Reviewer's report

Title: Family meetings in palliative care: multidisciplinary clinical practice guidelines

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Reviewer: Bob M Arnold

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BMC Palliative Care
Manuscript: Family meetings in palliative care: multidisciplinary clinical practice guidelines
Type of article: Research article
Authors: Peter Hudson, Karen Quinn, Brendon O'Hanlon, Sanchia Aranda

General Comments/Major Compulsory Revisions:
1. The authors should be commended on pursuing an important and understudied topic but we have several concerns iterated below.

2. The review of the literature is incomplete. There are too many articles not included to list, especially from the ICU and decision-making literature. The two most glaring omissions, however, are the recent article by Lautrette et al in the New England Journal of Medicine (A communication strategy and brochure for relatives of patients dying in the ICU) and the Lilly article from American Journal of Medicine (An intensive communication intervention for the critically ill). The Lilly article introduces the important concept of “clinical milestones” which is not mentioned in the article. The Lautrette article addresses the exact topic of interest for this paper (end-of-life conferences) in a randomized controlled trial and builds upon a wealth of data from Curtis’s group, including the VALUE mnemonic for the 5 objectives for caregivers in an end-of-life conference. Although this trial is recent, it would be important to include.

In addition, there is much literature that would have been found if the authors looked at non-palliative care family meetings (and if they do not want to do this, they need to justify this.) They might also have found much more if they looked at the grey literature (EPEC, Up-to-Date) or topics in which family meetings are discussed (eg futility)

3. The literature review is not clearly organized and comes across as almost a list of unrelated abstracts. It would be helpful to extract the items of interest in a more systematic fashion that illuminates how this literature review informed the formation of the guidelines. For example, the authors could have reviewed all of the data about specific topics within the realm of family meetings and come to a conclusion about each. An obvious starting point would be their “key questions” on page 4 (how should family meetings be structured, what content is essential, and who should attend/lead them).
4. The discussion of the conceptual framework has problems. First, the authors never justify why these choose these rather than other models such as family systems, mediation, etc. Second they provide such brief and superficial descriptions of the various models that it becomes uninformative to the reader. The models are also presented completely separately with no discussion about how they might work together to inform guidelines about how to conduct a family meeting.

5. There is no discussion of how the review of the literature and the conceptual framework were integrated to establish the guidelines. Each section is presented separately and then the guidelines are presented with little explanation. Presumably this was done in the focus group but there is minimal information presented about this process. There is no explanation of how the focus group data was analyzed, making the reader wonder about the rigor of the qualitative data analysis. The authors spend a great deal of time bemoaning the fact that current practice is guided only by expert opinion but the lack of transparency in their process makes these guidelines seem like just another expert opinion.

6. In the boxes, the authors present very detailed guidelines for conducting family meetings, pre- and post-meeting questionnaires and a document for the outcome of the meeting but provide no discussion about how these were formulated or how they may be used. For example, in box 4, there is a chart with column headings which are not intuitive (current situation, goal, action, key person, review date) with no explanation.

7. There is no concluding discussion of the strengths and weaknesses of the proposed guidelines or future directions for research.

8. While the authors emphasize the interdisciplinary nature of family meetings, they do not spend much time talking about how the different health care providers should work together to run the meeting.

Specific Comments:

1. The authors should be clearer in delineating that their focus is on family meetings in palliative care and should define how this may be different from other family meetings. This is especially unclear in the abstract.

2. Page 4, paragraph 1: Clarify “Who should attend lead them”

3. Page 4, paragraph 2: “Decision making” may have been a helpful search term

4. Page 4, paragraph 3: Which textbook was identified? There are sections in the Oxford Textbook of Palliative Medicine, Principles and Practices of Palliative Care and Supportive Oncology and in the EPEC curriculum to name a few. The JAMA Care at the close of life series also contains many communication articles which would be relevant, including one on how to conduct a family meeting “Supporting Family Caregivers at the End of Life” by Rabow et al in 2004.

5. Page 5, paragraph 2: The topic of this paragraph is unclear.

6. Page 5, paragraph 2: “Endorsement for the importance of family meetings was clear as outlined by the following points.” Is what follows meant to be a list? Might it be clearer if it was separated by a colon?
7. Page 6 - many of the references here come from the same data – and this should be acknowledged.

8. Page 7 – there is data that provides data on what families want to learn in meetings, about their satisfaction with the meetings, and related topics (particularly in the ICU – look at the University of Washington and French groups).

9. Page 7, full paragraph 2: The first sentence is very confusing and should be reworded.

10. Is it a problem to compare family meetings to family consultation when the family is not the unit of “treatment” and the family does not consent to such “treatment”.


12. Page 11, full paragraph 2: what specialty was the “medical consultant”? More data about the experts would help us better understand and agree with their conclusions.

13. Page 12, bullet 2: While we agree, the authors have spent the first half of the paper discussing the lack of evidence for family meetings so it is unclear how they can make this statement. Perhaps some acknowledgment of the lack of data would soften this statement.

14. What are the “appropriate skills”

15. Page 14: As noted above, the guidelines are presented without explanation or discussion. It would be helpful to know which areas are well supported by evidence, which are based on the conceptual models and which are based on expert opinion. A thoughtful discussion of the strengths and weaknesses of the guidelines and future areas of research would strengthen the manuscript.

16. Box 1, 1a: Are the authors suggesting a family meeting for all patients in the hospital?

17. Box 1, 1b: It would be helpful to clarify whether they are discussing identification of a formal decision-maker.

18. Box 1, 1e: awkward wording of first sentence

19. Box 1, 1g: second sentence is awkward because of the dual meaning of the word attending (ie physician) and lack of a comma after “attending”

20. Box 1, 1g: clarify referral. Does this mean including the social worker in the meeting?

21. Box 1, 1h: how many is too many participants?

22. Box 1, 1i: Why circular? There is some data supporting sitting at the angle of the table.

23. Box 1, 1i: We find having tissues in the room to be helpful.

24. Box 1: I was worried about the view that a genogram should be done. First, how does not explain a formal genogram before every meeting. Second do you do the genogram around the family members or the patient. And what is the data
25. Box 1, 2aii: “mobiles” sounds like slang

26. Box 1, 2bi: Outlining the purpose of the family meeting, unless done in very broad terms, can be problematic if you haven’t first ascertained the family’s understanding of the situation.

27. Box 1, 2c: before providing information about prognosis etc, it can be helpful to determine the desired level of information. This is alluded to by the authors in their review of the data but not included here.

28. Box 1, 2c: although the data is sparse, many recommend a clearer explanation of the shared decision-making process to family members of patients unable to communicate. A patient value-centered recommendation has also been endorsed in the literature.

29. Box 1, 2h: clinical milestones by which the success of a plan can be determined, are supported by the Lilly article mentioned above but not mentioned here.

30. What is the purpose of a break in the middle of the meeting? How does this get negotiated?

31. Box 2: The JAMA Perspectives on Care at the Close of Life series contains many relevant articles as mentioned above. The EPEC curriculum may also be considered.

32. Box 3: It is unclear how the 1-10 scales would be administered by phone. Since there is just a line, how would the patient mark an x on the line by phone? There are no numbers to guide an interviewer if a number is given verbally.

33. Box 4: as noted above, the columns in the Key Actions table are not clearly labeled. It also may be helpful to include milestones in this table.

34. Box 5: is this meant to be a research tool or do the authors propose value in completing this after every meeting?

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

We declare that we have no competing interests’ belo