Author’s response to reviews

Title: "They don't care about us": Older people’s experiences of primary healthcare in Cape Town, South Africa

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Author’s response to reviews:

Suguru Okubo (Reviewer 1): The research theme is important, and it is of value that focus groups were conducted in three different districts. However, I think minor revisions are necessary before publication. Please check the following things.

Data collection

1. The focus group discussions were held in the home language of participants (English, isiXhosa or Afrikaans). Which language was used for analysis? If one language (e.g. English) was used, were transcripts by isiXhosa or Afrikaans translated into English? How did the authors ensure the credibility of translation?

The following has been added to the text: “All focus groups were transcribed in the original language and then translated into English. To ensure the accuracy of translation, translations were carried out by the focus group facilitator and checked by the co-facilitator, who was also present during the focus group and therefore aware of the conversational content and context.”

2. I think references for the methodology of focus groups should be added.

Based on your comments and those of other reviewers, we have now added a section entitled “Methodological approach” and here we have justified our use of focus groups and included references to this data collection method.
Data analysis

3. Interfaces and functions are different among NVivo versions. Please specify the version of NVivo which the authors used.

Version 11.4 was used. This has now been included in the text.

4. I think references for the methodology of analysis should be added, too.

Thanks. We used a grounded theory approach to data analysis and have included references to this under the “Methodological approach section”.

5. I think it is critical to eliminate prejudices of researchers for qualitative analysis. If any methodology was used for prevention of confirmation bias, please write it.

Yes, we agree. We have inserted the following text: “The first and second author, who did the majority of the data analysis, come from different cultural and language backgrounds, providing opportunities for rich discussion around interpreting the data. It is important to engage in reflexive practice to improve the credibility of qualitative research and reduce confirmation (Altheide & Johnson, 2011). To achieve this, the facilitator and co-facilitator compared and discussed their field notes after every focus group. Referring back to these notes during the analysis ensured that the findings remained grounded in the data.”

We also carried out participant validation which is also explained in the data analysis section – now in a bit more detail.

Limitations of approach

6. I think it is better to insert this section into discussion.

Thanks, we agree and have moved this to the discussion section.
Results

7. I recommend tables which show demographic variables of each focus group (e.g. sex, age, languages, duration of time, number of participants) should be included in Methods or Results section.

Thanks. We have inserted the table as indicated.

8. Explanation of excerpts should be written for readers who are not familiar with qualitative researches. e.g. Excerpts are written in an italic type and FG or FG1 means the identification number of each participant.

We do not think that explaining excerpts is necessary as it is quite clear that the excerpts are quotes from participants – this is standard practice, not only in qualitative research but the printed press in general. With the table that now describes each focus group as Sea Point FG1, Khayelitsha FG 2 etc. readers should now understand that this refers to the focus group that the participant being quoted participated in.

9. How about explaining an outline of results in the first paragraph of results section (before Health service use). It may be helpful for readers to grasp the comprehensive image of results.

Thanks, good idea. We have now added this.

10. I recommend the authors explain "medical aid" for the readers. Those who live in South Africa will understand the meaning, but others might not comprehend it.

Medical aid is a local term for health insurance. To avoid confusion for international audiences, I have changed this to “health insurance”, which is also commonly used in South Africa, in the text.

11. I think the following sentences be put in Discussion, not in Results. For me, the sentences are not results which emerged from only this analysis.
From "In their study of (p14)" to "by the doctor" (the bottom of p14).

Agreed. We have incorporated this into the discussion section.

12. I felt senior's clubs had very important role in management of community care. How about making another category for explaining the role of senior's clubs. In this manuscript, it is written in the paragraphs of "perceptions of treatment by healthcare workers", but it is not suitable to explain the role of senior's clubs.

Yes, we agree. We have now moved this information to a new section entitled “The role of seniors’ clubs in facilitating access to services” and slightly expanded it.

13. In addition, the paragraphs of "perceptions of treatment by healthcare workers" are too long and contains various themes. How about splitting them into some categories?

We have now created a number of additional sub-headings to help make this section more clear.

Discussion

14. It is good to write limitations and future researches in the Discussion section.

Thanks we have moved limitations to the discussion section and added the need for future research in the conclusion section.

15. I think difference of health literacy among each population may influence on the results. How about discussing it?

We agree with you here, but we did not gather data on level of education or health literacy specifically and we would only be making assumptions about level of health literacy based on socioeconomic status, which might not be accurate. We have therefore decided against including this.
Catherine Tong, PhD (Reviewer 2): Thank you for the opportunity to review this paper. The authors provide a thoughtful analysis of multilingual data collected with diverse, difficult-to-access older adults, and their efforts should be commended. Below, I provide specific edits and questions, which I believe would improve the clarity of this manuscript. In addition to these specific comments, this paper lacks a theoretical framework and/or positioning. Perhaps tapping into the "person-centered care" literature in both the introduction and discussion would ameliorate this.

Abstract

Line 5: as people age, they may have different health needs to younger people.

- "may" is incorrect. They most definitely have different needs. Also, there is a word missing. Perhaps "different needs compared to younger people"?

- Also, "as people age… people are "aging" from the day they are born. It would be more accurate to write "older adults" or "older persons"

Thanks. This has been corrected in the text.

