

# Perceptions and experiences of epilepsy among patients from black ethnic groups in South London

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**Objective:** The National Institute of Clinical Excellence suggested black ethnic minorities with epilepsy have different cultural, communicative and health-care needs. However, little is known about these despite increasing migration of black African and Caribbean people to Europe. This study aims to explore perceptions and experiences of epilepsy among black African and Caribbean people in South London. **Methods:** Semi-structured interviews were undertaken with 11 participants, to examine their beliefs and perceptions of living with epilepsy. Interviews were recorded, transcribed, codes generated and thematic analysis undertaken. **Results:** African participants described supernatural causes for epilepsy and experienced considerable stigma whereas Caribbean participants described epilepsy as a 'normal illness'. However, both African and Caribbean participants experienced social restrictions arising from their epilepsy. **Conclusions:** The findings of higher levels of perceived stigma and social restriction seen in African participants may be a continuation of beliefs reported in participants' country of origin. There is also evidence that views regarding epilepsy transition through generations vary depending on place of birth. **Practical Implications:** Health-care professionals need to be aware of and engage with the particular beliefs and concerns of black African and Caribbean people to achieve equity in health outcomes.

**Key words:** attitudes; epilepsy; ethnic minorities; perceptions; stigma

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## Introduction

Epilepsy is a common serious neurological condition, with an estimated 50 million people affected world-wide (World Health Organisation Media Centre, 2012). People with epilepsy (PWE) are at heightened risk of experiencing physical (eg, injury), psychological (eg, anxiety and depression) and social burdens that arise not only from the condition itself but also from its social meanings

and actual or feared discrimination. This situation is often conceptualised in terms of 'stigma'. The notion of stigma was developed by Goffman (1963) in interactionist terms, defining it as 'the process by which the reaction of others spoils normal identity'.

Following Goffman, a considerable body of work has focused at an individual level and examined how people manage a stigmatising condition. Scambler and Hopkins (1986) describe a situation where stigma could be 'enacted' where experiences of social rejection has taken place as a result being discredited. More often, it can be 'internalised' and 'felt' where they may not be an obvious disvaluation by

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others but rather a feeling of shame associated with having epilepsy. In a qualitative study of a Caucasian British population Scambler and Hopkins (1986) found that the felt stigma experienced by their group of patients was much greater than instances of enacted stigma or what Muhlbauer (2002) refers to as interpersonal stigma; whereas nine out of every 10 people described felt stigma, only a third could recall ever having encountered enacted stigma. Conrad and Schneider (1980) showed how this sense of felt stigma can have its origins in the 'stigma coaching' of others.

Goffman noted that stigma is not an inherent aspect of a condition. Thus a condition that is viewed as unacceptably different in one situation may not be in another. This is supported by evidence of variation in the stigma attached to epilepsy both between societies and over time, reflecting what Muhlbauer (2002) refers to as 'institutionalised' stigma or the position taken by the society/culture. A cross-cultural study of epilepsy-associated stigma in 10 European countries demonstrated that more than half of all respondents did not feel stigmatised at all by their epilepsy, while respondents in the Netherlands (27%) and Spain (31%) were significantly less likely to feel stigmatised than were those in Poland (56%) and France (62%) (Baker *et al.*, 1999). Studies of PWE in several African countries including Tanzania and Ghana have also identified a reluctance to disclose epilepsy due to fear of discrimination. For example, a study in Tanzania indicated that 62.7% of the respondents would not allow an epileptic child to go to school and 33% would keep away from a PWE when having a seizure (Rwiza *et al.*, 1993). Osuntokun *et al.* (1987) also described patients in rural Nigeria being abandoned by their wives because of nocturnal enuresis due to seizures. This reflects Plummer's (1979) concept of deviance, a violation of social norms, which can be societal or situational. This reinforces the idea that a behaviour considered deviant in one situation may be non-deviant in another. Community representatives in Africa explained that females with epilepsy were viewed as poor wives as they were unable to look after children, and other chores expected of a wife (Jilek-Aall and Rwiza, 1992). However as Link and Phelan (2001) have noted, there is a need to move from a purely individualised focus on the ways in which individuals cope with stigma to give greater attention to the structural conditions within which people experience

conditions such as epilepsy, together with the resulting impacts for individuals life chances that arise from status loss and discrimination.

