Author’s response to reviews

Title: Is care staff equipped for end-of-life communication? A cross-sectional study in long-term care facilities to identify determinants of self-efficacy

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Author’s response to reviews:

Dear Mr. Sinclair,

First of all, we would like to express our sincere thanks to the editor and the reviewers, who read our manuscript (PCAR-D-18-00110) and identified areas that needed corrections or clarification.

The page numbers and line numbers refer to the revised manuscript. Added sections are printed in bold font and removed sections are crossed out.

Yours sincerely,

Kirsten Evenblij, on behalf of Maud ten Koppel, Tinne Smets, Guy Widdershoven, Bregje Onwuteaka-Philipsen and Roeline Pasman

Editors comments

Comment 1:
Comment: Thank you for your submission. Upon review, you are invited to make minor revisions to your manuscript as identified by the three reviewers.

Reply: We have addressed all reviewers’ comments in the manuscript and describe this in more detail in the response to the reviewers below.

Reviewer 1

Comment 1:

Comment: You note on p.6 that care staff were given a unique identifier and that the identifiers of staff who did not respond were provided to a contact person at each site? I assume then that the contact person was able to match the identifier with the person to send the reminder? How did you address anonymity for non-responders given that the contact person would know who had participated and who hadn't and, as it is often a manager or senior leader in the site who undertakes this role, what protections were in place for non-responders to avoid coercion?

Reply: For each deceased resident, a questionnaire was sent to a nurse involved in the care for this resident. The questionnaire was given a unique identifier. Nurses could send the completed questionnaire directly to the researchers. This guaranteed anonymity of the respondents. If they did not respond, the contact person could indeed match the identifier with the person to send the reminder. Due to this procedure, the authors understand the reviewers concern with regard to coercion. However, in order to be able to send a reminder, we had to had to choose between anonymity to the researchers and anonymity to the contact person. The authors think it is unlikely that nurses felt coerced to participate in this study. This is supported by the fairly low response of 52%. Moreover, the contact person could be a manager, but it could also be an administrator.
Reviewer 2

Comment 1:

Comment: "Results on nurses' experiences with and barriers to providing palliative care to psychiatric patients have been published elsewhere (Evenblij et al. 2016)" - should a summary be provided in the paper.

Reply: Some results of this study ("Palliative care in mental health facilities from the perspective of nurses: a mixed-methods study" by Evenblij et al., reference number 14) have already been incorporated in the current paper, see Discussion section, page 10, line 249-252: Previous studies have reported high time pressure, caused by inadequate staffing levels and heavy time commitment of palliative care provision, to be a barrier for palliative care in facilities. The shift towards ambulant mental health care which is accompanied with large budget cuts might increase time pressure in mental health facilities even more.

In the introduction, page 3, line 62-63 we added: ‘Around two-fifth of the nurses working in these facilities [mental health facilities] provides palliative care to a psychiatric patient.’ This is also a result from the study by Evenblij et al. We could add more information about the study if it would please the reviewer, however, the authors are of the opinion that this would not be relevant for the current paper.

Comment 2:

Comment: The MOVE2PC Questionnaire - The original 3-point Likert Scale was converted into a dichotomous scale: 'answered according to the definition' and 'not answered according to the definition-will this affect the validity?

Reply: The MOVE2PC Questionnaire was measured on the original 3-point Likert Scale, hence validity was not affected on measurement level. We dichotomized the scale for analysis. The dichotomous scale was not validated, therefore we cannot rule out that dichotomizing the original 3-point Likert Scale has affected the validity. However, we made this choice because we were interested in the knowledge of nurses regarding the components of palliative care. Nurses
who answered ‘do not disagree/agree’ were not certain whether or not the statement was correct. Therefore, we argue that it is legitimate to merge this category with the group who answered incorrectly. By being transparent about this procedure the reader can consider this when interpreting the results. Because the procedure and rationale was unclear to the reviewer, we decided to make some changes to the text and provide more detailed information, see Data collection and measurements, page 5-6, line 125-133: The questions were measured on the original 3-point Likert Scale (disagree, do not disagree/agree, agree with the statement). For analysis, the original scale was first converted into a dichotomous scale: ‘answered according to the definition’ and ‘not answered according to the definition’ as we were mainly interested in nurses with knowledge of the definition of palliative care. Nurses who answered ‘do not disagree/agree’ were not certain whether or not the statement was correct, therefore this group was merged with the group that answered incorrectly. Next, we calculated the sum of the number of correct answers for each individual (range 0 to 5) and categorized the sum into three categories to make a distinction between those who had poor knowledge of the definition (0-1 correct answers), average knowledge (2-3 correct answers), and good knowledge (4-5 correct answers).

