Author’s response to reviews

Title: A sense of security in palliative homecare in a Norwegian municipality; dyadic comparisons of the perceptions of patients and relatives. A quantitative study

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Dear Editor–In-Chief

Thank you for reviewing the manuscript and for giving us the opportunity to revise it. We much appreciate the comments and suggestions from the two reviewers, which we found interesting and valuable. To comply with the reviewers’ suggestions and recommendations, we have scrutinised the manuscript and made several changes, which we hope have improved it. Some sections of the manuscript have been rewritten, while others have been adjusted and some text has been moved from one place to another within the article. The black fonts are the original manuscript, while text that has been moved is indicated by blue fonts and new text is in red fonts. As a result of these changes the line numbers in the revised manuscript differ from those in the original manuscript.

The reviewers’ comments refer to the line-numbers in the original manuscript. We refer to the line-numbers at the end of each of our listed revisions in the revised manuscript. The reviewers’ comments are presented in italics and arranged point by point. Our responses are in green fonts.

Please note our corrections below.

Response to the editor.
Response to reviewer 1

General comments

1. The use of "higher" and "lower" is sometimes unclear (e.g. in abstract, in result section). As a reader one is not sure if the authors refer to "higher scores" as the mean variable being 3.55 or higher, or if the patients' scores are higher than the relatives within the dyads. (Theoretically it could also refer to inter-group comparison between patients as a group compared to relatives as a group, although the authors have not conducted such comparisons).

We understand that the presentation may be unclear and have therefore changed the words to high (≥3.55) and low (<3.0) when referring to the mean scores of dimensions and the context-specific scales. When comparing patient-relative dyads, we refer to the differences between them as higher and lower (Abstract L. 39, 41. Main document p. 13. r. 265-268).

2. The result section needs also to be clearer that the comparisons between patients and relatives are intra-dyadic comparisons, and not inter-group comparisons. And as it stands now there is no descriptive presentation of how small or large the intra-dyadic differences are, this must be added.

The entire result section has been rewritten and we hope that it is now clearer and more reader friendly. We have clarified the text pertaining to the results from the whole group of patients and relatives, as well as the presentation of the results from the intra-dyadic comparisons. (Main document p. 12 and 13. r 259-281). This also involved changes in the abstract (r. 39-48).

3. The results are presented in too much details, e.g. the presentation of the results of the individual items in the abstract and in the results section. To me it would be easier to read, if the authors stick to the dimensional level in the result presentations. Ok to keep the items in Table 2, but a result from a single item in a sample of 32 dyads is not so strong.

We agree that the result from a single item in a sample of 32 dyads is not very strong. The results are now presented on a dimensional and context-specific scales level (Table 3. p.12 r. 263). The detailed table with items (previously Table 2) without values has been added as an Appendix 1. A new shorter version of Table 2 with the Cronbach alpha has been developed and added to the manuscript (p. 12 r. 257).

4. As a reader I wonder why the authors have chosen Wilcoxon signed rank test, i.e. with no effect size presentation, only p values. There are other statistics giving effect sizes, and then the results could be included in systematic reviews and meta-analysis in the future.
In this study, we considered that the measurement scales were of ordinal-level character. This is in line with several studies where the QPP has been used in other kinds of care context. Given this, we understand that it is best to present Z-scores and report whether they are high enough to indicate a 95% confidence interval for a two-tailed test and directionality. Z-scores have now been included in a new table (Table 3) (p. 12 r. 263).

Abstract

5. - p2 r27. The first aim (to describe the characteristics of patients and relatives in palliative home care) seems too trivial, especially considering the low number of participants (n32+32), and from a single urban municipality. I suggest deleting this aim.

We have followed the reviewer’s recommendation and deleted this part of the aim. The characteristics of the patients and relatives are now described in the method section under the heading of “participants’ characteristics.” (p. 8 r. 169 – 179). Due to the new measures, the aim has been slightly amended (Abstract r. 26-28; Main document p. 5 r. 102-104).

6. - p2 r41. In the Results the authors state that there were statistically significant lower scores from relatives in the following dimensions: medical-technical competence, identity-orientation of caregives and some context aspects. Why is not Physical-technical competence included? (According to Table 2, there was a significant lower scoring for realtives with p-value 0.034.

The «Physical – technical competence» dimension is measured by one item. This dimension is now included in Table 2 and Table 3.

7. p2r45. "Patients and relatives scored the subjective importance of the care higher than the care received:…" (Also in p3 r49 Conclusions). Is it possible to make this conclusion?

