Author’s response to reviews

Title: Action research study on advance care planning for residents and their families in the long term care facility

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Author’s response to reviews:

Maria Zalm
Editor
BMC Palliative Care

2019.10.04

Dear Dr. Maria Zalm:

Re: Document reference No. PCAR-D-19-00138 - [EMID:340ce54bcefc5c85]

Please find attached a revised version of our document “Action research study on advance care planning for residents and their families in the long-term care facility”. We would like to resubmit for publication as an original article in BMC Palliative Care.

Your comments and those of the reviewers were highly insightful and enabled us to improve the quality of our document. In the following pages are our responses to each comment from the reviewer(s) as well as your own comments.

Revisions in the text are shown red words. We hope that our revisions to the document combined with our accompanying responses will be sufficient to render our document suitable for publication in BMC Palliative Care.
We look forward to hearing from you soon.

Yours sincerely,

Sincerely,

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Responses to the comments of Reviewer #1: Emma Lea

1. This paper reports the testing of a set of culturally-appropriate questions to prompt discussion about advance care planning with aged care residents (n = 10) and their family members (n = 20) in Taiwan. The topic is an important one and the assembled questions appeared to be useful in promoting such discussions and facilitating advance care planning and advance directives; the questions and/or this approach may be useful in other contexts too. (1) However, there are some methodological and other concerns with the manuscript. In particular, although the authors state that an action research approach was utilised, it is not clear from how the study is currently reported that this approach was actually used. Typically with action research, the chosen action arises from a planning period which follows an initial period of investigation and problem identification; in contrast, the action reported here (a set of questions) appears to have been derived very early on (before any formal participant recruitment happened and "before commencing this study" (pg 8)) solely from one researcher's informal conversations with residents and families (pg 8) - it was not an iterative process at all, as these questions remained unchanged over the course of the study (i.e. across all of the interviews). Thus, "the purpose of this study…to develop an advance care planning interview guideline" (pg 2) is not strictly accurate as the interview guideline was developed prior to what is reported as being "the study" - the purpose perhaps is more around testing than developing these questions. (2) On page 2 it states that "this information [from meetings with staff members] was synthesised and used to modify the care model", but this modification is not reported in the Results; (3) it is not clear how the care model was modified (it does not appear to have been modified) or how "revised", presumably person-centred, ACP directives could be "applied to the next resident and family pair" (pg 7). Furthermore, action research tends to be collaborative, yet the staff mentioned in this manuscript did not appear to be considered as participants (e.g. see phrasing lines 192-3, page 11) - it is not clear who the action research participants are (the residents and family members do not seem to be actively involved in action planning, reflection etc.). (4)
Response:
(1) → Thank you for the kind and encouraging remarks.
(2) → Thanks the review’s kind of indication. A staff member of the long-term care facility expressed to the first author that the facility encountered numerous difficulties when promoting ACP and requested the researcher’s assistance in developing a suitable ACP guide and caregiving model for the facility. Therefore, the first author participated in the resident caregiving process alongside other facility staff members to better understand the residents’ and family members’ attitudes and their understanding of end-of-life care. After discussion with facility members, the researcher established an initial ACP interview guide for the facility and began recruiting research participants, officially initiating the first cycle of action research. After interviewing the first pair of resident and family member, the first author discussed the interview results with the facility staff members. The interview guide was revised and expanded according to the suggestions of the residents and family members before starting the second cycle of action research. After separately interviewing the second pair of resident and family member, the researcher discussed the results with the facility staff members again, then revised and expanded the interview guide before initiating the third cycle of action research. This process was repeated until the tenth cycle, at which point the interview guide had been saturated with information. Furthermore, the developed ACP care model was deemed suitable for the facility residents and family members, thus completing the development of the interview guide and ACP care model. Please see the manuscript Page 8 (line 137-141), Page 10 (line 185-189), and Page 11 (line 190-208).

(3) → Thanks the review’s kind of suggestion. We have included information from the meetings with staff members in the results, please see the manuscript Page 14 (line 251-253; 263-264), Page 15 (line 274-277), Page 18 (line 323-334), Page 20 (line 367-378), Page 21 (line 379-381), Page 23 (line 423-435), Page 24 (line 436-441), Page 26 (line 479-492), and Page 27 (line 493-498).

