Author’s response to reviews

Title: Non-Spouse Companions Accompanying Older Adults to Medical Visits: A Qualitative Analysis

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Non-Spouse Companions Accompanying Older Adults to Medical Visits: A Qualitative Analysis.

Response to reviewer’s comments:

Thank you for your thorough review of our manuscript and for the insightful comments and suggestions. We appreciate the opportunity to strengthen our paper through our responses below.

Reviewer’s comments in this response letter are in bold and changes to the manuscript are in red font.
Technical Comments:

1. Please place the List of Abbreviations under the Declarations section.

Response: We have done this, thank you.

2. Tables:

Please place your tables in the main manuscript file after the references.

Response: All tables are now in this position.

Reviewer reports:

Sonia Hines, BN, Grad Dip Ed, MAppSc(Research) (Reviewer 1): Thanks for an interesting paper.

Please consult the journal's author guidelines for the correct referencing style.

Response: We have done this, thank you. Specifically we have noticed our error and replaced our round brackets with square brackets.

A statement about the research paradigm and theoretical framework would add to the quality of the paper.

Response: We are happy to provide this. Our research paradigm began with a conceptual model of patient centered care where social facilitation improves healthcare efficiency. We felt that understanding the experience of MVCs would allow us to improve that experience and ultimately improve the quality of healthcare received by older adults. We have added a statement about this to the last paragraph of the introduction.

It's unclear from the text why churches were chosen as a site for recruitment. The participant selection and setting section lacks description and detail.
Response: We recruited from churches for a number of reasons. In conducting this research we adopted a Community Based Participatory Research (CBPR) approach. As part of this we partnered with a faith based community organization, who had access to and experience of community recruitment through local Baptist churches and who felt this would be an appropriate recruitment mechanism. We also wished to explore if cultural differences exist in the experience of Caucasian and African American MVCs and the structure of the Baptist churches in Baltimore with the members of each church comprised predominantly of one race allowed us to do that. We felt that participants might be more willing to talk about their experience in a familiar community setting such as their church rather than in the waiting room of a healthcare facility. In the manuscript we have now added further detail to the participant selection and setting section of the methods and expanded upon our cultural findings in the results and discussion sections.

I understand that the chronological events were useful for organizing responses from the groups but before, during and after aren't themes, they're the organizing structure for your interview guide. Themes are the patterns across responses important to the description of a phenomenon. I suggest a thorough re-analysis of the data, listening for the actual subjects the participants were concerned about and picking up the narrative threads, integrating their voices into the text, rather than decontextualized in a table. It is very important in this kind of research to let the participants' voices and responses come to the foreground. At the moment this paper reads more like quantitative research. Naming the participants by solely their race and sex seems reductive.

Response: Thank you for your comments. We agree that the timeline structure we used to organize the interview guide and the results section (before, during and after the visit) are not themes. Our themes emerged from the discussion about MVC roles at these time points e.g. transport emerged as a theme in the discussion around roles before the visit. We have edited the abstract to clarify this and reworked the results section, maintaining the organizing structure, discussing themes as they emerge and using participant voices to illustrate each theme. We completely agree that the richness of qualitative data is in the voices of the participants and to highlight this we have deleted Table 3 and added all quotations to the results section. We have removed the race and sex descriptors and now refer to participants by their study ID and describe their relationship to the person they accompany.

Paulette Hunter (Reviewer 2): Summary

This cogently written manuscript describes the experiences of non-spouse medical visit companions of older adults as ascertained by interviewing these companions.
General comments:

Thank you very much for the opportunity to review this paper, which relates to my own interests in thematic analysis and in older adults' participation in healthcare processes and programs.

Overall, I found the study to be well conducted and the manuscript very well written, with the exception that the discussion can be further strengthened and some details about the methods clarified. The study provides a valuable inside look at the experiences of non-spouse medical visit companions.