Negative social attitudes to epilepsy are often explained in terms of its perceived cause. Studies in Sub-Saharan Africa (Baskind and Birbeck, 2005; Akinsulore and Adewuya 2010) describe a supernatural element to the aetiology of epilepsy, where it may be viewed as an infectious disease (Sanya *et al.*, 2005) or even a curse from god (Ojinaaka, 2002). Some attribute epilepsy to supernatural causes and a few of the more elderly Asian population in the United Kingdom felt epilepsy was contagious (Ismail *et al.*, 2005). Interestingly, even in the United States, 30% of people believed that epilepsy is a mental contagious disorder (Long *et al.*, 2000). These views can lead to many difficulties for the lives of PWE. In some parts of Africa, it is difficult to marry if one has epilepsy (Komolafe *et al.*, 2012). However, this stigma and disadvantage is not just limited to minority ethnic backgrounds. For example, a study of Canadian college students reported 5% objected to a future child associating with a child with epilepsy, and 4% objected to a relative marrying a person with epilepsy (Young *et al.*, 2002).

In terms of healthcare, it is important to understand the social meanings and impacts of epilepsy for patients and how this may vary for different ethnic groups. The United Kingdom's National Institute of Clinical Excellence (NICE Clinical Guideline 137, 2012), which provides guidance and standards on the prevention of ill health, stated that adults with epilepsy from black and minority ethnic groups may have different cultural and communication needs and these should be considered during diagnosis and management. NICE were though unable to cite any original studies for black ethnic minorities, thus limiting the provision of evidence-based care.

This is a very relevant topic since studies in the United States show non-white individuals are less likely to access specialist care, but have higher rates of emergency department (ED) visits (Burneo *et al.*, 1990; Kelvin *et al.*, 2007). In the United Kingdom, evidence suggests that those ethnic minority groups are particularly high consumers of expensive services for their epilepsy (Ridsdale *et al.*, 2013). Noble *et al.* (2012) showed that a stigma level in the highest quartile was associated with more ED visits. Noble *et al.* (2014) reported that the 60% of PWE who do attend frequently reported more felt stigma.

The principle minority ethnic groups in the United Kingdom are currently Asian/Asian British (7.5%), black/African (1.8%)/Caribbean (1.1%) (Total 3.3%), and ‘mixed’ (2.2%) (Office for National Statistics, 2011a). One of the largest changes in recent years has been a growth in the number of people who classify themselves as being of a ‘black or mixed white and black’ ethnic background (2.9% in 2001 to 4.5% in 2011 (Office for National Statistics, 2011b)). This is partly accounted for by the increase in migration from West Africa, with migration from Nigeria to the United Kingdom having doubled between 2001 and 2011 (Office for National Statistics, 2011a).

To begin redressing the gap in the literature identified by NICE we conducted qualitative interviews with PWE who classified themselves as of a ‘black or mixed white and black’ ethnic background to examine social meanings of epilepsy among people of Caribbean and African origin living in South London and how this condition impacts on experiences and life chances. We were cognisant of the potential diversity of ethnic backgrounds that can be found under such a wide ethnic label and we therefore examined whether the perceptions and experiences of living with epilepsy were similar for people of African and Caribbean backgrounds.

## Methods

Qualitative methods were ideally suited for exploring issues of stigma among minority groups, given the limited research in this area and importance of minority ethnic groups being able to raise what they personally regard as important aspects and concerns.

The study was approved by King’s College London’s Psychiatry, Nursing & Midwifery Research Ethics Subcommittee. The research ethics reference number is PNM/11/12-82.

## Design

This qualitative study was nested in a larger cohort study, consisting of 85 participants, that described the characteristics and service use of adults with established epilepsy (diagnosed > one year) who had visited the EDs of three teaching hospitals in South London (King’s College Hospital, St. Thomas’ Hospital and University Hospital, Lewisham

(ISRCTN06469947) between May 2009 and March 2011. We have previously described the recruitment of participants for the cohort study and participants’ characteristics (Noble *et al.*, 2012) and outcomes at 12-month follow-up (Noble *et al.*, 2014). In brief, recruited participants completed validated generic and epilepsy specific self-report questionnaires (Cramer *et al.*, 2000; Scott-Lennox *et al.*, 2001; Taylor *et al.*, 2011). This study found that ED attendees experienced more seizures, anxiety, had lower knowledge of epilepsy and its management and greater perceived epilepsy-related stigma. Upon recruitment into the cohort study, participants were asked to classify their ethnicity. Following the 12-month follow-up, the 25 participants who identified their ethnicity as Caribbean or black African were invited by letter to participate in this current qualitative study. A follow-up phone call was made to non-responders.

