Author’s response to reviews

Title: A review of paper-based advance care planning aids

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Author’s response to reviews:

Matteo Pasini
BMC Palliative Care

Dear Matteo,

Thank you for your consideration of our manuscript titled "A review of paper-based advance care planning aids" (PCAR-D-17-00033). We welcome the comments by the reviewers and your assessment as Editor that our manuscript may be potentially acceptable for publication in BMC Palliative Care. We have addressed all the comments by the reviews and carried out the essential revisions that have been suggested. Below you will find a point-by-point response letter that details the modifications made to our manuscript.

We believe that the modifications we have made to the manuscript have greatly improved the paper. We hope that you find that it is now acceptable for publication.
Reply to editor’s comments:

Point 1: Please amend the references in the main manuscript text, replacing the superscript with numbers in square brackets.

Reply 1: Thank you for bringing this mistake to our attention. We apologize for using the incorrect formatting style in our previous submission. We have amended the style of the references using the kindly provided Endote plug-in on the BMC Palliative Care website.

Reply to reviewer 1 (Ana Johnson)

Point 2: This paper addresses an important topic affecting a large proportion of the population. It is very well written and organized.

Reply 2: We greatly appreciate this feedback. We are pleased that you found the topic important and the manuscript to be well written. We spent a good deal of time conceptualizing this study and writing the manuscript, and we hope that this shows.

Point 3: Methods appear to be sound, consisting of a stakeholder summit and a content analysis.

Reply 3: Thank you very much for this feedback. We are pleased that you found this approach to be an acceptable and sound method.

Point 4: Stakeholder summit appears to be robust, including adequate representation: family advocates, clinicians, and researchers. Authors could indicate why these stakeholders were chosen.
Reply 4: Thank you very much for this comment. We are committed to including a diversity of perspectives in our research, and are very pleased to have been given the opportunity to expand upon the selection process for this engagement here. As we have now included in the methods section on page 2 line 33, this group of stakeholders was deliberately engaged so as to solicit a wide-range of perspectives in the discussion surrounding decision aids. Invited participants from each of these stakeholder groups were also selected based upon their interest in advance care planning and previous experience with the research team.

Point 5: Expand briefly on the "design-thinking techniques."

Reply 5: Thank you for this recommendation, our apologies for not initially providing sufficient detail. We have briefly expanded the methods section on page 2 near line 41 to better describe the design-thinking techniques that were utilized, which included activities such as brainstorming ideas for ACP aids, dot voting on preferred attributes of aids, and group discussion about the benefits and risks of aids so as to engage stakeholders to provide opinions and insight that would ultimately help the research team develop a new ACP aid. We have also added an additional reference from Curedale 2013, who describes in more detail the methods of these techniques.

Point 6: Likewise, content analysis appears to be sound with two reviewers and a third reviewer to resolve any discordances. Good explanation on the qualitative content analysis. Further detail would be good for the structured abstraction tool used; coding categories based on "existing ACP conceptual frameworks".

Reply 6: Thank you very much for your positive feedback regarding the content analysis. In our original version of the manuscript, we had included the coding categories that are based on existing ACP conceptual frameworks in the results section of the manuscript. Based on your feedback, and because the codes were predetermined prior to analysis, we have moved the code categories to the methods section on page 4 line 32. We hope that this addresses your concern and better clarifies the coding categories to the reader.

Point 7: How do the findings from the stakeholder summit correspond/interrelate with the content analysis, specifically relating to "patient priorities and values in general"? Were criteria gathered from the stakeholder summit? Were these prioritized? Was a decision-theoretic framework used?
Reply 7: Thank you very much for this thoughtful point. The findings from the stakeholder summit were largely complementary to the content analysis and helped the research team to elicit general user feedback on patient, caregiver, and other stakeholder’s preferences and priorities for ACP aids. A sentence clarifying this point has been added to the methods section page 2 line 55. Engaging with stakeholders at the summit gave the research team a sense of what individuals liked and did not like about ACP aids, and ultimately helped steer the development of the ACP aid that the research team was creating. This feedback was not used to directly inform the content analysis of the paper based aids, but rather to solicit feedback on the paper based aids with the ultimate intention of creating a new and improved aid. We recognize that integrating engagement work with research activities is challenging, and we thank you very much for raising this excellent point. We are in the process of developing a manuscript that addresses this topic head-on, as we completely agree that there is room for improvement in the interrelation of research and engagement approaches.

Point 8: Explain further "users to complete wallet cards that specify emergency contact information".

