Author's response to reviews

Title: Nurses’ and care workers’ experiences of spiritual needs in patients with dementia disease in nursing homes: a qualitative study.

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**Review 1**

Reviewer’s comments:

Point number 6:

Are the limitations of the work clearly stated? No

Our comments:

We have added limitations on page 23.

**Limitations:** Findings from this study cannot be generalised. Nevertheless, many of the issues and challenges can be recognised in different contexts within dementia care. Norway is considered to be a multi-cultural society to a greater extent than before. Yet the majority of patients in the nursing homes in this study where ethnic Norwegians, well known with the Norwegian church traditions. One limitation is therefore that the nurses had limited experience with different religions. A greater diversity could have expanded the perspectives some more.

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**Review 2**

Reviewer’s comments:

Specifically, it is unclear how the context of the study is related to the themes. For example, the abstract results section refers to the relational context as trust, safety and self-worth then identifies theme as “suitably involvement”, “search for belonging” and “faith expressions.” What is the relationship or meaning between the context of the findings and the themes?

Our comments:
We find the reviewers comments very useful and have changed the result section in the abstract (p 3):

The nurses’ and care workers’ experiences of patients’ spiritual needs were related to three main themes; i) The need for serenity and inner peace, described as “contemplative and restful...
moments” or “calmness due to recognition”, ii) The need for confirmation, described as “love and proximity” and iii) The need to express faith and beliefs described as “participate in worship and prayers” or “approaching the death”.

Reviewer’s comments:
Authors refer to nurse’s perception of patients’ non-verbal behavior and state that there were some verbal expressions. It would be interesting to have patients comments added were possible.

Our comments:
The study was not aimed to explore the patients’ comments, but the nurses did refer to some thoughts from the patients’ perspective.
We have added the following: (Page 16-17 under the heading: “love and proximity”)

Some of the patients could express thoughts’ like: “I am just stupid” or “I am totally alone”.
The nurses found that closeness and love was basic spiritual needs that were important to take into account when patients struggled with low self-esteem and felt lonely.

The citation on page 19, also reveal one of the patients comments to a nurse in the conversation.

Reviewer’s comments:
It is recommended that the relationship between the context of the study and themes be clarified. At this point these findings seem independent.
The manuscript still needs some editorial help to make some of the meaning more clear, e.g. is the theme “suitably involvement” supposed to be suitable involvement?

Our comments:
We agree with the reviewer at this point and are thankful for the comments. We have thus tried to clarify the meaning in the text. This is marked with red color. We have moved some sentences in the text to make it clearer. This is marked with blue color.

The themes:
We have changed the themes to be like:

§ Main theme: Suitable involvement is changed to: The need for serenity and inner peace (13).
Sub-theme: Passivity and restlessness is changed to: “Contemplative and restful moments (p 13),” and Moments of something more, is changed to: “Calmness due to recognition”(p 14).
Main theme: Search for belonging is changed to: The need for confirmation (p 15).

Sub-theme: Seeking contact with nurses and relatives, is changes to: “Love and proximity” (p 16).

Main theme: Faith expressions, is changed to: The need to express faith and beliefs (p 17).

Sub-theme: Solemnity of the devotional and the priest is changed to: “Participate in worship and prayers” (p 17) and

Sub theme: To express the needs for religious activities is deleted.

Sub theme: Facing death is changed to: “Approaching death” (p 18).

The meanings:

1  The need for serenity and inner peace (p13). The entire paragraph has been worked through:

In spiritual experiences, the nurses realised something transgressed in the form of a peaceful moment. These experiences focused nurses’ attention on important values in patients’ lives. Nurses observed that the dementia caused confusion and uncertainty for the patients. They also experienced that the patients’ changed between a state of passivity or apathy and a state of inappropriate restlessness. Restlessness was interpreted as an expression of discomfort or lack of inner peace, and the nurses wanted to help the patient into a state of rest.

2  Calmness due to recognition (p 14-15). Some sentences are added in this paragraph to clarify the meaning.

Many restless patients became tired during the day. Nevertheless, the nurses experienced that the patients could not manage to sit still, and the nurses believed they should not force them to be still. A better way to meet the patients’ needs was to engage them in familiar activities as a way to deflect the aimless wandering in the department. The nurses’ observed that patients benefited from activities that were adapted to them individually.

3 Love and proximity (p 16). Here we have moved text parts to clarify the meaning.

Paragraphs one and two have switched places.

“The nurses reflected upon that they perhaps were the most important persons in patients’ life, and they perceived that as a big responsibility. The nurses observed that some patients’ were socially isolated, and thus the nurses emphasized to establish an atmosphere of tenderness and
love. Many patients’ could enjoy being taken around or get a hug, holding hands, or just be around the nurses. One nurse expressed it this way:

A 2: “They do not have to feel that they have lost themselves completely, but that they still are a full-fledged human being. We can try to maintain and enhance the patient’s interests and preserve what is left. Then they can feel like a whole person and not just one that loses more and more of “self” and “disappears.” (p 10)”

4 The need to express faith and beliefs (p 17), - has been clarified:

The nurses considered faith and beliefs to be important aspects of the patients’ lives. Nevertheless, these components were modestly discussed among the nurses. Commonly, the priest came and maintained worship in the nursing homes once a week and the nurses felt that this was helpful and that they could rely on the priest.

Review 3
Reviewer’s comments:
1) There are errors of language throughout. These are distracting and there are some instances where I cannot be sure what the authors want to say.

Our comments:
The article is proofread.

