Reviewer’s report

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

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Reviewer: Emma Lea

Reviewer's report:

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. 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. 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; 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.).

Some minor comments follow:

1. 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)?
2. Some statements need supporting; e.g. a citation is needed re the obstacles to ACP in Taiwan (line 53, pg 3).

3. 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.

4. 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.

5. 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.

6. 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. A comment on cognitive status of participants would also be useful, perhaps in relation to setting and inclusion/exclusion criteria.

7. Were the interview guides also based on the literature (as well as the informal discussions)? (pg 8)

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

9. 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.

10. 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".

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

12. 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. 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).

13. 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.

14. 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?

15. 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.

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

17. A Limitations and future research section is missing.

**Are the methods appropriate and well described?**
If not, please specify what is required in your comments to the authors.

No

**Does the work include the necessary controls?**
If not, please specify which controls are required in your comments to the authors.

Yes

**Are the conclusions drawn adequately supported by the data shown?**
If not, please explain in your comments to the authors.

No

**Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?**
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

Not relevant to this manuscript

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