Author's response to reviews

Title: Under the banyan tree - exclusion and inclusion of people with mental disorders in rural North India

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Author's response to reviews: see over
Dear BMC

I have systematically gone through and responded to each comment or suggestion by reviewers. These comments have also been reviewed by IG the last author.

Changes made in response to comments are also given.

Thank you

Yours sincerely

Kaaren Mathias – First author

Comments from Reviewer One
It has been mentioned that out of 20 PMWDs included in the study, 19 had severe disorders. Please mention clearly if care givers were interviewed for all patients with severe disorders.

RESPONSE: I have clarified in Methods section in Line 133 that while all caregivers were interviewed, only the data of the 7 caregivers of the most severely unwell PWMD was included in data analysis.

It is also mentioned in the manuscript that 13 PMWD were interviewed separately from the care givers. Did any important finding emerge when the PMWD were interviewed separately.

RESPONSE: I have added a new sentence in line 134 which responds to this query “These interviews did not reveal data importantly different to those conducted with both caregiver and PWMD present.”

Second reviewer
1. It would be nice to mention the approach to research such as descriptive, ethnography, phenomenology etc. as a theoretical underpinning of the research.

RESPONSE: Line156 already clearly states ‘research was analysed using qualitative content analysis.

2. It would be better to mention the qualification of authors in qualitative research (e.g. trained\experienced in qualitative research)

RESPONSE: added to Line 140 “The first author, who is trained and experienced in qualitative research ....”

3. The details as how transcripts were prepared, how field notes were taken would be nice

RESPONSE: Lines 145-147 now have increased detail as follows : “Interviews were recorded verbatim with a digital voice recorder, then listened to repeatedly, translated and transcribed from Hindi to English using word processing software by the research assistant.”
4. Please follow some guidelines for reporting qualitative research (for example Consolidated Criteria for reporting qualitative research)

RESPONSE: First author has gone through the 32 point Checklist of Qualitative research Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups Allison Tong, Peter Sainsbury, Jonathan Craig International Journal for Quality in Health Care (2007)(1). The manuscript was nearly fully compliant with this checklist however Additions made to the manuscript in response were to add in location of data collection (in participants homes) and to clarify presence of some non-participant relatives at several interviews. (Line 143,144)

5. In discussion, it would be better to mention the ethical issues faced and the way it is addressed.

Response – Ethical concerns are outlined in the Ethics section of the Methods section (Lines 162 – 165) and sit better here rather than in the body of the discussion.

Reviewer Three

The sentence in the line 94 “the halo effect of stigma” is not clear.

RESPONSE Line 94 is expanded to make it clearer now saying “the halo effect of stigma i.e. the excluding social processes such as reduced marriage opportunities for female relatives, that impact whole families.”

Lines 101 and 102 should be transferred to “setting” in the methods section.

RESPONSE: Completed and moved to Lines 107 and 108.

Methods section

Lines 107-108, “the study was set in two administrative blocks of western Uttar Pradesh”. What kind of place is that? Where exactly were the data collected? Is Emmanuel Hospital Association part of the location where the data were collected? Is that association important in the context of the data collection?

RESPONSE: We have expanded the information on the setting following this reviewers suggestions to now read at Line 109-112:
We worked with two project teams of Emmanuel Hospital Association (EHA) (www.eha-health.org), an organisation that works across North India in community health and development. These teams had been focussing on community mental health promotion since April 2012 (Saharanpur district) and April 2013 (Bijnor district).

There is also more detail on the type of place where data were collected in Lines 122 – 127.
You should also explain briefly the mental health plan in India. See line 115.

RESPONSE DMHP is expanded briefly so that Lines 117,118 now read
“The national District Mental Health Plan seeks to ensure that there is a psychiatrist and psychologist as part of a mental health team for each district.”

Some others points are not clear:
- Which criteria were used by the researchers to select the participants of the study?
- How were the participants selected and recruited?

RESPONSE: Lines 129-135 has been revised to address above concerns and now reads:
EHA community workers identified potential participants fulfilling the following inclusion criteria: A People with a likely mental disorder; B People greater than 17 years of age; C People willing to participate in this study and D People living with family members/ a caregiver. The first author screened these potential participants for a mental disorder using the Global Mental Health Assessment Tool (2) and identified 20 PWMD/primary caregiver dyads (pairs) who consented to be interviewed for this study. 19 of 20 PWMD experienced severe disorders (E.g. schizophrenia or post-partum psychosis).

In the lines 117 and 118 you referred that PWMD visit “local doctors and traditional healers”, aren’t they the same? If they are not, please explain it.

