Author's response to reviews

Title: A qualitative study of the health-seeking behaviours of people of South Asian origin in the UK with a diagnosis of epilepsy: biomedicine, complementary and alternative medicine and ethnomedicine

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Version: 2 Date: 28 December 2007

Author's response to reviews: see over
Reviewer's report

Title: A qualitative study of the health-seeking behaviours of people of South Asian origin in the UK with a diagnosis of epilepsy: biomedicine, complementary and alternative medicine and ethnomedicine

Version: 1 Date: 7 September 2007

Reviewer: Sivasankaran P Sashidharan

Reviewers report:

General

The paper is too discursive. Needs to be tightened by

(i) shortening the introduction

The Background section has now been shortened.

(ii) expanding the methods section including

The Methods section has been considerably extended.

(iii) further description and details of sampling frame,

Further detail has been included.

(iv) inclusion criteria

Further detail included.

(v) and reasons for the very high non-response rate, not 66% as the authors say but 78% (based on 30/139).

139 was the sampling frame, not the final sample, which was 60. More detail and clarification of sampling methods have been included. The overall non-response rate was 50%.

(vi) Must give more information on how the interviews were conducted, whether the 2 interviewers approached the subjects similarly, how the focus group was set up, characteristics of attendees and how they differed from the interview sample.

Further detail on the conduct of the interviews included.
The interviewers worked in close collaboration with each other. This point has now been added to the text.

As this was a qualitative research project, the interviews were not standardised. The content of the interviews was guided by the topic guides to ensure that the same basic topics were raised in each interview, but additional topics were raised by the interviewees themselves. This has now been explained in the text for those not familiar with the techniques of qualitative research.

(vii) providing the data separately for focus group and interviews before drawing on common themes,

Only brief reference is made to the focus groups, since the groups were not asked specifically about CAM and data from the groups have not been included in this analysis. Similarly, data from interviews with health professionals have not been included. Findings from the full study have been reported elsewhere (Ismail et al.2005a,b,c; Small et al. 2005; Rhodes et al. 2008). This has now been clarified in the text.

(viii) providing age, gender and ethnicity for the individual quotes which are identified only by name now

This information has already been provided in Table 5. However, these details have now been included with the quotes.
(ix) making the conclusion section relevant to the findings of the study by abandoning the section Speculations for the future.

As suggested, this section has now been abandoned and integrated with the Discussion.

Major Compulsory Revisions (that the author must respond to before a decision on publication can be reached)

All the above requirements to be met.

Minor Essential Revisions (such as missing labels on figures, or the wrong use of a term, which the author can be trusted to correct)

Discretionary Revisions (which the author can choose to ignore)

What next?: Unable to decide on acceptance or rejection until the authors have responded to the major compulsory revisions

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests
Reviewer's report

Title: A qualitative study of the health-seeking behaviours of people of South Asian origin in the UK with a diagnosis of epilepsy: biomedicine, complementary and alternative medicine and ethnomedicine

Version: 1 Date: 1 October 2007

Reviewer: Sarah Gehlert

Reviewer's report:

General

Title: A qualitative study of the health-seeking behaviours of people of South Asian origin in the UK with a diagnosis of epilepsy—biomedicine, complementary and alternative medicine and ethnomedicine

Research article

Description: This article seeks to understand the use of CAM and ethnomedical treatment in addition to standard biomedical treatment for epilepsy among a group of South Asian patients obtained from epilepsy registers and hospital data bases in Leeds and Bradford. Inclusion criteria were age 18 years of age and older and listed in the epilepsy registry or hospital data bases as having epilepsy. In addition, South Asian origin was determined using data on “ethnicity, religion, and analysis of names.” (p. 5, last para., line 5). The authors tell us that 139 people met the inclusion criteria. Thirty people with epilepsy and 16 caregivers made up the final study sample.

Overall assessment: The information in this article is very interesting and potentially important for practice. For all intents and purposes, non-biomedical treatment for epilepsy has only been given serious consideration in the literature in the past decade. The authors gained some valuable insights about how decisions are made to use non-biomedical treatments. It is also quite interesting that CAMs are used so infrequently. I also think that framing with three theories of why people use CAM is a nice approach. Unfortunately, we have had to omit this last in order to comply with other reviewers’ requirement that the Background section be reduced in length.

Better explicating the methods would allow us to have much greater faith in the results.

The Methods section has been considerably expanded as suggested.

The abstract is less well written than the later parts of the article. In general, the article is acceptably written.

The abstract has now been revised.

