Author's response to reviews

Title: End of life Care in Sub-Saharan Africa: a Systematic Review of the Qualitative Literature

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Author's response to reviews: see over
Dear Editor(s),

Please find below the response to the reviewers’ comment on the article:

**End of Life Care in Sub-Saharan Africa: a Systematic Review of the Qualitative Literature**

(Please note that the title has been changed from Palliative Care in Sub-Saharan Africa: a Systematic Review of the Qualitative Literature)

We would like to take this opportunity to thank the reviewers for their comments, we have reconsidered the paper in the light of each of the points that were raised and we have found them very helpful.

The comments below are organized alphabetically by reviewer. We have attempted to separate out specific points from the reviewers’ comments and address them on a point-by-point basis as requested by the journal.

A revised version of the manuscript with the corresponding changes has also been included.

Yours faithfully,

The authors

**Dr. Grant**

Major Compulsory Revisions/Minor Essential Revisions

1. “…the purpose of the review to provide additional evidence for policy makers, practitioners and researchers and to provide a sound evidence base is not fully addressed, as further analysis is necessary.”

   In the introduction we have elaborated on the need for evidence in EoL care, the type of evidence usually generated and the value of qualitative research to the evidence base, which can inform policy making and practice and future research. The aims and objectives have been clarified in the introduction.

2. Process of the review partially explained
   a) Include relevant journals searched in the text

   This would break the flow of the methods. The authors propose that appendix one be included as a box and published as part of the article.

   b) Explanation is needed why papers on cost of care are excluded
These articles were quantitative articles and were excluded for this reason, in addition to their focus on cost of care. There is therefore no need to mention this as an exclusion criterion and we removed this from the methods and the figure (with the numbers changed accordingly).

c) Fair/good judgment should be explained in the text

This has been added.

3. No response required.

4. Results
   a. Some of headings overlap

The headings represent the main themes identified during the qualitative synthesis. The themes, although clearly distinguished by their focus, are interrelated, which explains the overlap. Eg. Under the heading of home care, the burden of care for the informal carer is also central.

   b. Study analysis and interpretations not fully reported

The sentence indicated in the comments was clarified by rephrasing it. We did not add more explanation as this would become too detailed and we referred for further information to the primary studies.

5. Discussion and conclusion

   a) Lack of clarity re why new titles are added to discussion

The headings in the results section represent the main themes identified during the qualitative synthesis. The results section stays close to the findings of the reviewed studies. The discussion then looks at the literature we reviewed as itself an object of scrutiny, in terms of its foci and gaps, and examines what is specifically relevant to the African contexts by placing the findings in the context of the wider literature. We added an explanation in the methods section of the paper.

   b) Good death vs bad death and stigma needs to separated and discussed more analytically

We have revised the organization of the discussion, integrated the good and bad death section and the part on stigma under a broader heading so that stigma also has broader relevance. The reflection on stigma still follows the discussion of good and bad death as stigma has such a profound influence on dying and death.

   c) Does not show how findings from research can be integrated into the design of training interventions

The final sentence of the third paragraph from the section on “Caring for patients with EoL care needs” has been rephrased to clarify its meaning: that the training for health
professionals should take the conditions that they are likely to work under and the challenges that they are likely to face into consideration.

d) Need to explain how the predominance of papers focusing on HIV/AIDS provide evidence to address wider needs for palliative care

As the evidence produced so far predominantly comes from work on HIV/AIDS, the insights gained can function as a starting point for the development of care in other conditions. We have integrated this point into the discussion (at the end of the first paragraph).

We have now provided a reference for the assertion that the studies in this review support and complement the findings from quantitative research: Harding R. and Higginson II.: Palliative care in sub-Saharan Africa. Lancet 2005, 365: 1971-1977.

We have added a sentence that explains what we mean by the conclusion. In this way it points to future directions for research where the findings of this review can be used on a more theoretical level. The findings were already put in this light in the discussion section. This needs to be explored in another paper as it deserves separate attention and needs further evidence to underpin this line of thinking.

6. Limitations
   a. More information on inaccessible articles required

We added this information to the limitations section.

   b. More details of the non-English language papers required

These papers were excluded because they were not in English. However, they would also have been excluded on other criteria had they been in English.

7. No response required

8. Title and abstract
   a. Full number of articles reviewed required

We have now included this.

   b. How many studies describe home-based care?

A sentence has been added to the first section of the results. The number has been included in the abstract.

   c. Correct spelling errors

Addressed.

   d. No reference to quantitative data
(We addressed this point above)

9. Acceptability of writing
   a. Typos

Corrected
   b. Verb and adjective construction tightened (e.g. “described widely”)

Reviewed and corrected
   c. Assertions and assumptions that require evidence e.g. “Epidemiology of HIV widely described”

This sentence has been deleted
   d. Integration of services into Ugandan, South African, Kenyan and Zambian into existing health system

We have now referenced this sentence.
   e. Clarifying complexity and diversity of “African context” required

This has been made clear in the background section – reference is made to “African contexts” rather than “context”.
   f. Not true to say that palliative care planners rarely consult qualitative research

We have changed this to ‘consulted less often’. We can base this on evidence from the research literature, see for example Leys 2002, or the latest issue of the Journal of Research in Nursing that starts from this problem that qualitative research is less consulted by health planners.

   g. Changes in tense structure

This has been addressed: general statements have been made in the present tenses, whereas references to the findings from particularly studies are made in the past tense.