Comment 3:

Comment: As detailed above and checking the manuscript for English as there are some errors

Reply: We have had the revised manuscript proof read by a native English speaker. Accordingly, grammatical and spelling errors were corrected.

Reviewer 3

Background

Comment 1:

Comment: It would be worthwhile to clarify what is meant by end of life conversations. The self-efficacy scale contains items that would be relevant for advanced care planning and for
discussions about care at the end of life. The cited literature about the effects of end of life conversations is about both conversations at the end of life and advanced care planning, similarly for the literature about predictors of self-efficacy. As these are different kinds of conversations, with different professionals typically responsible for them, there may be different factors associated with self-efficacy. It is also relevant to the reader judging the validity of the self-efficacy measure.

Reply: Indeed, the self-efficacy scale contains items relevant for advance care planning and for discussions about the end-of-life. The authors argue that the two are strongly related to each other as these discussions can be input for ACP discussions, while ACP discussions may lead to more general discussions about the end of life. Therefore, the authors define end-of-life conversations in this paper as: communication about issues of physical, psychological and existential nature raised by the approaching end of life, with the aim to provide the opportunity for residents to cope with their condition, to assess residents’ care preferences, and to relieve suffering. Although, informing residents about for example their prognosis is generally seen as a task for physicians, this could very well be a topic for discussion between nurses and residents once the resident is informed or when the resident brings it up. Existing literature indicates that indeed others than physicians can have a role in this and that these conversations are already held by nurses, care assistants, social workers and even laypersons. Nurses and care assistants spend more time with residents on a day to day basis and are therefore in a better position to assess the patient’s condition and initiate end-of-life conversations. Although, in other countries these tasks are often allocated to other care providers such as physicians, Dutch nurses are expected to work relatively independent, especially in care homes and mental health facilities where no on-site physician is available.

This explanation was added to the Introduction section, page 3-4, line 70-77.

Comment 2:

Comment: Additional information about staff experiences of death in psychiatric/mental health facilities would be helpful to understand the rationale for the study. Does mental health facility mean chronic psychiatric hospital? If 400-450 people die annually due to somatic comorbidity (I'm assuming not suicide), then how often would staff encounter death? It seems like it would be rare. The authors state that patients might require long-term complex care until death from a somatic comorbidity. Is there evidence that this is true?
Reply: With mental health facility the authors indeed mean chronic psychiatric hospital. In the Netherlands approximately 27,000 people with chronic psychiatric disorders are admitted to such facility, 400-450 of them die annually (this number of deaths does not include people with chronic psychiatric disorders who die and who were treated in an ambulant setting). A previous study showed that almost two-fifth of the nurses working in mental health facilities had experience with providing palliative care to a psychiatric patient with a chronic physical co-morbidity or of old age. In 40% of the cases the nurse had provided palliative care to more than 3 patients in the past 2 years. Given that psychiatric disorders are found to hamper adequate and timely end-of-life conversations and palliative care provision, we are of the opinion that studying this subject is highly relevant. We made the following changes in the manuscript to make this more evident, page 3, line 56-64:

Other long-term care facilities specialize in mental health care. In the Netherlands, approximately 27,000 individuals with chronic psychiatric disorders are admitted long-term or permanently to a mental health facility. Residents of mental health facilities are relatively young. The treatment focuses on psychiatric problems. However, as psychiatric disorders are associated with significantly higher morbidity and mortality rates, in mental health facilities the staff is also involved in the care for seriously ill and dying residents. In the Netherlands, annually 400-450 people with chronic psychiatric disorders die within a mental health facility as a consequence of somatic co-morbidity. Around two-fifth of the nurses working in these facilities provides palliative care to a psychiatric patient. Hence, while mental health facilities and nursing and care homes differ in patient population and care focus, all residents (may) require long-term complex care until death.

Methods

Comment 3:

Comment: I wonder about the validity of the comparison of type of facility. The authors point out that mental health facilities differ with respect to who provides direct care at the end of life. This results in confounding of setting and professional designation. RNs, who are more likely to do direct care in mental health. RNs are also more likely to have authority to have end of life conversations. In many settings, care assistants do not have this authority or do not perceive that they have this authority. This should influence self-efficacy and possibly knowledge. I'm not sure that it's possible to separate the effects of facility and professional designation. Based on the education level data provided, it seems that there would be very small numbers in some cells if professional designation were controlled for.
If it is not possible to disentangle type of facility and professional designation, the authors might consider discussing the likelihood of having had conversations about end of life in the facilities by professional designation when interpreting the findings - or leaving out this research question and focusing on a more fleshed out analysis and discussion of factors associated with self-efficacy.

