Author’s response to reviews

Title: Factors underlying surrogate medical decision-making in Middle Eastern and East Asian women: a Q-methodology study

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Version: 1 Date: 25 Jun 2020

Author’s response to reviews:

Dear Dr. Smith,
Thank you for considering our manuscript "Factors underlying surrogate medical decision-making in Middle Eastern and East Asian women: a Q-methodology study" (PCAR-D-20-00068) and for giving us the opportunity to submit a revised manuscript.

We appreciate the reviewers’ constructive feedback. The feedback is mainly on the readability of the manuscript including its aim, results presentation, and organization style. There were no negative comments on importance of the study or validity of results and discussion. We therefore made three “big” changes: 1) We removed the section on comparing averaging-analysis with Q-methodology. 2) We transferred most of the Q-methodology result subsection to a new supplementary file (Additional file 5-Q-methodology technical report) and changed the subsection accordingly. 3) We substantially revised the presentation of results under averaging-analysis subsection and created two new tables (now Tables 2 and 3). There was no change in the content of the results, only the way they are presented. We also made other changes as detailed below. The following is our point-by-point response to the reviewers’ comments.

We think that the reviewers’ comments have clearly improved the manuscript and hope that you find the revised version satisfactory to be published in BMC Palliative Care.

Best regards,
Muhammad M Hammami, MD, PhD
Reviewer 1:

Main Impressions
Overall strengths of manuscript: The study addresses an important topic. Loved ones are often asked to participate in treatment-related decision making, especially at or near end-of-life or in advanced illness. It is challenging for clinicians to assist surrogate decision makers without an accurate understanding of the factors that influence decision making. Similarly, there is a dearth of literature on non-Western viewpoints, which again makes it difficult for clinicians to be inclusive.

Authors’ response: Thank you.

Overall weaknesses of manuscript: There is too much going on in one manuscript. Not entirely clear whether the main objective was to compare 2 different methodologies (averaging analysis vs. Q-methodology), to compare EA and ME women's perspectives or to identify the most salient factors influencing non-Western surrogate decision makers. The results and methods sections are not well-organized.

Authors’ response: We agree that the manuscript addresses a lot of data and several comparisons, which reduced its readability. The main aim of the study was to explore the relative importance of surrogate decision-making factors to Middle Easterners (ME) and East Asians (EA). Since this may be viewpoint-dependent, it was studied from three perspectives. The same data were analyzed by averaging-analysis and Q-methodology and led to complementary results. To simplify, as detailed below, we removed average-analysis vs Q-methodology comparison from the manuscript and clarified the aim of the study.

Title
The title is an accurate depiction of the study.

Authors’ response: Thank you.

Abstract
The abstract was difficult to follow. Even after reading 3 times, I am still not clear on the purpose, methods or most salient results.

Authors’ response: The entire Abstract is now edited and simplified; especially Abstract’s Background (lines 1-3).

Introduction/Background
The background or introduction section is missing a clear problem statement, leaving the reader to assume the research problem or question. It seems that your (the authors’) problem is that we do not have a clear understanding of the factors that influence female surrogate decision makers from Middle Eastern and East Asian cultures. If this is so, you should provide some background as to how this came to be (i.e. the prevailing model for surrogate decision making is "substituted judgment", which is a uniquely Western concept and may be a poor fit for other cultures) and the adverse consequences of the problem. Once you have a clear problem statement, you can state your aim, which would be to describe the most important factors in surrogate decision making in ME and EA women acting as surrogate decision makers, and whether these factors are consistent with larger societal norms and between groups. You need to better explain the 3 perspectives and how you arrived at them. Your background section should end with some sort of significance statement. Why is it important that we understand this phenomenon? In addition, later on in the
manuscript you discuss comparing Q-methodology to averaging analysis. Was this part of your purpose as well?
Authors’ response:
The background now includes:
1) Starting with a problem statement (page 4, lines 2-4).
2) Explanation of the three perspectives (page 5, lines 10-14)
3) Clearly stated aim (page 5, lines 21-23).
Further, the comparison between averaging-analysis and Q-methodology (not essential to the manuscript) is now removed.

Methods
Key information is missing from this section, especially concerning Q-methodology. I recommend that for clarity you use subsections to organize the Methods section. Please see below.
Authors’ response: METHODS section is now divided into subsections as suggested, and the content was rearranged accordingly.

Design
You need to describe Q-methodology, justify why you chose it and provide a reference in case readers want to learn more.
Authors’ response: A referenced paragraph describing Q-methodology and its advantage is now added (page 6, lines 6-14). Also a related paragraph under BACKGROUND is now expanded (page 5, lines 15-20).

Sample/Setting
Authors need to identify their target sample (who; inclusion/exclusion criteria); how they obtained sample (sampling strategy). The setting and how participants were enrolled is not adequately described. How did you determine that participants could adequately understand study aims and procedures? Had participants ever had experience acting as surrogate decision makers? Why were only women involved?
Authors’ response:
1) Target sample and sampling strategy are now under Sample/ Setting (page 6, lines 15-21).
2) Participants’ understanding was determined subjectively by study coordinator. The related sentence is now modified to reflect that (page 6, line 17). Some of the participants did report experience as surrogate decision-makers. This is shown at the end of Table 1.
3) The study did involve men and women, but because of the extent of data, only the results on women are reported here. A statement to this effect is now added (page 6, lines 18-20).

Protection of Human Subjects/Ethical Considerations
The authors adequately addressed.
Authors’ response: Thank you.

