Author's response to reviews

Title: Caregivers' active role in palliative home care - to encourage or to dissuade? A qualitative descriptive study

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Caregivers' active role in palliative home care - to encourage or to dissuade?
A qualitative descriptive study
Anna Weibull, Frede Olesen, Mette Asbjoern Neergaard

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 revised the manuscript regarding to the 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 especially in concern of relatives’ active involvement in palliative care.

We believe that especially the aspects of which prerequisites should be kept in mind in this field could be useful aspects in palliative care in most other western countries.

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

On behalf of the authors,
Yours Sincerely

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Referee 1

1. This qualitative study sought to explore the impact of bereaved family caregivers’ active involvement in medical and physical care on their experiences of the palliative care course of disease. Unfortunately, the central concepts in this question were not operationally defined. Definitions of the attributes of family caregiver and active involvement would have strengthened the paper. “Family caregiver” is a well described term in the literature, but we agree, that “active involvement” is not. In line 11 and 12 in the introduction examples of active involvement is mentioned. Furthermore, table 1 was added.

2. Moreover, these definitions would have provided clarity concerning the inclusion criteria for bereft family members, and the ways in which determination of active involvement in care was discerned. We agree that the inclusion criteria were not sufficiently described. Table 3 was added. Concerning active involvement again table 1 was added.

3. What is the theoretical framework for this study? Since the method used is “Qualitative Description” we did not start out with a framework since the categories in this method are supposed to evolve from the data instead of imposing a framework a priori. We refer to the literature listed in the article.

4. The authors state that it is unclear whether active involvement of family caregivers could be harmful or have a negative effect on their experiences of the palliative course of disease. I am not clear exactly what this means. Does it refer to the psychological and physical health of the family caregivers? If so, research has been conducted examining the issue of caregiver burden in end of life care that indicates whilst the caregiving experience has its rewards, it also has negative effects. That being the case, it is not clear why the authors conducted more qualitative work asking this question. If the authors believe that extant work in the field requires more descriptive work, it would have strengthened the manuscript if a compelling case had been made in that regard. We have changed the introduction. It is true, that there has been previous work on caregiver burden in relation to palliative home care as we also state in the article, but not much work has been done on caregiving experience in specific relation to active involvement. We therefore believe that this study has its justification.

5. The setting is well described in this paper. Thank You!

6. The sample for this study consisted of 7 spouses of terminally ill cancer patients who had been cared for at home. There is no description of inclusion criteria for family caregivers, (We added table 3) save that they be bereft within the past 1-3 years. Contacting family members at this time shows ethical sensitivity, as hopefully issues of acute grief will have begun to be resolved. This is one of the reasons why we asked the GPs to find potential informants. They know their patients and know if it is ethically correct to ask the spouse after the given time. We also believe, that the immediate grief should be over before you can reflect on the
experience in this case and to describe how the events have influenced bereavement. Changes in the text has been made in the sample section

7. It is not clear in the paper how many participants were contacted in total for the study. How many refused? Do we know if there are statistically significant differences in terms of demographic characteristics between participants and those who did not take part? All contacted participants agreed to participate! Changes in the text has been made in the sample section

8. There is no mention in the paper of whether or not this study received approval from a Research Ethics Board, and no mention of participants providing written informed consent. A section on Ethics has been added to the method section.

9. That some participants were family members recruited by a physician who had cared for their deceased relative is, in my mind ethically problematic. Despite the benevolent intentions of the researcher, issues of coercion and power differential exist in this instance, and thus an intermediary should have been used to recruit these individuals. We were very aware of this problem and kept these two interviews separate in the initial coding process, but since it was very clear after that, that they did not differ in content from the others, we decided to include them. Changes in the text has been made in the analysis section

10. In qualitative research, data collection and analysis occur concurrently. Did this happen in the study? Yes – sorry we did not clarify this… Changes in the text has been made in the analysis section

11. How were differences of opinion regarding the thematic categories that emerged in the data reconciled amongst the research team? There were no differences of opinion regarding the thematic categories among the research team!! Changes in the text has been made in the analysis section

12. The authors identify the use of triangulation within the group of researchers as ensuring the quality of the coding. This needs to be described more fully and See above.

