Author’s response to reviews

Title: What are essential elements of high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer

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Author’s response to reviews:

Dear editor,

Thank you for the opportunity to revise our manuscript. Below we provide a detailed response to the comments of the reviewers.

Sincerely, on behalf of all the authors,

Mariska Oosterveld-Vlug

Reviewer reports:

Yvonne Engels, PhD (Reviewer 1): This is a well-written, interesting paper in which patients and relatives were interviewed about their palliative care experiences in primary care.

I have the following questions and suggestions:
1. Title: 'and their families' suggests that Always dyads of patient-family were interviewed, which is not the case.

Response: We changed the title as follows:

What are essential elements of high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer

2. Background:

lines 39-40: Accordingly...... palliative care. Indeed, these are indicators for palliative care, but it does not say anything about the quality of the palliative care provided at home. For instance, the fact that in the Netherlands so many patients who die at home receive palliative sedation implies that they had refractory symptoms, which is not in line with home death is high quality. Of course this discussion does not need to be added to the introduction, but just mentioning these indicators seems not ideal to me.

Response: The reviewer is right that dying at home is not similar to receiving high-quality palliative care at home. We removed this sentence from the introduction.

3. Line 52: They have opportunities .....: add that this is mainly consultation by Phone.

Response: We changed the sentence as requested:

In the event of complex problems, such as managing refractory symptoms, they have opportunities to consult specialist palliative care teams by telephone, which are available all over the country.

4. Page 6 lines 68-69: the palliative patients received.... I don't understand the sentence. Did you forget a word?

Line 71: patient's illness instead of patient's illness (earlier in the sentence you also use plural)

Response: We rewrote the sentence as follows:

In general, the palliative care that patients received matched with what they considered as important. However, improvements could be made in the provision of support to patients suffering from fatigue and in the provision of information on the expected course of patients’ illness.
5. Methods:

You used the surprise question as inclusion criterion. I have the impression that most data concerns
the terminal phase (many aspects concern home visits of nurses and doctors). Can you add
something about the stage and condition of the patients about whom the participants shared the
experiences?

Response: The survey study that we used as a framework for our qualitative study indeed used the
surprise question as an inclusion criterion. The recruitment of participants for the survey study
took place from June 2015 - January 2016. The interviews for the current study were performed
from September 2015 - May 2016; around four months after asking the surprise question to GPs.
Therefore, it is expected that quite a few patients (and the patients that relatives represented) were
indeed in the terminal phase.

We added the timeframes for recruitment of patients in the Methods section:

In this way, 72 patients and 63 relatives were recruited between June 2015 and January 2016 and
participated in the survey study. Of them, 28 patients and 22 relatives stated in the survey that they
would also be willing to participate in an additional interview. Because of rapid deterioration in
health or the patient’s death, 13 patients and 14 relatives could finally be interviewed between
September 2015 and May 2016.

6. I miss information about data saturation. If you did not have data saturation, that is also needed
to be mentioned.

Response: Data saturation has been achieved in this study. We added to the text:

At some point, the evolving code list remained unchanged at each subsequent interview, indicating
that data saturation has been achieved.

7. I miss information about the interrelatedness of themes which you describe in the results section
and should be mentioned here. How did you do this?

Response: We added to the methods section:

The emerging themes were constantly compared with the content of the interview transcripts. This
process revealed that multiple linkages between emerging themes existed. To identify overarching
themes and to visualize their interrelatedness, we made use of a visual concept map.
8. Results:
Page 11, theme 3. Before you mention the three categories of this theme, you already start with a quote and some information. Does this first paragraph not belong to one of these three categories?
Response: The quote is an illustration to the subtheme ‘personal interest’. We integrated the first paragraph and the quote within the other text.

9. Page 12: Taking the patient and THEIR relative. Should be his or her (singular)
Page 12 line 218: one 'can' should be deleted (can subsequently can)
Page 15 line 303: as a partners should be as a partner.
Medical record: I would say individual care plan.
Page 16 line 329. Costs instead of cost
Response: Thank you for pointing us to these errors. We changed them according to the reviewer’s suggestions.

10. Discussion:
Start with including the research question in the first lines.
Response: We repeated the study aim in the discussion.
The aim of this study was to get insight in the elements that patients with advanced cancer and relatives consider essential for high-quality palliative care, and whether these essentials are present in the actual care they receive.

11. Page 18 line 396: interviewees had (instead of have)
Response: We changed this.
Jun Hamano (Reviewer 2): This qualitative semi-structured interview was aimed to reveal the essential elements of high-quality palliative care at home.

The result seems to have good implication, though there might be better to clarify the several points which described below.

1. It might be better to described the interview methods; "the patient and their relative (partner or daughter) were interviewed – separately from one another" which was described in Result section, in the data collection section.

Response: We think the reviewer points to the sentence that describes the design, in which we write that patients with advanced cancer and their relatives were interviewed.

We changed this sentence into:

The research questions were addressed in semi-structured qualitative interviews with patients with advanced cancer and with relatives of patients with advanced cancer.

We also changed the title. See our reply to comment #1 of reviewer #1.

2. It would be better to clarify the reason and rationale to make schematic diagram which was presented in Figure 1. If possible, author could present the references or the details of discussion between the authors.

Response: We added to the methods section:

The emerging themes were constantly compared with the content of the interview transcripts. This process revealed that multiple linkages between emerging themes existed. To identify overarching themes and to visualize their interrelatedness, we made use of a visual concept map.

This concept map formed the basis of Figure 1.

3. It would be better to explain the Figure 1 with more detailed description in footnote.

Response: At the end of the manuscript, some footnote descriptions for Figure 1 can already be found. If the reviewer has additional suggestions for more detailed description, we are willing to include this.
4. Authors should clarify the answer of RQ: Does the actual palliative care provided match what these patients and their family consider in discussion section or conclusion.

Response: To clarify the answer of this research question, we added to the discussion:

The interviews also reveal that most interviewees had positive care experiences with regard to the aspects they consider essential for good-quality primary palliative care. However, the requirements of ‘proper information transfer between professionals’ and ‘clear and rapid procedures’ were mentioned as more difficult to meet in actual practice.

5. As authors mentioned this study was conducted in one country with small number of patients who might have good relationship with their GP, it might be better to describe the limitation of this study clearly in terms of generalizability.

Response: We added to the methodological considerations:

GPs might have selected patients with whom they had a good relationship, possibly resulting in too positive a picture of the patient-GP interaction. Furthermore, the participants were relatively highly educated, which could have led to a bias in the findings, as well as might limit their generalizability. However, the fact that even these people, who were relatively highly educated and have a good relationship with their GP, have difficulties with bureaucracy and formalities underlines the importance of simplifying this.