The mean values from patients and relatives are higher on the SI than on the PR-scale. We have now tested this (Wilcoxon’s signed rank test). Relatives scored significantly higher on all dimensions and contextual scales, whereas patients scored significantly higher on one dimension (MT), and one aspect (continuity) on the contextual scales. This has been described in both the Main document (p. 13 r. 271-274) and the abstract (r. 43-45.)

8. PR (perceived care) statements were measured with a scale ranged from 1 (Secure!!!do not agree at all) to 4 (fully agree), and the SI (subjective importance) statements were also measures with a scale from 1 to 4, but with the wording "little or no importance" (1) to the very highest importance"(4). Although the Likert-scales had the same numbers, I would be cautious to make this conclusion, when the respondents also had the wordings. Are the wordings really comparable?

This is a valid point and the text has now been altered in order to make it purely descriptive within both kinds of evaluations: Method section “questionnaire” (p. 10 r. 201-204), and result section.
Method


We have moved the aim to the final part of the introduction (p. 5 r. 102-104).

10. p7 r137. Too few details about the sampling procedure. The authors describe a setting with 3 palliative SDWTs in the studied municipality, "each of which cares for an average of 28 patients". This yields about 84 possible study dyads. 60 patients and 38 of their relatives were included in another study, and in this paper 32 patient/relative dyads were included. 32 of 84 possible patients are 38%. I miss description of how many patients were eligible, how many were excluded (and the reasons for exclusion), how many were asked for participation, how many of them participated. And the same detailed presentation of the sampling of the relatives. Without these details, it is difficult to assess to what settings/patients the results can be generalized.

As a palliative SDWT in the municipality also cares for patients who are receiving curative treatment as well as patients in the early and late palliative phase and terminal phase, it was difficult to estimate the number of eligible participants. The cancer care coordinator keeps track of patients who need palliative care and she estimated about 180 patients in a late palliative phase during one and a half year. We also scrutinised the reports from the cancer care coordinator and found that she reported 56 deaths in 2013, (2014: n= 54). We have included information about the sampling p. 8 r. 150-158. We have also added a more detailed description of the number of patients who were asked to participate, how many did not give their consent and how many died before the interview took place as well as the amount of the participating relatives. (p. 8 r. 150-158).

The inclusion of participants was problematic as the SDWT leaders reported that they forgot to invite the patients to participate due to their heavy workload. The first author (RH) was in regular contact with the SDWT leaders to remind them about the study and answer questions about inclusion.

A sentence about this has been added (p.8 r. 153-154; p. 18 r. 396-397).

11. p8 151. The author collected data of "language/ethnicity". I do not find the result of this variable in the text or in Table 1.

This has been added in the “participants’ characteristics” section (p. 8 r. 171).

12. p8 r167. QPP "consists of 44 items, of which 26 were chosen from the following three of QPP dimensions: (MT, PT, ID). How did the author choose these 26 questions? What guided them? Theory? Literature? Or what? I also miss information on how many items there are in each of the dimensions in the original QPP.

The section has been rewritten with more information about the original QPP (p. 9 r. 187) and how the modified version of the QPP was developed (p. 9 r. 190 - 197).
13. p10 r196. "... as it was unnecessary to obtain approval from The Regional Committee for Medical and Health Research Ethics ...". Unnecessary according to Norwegian law? Or according to whom?

The sentence has been reworded (p. 11 r. 228-232). The decision that approval was not required was made after an assessment by The Regional Committee for Medical and Health Research Ethics (REK). REK is publicly appointed, and has the main responsibility for research ethics in Norway.

Results

14. -p11 r235. ".. more than half suffered from cancer." How many? 50%? 95%? I would appreciate the specific number.

The number of patients with cancer is 17 (p.8 r. 173). (Moved to the section “participants’ characteristics”).

15. -p12 r237. "In the weeks prior to the interview, ...." How many weeks? 2 w? 6w? I would appreciate the specific number also here.

This now reads “In the two to three weeks prior to the interview…” (p. 9 r. 175). (Moved to the section “participants’ characteristics”).

16. -p12 r247. "On the dimension level, the PR scale shows one higher score =/>3.55 for patients (MT dimension) ...". Why do the authors not mention the Physical-technical competence (PT een dimensjon ) dimension/item (=3.74)?

We have now reported the Physical-technical competence scores (PT-dimension) (see also point 6 in this letter).

