Author's response to reviews

Title: 'We call it the shaking illness': perceptions and experiences of Parkinson's disease in rural northern Tanzania

Authors:

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Version: 2 Date: 6 March 2011

Author's response to reviews: see over
Dear Prof Ovbiagele,

Re: MS: 1204544795455967 ‘We call it the shaking illness’: perceptions and experiences of Parkinson’s disease in rural northern Tanzania.

Many thanks for your email of the 17th of February 2011. Please find attached a revised version of the manuscript addressing the reviewer’s comments (in track changes). Following is a detailed response on their comments:

Referee1 (Gretchen L Birbeck)

Minor essential revisions
1. Page 5, paragraph 2, line 3: “only a matter of perception”. A person’s self report of sexual satisfaction is by its very nature limited to a perception.

Response: We have removed the words ‘may only be a matter of perception’ in the sentence. The sentence now reads ‘This is a matter of perception’ to take into account the reviewer’s comment.

Page 6, paragraph 2, line 3: “geographic” features is probably more appropriate than “physical”

Response: We have replaced the word ‘physical’ with ‘geographic’.

Discretionary Revisions
The study that led to this work was a population-based prevalence study. It would be helpful to provide this prevalence information and/or cite the study that does. The treatment gap was massive (26/28 untreated). What evidence did you encounter for the problem being missed by healthcare workers who saw the patient but failed to make the diagnosis? PD is an “across the room” diagnosis once someone has any significant disability. Were these untreated patients people who were never seen by HCWs? Never diagnosed? Or diagnosed but treatment not available?

Response: We have added a paragraph in the background (2nd paragraph) providing information from the prevalence study. We state that 32 PD cases were detected and provide age standardised prevalence rates. We also say that the majority of the 32 cases were not diagnosed nor treated prior to our study. As pointed out in our results
section, there are widespread misconceptions about PD even among the health workers in the study areas. In addition, none of the healthcare workers had specialised neurological training, hence it was difficult for them to make the appropriate diagnosis. We have also added references 6 and 7 in the paragraph to contrast our findings with those from other countries.

Referee 2 (Elialilia S. Okello)

1. Minor Compulsory Revision

The objective of the paper is stated in the abstract at the very beginning of the manuscript and it read: “There are no Parkinson’s disease (PD) social science studies published from Africa. This paper presents findings from a qualitative study on how PD is perceived and treated in a rural Tanzanian setting” To me it is only the last sentence that seems to tell the reader what the manuscript is all about. I will recommend that the authors either transfers the first sentence to the introduction which apparently is missing from the abstract or delete the sentence altogether.

Response: We have added some information within the background of the abstract to put the study into context e.g. we have added a sentence at the beginning of the section. The section now reads:

Background: Parkinson disease (PD) may cause physical disability that negatively affects the quality of life of the sufferer’s and their families. There are no Parkinson’s disease (PD) social science studies published from Africa. This paper presents findings from a qualitative research study on how PD is perceived and treated in a population of approximately 161,000 within a demographic surveillance site in rural Tanzania.

Soundness of the data

The data were sound as evidenced by the quotations used. However, data from some of the source is not reflected in the finding section. For instance the authors tell the reader that data sources included Traditional healers, health workers and community members, but from the quotation used a reader gets a feeling that the voice of these group of respondents is lacking. One would love to know whether all these data were used in this article or not.

Response: Our paper draws from all the stated data sources i.e. semi-structured interviews with PD sufferers, carers, health workers and traditional healers. It is true that the quotations have come from the sufferers and carers, but we also present data from the health workers, traditional healers and participants of the Focus Group
Discussions (FGDs). We have summarised the views of the different groups and data source in Tables 1 and 2. Table 1 summarises findings on perceived causes, symptoms, and prevention from the sufferer’s, carers and health workers. Table 2 summarises the same information from FGDs participants.

In another example, in page 14 (under the section on Awareness) we report about the views of the traditional healers as follows:

The 2 traditional healers expressed similar PD views as other community members. They could not give a specific name for the illness but talked of it through describing the major symptoms such as the tremor and walking difficulties. Their treatment regime comprised of undoing the witchcraft and treating the visible symptoms.

Adherence to the relevant standards for reporting and data deposition
The manuscript adheres to qualitative data reporting standard. The authors chose to report the finding by data source, which the approach best suited for data that used multiple sources. However, as noted above following this approach of data presentation the reader would have expected to see findings from the entire data source described in the method section. But the manuscript is silent about some of the data sources as evidenced by the quotations used.

Response: Please refer to our response to the previous comment

Under the theme: treatment seeking, the authors mention in passing the issue limited or lack of access to treatment. To me this is an important issue that deserved more attention.

Response: We discuss issues of access, diagnosis and treatment in the discussion and conclusions. Please see our response to the next comment below.

Discussion and conclusions
The discussion section is well written. However, as indicated above the issue of lack of access to treatment for PD is an important issue in resource limited settings like Tanzania. One would have loved to see it come up in the discussion, unfortunately this did not happen. I would recommend that the authors comment on the issue of lack of access to treatment, and may be provide some recommendation on how the issue should be dealt with.

Response: We have added some sentences at the end of the discussion to address this comment. The sentences (on page 18) read:

Furthermore, any PD treatment programmes in developing countries settings must ensure that the costs of the lifetime treatment drugs is
affordable to resource constrained populations residing in the rural areas. An example of such an approach may involve technical corporation and joint efforts to fund-raise for the treatment programmes between local health authorities (such as the office of the district medical officer) and national and international partners.

**Comprehensiveness of the abstract**
Generally the abstract conveys what was found out. But as mentioned above the abstract needs polishing especially the objective which needs to be stated more clearly.

*Response: Please refer to our response to the 1st comment of the referee.*

Comment from the editor:

*Response: We have also included contextual information about our study in the background of the abstract. The background now reads:*

**Background:** Parkinson disease (PD) may cause physical disability that negatively affects the quality of life of the sufferer’s and their families. There are no Parkinson’s disease (PD) social science studies published from Africa. This paper presents findings from a qualitative research study on how PD is perceived and treated in a population of approximately 161,000 within a demographic surveillance site in rural Tanzania.

I hope we have adequately addressed the reviewer’s comments to warrant publication of the manuscript in your journal. I look forward to hearing from you.

Sincerely,

[Signature]

Dr. Gerry Mshana.