Reply 8: Thank you for this comment, we see now that this point was not well explained. As we have now included in the results section page 8 line 21, the purpose of these wallet cards were such that emergency or medical personal might be able to contact a family member or other loved one in the event that the cardholder was unable to speak for him- or herself. Thank you for providing us with the opportunity to better explain this important feature of the ACP aids.

Reply to reviewer 2 (Salimah H Meghani)

Point 9: This paper has potential to make a significant contribution. The methods are innovative; the qualitative procedures used for content analyses and characterizing paper-based ACP decision aids are generally rigorous. The results are informative.

Reply 9: We greatly appreciate this feedback, and are honored that you think this paper has the potential to make a significant contribution. Thank you for your positive feedback on the methods and characterization of the results. We spent a good deal of time designing this study and crafting this paper, and we are very glad that this shows.
Point 10: The procedures pertaining to the stakeholder summit may be clarified further. What was included in the representative sample of 7 aids? How was the representative sample determined?

Reply 10: Thank you for this question, and our apologies for the ambiguity. The diverse sample of seven aids were purposefully selected by the research team as they collectively demonstrated how ACP aids vary in terms of structure, length, presentation style, and content. This language has been added to the methods section page 2 line 50.

Point 11: How was the stakeholder input utilized in the analyses and synthesis? This latter point is not very clear.

Reply 11: Thank you very much for this thoughtful comment. As we wrote to the first reviewer above, the findings from the stakeholder summit were largely complementary to the content analysis and helped the research team to elicit general user feedback on patient, caregiver, and other stakeholder’s preferences and priorities for ACP aids. A sentence clarifying this point has been added to the methods section page 2 line 55. Engaging with stakeholders at the summit gave the research team a sense of what individuals liked and did not like about ACP aids, and ultimately helped steer the development of the ACP aid the research team was creating. This feedback was not used to directly inform the content analysis of the paper based aids, but rather used to solicit feedback on the paper based aids with the ultimate intention of creating a new and improved aid. We recognize that integrating engagement work with research activities is challenging, and thank you very much for raising this excellent point. We are in the process of developing another manuscript that addresses this topic head-on, as we completely agree that there is room for improvement in the interrelation of research and engagement approaches.

Point 12: How was unpublished and grey literature identified?

Reply 12: Thank you very much for raising this question. Unpublished and grey literature were identified through a search of the Lexis Nexis Academic database to identify news, financial information, and some legal information. Unpublished dissertations and theses were searched for using the ProQuest database. Information regarding ongoing research projects were gathered from Health Services Research Projects in Progress, which describes in-progress Federally and privately funded projects. A web search of relevant organizations was also conducted, including
a review of videos on YouTube. The protocol for this search has been described in detail in Aslakson et al. 2014, An Environmental Scan of Advance Care Planning Decision Aids for Patients Undergoing Major Survey: A Study Protocol. We had not specifically cited this environmental scan after noting that unpublished and grey literature were identified. We have now added in this citation immediately following the statement about unpublished and grey literature in the methods section on page 3 line 3. We hope that adding this citation has helped to clarify our methods.

Point 13: Is there a gap in the identification of the published literature since the included systematic review (Aslakson 2015) and this review?

Reply 13: Thank you very much for this question. This review was conducted within just months of completing the environmental scan. Therefore, we do not believe that there was a gap between the two wherein we would have missed tools for inclusion. We have added this clarification to the methods, page 2 line 23. Thank you for pointing this out, and we hope that the clarification of timing assuages this concern.

Point 14: How many aids were identified using grey literature? This may have implications for how widely these may be used.

Reply 14: Thank you very much for raising this question, and our apologies for not clearly denoting this in the original text. Of the 15 aids that met the inclusion criteria, 10 were identified by the grey literature search, 4 were identified by the systematic review, and one was identified from a key informant interview. This information has been added to the results section page 5 line 24. All of the aids are openly accessible and can be accessed, and therefore we believe that each aid has the potential to be widely used.