## Data collection

Semi-structured interviews were undertaken by a researcher independent of the larger cohort study (S.S.). This method enables participants perceptions and experiences to be explored in-depth through allowing participants to talk freely and for the interviewer to probe responses as required (Pope *et al.*, 2002; Green and Thorogood, 2004).

A topic guide was used to frame the interviews (Ritchie and Lewis, 2003). This was developed on the basis of themes identified from the literature and refined through open interviews with three people who were not involved in the study, but who had epilepsy and identified themselves as being of a ‘black or mixed white and black’ ethnic background.

Topics included epilepsy history, support from family/friends, cultural beliefs (including their beliefs about the causes of their epilepsy) and stigma (including how their epilepsy was perceived by others), health-care professionals support, affect on family/relationships/work (see Appendix 1). Participants were encouraged to talk freely and the interviewer probed and prompted responses as required. Socio-demographic information recorded included place of birth and length of time in the United Kingdom. The number of seizures participants had historically experienced was obtained from a database of information collected for the cohort study in which these people had previously participated (Noble *et al.*, 2012).

**Table 1** Demographics of participants interviewed including age, gender, back, number of years in the United Kingdom, occupation and seizure frequency

Participant	Age	Gender	Background	Born	No. of years in the United Kingdom if moved to the United Kingdom	Occupation	Severity: number of seizures in 12 months (2011)
1	23	Male	Caribbean	United Kingdom	Born in the United Kingdom	Unknown	>10
2	55	Male	Caribbean	Caribbean	30 years	Unemployed	>10
3	79	Female	Caribbean	Caribbean	60 years	Retired	>10
4	35	Female	Caribbean	Caribbean	20 years	Trainee teacher	>10
5	22	Male	Caribbean	United Kingdom	Born in the United Kingdom	Retail	3
6	26	Male	Caribbean	United Kingdom	Born in the United Kingdom	Waste collector	>10
7	27	Male	Caribbean	United Kingdom	Born in the United Kingdom	Unknown	4
8	24	Female	African	Africa	16 years	Student (college)	>10
9	69	Female	African	Africa	20 years	Retired	2
10	32	Female	African	Africa	24 years	Unknown	8
11	44	Male	African	Africa	19 years	Chef	4

Each interview lasted 45–60 min, and was conducted in a location of the participant's choice (three interviews at home and eight interviews at our university centre).

### Data analysis

Interviews were audio-recorded with respondents' permission and transcribed verbatim. Data were analysed thematically. S.S. read each transcript line by line and open coding undertaken, with codes then categorised thematically (Green and Thorogood, 2004). Relationships between themes were identified through constant comparison of codes and categories, with particular emphasis given to variations by age group, place of birth and ethnicity. Codes and interpretations were reviewed and discussed by all authors.

### Results

From the register of 25 participants, seven were no longer contactable by mail/phone, three were contactable, but declined to take part in the study, and four agreed to participate, but did not attend for their interview. Eleven people consented to interview and attended.

Of those, four were born in West Africa, and seven classified themselves as being of a Caribbean background, of whom three were born in the Caribbean. Six participants were male and five were female. Three of the four African participants were female, and two of the seven Caribbean participants were female.

African participants were slightly older (mean age 42 years compared with 38 years for Caribbean participants) and reported experiencing fewer seizures in the year before recruitment compared with Caribbean participants, using data collected from a previous study (Noble *et al.*, 2012) (one of four African participants with over 10 seizures in the previous year compared with five of seven Caribbean participants) (Table 1).

Quotations are presented to illustrate themes. There has been minor editing of some to preserve anonymity and ensure meaning of extracts. A key has been used to cross-reference which participant a quote has been taken from, where p = participant A = African C = Caribbean M = male F = female.

