Author’s response to reviews

Title: “Whatever Happens, Happens” Challenges of End-of-Life Communication from the Perspective of Older Adults and Family Caregivers: A Qualitative Study

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Version: 1 Date: 14 Aug 2019

Author’s response to reviews:

August 9, 2019
Manuscript Revisions

Dear Dr. Naveen Salins,

Thank you for considering our manuscript for publication. We appreciate the reviewers’ comments and have outlined our responses to their comments in the table below.

Reviewer 1 Comments:

1. Adaptations were made to the interview guides as data collection and analysis progressed to refine questions and exhaust emerging concepts. – Does it mean the questions asked might be different for the initial interviews compared to the later ones? How different?

All participants were asked similar open-ended questions about participant’s understanding of illness, their goals of care, and prior engagement in end-of-life discussions. Adaptations that were made relate to adapting the ways in which questions were made so that patients and caregivers could understand what was being asked better. For example, we changed the phrasing of “what are your goals and priorities” to “can you tell me about the things that are most important in your life” which related better with patients and caregivers. The participants that were interviewed later were asked questions that inquire on the three areas of interest, however, if a theme had not been exhausted, we probed more in those areas, which follows the common practice in qualitative research. We thank the reviewer for pointing out this comment. However, we have decided not to include such explanation as part of the text as they refer to nuanced details that are common in qualitative studies.

2. The interviews lasted from 25-90 minutes. Its a huge range. any reason why? was it patient's reluctance/ any difference when interviewed singly/dyad?
Thank you for noticing this. Indeed, it is a wide range because one participant was more laconic in his responses while another was loquacious in responding to the questions. However, the length of these interviews did not diminish the quality of data to help answer the research questions. Most interviews lasted between 45-60 minutes. We’ve revised the wording in the methods to reflect this (see lines 157-58 on page 8).

3. Theme 1: Trivializing Illness – “Everything is…I’m managing fine” Is it trivializing? Or normalizing?

Although normalization is a related phenomenon, we felt that trivializing illness was more appropriate for the findings that are described. The intent was to convey the ways in which patients and caregivers downplay their illness. Therefore, we’ve left the theme as is.

4. Participants and patients word is used interchangeably in Theme 2. I think there is a huge difference between why a patient would not see the point of an end of life conversation compared to the caregiver. May be that should be addressed too?

Thank you for pointing this out. Interestingly, in our sample, in addition to patients not seeing the point of end-of-life discussions, although caregivers thought it would be important, they appeared to brush it off as well. However, we have revised the use of wording to distinguish between patients perception of lacking control over end-of-life events and caregivers acknowledging the important, but further also brushing the issue aside. Please see the revised paragraph on page 11.

Reviewer 2 Comments:

1. The study design, setting and participants:
* When was the study done?
* What was the duration of the study?
* What were the inclusion criteria for the caregiver?
* Line number 39-49- "participants were contacted and thematic saturation was determined based on no new data on relevant phenomena of interest being generated. Of the 22 participants, two patients declined to be approached by the researcher and one candidate could not be approached due to cognitive decline": This sentence show that researcher has interviewed 22 participants. Not clear about how the total participants became 19. saturation will be achieved only after collecting the data. so, not clear about the three how they were included. clarify.
* Mention the total sample size i.e. total 19;12 patients and 7 caregivers.
* Interviews were conducted in English?
* Add information on how many dyad interviews were conducted.
* The presence of the caregiver may influence the perspective of the patient and vice versa. Was this considered while analyzing the transcripts?

Thank you for these comments. The study period has been added (see line 157 on page 8).

We have revised the wording to clarify that 22 study candidates were contacted for recruitment into the study. We’ve also restructured the sentences so that it is written more clearly that this was recruitment of participants and not necessarily all 22 candidates became participants. Please see lines 122-29 on page 6.
Please see line 184 on page 9 for mention of the total sample size and its breakdown.

All interviews were conducted in English - this is included in our inclusion criterion. We’ve added this to the text in line 156 on page 8.

We’ve added the details of interview structures in line 185 on page 9.

Thank you for raising this important point regarding the influence of dyad interviews. It is our view that the inclusion of both solo and dyad interviews provides a fuller context in our dataset. Although it is possible that the presence of a family member influenced the data, we found the presence of family members to contribute to the richness in the data as patients and caregivers elaborated on each other’s responses. Nonetheless, we’ve highlighted this under limitation (see 380-84 on page 18).

2. Findings:
* Data in table 1: Add how many were females. under married, "other" means what?
* Four were living alone? if so, who were the caregivers?
* The characteristics like type of caregiver, gender, living status are important to be included and explained for the interpretation of qualitative research analysis.

We did not explicitly mention the number of female participants in the study as we include 7 male participants / n of 12 to save space. We’ve added qualifiers to clarify what is meant by other under marital status and living status.

We’ve added living status into the caregiver characteristics table. Similar to the patient characteristics table, we provide that 5/7 caregivers were female which leaves 2/7 to be male but left out to save space.