Author's response to reviews

Title: Palliative care for cancer patients in a primary health care setting - Bereaved relatives’ experience. A qualitative group interview study

Authors:

Mette Asbjoern Neergaard (man@alm.au.dk)
Frede Olesen (fo@alm.au.dk)
Anders Bonde Jensen (abjen@as.aaa.dk)
Jens Sondergaard (js@alm.au.dk)

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Author's response to reviews: see over
Dear Editor and referees

We thank you for your useful comments and suggestions to improve our manuscript. We have taken all the comments into consideration and have made changes in the manuscript regarding to almost all comments. We hope you will consider publication of our article once again as we find it valuable in the effort worldwide to optimise palliative home care in a primary care setting. We believe that especially the aspects of the lack of shared care and “professionalisation” of the relatives could be useful aspects to keep in mind in most other countries with a primary and secondary health care sector.

Below are our comments to the referees’ comments. Our comments are written in red.

On behalf of the authors,
Yours Sincerely

Mette Asbjørn Neergaard
GP, ph.d.-student
The Research Unit for General Practice
University of Aarhus
Vennelyst Boulevard 6
DK-8000 Aarhus
Denmark
Phone: +45 8942 6028
Email: man@alm.au.dk
Comments to peer review

Referee 1:
1. In the introduction to the paper, the authors introduce the reader to the concepts of collaboration and shared care, however these terms are not operationally defined. Doing so would help to clarify this for the reader. To clarify the concept of shared care table 1 is added.

2. In the introduction, the authors suggest that cancer patients and their relatives’ perspectives of the care experience have not been well examined in the terminal phase of illness. In fact, there is quite a well developed body of literature examining family satisfaction with end of life care, and bereaved relatives’ perspectives have been accessed as part of this work. We state in the introduction that evaluation of palliative care has often focused on clinical measures, e.g. the professionals’ ability to provide symptom control, at the expense of the cancer patient’s and relatives’ perception of the total care delivery in the terminal phase, which we still believe. Of cause studies have been made previously, as shown in the discussion section.

3. There appears to be lack of clarity regarding the defined purpose(s) of this study. In the introduction, the authors note that there is a profound need for a deeper insight into barriers and facilitators for delivery of good palliative home care. At the bottom of page two, it is stated that they aimed to analyze bereaved relatives' experiences and preferences for delivery of palliative home care to terminally ill cancer patients in a primary care setting. The paper would have been strengthened had the authors identified the overarching purpose of their project, and articulated specific research questions that were addressed. The aim in the end of the introduction have been further explained. We do not feel that specific research questions are needed.

4. The rationale for using group interviews to collect information for this study is not provided. While it is an appropriate approach, it is only one of several qualitative methods that could have been used. Justification of the focus group approach would have strengthened the methods section of the paper. We have chosen to keep the discussion of the method chosen to the Discussion section. It is now further elaborated at page 14.

5. It is noted that the sample for this study were close relatives of recently deceased cancer patients. Was there any consideration given to a broader definition of family for the study? Why or why not? We agree that our phrasing in the sample section is insufficient and actually incorrect. The participants met the inclusion criteria, and the specific relation to the patient was not the important issue. The important issue were that the relative had been close to the patient in the course of disease at home, at had been involved in the palliative care (table 2). The text has been changed on page 4.

6. What is the rationale for the death of the patient being less than one year before the inclusion of the relative in the study? Is this to prevent memory decay?
Yes, thank you for reminding us. Text has been changed on page 4.

7. It is noted that there is great variability in the months from the patients death to the time that family members participated in the interview. In one case, only 1 month had elapsed. It would be helpful for the reader to understand why and how the decision was made to include family members who are so recently bereft. Yes, thank you for reminding us about the relative only one month past bereavement. Text has been changed on page 4. In table 3 you also see that participant nr 10 at the time of the interview were 16 months from the death of his wife, and the further delay is due to the practical issue of arranging the focus groups.

