Author’s response to reviews

Title: When do patients with dementia receive spiritual care at the end of life? A prospective study on predictors of the provision of spiritual end-of-life care as perceived by physicians

Authors:

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Author’s response to reviews: see over
Response to reviewers’ comments on manuscript BMC Palliative Care 1926985760131666, entitled “When do patients with dementia receive spiritual care at the end of life? A prospective study on predictors of the provision of spiritual end-of-life care as perceived by physicians,” JT van der Steen et al.

**REVIEWER 1: KATHARINA HEIMERL**

**- Major Compulsory Revisions**

1. There is a paucity of data and published papers concerning the important issue of spiritual care for people with dementia. Therefore I am convinced that it would be of merit for research if this paper was published.

   **Authors:** Thank you for recognizing the importance of researching and developing spiritual care in dementia, which is, or should be, part of palliative care for these people.

2. I understand the necessity to operationalize spiritual care in order to subject it to statistical analysis.

   **Authors:** Indeed, there are many definitions, but there is no single accepted definition of spiritual care. We defined spiritual care pragmatically as the spiritual care as perceived by the physicians, leaving room for their individual definitions of spiritual care.

3. I do agree with the statement of the authors: “Nurses provide spiritual end-of-life care that is not formalized in care plans and is perhaps not be documented either…” (discussion, p. 17)

   **Authors:** Using a broad definition of spiritual caregiving, we found in ethnographic work that in practice, nurses are providing spiritual care in nursing homes in an informal way, also for nursing home residents with dementia. This included, for example, supporting closure or the restoring of family bonds, but it was not labelled spiritual care by those involved.

   To clarify the difference with our outcome, we added “informal:” “Nurses provide spiritual end-of-life care that is not formalized in care plans and is perhaps not be documented either, as observed in Dutch ethnographic work [42]. Predictors for such an informal spirituality-focused rather than religiousness-focused outcome…”

4. Nevertheless I have the following major concern: As the authors state on page 17 “Our outcome purposefully referred to more formal, religion-related and ‘visible’ spiritual care (…)”. I do not support the hypothesis of the authors that ‘last sacraments and rites’ can be used as operationalization of palliative care, nor is it valid to conclude on spiritual care from the provision of last sacraments and rites. Similar approaches have been denominated as “highly reductive constructs” in the literature (Cobb, Dowrick, Lloyd-Williams 2012). Spiritual care is much more comprehensive, covering a wide range (Twycross 2003 quoted in Watts; Psaila 2010; Kellehear 2002), drawing on broad understandings of spirituality (Holloway et al. 2011).

   **Authors:** We fully agree that spiritual care covers more than religion, or an activity part of a specific religion, such as last sacraments and rites, which have been described in the model by Cobb et al. as: behaviour and practice. Although these are the visible expressions of spirituality, we also included any other type of spiritual care provided by a spiritual counselor or by nursing home staff. That is, in the Methods, we provided the full definition of spiritual care, which includes both the item and the response options, as: “The outcome was spiritual care provision “shortly before death” as perceived by the on-staff elderly care physician. For this, we combined the categories of “spiritual care provided involving the last sacraments, or another last rite,” “no last rites but spiritual care was provided to patient by a spiritual counselor,” and “no last rites but spiritual care was provided to the patient by nursing home staff not specialized in spiritual care.” ”).
Although we suggested possible activities and a range of providers of spiritual care, our outcome measure was thus limited to spiritual care as perceived by the physician. We probably missed the informal spiritual caregiving by nurses. Indeed, as stated in the Results, in only 1.4% of cases, the physician found nursing home staff provided spiritual care.

We added there, “a total of” and “Further” to more clearly indicate that this unspecified spiritual caregiving by a spiritual counselor and staff was part of the outcome measure. Adding of numbers of each form of spiritual end-of-life care may further clarify the outcome. In the Discussion, we clarified our outcome measure as foremost a physician-perceived measure by changing the order and rephrasing the sentence “Our outcome purposefully referred to more formal, religion-related and “visible” spiritual care as perceived by the physician.” We also clarified the outcome in the abstract. Finally, we also emphasized in the Discussion that the physicians infrequently noted spiritual caregiving by non-specialized staff, and related this to the broader conceptualizations in the literature, adding reference to the model of Cobb et al., and the model we published previously.

