Author's response to reviews

Title: Creating an advance-care-planning decision aid for high-risk surgery: A qualitative study

Authors:

Anne Schuster (alschust@jhsph.edu)  
Rebecca Aslakson (raslaks1@jhmi.edu)  
John Bridges (jbridges@jhsph.edu)

Version: 2  
Date: 22 May 2014

Author's response to reviews: see over
Dear Dr. Bausewein,

Thank you for the valuable peer review pertaining to our manuscript, “Creating an advance-care planning decision aid for high-risk surgery: A qualitative study,” that was submitted recently to BMC Palliative Care. We appreciate the opportunity to revise and resubmit the manuscript for further consideration and, based on the reviewer’s comments, have modified the manuscript and its title accordingly. The relevant amendments are detailed below.

The authors thank you for your interest in our manuscript.

With best regards,

Anne Schuster

Anne Schuster, MHS
Research Assistant
Department of Health Policy and Management
Johns Hopkins Bloomberg School of Public Health
Response to referee 1 comments:

General remarks:

Point 1: Highly relevant topic! Recipe very interesting and useful outcome! However, based on the introduction this is not what I, as a reader expected. A better explanation of the purpose/goals of the study will improve the article!

We are pleased to hear that this is a highly relevant topic and that the recipe is an interesting and useful outcome. We have revised the abstract and the last paragraph of the introduction and believe this has improved the manuscript by more clearly articulating the purpose and goals of the study.

Point 2: Background: decision aids for ACP are useful in other settings, but non-existent for high-risk surgical settings. Two questions are investigated:

- Is a decision aid for ACP in high-risk surgical settings appropriate? (needed and/or desired)
- If it is appropriate, what are important elements for the development of such an aid? I would avoid the term buy-in, especially in the title.

The reviewer nicely summarized the background section and the questions we sought to investigate with this study.

Major compulsory revisions:

Point 3: The purpose of the study could be explained more clearly, to prepare the reader for the outcome. From reading the last sentence of the background section in the abstract I first had the impression that existing decision aids for ACP in high-risk surgical settings were examined on their appropriateness and design. However, it is clearly mentioned in the previous sentence that there is a lack of decision aids. Therefore, my next thought was that existing decision aids for ACP developed for other settings were examined on their appropriateness and design for the setting of high-risk surgery.

Thank you for this comment. We have revised the background section of the abstract and believe this has added clarity about the study and reduced ambiguity within the manuscript about the study’s purpose.

Point 4: In the result section it is stated that ‘decision aids were viewed as an appropriate approach to support ACP’ [line 32-33] –does this refer to existing, specific, decision aids or to decision aids more in general?

This comment makes a very good point. We have modified the text to specify that the line refers to decision aids in general.

Point 5: The last part of the result section in the abstract [lines 33-35] makes it clear that a recipe emerged on how to design a ACP decision aid for high-risk surgical settings. It remains unclear whether existing ACP decision aids were used as input or that key informants brainstormed more in general about the ingredients for an ACP decision aid for high-risk surgical settings.

We really appreciate this comment. We revised the methods sections in the abstract and the
main document to describe the interview’s content and its process. This modification strengthens the manuscript by giving readers the necessary information to understand the interviews and the findings that emerged from them.

Point 6: Line 227 refers to ‘reflections of (on?) current decision aids’ – here again it is unclear which decisions aids are meant.

This point is very helpful. We edited the text to explain that stakeholders were reflecting on decision aids that they were familiar with or had used. This change improved the manuscript’s clarity.

Point 7: In the last sentence of the abstract it is stated that a ‘new’ ACP decision aid for high-risk surgical settings is developed. This is confusing. I would say a ‘first’ ACP decision aid for high-risk surgical settings. (a ‘new’ decision aid suggests there was already such an aid)

Thank you for pointing out this ambiguity. We revised the text in agreement with your suggestion and believe that it added cohesion to the manuscript.

Point 8: In line with the clarifications in the abstract, the final part of the background section [lines 74-75] should be adapted also. Lines 87-89 of the method section are very clear in this respect!

