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

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Author’s response to reviews:

Dear Editor and reviewers

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. Under we have outlined the changes and considerations made to the article. Our comments are made in red.

Editor Comments:

Please attend to reviewer 2 comments. In addition please reconsidered your conclusions: in the abstract there is some repetitiveness with your findings section and in the main text it would be helpful to give more detail on your recommendations (such as more detail on more research).

Abstract: We have revised the conclusion, and removed the repetitiveness from the result section. The result section also provides a more detailed description of the findings (see Abstract, results section page 2, line 3-9).

The conclusion in the main text: Both our conclusions and recommendation for further research is described in more detail (see Conclusion section page 15, lines 3-19).

Reviewer reports:

Kathryn Lord (Reviewer 1): Thank you for the opportunity to read this interesting and well written paper. The impact of providing palliative care on healthcare professionals is of great interest and something which has limited focus in the wider literature. I really enjoyed reading
this paper and felt that the authors explained why the research needed to be carried out well. The results section provided an interesting overview of the emotional challenges faced by healthcare professionals in this scenario and some interesting points for consideration in future training and support for individuals carrying out this role. There is currently some interesting work emerging on how prepared healthcare professionals feel to care for someone living with dementia and I would suggest that this be explored specifically in terms of palliative care with this patient group in future research. Disseminating these findings to improve healthcare professionals training would be great.

We have included her suggestion on research about how prepared healthcare professionals feel to care for someone living with dementia and explored specifically in terms of palliative care (see Conclusion section page 15, lines 17-19).

Ladislav Volicer (Reviewer 2): This manuscript describes results of phenomenological study reporting experiences of nurses caring for residents with advanced dementia in four Norwegian nursing homes. While it is interesting, it needs some modifications before it is suitable for publication. After reading the manuscript, I believe that there are three separate issues that are painful for the nurses. They are coping with behavioral symptoms of dementia, providing palliative care, and coping with transfer of residents from the sheltered unit to somatic long-term unit. It would make the paper more informative if these issues were clearly differentiated.

The reviewer points out three separate issues, which is particularly painful for the healthcare professionals and suggests that we clearly differentiate these issues. This phenomenological study aim to describe the meaning of the phenomenon as it is experienced by the informants in one general meaning structure. According to our analysis the general meaning structure of the healthcare professionals’ experiences with providing palliative care to people with severe dementia is; painfulness due to their limited understanding of the patients’ individual mode of expression when they are no longer able to explain their own situation. This meaning structure has in our interpretation different shades that we have described in four themes: 1) Challenges related to reading the patient’s suffering, 2) Coming up short despite occasional success, 3) handing the patient over to strangers and 4) Disagreeing on the patient’s best interest.

In the revision, we have tried to better differentiate these four themes to avoid overlap between them. We find it difficult to name one of the themes palliative care (as we think that reviewer 2 suggests), as we regard the four themes as different aspects of the informants’ experience of palliative care. I addition we have changed the naming of the themes a little bit to clarify the meaning (see Results section, page 6, page 8, page 9).

1. Behavioral symptoms of dementia. It should be explained what these symptoms are and that one of the most disturbing one is rejection of care (this name should be used because rejection alone does not describe what is happening). It would be useful to include strategies that the nurse use in coping with the behavioral symptoms, if they reported those during the interviews.
Behavioral symptoms of dementia: We have explained what these symptoms are and pointed out that rejection of care is the most disturbing symptom (see Result section page 8, lines 3-7). We had already included some strategies that the healthcare professionals used, but we have now written a little more complementary about this (see Results section page 8, line 20-25), and removed a section from page 7, lines 9-14. Behavioral symptoms of dementia is also pointed out in the Abstract (see Abstract section page 2 lines 4-5), in the Discussion (see Discussion section page 11, line 7) and in the Conclusion and implications for clinical practise (see Conclusions page 15, line 8).

2. Palliative care. Which medical procedures were limited if the family agreed to palliative care? Were behavioral interventions used before drug use?

We have included information of which medical procedure were limited when the family and the healthcare professionals agreed to palliative care (see Results section page 10, Disagreeing on the patient’s best interest – lines 3-5). In addition, we have tried to describe how behavioral interventions like familiar music and the presence of the staff calming down the patient may be important (see Results section page 10, Disagreeing on the patient’s best interest – lines 5-7). Unfortunately, it was not reported in our interviews if these interventions were tried out as an alternative to drugs.

3. Transfer. What was the reason for the policy that requires transfer of residents from the sheltered unit to somatic long-term unit? How did the care differ in these two settings?

The abstract should have a more informative section of results and conclusions should be only one or two sentences. There is no need for long explanation of Gadamer's theory because it does not seem to be related to better understanding of residents.

The reason for the policy that require transfer of resident from a sheltered unit to a somatic long-term unit is now explained, and we have explained how the care is different in these two settings (see Results section page 9, Handling the patient over to strangers – lines 3-19). We have also clarified this in the “Participants and Recruitment” section (see Participant and recruitment section, page 5, lines 5-8).

As written under the “Editor comments” we have now written a more informative section of results and a shorter conclusion in the Abstract (see Abstract page 2, lines 3-13) Further, we have shortened the description of Gadamer’s theory and emphasized the hermeneutic perspective on understanding (see Discussion page 12, removed lines 3-9). Throughout the discussion and in the conclusions we have tried to argue that being open and trying to look beyond one’s one horizon is a significant prerequisite for new understanding.

In addition, we have done some small changes in the text (see Discussion, page 12, line 13 and 14, line 19, page 13, line 15 and 23, page 14, line 1) and in declarations (see Availability of data material page 16, lines 2-3). In the reference list, we have added a URL to reference no 1, 2 and
11 (see References, page 17). We have also changed the order of authors, and completed a “Request for change in authorship” (email 9.jan.2018).

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

Sincerely,

May Helen Midtbust

Aalesund 16.jan.2018