Author's response to reviews

Title: Selecting renal replacement therapies: what do African American and non-African American patients and their families think others should know? A mixed methods study

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Version: 2 Date: 11 November 2012

Author's response to reviews: see over
November 11, 2012

Hayley Henderson, PhD
Executive Editor, BMC Nephrology

RE: MS: 1702226370749081

Dear Dr. Henderson,

We respectfully resubmit our manuscript, “Selecting renal replacement therapies: what do African American and non-African American patients and their families think others should know? A mixed methods study” for consideration for publication by BMC Nephrology. We appreciate the thoughtful reviews our manuscript received as well as the opportunity to resubmit our paper for consideration for publication. The reviewers have made a number of suggestions regarding our manuscript to which we have responded, point-by-point, in this attached document.

We believe our responses to the reviews have enhanced our manuscript, and we hope it is now more suitable for publication. We welcome any further revisions you deem necessary.

Sincerely,

L. Ebony L. Ebony Boulware, MD MPH
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REVIEWER COMMENTS:

I. Reviewer 1:

1. The study focus is original in design and adds to the current evidence. Although not extensively, a short summary of contextual influences of information type is warranted to better interpret the findings, in particular sub-group analysis.

Response

We agree with the reviewer that contextual factors (including education level, financial resources, available family support, and patients’ independence) could influence patients’ and their family members’ perceived information needs. Because our groups were small, we were not able to explore the potential influence of these contextual factors among groups. We further believe our inferences regarding differences between African Americans and non-African Americans should be interpreted with caution. We have revised the discussion section on page 14, paragraph 2 to discuss this in greater depth:

"Many contextual factors could influence patients’ and their family members’ perceived information needs, including their education levels, financial resources, available family support, and independence. Family members’ perceived information needs might also vary according to the closeness of their relationships with patients. Moreover, the total number of participants in our groups was small, limiting our ability to make inferences regarding whether participants’ information needs might vary according to these factors. Our findings of potential differences between African American and non-African American groups could be influenced by differences in the education or financial status of participants and should therefore be interpreted with caution."

2. There is mention of a written questionnaire administered to the group individuals at the outset to collate demographics, opinions and interest in educational resources, but the findings from this instrument appear to not be discussed again throughout the paper. It may be useful then to remove this aspect and focus only on the group interviews or consider adding further explanation of the questionnaire, why it was introduced, what data it captured and making clear the findings.

Response

As suggested by the reviewer, we have removed our detailed explanation of the written questionnaire. We instead state the following on page 5 paragraph 2:
“All participants completed a written questionnaire describing their demographic characteristics and their relationship to patient participants (for family members or friends).”

3. The findings lack detailed sub-group analysis, particularly with respect to demographic characteristics, was the type if information selected as a priority influenced by age, gender, socioeconomics or ethnicity. Indeed was there a difference between selections of different family members (partner, spouse, sibling etc) inside of groups could have been explored. Having collated this information it would have been useful and interesting to have presented it within the paper, even if no influence could be determined.

Response

Although we did design our study to explore differences in information needs according to patients’ and families’ race/ethnicity, we did not design our study to explore the influence of other factors, such as age, gender, or socioeconomic status. In an effort to better display our findings according to participants’ race, we have revised our main results in Table 4 to provide an explicit comparison of findings according to race/ethnicity for both patients and family members. We have also added a section entitled, “Evaluation of Differences in Information Needs by Race and Modality,” on page 11, paragraph 3 of the manuscript in which we state that we did not find any differences in factor selections by race or treatment modality.

As discussed in our response to comment #1 above, we have revised the limitations section of our study to discuss our inability to explore differences in findings according to these factors on page 14, paragraph 2:

“Many contextual factors could influence patients’ and their family members’ perceived information needs, including their education levels, financial resources, available family support, and independence. Family members’ perceived information needs might also vary according to the closeness of their relationships with patients. Moreover, the total number of participants in our groups was small, limiting our ability to make inferences regarding whether participants’ information needs might vary according to these factors. Our findings of potential differences between African American and non-African American groups could be influenced by differences in the education or financial status of participants and should therefore be interpreted with caution.”

4. The weakness of the paper, which requires further work, lies in the discussion and the full analysis of the demographic characteristics recorded and the findings. The hypotheses listed are not revisited and or proven and having taken the trouble to list many different hypotheses at the outset I would expect some discussion as to whether they were upheld. The relationship between the context of an individual and their information type/need within the literature is explicit and
could be reflected on in more depth within the discussion. This would add more
detail with respect to the usefulness of the findings when developing not just
ethnically pertinent education programmes but information that is age and
gender specific.