5. I recommend replacing the term “spiritual care” in the title as well as in the discussion and conclusion by “last sacraments and rites” or (second choice) by: “selected aspects of spiritual care”.

Authors: As pointed out above with point 4, last sacraments and rites was only a part of our definition of the outcome. We feel “selected aspects” may not help clarify the relation with “as perceived by physicians” as it was the physician who selected the aspects, guided by the three answering options in our outcome measure. We are happy to consider any other suggestions for a title that covers the outcome measure better, yet clearly links the physician’s perception to our outcome measure that also included any kind of spiritual care by specialized or non-specialized staff.

-Minor Essential Revisions

6. P. 7 paragraph 3 “Physician and family assessments” should be: “Physician and family care givers assessment”; since not the family as a system has been assessed but the family care givers perceptions of resident’s needs.

Authors: Adopted, and we also added caregiver as appropriate on page 9 and 11.

7. P.8: “…possibly also to factors such as demographics” is a little bit vague 8. P. 8: “…palliative care is person-centered by definition”: interesting statement, please elaborate or reference.

Authors: Thank you, this is indeed not fully explicit from palliative care definitions. We added the reference to the WHO definition here, and explained that palliative care addressed the specific needs of individual patients and families.

9. Please explain, what is considered to be “last sacraments and last rites”

Authors: This was last sacraments and last rites as perceived by the physician. We did not explain further, similar as with the other response options where we did not further limit spiritual care to a specific definition. To clarify, we replaced “categories” by “response options provided to the physician.”

10. P. 14: Subheading: Independent predictors of end-of-life care should be Independent predictors of spiritual end-of-life care. Following my above recommendation it should be replaced by “last sacraments and rites”.

Authors: Thank you for catching this omission. We added “spiritual.” For the definition of spiritual care that covered more than last sacraments and rites, we refer to points 4 and 5.

11. P. 17. : Discussion: the comparison with the four-state study is only correct, if they are using the same operationalization for spiritual care.

Authors: We agree that comparisons should involve the same outcomes, ideally. However, we feel we cannot ignore this study because did not find any other study relating spiritual caregiving in the nursing home to patient, family and facility characteristics. In this study, the outcome measure
referred to a family perception of “support the resident received for his/her spiritual needs during the last month of life.”

To clarify, we added that the four-state study asked bereaved family on spiritual caregiving during the last month of life. On the next page of the Discussion, where we said that, to our knowledge, our study is the first prospective study and the first to predict physician perceptions of spiritual care, we also added reference to family perceptions, clarifying also that this is about the same study as referred to on page 17: “The retrospective US four-state study on correlates of spiritual care did not include physician perceptions but family perceptions,...”

**Reviewer 2: Lucy Selman**

“This is a very interesting paper in a neglected but important area of research: spiritual care for patients with dementia in long-term care.”

**Authors:** Thank you.

I first consider the points required in the review and then give more detailed feedback.

1. Is the question posed by the authors well defined? Yes
2. Are the methods appropriate and well described? Yes, although in some parts the methods could be expressed more clearly. I discuss this below.
3. Are the data sound? Yes, they appear to be sound and come from a large study which has already been published.
4. Does the manuscript adhere to the relevant standards for reporting and data deposition? Yes.
5. Are the discussion and conclusions well balanced and adequately supported by the data? Yes, although I comment on the conclusion below.
6. Are limitations of the work clearly stated? Yes.
7. Do the authors clearly acknowledge any work upon which they are building, both published and unpublished? Yes.
8. Do the title and abstract accurately convey what has been found? Yes, although I have suggested some changes to the abstract.
9. Is the writing acceptable? In places there are problems with language and some clarity is lost.