(4) → Thanks the review’s kind of indication. After completing the interview of each pair of resident and family member(s), the author held meetings with the facility staff to discuss the results. Subsequently, the interview guide content was amended or expanded according to the residents’ and family members’ opinions and the ACP process was adjusted before conducting the next cycle (see following Figure). The aforementioned process was continued until the completion of the tenth cycle.

2. Some minor comments follow: The study was conducted in Taiwan, but given the international nature of the journal, the international context needs to be provided; for e.g., what is the situation re advance care planning in other countries, including implementation rate in comparison to Taiwan (line 52-52, pg 3; line 61, pg 4)?

Response: → We thank the reviewer for this suggestion. The international context related to ACP has been revised in the manuscript page 3 (lines 56-57), and page 4 (lines 58-65).
3. Some statements need supporting; e.g. a citation is needed re the obstacles to ACP in Taiwan (line 53, pg 3).

Response: →We thank the reviewer for this suggestion. The citation (a citation regarding the obstacles to ACP in Taiwan) has been added to the manuscript page 4 (line 66).

4. More detail needed in some sections, e.g. line 76, pg 4 - Lee et al. study requires more details on participants and location of the study. In addition, more detail is needed on what advance directives are exactly, including any cultural differences.

Response: →We thank the reviewer for this suggestion. The content has been revised as advised. Please see manuscript page5 (lines 90-95).

5. The two aims reported on pg 6 do not seem very distinct from each other. As noted above, the aims will likely need revising to be more around testing a set of questions in facilitating the ACP process.

Response: →Thanks the review’s kind of indication. The substance of the two aims detailed on page 6 have been revised per the reviewer’s suggestion. Please see the manuscript Page 7 (lines 116-121).

6. It is not clear how an action research approach is "especially relevant in palliative care" (line 112, pg 6), i.e. more so than for other areas.

Response: →Thanks the review’s kind of indication. The contents have been revised as review’s suggestions. Please see the manuscript Page7 (lines 127-130).

7. More detail is needed on the long-term care facility which is the study setting (e.g. size, funding model, level of care), the eligibility criteria, which are not reported (pg 8), and on the (purposive) sampling methods used. (1) A comment on cognitive status of participants would also be useful, perhaps in relation to setting and inclusion/exclusion criteria.(2)

Response:
(1) →Thanks the review’s kind of indication. The contents have been revised as review’s suggestions. Please see the manuscript Page8 (lines 150-152) and Page 9 (lines 153-157).

(2) →Thanks the review’s kind of suggestion. The contents have been revised as review’s suggestions. Please see the manuscript Page 9 (lines 158-170) and Page 10 (line 171).

8. Were the interview guides also based on the literature (as well as the informal discussions)? (pg 8)
Response: →Yes, the interview guides based on the literature and discussions with staff and the fifth author. The contents have been revised as review’s suggestions. Please see the manuscript Page 10 (lines 179-181).

9. Were the interviews audio-recorded? (pg 9) This needs to be made clear in the Study procedure section.

Response: →Thanks the review’s kind of indication. Yes, informed consent was obtained from participants prior to each interview or meeting with staff, each of which was audio recorded. The content has been revised per the reviewer’s suggestions. Please see the manuscript Page 10 (lines 183-184).

10. Why was data not collected from staff (i.e. why were staff not included as participants)? There seems to be confusion around this, as on pg 12 it is noted that "records of each meeting with long-term care facility staff were analysed", yet data are not shown.

Response: →Really appreciate for the review’s kind of indication. The contents have been revised as review’s suggestions. Please see the manuscript Page 14 (lines 251-253).

11. Residents "being relocated...following discharge from the hospital" (pg 11) needs clarification, as participants have been stated to be long term care residents. Perhaps rephrase as "...discharge after a period of hospitalisation".

Response: →Thanks the review’s kind of suggestion. The sentence regarding “being relocated...following discharge from the hospital” (page 11) has been rephrased as “being relocated...following discharge after a period of hospitalisation” and has been added to the manuscript. Please see the manuscript Page 14 (lines 253-256).

