Author's response to reviews

Title: The Journey with Dementia from the Perspective of Bereaved Family Caregivers: A Qualitative Descriptive Study

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Author's response to reviews: see over
Dear Dr. Cornacchia,

Please accept the revised manuscript, entitled: *The Journey with Dementia from the Perspective of Bereaved Family Caregivers: A Qualitative Descriptive Study* for consideration in the journal *BMC Nursing*.

My co-authors and I have no competing interests to declare related to this work. This manuscript has not been published elsewhere and is not currently under review by another peer-reviewed journal.

As noted in the cover letter with our original submission, this manuscript contributes new knowledge as few studies exist that examine the dementia caregiving journey in its entirety nor is the perspective of bereaved caregivers readily sought in the research literature. We could find no qualitative research that describes the overall dementia caregiving journey from the perspective of bereaved caregivers. Thus, this work is essential to adding to the current literature regarding the overall dementia caregiving experience as it incorporates the unique perspective of bereaved caregivers and fits with intent/aims of the journal.

Below are detailed comments that address the concerns of both reviewers, when necessary you are referred to the lines in the manuscript where the added comments are found. Please do not hesitate to let me know if you require anything further; I can be reached by email (shelley.peacock@usask.ca) or telephone (306.966.7375). I look forward to hearing back from you.

Sincerely,

Shelley Peacock, RN, BSc, PhD
Comments added (in Times New Roman) by the authors to each point to address each reviewers’ concerns.

Referee #1 (Dr. Wanda Martin)

Minor Essential Revisions:
1. There is a missing name on line 250 that does not correspond with the reference number indicated.
   I have added the author “Davies” for this missing point (see line 281).

Discretionary Revisions:
1. The background is well defined and the need to understand the experience of family caregivers of people with dementia is clear, given the projected numbers. However, it is less clear what understanding this experience will provide. The background section indicates the lack of research with bereaved dementia caregivers; an additional comment has been added between line 123 and 125 to clarify this.

2. The data is sound, with good description of how it was collected and who the participants were. There are some minor questions, for example, on line 157 the authors indicate the interviews resulted in rich data calling for further analysis. This is a bit of teaser, leaving the reader to wonder why more is not mentioned here, or more analysis is not provided here.
   I have added a comment to clarify the detail participants shared and that they did not limit themselves to end-of-life care only, rather they shared in detail about the overall journey with dementia (please see lines 170-176).

3. The authors are not clear on how they identified the major themes. The major themes fell in line with particular points/transitions over the dementia caregiving journey; comment added to add clarity to this (see lines 180-184).

4. They provide tables with sub-themes and quotes to be transparent on the formulation of sub-themes. I find it more effective to have the quotes embedded in the results/discussion as an indication of a particular point. I acknowledge that one way of presenting data is to narratively weave it within a discussion; I would respectfully suggest that due to the richness (and volume) of the quotes as they relate to the subthemes that use of narrative tables is a succinct way of sharing those quotes.

5. The structure of results and then discussion does not work well for qualitative research in general, but that may be what is required of the journal. Again, I would respectfully suggest that there can be more than one way to discuss/present a study and we have chosen to separate out the results from the discussion.

6. Generally the writing is clear. There is some passive voice in the introduction, which is distracting, and the occasional correction needed, as I indicated in the manuscript. The discussion flows very well, but I would like to see a “so what” in the conclusion beyond “appropriate support”.
A comment has been added to the conclusion to emphasize the need for health care providers to be cognizant of the complexities of the dementia caregiving journey (please see lines: 426-429).

Referee #2 (Dr. Sharon Kaasalainen)

Major Compulsory Revisions

1. I think including the word “journey” in the title and elsewhere to describe this paper is a bit misleading as I expect to see multiple interviews taking place at various points in time to capture the actual ‘journey’. As such, I am not sure multiple interviews were completed or not? If they were then this needs to be spelled out better and made clear. If not, I think it would be better to replace the word ‘journey’ with ‘perceptions’ which aligns itself better with interviews at one point in time as well as qualitative descriptive designs.

Respectfully, I use the term “journey” because that is how a few of my participants retrospectively described their experience over many years of caregiving. The key to this term is that the participants can provide their perspective on the dementia journey because they are in its final stages (i.e., bereavement); the results are then discussed with respect to other work conducted at various points in the journey, from the perspective of active or engaged family caregivers.

Yes, multiple interviews were conducted, but all of them were during bereavement. I hope this has been made clearer between lines: 157-159; 166-176.

2. In the same vein, under Methods – Data Collection, it is unclear whether there were multiple interviews (27) with the 11 participants for this paper or just the original study? Can you clarify this?

This has been clarified, please see lines: 166-176.

If not, I would remove the ‘27’ as it tends to confuse the original study with this one. But if there were multiple interviews for the participants of this study, then I think it would also be helpful to describe, how many interviews were conducted per participant so the reader can see the variability and how many participants had multiple interviews and exactly how many/participant as this is important information to include.