Reviewer’s comments:
Dementia is best referred to as ‘dementia’ not ‘dementia disease’. ‘Patients’ are better described in this context as ‘residents’

Our comments:
We have changed the term “dementia disease” to “dementia” throughout the document.

We do prefer to use the term "patient" because it applies to residents of a specific disorder and that the dementia disorder requires special health care initiatives placing these residents in a patient role. We have also used the term “patient” in another study from the interviews in the focus groups.

Reviewer’s comments:
Point number 2) The method and setting of the study are not adequately described. I would
wish to know more about the Nursing Homes – their size and locality and whether they cater only for people with dementia or have a mixed clientele. This may have influence on how residents and their spirituality are seen by care-staff.

Point number 3) We have some details of the characteristics of staff who gave their time to the study. It would be helpful to know how big the pool from which they are drawn is, and the characteristics of the whole workforce so that we have an idea of how representative the views gathered are likely to be.

Our comments: We have clarified the “setting”:

“Setting”, (p 8)
Four nursing homes participated in the study. All four nursing homes had special expertise in caring for patients with dementia by employing competence-raising measures for nurses and care workers for several years. Studies conducted in a Nordic context reveal that 81% of patients in Norwegian nursing homes have dementia and are in need of extensive help throughout the day [39]. The nursing homes in this study were located in southern Norway. The nursing homes had the following characteristics: Nursing home A consisted of 216 employees (51 registered nurses (RNs), 129 care workers, and 36 assistants) and included four departments with a total of 103 patients; Nursing home B consisted of 207 employees (48 RNs and 68 care workers and 91 assistants/other) and five departments which included a total of 116 patients; Nursing home C consisted of 74 employees (20 RNs and 32 care workers and 22 assistants/other) and included four departments and a total of 29 patients; Nursing home D consisted of 70 employees (30 RNs and 40 care workers) and three departments with a total of 54 patients. The total number of employees who were not ethnically Norwegian was 44, and they all were fluent in the Norwegian language. Ethnicities included Hispanic, Polish, Dutch, Swedish and African nurses or care workers.

Reviewer’s comments:
4) One example cites a Spanish career interacting with a Norwegian resident – the limits of language and how these were overcome. Issues of ethnicity and language might be addressed for the whole group of careers.

Our comments: We have added some information:

Participants
Purposive sampling was used to select participants, and information was given orally and in written form to the head nurses, who chose and requested two participants from their department to interview. Participants had to be permanent employees in the nursing home and have worked more than one year in dementia care. Because there were more care workers
than nurses, we invited both professions to participate in the study. A total of 30 women and 1 man were included, fifteen nurses and sixteen care workers, and four of them were educated in palliative care, mental health and geriatric nursing. Four of the participants were under 30 years of age, one between 30 – 50 years, and sixteen of the participants were older than 50 years. The participants’ working experience included the following: <5 years (n= 4), between 5-10 years (n= 10) or more than 10 years (n= 17). Twenty six nurses and care workers from the four institutions participated in the first interview. In the follow-up interview, twenty participated. We preferred that the same professionals participated in both interviews, but because of different shifts, five new participants were included in two of the follow-up interviews.

Reviewer’s comments:
5) The study used a two-part focus group strategy – I have not understood what advantages this gives or what was gained by having a second focus group with the same (predominantly) staff. Perhaps this can be explained

Our comments:
We have added some information on page 9 under the heading: “Data collection”

Research shows that recurrent knowledge dialogue in a particular group may increase the understanding of a theme [40, 41]. Through having a follow-up interview, we wanted to obtain the participants’ reflections after the initial interview and deepen some of the topics that the nurses discussed in the first interview [40].

Reviewer’s comments:
6) Whilst the tables summarize useful information and might be helpful in oral presentations, I suggest none are necessary in a paper as the information can be conveyed in a few words in the text

Our comments:
We have removed the tables from the document.

Editorial board:
Research studies in Norway shall be reported to the Data Protection Officer who undergoes study design and looks whether it satisfies the requirements of good research ethics.

Ethical considerations (p 11-12), we have added one sentence:
Consistent with Norwegian legislation, collecting data about professional healthcare workers job experiences has to be assessed ethically by Data Protection Official for Research at the Norwegian Social Science Data Services (NSD). This was done in the current study in April 2011 (with reference number 26783). NSD confirmed that the study met the requirements for ethical soundness in relation to standards and codes of ethics.
Other changes

In the article:

1. We have shortened the “Background” section.

2. **Methods.** We have added some information, marked with red color.
   
   The number of group members ranged from 4-8.

3. **Results.** We have added information regarding references to the citations:
   
   The term "patient" is used instead of residents, because it applies to residents with a specific disorder that require special health care initiatives that place these residents in a patient role. The quotes are presented indicating the specific interview (specified in capital letters), which of the informants that spoke in the group (indicated by numbers) and the page number in the transcribed text.
   
   To be sure that we have safeguarded the anonymity of the nurses in the study, we modified the association from Spanish to Polish in the quote on p 18 (2 D, p. 2)

4. We have followed the instructions for “preparing main manuscript text” and changed the heading “Comprehensive understanding” to “Discussion” on page 19.

5. The text in the discussion section are processed and clarified.

6. **Methodological considerations:** We have added the following sentences:
   
   All four authors also worked together in the analysis process and made agreement regarding sub theme and main theme. Findings were presented to other independent researchers at seminars and research groups, as well as for nurses and care workers in practice as part of the validation of the themes.

The title page:

Author 2 and 3 have changed addresses, and the changes are marked with red color in the document.