13. issues of rigor as they apply to qualitative research that were used in the study need to be discussed. What were they and what were they intended to achieve? If additional measures to ensure rigor were not part of the study, what do the authors see the impact of this being on the merit of their work? We agree. Changes in the text has been made in the analysis section

14. The conclusions drawn by the authors that their data, based on interviews with 7 family caregivers are “qualitatively representative of experiences among caregivers assisting with palliative care at home” is not defensible. Only spouses were interviewed in this study. There are many other categories of family caregivers whose experiences were not accessed. Therefore, a comprehensive
understanding of the impacts of this caregiving cannot be empirically claimed.
We agree, and have rewritten the article with this in mind.

**Referee 2:**
1. The sample size of this study was small. This greatly limits the conclusion of the paper. For example, the author insist that the study explore the impact of bereaved family caregivers’ active involvement in medical and physical care on their experience of the palliative course of disease. The author may be able to list the opinion concerned with the impact but cannot conclude what is the biggest impact or the most important impact. Therefore, The statement, "This study showed that family caregivers’ active involvement in palliative care has a positive effect on bereavement given that certain preconditions are fulfilled" was overly concluded. The author should modify the discussion and the conclusion.
We agree, and have rewritten the article with this in mind.

2. Overall, the description of the analysis is insufficient. Especially, it is unclear how four main categories were identified. The author should clarify the detailed process of analysis. Changes in the text has been made in the analysis section.

**Referee 3**
1. This paper reports the results of a small descriptive study of family caregivers of cancer patients, who are cared for at home in Denmark. The authors argue that the experiences of family care givers caring for a family member at home have been relatively neglected in the literature. While there is some evidence for this, there has been a body of knowledge focused on the experiences of family carers predominantly from Australia, Canada and the UK. There are now many small scale descriptive studies. However, the authors have sought to illuminate the impact of carer’s direct involvement in patient care at home during the dying period, and this is potentially useful as policy drivers in many European countries seek to increase home death rates, with often scant regard to the impact on family carers.
We agree. See our comments to referee 1, nr 1, and we have made changes in the introduction so that the focus on the active involvement is clearer.

2. There are a number of limitations to the research that need addressing: Sampling – it appears (only in the Discussion) that some of the participants were selected from patients under the care of their own GP. Therefore the researchers have a pre-existing relationship with these families. There is a potential for bias which should be discussed.
We agree. Changes have been made in the discussion section. See also changes in the analysis section.

3. Claims for the research – the study offers a retrospective account of care giving from a very small group of seven bereaved carers. The analysis is presented in descriptive terms. I therefore think it is not justified to make claims that ‘active
involvement in palliative care has a positive effect on bereavement’ (Discussion). We have modified the text.

4. There were no measures of bereavement outcome. This was not intended since we kept an open mind to what the spouses felt were important. (Using Qualitative Description it is important to stay close to the data)

5. participants varied in the time since bereavement (1-3 years). This is to assure that the time since bereavement did not have an influence. (Still there were robust and uniform information)

6. and there is no comparison group. We do not normally use a comparison group when we do this kind of qualitative research.

7. A more nuanced and contextualised account is required that acknowledges that these are self-reports from a small group. The article was rewritten with this in mind.

8. Otherwise the paper is well written. There is a typographical error on Table 1 – pancreatic cancer. We believe you mean the term Pancoast Tumour? A pancoast tumour or superior sulcus tumour, is a tumour of the pulmonary apex i.e. a type of lung cancer defined primarily by its location situated at the top end of either the right or left lung. We chose to call it pancoast tumour to specify that the symptoms are somewhat different from a normal lung tumour.

Assistant editor’s comments:
Additionally, we will require the following changes in your revised manuscript:

1. Ethics - Experimental research that is reported in the manuscript must have been performed with the approval of an appropriate ethics committee. Research carried out on humans must be in compliance with the Helsinki Declaration (http://www.wma.net/e/policy/b3.htm), and any experimental research on animals must follow internationally recognized guidelines. A statement to this effect must appear in the Methods section of the manuscript, including the name of the body which gave approval, with a reference number where appropriate. We can not continue without this information. A section on Ethics has been added to the method section.

2. Informed consent must also be documented. Manuscripts may be rejected if the editorial office considers that the research has not been carried out within an ethical framework, e.g. if the severity of the experimental procedure is not justified by the value of the knowledge gained. See section on Ethics in the method section.

3. Please also ensure that your revised manuscript conforms to the journal style (http://www.biomedcentral.com/info/ifora/medicine_journals). It is important that your files are correctly formatted. We have revised the article according to the directions.