2	1	1	0	0
Other	0	2	2	0	1

All groups felt that accurate and comprehensible information about epilepsy was of paramount importance. It was also deemed important for the Chinese and Pakistani groups to learn about First Aid for Seizures. Befriending, Advocacy and group work activities seemed the most popular ways of support provision to BME people. The two participants with epilepsy thought that people should be educated more so that they were not frightened of epilepsy so much and relatives and carers of people with epilepsy wanted training in what to do if a seizure occurred.

“ I have seen people having seizures. It's very scary. You don't know what to do. People put spoons in their mouths and hold them down tightly to stop their muscles moving....”

7. DISCUSSION

The overall aim of this study was to identify ways the information and support needs of people with epilepsy in BME communities in Greater Glasgow and to address these needs in a culturally and religiously appropriate manner.

Since the aim of the study also was to explore attitudes towards epilepsy in general and to begin to identify services that could be accessed by the different communities, all members from BME communities and not just people with epilepsy were invited to participate in the study. Also, the number of people from BME backgrounds on the service user database at Epilepsy Connections was very small (5 people) and access to medical records to identify people with epilepsy from a BME background (where ethnicity may incidentally not necessarily be recorded) was not possible. Only two people with epilepsy took part in the study unlike the Bradford study where the opinions of 30 people with epilepsy from the South Asian community were gathered.

The Pakistani community is the largest BME community in Glasgow (2.1%) followed by the Chinese community (0.6%). A total of 69 subjects participated in this soft research study (27 participants in focus groups and 42 participants completing questionnaires). The subjects were

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from the following groups: Chinese (37); Pakistani (18), Indian (7), African (4); Russian (1); Afghanistani (1); Malaysian (1). Only two people with epilepsy (service users at Epilepsy Connections) were interviewed but a number of parents (2) and relatives (8) of people with epilepsy and a learning disability also participated. The individuals themselves were not interviewed because of communication difficulties. Furthermore, more than one relative of the same person with epilepsy was interviewed. This point is highlighted because although relatives may know the same person with epilepsy, their opinions, knowledge and expectation from services differed considerably. The carers group included those caring for other conditions and disabilities e.g. person who was physically disabled due to a stroke, caring for someone who had bowel cancer and not exclusively for people with epilepsy.

It is recognised that the numbers in this study are small, particularly for the Indian and African groups and especially so for the Afghanistani, Malaysian and Russian communities where the opinion of only one individual from these ethnic backgrounds was obtained. Views and opinions expressed here may not be fully representative of the different groups but are important nonetheless in the recognition of the different needs for provision of appropriate services and in raising awareness of epilepsy within BME communities in Glasgow.

This study was modelled on the research project commissioned by Epilepsy Action and carried out by Bradford Hospitals NHS Trust in 2001 on "South Asians and Epilepsy- understanding the health experiences, needs and beliefs in communities in Bradford" (5). This project examined the experiences, health needs and beliefs of South Asians living with epilepsy in Bradford and the provision of information and services there.

Based on the above, three main themes were explored throughout focus groups and questionnaires. These were:

7.1. Existing knowledge and understanding of Epilepsy

The majority of people who participated in the study across all ethnic groups had heard of epilepsy and often described seizures that they had witnessed. A few people namely, a nurse, a doctor, carers, parents and family members of people with epilepsy could describe seizures in detail and link this to a 'disturbance in the brain'.

When the cause of epilepsy was explored, photosensitivity was commonly mentioned. One person talked about the lack of sleep. The sun's rays, reflection of the sun on water, the motion of swirling currents and flames of fire were described as seizure triggers mostly by the older people interviewed who had grown up in and spent most of their lives in India or Pakistan. Photosensitivity is often thought to cause seizures when in fact it only affects approximately 5% of people with epilepsy. (Epilepsy & Photosensitivity, Epilepsy Connections information leaflet).

Epilepsy was generally not considered to be an infectious condition amongst the Pakistani and African people interviewed. The overall knowledge and awareness of epilepsy was quite high in participants, especially in the Pakistani community. An interesting observation was the number of people who had witnessed seizures and were able to talk about the subject with a good knowledge even though none of their family members seemed to have the condition. However, one of the two people with epilepsy interviewed said:

" they thought I was going to give them it, they wouldn't come near me"

Indeed, Ismail *et al.*, 2005 (4) explored the cause of epilepsy and the influence of religious and spiritual beliefs in the South Asian community of Leeds and Bradford. They found that people with epilepsy believed that members of the community treated them with prejudice because they thought epilepsy was contagious.