8. As regards the focus group method used, it seems that a focus group of 3 is rather small compared to the recommendations cited in the literature regarding the successful conduct of focus group interviews. It would strengthen the paper if the authors explained why and how the groups had such varied composition and size. Did this difference in size influence the interaction that occured in the groups? Explanation is given in the text on page 4.

9. As regards data analysis, who transcribed in the focus group tapes? Explanation is given in the text on page 5.

10. A brief explanation is required regarding NVivo and its relationship to the coding procedures undertaken. This will be particular important for readers unfamiliar with this software. We write: “We used the software package NVivo, ed. 6 (QRS international, Melbourne, Australia) to assist in the coding, sorting and retrieval of data.” We find that further explanation would be too detailed.

11. Was saturation reached in the course of data analysis? We have now added: “No new themes were added after the two following interviews on page 5.” We think that to speak of “saturation” is a bit out of place in our 3-interviews study.

12. There is no information provided in the manuscript regarding the measures taken in this study to ensure rigor as it is understood in qualitative research. This needs to be included, particularly given the comment on page 13 concerning the issue of researcher bias. We have added explanation on how we exchanged rigor in our analysis in the analysis section page 5.

13. The authors need to be more specific about their claim of disproportionate added value as concerns accessing the perspectives of palliative patients. That there are ethical and practical challenges inherent in conducting research with this patient population does not mean that such work should not be done. Their point on this needs to be clarified.
We agree that studies with palliative patients should be done when it makes sense, but if the relatives' experiences are enough one should spare the vulnerable palliative patients in such situations. The text had been revised a little on page 14.

14. The situation of the findings from the study to extant literature is somewhat limited.
Sorry, we do not agree, and did therefore not change this section.

15. The implications for future research and practice need to be more clearly described. For example, how do the authors suggest that a shared care culture be developed within the healthcare system?
This has been elaborated at the end of the discussion section page 16.

Referee 2:
1. I recommend that the term “GPs” be included in the Title.
Title has been changed but we think that adding GP to the title could have the effect that primarily GP researchers would read the article, and the findings are also very important for other researchers.

2. The Introduction section should include more articles regarding home palliative care and bereaved family surveys to clarify the relevance of this article to palliative care research worldwide.
Reference 10 and 11 are such studies, and more are presented in the discussion section.

3. Please provide more detailed information in the Methods section about the Danish palliative care system, especially the role of home care and the environment of death. In addition, a comment regarding palliative care education for GPs should be included.
A more detailed information about the Danish system and education in palliative care are added to the method section page 3 and 4.

4. The theme of the group discussion presented by the interviewer should be described more precisely in the Methods section.
The themes of the topic guide are described further at page 5, and the themes in the interview followed this topic guide. Table 5 is added.

5. The subsection title in the Discussion section is unnecessary.
They are now removed.

6. The novel findings of this study should be more emphasized in the first paragraph of the Discussion section.
Changes have been made on page 14.

7. The authors concluded in the Discussion section that the reason for the low appraisal of GPs stemmed from participants wishing to describe negative experiences. However, in the country where I live, bereaved family members who have experienced positive end-of-life care are more likely to want to be recruited
for such a study. However, the participants in the present study pointed out that the GPs provided a low quality of care. This might be because Danish GPs in fact do provide low quality care. Thus, the conclusion might be misleading. I recommend that you reconsider the conclusion taking into account the actual situation in Denmark. For example, the theme of the group discussion might affect the comments of participants, and so should be described clearly. We agree. Changes have been made in the text on page 14 – 15.

8. Why did the authors perform group and not in-depth individual interviews? The merits and limitation of focus group interviews should be discussed. Changes with elaboration in the discussion section have been made on page 14.

9. The implications and future desirable actions should be more precisely and concretely described based on the findings of this study. Changes have been made in the text on page 16.

10. Cultural issues such as “professionalization” in Denmark should be more precisely described as this would an interesting topic for readers from other countries. Since this also is a new issue in palliative care in Denmark, there has been no previous description of this aspect… It requires further research as described more precisely in the end of the discussion section and in the conclusion.