Reply: We agree that professional designation could be confounder in the relation between setting and self-efficacy. Unfortunately, we do not have information about the professional designation of the care staff working in mental health facilities. The authors are of the opinion, however, that education level is a good proxy for professional designation as higher education is generally accompanied by a higher responsibility/authority. Our results showed that the level of education was not significantly associated with self-efficacy. If corrected for education level (and the other background characteristics), differences between settings in knowledge of the palliative care definition remained significant.

Comment 4:

Comment: Sampling and participants: It seems like the mental health facility participants include some people who are not nurses (p. 5, line 6 and line 21). Please clarify and explain the rationale for having them in the analyses.

Reply: Since the focus of mental health care is on psychosocial care, social welfare workers provide an important part of care in mental health facilities. In our sample 13% was a social welfare worker but the majority of them also finished a nurse training (this is stated in the same section, Participants section, page 5, line 116-117). Therefore, we are of the opinion that including them in the analyses does not comprise the validity of our results.

Comment 5:

Comment: I was confused about the measures and scoring the measures presented in the data collection and measurements section and the data analysis section.
I would have found it easier to follow if all information about scoring (e.g., cut-off scores or calculation of summary scores) was included with the description of the measures. This would help to clarify the level of measurement of each of the measures and understand what analysis approach is appropriate.

Reply: We understand the confusion and transferred the information about measures and scoring of measures from the data analysis section to the measurements section as requested.

Comment 6:

Comment: The item level responses to the S-EOLC scale are reported in categories (0-3, 4-5, and 6-7). For interpretation, it would be helpful to provide information about what the middle category means, in addition to the information about the definition of 0 and 7. On the other hand, it may be that it is reasonable to just report and analyze item means.

Reply: The definitions of 0 and 7 are provided in the section ‘Data collection and measurements’, page 6, line 140-141: ‘8 items that were scored on an 8-point scale ranging from 0 (‘Cannot do at all’) to 7 (‘Certain can do’)’. As the mean scores were highly skewed to the left (negative skewed) which could not be corrected by log-transformation, we felt it would be informative to categorize the data. We made a distinction between those who had a really low self-efficacy (category: 0-3) and those who scored just below the average of 5.5 (category: 4-5). Since we do not report on the item mean scores for each setting nor test for differences between settings, we chose to delete the item mean scores from the table to make it more comprehensive.

We clarified the procedure in the text, Data collection and measurement section, page 6, line 148-150: ‘Next, a mean score was calculated for all S-EOLC items for each setting as well as one overall mean score was calculated for each setting. Because the mean S-EOLC scores were highly skewed to the left, the item responses were reported in categories: 0-3 (very low S-EOLC), 4-5 (below average S-EOLC), 6-7 (high S-EOLC).’

Comment 7:

Comment: What is the rationale for the cut-off for the number of knowledge items correct?
Reply: We wanted to make a distinction between those who had poor knowledge of the definition (0-1 correct answers), average knowledge (2-3 correct answers), and good knowledge (4-5 correct answers). This explanatory note was added to the Data collection and measurement section, page 6, line 130-133. (see also Reviewer 2, comment 2)

Comment 8:

Comment: Is it possible to create a summary score for time pressure? How is this calculated? What is the rationale for dichotomizing items? The description of cut of scores for this construct seem to be contradictory in the data collection and data analysis sections.

Reply: Unfortunately, there was unclarity about the cut of scores. Now that we merged the information from both sections together in the data collection section as requested (see comment 5), this problem is solved.

No summary score for time pressure was created because of the heterogeneity of the questions. The original 5-point likert scale was dichotomized according to the same rationale of dichotomizing the knowledge questions. For example, nurses who completely agreed or agreed with the statement ‘I have sufficient time for direct care to residents’ were categorized into ‘agree’. Nurses who did not know whether or not they agreed, disagreed or completely disagreed were categorized into: ‘do not agree’ as they did not think the time was sufficient or they were not sure that the time was indeed sufficient. This explanatory note was added to the Data collection and measurement section, page 6, line 137-138: ‘Those who did not agree/disagree were categorized into ‘do not agree’ as they were not sure that the available time was sufficient.’

