Author’s response to reviews

Title: Perspectives and experiences of compassion in long-term care facilities within Canada: A Qualitative Study of Patients, Family Members and Health Care Providers

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Author’s response to reviews:

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Re: Response to Reviewers Comments regarding BGTC-D-18-00179 “Heart work: A thematic analysis of compassion in long-term care”

Thank you for reviewing our manuscript entitled “Heart work: A thematic analysis of compassion in long-term care”. We greatly appreciate your astute comments and the considerable thought that was evident in each of your responses related to this complex, but vital topic.

We have addressed each of your concerns in the table below and modified the manuscript using track changes. As a result, we feel that our manuscript has been considerably enhanced.

Thank you again for your time, effort, and consideration of our manuscript.
Sincerely,

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Katrien Ger Luijkx Reviewer #1

Response

1. In my opinion, the title does not justify the rich data of the manuscript. Therefore, I would like to ask the authors to reformulate the title of their manuscript. The words "thematic analysis" are not really of added value, I think.

Thank you for your comment, we have taken this under consideration and have modified the title.

2. Although I agree with the authors that compassion is an important issue, it is introduced very quickly in the background section and is therefore not convincing. The authors should pay more attention to introducing the elaborate more on the introduce the aim and research question.
Thank you for raising this point. While other reviewers indicated that they felt that the intro was succinct, clear and to the point, we have modified the intro to address this issue including removing the sub-heading compassion, as we agree that it was unnecessary and confusing.

3. Moreover, the concepts 'long-term care' and 'palliative care' are used alternately in the background section. That is confusing. However, the results section seems to be about long-term care. I agree that residential LTC is mainly about care in the last phase of life. Nevertheless, most LTC facilities, at least in the Netherlands, do have separate units for palliative care. So, residential LTC is not exactly the same as palliative care. Therefore, I ask the authors to explain the difference and similarity between the two more carefully or to focus the whole manuscript on LTC. I do understand that this is due to the fact that this study is part of a larger study, but this should explained more extensively.

Thank you for raising this important contextual point. We have added a number of sentences within the introduction to both delineate palliative care from long term care, while also describing an integrated approach to palliative care within long-term care, including some contextual features specific to Canada as per your suggestion.

4. The authors should explain why holding focus groups is the best method for data gathering for this topic. I think, observations or individual interviews could also provide very valuable data and insights. Furthermore, compassion is a topic that everyone embraces in theory, but to bring it into practice is a real challenge. Therefore, I expect that answers will be socially accepted. How did the authors account for this?

Thank you for raising this point. While individual interviews could have provided more rich details, focus groups were chosen for pragmatic reasons. First, with having 5 different participant groups for 4 different sites in across the nation, we wanted to ensure an accurate representation of participants for each group within each site. Second, we were also very cognizant of time issues for both healthcare staff and families and therefore wanted to maximize the ability to gather data while also not adding undue time burdens onto potential participants. We have added a sentence on p.7 in the Data Collection section to elucidate this point. In addition, we have added a sentence in the limitations section describing the potential issues associated with social desirability bias.

5. The authors should be more explicit about how they came to their two main themes. I expect them to be formulated beforehand.

Thank you for this question.
In keeping with thematic analysis methodology, themes are not formulated a-priori, but rather are generated from the data vs. being determined beforehand. Further details on the method of analysis and the development of themes can be found in the methods section, in accordance with thematic analysis methodology.

6. 117 individuals participated in this study: that is a great number, certainly in qualitative research! Data of all participant groups seem to be merged in the results section. That is a pity because it can be expected that various participant groups (e.g. residents, family and employees in LTC) experience and value compassion in their own way. In the results section this is accounted for a little bit by mentioning the participant group for each result and citation. Because I expect that the experiences and value of compassion will be considerably different for employees in comparison to residents and family members, I would like the authors to address this issue, at least in the discussion section. I am even of the opinion that the perspectives of residents and family members should be of more leading in studies about compassion or for instance person centered care, compared to that of employees in LTC.

We agree with the reviewer’s comment that having the data organized according to the participant group would have provided interesting insights. However, when we conducted the thematic analysis between and across the various focus groups, we were surprised to find strong similarities and congruence between groups. In particular, compassion was conceptualized across the groups in a similar manner, and therefore we decided that it would be more appropriate to report the results in this manner.

7. Moreover, in residential long-term care a considerable percentage of residents has dementia or other cognitive limitations. How is this accounted for in this study?

Thank you for highlighting this oversight on our part. We have included more detail about how patients were selected for this study, including the importance of including patients with mild cognitive impairment and the exclusion of those with significant cognitive impairment (please see the final paragraph before the Data Analysis section).

8. Finally, reading this manuscript, several similarities between compassion and person centered care came to the front. I would like the authors to elaborate on the similarities and differences between compassion and person centered care, or show the added value of compassion to person centered care.

Thank you for raising this important point. We agree that there is great conflation within the literature between compassionate care; person-centered care; holistic care and many other care
monikers. Rather than try and wade through the confusion with these conflated terms, our sole focus was to define and delineate compassion—while we anticipate that it would be a fruitful dialogue to compare and contrast between these terms, we felt it was unwise to confuse readers herein and therefore see this important dialogue being the focus of a future manuscript.

Reviewer #2
Response

1. Just for clarification, there should probably be the word Canada in the title or a short paragraph in the discussion to state what ramifications that this has globally.

Thank you for this comment we have added in “Canada” to the title.

2. It would be useful for the reader to know what are meant exactly by long term care (LTC) sites in Canada e.g., compared to Nursing homes in the UK and Veteran facilities in the UK.

Thank you for raising this important contextual point. We have added 3 extra sentences within the introduction describing more details about what is meant by Long-Term-Care in Canada.