17. -p12 r249. "On the aspect level...". A bit unclear to me as a reader. Change to "ON the Contextual aspects level..."? Context specific scale …

This has been changed to “context-specific scales” in the abstract, manuscript and tables - in line with the reviewer’s suggestion.

18. - It is not so easy as a reader to always grasp what comparisons the authors make, because there are several different kinds of comparisons in the results: comparisons with "cut-offs" for being a "higher score" ( =/>3.55) or a "lower score" (<3.0), comparisons within dyads. I suggest to add subtitles in the Results section to clarify this.

We are aware of the difficulty of understanding what we are trying to express. Therefore, in line with the reviewer’s advice we have rewritten the result section (p. 12-13, r. 258-281).,
19. The result section regarding the results of all the items are quite long. All these results are in Table 2, and as I see it, these individual items are not the main results (I see the dimensions as main results). I suggest that the authors omit the text about the individual items (but may keep them in Table 2).

This is a good point. The result section is rewritten. The table has been reduced and all included items are now shown in an appendix (see also points 2 and 3 in this letter).

20. TABLE 1:

- "73,75" should be "73.75", and so on.

The table has been corrected and explanations are added.

21. TABLE 2:

- The Mean values presented, I guess, are the group mean values (the whole patient group and the whole group of relatives, and not the dyadic values)? To me this I not logic, when the p values in the following column (as I understand it) refer to testing the differences within the dyads. I think the authors have to clarify this to the reader, preferably by adding a column showing the mean values and confidence intervals of these inter-dyadic differences.

The presented mean values are group mean values. The Wilcoxon’s signed rank test was used to examine potential differences in perceptions of security between the patient-relative dyads in PR and SI (in dimensions, aspects and items) and in potential differences in perceptions of security between PR and SI from patients and relatives. We hope that we have clarified this in a new table (Table 3) for mean scores, z-values and p values.

22. The footnote about "P values refer to differences between patients and family members (Wilcoxon signed rank test)" should also have information that it is "...between patients and family members within the dyads" (if that is the case – yes that is the case ...).

This has been clarified in Table 3.

Discussion

23. The discussion of the characteristics is less interesting, because these results refer to only 32 patients. Delete?

Several parts of the discussion have been rewritten due to the new presentation of the results. The present discussion does not contain the same amount of details as the previous version. However, we would like to retain a discussion about patients who live alone because, in our opinion this will constitute a major challenge for future palliative home care as a consequence of changing family structures in western society.
24. - p17 r358. "... except for information of prognosis, about which they felt fairly insecure." Which dimension?

Due to the rewriting of the results there are now less details in the discussion.

25. - p19 I miss the problem of multiple testing in the section of Methodological considerations.

There is no longer a problem of multiple testing because all individual item comparisons have been deleted.

26. Title patients' instead of patients

To the best of our knowledge, the rule is that when two or more nouns share ownership, possession should be indicated only once on the final noun in the group, thus the apostrophe + "s" is only added to the last noun. However, as it is confusing we have changed the title to “... the perceptions of patients and relatives …”

Response to reviewer 2

The issue addressed by the authors is highly relevant for palliative care and the paper is well written. However I have major concerns, that may hamper a publication. The main drawback - from my perspective - is that the authors used a modified version of the QPP Instrument (Quality from the Patient’s Perspective) with some items taken out und some added on Contextual issues. In the paper there is however no information on the the psychometric properties of this modified instrument. Hence it is unclear how valid and reliable the findings are. I propose that before publication the authors add this essential information.

The reviewer is correct about the lack of established psychometric properties of the instrument used in this study. Our second best solution can be summarized as follows.

(1) A description of how the reduction of items was made from the original QPP version has been added (p. 9 r. 190-197).

(2) A detailed description of how the new context-specific items and scales were constructed, as well as their theoretical sources, has been added (p. 9 r. 190-196).

(3) A table presenting all 24 scales Cronbach-alphas that could be calculated has been added (p.12 r. 257). In the discussion it is noted that 21 of 24 coefficients are 0.70 or above.

(4) Broad visual inspection comparisons were made between the mean QPP dimension scores obtained in this study and the mean scores reported in another study (Please see Method, p. 10 r. 211-213, Methodological considerations p. 18 r. 410 – 417). As reported
in the manuscript, somewhat higher mean scores were found in another study on quality in palliative care (Sandsdalen et al 2016/ref.list 46).

We hope that the amended manuscript is clearer and that it will be accepted for publication in the BMC Palliative Care.

On behalf of the research group

Kind regards,

Reidun Hov