Major Compulsory Revisions (that the author must respond to before a decision on publication can be reached)

Critique: In general, the methods section is terse and much is left inadequately explained. For example, the final sample consisted of Muslims from Pakistan, but also Sikhs and Hindus, presumably from India. A required revision would be to explain exactly how and by whom (i.e, a question of inter-rater reliability) persons were determined to be South Asian. “Using recorded information on ethnicity and religion and analysis of names” is too vague. What actually was done?

A specifically designed computer programme was used to determine ethnicity and religion. This has now been explained in the Methods.

Another required revision would be to define South Asian in terms of the population of Leeds and Bradford and to provide a breakdown by country of origin and perhaps by religion. Otherwise, it is difficult to evaluate the success of the authors’ sampling efforts. What was the target sample for the study?
A brief description of the study site and population has now been included. For clarity, we have omitted reference to Leeds, as only one person was recruited from there.

Likewise, the procedure for drawing a final sample from the 139 persons in the inclusion sample is confusing.

Further explication and clarification of the methods used have now been included.

What was the authors’ intended purpose for dividing into age bands (And, why these particular age bands? Based on what theory or prior work were the age bands constructed?) and gender. I can guess why this might have been done, but a reviewer should not have to guess.

As explained, this was done to obtain a sample which reflected the age and gender demographics of the population of people of South Asian origin in Bradford with a diagnosis of epilepsy. However, more detail of the sampling procedure has been included.

Why, for example, was professional status or SES not also used as a criterion (in other words, why did the authors think age and gender were the most salient criteria for stratifying their sample?)? Did this have something to do with available information (was only age and gender available? If so, how might this affect results)?

The reviewer correctly identifies that we did not have access to socio-economic data on individuals. However, the South Asian population live predominantly in the most socio-economically deprived inner city wards and our sample reflects this, with most participants at the lower end of the socio-economic scale. We have now explained this in the text.

Likewise, why did the authors assume that “our population would reflect a distribution of severity typical of any community-based population?” (p.6, last sentence, para. 1). What characterizes a “typical community-based population”?

We accept this point and have omitted this sentence. However, we note that the eventual sample comprised individuals with a range of severity and adequacy of control through anti-epileptic drugs.

Bottom of page 2, penultimate line: What do the authors mean by “professional South Asian approaches to health care?” This is not transparent.

This has now been changed to "a well-established network of community-based, traditional South Asian approaches to health care".

Page 3, third para.: The authors write about a “small study of health beliefs and experiences.” Do they mean the present study? If not, the study to which they refer should be cited.

This point has now been clarified.

How data from caregivers were used is unclear. Were these data used in the same way as data from informants with epilepsy?

The data from the interviews with carers were analysed separately and this has been made clear in the text.

Fourteen informants did not provide names of caregivers. Were they asked why? Did they lack caregivers or were they uncomfortable having them interviewed? This is important to interpreting the study’s results.

This information has now been provided.

Providing more detailed information on interviews is as compulsory revision. It seems quite good that many sources were used to develop the interview guide. What was the process of collecting this information, however (e.g., how systematically was it done? What was the modality? Focus groups?)? How/by what process were the data reduced?
Further details of this process have been included in the text. The topic guides were informed by a literature review and informal discussions with patients and health professionals, and were developed in collaboration with the research advisory group, which included representatives from local communities and the hospital and community epilepsy service.

We are told that interviews were done by three persons? How was reliability of the interview across interviewers determined/insured? Were tapes reviewed for this purpose?

The interviewers worked in close collaboration with each other. This point has now been added to the text. As this was a qualitative research project, the interviews were not standardised. The content of the interviews was guided by the topic guides to ensure that the same basic topics were raised in each interview, but additional topics were raised by the interviewees themselves. This has now been explained in the text for those not familiar with the techniques of qualitative research.

Who conducted the interviews in Urdu and Punjabi? What were the credentials of the interviewer(s)?

This information has now been provided.

More importantly, how many individual interviews were conducted?

This has already been stated but we have provided some further clarification.

Why were some people interviewed in focus groups? I would expect that whether the interview was focus group or individual would influence responses. People generally are much less forthcoming in groups. How exactly were the focus groups conducted? How were groups assembled? In reports of focus groups, authors generally tell whether efforts were made to include persons who did not know one another previously, etc. Were Muslims and Hindus put in the same groups?

Only brief reference is made to the focus groups, since the groups were not asked specifically about CAM and data from the groups have not been included in this analysis. Similarly, data from interviews with health professionals have not been included. Findings from the full study have been reported elsewhere (Ismail et al. 2005a,b,c; Small et al. 2005; Rhodes et al. 2008). This has now been clarified in the text.