12. How was the health and demographic data noted on pg 11 obtained? (e.g. questionnaires, health records, during interviews)

Response: →Thanks the review’s kind of suggestion. The demographic data of participants were obtained during interviews, and this information has been added to the manuscript. Please see the manuscript Page 14 (lines 263-264).

13. The discussion of sharing of information between family members raises interesting ethical issues - was permission obtained to share information from individuals during interviews with other family members? (e.g. pg 14) Some discussion around this would be useful in the Discussion as well.(1) The Discussion notes the role healthcare professionals play in "communicating between residents and their families to facilitate the process of ACP" (pg 22), but this was not clearly outlined as being part of the process (e.g. in Study procedures).(2)

Response:
(1) →Thanks for the review’s kind of indication. The residents stated that they wished to express their opinions on end-of-life care to their family members through a third party. Additionally, family members also agreed to exchange opinions through a third party acting as a mediator.
Therefore, the researchers took the initiative to ask residents and family members if they were willing to share the interview content with other family members after each interview. The contents have been revised as review’s suggestions. Please see the manuscript Page 31 (lines 571-575).

(2) →Thanks the review’s kind of suggestion. The contents have been revised as review’s suggestions. Please see the manuscript Page 11 (lines 190-198). Otherwise, page 45, Table 5 states “3. Gradually changing the topic to the end-of-life care issues → 3-2 with families → Inform families of resident’s decisions regarding EOL care and the reason why they did not discuss this topic with their families.” Please see the manuscript Page 45, table 5 (lines 10-12).

14. Residents were interviewed separately to family members and more than one interview was held with each individual. How practical is this if the ACP interview guidelines suggested in this manuscript are to be implemented in care facilities, e.g. given possible staffing and financial constraints? This would be important content for the Discussion. In the Discussion it is implied that "medical staff" (pg 24) may be involved in holding such interviews - is that nurses and medical doctors? What training may they need to be able to do this well? This should be an important aspect of the manuscript, as it is about the implications of the research.

Response: →First, the reviewer’s concern was valuable to this article and we apologize for the way we previously presented things in this section, which might not have been clear due to language limitations. The content has been considerably revised per the reviewer’s suggestions. Please see the manuscript Page 31 (lines 582-587) and Page 32 (lines 588-596).

15. It is stated that families "were aware that the life quality at the facility was less than satisfactory" (pg 15) - is there data to show that this is the case for this facility, or should perhaps the phrasing change to state that this was a perception?

Response: →Thanks the review’s kind of suggestion. The phrasing has been changed to “perceived” per the reviewer’s suggestion. Please see the manuscript Page 19 (lines 357-358).

16. The concept of a "good death" is raised (pg 16-17), but more detail is needed on perceptions of what this comprises, including cultural influences on these perceptions. Given the focus of the paper, this should be a point in the Discussion.

Response: →We thank the reviewer for this suggestion. The reviewer’s concern was valuable to this article. The contents have been revised as review’s suggestions in the discussion. Please see the manuscript Page 29 (lines 542-549) and 30 (lines 550-561).

17. Some new data is reported in the Discussion (e.g. line 405, pg 22) - this should be moved to the Results.

Response: →Thanks the review’s kind of suggestion. The contents of some new data reported in the discussion (e.g. line 405, pg 22) have been moved to the Results. Please see the manuscript Page 14 (lines 256-260).
18. A Limitations and future research section is missing.

Response: →Thanks the review’s kind of indication. The contents of limitations have been revised as review’s suggestions. Please see the manuscript Page 32 (lines 605-606) and Page 33 (lines 607-618).