Abstract

It is somewhat common to combine the terms qualitative and inductive as descriptors; for instance: "qualitative, inductive" or "qualitative (inductive)". However, the term "qualitative inductive analysis" is not regularly used in North American health research. It is better to say directly which method you are using, and I think the method you are using is thematic content analysis.

Response: Thank you for your observation with which we completely agree. The abstract (line 44) has been changed to reflect this as has the methods section paragraph “Qualitative Data Analysis” (lines 131-142).

The conclusion of the abstract speaks to the experiences of older adults, whereas the results section suggests the focus is on the experience of the visiting companions. The conclusions should reflect the results.

Response: We have edited the conclusion to reflect this, thank you. It now reads

“Our increasingly complex healthcare system can be challenging for older adults to navigate successfully. The diverse nature of tasks performed by companions in this study highlight the many benefits of having a companion accompany older patients to medical visits. The positive experience of the companions studied and their willingness to continue their role in the future highlights the untapped potential for increased social facilitation to improve the quality of healthcare visits and achieve patient-centered care for all older patients.”

Introduction

The introduction is well written and provides an appropriate rationale for the study.
Response: Thank you.

The third paragraph was less clearly integrated into the argument of the paper. Part of the issue (but not the whole issue) is that some details can be expounded. For example, what do you mean by “demographically driven”?

Response: Your point is well made. By demographically driven we were referring to the shift in the population demographics that is leading to the proportion of the population made up of older adults continuing to rise. We have rephrased this in the paragraph and edited it to make our points about the relationship between population demographics and increased health care costs and the potential for MVCs to contribute to the quality of care received by older adults. We have removed the line referring to people with multiple chronic conditions, as it is tangential to our point. The paragraph now reads (lines 78-82):

“In recent years the aging of our population has led to increased health services utilization by older adults which has generated increasing concerns about possible deficits in care quality and rising health care costs [15]. New initiatives to address patient concerns seldom consider the experiences and capabilities of MVCs during face-to-face medical encounters even though such experiences may represent an important quality of care indicator [16-18].”

For appeal to a broader audience, some US-specific context can be offered to support later findings. For example, you can explain the relevance of having insurance cards ready, the reason(s) that hospitals (rather than clinics) were a major setting for health appointments, and the reason for using a $50,000 income cut-score in the demographic data. This contextual information need not be placed in the introduction, but it should be offered before or just as the need for this interpretive information arises.

Response: Yes, we agree that adding some U.S. context will add to the interpretability of the work. As you suggested we have added relevant information where the need to interpret it arises. We have added information on the need for provision of insurance cards before a healthcare provider will see a patient to the description of tasks performed by MVCs before the visit in the results section paragraph “Gathering Relevant Information”(line 194). Prior to the participant’s description of the difficulties obtaining transport to hospital the following statement has been added “As is common in the U.S. participants described accompanying older adults to many different hospital-based specialists and less frequent visits to community based primary care providers” (line 180-181). We included six income categories in our demographics questionnaire (Less than $10,000, $10,001 - $30,000, $30,001 - $50,000, $50,001 - $70,000, $70,001 - $99,999, $100,000 or more) and chose to present the results of the lower three versus the upper three categories.
The rationale for your study is supported: there are "virtually no studies" about the experiences of non-spouse medical visiting companions.

Response: Thank you.

You introduce the fact that reports of African American medical visiting companions' experiences are rare. You seem to be building a rationale for your research questions, but then you do not explicitly state whether your research will address this.

Response: Thank you for this observation. We did set out to examine if there were differences in the experience of Caucasian and African American MVCs but as we observed few differences we did not emphasize these in the manuscript you reviewed. To address this we have added information on our cultural observations throughout the paper in the introduction, methods, results and discussion sections.