**Authors:** Thank you for your thorough review which helped to improve the manuscript.

**Detailed comments:**

**Major Compulsory Revisions**

1. Abstract requires some work to make clearer and easier to read. Change aim to 'to examine' not 'at examining'. Define what you mean by spiritual care as you have quite a narrow definition and this is not explicit in abstract. The sentence about levels of predictors is confusing, especially as these are not related to the potential predictors mentioned in the previous sentence. These could be combined and written more clearly. In the Results you also mix up the terms 'spiritual care' and 'end of life care' - I think best to stick to 'spiritual care'. Please specify you mean female informal/family caregiving. I think your conclusions should focus on the significant predictors identified. The point about definitions of palliative care is not directly related to your findings.

**Authors:** We revised “at examining.”

Our definition of spiritual care was care as perceived by the physicians, even though in the response options, we used “last sacraments and rites” and (any) spiritual caregiving by a spiritual counselor and nursing home staff. We added “last sacraments or rites or other spiritual care provided by a spiritual counselor or staff” to: The outcome of Generalized Estimating Equations (GEE) regression analyses was whether spiritual care was provided shortly before death as perceived by the on-staff elderly care physician who was responsible for end-of-life care (last sacraments or rites or other spiritual care provided by a spiritual counselor or staff).
We added examples to clarify the level of observation of the variables (patient, physician, or facility). Because this increased the length of the Methods paragraph in the Abstract substantially, we deleted detail.

We used “spiritual care” without the adjective “end-of-life” only where it was linked with the end of life: “...spiritual care was provided shortly before death...” Because our study is really about spiritual care at the end of life, we feel it is appropriate to use “end-of-life spiritual care.”

Female informal caregiving is what we referred to, and because we used informal caregiving in the text later on only in the context of nurses’ caregiving, we clarified by adding “family:” “Further, female family caregiving was an independent predictor...”

We strongly feel that finding of insignificant results deserve as much attention as findings of significant results because we had hypothesized significant results for all. The fact that we did not find palliative care indicators related to spiritual caregiving at the end of life is important, and probably context-related as we considered in the Discussion section.

2. Background - the Background requires some work; at the moment it jumps around a little and the flow from one paragraph to the next is not smooth. Each paragraph should contain one idea and build towards the rationale for the study. I think it makes more sense to start with why spiritual care is important, including in this group, and then go on to discuss its neglect in practice. Please be more specific about some of the findings of the studies you reference and the gaps in evidence as these show the need for your study. It is not enough to say that studies using your study design are lacking. The reason why you are focusing on physicians (in terms of gaps in the evidence) is not established.

Authors: We agree that the flow of the paragraph could be improved, and to start with the importance of palliative care at the end of life more generally, we moved a sentence referring to this from the second to the first paragraph.

The second paragraph now exclusively focuses on challenges in practice of the provision of spiritual care in dementia.

The third paragraph focuses on possible predictors of spiritual caregiving at the end of life. We are aware that these are dissimilar and relate to different levels (such as patient and facility level) but it is important to keep them together in one paragraph as these all relate to our hypotheses. We added an introductory sentence which indicates that the paragraph is about literature on predictors of spiritual end-of-life care. We choose to address literature globally in the Background and extensively reference the literature suggesting the potential predictors in Table 1. This avoids a long literature review in the Background and provides the opportunity to more systemically and accurately relate the literature to how we operationalized the predictors we tested in the Methods section.

The fourth paragraph is about what kind of study is needed to assess predictors. We feel it is appropriate to refer to a lack of prospective studies, as we relate it to temporal relationships. In the third paragraph, we showed that retrospective or cross sectional studies are more difficult to interpret (“This retrospective work suggests that families appreciate spiritual end-of-life care, or, that a high quality of care standard promotes spiritual caregiving at the end of life.”) We acknowledge that the link to the former paragraphs could be improved, and we added “relating such potential variables to provision of spiritual care later.” It now reads: “However, prospective studies with a clear temporal relationship relating such variables to the provision of spiritual end-of-life care later are lacking.”

