Author's response to reviews

Title: The use of biomedicine, complementary and alternative medicine, and ethnomedicine for the treatment of epilepsy among people of South Asian origin in the UK

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

Title: The use of biomedicine, complementary and alternative medicine, and ethnomedicine for the treatment of epilepsy among people of South Asian origin in the UK

Version: 2 Date: 5 January 2008

Reviewer: Sarah Gehlert

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

Research article

Description: This article seeks to understand the use of CAM and ethnomedical 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. South Asian origin was determined using a computer programme to review names. The authors tell us that 139 people met the study's inclusion criteria. Thirty people with epilepsy and 15 caregivers made up the final study sample.

Critique: In general, the authors have successfully addressed previous comments. The methods section is less terse and more explanation is provided. Nonetheless, concerns remain.

Major Compulsory Revisions:

In discussing their focus group activities, the authors refer (on the bottom of page 7 and the top of page 8) to the full study that has been reported elsewhere, and provide a number of references for the latter. The reader very well may not be privy to the larger study. By way of explaining the purpose of the focus groups, the authors say that views were sought on unrelated subjects (presumably unrelated to the present study). They go on to say that focus group members were not asked specifically about CAM and the data have not been included in this analysis. Because the paragraph on focus groups is tangential to the study being reported, it should be omitted from the manuscript.

This paragraph has been duly omitted.

Likewise, in two places in the manuscript (second line of page 6 and middle of page 8), the authors make reference to a project advisory group. Because the study is never explained, and thus its structure is not known, the tacit mention of the advisory group only confuses. It is admirable to have a project advisory group, but it should either be explained as part of the study's description or omitted.

A paragraph detailing the project management structure has now been added.

In the abstract and elsewhere, the authors say that they analyzed data using a framework approach. They reference a 1984 chapter by Ritchie and Spencer on qualitative analysis in general. The term framework approach is not common among those of us who conduct qualitative research (at least in the United States). The authors should use different words to describe their qualitative data analytical method.
We have amended the wording to clarify the procedure.

Results are presented in first sentence of the last paragraph of the background section of the manuscript. These should be reserved until the results section.

We are not talking about specific results but about why a study of this nature is likely to be of wider relevance beyond the immediate group studied.

The authors responded to initial reviewers’ concerns about reliability of interview data by commenting that: (1) interviewers were experienced in the techniques of qualitative research and (2) interviews were guided by topic guides to ensure that the same basic topics were raised in each interview. The threat of drift from a topic guide is real and never completely ameliorated by training. Fidelity in using a topic guide is a real issue that should be assessed to ensure that, in the authors’ own words, the same basic topics were raised in each interview. Some systematic review of a sample of the recorded transcripts should be undertaken.

We agree with the reviewer that drift is a potential problem for all, despite experience and training. However, these were not, or ever intended to be, standardised interviews. Qualitative techniques were used precisely because they allowed the interviewer to explore issues which he/she deemed relevant but which were not covered in the topic guide. In this context, we think it significant that both interviewers were highly experienced in the method and worked in close collaboration and that all transcripts were reviewed by the principal interviewer. With this approach and resources at our disposal we feel we have engaged with the challenge of drift as well as we might have. In our experience, "drift" can prove to be a rich source of data. Moreover, if one takes the view that qualitative interviewing involves more than simply a one-way traffic of information, drift can be seen as a necessary component of exchange (See the widely influential work of Oakley, A. 1981 “Interviewing women” in Roberts, H. Doing Feminist Research, Routledge or Graham, H 1984 Surveying through stories, in Bell, C. and Roberts, H. Social Researching, Routledge.) A whole generation of UK qualitative researchers has grown up referring to Oakley and Graham!

Likewise, frequent meetings do not ensure that themes and sub-themes were extracted in the same way by all who undertook the task. Some method of assessing inter-rater reliability should be used.

The initial coding was undertaken by the principal interviewer (HI) to ensure consistency and was reviewed by members of the research advisory group. Our intention was not to aim for inter-rater reliability in that, like Barbour in an influential article in the British Medical Journal (2001), we take the view that:

'the degree of concordance between researchers is not really important; what is ultimately of value is the content of disagreements and the insights that discussion can provide for refining coding frames. The greatest potential of multiple coding lies in its capacity to furnish alternative interpretations and thereby to act as the "devil's advocate"...... in alerting researchers to all potentially competing explanations. Such exercises encourage thoroughness, both in interrogating the data at hand and in providing an account of how an analysis was developed. Whether this is carried out by a conscientious lone researcher, by a team, or by involving independent experts is immaterial: what matters is that a systematic process is followed and that this is rendered transparent in the written research project.' (Barbour 2001 p.116)
We have now added this point to the text.

The authors move directly from the results section to a general discussion of results without first outlining the study’s basic conclusions. This is confusing. A summary of conclusions should be added prior to the discussion. A summary has now been added.

The authors address the possible effect on results of jointly interviewing patients and caregivers. They should add a sentence explaining why joint interviews occurred. Nominated carers were interviewed separately, except on four occasions when joint interviews were conducted at the request of participants.

Minor Essential Revisions:

The phrase “the eighth most deprived health community” on page 4 is not clear. What is a deprived health community? This has now been clarified and a reference added.

Five arguments are offered for why clinicians should be interested in CAM and ethnomedicine. The first is not a complete thought. It should be completed (an increasing number of patients are now using CAM both for general health purposes and specifically for the treatment of epilepsy, and thus...).

The sentence has been changed to: 'First, an increasing number of patients are now using CAM, both for general health purposes and specifically for the treatment of epilepsy: clinicians need to be aware that it may feature among the options being actively considered by patients.'

The authors might want to include at some point the issue of interactions between ethnomedicines and anticonvulsant drugs. Being aware of ethnomedicines can prevent adverse interactions. This point has already been made. However, we have changed the wording to give it greater emphasis.

In mentioning the a study of people with epilepsy of South Asian origin living in the north of England in the abstract, the authors should make clear that this is their (the present) study. This point has now been clarified.

Discretionary Revisions:

The authors leave some procedures unexplained. Although they have greatly improved the methods section, a few issues remain. Stratifying the sample makes sense, but why did they choose the age bands that they used? These bands range from 7 to 12 years. This is odd and begs explanation. The following sentence has now been added: The European Standard population age bands were used, based on previous epidemiological research [21].

Also, the reader need to substantiate their assertion that responders and non-responders did not differ in terms of age banding or gender (page 6).
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.

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 outstanding merit and interest in its field

Quality of written English: Acceptable

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