RESPONSE: Clarified the difference by changing text to “local doctors and traditional religious healers”

Participants

The expression “mentally unwell” does not seem appropriate and it is cited throughout the text, what do mean by it? I am wondering that those people have presented psychotic symptoms, delusion, depression, etc. Please, clarify what exactly you considered “mentally unwell”.

RESPONSE: I have expanded the ‘definition’ of mentally unwell to clarify what it means and I believe it is appropriate in this setting. Now Lines 138 and 139 read:
“Seven (of 20) PWMD were too unwell to contribute to interviews (i.e. they were psychotic or non-responsive and unable to concentrate)”

In the line 126, I would suggest “the first author screened potential participants identified by……” instead of “a female medical doctor of …..speaks Hindi”.

RESPONSE: The ‘Consolidated criteria for reporting of qualitative studies (2007)(1) supports reporting the gender and role of investigators so we have written the above sentence as:

The first author (a female medical doctor) etc

In line 128, you should clarify what is “dyads” and “who fulfilled specified criteria” (which criteria are you talking about?) Please, revise the paragraph.

RESPONSE: Lines 129 – 135 Paragraph has been revised to address these concerns – pasted above.

In lines 143-144, I would exclude the sentence “there appeared to be a trusting relationship between the interviewer and participants”. You do not need to write it.

RESPONSE: Removed as suggested

In the lines 152-153, I suggest to exclude or to modify the table 1, because it does not show, in my point of view, the process of coding.

RESPONSE: Isabel – I think this is not a fair comment so I suggest my response as follows – but what do you think

Table 1 shows how qualitative data was condensed from a Code to a Category to a Theme. Reporting of this process is supported in the Consolidated Criteria for Reporting Qualitative research (2007)(1)

Results and Discussion section

I would suggest to reorganize this section including sub-headings separating exclusion’s categories, inclusion’s categories and the experiences of inclusion and exclusion together.

RESPONSE

This has been reorganized using the headings suggested

The sentence in line 167 “a dappled texture rather than uniform darkness” is not clear. What is the meaning in the context of the study?

RESPONSE

167 alludes to the fact that exclusion and inclusion are both experiences of PWMD so that there is not uniform darkness for PWMD. Now line 175 reads “showing experiences to have a dappled light mixed through the darkness of exclusion”

In line 190 the sentence “participation in family fora” is unclear.

RESPONSE changed to “participation in family discussions”
In line 229 “this was built on ignorance”, is this statement referred to author’s reflections or an interpretation of the participants? It seems that this is a case of cultural beliefs, some kind of symbolic contamination. You can maintain if this interpretation came from the participants.

\textit{RESPONSE} removed the phrase ‘this was built on ignorance’ as not necessary to the commentary

In line 269, the category “verbal, economic and physical violence” does not seem appropriate in relation to the meaning of the statement, which follows in lines 272,273-274. You could exclude, put the statement in another category or rename the category.

\textit{RESPONSE} This category refers to experiences of participants of verbal abuse (violence), economic exclusion (disinheritance) and physical violence – I believe that these experiences are well captured by a heading “verbal, economic and physical violence” so have the retained this category (ISABEL any thoughts?)

“Virtual excommunication” is not clear in lines 278 and 279.

\textit{RESPONSE} This relates to the respondent describing her family choosing to stop all communication with her – I believe this is clear in the quote and substantiated so feel it should remain as it is.

The “Methodological consideration” section should be put in the methods section.

\textit{RESPONSE: This is a discussion of the relevant methods considerations / limitations of the study and in most studies this is retained after the Discussion so as this was not a concern for Reviewers 1 and 2 we have chosen to retain its original position}

The last sentence in the conclusion section in lines 493-494, “exclusion is a chaotic mix of light …..dappled shade beneath a banyan tree” - this is a metaphor that does not make sense for people outside the Indian culture. So you could explain or change it.

\textit{RESPONSE} : The last 2 lines now read: The banyan tree typically stands sentinel in most Indian villages, a large umbrella of branch and leaf, with shafts of sunlight filtering through. Like most facets of human experience, inclusion and exclusion are a chaotic mix of light and shadow as complex as the dappled shade beneath a banyan tree.

See the Table 3 line 657. I think that you should not use psychiatric diagnostic, if the participants do not have one. I suggest excluding the column of “possible illness”.

\textit{RESPONSE –Table 3 is helpful to interpret and understand the context of comments of}
participants. The psychiatric diagnosis of post partum psychosis for example is a short term severe mental disorder and provides the reader with understanding as to why these respondents are so lucid in their responses. It is given clearly with the proviso in the Methods section that this is just a presumed diagnosis given by a primary care practitioner (First author).