Although there seems to be a generally high level of awareness of epilepsy exhibited in these two groups studied it then becomes interesting to speculate why the stigma associated with epilepsy still appears to be so strong. Does stigma affect the way people access support services even though awareness of the condition is high? There may not be need expressed for perceived additional support because of the extended family system or the idea of 'people look after their own', or, people might be reticent to access support services as it may be perceived as an admission of 'weakness' and failure on the part of the family to provide adequate support for that individual.

Notably, six Chinese people hadn't heard of epilepsy. Perhaps more awareness should be arranged to discuss this chronic condition within this group.

The vast majority of participants thought medical treatment was used to control epilepsy. Other treatments mentioned were traditional Chinese medicine, herbal remedies and the use of 'brain strengthening herbal 'jams' to control seizures. Those from the Indian subcontinent often mentioned the 'sniffing of a leather shoe' theory, however people varied in their belief of its effectiveness and the practice was thought to be 'degrading'. A combination of treatment by antiepileptic drugs (AEDs) and prayers was considered best. These results are in accordance with the Bradford study where South Asian people with epilepsy most often combined prayers with the use of AEDs. Prayers alone were not found to be as effective as the combined method (Ismail *et al.*, 2005, (4)) but were used as an adjunct to medicine.

7.2. Cultural and Religious attitudes

The Pakistani group had the most negative perceptions of the condition whereas the Chinese group had the most positive perceptions. Perhaps attitudes towards epilepsy are less tolerant in the Pakistani community due to the nurturing and passing down of misconceptions that may be rooted in superstitious beliefs associated with seizure activity. People who are having a seizure appear frightening as they are non-responsive and in a trance-like state with none or little voluntary control over their bodies. Superstitious beliefs were not apparent in discussions with members of the Chinese community with the exception of one person who was of the Buddhist faith.

Marriage (Indian, Pakistani, African groups) and employment (Chinese) were the two overarching lifestyle issues affected by epilepsy that were discussed most often in focus groups and the questionnaires. Participants often declared that marriages would be far more difficult to arrange for people with epilepsy for fear of introducing epilepsy as an inherited genetic factor that would affect future bloodlines. UK research indicates that marriage rates are inversely correlated with the severity of epilepsy (Manford, 2001) and may also be affected by social isolation and lack of confidence. Again, in the study commissioned by Epilepsy Action (5), all aspects of life were affected by epilepsy, particularly marriage.

It is interesting to note that all aspects of life were severely affected for the two people with epilepsy. The social isolation faced was very difficult for both of these people with one woman saying she particularly missed the company of other women from her community. She would have liked to go shopping with friends and take part in weddings and other community events but because of the risk of taking a seizure in the community she didn't go. The second woman with epilepsy had suffered from her marriage breaking up but it was unclear whether the marriage had ended because the woman had epilepsy or for another reason or a combination of these.

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Trained befrienders and bilingual support workers may be solutions. Confidence to go out, becoming independent and overcoming the fears of having seizures in public may develop as a result of support from the aforementioned people. Service provision such as art groups, sewing groups, workshops to improve mental health, English classes, living well with epilepsy workshops, computer training classes, assertiveness training and confidence building training to make people with epilepsy more comfortable with themselves delivered in culturally appropriate ways may be another method of reducing isolation and promoting good mental health. However, the Bradford report noted that not all people with epilepsy interviewed were keen on support groups as they wanted to get away from being reminded of their epilepsy (5).

Negative stereotypes of people with epilepsy and the associations with learning disability should be challenged and positive models of people with epilepsy should be presented to the ethnic minority community to encourage tolerance and respect for individuals with this condition. Basic first aid for seizures should be widely taught in the community to discourage hazardous practices such as placing a spoon in the mouth (which may break the teeth or hurt the mouth) and restricting a person's movements during a tonic-clonic (convulsive) seizure (which may result in injuries to both parties). This would also dispel the fear of seizures and provide confidence in dealing with a seizure which may encourage more interaction and allow social bonds to develop thereby reducing the isolation of people with epilepsy and overcoming stigma.

Demonic possession and the supernatural beliefs associated with epilepsy could also be tackled by more activity to raise awareness and knowledge of this condition. Simple images and videos to explain the cause of epilepsy (perhaps dubbed over in Urdu, Punjabi, and Cantonese) and what happens to messages going in and out of the brain during seizures may demystify and explain the odd mannerisms or behaviours that may occur as a result of seizures. Raising awareness of epilepsy in the Black and Ethnic Minority could continue in community and voluntary organisations that work with the parents and families of learning disabled or physically disabled children. Since the incidence of epilepsy is higher (1 in 5) in the learning-disabled population, conceivably mini epilepsy awareness sessions could be undertaken by bilingual support workers to educate and inform parents and other family members during home visits.