Responses to the comments of Reviewer #2: Mary Turner

This paper reports an action research study to develop a culturally appropriate interview guide for use in advance care planning, a topic that should be of interest to readers of the journal. I have suggested a number of amendments that would improve the paper, and I would encourage the authors to undertake the work required to bring it to a publishable standard.1 The background section outlines a number of obstacles to ACP, but it is not clear why these particularly apply to residential care facilities rather than any other care setting. There is also no clear definition of advance directives (indeed the abbreviation 'AD' is used without explanation on p.3), and 'AD' and 'ACP' seem to be used interchangeably throughout the paper.2 On p.7 the term 'ACP directives' is used, but it is not at all clear what is meant by this. Advance care plans and advance directives are distinct concepts, and the confusion between them needs to be resolved. 3 The authors state that the findings from the first action cycle were discussed with the facility staff; were these staff therefore participants in the research? If so, they should be included in the number of participants.4 There is a lack of rationale for some of the decisions taken about sampling; for example, why were 20 family members included and only 10 residents? Were only those residents with two family members included, and why? Why were multiple interviews undertaken with each participant? How many interviews were conducted in total? These issues need to be clearly explained.5 The study inclusion/ exclusion criteria should be stated clearly. Although the study purports to use action research methodology, there seem to be two distinct groups of people: those who were interviewed, and those who conducted or discussed the interviews. Usually action research involves active participants who make changes to practice that are then evaluated. In this case, it is not clear how the interviewees were active participants in the research; this requires further explanation.6 It is reported that the first author spent six months working in the facility prior to the research; did this raise any ethical issues related to role confusion (researcher versus care worker)? Were any assessments of capacity to consent undertaken with the resident participants? If so, who undertook the assessments? 7 The findings section reports occasions where residents told the researchers something that was then communicated by the researchers to family members. This raises questions about confidentiality, and whether the confidentiality of the residents was breached.8 Overall, the English is of a good standard, but there are a few errors that require correction, for example: * On p.7, the phrase 'The first cycles of the action was that the first author…' would be better expressed as 'In the first cycle of action the first author…' * In the section on ethical approvals, the word 'approached' is used - should this be 'approved’? Please ensure the whole manuscript is checked thoroughly for grammatical and typographical errors. 9

1. “This paper reports an action research study to develop a culturally appropriate interview guide for use in advance care planning, a topic that should be of interest to readers of the journal.
I have suggested a number of amendments that would improve the paper, and I would encourage
the authors to undertake the work required to bring it to a publishable standard.”

Response: →Thanks the review’s kind of encouragement. We will do our best to undertake the
work required to bring it to a publishable standard.

2. “The background section outlines a number of obstacles to ACP, but it is not clear why these
particularly apply to residential care facilities rather than any other care setting. (1) There is also
no clear definition of advance directives (indeed the abbreviation 'AD' is used without
explanation on p.3), and 'AD' and 'ACP' seem to be used interchangeably throughout the paper.”
(2)

Response:
(1) →We thank the reviewer for this remark. These obstacles to ACP were compiled from the
results of studies that adopted Taiwan nursing homes as their research setting. The content has
been revised per the reviewer’s suggestion. Please see the manuscript Page 3 (lines 56-57) and
Page 4(lines 58-65).
(2) →Thanks the review’s kind of suggestion. The contents have been revised as review’s
suggestions. Please see the manuscript Page 3 (lines 47-51).

3. “On p.7 the term 'ACP directives' is used, but it is not at all clear what is meant by this.
Advance care plans and advance directives are distinct concepts, and the confusion between
them needs to be resolved.”

Response: →We thank the reviewer for the kind indication. We have changed the sentence
“Based on suggestions from the residents and their families and the outcome of the discussion,
the researchers analysed and revised the contents of the interview guidelines and the ACP care
model, which were then incorporated into the second cycle of action and applied to the next
resident and family pair”. Please also see the manuscript Page 8 (lines 137-141).

4. “The authors state that the findings from the first action cycle were discussed with the facility
staff; were these staff therefore participants in the research? If so, they should be included in the
number of participants.”

Response: →Thanks the review’s kind of indication. The contents have been revised as review’s
suggestions. Please see the manuscript Page9 (lines 155-157, 158-159, 167-169).

5. “There is a lack of rationale for some of the decisions taken about sampling; for example, why
were 20 family members included and only 10 residents? Were only those residents with two
family members included, and why? (1) Why were multiple interviews undertaken with each
participant? How many interviews were conducted in total? These issues need to be clearly
explained.” (2)

Response:
(1) →Thanks the review’s kind of indication. Originally, the interview participants only
consisted of one resident and one family member. However, after completing the interview with
the family member, most of family members of other residents (2nd-10th) in the nursing home directly expressed to the researcher that they wanted to introduce the researcher to other family members (see following table). This is why the research sampled 10 residents and 20 family members.