Methods

Sampling: The significance of recruiting from churches that are primarily Euro American and African American was not completely clear to me. You draw attention to the representation of African American experience at the end of the introduction and when you report on your sample, and you also indicate the gender and ethnicity of the interviewees whose quotations you select. However, the rationale for an occasional focus on ethnicity in the paper is absent. Here are some options to consider: (1) If the rationale is to represent African American caregivers' experiences because they are currently underrepresented, then perhaps the focus should be strictly on their experiences. (2) If the rationale is to ensure representativeness or diversity in sampling, then values around this should be stated, and this goal should be fully integrated into the paper. For example, you should state what your sampling approach was and why you used it, and you should report on whether or not you observed diversity in the results, and you should discuss any experiences that did seem to differ by ethnicity. (3) One further option is to treat ethnic diversity the same way you did gender diversity. Describe your sample, but avoid emphasizing personal characteristics unless they are relevant to your research questions.

Response: Once again thank you for your observations and suggestions. As described above we sought to examine if cultural differences exist in the MVC experience. Although we found few differences, we have now included this information throughout the manuscript.

Interview: What training or relevant experience did the interviewers have? Was the interview the first encounter with participants?
Response: The lead interviewer had over 20 years of experience with both key informant interviews and focus groups conducted in a wide variety of settings and covering many different content areas. The second interviewer received formal training in addition to practical experience. We have edited the paragraph on “Focus Groups” (lines 118-129) in the methods section to reflect this. Yes, this was our first encounter with participants.

Analysis: Although I think I have a good general understanding of how you analyzed your data, and I think it was appropriate, the reporting is non-standard. I think you did thematic content analysis, yet you cite Glaser and Strauss’ grounded theory text. (There are some reasons to do this, but these are not given. I think it is more straightforward to cite resources associated with the approach to analysis that you used.)

Response: We have done this thank you for your observation.

Analysis: You claim in the abstract that you used an inductive approach, yet the description of your method suggests it was both inductive and deductive. For example, the close correspondence between your interview guide and your major themes suggests you drew these themes from those already defined for your questions (a deductive approach). Your description of methods suggests that you used an inductive approach to design your codebook, but thereafter used a deductive approach to classify text units from the interviews. I think you might find that Crabtree & Miller's description of the template organizing style speaks well to the approach you employed.

Response: Thank you for your insightful comments. We have edited the “Qualitative Data Analysis” paragraph (lines 130-142) of the methods section to reflect our both inductive and deductive approach to analysis. As you suggested Crabtree and Miller’s template organizing style and suggestions for codebook preparation fits very well with our analysis method. We have added a reference to their book (Crabtree, B., & Miller, W. (1999). Using codes and code manuals: A template organizing style of interpretation. In B. F. Crabtree & W. L. Miller (Eds.), Doing qualitative research (2nd ed.) (pp. 163-177). Thousand Oaks, CA: Sage Publications).

Analysis: Details of organization of labor during analysis are not completely clear.

Response: We have added further detail to the “Qualitative Data Analysis” methods paragraph (lines 130-142). The initial draft of the codebook was prepared by one member of the research team (AGP). It was then reviewed and refined by the three other coders. The four coders divided the labor by working in pairs. Each coding pair was assigned two organizing themes before each
coder coded all transcripts to identify these themes. The other coding pair resolved any discrepancies.

Research Paradigm: In the introduction, you mention that you partnered with a community-based organization. In the methods, you expand on this a little by saying that the organization recruited and paid your participants. You also note that the community partners participated in data analysis. Is there a community-based research approach to research here? If there is, I would suggest expanding on that a little. This might include your philosophy and details of the partnership (including how the research team contributed reciprocally to the partnership).

Response: Our partnership with The THREAD Institute was, as you observed, part of our Community Based Participatory Research approach. THREAD took responsibility for recruitment and provided two of the four members of the analytic team one of whom prepared the initial draft of the codebook. We designed the study, obtained funding and IRB approval, approved the recruitment strategy, developed the interview guide (in consultation with our partner), arranged transcription, analyzed the data and prepared the manuscript. The lead moderator was a member of THREAD. Our goal in collaborating with a community partner was to gain a shared understanding of the experience of MVCs. Ultimately we hope that this shared understanding will allow us to achieve the ultimate goal of CBPR, namely, integrating the knowledge gained with interventions and social change to improve the health and quality of life of community members. We have added this information to the first paragraph of the methods section “Participant Selection and Setting” (lines 102-117).