Superstitious beliefs were not mentioned by the Chinese people interviewed with the exception of one lady who practised Buddhism. This lady also seemed to have ideas of punishment for sins committed on earth and the occurrence of epilepsy. Faith and prayers for healing were strong sentiments from Muslim and Christian people. Ideas of tests of faith and the will of God were also mentioned. Raising awareness of epilepsy might give an understanding of the biological changes that occur during a seizure, but, the overall belief of predestiny and the will of God may not be altered and this is confirmed by Ismail *et al.*(4). It is hoped that giving information on epilepsy and first aid for seizures will be of practical use and that the social isolation experienced by people with epilepsy may be reduced with greater understanding and acceptance of the condition through proper education of the different community groups.

7.3. Knowledge and accessibility to statutory and voluntary sector services

This study found language to remain the first and foremost barrier in accessing information. Explanation of complex information to people who are not fluent in English may cause increased anxiety and incomprehension and misunderstandings. Bilingual information is very useful to overcome these problems and work should continue to identify ways of doing this e.g. use of an interpreter, bilingual support staff, translated resources etc. Epilepsy Connections already offers a number of leaflets in Urdu, Punjabi and Chinese. Also, websites that give translated information about epilepsy should be investigated further where individuals could be directed on where to access information in a language other than English e.g. knowledge of a website with information on epilepsy in Chinese based in Hong Kong.

There is an obvious need to educate the BME communities on issues surrounding epilepsy in order to reduce the stigma associated with epilepsy, which was found to be the second most important barrier to the use of services. Respecting the dignity of a person during a seizure should be a must regardless of whatever community the person is from. Although this applies to all communities, the Muslim group in particular seemed more concerned about this issue. Perhaps this has religious connotations where modest dress and mannerisms are encouraged at all times irrespective of age and gender and the loss of voluntary control during a seizure is of concern e.g. undressing and use of sexual language during complex partial seizures.

Since GP surgeries and hospitals are still the first place to go to for information and support services, literature should be made available to GP surgeries in areas where many people from BME backgrounds reside. Posters advertising services and the availability of bilingual information and support services should be, if possible, prominently displayed in GP surgeries and Pharmacies or at least patients with epilepsy from BME if not all communities should be given this information. Perhaps when patients go to pick up their antiepileptic medication the information could be put into the bag at their local pharmacies. Dissemination of literature either Glasgow wide or in areas of high BME communities should be carried out paying particular attention to the languages spoken in that area e.g. South West- Urdu /Punjabi, North West Chinese etc and ensuring availability of appropriate resources.

Confidentiality was also an issue for the Chinese community. Perhaps the development and use of a contract that would include organisational confidentiality policy and that would be signed by the service provider and service user might offer sufficient reassurance for people using voluntary sector services.

Education should relieve anxiety and stigma and also increase confidence in people's ability to deal with a seizure should they ever have to help someone as well as abolishing misconceptions e.g. about sniffing the shoe etc.

There is a lack of knowledge about services provided in the voluntary sector. Organisations like Epilepsy Connections are registered charities and most services are free. Proper education about voluntary sector services should be provided and people should be referred on from GPs and nurses so that information and further support can be provided.

There appears to be active use of registered charity services which are accessed by learning disabled people and their carers in Asian community. Many people use services such as Ethnic Enable (based in the North of Glasgow) and Barnardos (South East of Glasgow). Targeted Epilepsy Awareness raising to groups from BME backgrounds may enable dissemination of services by word of mouth which is a common way of spreading information in BME communities.

In conclusion, a number of strategies could be put into place to address the information and support needs of people with epilepsy in BME communities. Raising epilepsy awareness could begin the process of reducing stigma and social isolation. Culturally appropriate befriending services also seem to be key in supporting people with epilepsy on a one-one basis. Group activities may also encourage friendships and informal support networks, and this may lead to further increase in self-confidence and reduction of isolation.

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9. APPENDICES

Appendix 1: Letter Inviting Organisations to Participate in the Study

Dear Dorothy,

Re: Identifying the Information and Support Needs of People Living with Epilepsy in BME Communities

I recently started working with Epilepsy Connections at the beginning of June. We are a voluntary organisation of registered charitable status funded in the main by the GGNHSB. We provide information and support services to people with epilepsy. My job title here is Multicultural Outreach and Liaison Worker with the remit of reaching out to people with epilepsy from different ethnic community groups.