### Beliefs about cause

Three of the four African participants described a belief in a supernatural cause for their epilepsy, reflecting traditional beliefs. They described beliefs

in spirit possession as a possible cause of epilepsy and alluded to spiritual treatments for epilepsy:

*'they believe (in Nigeria) it was a spiritual attack...they might do some cleansing'.*

(P9,A,69yoF)

*'because you've got something bad inside you so you're going to go and see witch doctors, who going to give you something, maybe talisman... They will write something maybe in Arabic... or drink this thing or when you're sleeping in the night, you put something under the pillow or wherever you're sleeping and maybe that devil will come to you'.*

(P8,A,24yoF)

An older lady born in Nigeria believed the cause of epilepsy was 'black magic' (P9,A,69yoF), illustrating that both younger and older generations born in Africa have this view.

All four African participants described epilepsy as a contagious disease; they depicted it as a malaria type illness, airborne disease or as a sexually transmitted infection such as HIV.

*'They believe it's like a plague....People are believing it's airborne disease, they could contract it. They feel, oh, when you touch her... when you play with her, you're going to have what she's having'.*

(P10,A,32yoF)

African participants traditional notions of the causes of epilepsy was reflected in their perception of epilepsy as a stigmatising condition – with feelings of embarrassment, shame and stigma described throughout the interviews.

*'The shame on me, it was too much [on her] and the name on the family.... Another family doesn't want anything to do with your family'.*

(P10,A,32yoF)

In contrast, only one Caribbean participant shared this belief of a supernatural cause of epilepsy or an association with witches. With the exception of this one participant, who also described a connection of epilepsy with HIV, the other participants from the Caribbean did not share the view that epilepsy was a contagious disease.

*'It's a certain condition, it's not something that you can catch. It's something that you're born*

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*with, it's not something you can catch like a cold. It's naturally there your system'.*

(P1,C,23yoM)

Instead the Caribbean participants viewed epilepsy as a common chronic condition and did not feel they were different from anyone else in the wider population. Five of the seven Caribbean participants said that they did not conceal their diagnosis from others.

*'It's just normal. They just find it...it's just... something you have... like having eczema or asthma. Those type of stuff. Nobody teases each other...if you've got it you've got it'.*

(P1,C,23yoM)

However, there was some evidence of generational changes in perceptions for people of Caribbean origin. For example, one young Caribbean participant commented on the views of her grandmother, that she herself did not believe in, indicating that views were not fixed in culture, but rather a spectrum with differences between the generations.

*'Even my grandmother... she told Mummy that I have an evil spirit in me. That needed casting out. Um...and that was horrible...I guess that's the good thing about being in this country instead of Trinidad. I don't think people think that way anymore, although that generation might....And she wanted the Iman to bless me and purify me, to get the spirit out of me ... thankfully Mummy said, "no"...Mummy pacified her slightly by saying, "If the doctors cannot find anything, we'll come back to you".'*

(P4,C,35yoF)

When asked if her mother shared the same beliefs as her grandmother this participant commented:

*'I don't know...Mummy seems to have an internal battle, sort of with the old ways and the new ways...she's at odds with herself. She doesn't know what to believe'.*

(P4,C,35yoF)

### **Felt and enacted stigma**

Those born in Africa frequently reported experiences in Africa of persecution and discrimination and talked about how they were viewed by their community (P8,A,24yoF, P10,A,32yoF).

*'If I keep having fit, my dad or my step-mother, they put me in a kind of small cage...they closed the door. I would stay there for two days. Without eating, without nothing because...they don't want to see me having the fit'.*

(P8,A,24yoF)

*'A girl of your age doesn't want to come around you. She believes, "If I go around, playing with her, then I'm going get what she's having." Parents do tell their kids, "Don't go there".'*

(P10,A,32yoF)

Three of four African participants said that as a result they came to believe themselves as being 'witches' (P8,A,24yoF, P10,A,32yoF, P9,A,69yoF). They also expressed a fear of being taunted because of their epilepsy and often described themselves as outcasts from their community in Africa:

*'Nobody want to come you, you can stay there whole day hungry and no one in the community want to come and run to you because they're always say that you're going to give them, you're going to transfer the illness to them'.*

(P8,A,24yoF)

African participants also reported that their epilepsy had consequences for their relationships with others and potential to marry. One African female actively avoided relationships in the past as she was worried about perceived reaction of her partner on knowing about her condition.