Results

Percentages and standard deviations are both reported in parentheses in the demographics table, and this is confusing.

Response: Thank you. We have removed the standard deviation so that all parentheses report percentages.

In the same table, it might be just as important or more important to know how many ADLs caregivers reported supporting.

Response: Thank you. We agree with your observation and have added this information to table 2. The mean number of ADLs/IADLs for which companions reported providing help was 5.4.
The three themes and the subthemes were generally coherent and well presented even if very concise. Since quotations are sparse in your table, they could just as easily be integrated into the text, but I have no preference one way or the other. An example would be useful at the end of the "communication" subtheme. In the same subtheme, it was unclear who writes the visit summaries (physician or MVC).

Response: Thank you. The quotations have been added to the results section and table 3 has been removed. The physician writes the visit summaries and this has been clarified in the text in the paragraph on “Communication” (line 242).

To what extent were themes saturated? There was no way to tell how closely the information you provided represented participants' experiences. Since you have mentioned that your sample has gender and ethnic diversity, to what extent did results vary by ethnicity and gender?

Response: Thematic saturation was largely achieved after four focus groups with only one new theme emerging in the fifth group and none in the sixth. The experience of MVCs was largely similar across cultural groups. Any differences observed are outlined in the last paragraph of the results section (lines 340-356) and elaborated on in the discussion (lines 394-407).

You should provide a unique identifier such as a participant number for the quotations.

Response: We have done this. The unique participant ID and relationship to the person they accompanied has been added for each quotation.

Discussion & Conclusion

The discussion is quite circumscribed. Results are not directly discussed, although some implications are (e.g., need for better care coordination). I think it is important to directly discuss your results in this section.

Response: We appreciate your observation have added to the first two paragraphs of the discussion section to address this (lines 359-379). We have also added a new paragraph to the discussion on the observed race differences (lines 394-407).

The discussion addresses some general impressions from the results, such as a focus on roles before and after the visit, but not during. Since this was not a reported result, and since this
impression does not align with the distribution of subthemes related to before, during, and after
time segments, I would prefer to see you avoid this, and instead discuss the results you reported.

Response: Thank you. Information participants shared on their roles and experience during the
visit has been added to this paragraph (lines 372-374).

What were some limitations associated with this study?

Response: Limitations of our study are outlined in the last paragraph of the discussion.

“Limitations of our study include the potential for bias in the self-reported data of all focus
groups with data limited to the contributions of those who voiced their ideas and experiences
(25). We conducted the focus groups in the community and not in a healthcare setting to
encourage participants to talk freely about both positive and negative aspects of the MVC
experience. The church-based setting, however, may have additional limitations on the extent to
which these findings apply to the general population, and it may have discouraged some
participants from reporting negative feelings about their relative that they did not wish other
church members to hear.”

Typographical:

There were occasional and minor typographical errors including agreement errors in lists,
comma placement errors, and word choice errors (e.g., I questioned "coerced"; if this is correct,
it needs some discussion since it implies a violation of rights).

Response: Thank you for your observations. We have attempted to identify and correct these
errors and agree that “coerce” is not the correct word choice and replaced it with “convince”.

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Response: We have reviewed and verified our declarations. Please note that we have chosen not to place our data in a publically available repository due to the potentially identifiable nature of the data (small number of participants with both religion and city of residence known) but would be happy to make it available on reasonable request in a de-identified format.

Declarations

- Ethics approval and consent to participate
- Consent to publish
- Availability of data and materials
- Competing interests
- Funding
- Authors’ Contributions
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