I would be very interested in liaising with the centre in order to do some work around epilepsy and related issues. As you probably know already, 1 in every 131 children and 1 in every 200 adults have epilepsy. I am hoping to promote epilepsy awareness within the Chinese community focussing on women. This is because women (from any culture or background) play a central role in looking after the health of their families, they are more open about discussing health issues, and are more likely to pass information on through word of mouth

In order to promote the service I must first determine what the experiences and cultural attitudes are towards epilepsy in different ethnic groups. The work would involve:-

- An initial visit to the Centre by myself at a convenient time when a women's group is running, to complete questionnaires addressing knowledge and experiences of epilepsy and expectations from services.
- Or to run a focus group with women from the Chinese community to gather opinions on attitudes and cultural/religious beliefs on epilepsy either here at Epilepsy Connections offices in 100 Wellington St., (where we could provide lunch and travelling expenses) or with your consent, at the San Jai Centre (lunch only).
- And lastly to give a presentation on epilepsy awareness and where to access support services.

I hope you will participate in this piece of work, which will add to our knowledge base considerably and enable us to provide culturally appropriate services to people with epilepsy from ethnic minority communities.

I would appreciate your reply. Please feel free to get in touch with me (contact details enclosed) if you have any further questions. Thank you.

Yours sincerely

Farhat Khan
Outreach and Liaison Worker

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Appendix 2: List of Community Organisations Invited to Participate

Organisation	Address	Contact	Group
Multicultural Health team	William Street Clinic, 120-130 William Street, Glasgow, G3 8HS	Multicultural worker	Chinese population
Deaf Connections,	100 Norfolk Street, Glasgow, G5 9EJ	Multicultural Worker	BME group with hearing impairment
Meridian	30 Clyde Place, Glasgow, G5 8AQ	Development Worker Development Worker	African women South Asian women
Sandyford Initiative	2/6 Sandyford Place, Glasgow, G3 7NB	Asian Women Host Helpers Volunteers	Muslim Women's group
Hindu Mandir	1 La Belle Place, Glasgow, G3 7LH	Chairman	Hindu women's group
Andersen Mel Milaap Elderly Day Care Centre	134 Berkeley Street, Glasgow, G3 7HY	Unit Manager	Elderly South Asians
Muslim Elderly Day Care Centre	1 Mosque Avenue, Glasgow, G5 9TA	Unit Manager	Muslim Pakistani
Chinese Healthy Living Centre	138 Holland Street, Glasgow, G2 4NB	Project Manager	Chinese population
NCH San Jai Chinese Project	53 Rose Street, Glasgow, G3 6SF	Project Manager	Chinese Population
Youth Counselling Services Agency	11 Forth Street, Pollokshields, Glasgow G41 2SP	Drug and Alcohol Worker	South Asian Youth
Pollokshields Development Association	15 Kenmure Street, Glasgow, G41 2NT	Project Manager	South Asian Women

Community nurse Voluntary sector Internet Mental health services

Other (please specify) _____

2. a. Do you think a person with epilepsy would require specialist help that would take into account their cultural and religious needs (tick one)?

Yes No Don't know

b. If yes, what would these need(s) be?

3. What would prevent people from your community from using epilepsy support services (tick as many that apply)?

Stigma Language Racism Cultural/religious beliefs

Breach of confidentiality Fear of meeting some-one you knew

Male workers Cultural background of workers

Other, please specify _____

4. In your opinion, what support services would help people with epilepsy (tick as many that apply)?

Information about epilepsy Listening ear support Safety

First aid for seizures Advocacy

Support to go out and enjoy social activities e.g. cinema, shopping

Parents group Women's group Art group Computer training

Other (please specify) _____

5. Use the space below to add any other comments e.g. personal / family experiences of epilepsy and epilepsy services.

Thank you for completing this questionnaire. The results will help us to understand the information and support needs of people from ethnic communities and to include these in our service provision.

Appendix 4: Sample Agenda and Questioning Route for Focus Group

FOCUS GROUP CULTURAL ATTITUDES AND RELIGIOUS BELIEFS ON EPILEPSY IN SOUTH ASIAN MUSLIM WOMEN

Meeting- Wednesday 30th November 2005

100 Wellington St., Glasgow, G2 6DH

AGENDA

- 1.00pm Introductions
- 1.15pm Aims of the Focus Group and the importance of confidentiality
- 1.30pm Group Discussion
- 2.00pm Video
- 2.15pm Conclusion

1.00pm Introductions

Thank you everybody for coming. I'll run through the programme so that we know what we will be doing today and what time we can aim to get finished

Ok let's get started on the introductions then

- Getting to know each other/ ice-breakers. Tell the group three things about yourself that you feel comfortable about sharing. Start with myself, then Min. My name, I'm married with one child, a boy who is four years old and my parents are Punjabi and they come from Karachi.

