Author’s response to reviews

Title: Honoring the Voices of Bereaved Palliative Caregivers: A Metasummary of Qualitative Research

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Date: August 2, 2017

Dear Editor BMC Palliative Care, Sean Hughes, Ph.D,

Re: PCAR-D-16-00148

This letter contains a point-by point response to accompany a revised manuscript for your consideration entitled: Honoring the Voices of Bereaved Palliative Caregivers: A Metasummary of Qualitative Research
We wish to thank the reviewers for their comments and suggestions which certainly have improved the precision, clarity and readability of this manuscript. Here are a list of the amendments that have been made, and our response to each of the reviewer's comments. We made these edits to the manuscript and tables and they are indicated with "Track Changes".

Reviewer reports:

Roger Manktelow, PhD (Reviewer 1): This is a well written manuscript and ready for publication once the following issues have been addressed:

1. Minor typos: line 238 page 10

Response: Thanks, corrected.

2. I am unsure of the value of the Intensity Effect section - not convinced of the use of measurement to assess qualitative research

Response: Agreed: Intensity Effect Sizes were a concern for both reviewers. (Abstract, and page 11) and any other reference to intensity effect size and frequency effect size in the manuscript have been removed. The entire section titled “Intensity Effect Size” was removed as it may only distract from the overall analysis and findings. Instead of “Frequency Effect” we have adapted our approach and are reporting as a calculated frequency of themes (Table 2) since this was an important step in our analysis and gave us insight as we interpreted the meaning and importance of each theme. This quantitative approach is a key element of Sandelowski and Barroso’s Qualitative Metasummary methods and gave us information about how many studies included the same themes. This was clarified in the manuscript as well.

3. Please include percentages for sample characteristics as well as frequencies. Also please include duration of caring.

Response: Percentages for sample characteristics were added to the text (Results section, pages 10 and 11) as well a calculation of the duration of caring when available from the reports was added.

As regards the thematic analysis, the first mention of spirituality is in the final concluding paragraph. To me, given the topic of 'end of life caring', this approach is too secular and some
explicit analysis of spirituality, beliefs and practice, is required. This could be achieved by elaboration of the 'serenity' theme.

Response: As recommended, a note about faith in God and the role of spirituality was added to the findings in the “serenity” theme (Results section page 13) as it certainly was an important aspect of our findings.

4. Please identify the criteria employed to select the forty seven studies from the full sample

Response: The inclusion criteria employed to select the 47 studies was explained with additional detail in the Literature Search section (page 5) as well the process of selecting the studies was expanded prior to referring to Figure 1 PRISMA diagram (Results section, page 10)

Jan Christian Frich (Reviewer 2): This manuscript reports findings from a literature review/metasummary of qualitative research on experiences of bereaved family caregivers. The aim is to explore the experiences of bereaved family caregivers of people who received palliative care, regardless of their underlying disease.

The manuscript states that nearly half of all Canadians will act as family caregivers at some point in their life. There is no reference to document this statement, and it also seems strange to use Canada as a starting point as long as the scope of the study is global. The fact that availability and content of palliative care services probably varies a lot world-wide should be addressed in the introduction, as the study focuses specifically on people who have received palliative care.

Response: Thanks so much for pointing this out, the use of Canada as a starting point only appeared in the Abstract, so we removed that statement (Abstract). We have highlighted the fact that availability and content of palliative care services varies greatly world-wide. We added a statement right at the start of the paper, with a reference from the WHO and added a comment in the Limitations section (page 23).

The abstract lists major findings in the conclusion section. I would prefer to place these major findings in the result section, and rather list conclusions/implications based on these in the conclusion section.

Response: We rearranged the Abstract to remove findings from the conclusions section, and added some actual conclusions, thanks so much for your attention to this oversight.

Sandelowski and Barroso's qualitative metasummary method is used, and 47 qualitative studies are included. The PRISMA flow chart is okay, but it would be nice to know more about the
search strategy. I do not think is appropriate that this is «available on request» (page 6) when it may be available in an appendix published online.

Response: The search strategy is now included as Appendix 1.

The metasummary method seems to rely partly on a quantitative approach. I question the whole concept of «effect size calculation» in qualitative research (Onwuegbuzie). The whole concept confuses very different study designs. I think it is fair to study the distribution or frequency of themes, but I oppose both the idea that such frequencies represent any «effects», and I also oppose the idea that a more frequent occurrence of a theme correlates with a higher «validity». Valid for whom? Valid in which context and setting? Validity is something you have to put forward arguments for. With regards to this it is interesting that an important conclusion seems to be that health professionals should acknowledge «the unique situation of the caregiver cautions against the danger of generalizing the bereaved caregiver experience» (page 24).

Response: Yes, as noted in response to Reviewer 1, we have clarified our quantitative approach to the analysis, removed the Intensity Effect Section (page 9 and 11) and the Frequency Effect has been edited throughout to only include a calculation of the frequency of themes. On Page 5, we removed reference to “validity” and clarified the rationale for the frequency calculations.

Results: I think the themes identified in the literature captures many important dimensions of caregivers' experiences. The material is well organized. The aim of the study was «to explore the experiences of bereaved family caregivers of people who received palliative care, regardless of their underlying disease». What I miss is an exploration of the experiences with palliative care services. Where there no mentioning of this in the studies? This study was published later than the time scope of the present review, but the interaction with professionals was an important theme, just to mention one example: Lerum SV, Solbrække KN, Frich JC. Family caregivers' accounts of caring for a family member with motor neurone disease in Norway: a qualitative study. BMC Palliative Care 2016; 15: 22. This is another study exploring caregiver experiences and expectations when interacting with professionals: Røthing M, Malterud K, Frich JC. Family caregivers' views on coordination of care in Huntington's disease: a qualitative study. Scandinavian Journal of Caring Sciences 2015; 29(4): 803-809.

Response: Thanks for raising the important aspect of the caregivers’ experiences with palliative care services. We have edited the manuscript for clarity including the Abstract, and page 4, as well we highlighted in our inclusion criteria that all the studies we included involved bereaved caregivers who had received palliative care services. Thank you so much for referring us to additional important research that reinforces our key findings in this regard. We added the reference from BMC Palliative Care (Lerum, Solbraekke, Frich, 2016) to the discussion section.
Discussion: Should the paragraph «overarching findings» at p. 21 be placed in the discussion section? I miss experiences/interaction between caregiver and professionals in the discussion section. The conclusion focuses on assessments, recognition, services and professional support. What does the current literature have to offer of insights in support of any recommendations about how palliative care services can interact with caregivers to alleviate their suffering?

Response: The paragraph “overarching findings” on page 21 was placed in the discussion section.

Response: Yes, the conclusion was a set of recommendations to improve support both during and after caregiving, many of which emerged from the studies we included in the metasummary. This was clarified in the Conclusions section (page 24) specifically referring to our first meta-theme, that the caregivers’ experiences during active caregiving can and does affect them into bereavement. This was an important finding and specifically palliative care services need to recognize and value this as it will have long term consequences for the caregiver's bereavement outcome.

Thank you very much for your consideration in this re-submission.

Sincerely,

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