Author’s response to reviews

Title: “I feel myself incomplete, and I am inferior to people”: Experiences of Sudanese Women Living with Obstetric Fistula in Khartoum, Sudan

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Author’s response to reviews:

The authors thank the editor and the reviewers for the useful and informative comments. Regarding the quality of writing and English language, the manuscript was sent to a native English speaker (a British PhD student) to be revised. The authors revised the manuscript according to his feedback.

Editorial feedback:

In the revised version, please refer to the COREQ reporting guidelines for qualitative research (Tong 2007): https://www.ncbi.nlm.nih.gov/pubmed/17872937. Please include a table as an appendix outlining where in the manuscript each reporting criteria can be found.

The authors thank the editor for the suggestion, the COREQ reporting guidelines for qualitative research were followed and included in the references list (please refer to lines 5 and 6, page 8), in addition a table that highlights where each reporting criteria is located in the text has been submitted as an appendix.

Reviewer 1:

While I commend the efforts of the authors to share the Sudanese experience of living with fistula, they need to present some novelty on the topic. Stigma as a result of fistula has been among the most documented topic on fistula. I expected to read about women who are still experiencing stigma and some women who are not (Those experiencing iatrogenic fistula for instance). Also, we know that some husbands, partners or families are very supportive and I think that these good practices need to be highlighted. I miss that in the paper

- The authors would like to thank the reviewer for all the comments. They found the comments to be useful and have worked on them as suggested.
There are studies about stigma connected to fistula from other countries but to our knowledge, none is published about the experience of Sudanese women living with obstetric fistula. The Sudanese people on the ground would appreciate being represented and their own voices heard. We think that the study is valuable to Sudanese researchers as reiterated by the 2nd reviewer who stated that this paper will make obstetric morbidity visible.

This paper is specifically about obstetric fistula i.e. the fistula that happens as a complication of childbirth therefore, iatrogenic fistula is outside the scope of this paper.

Regarding support from the families and husbands, according to the findings of this study, the majority of our study participants did not receive support from their husbands, many were divorced because of fistula. We only had one case where the support of the husband was very prominent and it was reflected as part of emotional-based coping – emotional support. Please see page 13, line 30.

The previous sentence says "the ward was constituted...floors" while you say here "The first floor contained two postoperative wards". This is confusing. Comment on page 6, line 27;

The paragraph was revised to avoid confusion, please refer to page 6, lines 12-21.

This section contains many information that belong to the "result section, page 6, line 37

The authors moved all information related to the demographic characteristics of study participants to the findings section as advised, please refer to page 9 lines 21 – 32, also table 1 was transferred to the findings section please check page 10.

Confusing, comment on page 6, lines 40 -41 and 45 -47.

The subsection about study participants was revised to avoid confusion, please see page 6 lines 21 to 32.

( : ) to be excluded from the text, comment on page 8, line 14

Deleted as advised, please see page 7 line 16.

Not useful in the text, comment on page 8, line 24; “the first author is fluent in Sudanese Arabic dialect”

The sentence was deleted as advised, please see page 7 line 24.

One would wonder what are these frameworks. I do not recall that you have described them somewhere in the methodology, comment on page 8, lines 39 & 40,

This study drew upon the concepts of stigma and the transactional model of stress and coping by Lazarus and Folkman, they were used to inform the data analysis and to
explain findings. The theoretical frameworks were highlighted on page 5, lines 15-34 and page 6 lines 1-6 in the theoretical frameworks section.

How did the first author address this challenge? Comment on page 9 lines 5 & 6 “The first author is a medical doctor and, in Sudan, the relationship between doctor and patient is authoritative and it potentially would have affected the quality of the data collected”

- The authors added three sentences to address the challenge, please refer to page 8 lines 19 – 23.

The reviewer commented on the findings section on page 9 that the authors should first describe their population. The information has been put in different sections of the methodology, affecting the structure of the paper as compared to the IMRAD format

- The authors thank the reviewer for the comment, characteristics of women who participated in the study were moved to the findings section as advised.

Are the names changed or is it their real names? Ethically you should not use their real names. Adding the age of the woman you are citing would give more perspective. Page 9, line 27

- All participants were given pseudonyms i.e. alternative names – please check table – 1, page 10. Pseudonyms were used to anonymize the identity of the women. Only the first author had access to the list linking pseudonyms to real participants names.

- Regarding inclusion of the age of the women, we have included the ages as advised throughout the findings section.

This is an interesting finding and I do not recall reading it somewhere else, did you explore if this practice had any health consequence for women and if that reduced their stigma? Page 13, line 21

- Smoke bath is a Sudanese tradition. Unfortunately to our knowledge there are no published papers about the health consequences of smoke bath. According to our study participants, it helped them conceal their condition by hiding the smell of urine and reducing the amount of urine dispensed. As such this manner of concealment might have reduced the degree and frequency of stigmatization experienced by our study participants. Please see page 17, lines 20-21.

The discussion can be reduced to focus on the main findings. These main findings are not highlighted at the start of the discussion. The authors could identify three to four key findings and build their discussion on that, to make the reading clear and well-articulated. I am missing that.

- The authors thank you for the comment, a small introduction to the discussion was included as suggested. The introduction briefly highlights the aim of the study and the
main findings. In addition, the discussion section has been reduced to focus on the main findings highlighted as advised. Please see page 15, lines 16 – 26.

The authors responded to the concern raised by both reviewers that ethical approval and consent should be shortly mentioned in the methodology section by moving the ethics section on page 17 and 18 to be part of the methodology section on page 9 lines 1 – 19.