We value this recommendation. As described above in regards to the abstract, we also changed the text of the background section and referenced lines 87-89 in the methods section when doing so. These amendments enhanced both clarity and consistency of the manuscript.

Minor essential revisions:

Point 9: Page 3, line 54: term CDC is not explained

This was a helpful find. We have defined the term.

Point 10: Methods: study subjects
Good initiative to include key informants of different countries: there is a huge difference in involvement of physicians in ACP in different countries and also differences in the development of palliative care exist!! I miss information about where the 22 stakeholders came from and what their background was in some more detail. Adding a table might be helpful?

Thank you for this observation and suggestion to provide more detail about the key informants. Instead of a table we added in details about where stakeholders reside and have provided the number of participants who provided specific content expertise. Adding this information provided important contextual information about the study participants.

Point 11: The reluctance to acknowledge or discuss death [lines 157-158] might be explained (partially) by cultural differences.

This is a good point. We clarified the text in this part of the manuscript to note that key informants observed a particular reluctance to discuss death within the field of surgery.

Point 12: Method: it remains unclear how the interview was conducted. Either further specification of the interview guide (interview questions or topics) or adding it as appendix, will
Thank you for this comment. We revised this section of the manuscript so that it now includes both example topics and questions. This not only facilitates a better understanding of the interview but also helps contextualize the findings.

Point 13: Do the ‘sections’ [line 124] in the result section refer to the themes or the thematic clusters as described in the method section [lines 108-109]?

Thank you for asking this clarifying question. We have updated the content in the results section to better specify how the results align with the data analysis methods and believe that clarifying this information helped make the manuscript more cohesive.

Point 14: The process of analysis, other than the general description of the four stages, remains a bit unclear. [a problem which is often seen, and perhaps unavoidable, in qualitative research]

Clarification about the process of analysis is recommended!

This comment is very useful. We added more detail to this section of the manuscript. This clarification of the analysis process strengthened the methods section of the manuscript.

Point 15: Lines 141-144: Some surgeons…might be more ready to integrate…. Is this something indicated by the respondents themselves or is it interpretation of the researchers? (if it is interpretation it should be moved to the discussion). And what is meant by ‘might’ be more ready? Are they more ready, should they be more ready or do respondents think they are more ready???

We appreciate these questions. These lines were edited to make it clearer that these were thoughts from one of the respondents. Making it explicit that these comments belong in the results section enhanced the integrity of the manuscript.

Point 16: Conclusion: Lines 150-152 are very clearly written and makes it very clear what this study delivered.

Thank you so much for this comment. We’re pleased to hear that the outcome of the study was easy to discern.

Point 17: But I don’t see how this study ‘creates buy-in’ [line 349]. Doesn’t it create the necessary input for the development of a decision aid for ACP in high-risk surgical settings?

We are grateful for this question. While the study does outline the necessary inputs for creating an ACP decision aid, it also shows that there is support for advance care planning within high-risk surgical settings. We revised the conclusion to explain this better, and in modifying it have improved the clarity of the manuscript’s main findings.

Discretionary revisions:

Point 18: I am not sure the term ‘surgical buy-in’ should be used in the title. Surgical buy-in refers to reaching consensus on post-operative treatments [lines 68-69]. However, ACP is broader than operative treatments only; it is also about the patients’ values or, for example, preferences with regard to artificial nutrition/hydration. In my opinion changing the title into ‘A recipe to create an ACP decision aid for high-risk surgery patients’ simplifies the title and adds...
to its clearness. Another reason to avoid the term ‘surgical buy-in’ is the fact that stakeholders reference this practice of surgical buy-in as a barrier to advance care planning [lines 164-165].

Thank you for this comment. We changed the title to “Creating an advance care planning decision aid for high-risk surgery: A qualitative study, and agree that this change improved the title’s clarity.

Point 19: Line 195-196: unclear. Focus groups with whom and when? And to gather input for what?

This is good point. Thank you. We have fleshed out the details surrounding who should be involved in the focus groups and what the focus groups should address, which made this section stronger by reducing vagueness and adding context.