We feel we justified the focus on physicians in the Background by saying “Further, spirituality is an important theme in the nursing literature, but less is known about physicians’ perceptions of spiritual caregiving, even though they are part of the team or have an important role in providing palliative care at the end of life, which includes spiritual caregiving.” Further, both from the Methods section of the abstract and the main Methods section in the text, it should be clear that we studied a health care system where the physician is the one who is available (on the staff) and the physician’s role is to coordinate the care, and this may include spiritual care. Our findings may therefore have some relevance also for health care systems where other professionals may coordinate the care. We
added this to the Discussion section: “Further, it may be relevant to systems where not the physician, but another professional may have the role of coordinating the care, which may include spiritual care.”

3. Methods - I think you need to discuss the assessments earlier, i.e. what items/measures were included and which were selected for this analyses. I was confused by the sentence about delegation of nursing-related items without knowing anything about the items. You need to think carefully about how much of the original study to describe - i think you should focus on what you did in this analyses to avoid confusion. The discussion of when variables were assessed is not very clear.

Authors: We understand that the potential predictors and outcomes are very important in this manuscript, but the study design and setting still needs explanation which usually precedes detail on the items included in the study. We referred to Table 1 which operationalizes the relevant items earlier, where we also referred to the paper detailing the study design.

The nurse-completed items were described as such in Table 1 where we describe the perspectives of all variables. We agree that we can be more specific is in the text of the Methods as in this manuscript, it referred to only one item (dementia severity), and we clarified.

The timing of assessments differed for different respondents regarding resident-level variables (physician and family), and was yet different for the physician-level (one time, midway study) and facility-level data (beginning, midway, end of study). While we wanted to avoid too much detail on the general design of the study, we clarified adding “after death” in the text, and we added reference to “Time frame” in Table 1. In Table 1, with a footnote, we linked the assessment to the exact timing as we did in the text of the Methods. We kept “semi-annual” in the text describing the study although we did not use the particular assessments in the manuscript, to be clear about the prospective design (i.e., baseline was not baseline assessed only after death).

4. Setting - please add a section on the setting. At the moment you have some information under study design but this is not enough. How many spiritual counsellors were available? were they full or part time? were they chaplains or non-religious/either? how much training did they have? were they certified?

Authors: We added a heading “Setting,” and we referred to a Dutch care standard for general information about availability of trained and certified spiritual counselors serving all denominations in Dutch long-term care facilities. Unfortunately, we do not have data such as fte per resident for the participating facilities.

5. Thoughout, please note the correct term is 'individualised' (tailored to the person) not 'individual' (separate)

Authors: Thank you. In text and tables, we replaced “individual” by “individualised” at places where we refer to the approach.

6. Table 1 is useful but there are some errors/suggestions I include as attachment.

Authors: Initially, we were did not find the suggestions for revision in the pdf of the Tables that was available from the BMC website. We later noted some changes in the text of the Tables which were not indicated as such or possibly the pdf just failed to show the changes the reviewer made to the document. We have checked word-by-word to identify changes and we found the following changed which we implemented in the revised version (other than missings -> missing values, home -> facility as under Minor points, and individual approach -> individualised approach under Major points):

-Table 1 page 1, Urbanization level: “…spiritual caregiving through other ways.” -> “…spiritual caregiving in other ways.”
-Table 1 page 3, Religious affiliation: “religion oriented homes”-> “religion-oriented homes.”
-Table 2, title: “...in which the selected 207 residents had resided, including..”-> “...in which the selected 207 residents resided including..”

5
-Table 3, title: “..the potential predictors in previous work indicating quality of care” -> “potential predictors related to quality of care.”

-Table 4, title: “…with the potential predictors in previous work indicating a more individualised, or more person-centered approach of care and including religiousness variables”-> with potential predictors related to individualised, person-centered care and religiousness variables.”

-Table 5, title: “..with the potential predictors in previous work indicating palliative care” -> with potential predictors in previous work related to palliative care.”

-Table 6, title: “..with the other potential predictors in previous work including demographics”-> “..with other potential predictors including demographics.”

Please let us know if we missed any changes.

7. Results: Please include number (n) as well as % in your results.

Authors: All numbers can be inferred from Table 1, where we reported any missing values in the potential predictors so as to increase readability of the Results section, which already includes a number of %%, ORs, CIs and more types of quantitative information.

8. Discussion: A good discussion but I am not sure the balance of your conclusions is quite right. Does it get the important findings across? As mentioned, for me the conclusion about definitions of palliative care is not one of the main take-home messages.

Authors: Ignoring non-significant findings is becoming a major problem threatening the credibility of health care research. We feel it is appropriate to discuss possible explanations for not finding associations contradicting our hypotheses. Moreover, as discussed, we believe that the absence of an association between palliative care and spiritual caregiving at the end of life, may point to an important problem and lack of conceptualization of palliative care in Dutch nursing home practice. At the beginning of the paragraph, we emphasized its relevance, adding reference again to palliative care definitions.

Minor Essential Revisions

1. Methods - please state design in first sentence and then go on to explain it, i.e. a secondary analysis of...

Authors: We must admit we do not understand this suggestion, as the design is stated in the first sentence and we then explained the secondary analysis. Note that in response to major issue no 3, we added reference to Table 1.

2. Methods - I was surprised that religious background was included in person-centred approach category rather than demographics. Perhaps reconsider this as I think others will also be.

Authors: A more individualised approach did not refer to religious background per se, but to “Religious backgrounds and concordance care provider – patient” (Table 1). We added and explained this in the Methods as an example of how we categorized items that may go under more categories. We also added explanation to Table1: That is, providing spiritual care when physician and patient have the same spiritual background does not need a special individualised approach, but it is indicative of such approach if spiritual care is being provided despite dissimilar spiritual backgrounds.”

3. Methods - I am not sure that it follows that religious facilities would necessarily be more likely to implement palliative care, although I agree that they may be more likely to implement/offe spiritual care consistently. I wonder where this idea came from.

Authors: In Table 1 we supported our hypotheses referring to previous studies in the Netherlands and the US. In other analyses of the same dataset (de Roo M et al., Palliative Medicine), we also found that residents who died in facilities with a religious affiliation, died more peacefully. More specifically, regarding the linking of palliative care to spiritual care, we hope to have clarified with the revisions to the Background and Discussion section in response to major points 1, 2 and 8.
4. I think important to be consistent with terms and say 'facilities' not 'homes'
Authors: Thank you. We revised for consistently, using facility or long-term care facility as appropriate.

5. Define 'enough nurse staffing' page 9
Authors: We added “as perceived by the coordinating physician” to clarify even if this is also under “Perspective” in Table 1.

6. Table 1: It was not 10% clear to me what you did in relation to the additional variable for concordance of importance of faith. Also suggest reviewing definition of palliation as care goal.
Authors: As pointed out above under minor point 2, we added explanation to the text of the Methods and in Table 1.

7. Missingness (not 'selective missing') (p.11), missing values (not 'missings') (Table 1), 'variable that adjusts for'
Authors: We checked for concern of selective missing, not missing per se, by comparing results of different samples. We replaced missings by the more formal term missing values. We could not find back “variable that adjusts for.”

8. 'some of the residents' not 'part of the residents' throughout e.g. p12
Authors: We also found the error in two other places, in the Tables and we corrected.

9. 'majority had attended religious services' please state % (p.12)
Authors: We added 62% to the text of the Results (the combined frequencies reported in Table 1; 61.9% 120 of 194 answers excluding 1 case “don’t know”, and for all valid answers: 61.54%, 120 of 195).