Data analysis

Comment 9:

Comment: Provide information about final sample size after eliminating missing and not my responsibility responses.

Reply: The sample size is provided in the Results section, page 8, line 186-188. Since we would lose to many respondents, especially of the mental health nurses, if we would have only include
those who answered all questions, the exact sample size varies per question. Instead of reporting
a different total N for each setting for each Table, we are of the opinion that it is more clear to
provide the number of missings below each table. The number nurses who were excluded from
analysis because they responded not my responsibility to 4 items or more is provided in the Data
collection and measurements section, page 6, line 146-148.

“Respondents who answered NMR to ≥4 items were excluded from further analysis as they were not considered to be relevant for the outcome of this study. This concerned a total 54
nurses/care assistants: 8 (6.6%) working in a mental health facility, 10 (5.8%) working in a
nursing home and 36 (13.9%) working in a care home.”

Comment 10:

Comment: What is the rationale for using non-parametric statistical analyses?

Reply: The overall mean S-EOLC scores were not normally distributed (see also comment 6)
and log-transformation did not correct this. Therefore, we decided to do a non-parametric
statistical analyses, besides the Chi-square tests on the categorized data.

We added this reasoning to the Data analysis section, page 7, line 168-170: ‘As the
overall mean S-EOLC score was not normally distributed, a non-parametric test (Kruskal-Wallis)
was performed to test for differences in the overall mean S-EOLC score between settings.’

Comment 11:

Comment: Explain the rationale for creating a dichotomized self-efficacy score and
conducting logistic regression for the prediction of self-efficacy - and for the particular cut-point
for dichotomizing.

Reply: Please see also comment 6, and 10. The overall mean S-EOLC scores were not normally
distributed and log-transformation did not correct this. Therefore, we could not use linear
regression analyses and chose for logistic regression analyses. The overall mean score across all
settings was 5.51 and the overall median score across all settings was 5.87. Therefore, we
decided to use 6 as a cut-off point. A 6 or above was defined as high self-efficacy (because
above average and all items scored a six or higher), a score lower than 6 was defined as lower self-efficacy.

In the data collection section, page 6, line 150-153 we describe this as following: ‘For logistic regression analyses, overall mean S-EOLC scores were dichotomized into score <6 = lower (n=247), and ≥6 = high (n=219). The cut-off point was based on the median score of all care staff (5.87). Staff in the high self-efficacy group had scored their efficacy a six or seven on all items.’

Comment 12:

Comment: Explain the rationale for step-wise modeling to control for background variables that seem to be all related to self-efficacy and to setting.

Reply: First univariable analyses were performed to assess which variables (background characteristics (including setting), knowledge, time) were significantly associated with self-efficacy. However, univariable relations do not provide the best description of the real-life situation as an outcome is usually dependent on multiple factors. Therefore, multivariable regression analysis was performed. We started with all variables in the model. The step-wise backward procedure was used to select the combination of variables that described best the relationship with self-efficacy, rather than to control for these variables. In each step, the variable with the highest p-value was excluded from the model, until all variables in the model had a p-value of <0.05. Since this was unclear, we added some details of this process in the Analysis section, page 7, line 172-176: ‘First, univariable logistic regression analyses were performed to assess which variables (background, knowledge, time) were significantly associated with self-efficacy. Next multivariable logistic regression analysis was performed to create a model that describes best which factors are associated with a high self-efficacy. In each step, the variable with the highest p-value was excluded from the model, until all variables had a p-value of <0.05.’

Comment 13:

Comment: Consider reporting on tests for assumptions being met for the multivariate analyses. It seems that there would be some very small or zero cells for comparisons involving setting and level of education. Maybe I misunderstood the analyses.
Reply: In the logistic regression analyses (uni and multivariable), the data is no longer stratified for setting. Setting and education are however two of the variables in the model. As you can see in table 5, the dependent variable is categorized into two groups: self-efficacy < 6, n=271, and self-efficacy ≥6, n=271. For each of the variables the number of respondents per category is provided as well as the distribution (row %) of these respondents in the <6 and ≥6 outcome group. So for example for Setting (see Table in supplementary file):

<table>
<thead>
<tr>
<th>Setting</th>
<th>S-EOLC &lt;6</th>
<th>S-EOLC ≥6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health facility (n=113)</td>
<td>42.5%, n=54</td>
<td>57.5%, n=65</td>
</tr>
<tr>
<td>Nursing home (n=161)</td>
<td>66.5%, n=107</td>
<td>33.5%, n=54</td>
</tr>
<tr>
<td>Care home (n=223)</td>
<td>52.0% n=116</td>
<td>48.0%, n=107</td>
</tr>
</tbody>
</table>

The cell with the lowest count would be: Knowledge category 0-1 for the ≥6 self-efficacy N=48x25%=12. A low cell count is thus not a problem. If a low cell count would have been a problem, the model would also not have converged. We hope this sufficiently explains and clarifies the analyses.