This is now clearer in the data collection section.

If you indeed did interview participants over the course of their caregiving, - this study used a retrospective approach; this is commented on in the Sample section, lines 157-159.

I’m wondering why you would not use a narrative design as it seems more fitting and stronger, compared to qualitative descriptive. You might want to address this in the limitations if this is the case.
Since we could not return to the participants to check the narratives we used qualitative description to describe the dementia caregiving journey using the words of persons who lived that experience. I believe qualitative description is justified in this study (and is a strong approach to do this) as a means to describe the experience as shared by the participants.

3. If you interviewed the participants only once for this study (at bereavement) then I think you need to address the limitations of this as many factors could have impeded their description of their experiences along the way (e.g., memory, unresolved grief etc).

All interviews were conducted within bereavement; I have now added a comment to the limitations section in regard to this, please see lines 405-409.

4. The paper gets very confusing in the Data Analysis section with respects to what was done for the original study versus this current one. I don’t understand why you had to verify (clean) the recordings differently for the substudy as this should have been done for the original one and wouldn’t be any different for this one if you’re using the same transcripts?

In Data analysis section, comments added with respect to the RA needing to immerse herself in the data (please see lines: 179-180), thus listened to and re-verified the transcripts as she was not part of the original study.

5. How were the initial themes developed? For qualitative description, usually you have to undergo open coding and the develop themes later on; otherwise it seems to me that you would be using a template organizing style methods and analysis if these themes were pre-determined.

Please see lines 180-186 for clarity; the major themes arise from the data, as they reflect (or describe) the caregiving journey as told by the participants. Sandelowski (2000) advocates that qualitative description stays close to the data (perhaps more so than other qualitative methodologies). Describing the dementia caregiving journey as it would typically unfold (i.e., before diagnosis and as the disease progresses, to end of life and resulting bereavement) is a logical way to describe this journey and how it was in fact shared by the participants – these main themes then guided the remaining analysis; I realize this may be a unique way to work, yet it was how we looked at the data given the way the participants described their caregiving.

6. Although you acknowledge that your sample is small, I think it would be prudent to speak about data saturation. Were any of the themes reaching data saturation, any new ones emerging from pre-determined themes? Any themes not saturated but require further exploration? You could frame this as a pilot study since the sample size was so small and to avoid too much scrutiny.

This was not a pilot study and I will not describe it as one; it is not uncommon for qualitative studies to have small sample sizes, I respectfully comment that it is about the (quality of) data and not quantity of participants.
A comment about data saturation is added (lines 197-198) as it is reflected by only presenting subthemes that were identified by 10 of the 11 participants; the discussion closes with comments related to how participants spoke about their grief in bereavement, an additional comment was added (please see lines: 385-387).

7. I found it difficult to read the results sections since I had to flip pages to look at quotes in the table and then go back to the text in the paper. I think it would really strengthen this section to try to integrate the important quotes into the text of the paper to help with flow, show depth to your analysis and provide solid evidence that your quotes support your themes. I’m not sure of the text limits to this particular journal, but my thinking is that it might allow for more text, even a few quotes to add to your findings section, would be very helpful to the reader.

In addition to comments to the first reviewer in section #4, due to the richness and length of many of the quotes we felt it would be useful to allow the quotes to “speak” for themselves within the tables. Perhaps some of this flipping of pages will be alleviated in the final manuscript when the data table will be available immediately with the individual themes as they are discussed in the manuscript (rather than be grouped at the end of the paper).

Minor Essential Revisions

1. Your references seem off, noticed #26 & 27 do not align with those in ref. list...should be 27 & 28?

Yes, the above mentioned references should have been #’s 27 and 28. I noted after reference #18 (originally line 101) should have been #19; this error set off the remaining references off by one number. All references have been updated and verified to the body of the manuscript (as an additional reference was subsequently added to the introduction).

2. You should include SDs for your participants’ age to show variability.

Under sample, Means and SDs are now included in the paper, see lines: 162-163.

Discretionary Revisions

In the Introduction section, more referencing with exact numbers would strengthen this section (first sentence in particular) to add more context for your statements and help support them.

Respectfully, there are 26 references cited in the introduction to support the comments made; in the first paragraph 4 of the 7 sentences are supported with references. I would disagree and consider the introduction is appropriately referenced.

Also, I think you need to describe your original study in the background towards the end to provide context for this substudy. What was the purpose of this original study, its design, and what were the main findings?

At the end of the introduction I have added comments to address the intents of the original study and provided a reference to the findings (#27) (please see lines: 135-143).
Given the challenges of recruiting in this population and the novelty of this topic area, I think this paper could be publishable but needs further clarification in some areas and its limitations explicitly addressed so the reader is fully informed about how to interpret all of your findings, given their strengths and weaknesses.