Reviewer’s report

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

Version: 2 Date: 28 September 2014

Reviewer: Sharon Kaasalainen

Reviewer’s report:

Thank you for the opportunity to review this manuscript. This is a well organized and well written paper and addresses a very important topic area. However, I had a few questions and concerns that are listed below. Most of my concerns stem from the fact that I am unsure whether multiple interviews were done with the sample for this paper or only for the original study.

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.

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? 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. If you indeed did interview participants over the course of their caregiving, 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.

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).

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?

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.

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.

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.

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

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

Discretionary Revisions
1. 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. 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?

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.

**Level of interest:** An article of outstanding merit and interest in its field

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**
I declare that I have no competing interests