*'And I had, I never had, as a teenager, I never had a boyfriend or anything... Because I was scared of people knowing. "I don't know what your feelings about it would be".'*

(P10,A,32yoF)

Another suffered violent abuse from her partner in Africa.

*'I had a couple of fits... and I think he (her boyfriend) left me because of that...he beat me up, I was bleeding everywhere and... And all the time he would come to my flat and then go there and telling everybody who knows me and him that "oh, she have bad disease, she fall down"'*.

(P8,A,24yoF)

These experiences described by African participants in childhood extend to cause continued shame, stigma and social restriction into the present – a feeling others will be 'laughing at them' (P9,A,69yoF).

*'I'm still not a 100% comfortable telling somebody. I don't know what they'll feel about me'.*

(P4,A,24yoF)

In contrast, the Caribbean participants did not report discrimination because of their illness. However, they did report feelings of potential embarrassment of the event of a seizure itself (situational deviance). For example, one of the older Caribbean participants described an 'embarrassing feeling' (P2,C,55yoM) (when having a seizure on the bus). He explained it was the helplessness of the situation when 'people seeing me lying on the floor' (P2,C,55yoM).

*'it's an embarrassing feeling. Especially when you see children, and my wife told me at one time, that children, they were crying. So it, it wasn't a good feeling this, I didn't have the confidence, without my wife'.*

(P2,C,55yoM)

Three of the Caribbean group denied that epilepsy impacted marriage/relationships or family life at all and believed that in their culture it was not more difficult to marry if one had epilepsy.

*'they seem to be cool with it. Understanding and everything. They've got no problem with it'.*

(P6,C,26yoM)

Epilepsy was though believed by the Caribbean group to impact on one's work status as there was discrimination when applying for jobs. Three of these seven participants had left their jobs or were made redundant. One participant described the reason behind concealing his epilepsy when going for job interview in the United Kingdom.

*'there's certain times when I concealed it for a time....For example, going for a job...I would conceal it up until the point where they make that decision. Because although...you've got the disability discrimination act... if someone*

*is going to, you know, discriminate against me for having epilepsy in their mind, there's no way of proving that'.*

(P7,C,27yoM)

### **Managing fits and social restrictions**

Although participants of Caribbean backgrounds did not acknowledge discrimination as a major issue for them, epilepsy still placed significant restrictions on them. Older participants described a fear of leaving their house which meant they could feel isolated which in turn was described as having implications for their emotional state:

*'Even travelling on the buses now, if I get on the bus now, my wife will come and keep a hand on the seat'.*

(P2,C,55yoM)

The unpredictability of the seizures was described by participants as particularly disabling.

*'If I had a feeling that epilepsy is coming on, and I have thirty seconds...then I could sit down, but no warning... to say that it is coming now...that's the worst feeling'.*

(P2,C,55yoM)

Younger participants frequently felt the type of activities they could participate in were restricted and perceived this as isolating them from friends and others of the same age group.

*'I couldn't go swimming; I couldn't play computer games, bike riding. I couldn't go too far because my parents were worried about where I was going and if I had a fit'.*

(P5,C,22yoM)

African participants described restrictions with regards to relationships, family, driving and occupation. However, as they were of a younger age group, they experienced less isolation and impact on activities of daily living.

### **Discussion**

Differences were seen between African and Caribbean participants in their experiences and

perceptions of epilepsy. The views and experiences of African participants', including perceptions of a supernatural element to the aetiology of epilepsy, reflected traditional views probably learnt in childhood, and were similar to those reported

by studies undertaken in Sub-Saharan Africa (Baskind and Birbeck, 2005; Akinsulore and Adewuya, 2010). African participants in this study also recounted being ostracised because of their epilepsy in Africa and experiencing violent abuse (enacted stigma) and thus suffered from status loss and discrimination. They and their families were seen as outcasts from the society, reflecting Muhlbauer's (2002) concept of 'institutionalised' stigma. The African participants therefore continued to experience considerable felt stigma in the United Kingdom, with impacts on work, relationships and family, and as a result concealed their condition from others. These experiences are also seen in studies carried out in Africa in which participants describe feeling worthless and outcasts from society (Birbeck *et al.*, 2007; Komolafe *et al.*, 2012), resulting in marital problems (Komolafe *et al.*, 2012) and concealment of their condition from others.