Dr. Ingleton

Major Compulsory Revisions:

1) Background
   a) A short synthesis of the beginnings of palliative care in Africa is needed
   b) The work of Wright 2003 is relevant here
   c) Strjernsward and Clark 2004 is another source

We have added the two suggested papers to the introduction and integrated their findings.
2) Methodology
   a) There is not a clear research question. Objectives are vague and key concepts not well operationalized

   The aim has been clarified and research questions listed. This has also been added to the abstract.

   b) Palliative care and end of life care are terms which are used interchangeably

   The term palliative care has been largely replaced with end of life care – the searches employed encompassed palliative care and other types of care at the end of life so the term end of life is more appropriate.

   c) Lacking critique of systematic reviews of qualitative literature and acknowledgement of limitations

   We have acknowledged the limitations of systematic reviews of qualitative research in the background section. However, we feel it is not necessary to enter into a full critique here and we referred to relevant papers in this area.

   d) Scoping review of literature to identify a systematic review of this topic carried out?

   This has been undertaken and a statement to the effect that no such study was found has been added.

   e) There are problems with searching electronic databases for qualitative studies.

   For this reason hand searches were conducted of bibliographies of all the identified papers, as well as in 13 journals – a sentence has been added to this effect. In addition, we have now also searched the electronic databases that contain African journals which was recommended by one of the other reviewers.

   f) How were search terms divided into categories?

   The search strategy was applied as it is laid out in box 1 (formerly appendix 1). We opted for broad search terms seeing the exploratory purpose of the review.

   g) What steps were taken to ensure that quality assessment enabled a high degree of reliability and validity?

   Quality assessment enabled a high degree of reliability and validity by the use of a standard grading system, by having the studies graded independently by two reviewers and having the gradings compared, and discussed where they differed.

   h) Surprising all the studies were deemed good

   Not all studies were deemed good – as it says in the text 30 of 51 studies were reported as good.
i) Exclusion of non-English and unpublished studies creates bias

Non-English studies were excluded for practical reasons. This is acknowledged in the limitations.

Unpublished studies were excluded to ensure a minimum quality of research, based on the peer review process they went through.

j) Unclear if two investigators involved in study selection

One investigator took the lead on this, but consulted another on a regular basis and in case of doubts – this is now indicated in the text.

k) No detailed critique of any of the studies

The objective of the quality assessment was to provide a general idea of the quality of the studies we included in the review. We have indicated the number of studies that scored according to the categories distinguished in the grading tool. We added a description in the methods section to show the areas against which the studies were assessed for methodological quality.

3) Findings
   a) Unclear why the review excluded cost of care and then went on to examine financial burden

These articles were quantitative articles and were excluded for this reason, in addition to their focus on cost of care. There is therefore no need to mention this as an exclusion criterion and we removed this from the methods and the figure (with the numbers changed accordingly).

   b) No critical examination of bias created by methodological variation

We did not go into detail about bias due to methodological variation of the studies as they all scored fairly well on the grading system (except for one). We did however mention the difference between the more rapid conventional qualitative studies mostly conducted in the context of health research projects and the long-term ethnographic studies.

4) Conclusion
   a) Not enough limitations discussed

More limitations have been added.

   b) Conclusions non specific

We have revised the conclusion and made it more specific.

   c) Unclear sentence: “the concept’s defining features”
We have added a sentence that explains what we mean by this conclusion. In this way it rather points to future directions for research where the findings of this review can be used on a more theoretical level. However this was discussed in the last paragraph of the discussion and the end of the conclusion sums it up.

Dr. Powell

Major Compulsory Revisions:

1. Searching Africa journals

A search has been undertaken in AJOL as suggested. No relevant articles were found—the reduced search carried out produced 4 results but none of the articles was about palliative or end of life care.

Minor Essential Revisions:

1. Abstract para 1 – culturally competent or culturally appropriate?
We have changed this to culturally appropriate

2. Abstract para 1 – spelling: objective(s)
We have corrected the spelling

3. Abstract results – include total number of articles identified
We listed the total of articles and total of identified and total included in the qualitative synthesis.

4. Background para 1 – citing 2010 global HIV report data
We have updated the data and changed the citation.

5. Background para 5 – split infinitive
We have changed this.

6. Results para 4 – “the burden of care borne”
We have corrected this.

7. Results para 5 – “due to the costs and lack”
We have corrected this.

8. Results para 7 – “impacts of the care burden were”
We have corrected this.
9. Results para 7 – “AIDS;”
We have corrected this.

10. Results para 24 – “grief was a luxury”
We have corrected this.

11. Discussion para 5 – “unmet”
We have corrected this.