Point 15: Exclusion criteria of advance directives needs to be qualified more clearly in the text and the Figure 1. Page 2 lines 57-58: The authors state that "General advance directives, such as a state-sanctioned living will or advance directive form, were excluded from the study". Figure 1 also illustrates "advance directives" as an exclusion. However, the table 2 lists "Five Wishes"—which qualifies as an advance directive document in all 50 states. I believe, to be consistent, "general advance directive" language may be eliminated and exclusion may be "state-sanctioned AD".
Reply 15: Thank you for pointing out this inconsistency. You are correct that we did not include state-sanctioned advanced directives, but did include tools that might count as advanced directives (e.g. Five Wishes). Our preliminary data supported that state sanctioned forms only addressed what the person would want in the situations of being either brain dead, in a persistent vegetative state, or in an imminently terminal state. These three situations are quite rare. Moreover, the state forms provide no contemplative scaffolding to help individuals weigh and choose between options. Thus, we concluded that these state sanctioned forms were not meaningful or applicable for this study. We have modified the Paper Based Aids Content Analysis section of the methods on page 3 line 15 to reflect your recommended change.

Point 16: The presentation of the results may be improved. It is not clear which specific aids/set of aids are referred to in the text (pages 4-7).

Reply 16: Thank you for pointing this out. Throughout the results section, we have added in identifiers linking statements to specific aids from Table 2. We think that this modification will make it easier for readers to identify features of specific aids.

Point 17: Also, to improve replicability of the study, the authors should provide specific site links/or references for each of the aids in Table 2; especially given that some of the names of the aids are very generic (e.g. Advance Care Planning (8); Living Will (13). Year of publication of the aids or some indicator of if these aids are currently in use or available may be relevant in Table 2, especially given that these are paper-based and newer aids are expected to be more web-based.

Reply 17: Thank you very much for this feedback. Due to the nature of the published versions of the aids, it is challenging for us to make this requested modification. Many of these aids have been updated since we conducted this review in 2015, and are no longer publicly available online in the exact form that we used for our review. However, all aids are still available in a form that is often very similar if not exactly the same as the version we used in this review. We have not included site links to the aids as we do not want to insinuate that we reviewed versions of the aids which we did not.

Further, the aids are often inconsistent in their reporting of a year of publication/copyright, and we are concerned that including information about year in Table 2 may bring confusion rather than clarity. For instance, the only year identifier for one of the aids featured in this review is copyright 1999-2005. For another, the year identifier is copyright 2005, but with an update in
2008. A third aid describes only that it was “updated in 2002.” A fourth has no year at all on the physical aid, but was produced from a paper published in 1989. Other information that might be included in a reference, such as publisher and origin, has been included in Table 2. We have added the issues surrounding referencing these aids as a limitation of the review on page 10 line 23. Of note, however, because this activity did successfully help us to accomplish the task of developing an advance care planning video, we have not described this limitation as one of the study, but rather a limitation for replication of the study. We hope that you understand the difficulty we face in referencing these aids. We also hope that by providing many other details about the aids (e.g. pages, color, length, etc.) that individuals could identifying which version of the aid we are referring to. Thank you again for raising this very important point about replicability of findings.

Point 18: The presentation of Figure 2 can be improved (e.g. denominator/%); Also, what is "not addressed" referring to? I understood it was an exclusion if ACP was not addressed in the aids.

Reply 18: Thank you very much for making this observation. We agree that the presentation of Figure 2 could be improved, and that the category “not addressed” is confusing. This figure is meant to describe the frequency at which aids describe certain features of the ACP conversation. The four “not addressed” pertain specifically to aids that did not distinctly address the major talking points outlined as the other categories of the figure. This is not to say that these four aids did not discuss ACP; had they not discussed ACP, they would have been excluded from the review as you rightly pointed out. We are submitting a new Figure 2 that is both more aesthetically pleasing and that also omits the “not addressed” category in order to reduce confusion. Thank you very much for bringing this to our attention, we are much happier with the revised figure than we were with the original.

Point 19: Reference needed on page 2. Line 53 (Cochrane review of decision aids)

Reply 19: Thank you very much for this comment. We had included the reference at the end of the sentence in the original manuscript, but have moved it to immediately follow our discussion of the Cochran review. Thank you for pointing out that this was unclear.

Point 20: Table 1. Delete "name of the producer"
Reply 20: Thank you for providing this recommendation. We agree that the “name of producer” should be deleted, and we have done so on Table 1. The table looks cleaner following this change.

Point 21: Table 3. Check spelling of quotation under "Category"

Reply 21: Thank you very much for bringing this to our attention. We have corrected the spelling of “quotation” to the correct “quotation” in the column title for Table 3. Our apologies for this typo.

Point 22: Hope these comments will be helpful in refining the manuscript.

Reply 22: The comments you have provided were very helpful. Thank you very much for taking the time to review our paper in detail and to provide us with such meaningful feedback. We are confident that the paper is stronger as a result of your direction, and we hope that we have sufficiently addressed each of your questions and recommendations.