Caribbean participants did not typically share the views of African participants, and regarded epilepsy as just a normal chronic disease, such as asthma. They described little felt or enacted stigma and were not ashamed of their epilepsy. However, they described feeling embarrassed about the event of a seizure itself. Caribbean participants did not regard epilepsy as impacting upon relationships or marriage, but did regard it as affecting their occupational prospects. From the Caribbean participants, there was no real difference in perceptions and attitudes between those born in the United Kingdom and those born in the Caribbean. This is consistent with a quantitative study in Kingston, Jamaica where 81% of those surveyed indicated they would not be afraid to reveal a personal diagnosis of epilepsy, and stigma was lower than in other populations (Ali *et al.*, 2011). This suggests that the low felt stigma reported by Caribbean participants in this study may not simply reflect their 'assimilation', but also reflect lower baseline levels in the Caribbean.

We have added to existing literature (Rwiza *et al.*, 1993; Nyame and Biritwum, 1997; Baskind and Birbeck, 2005; Birbeck *et al.*, 2007; Ali *et al.*, 2011;

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Komolafe *et al.*, 2012) by demonstrating the immense effect of the social and cultural meanings of epilepsy on the lives of PWE of African background here in the United Kingdom. We have also identified an important contrast between African and Caribbean participants demonstrating that the 'black ethnic population', is not homogeneous and expresses different experiences, perceptions and beliefs with regards to epilepsy.

We recognise that neither African nor the Caribbean populations are themselves homogenous, comprised as they are of many different islands or countries with unique ethnic and cultural influences. In addition differences may arise through length of time in the United Kingdom. It is notable that all four African participants were born in Africa, while four of seven Caribbean participants were born in the United Kingdom and thus been exposed to western culture for longer.

In addition, gender may have had an influence upon both the felt and enacted stigma experienced. Studies from Africa (Baskind and Birbeck, 2005; Mosaku *et al.*, 2006; Komolafe *et al.*, 2012) have shown greater stigma and social impact in females. Although there were no differences in perceptions and experiences expressed by male and female participants of Caribbean origin and both African males and females described stigma and views of contagiousness of the disease, only African females reported a need to conceal the disease, views of witchcraft and acts of domestic violence. The influence of gender on perceptions and experiences of stigma has been explored in other studies (Jilek-Aall and Rwiza, 1992).

We are also able to add to existing literature with possible generational affects: whereas the Caribbean participants described epilepsy as a normal illness, there were generational differences in beliefs, with the older generations (a grandmother) expressing beliefs in spirits and the supernatural and the middle generation (mother) battling with the perspectives of the older and younger generations. A spectrum of ideas and views was also reported by Ismail *et al.* (2005) who explored views of South Asian PWE. These findings illustrate changing perspectives between generations, dialogue and negotiation between people.

With NICE suggesting black ethnic minorities have different cultural, communicative and health-care needs (NICE Clinical Guideline 137, 2012), it seems prudent to evaluate if this is in fact true.

Previous studies have shown high levels of felt stigma and concealment of epilepsy from others in the Caucasian population in the 1980s (Scambler and Hopkins, 1986). More recent studies however have explored stigma in multiple cultures and less so in the Caucasian population.

Multiple studies show that those from minority ethnic backgrounds such as African or Caribbean backgrounds may experience more stigma than Caucasian populations. In a case-control study of a paediatric epilepsy clinic population, Snodgrass *et al.* (2001) found that non-Caucasians were more likely than Caucasians to be non-compliant with anti-epileptic medication. In addition black ethnicities attend ED more than Caucasian populations (Begley *et al.*, 2009) and with studies showing that ED use is related to high levels of stigma (Noble *et al.*, 2012), it suggests high levels of stigma in this group.

### Strengths and limitations

This is the first study in the United Kingdom to explore perception, beliefs and social restriction on black African and Caribbean PWE. However, the numbers were small with only 11 of the 18 (61%) who were contactable participating in the study. This has been reported in other studies, exploring perceptions of epilepsy in ethnic minority groups (Colombo and Tapay, 2004; Rhodes *et al.*, 2008). Difficulty recruiting participants reflects the challenge of managing this group, and impacts on their self-management of epilepsy but also reinforces the importance of our findings.

All participants were recruited from a cohort of patients attending an ED for epilepsy at one of three hospitals in south London. Compared to other groups of PWE in the United Kingdom, the group as a whole reported more psychological distress and felt stigma, and had on average experienced a large number of seizures in the previous year (Noble *et al.*, 2012). However, it is these patients for whom our findings are most relevant, and in turn who need most support with the need for health-care professionals to take a bio-social as well a 'whole person' approach to African and Caribbean ethnic groups and to recognise the heightened level of stigma and increased levels of social restriction they may experience.

### Practical implications

Six out of seven hospital admissions for PWE are unplanned and are the result of them attending

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an ED. Total inpatient costs are £56.2 M with health service costs of black ethnic minorities found to be higher than the Caucasian group (Ridsdale *et al.*, 2013).

Noble *et al.* (2012) showed that a stigma level in the highest quartile was associated with more ED visits. Furthermore, Ridsdale *et al.* (2013) argued that felt stigma may be a driver of ED use and not simply a consequence.

Findings from this study may allow health-care professionals to target this group in terms of education and interventions to act upon their negative perceptions and experiences. Addressing perception of stigma and potential reducing stigma may lead to an improvement in self-care, reduces ED use (Noble *et al.*, 2012) and promote quality of life and equity in health outcomes. Indeed, a recent study illustrated that a nurse intervention reduced hospital IP stays following ED attendance (Ridsdale *et al.* 2013).

It is important that researchers as well as health-care professionals take account of the diversity of beliefs and perceptions among the 'black ethnic groups' and understand the influence of gender, geographical and generational factors.

This study may serve as a catalyst for similar comparisons in other countries with similarly high immigration rates with potentially interesting observations in regard to the impact of assimilation in different western countries.

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## Conflicts of Interest

None of the authors has any conflict of interest to disclose.

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## Topic guide: Appendix 1:

### Topic guide

#### 1. Personal circumstances

How old are you?  
 What ethnicity/background are you?  
 Are you religious? What religion do you follow?

#### 2. Life history

Where were you born?  
 When did move to the UK? (If applicable)  
 What do you do for a living?  
 What jobs have you done in the past?  
 How was school for you?  
 Did you study anywhere after school?  
 Tell me about your family?  
 Are you married? Partner? Children? Siblings?

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### **3. Epilepsy history**

Tell me about your epilepsy?  
When it was first diagnosed and what were the circumstances?  
Who looks after you epilepsy now?  
How have you been coping with your epilepsy?  
How does it affect your life? How has life changed?  
Have you encountered any problems at any time?

### **4. Support**

Who has helped you with your epilepsy? Any doctors or nurses?  
How have you found their help?  
Is there anything you feel they could have done differently which would have helped you more?  
How much support do you get from family and friends?  
Are there any other ways you have dealt/which has helped with your epilepsy? Other people you may have seen or other treatments tried?

### **5. Cultural beliefs and stigma**

What are your beliefs about epilepsy? Does culture/ethnic background play a role and if so in what way?  
Does some of your family or friends have different beliefs? If so, what are they? Does this affect the way you are able to talk about your epilepsy around them?  
How does religion affect the way you view epilepsy? Does religion play a role?  
What other ways does your culture affect the way others from your background or culture, but not necessarily yourself, view epilepsy?  
Does culture affect the way that you manage with your epilepsy? Does it provide or suggest alternative ways that may treat or cure epilepsy?

Do you feel you are viewed differently because of you epilepsy? By whom? How does it make you feel?

Do you feel at all stigmatised?  
How would you feel if your epilepsy doctor was the same background as you? Would it make much of a difference?

### **5. Health-care access and provision**

How well do you feel your epilepsy doctor understand your views about epilepsy?  
Are there any times when you feel you disagree with your epilepsy doctors views?  
What has your epilepsy doctor told you about the condition and medications?  
Do you always take your medication?  
Do you have any side effects?  
Do you take your medication in front of others?

### **6. Impact on life and social circumstances**

Has epilepsy caused any problems with your work?  
Has epilepsy caused any problems with your family?  
Has epilepsy caused any problems with your friends?  
Has the condition caused any problems in your relationships/marriage?  
How do people react to people with epilepsy in your culture?  
How do families react if their children or partners have epilepsy?  
In your culture, how common is it for people to hide they have epilepsy? Does this cause any consequences?  
Why do you think it is that people try to hide the fact they have epilepsy? (if applicable)?