Data Collection
There are issues with this section that need to be addressed. The section is not well organized for the reader. You may want to begin with a better description of the Q-sort tool. You should clarify that participants completed 3 survey parts, the respondent characteristics, social value
questionnaire, and the statement sorting. Then describe each one, spending the most time on the sorting sheet.
Authors’ response:
1) The section is now reorganized as suggested.
2) A statement to clarify that participants completed 3 survey parts, the respondent characteristics, social value questionnaire is now added at the beginning of the subsection (page 6, lines 27-28 and page 7, lines 1-2).
3) Description of the Q-sort tool is now on page 7 lines 3-16 and description of the sorting sheet is on page 7, lines 17-22.

You do mention that the items (representative statements) were taken from previous work and the literature and underwent pilot-testing. This is excellent. Follow this up with a brief explanation of each of the 8 domains and the ranking criteria, in words and numbers (e.g. from 1, representing very strongly disagree or not at all important to 9, which is strongly agree or vitally important). This will help the reader grasp what you did.
Authors’ response:
Description of the Q-sort tool is now on page 7 lines 3-16 and description of the sorting sheet is on page 7, lines 17-22.

Data Analysis
The information on data analysis was complete. My only recommendation would be to add some "lay person" language. Begin with a brief explanation of what a Q-sort model is and that you used specific software to achieve. Chi-square and Fisher's appropriate for categorical variables; ANOVA and t-test appropriate for continuous level variables. Significance levels included which is good.
Authors’ response: Thank you.
A brief explanation of what a Q-sort model is and a statement that a specific software was used are now added (page 8, lines 15-18, and page 8, lines 14-15, respectively).

Results
Your main findings are lost. The results section needs to be substantially revised so that it is more concise and easier to follow. Much of the information presented in tables is also presented in narrative form. This is too repetitious. Begin each subsection of results with a narrative summary of the results then support as needed with statistics. Present the most salient findings in tables and provide only brief narrative in body of the manuscript.
Authors’ response:
The presentation of results under RESULTS section is substantially revised in line with the suggestions above. Specifically,
1) We removed the subsection on comparing averaging-analysis with Q-methodology.
2) We transferred most of the Q-methodology result subsection to a new supplementary file (Additional file 5-Q-methodology technical report) and changed the subsection accordingly.
3) We substantially revised the presentation of results under averaging results subsection and created two new tables (now Tables 2 and 3).
Discussion
The discussion needs to be reorganized to begin with a recap of the main study findings, followed by situating these study findings in the extant literature. Because many of the readers are clinicians, I suggest including clear sections on implications for practice and education. You do address in conclusion but recommend moving up.
Authors’ response:
1) A recap of main study findings is now added at the beginning of Discussion (page 16, lines 2-13).
2) The subsection on implications for practice and education is now moved up (to page 21, lines 1-9)

Conclusions
Well stated.
Authors’ response: Thank you.

Note to authors: I realize the critique may seem harsh and hope you will not be disheartened. You have very likely conducted a high-quality study. However, that is not accurately reflected in the current manuscript. Please consider rewriting the manuscript taking this and the feedback you receive from others into consideration.
Authors’ response: Thank you. The critique was constructive.

Reviewer 2: PEER REVIEWER ASSESSMENTS:

GENERAL COMMENTS:
Detailed report of a Q Sort methodology. The authors have provided an extremely detailed account of the findings. However, given that this methodology is largely a qualitative approach the paper is very 'heavy' to read, is overly inclusive of narrative of the findings and complicated for the reader. The figure that gives a graph type presentation of the findings is equally difficult to comprehend. It is not clear how the researchers arrived at the 'models' and seem to make their entrance to the findings as being derived of six factors - how this is achieved is unclear to the reader. The results section is overly lengthy and very confusing. It is not clear why the sample was only female.
Authors’ response:
1) The paper has been simplified (please see above).
2) The Figure axis is now modified to ease comprehension.
3) How the models were reached is explained under METHODS (page 6, lines 11-14, and page 8, lines 13-21) and under RESULTS (page 11, lines 24-28 and page 12, lines 1-6).
4) The RESULTS section is now shortened and reorganized as detailed above.
5) The study did involve men and women, but because of the extent of data, only the results on women are reported here. A statement to this effect is now added (page 6, lines 18-20).
REQUESTED REVISIONS:
There should be clear objectives to support the study aim; repetitive. The design and execution of a Q sort study is fine if the reader is already familiar with this methodology. The paper does no clearly and simply describe the processes. It is difficult to understand if their interpretation of data is acceptable as the findings are too long, too repetitive, too wordy and the reader loses sight of the main issues/findings. The results are lost in 'to much noise' so are left with no clear messages other than those two group of women seem to have different priorities in decision making. Why only female sample not argued or even seen as a limitation - do only women make such decisions in these ethnic populations?
Authors’ response:
1) A clearer rationale/aim is now stated. Please see first paragraph under ABSTRACT, last paragraph under BACKGROUND, and first Paragraph under DISCUSSION.
2) A more detailed description of the Q-methodology can be seen under BACKGROUND (page 5, lines 16-20) and under METHODS (page 6, lines 6-14, page 7, lines 17-22, and page 8, lines12-21).
3) The result section is now simplified and non-essential analysis is removed.
4) The study did involve men and women, but because of the extent of data, only the results on women are reported here. A statement to this effect is now added (page 6, lines 18-20). Study limitations section is now modified to include this point (page 21, lines 21-22).