Results

Comment 14:

Comment: There are significant between group (setting) differences for "background" variables. Could these be controlled for in other between group analyses? If not, consider discussing the implications (not reported for knowledge analyses or confidence section).

Reply: We did control for background variables in Table 2 (Knowledge) and Table 3 (Time pressure), please see the text below the tables and Analysis section, page 7, line 166-168 ‘To correct for possible confounding in the association between setting and knowledge and between setting and time pressure, logistic regression analyses were conducted in which all background characteristics were added to the model.’ For knowledge: 3 out of 4 items for which a significant between group difference was found, remained significant after controlling for background
characteristics. For Time pressure: for only one item a significant between group difference was found, which did not remain significant after controlling for background characteristics. We did not control for background variables in Table 4 (self-efficacy) as we also performed multivariable logistic regression analyses to identify factors associated with self-efficacy including all background characteristics as well as setting (Table 5).

Comment 15:

Comment: Clarify presentation of results of the multivariable analyses. Did all control variables stay in the model?

Reply: Multivariable analyses were performed to identify determinants of high self-efficacy. All background characteristics (including setting), knowledge and time pressure were added in the model. All variables with a p-value <0.05 remained in the final multivariable model (Data analysis, page 7, line 175-176). In Table 5 in the multivariable model column, ORs and 95% CI of the variables which remained in the model are provided. Variables which were not significant (p>0.05) and thus deleted from the model are indicated with NS (not significant). Since this was not clear, we added below table 5: ‘NS: Not significant: all variables were included in multivariable analyses. Using a stepwise backward selection method, all non-significant variables (p-value > 0.05) were excluded.’

Comment 16:

Comment: I was surprised to see item level reports of time pressure in Table 5. This is inconsistent with the analytic approach to the other constructs being tested.

Reply: Given that we did report an overall score for knowledge and self-efficacy, we do understand this comment. However, in case of knowledge and self-efficacy, the items measured the same construct whereas in the case of time, the items are to heterogenous to report one overall score. Therefore, we reported the response for each item. Please see comment 8.
Discussion

Comment 17:

Comment: Consider including literature about authority to have end of life discussions and, as previously noted, clarifying the difference between end of life discussions and advanced care planning. The recommendations for enhancing nursing education do not account for the differences in responsibilities of the various worker categories in the study.

Reply: Please see comment 1. Although, discussing end-of-life issues including care preferences with a patient is generally seen as a task for physicians, nurses can have a major role in this once the resident is informed or when the resident brings it up. Nurses spend more time with residents on a day to day basis and are therefore in a better position to assess the patient’s condition and initiate end-of-life conversations. Literature also shows that indeed nurses, but also care assistants, laypersons, and social workers can initiate this. This literature has been added to the paper, Introduction section, page 3, line 75. Clarity about who should take responsibility is crucial as well as adequate training. A lack of knowledge and training has been reported to hamper end-of-life conversations by both nurses and physicians. Our results did not show a significant difference in self-efficacy between nurses with a low or high education level which was used as a proxy for the various worker categories.

Comment 18:

Comment: The criticism that nursing education focuses on acute care rather than chronic care or palliative care may be less relevant to care aide education than to RN education.

Reply: We agree with the reviewer that this is not correctly formulated. We meant that education programs lack training in issues that are important at the end of life care and palliative care. We rephrased the sentence, Discussion section, page 11, line 276-277: ‘Nurse education programs often focus on acute care nursing and fail to address issues that are important in facilities such as frailty, complex chronic (multi) morbidity end-of-life care.’
Comment 19:

Comment: Could the high self-reported self-efficacy be an overestimate for participants with limited experience?

Reply: Indeed it is possible that those with a low ability have assessed overestimated their ability (Dunning-Kruger effect). We added this to the Discussion section, page 10, line 257-260:

‘Although this may very well be true, it is also possible that some of the staff may have overestimated their ability to converse about these difficult issues. Due to a lack of self-awareness, low-ability people may be unable to objectively evaluate their actual (in)competence. This is referred to as the Dunning-Kruger effect. (Dunning & Kruger, 1999).’