Whereas the methods section is terse, the Speculations for the future section is much too long. It is indeed speculation. The authors’ views are interesting, but should be used to illuminate the discussion section rather than be afforded a separate section. The second and third paragraphs on page 18 are really not pertinent for a research article.

We have now integrated this last section with the Discussion, as suggested.

Minor Essential Revisions (such as missing labels on figures, or the wrong use of a term, which the author can be trusted to correct)

Discretionary Revisions (which the author can choose to ignore)

What next?: Unable to decide on acceptance or rejection until the authors have responded to the major compulsory revisions

Level of interest: An article of importance in its field

Quality of written English: Needs some language corrections before being published

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests.
Reviewer's report

Title: A qualitative study of the health-seeking behaviours of people of South Asian origin in the UK with a diagnosis of epilepsy: biomedicine, complementary and alternative medicine and ethnomedicine

Version: 1 Date: 21 October 2007

Reviewer: Magdalena Szaflarski

Reviewer's report:

General

Major Compulsory Revisions (that the author must respond to before a decision on publication can be reached)

Minor Essential Revisions (such as missing labels on figures, or the wrong use of a term, which the author can be trusted to correct)

Discretionary Revisions (which the author can choose to ignore)

REVIEWER'S GENERAL COMMENTS:

The paper describes attitudes and behaviors associated with CAM and ethnomedicine use among South Asians with epilepsy living in the north of England. The question is interesting, as there is an emerging literature about the role of CAM and traditional beliefs affecting therapy in people with epilepsy. Important implications for biomedicine include treatment interactions, adherence, and the need for culturally sensitive health care delivery. This study, despite its limited scope, could potentially inform epilepsy providers and improve health care delivery. However, the paper needs to be strengthened in several areas in order to be effective. The main weaknesses of the paper include

1) limited application,
2) lack of clarity in the main purpose of the study (background section), and
3) incomplete description of and rationale for the methods. Also,
4) the abstract could be improved to better communicate the study's purpose and message.

We have addressed each of these points. See below.

REVIEWER'S SPECIFIC COMMENTS:

Major Compulsory Revisions:

1) Limited application

This study focuses on a specific ethnic and disease population within one geographic area. It is not clear how the findings apply to other populations and other locations. While health care providers in the north of England could be interested in the study, there is limited justification for presenting the study to a broader (international) audience.

In recognition of this point, we have made stronger reference to the wider relevance of the study to areas of South Asian settlement worldwide. We have also included a section on the implications for clinical practice.

The study lacks a stronger link to the existing literature on the use of CAM and ethnomedicine in other countries/populations (e.g., research on Native American Indians in the United States – Debruyyn 1990).

There are many studies of the use of ethnomedicine in different ethnic groups and cultural contexts and we have taken account of the literature relevant to the ethnic group discussed in the study and more widely
where appropriate, for example we refer to literature on the health-care strategies of migrant groups more generally. We found deBruyn's work very informative.

Implications of the findings for other populations and locations should be further explored in the discussion. It is important to demonstrate a broader application of the findings.

As suggested, we have extended the discussion to include these issues. We have made stronger reference to the wider relevance of the study to areas of South Asian settlement worldwide and have included a section on the implications of the findings for clinical practice.

2) Purpose of the study

The purpose of the study is not well explained. It is not clear if the primary focus is on the disease (epilepsy), the South Asian population, or ethnomedicine.

We are grateful to the reviewer for bringing this to our attention and have provided greater clarification by explaining how the study addressed a gap in the published literature by extending the study of ethnomedicine in relation to epilepsy to a migrant population and a western urban context.

There is little in the background about epilepsy except to say that “it might be considered a prime candidate for the use of CAMs” (p. 3). At the same time, much space is devoted to defining or describing “CAMs”, ethnomedicine, and the South Asian community and its practices. The role of epilepsy appears peripheral.

We have redressed this imbalance by extending our discussion of epilepsy and reducing that of CAM.

It would help to clarify whether the purpose is to inform about the role of ethnomedicine in the treatment of epilepsy or whether epilepsy is used to illustrate a group-level phenomenon (health care practices of an ethnic population). The background section could be tightened up to better present the argument for the study. The section is currently on a longer side, presenting ideas coming from different angles; it could use more focus.

In light of this comments, we have revised the Background section. Epilepsy is presented as an example of a chronic condition, in which conventional biomedicine has limited efficacy and for which people are known to turn to CAM.

On a substantive note, the statement indicated above about epilepsy being a prime candidate for the use of CAMs is confusing: what is the purpose of CAM in epilepsy if it ‘can usually be controlled with AEDs’? Perhaps attention should be drawn to the issue of medication-resistant epilepsy and seeking alternative treatments for that particular type of epilepsy.