Response

We have clarified in the methods section on page 4, paragraph 2 to state that we
explored four (4) a priori hypotheses in our study, related to (1) the range of information
patients and family members would seek, (2) differences in patients’ and family
members’ information needs, (3) racial/ethnic differences in information needs and (4)
differences in information needs according to patients’ experiences with ESRD
therapies:

“We explored four a priori hypotheses in our study. First, we hypothesized that
patients and families would view a broad variety of factors as important to include
in educational resources. Second, we hypothesized that patients’ perceived
informational needs would vary from those of family members, who would have
less direct experience with RRTs and would experience RRT mostly in the role of
caregivers. Third, in light of well-documented race differences in the types of
RRTs initiated in the U.S., we hypothesized that patients’ and families’
informational needs might vary by race. Fourth, we hypothesized patients with
and without prior RRT experience would have different views about the types of
information that might best inform RRT selection decisions. For example, we
hypothesized patients and families with advanced CKD (non-dialysis dependent)
who had not previously experienced RRTs might be concerned about
transitioning to ESRD. In contrast, we hypothesized patients and families who
had previously experienced different RRT modalities might articulate experiences
related to receiving these modalities but might not recall concerns they had prior
to initiating RRT.”

We agree with the reviewer that our previous presentation of findings did not optimally
describe how findings informed these hypotheses. We have revised the methods
section to more directly present our findings in a way that addresses our hypotheses
and we have restructured our findings into three sections addressing these hypotheses,
ettitled “Range of Information Most Desired by African American and non-African
American Patients” (page 7); “Range of Information Most Desired by African American
and non-African American Family Members” (page 9); and “Evaluation of Differences in
Information Needs by Race and Experience with ESRD Treatments” (page 11).

Reviewer 2:

1. Authors should specify how many participants (or the percentage of
participants) in each group selected each factor. While it is interesting that
someone in each group (or in a certain number of groups) selected a particular
item from a factor, it can be misleading. Did one person in each group select the factor? For instance, every group (AA and non-AA) selected morbidity/mortality factor. One person from each group selecting this factor is very different than a majority of participants selecting the factor. In addition, did more AA or non-AA within the groups select this factor? It is difficult to say that AA and non-AA both equally believe Morbidity/Mortality is a factor when 100% of the participants could have chosen that factor vs. 50% in another racial group, but since at least one person in each group selected that factor it is being counted as equal. This holds for all factors. This would be much more informative and compelling if you could quantify the number of participants who selected each factor.

Response

As suggested by the reviewer, we have revised our tables to provide a direct comparison by race between patients and family members (Table 4, page 27). The numbers in Table 4 reflect the total number of participants across all focus groups, stratified by race, that selected a particular factor (e.g., living longer). We also added tables in our Appendix (Appendix 1a on page 27 and Appendix 1b on page 34) that provide the number of participants within each focus group, stratified by race and treatment modality, that selected a particular factor.

2. Report the selections from Stage 1 as well. Stage 3 selections were after group discussions. This could be considered to be a small intervention. A comparison of selections before and after discussions is interesting and would add to this manuscript immensely.

Response

We now report patients’ and family members’ factor selections for both Stage 2 and Stage 3 in Appendix 1a on page 27 and Appendix 1b on page 34. Appendix 1a provides factor selections from Stages 2 and 3 for patients, while Appendix 1b provides factor selections from Stages 2 and 3 for family members. We did not find that sentiment changed dramatically for either patients or family members between Stages 2 and 3. Findings are presented on page 12 paragraph 2:

“Discussion among participants between rounds 1 and 2 of the ranking exercise did not appear to substantially change their perceived information needs. However, participants did seem to shift their ranking somewhat after round 1 discussions. For example, more patients and family members ranked “living longer” as important to feature in educational resources in the first round than in the second round. (Table 4)”

3. Tables should not be broken down by stage of ESRD if analyses did not focus on the differences between these groups. Much of the procedure focuses on the different groups stratified by ESRD stage, yet analyses and results were
completed. The tables could be collapsed across ESRD stage to make them more readable. In addition, once comment 1 is addressed, the tables should include a measure of how many people in each group endorsed each item or factor.

Response

As suggested by the reviewer, we have revised our tables. Table 4 is now stratified by race and provides a direct comparison between factor selections for patients and family members without regard to their ESRD treatment experience. However, in response to the request from Reviewer 1 to more directly address our a priori hypotheses related to differences in participants’ perceived information needs according to their ESRD treatment experiences, we have also now included two tables in our appendix (Appendix 1a and 1b) that stratify factor selections by treatment modality, race, and participant status (patients or family members). We have also now organized our findings to more explicitly address our a priori hypotheses into three sections addressing these hypotheses, entitled “Range of Information Most Desired by African American and non-African American Patients” (page 7); “Range of Information Most Desired by African American and non-African American Family Members” (page 9); and “Evaluation of Differences in Information Needs by Race and Experience with ESRD Treatments” (page 11).

4. Address why open-ended responses provided by the participants were not included. Did AA or non-AA come up with other factors that were not on your list of 36?

Response

We report selected open-ended responses from patients and family members to elaborate on the rationale behind factor selections throughout the results section on pages 7 through 11. Participants only chose factors on the list and did not come up with additional factors. We have now clarified this on page 7, paragraph 3:

“Patients only mentioned factors on the predefined lists provided to them and did not cite additional factors.”

and on page 9, paragraph 2:

“Family members only identified factors on the predefined list provided to them and did not cite additional factors.”