Point 20: Lines 198-201: sentence too long and too complicated. In addition: is palliative care a part of ACP or the other way around??

We have split this sentence apart to make shorter, less complicated sentences. We also modified the description of the relationship between palliative care and advance care planning. These changes refined the readability and content of the manuscript.

Point 21: Lines 287-288: I would leave out the reference to smoking cessation.

We appreciate this comment and have removed this reference.

Point 22: Discussion: do not forget to mention line 333: I don’t think it is relevant to mention that you are inspired by IPA although interesting to read. (does this mean it was your first experience with this method?!) It is however relevant to mention that when a decision aid is developed it should be researched for effectiveness (not in the paragraph about limitations).

This is a helpful comment. We modified the text to better explain this limitation and have specifically stated that decision aids, upon development, should be evaluated for their effectiveness. Making these changes strengthened the final two paragraphs of the discussion section.

**Response to referee 2 comments:**

Major compulsory revisions:

Point 23: The authors use two concepts which are far from simple and uniform, namely "advance care planning" (ACP) and "decision aids" (DA). As I understand it from the paper the authors combine both concepts in the sense of decision aid supported advance care planning.

We are pleased to hear this comment because as the reviewer states, we are indeed combining the concepts of ACP and DA and sought to understand if this approach would be suitable for high-risk surgical populations.

Point 24: It would be of help to the reader if it could be explained in more concrete terms what form of ACP (e.g. who is involved, procedural aspects, content of discussion(s) and DA (e.g. rather a list with questions or decision trees...) are meant in this context. While I am aware that at
the end the answer depends also on the result of the study I assume that the authors had concepts of ACP and DA in mind before the interview study started. In this respect it may be also of interest whether these concepts have changed during the research.

This is an excellent point and we have modified the data collection section of the manuscript to better explain how we had conceptualized ACP and DA as we entered the study. Providing these details contextualized the purpose and outcome of the study and enhanced the manuscript.

Point 25: The authors correctly point out in the limitation that there is quite a difference of analysing ad verbatim transcripts versus analysing protocols written by the researcher during or after an interview. However in the result section this gets sometimes blurred. For example it was not clear for me whether in line 166/167 this is an ad verbatim quote from the interviewee or a quote taken from the note of the interviewer.

Thank you for pointing this out. We added a sentence to the methods section to specify that researchers’ notes were shared with key informants to and we also modified the results section to more clearly indicate where quotes were taken from the interviewee.

Discretionary Revisions
Point 26: The manuscript in my view would gain if the key messages would be substantiated by more quotes taken from the researchers' notes (e.g. content of lines 135-144).

We appreciate this comment and have included more quotes from our notes in this section of the manuscript. They strengthen the results section and we hope more fully substantiate the study’s key messages.

Point 27: Line 142ff suggests that several surgical specialties have a "high probability that patients may be in some way limited afterward surgery". This sounds rather stark to me and could be put more nuanced since for example in cardiac surgery a considerable proportion of operations is routine care without such high risk of negative outcome.

This is a very good point and we revised the sentence to indicate that for high-risk operations within certain surgery sub-specialties there may be more interest in initiating advance care planning. Making this point enhanced the manuscript by better articulating the nuances of the issue.

Point 28: The authors may explain why patient representatives but not patients who experienced surgery were included in the sample (or if they were clarify).

Thank you for this suggestion. As part of a larger environmental scan, other components of our research aimed to seek input from patients who underwent surgery whereas we intended for this study to investigate professionals’ perspectives. We clarified this point within the study subjects portion of the methods section. It improved the manuscript by more clearly describing the scope and context of this study.

Point 29: Another limitation which could be discussed is whether the sample of stakeholders
(e.g. involvement in medical decision-making research/palliative clinical care and/or research/end-of-life care policy making/patient advocacy) may be relevant for the overall positive responses to the idea of ACP supported by a DA in the surgical context.

This is a very helpful comment. We have revised the first limitation in the discussion section to address this point. This change strengthened the manuscript by more clearly stating that the study sample could relate to the data collected and stakeholders’ expressed support for an ACP decision aid among high-risk surgical populations.