CAM is not used specifically to treat intractable epilepsy; one study found no relationship between CAM use and epilepsy severity (Easterford et al. 2006). There may be many different motivations for using CAM and more work is needed in this area.

In the same paragraph (p. 3), please give examples of CAM that people with epilepsy use, based on the literature.

Details of CAM therapies have now been provided.

Also, the use of CAM for general health purposes by people with epilepsy does not make them any different from people without epilepsy. Why would it then be important? Shouldn’t the focus be on the use of CAM specifically for epilepsy?

We accept this point and have omitted the reference to use for general health purposes.

3) Incomplete description of or rationale for the methods

The study uses appropriate methodology, but more clarification is needed.
a) What was the purpose and rationale for interviewing the carers?

In recognition of the role of families in people’s experience of epilepsy, where possible, the views of the person with epilepsy were supplemented with those of another family member. This rationale has now been included.

b) Please provide some background on the interviewers (e.g., whether of matched ethnicity with patients and level of training/experience).

Relevant information has now been provided.

c) Furthermore, how was the data analysis conducted – as a group? If as a group, please describe the group/qualitative process.

Regular meetings of the research team and research advisory group, where emerging themes were discussed, were held throughout the periods of fieldwork and analysis. Further detail about the process of analysis has been provided.

d) Also, please discuss any potential biases due to the respondent being interviewed at home, possibly in the presence of others, and the issue of conducting interviews in different languages.

We have addressed these points in our discussion of possible limitations to the study at the start of the Discussion section. Difficulties in translation were discussed between the interviewers and with the rest of the research team.

4) Abstract

The abstract lacks clarity and is somewhat misleading. The statement in the conclusions about “ignorance of the services on offer and a failure to market CAMs” is surprising and reflects a value judgment. It is not clear at all why these services would be needed. Nowhere in the paper is there evidence presented to the efficacy or usefulness of CAM in epilepsy. Also, the writing in the abstract could be improved (e.g., in the abstract’s conclusions, the referent is not clear: “Those who made the decision to and the recipients of the treatment were not necessarily the same people and their motivations, perceptions of safety and efficacy were often very different.”).

The abstract has been revised along the lines suggested.

Minor Essential Revisions:

1) P. 2, end of the middle paragraph, where CAM is defined. Please provide examples of CAM.

Examples have now been provided.

2) P. 3, bottom, Tandon et al. reference. It should be noted that others have presented similar ideas, e.g., John Astin (1998, 2000), Regis Blais; see Kelner et al. (2000).

We have now included references to these and others’ work.

3) P. 5, end of first paragraph. A very important issue is raised: beliefs about supernatural causes of a disease. This issue should be discussed further in the context of epilepsy.

This issue has been addressed in other published articles (Ismail et al. 2005; Small et al 2005; Rhodes et al. 2007) and it is therefore not appropriate to reiterate them here. However, we have now drawn readers’ attention to the relevant references.

4) P. 5, bottom paragraph: “reference to be supplied”

Reference has now been supplied.
5) On the results, it would be helpful to see the distribution of age, gender, and occupation in the whole sample (Table 1). This information is currently provided only for the subjects cited in the paper (Table 3).

A table detailing this information for the whole sample has now been included.

Discretionary Revisions:

1) The title could be more informative. It is not clear what the specific focus of the study was. The focus does not appear to be on qualitative methodology per se, so the reference to the specific type of study could be dropped. Suggestion for a new title: “The use of biomedicine, complementary and ethnomedicine among South Asians with epilepsy in the north of England.”

The title has been amended.

2) “Ethnomedicine” is used in the title but not in the abstract. “Traditional healing” is used in the abstract. Clarification/consistency in the wording would be helpful.

This has now been clarified.

3) The abbreviation “CAMs” is introduced in the abstract without any explanation. First, it is better to avoid abbreviations in an abstract. Second, “CAMs” is not a universal term. In the United States, “CAM” (singular) or CAM therapies/modalities (plural) are the preferred language. For a broader (international) audience, a clarification on this point could be helpful early in the paper.

The abbreviation has been amended as suggested.

4) Abstract’s conclusions could be shortened.

The abstract conclusions have been shortened.

6) Background is on a longer side. Parts of background could be moved to the discussion.

We have cut some sections from the Background and moved others to the Discussion.

7) P. 9, second paragraph, sentence “Given recruitment of the sample through medical records…” could be moved to the discussion as a limitation.

We have moved this to a new section on limitations at the beginning of the Discussion.

What next?: Unable to decide on acceptance or rejection until the authors have responded to the major compulsory revisions

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests.