**Author’s response to reviews**

**Title:** Views of professionals and volunteers in palliative care on patient-centred care: a Q-methodology study in the Netherlands

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**Author’s response to reviews:**

Reviewer 1:

Reviewer reports:

Maria Arantzamendi, RN, MsC, PhD (Reviewer 1): Thank you for the opportunity to review the article "Views of professionals and volunteers in palliative care on patient-centred care: a Q-methodology study in the Netherlands"

**Aim:**

1) The aim is to explore how professionals and volunteers involved in palliative care delivery view Patient Centred Care (PCC).

It may be worthy considering a secondary objective: to explore the views of volunteers on PCC and to see whether their views align with or differ from those of the professionals (This idea I get it from the last phrase of Background section).

We agree with the reviewer and added the secondary objective.
Background:

2) Article provides a definition of the key concept and the eight dimensions, which helps the reader to understand the conceptual framework. The suggestion is to include some evidence on the benefits of PCC, it will help to make argument stronger on the importance of this work.

We found a study (Dy et al. 2012) that systematically reviewed the evidence of the effectiveness of palliative- and health care interventions that aimed to improved outcomes for patients with advanced and serious illness. They showed that incorporated patient-centred quality improvement components, such as family, patient or caregiver education and self-management improves patient outcomes. We think this will make our argument stronger for the importance of this work and therefore incorporated this in the background (first paragraph).

3) In the background one of the arguments says "However, previous studies have shown that views on the relative importance of these eight dimensions for PCC may differ, between professionals as well as between patients [7, 8]. Understanding such differences is important because different views on PCC may translate into different priorities for care delivery. ..." The paper is about professionals views so the suggestion is to modulate the argument.

We agree with the reviewer and changed the sentence accordingly.

3) The background needs to include a wider international perspective considering the international audience. The suggestion is to reduce the information on Netherlands and set a worldwide context about PCC and Palliative care professionals views. Some of the information about Palliative care in Netherlands may be useful -if appropriate for the participants setting.

We added some information about the use of hospices in the UK and the US, to give a wider international perspective about the use of hospices and the urgency to understand PCC views of professionals especially in this palliative care setting (Institute of medicine 2015). Since this study was conducted in the Netherlands, we think it is still important to include sufficient information about palliative care in this specific context, but we reduced this information.

Methods section:

4) Design: The suggestion is to explain in more detail the Q-methodology, which may not be so familiar for readers. Start the design section saying: Q-methodology was used to achieve study objectives. Then explain how Q-methodology is adequate for a systematic study of subjectivity, a person's viewpoint, opinion, beliefs, attitude, and the like (Brown 1993).
We followed the reviewer’s advice and added some of your suggestions based on the article of Brown 1993. Hereby we explained why subjectivity is in this method and how person’s view and opinion is important in this method.

5) Participants: Add a section on setting and participants, including how they were sampled, total number of participants.

We added a section on setting and participants and included the number of participants.

6) Statements: It is clear that previous studies have been used to develop the final set of 35 statements. Where these final statements piloted? What can you add about them to show adequacy of them?

We clarified that the statements were first adapted based on the literature from the palliative care field. These new adjusted statements were then tested in a pilot study among three respondents. Based on this pilot study a few minor changes were made. We now present these alterations during each phase in an additional table in the appendix and summarize them in the manuscript.

Data collection:

7) The information that the study was performed in 2 hospitals and 6 hospices needs to go into participants section; with a description of the characteristics of these settings as it may influence professionals and volunteers perspective. Please also move to results the information of percentage of respondents, age of participants… The suggestion is to move Table 1 on Sample from Data collection to the beginning of results.

We moved table 1 to the ‘setting and participants’ section, since we also moved the information about hospitals and hospices to this section. Information about the percentages were moved to the ‘results’ section.

8) Table 1 includes specific names of participating centers. I wonder about possible risks for confidentiality and maintenance of anonymity. The suggestion is to anonymize the centers. Please also specify how access was negotiated and also how consent was negotiated with participants and the relationship between participants and researchers.

We anonymized the centers and we also specified how informed consent was negotiated and how we got access to the respondents.
9) Ethics: At Declarations section it is argued that "Since we investigated professionals only and this concerned an investigation of their experience with care delivery (no intervention to place) approval of the research ethics committee was not needed". Internationally this is difficult to sustain.

We added more information explaining more precisely the procedure that was followed. This procedure reflects how ethical review was arranged in the Netherlands at the time of the study.

10) At Table 1, it is used "attention nurses palliative care"; it is not clear what you mean with this.

Data collection section should focus on how, when, by whom was the information collected. Reading the information to this regard it seems that a structured interview was conducted in which participants ranked each of the statements from 1 to 9; and then ask them to explain their ranking. Is all this done in 1 interview? Who conducts these interviews? Where are these conducted (ie: working place, home…)?

We understand that readers who are not familiar with Q methodology may need more information on the data collection, and therefore provided more detail on how, when and by whom the data was collected.

Figure 1 does not seem to add much, maybe it could be erased.

We prefer to keep figure 1, as experience shows that it helps readers to appreciate the data collection procedure better; it makes understanding the ranking exercise more intuitive. However, we agree that table 1 was more detailed than necessary (also with regard to the description of the attention nurses) and might also not be clear enough. We slightly revised table 1, also deleting the names of the institutions to ensure anonymity.

11) Analysis: It is clearly explained. Please add information on the cutting points to identify 2 points of views. It is not clear if any analysis was conducted to explore whether there are differences between professionals and volunteers (Later in results it is mentioned that both viewpoints are supported by professionals and volunteers).

We added the requested clarifications in the text.
Results

12) The suggestion is to add a phrase providing an overview of how many statements were ranked similarly, different and statistically significantly. This would facilitate having an idea of how different may be the perspectives.

We add a sentence in the first paragraph of the result section detailing the amount of statements that were ranked similarly and statistically significantly differently.

13) The results provide two points of views of PCC: 1) Respondents believing that patients should be in charge of their own care and that professionals and volunteers should primarily support patients to achieve their goals and 2) Respondents considering it most important that patients, volunteers and professionals work together as a team with the patient in the passenger seat. It gets my attention that in group 2 it seems that they think as patients are not willing or capable to take decisions. This idea is worthy some discussion.

This is indeed more or less the central idea of viewpoint 2: shared decision-making in all aspects of care. However, if patients are not willing or capable at any stage of their care, the professional needs to step in and act in the interest of the patient. We added some clarifying sentences about this at the first part of viewpoint 2.

13) Besides, it mentions the similarities based on the 15 statements ranked similarly. Please specify the statement number so that reader can easily find in Table 2. For example: care should be provided keeping patients' preferences in mind (3;+2*, 8;+2**) Table 2, add below the table information about the scores (range and meaning)

We added the requested clarifications in the respective text and in the footer of table 2.

14) It would be interesting to integrate results and discussion in one section. This integration will help to highlight key results and avoid some repetition.

Following the instructions to authors rules of the journal, we did not integrate the results and discussion sections.

The discussion section focuses on specific statement results and the importance of these. It would be interesting to discuss the results considering previous studies that provide an overview of health professionals' perspective of PCC. Is this different? In which aspects exactly? Why you think is different?.
We now compare our findings with the related study of Berghout et al. and Cramm et al. and discuss some noteworthy differences between these studies.

It is noteworthy to mention that as any self-reported results, what people say may be different from what they do. Future studies should consider some observation of behaviors and interactions considering the 8 domains of PCC.

We agree with the reviewer and added this as a potential study limitation.

Reviewer 2:

Anette Alvariza, Ph.D., RN (Reviewer 2): This is an interesting paper about an important subject for future palliative care. However there are several parts of the manuscript that needs to be further elaborated. Please find my comments below:

1) All the way through the abstract and the manuscript I strongly react on the wording "palliative patients". There is no such thing as a palliative patients as it is not the patient him or her self that is palliative, but rather the illness (disease). This wording disturbs the reading of the manuscript. Please rewrite to a more proper wording, for example, patients with palliative care needs, or patients receiving palliative care.

We thank the reviewer for pointing this out. We have changed ‘palliative patients’ to ‘patients receiving palliative care’ or ‘patients with palliative care needs’ (depending on the context in the text).

Background

2) The authors have chosen the concept of patient-centered care but does not argue why this is chosen before the concept person-centered care which is used more frequently the latest years. This should be mentioned and preferably compared and discussed in the background. There are several publications on person-centered palliative care.

Since the IOM uses patient-centred care in its definition, and the eight dimensions are based on this definition, we used patient centred care as well.

Methods

3) The statements is a it confusing to read about. They could be further presented and it should also be explained how they were adjusted to palliative care. It would be helpful if the authors
presented what kind of adjustments that were made based on the pilot interviews and what literature that were used.

We agree with the reviewer that this could be explained better and changed the text accordingly (see our response to reviewer 1 with a similar remark). We also added a table in the appendix presenting and explaining the changes made to the statement set.

Data collection

4) More information is needed also here. How were the professionals approached? How many were asked for participation and by whom? Were there any that declined?

We clarified this in the data collection section.

Analyses

5) The analyses are a bit difficult to follow and the manuscript would benefit for a deeper description.

We have added more information about the analysis, hopefully this provides sufficient clarification.

Results

6) The results make me wonder, what is really the difference between the two viewpoints? To me the name of the viewpoint 2 is not quite correct, since this viewpoint is about shared descent, which at some point still puts the patient in the driver seat. Sitting in the passenger seat does not lead the thoughts of someone that's being involved in shared descent to me. Could this be revised and could the authors more clearly explain the difference between the two viewpoints?

In viewpoint 1, the main focus is on the patient as decision-maker in the care process, and not the caregiver. If a decision needs to be taken about medication, for example, the patient is the one who takes the final decision. The patient is in the lead.

In viewpoint 2, the caregiver is more in the lead and takes the initial decision about, for example, medication prescription, in consultation with professionals or volunteers. The patient trusts the caregiver to propose or even make decisions in their interest when needed, for example when they are too tired for taking the lead. However, in these cases the opinion of the patient is still
asked. Therefore, the shared decision component is important, but in this viewpoint it may be that the caregiver takes the initiative or the lead in the shared decision-making process.

We added a clarifying sentence in the beginning of viewpoint 2 that emphasizes the difference.

7) Also surprisingly, the family is not mentioned at all, not even in the discussion. As family is an important cornerstone if palliative care I believe this needs to at least be discussed in the discussion section.

We agree with the reviewer and therefore mention and discuss the role of the family in more detail throughout the manuscript (as one of the PCC dimensions, within the statements, within the results section and discussion).