Author’s response to reviews

Title: Socio-cultural contexts of end-of-life conversations and decisions: bereaved family cancer caregivers' retrospective co-constructions

Authors:

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Reviewer reports:

Reviewer 1:

1. Is the question posed original, important and well defined?

The authors have described an important research topic, addressing conversations regarding end of life with a sample of bereaved family caregivers in Kenya. However, the findings were not as clearly defined within the context of where the research took place. More attention to the context, perhaps in its own section, including the services and supports available, as a key finding would provide an important addition to the literature in this area.

Response: Thank you for your feedback. There seems to be a contradiction with this comment (e.g. see your comment no.3, paragraph 2) Rather than present it as a separate section, we preferred to interweave descriptions of the Kenyan context across the various sections of the paper e.g. in description of the background (pg. 4), in presenting the results (p.7-14), in the discussion (p.14 – 15) and the conclusion (p.16-17).

2. Are the data sound and well controlled?

More information needs to be provided about the data collection procedures. Recruitment is described as through snowball sampling of personal contacts and referrals. How did the authors themselves have this access? More about the role of the researchers is needed, especially since you have ethics from South Africa but conducted the study in Kenya. More about the research
Process is needed, such as obtaining of consent, recording of focus groups, questions asked at the group interviews and the location of the interviews.

Response: Thank you very much for your insight. We have added a more description of methods (see paragraphs 1 and 2 of the ‘procedures section’ highlighted in yellow.

3. Is the interpretation (discussion and conclusion) well balanced and supported by the data?

On page 6 you state that 2 end of life themes are presented. Did other themes also emerge? If so, you could position these results within the overall study findings. The interpretations were a little confusing, especially the terms used such as advanced directives, which seemed to be considered the same as "wills". These are 2 different concepts in our North American context. Wills are often used to address financial aspects whereas advanced directives deal with decisions for end of life. Please clarify and use consistent terminology.

What is the main overall finding? How do the 2 themes relate to each other? Were there other findings? Were the perspectives of the "professionals" different from the family groups? The name of the first theme was really interesting, and explains this complex concept well. It was described in the Kenyan context, which was very well done. The discussion section was well done and findings are compared to other research.

Response: This was very insightful, thanks. We have added a section addressing the issues raised above in paragraph 1 of the results section.

4. Are the methods appropriate and well described, and are sufficient details provided to allow others to evaluate and/or replicate the work?

Yes, the methods are appropriate but need more explanation, as in point 2, they need to be more clearly described.

5. What are the strengths and weaknesses of the methods?

Adding more detail to the process of data collection and the researcher role would improve the section on methods.
Response: Thank you. Please refer to our response to no. 1 which deals with the same.

6. Can the writing, organization, tables and figures be improved?

The writing is overall very good and the manuscript as a whole well-organized. A section on the implications of these findings for practice and research is needed, specifically in the Kenyan context.

Response: We have outlined the implications in the conclusions.

7. When revisions are requested.

Revisions are needed to the methodology section and to further organize the findings section which would add to the overall coherence of the paper.

Response: Please refer to our response to no. 1 which deals with the same.

8. Are there any ethical or competing interests issues you would like to raise?

There is mention of ethics approval but more detail is needed on the consent process, especially since the research was conducted in a neighbouring country from where the ethics was obtained.

Response: Thank you. We have added this in paragraph one of the ‘procedures section’.

Thanks for this opportunity to review this very important and interesting research.

Response: Thank you too for your very insightful feedback.
Karin Oechsle (Reviewer 2): The authors present a qualitative study of four mini focus group interviews with 13 female bereaved family caregivers concerning social-cultural aspects of end-of-life conversations and decisions in cancer patients in Kenya, Africa.

The evaluating these interesting palliative care issues in African patients who might different significantly from European or American patients due to their specific culture represents the main strength of this study. A first view on these cultural contexts seems to be clinically interesting.

In contrast, the study has some relevant deficits. In my opinion, the number of 13 interviewed family caregivers trends to be too low. Unfortunately, there is no explanation of the methodical rational for this number of interviewed persons in the manuscript. In addition, no methodical rationale for the different durations of focus group interviews is given.

Further, only female family caregivers have been included. Especially in the cultural context, the perspective of male family caregivers should have been included.

Response: Thank you for your feedback. We have added our rationale in the methods section under participants and also included a reference for readers who may want a detailed account of our process. The hallmark of IPA is fewer interviews/participants but more in-depth engagement with them.

The time between the patients’ death and the focus group interviews should be presented.

Response: Thank you for your input. After much consideration we are of the view that this data is not appropriate particularly because the focus of our argument end-of-life discourse in the terminal phases of care recipients’ lives i.e. prior to death.

In my opinion, the presentation of results is too long. Further, it gives rather the impression of a qualitative analysis of a case series than a systematic analysis of focus group interviews.

Response: Thank you for your comment. Yes, we agree with you. This is consistent with IPA approach whose credibility lies in detailed (often rather lengthy) descriptions of phenomena with a focus on idiographic claims which, in turn, give a case by case analysis ‘feel’.
Overall, the manuscript might be suitable for publication in BMC palliative care after major revision declaring the above mentions limitations and deficits more clearly.

Response: Thank you very much for your feedback and taking the time to review our manuscript.