Thank you. Now that we all know each other let me tell you why we are having this focus group meeting

1.15pm Aims of the Focus Group and the importance of confidentiality

- Talk about structure of the focus group and the duration, running through the programme. We will be doing two things today. First we will complete have the discussion on epilepsy. I will read out the questions in Urdu/Punjabi and if anyone doesn't understand the questions just let us know. Then we will go on to watch a short video about seizures and epilepsy while we have some lunch.
- Gain consent to use the tape recorder

Confidentiality:

- Anything you say here will remain strictly confidential.
- Any comments or quotes used in the report will be anonymous.
- Would like to remind all the participants that people might say things in this room that should stay in this room and not be discussed outside please.

Explanation of objectives:

Why are we doing this focus group?

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- To improve services to people with epilepsy, their family and friends from our community.
- To find out what peoples cultural attitudes and religious beliefs are regarding Epilepsy.
- To find out what kind of information and support our community needs regarding epilepsy.
- To provide services that take into account peoples cultural and religious beliefs.

1.30pm Group Discussion

Focus Group Questions

Understanding of Epilepsy

I'd just like to get us going on talking about epilepsy

- what is epilepsy?

(if no response then use prompts- is it a mental illness, physical condition)

- How would you know if somebody had epilepsy?

(probes- witness seizures, learning disability, absences etc.)

- Do you know of anybody (friends, family) who might have epilepsy?
- Do you know what causes epilepsy?
- Do you think epilepsy is infectious?

(probe: if no why? If yes probe attitudes towards people with epilepsy)

Ok. Now let's talk about the next part of the discussion

Cultural Attitudes and Religious Beliefs on Epilepsy

- Do you think people who have epilepsy are treated differently by their families and friends?
- What do other people in your community think about people with Epilepsy?

(probes: stigma, ignorance, pity, fear, sympathy, support)

- Why is Epilepsy not regarded the same as other health conditions like Blood Pressure and Heart Disease?
- Do you think having epilepsy stops you from doing things?

(Probe each subject separately and ask why)

- Socializing e.g. making friends

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- Domestic responsibilities e.g. cooking/cleaning
 - Religious activities e.g .namaz, attending the mosque, going to quran khaneeze
 - Driving
 - Working e.g. getting a job, following your chosen career
 - Marriage e.g. getting a rishta?
- What does our religion say about epilepsy and illness in general?
 - Why does this happen?
 - Will of Allah?
 - Test of faith?
 - Punishment for our sins?
- Do you know of any superstitions surrounding epilepsy?
 - Related to Black Magic (taweez /tagay)?
 - Possession by demons?
 - Superstitions during pregnancy?
 - Superstitions around when someone is having a seizure?

Thank you. Now lets move on to the last parts of the discussion

Understanding of treatment

- Do you think there is a cure for epilepsy?
- As you may know there is medication available for the treatment of epilepsy however, people have to take it on a long-term basis (sometimes for the rest of their lives). Have you heard off any alternative therapies?
- Hakimi (Herbalist)
- Dimaghi (Psychological)
- Roohani (Spiritual)

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- Desi (Traditional)

We are on to the last exercise!

Support Services

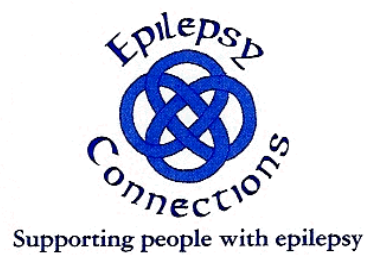
- How can we make support services sensitive to our culture and religion?.

To get you thinking, I will give you an example off an imaginary person with epilepsy.

- A Muslim
- man or women or child
- who had epilepsy that wasn't very well controlled
- they had frequent seizures
- they were frightened of going out in case they had a seizure in public
- they didn't participate in family gatherings
- they were lonely
- they didn't speak English

What could be done for this person which would take account their culture and religion?

- Do you think services (not just hospitals and doctors) but places such as ourselves are meeting the4 needs of people from BME communities?
- y/n: then why are there so few people that use voluntary organizations? Do they perceive language as an issue?
- If you wanted information on breast cancer for example where would you go?



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