Author’s response to reviews

Title: Prediction of life-story narrative for end-of-life surrogate's decision-making is inadequate: a Q-methodology study

Authors:

Muhammad Hammami (Muhammad@kfshrc.edu.sa)
Kafa Abuhdeeb (kabuhdeeb@kfshrc.edu.sa)
Muhammad Hammami (mhammami@health.fau.edu)
Sophia De Padua (jehans@kfshrc.edu.sa)
Areej Al-Balkhi (abalkhi1992@yahoo.com)

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Author’s response to reviews:

Dear Editor,

Thank you very much for the opportunity to revise and resubmit our manuscript. Attached please find a revised manuscript. All changes to the manuscript are highlighted. Our point-to-point responses to the Reviewers’ comments are below. We believe the manuscript benefited substantially from the review and we are grateful to our Reviewers.

Best regards,

Muhammad M Hammami, MD, PhD
Tenzin Wangmo (Reviewer 1): This study aims to evaluate surrogate's prediction of family member's life story narrative in relation to end-of-life issues. The authors have undertaken an interesting study. Some considerations would make the study easier to understand, read, and contextualize its significance to the available literature. AUTHORS’ RESPONSE: We thank the Reviewer for the constructive comments.

1. It is not clear what variables delineate "life story narrative" in the methods and the results sections. Also, the authors note that there are three life story narratives; which one was used in this study? AUTHORS’ RESPONSE: Thank you for an interesting question. The variables that are used to measure the life-story narrative in relation to end-of-life issues are the 47 end-of-life statements and their Q-sort, they have been previously published (reference 9) and are summarized under Methods (page 6, lines 22-26) and listed in details under Additional File 1. The three life-story narratives, authentic life, substituted interest, and patient’s endorsed life, are closely related. The patient’s life-story is taken as evidence of what the patient would have wanted to continue, of what the patient’s interests should be based upon, or of what the patient values, respectively. The aims are respectively, to continue the life the patient led (coherence of the patient’s life), promote patient’s best interests, or promote the life the patient valued. The three versions would differ in how the 47 statements are Q-sorted. We did not ask our participants to Q-sort the statements according to any particular version. The aim of the study was not to determine what version is preferred (or whether surrogates and family members use different versions) but to determine the accuracy in predicting the life-story narrative, whatever it is. We have transferred (per Reviewer-2 suggestion, see below) a paragraph from Results to METHODS-analysis (page 9, lines 16-22). We think this will make the point clearer.

2. Did the three steps of data collection happen on the same time or at three different time points? If at three different time points, I am surprised that there is no drop out. AUTHORS’ RESPONSE: Thank you. The three steps of data collection happened in the same session. To clarify, the related sentence (page 8, line 16) is now revised to read “The study was conducted in one session in three steps and study forms were collected after each step.”

3. In the same line, did the data collection stop when 30 pairs of participants were recruited for each type of relationships (husband-wife; sibling-sibling; parent-child)? How and why were 30 sets recruited? Did the pair of participants participate at the same time or at different times? When and how long did the entire recruitment take? AUTHORS’ RESPONSE: Per study protocol, study sample was stratified according to type of relationship (husband-wife, sibling-sibling, parent-child). So, yes, data collection stopped when 30 pairs of participants were recruited for each stratum. Study sample, as indicated in the manuscript (page 6, lines 10-11), was a convenience sample. The number 30 was selected because the program used for Q analysis (PCQ for windows) has an upper limit of 125 Q-sorts (30 pairs = 120 Q-sorts). The related sentence (page 6, lines 10-11) is now revised accordingly. Participants were
recruited as pairs but completed the Qsorts and other study instruments separately (page 6, line 12). The study was conducted between April 2016 and August 2016 for husband-wife and sibling-sibling pairs and between April 2016 and May 2017 for parent-child pairs. The first sentence under Methods is now modified to indicate study period (page 6, line 2).

4. It would be useful for the readers to know why three different relationship pairs were selected? What was the rationale for recruiting and comparing these three relationship pairs? AUTHORS’ RESPONSE: It is logical to expect that the accuracy in predicting life-story narrative may be related to type of relationship. So we wanted to make sure that we have a balanced sample. We are not aware of any previous empirical evidence. Please note that the association between type of relationship and prediction accuracy was a secondary aim that was explored in this study (page 5, line 13-15). The related sentence (page 6, lines 10-11) is now revised to read: “The sample size of 30 husband-wife pairs, 30 parent-child pairs, and 30 sibling-sibling pairs (total 90 pairs or 180 respondents) was based on convenience, limitation of the Q-methodology program (up to 125 Qsorts), and theoretical association between type of relationship and prediction accuracy.”

5. All the figures lack titles, making it difficult to interpret the figures on their own. For figures 1 and 4, descriptions are needed to understand which group each bar represent. AUTHORS’ RESPONSE: Actually, all Figures have titles and descriptions. Please see Figure legend (pages 23-25).

6. In the discussion, the implications for surrogate decision making based on types of relationships studied and compared is not fleshed out. Since an effort was made to recruit and analyse the data by type of relationships, there is expectation of in-depth discussion teased by these three groups. AUTHORS’ RESPONSE: Please note that the association between type of relationship and prediction accuracy was a secondary aim (not the primary aim) that was explored in the study. Nevertheless, the association was in fact addressed in several occasions under discussion. As examples, please see page 17, lines 19-23; page 18, lines 23-28; page 21, lines 3-6, 22-23, and 25-27.

7. The study concludes that substitute decision making may be inadequate. This is a known finding. Thus, it raises the question, what new does this study add? This could be made much clearer in the text, i.e., why is this study needed and how does it contribute to the field. Greater emphasis on explaining the life-story narrative and its value would be very helpful. AUTHORS’ RESPONSE: Our study concludes that surrogate decision making may be inadequate even using the life-story narrative model. This is not known. We believe that differentiating what is known (inadequacy of surrogate decision-making when tested using life-saving interventions and binary-decision scenarios) from what is new (inadequacy of surrogate decision-making using the life-story narrative model) is adequately addressed in
the manuscript. As examples: “However, surrogates’ prediction of individual healthcare decisions is often inadequate and may be based on shared background rather than patient-specific knowledge. It is not known whether surrogate’s prediction of patient’s integrative life-story narrative is better.” (ABSTRACT, page 2, lines 3-5), “Because of the demonstrated inadequate accuracy of substituted judgment and because of some philosophical challenges, other models of surrogate’s decision-making have been proposed. [10, 12-20] The patient’s life-story narrative model is based on understanding the personhood of the patient … Since the life-story narrative model simultaneously addresses multiple issues with a spectrum of answers rather than individual life-saving, binary-decision scenarios, previous results [4-7] showing inadequate accuracy of substituted judgment may not be applicable. The current study is the first to systematically evaluate surrogate’s accuracy in predicting life-story narrative.” (DISCUSSION, page 16, lines 18-29 to page 17, lines 1-42), and “Several studies [4-8] have documented inadequacy of substituted judgment in predicting individual choices. In the current study, we have shown that despite high self-reported surrogate’s decision-making confidence and healthcare-preferences familiarity, prediction of life-story narrative may be also inadequate.” (CONCLUSIONS page 22, lines 7-10).

8. Since the study is carried out in Saudi Arabia, the paper does not provide any rationale as to why this context is relevant or irrelevant for this topic? There is no mention of whether the country and the respondents affect the understanding of the topic or not as well as why is this topic important in that context? AUTHORS’ RESPONSE: It is not clear to us what the reviewer is aiming at. Justification why the study was carried out in Saudi Arabia? Of course, because the investigators are located in Saudi Arabia. Is prediction accuracy of life-story narrative more relevant or less relevant or in some way related to Saudi Arabia? We do not have theoretical bases to suggest so, only conducting similar studies in other countries will tell. However, please note that although the study was carried out in Saudi Arabia, more than half of the participants were Christians and non-Saudis and we did not identify a significant association with religion type. Do the results apply to other populations? We do not know. We clearly addressed this point by stating “If our findings are supported by studies in other settings, one may conclude that more attention should be given to exploring other models of surrogate’s decision-making, such as the population-based treatment indicators model, familisim, and the Golden Rule, i.e., what surrogates would want for themselves, [14] a fundamental concept of Judo-Christian and Islamic ethics.” (page 22, lines 10-14).

9. In the discussion, the study findings are compared with studies from the US, without any reservations about cultural differences. AUTHORS’ RESPONSE: Thank you. Our findings were compared to the results of published related studies including 2 systematic reviews and were found to be consistent. It is true that most (but not all) studies were conducted in the US. There are no similar studies conducted in Saudi Arabia. Comparing our results to published results, we did not find considerable differences in prediction accuracy. Should we
have found differences we could of course have addressed the culture issue. It does not sound logical to us to rationalize that the absence of difference in prediction accuracy may be due to cultural differences.

10. The paper is quite long which makes reading cumbersome. There are several places where brevity could be helpful. For example, there are many Tables and Figures that present the results quite descriptively, however, the text explaining them are also quite detailed. The first paragraph of the discussion and first paragraph of conclusion are redundant, one could be deleted. Also, the discussion repeats the study findings. A few of those could be avoided. AUTHORS’ RESPONSE: Thank you. We have transferred the first paragraph under RESULTS-Prediction accuracy of life-story narrative to METHODS, page 9, lines 16-22. We have also deleted the first paragraph under DISCUSSION per the Reviewer suggestion. We carefully reviewed the text again, we believe there is little and only necessary redundancy between the text and tables and figures. The paper is somewhat long, mainly because of the amount of data that need to be presented and discussed.

Daniel Drewniak (Reviewer 2): Dear authors, I was asked to review your manuscript entitled "Prediction of life-story narrative for end-of-life surrogate's decision-making is inadequate: a Q-methodology study". The manuscript examined surrogates' prediction of life-story narrative of family members regarding end-of-life issues. In addition the extend it is based on family specific knowledge in comparison to shared background was analysed. The research question is an important one as there is a need of knowledge on (surrogate) decision-making in end-of-life issues. Furthermore, the manuscript is well written and the study was well conducted. AUTHORS’ RESPONSE: We are immensely grateful to the Reviewer for this kind comment.

However, some recommendations may further improve your manuscript:

1. On page 6 (line 17) it is mentioned that one eligibility criteria was education > high school. What was the reason for this decision? Surprisingly the high education level is mentioned later in the manuscript (page 22; line 10) as a study limitation. Therefore, I think this point needs some more justification. AUTHORS’ RESPONSE: Thank you. > high school education was one of the eligibility criteria in order to improve the internal validity of the study, Q-sorting requires certain level of fluency and understanding. The relatively high education level mentioned under study limitation is in relation to external validity (i.e., generalizability to individuals with lower education level).

2. What was the mode of data collection? It seems to be a pen and paper survey. However, I would recommend to clearly name the mode of data collection (pen and paper, online, face
to face). AUTHORS’ RESPONSE: We agree with the Reviewer. Indeed, mode of data collection was “pen and paper survey”. We have now revised the relevant sentence accordingly (page 6, lines 13).

3. Based on point 2 on page 6 (line 56) it is mentioned that Q-sort completeness was checked immediately. What does that mean exactly? Was it "controlled" by a study member, and is this a potential source of bias? AUTHORS’ RESPONSE: Thank you. We meant immediately after completing the Q-sort. We have now revised the related sentence accordingly (page 7, lines 1-2). Occasionally, when completing a Q-sort, participants may use the number of one sentence more than once without noticing it (or may not write the number of the sentence clearly). Such mistakes were brought to their attention for correction without any further input from study coordinator. We have now revised the relevant sentence accordingly (page 7, lines 2-3).

4. On page 8 (line 28) the authors write that the study was conducted in three steps. Were there essential time spans (like several days) in between the different steps, or was it that the next steps followed immediately? AUTHORS’ RESPONSE: The next step followed immediately as the study was conducted in one session. We have now revised the related sentence accordingly (page 8, line 16).

5. On page 10 (line 48) it is explained how prediction accuracy of life-story was examined. However, I think this explanation belongs rather into the methods section than into the results. AUTHORS’ RESPONSE: We thank the reviewer for this suggestion. We totally agree. The paragraph is now transferred to Methods (page 9, beginning of third paragraph).

Beside these points I really enjoyed reading your manuscript. It is interesting and this sort can be useful for example for further developments in advanced care planning or shared decision-making tools. AUTHORS’ RESPONSE: We are immensely grateful to the Reviewer for this kind comment.