Reviewer #2:

I have enjoyed your paper titled: "I feel myself incomplete, and I am inferior to people": Experiences of Sudanese Women living with Obstetric Fistula in Khartoum, Sudan. This is a forgotten obstetric morbidity and your paper can potentially contribute to making it more visible. The background was well written and gave a good rationale why this study was important. I would have preferred a better description of the paradigm within qualitative research that you have used, for example, ethnography, phenomenology, grounded theory, etc.

- The authors thank the reviewer for the comment, this study is an exploratory phenomenological qualitative study since it aims at clarifying the meanings of phenomenon of stigma and coping from the lived experiences of the Sudanese women living with OF. Please refer to page 6, line 9 for the paradigm description.

In most qualitative study, we do not start with the theoretical framework except if you want to use the specific concept in the theory to collect data and/or analyze your data deductively. Theories are; however, often use to explain the findings.

- The authors affirm what the reviewer stated, this study drew upon concepts driven from the theoretical frameworks, the stigma by Goffman and the transactional model of stress and coping by Lazarus and Folkman. They were used to inform the data analysis and to explain findings.

The participants are an extreme marginalized group of women. I was wondering if you have received ethics approval for the study. I was expecting information on how your participants were protected from exploitation, especially as they were preoperative patients at a hospital. Please add information on informed consent, how you ensure anonymity and confidentiality, management of the data and if you have paid the participants any remuneration for participation.

- As mentioned above, the authors have addressed this on page 9 lines 1 – 19.

It will be helpful if you add more information on exactly how you have analyzed the data. You stated that all the interviews were conducted in Arabic and translated by the first author. How did you ensure the quality of the translation? I recommend that you look for literature on backward and forward translation. The manuscript needs more comprehensive information on how you ensured trustworthiness and rigor.
The authors thank the reviewer for the comment, they added more information about how the data was analyzed to read as follows:

Audio recordings were transcribed verbatim in Arabic along with notes taken by the first author during fieldwork. That gave her the chance to return to study participants for member checking. The first author then translated transcripts into English. The quality of translation was checked by a colleague that is fluent in both languages by doing backward and forward translation. The analysis process started during the data collection phase while still in the field by noticing patterns of potential interest. Through an iterative process, the transcripts were read carefully to form a general impression of what participants said about their experiences of living with obstetric fistula. The transcripts were then re-read repeatedly to gain familiarity with the text and to understand the context in which participants lived and coped with obstetric fistula. We employed theoretical thematic analysis. We coded manually all segments of the text that capture an idea related to our study questions using memo writing and highlighting data segments. Nonetheless, three transcripts were randomly selected and given to four Masters students at the University of Oslo to code, they provided similar codes. These emergent codes were compared across transcripts and categorized in an excel sheet. Deductively, we searched for themes derived from the stigma theory by Goffman and the transactional model of stress and coping by Lazarus and Folkman described in the theoretical framework section above. Themes included consequences of OF, the dimensions of stigmatization, and the coping strategies that women used. For each category, the transcripts were re-examined to determine whether subcategories were needed. The themes were interpreted further and compared to the objectives of the study to generate the final conclusion. The guidelines adopted from both Standards for Reporting Qualitative Research and the consolidated criteria for reporting qualitative research (COREQ) were followed in writing the study report (27, 28).

Furthermore, a subsection about trustworthiness and rigor was added as advised to read as follows:

Trustworthiness and rigor

To ensure the trustworthiness of the study findings, data collection continued until saturation level was reached i.e. there were no new concepts coming out from data. Reaching the level of data saturation is important to enhance the trustworthiness of research and it is concerned with the depth of data obtained rather than the number of participants (31). Audio recordings, member checking and feedback loops from the participants on transcripts ensured that quotations used accurately reflected the voices of the women thereby improving the credibility of the findings and interpretations.

Because the experiences of Sudanese women living with OF provided a rich text, in addition, the study participants, settings and the methodology used were described in as great details as possible, transferability of study methods to other similar contexts may be easily determined. Please see the bottom of page 8.

Start your findings section with a broad introduction to the main theme. You have multiple categories/ sub themes in your findings section without identifying the broader 2 - 3 theme. I
recommend that you re-think which categories/sub themes fits together in a theme. I could identify multiple subsection that could fit together. One example can be women's experiences with stigmatization and the sub themes can be experiences with self-stigma, Women experiences with enacted stigma, experiences of women with anticipated stigma, etc. The discussion that follow should then be re-organized to fit with your findings.

- The authors took the reviewer’s recommendation and added a broad introduction in the findings section as advised. The introduction briefly highlights the aim of the study and the main themes and subthemes. Please refer to lines page 9 lines, 28 – 32. In addition, the discussion section was reduced as advised.

Your paper needs a section on recommendation for practice, education, and further research and policy implications.

- The authors took the reviewer’s suggestion and added a section for recommendations for further research (please refer to page 18) to read as follows:

Recommendations for further research

There are areas for future research that would help decrease the ambiguity of the situation of OF in Sudan. One of them is a country-wide prevalence study of OF and the associated risk factors. This would be used in advocacy and to enlighten policy making and priority setting for budget allocation. This study focused on the experiences of women living with OF. There is no doubt that men also encounter challenges when they have wives with OF so it would be helpful to shed light on the experiences of these men as well. Experiences of women with OF in the community who do not seek or fail in their attempts to seek care was beyond the scope of this study, but such community-based studies are warranted if OF is to be addressed throughout Sudan. Those women might have more severe consequences of OF.

- In addition, recommendations for practice and policy were merged with the conclusion section. Please see page 18.