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(2) →Thanks the review’s kind of indication. This study conducted multiple interviews mainly because the researchers needed to introduce ADs documents. Because the nursing home residents and family members were unfamiliar with ADs, and some even expressed that they had never heard of the term, the researchers were requested to explain ADs multiple times. Therefore, aside from the fifth resident who was interviewed four times (because of hearing problems), all other residents were interviewed three times. Apart from the eighth family member (a resident’s daughter) who was interviewed three times, all other family members were interviewed twice. Therefore, this study conducted 31 resident interviews and 41 family member interviews, for a total of 72 interviews. Please see the manuscript Page 12 (lines 212-216).

6. “The study inclusion/exclusion criteria should be stated clearly. Although the study purports to use action research methodology, there seem to be two distinct groups of people: those who were interviewed, and those who conducted or discussed the interviews. Usually action research involves active participants who make changes to practice that are then evaluated. In this case, it is not clear how the interviewees were active participants in the research; this requires further explanation.”
Response: →Thanks the review’s kind of indication. The contents have been revised as review’s suggestions. Please see the manuscript Page9 (lines 159-167), Page 10 (lines 179-189), Page 11 (lines 190-208) and Page12 (lines 209-211).

7. “It is reported that the first author spent six months working in the facility prior to the research; did this raise any ethical issues related to role confusion (researcher versus care worker)? (1) Were any assessments of capacity to consent undertaken with the resident participants? If so, who undertook the assessments?” (2)

Response:
(1) →Thanks the review’s kind of indication. A staff member of the long-term care facility requested the researcher to have first-hand experience with the difficulties of ACP promotion in the facility and to assist the facility in developing suitable ACP interview guidelines and a caregiving model. Therefore, the researcher participated in the resident caregiving process for 6 months, alongside other caregiving staff, to understand the difficulties in promoting ACP in the facility. Through this process, the author learned about the residents’ and family members’ attitudes toward and understanding of end-of-life care. After discussion with the facility staff, the researcher established the initial ACP interview guide and operation method for the facility. Only after this did the researcher submit the application for the research project and send the research project to the institutional ethics committee for review (please see the manuscript Page10 (lines 179-184)). Therefore, the issue of role confusion between researcher and care worker is nonexistent.

(2) →Yes, potentially eligible nursing home residents were selected using the following inclusion criteria: 1. resident in the nursing home for ≥1 month, 2. age ≥65 years and ability to speak Mandarin Chinese or Taiwanese, 3. Mini Mental State Examination (MMSE) score ≥24, and 4. willingness and ability to share feelings with the researchers about end-of-life care. The first author assessed MMSE scores for the resident participants. Please also see the manuscript Page 9 (lines 159-163).

8. “The findings section reports occasions where residents told the researchers something that was then communicated by the researchers to family members. This raises questions about confidentiality, and whether the confidentiality of the residents was breached.”

Response: →Thanks the review’s kind of indication. Yes, informed consent was obtained from participants prior to each interview or meeting with staff, each of which was audio recorded. The content has been revised per the reviewer’s suggestions. Please see the manuscript Page10 (lines 183-184).

9. “Overall, the English is of a good standard, but there are a few errors that require correction, for example: * On p.7, the phrase 'The first cycles of the action was that the first author…' would be better expressed as 'In the first cycle of action the first author…' * In the section on ethical approvals, the word 'approached' is used - should this be 'approved'? Please ensure the whole manuscript is checked thoroughly for grammatical and typographical errors.”
First, the authors apologize for failing to identify and correct all errors present in the manuscript. We are very grateful to the reviewer for his comments and have made the necessary revisions. Please refer to Page 8 (line 137) and Page 13 (line 242) of the manuscript. The authors have ensured that the manuscript has been checked thoroughly for grammatical and typographical errors. Thanks again for the insightful comments and suggestions.