10. Throughout your results you give overall %s rather than % of the specific group you are discussing. E.g. p12 you discuss those who had not yet talked to physician at 8 week after admission, then say most (10.6%) were not satisfied with this. This sounds a bit strange to me - I would say, e.g. 'of those, most (86%) were not satisfied'. Also see the discussion of spiritual care before death, where it would be useful to see the proportions of different types of spiritual care provided among those who did receive it, rather than the overall % (e.g. 8.2% had a rite).
Authors: Combining to a new denominator suggests there was a routing in the survey and that we combined afterwards. However, the percentages of 10.6% and 1.8% on page 12 referred to separate answering options provided exactly as presented to the family as shown in Table 3. However, we can understand that using the smaller selected sample as the denominator eases interpretation. To avoid suggesting over precision with use of decimals, we added the numbers to the text (18/21 not satisfied). We also added detail to the reporting of the outcomes, also using %% without decimals for an appropriate level of accuracy when referring to the smaller number of 43 residents for whom spiritual end-of-life care was provided. We did not see other places where we could also report the proportions within subgroups.

11. Top p.14 I think first sentence is in error 'the main predictor of the importance...'
Authors: Thank you. We clarified, as we meant to say the main predictor of the important among the response options.

Authors: To clarify, we added “faith or spirituality was unimportant for themselves”: “The caregiving was person-centered in the sense that physicians for whom faith or spirituality was unimportant for
themselves also coordinated spiritual caregiving for the resident for whom this had been important.” We hope we have clarified this issue (minor point 2).

We deleted “In” which was erroneously included in the sentence about practice in Dutch nursing homes.

13. Note throughout it is frequent/lacking ‘provision’ of spiritual care, not ‘providing’ e.g. 16 Authors: We corrected also on page 6 and in the Tables.

14. You have spelt Tim Daaleman’s name wrong Authors: We corrected, adding the “e”

15. Not all statisticians would agree with your use of ‘univariable’ and ‘multivariable’ instead of ‘univariate’/’multivariate’ in the analyses you are running. However, I am aware this is debated. Authors: We prefer to distinguish between multiple independent and multiple dependent variables, and therefore use “variable” which clearly refers to the number of independent variables only. Obviously, the dependent variable is a single dichotomous outcome, in this manuscript.

QUALITY OF WRITTEN ENGLISH
Reviewer Dr. Heimerl indicates the quality of written English is acceptable, and reviewer Dr. Selman indicates it needs some language corrections. Authors: We feel that Dr. Selman’s thorough review helped to make the necessary language corrections.

STATISTICAL REVIEW
Reviewer Dr. Heimerl states it needs a statistical review but she feels inadequately qualified to assess the statistics. Reviewer Dr. Selman finds it needs a statistical review and she has assessed the statistics in her report.

OTHER CHANGES
-we added reference to a new and relevant study that related family involvement to likelihood of a chaplain visit in long-term care (Sudore et al., 2014).
-removed/added some spaces in Tables
-Table 4, replaced by correct figure: 0.5% to replace 0.05% with Frequency of attending religious services resident.

EDITORIAL COMMENTS
Dear authors, thank your for submitting your paper to BMC Palliative Care. We have send the paper out for peer review and have now received the reviewer comments. Both are quite positive about the paper but suggest some revisions before publishing the paper. The reviewers comments are attached and we suggest that you send us the revised paper with detailed response to the reviewer comments before we make a final decision of acceptance of the paper.

Editorial Request:
1. Title page - It should contain, at minimum, the names, institutions, countries and email addresses of all authors, and the full postal address of the submitting author.

2. Line numbering - Please revise your manuscript to include line and page numbers. Authors are asked to ensure that line numbering is included in the main text file of their manuscript at the time of submission to facilitate peer-review. Once a manuscript has been accepted, line numbering should be removed from the manuscript before publication. For authors submitting their manuscript in
Microsoft Word please do not insert page breaks in your manuscript to ensure page numbering is consistent between your text file and the PDF generated from your submission and used in the review process.

Authors: Thank you for your review. We have added email addresses of all authors to the title page. We have also added line numbering, in the cleaned version of the text.