Author’s response to reviews

Title: A painful experience of limited understanding: Healthcare professionals' experiences with palliative care of people with severe dementia in Norwegian nursing homes

Authors:

May Helen Midtbust (mmi@ntnu.no)
Else Lykkeslet (else.lykkeslet@himolde.no)
Rigmor Alnes (rigmor.e.alnes@ntnu.no)
Eva Gjengedal (eva.gjengedal@himolde.no;Eva.gjengedal@uib.no)

Version: 2 Date: 01 Feb 2018

Author’s response to reviews:

Dear Editor

Thank you very much for your specific and helpful feedback to our article. We have now carefully considered all your comments and have revised the article accordingly. You recommended a native English speaker colleague to reread the text to check the phrasing and chose of words. We were unable to get a colleague to reread the article, and we therefore chose a “standard editing” in American Journal Experts. They have made some changes as we hope have improved the quality of the English usage.

Editor Comments:

Abstract: In the abstract I don’t think ‘proper’ in reference to palliative care is inappropriate. Perhaps delete the word proper. The word “proper” is deleted (Abstract line 6).

In the abstract, the results need some restructuring. This is so they reflect a summary of all your results. I would start with stating the general meaning structure and four themes you found. Then give detail in brief of these themes, including one on positive as well as the negatives.

- In conclusions in the abstract, you need one first sweeping main statement on findings such as we found health professionals experiences of providing palliative care to people with severe dementia as painful. Then provide your recommendations based on your findings.

- To me the sentence ‘the major findings are illuminated by a hermeneutic perspective on understanding’ is out of place in the abstract. Perhaps delete this here and reserve this statement to the main text.
We have changed the abstract according to your recommendations (Abstract lines 20-42).

Introduction: In the introduction, the second and third sentence the choice of word ‘some’ may not be the best for this text. For the second sentence can you say instead ‘In 2015, globally it was estimated that 47 million people were living with dementia’, etc… For the next sentence instead of ‘some’, you could say ‘currently around’ or ‘In 20?? around ….’

- In the introduction, first sentence please delete ‘to’. In second sentence there is a missing comma between ‘thinking’ and ‘and’.

- The details in the third paragraph on palliative care are not needed as this is a journal of palliative care. I would delete this paragraph.

The choice of word “some” is changed (Introduction lines 2-5). We have changed the first sentence in the second paragraph (Introduction line 17), and put in the missing comma (Introduction line 20). The details related to palliative care are deleted (Introduction lines 33-46).

Methodology and Method: In the methodology section first paragraph, second sentence I feel the middle part could be clearer. I suggest: “of going to the things themselves”, in other words to do ‘full justice’.

We have changed according to your recommendations (Methodology and Method line 55).

In the section on participants and recruitment, first sentence I would not say ‘the management’ instead say either the ‘management team’ or ‘the manager’. When further in this paragraph you refer to ‘leaders’ instead I would call these person the ‘manager’ or supervisor, some thing that reflects more a conventional job title.

- Readers outside of Norway may not know what a licensed practice nurse is. You describe what they are in the conclusions. Instead please describe them in the methods section.

- The last sentence in this section on participants and recruitment, please replace wording 50 and 100% positions to full or half-time positions.

- You interchange between calling your sample nurses and health professionals. Try to be more consistent in what you describe them as.

We have now called it the “management team(s)”… and the manager(s) (Participant and Recruitment line 18, line 28, line 30). We have replaced and described what a licensed practical nurse is (Participant and Recruitment line 30-34). The wording 50 and 100% is replaced to full or half-time positions (Participant and recruitment line 36). Our interchanging between nurses and healthcare professionals has been changed to a more consistent use of healthcare professionals throughout the article.

Last sentence in data analysis. This sentence is a finding not a method, please move to results section as the opening sentence. We have removed this sentence from the analysis section (Data
analysis lines 29-30), and believes that the general structure of meaning with four essential themes are already presented in the section A painful experience of limited understanding (Result lines 36-46).

Results: Page 9. Last sentence first, first paragraph; the word ‘will’ needs to be replaced with ‘wish’.

The word is replaced (Results section, page 9 line 18).

Section handing the patients over the strangers, please replace the word ‘defined’ with ‘seen’. The word is replaced (Results section, page 9, line 25).

Page 10, the word 'fight' can mean physical force to try to defeat another. Please consider another word to describe their struggles.

• Page 10, section on disagreeing on the patient’s best interest. Sentence including medical relief needs to be rewritten. What do you mean by medical relief. Also why have you linked this in one sentence with familiar music and presence of a nurse? Please make this clear

The word “fight” is replaced with “argue against” (Results section, page 10 line 20). In order to make sense we have deleted the sentence about medical relief (Result section, page 10 lines 49-52).

Page 11, first paragraph, sentence starting ‘several informants referred to these…’ in this sentence you go on to state that intravenous fluids will cause more suffering. I would tone this down, to intravenous fluids may cause more suffering.

• Page 11, middle paragraph when you refer to a patient being stabbed by an injection, it may be better to use ‘’ as in ‘stabbed’. This is as it is not a usual term to describe such an action.

We have changed to “may cause more suffering” (Results section, page 11 line 9). We have also replaced the word “stabbed” with “injected” and abridged the quotation (Result section, page 11 line 27 and lines 34-38).

Discussion: Page 12, first complete sentence, starting ‘a hermeneutic perspective..’, please plural finding to findings. Corrected (Discussion, page 12, line 2).

Strengths and limitations: Page 14. Here and elsewhere you refer to ‘leaders’ in nursing homes, it would be clearer if you described this as a staff term, such as head nurse, manager or supervisor. We have changed to management team and manger(s) (Strengths and limitations, page 14 line 38 and line 47).This is also done in the “Participant and Recruitment” section.

For the “Availability of data materials’ section we have written: ”The datasets generated and/or analysed during the current study are available from the corresponding author on reasonable
request”. However, we want to inform that all raw data are written in Norwegian and thus not available in English.

We hope these changes adequately address your concerns, and are happy to address any other questions you might have.

Sincerely,

May Helen Midtbust

Aalesund 01.feb.2018