Line 7: community-based care and primary health care. In this sentence these two systems of care are presented as similar, but in many countries community-based care and primary health care are two very different systems of care, one delivered by physicians (primary care) and one delivered by paraprofessionals (community-based care). Please consider revising to make clear that in South Africa, community-based care includes primary health care, if this is indeed the case.

In South Africa most primary health care is provided by trained health workers, but community health workers connected to primary health clinics and NGOs also provide complementary primary services health services within communities. In this paper we are referring largely to care provided by nurses and doctors and have therefore removed the reference to community-based care from the sentence.

Line 38: "Patients who received more patient-centered care had more positive perceptions of healthcare providers and the quality of care they received." It is not surprising or particularly insightful that people receiving person centered care have more positive perceptions of their care.
Are there any other key findings that you could tease out of your data to shine a light on any new knowledge that your study generates?

Background:

Page 3, line 43. For a reader unfamiliar with the term 'coloured' as opposed to 'black', could you please distinguish the two. Also, is the term 'coloured' appropriate in the South African context? For international readers, for example in the United States, this is a highly racialized charged term that one would not use.

In South Africa, the term ‘coloured’ refers to the ethnic and cultural group made of persons of mixed-race, Khoi or Asian descent. The term emerged as a result of apartheid classification system, but is still commonly used today and is not considered to be pejorative. ‘Cape Coloureds’ are the largest population group in the Western Cape, the province where the study was carried out. The term connotes a specific cultural identity and set of demographic characteristics to the other large population groups (black African, white and Indian). We have added an endnote clarifying this, but don’t think it is appropriate to use another term.

Page 3, line 48. This is the end of a long sentence. 73.5% of which group is on medical aid, whites or non-whites? It isn't clear.

This has been clarified in the text. We have also now used the term health insurance instead of medical aid to make it clear that whilst there is good health insurance coverage amongst the white population, few black and coloured people have coverage.

Page 6, line 2. The sentence "Few of the studies that do exist are focused on community-dwelling adults, which comprise the majority of older persons [10, 23, 40, 42]" is not clear. Please revise.

This has been revised in the text.
Page 6, line 15. The statement... "and also demonstrates the stark income-related disparities that exist in terms of access to and quality of care" is more of a result/discussion point, please consider moving to a later portion of the paper.

Thanks for this. We have moved this statement to the discussion section.

Subheadings- Before 'Research Setting' consider adding a higher-level heading for METHODS.

We have added this additional heading.

Page 6, line 35. You note that Sea Point is largely English speakers. Are they also 'white'? (The other two sites list both the predominant language and race).

Yes, it is a predominantly ‘white’ English speaking area. We have added this in the text.

Page 6, line 45. Could you provide some sort of statistic or perhaps a USD or Euro equivalent of R1600, to give international readers a sense of how much money/purchasing power this is?

Have done this.

Page 7, line 1. As I'm sure you are aware, there are a multitude of established approaches to qualitative research. Which qualitative traditions informed your approach to data collection analysis. Please be more explicit about the type of qualitative research you used, your epistemology and approach to the data. If this was a 'generic qualitative study', or 'non-categorical' qualitative study, please say so, with appropriate references.

We have now included a section entitled “methodological approach” which has provided further details on our epistemological approach. Our approach is rooted in constructivist grounded theory.

Page 7, line 49. Earlier you note that this analysis was part of a larger study on "people's experiences of ageing in these communities". Were the 60-90 minute focus groups dedicated to the topic in this manuscript (experiences of the health care system) or were these focus groups
focus on the broader topic of "experience of ageing". If the later, approximately what percentage of the focus groups were dedicated specifically to discussions of the health care system?

The focus groups were focused on experiences of ageing, but many of the questions were focused on health systems experiences and most of the discussion centred around this. Based on data collected, we would estimate that after introductions about 50% of time was focused on health systems issues, but this obviously varied between groups, with some spending more time on it than others. This has been added in text.


All focus groups were transcribed in the original language and then translated into English. To ensure the accuracy of translation, translations were carried out by the focus group facilitator and checked by the co-facilitator, who was also present during the focus group and therefore aware of the conversational content and context. This has been added in the text.

Page 8, line 8. This is the first mention of field notes. When did the authors complete field notes? (During the focus groups? During analysis?)

Field notes were taken during the focus groups and additional thoughts and experiences of facilitating the groups were made directly after the focus groups. Both the facilitator and co-facilitator took notes. This has been clarified in the text and we have also clarified that a facilitator and co-facilitator were present during each focus group.

Page 8, line 8. Which version of NVivo, please. Also, please provide references for open coding and thematic coding.

Version 11.4.0 was used. This has been updated in the text and references have been added.
Page 8, line 16. How and when were findings shared with community partners? Verbally? In a report? In a Powerpoint presentation? And did their feedback impact the findings in any way? Were the findings shared during the analysis or after the analysis was complete? More detail please.

Feedback sessions occurred once the first draft of the paper had been developed. This was done via Powerpoint presentations. The purpose of providing feedback to improve the credibility and validity of findings and to disseminate findings to stakeholders to use for advocacy and clinical/community work. We have now provided more information on this process in the text.

Results

Page 10, line 8. Could you please (either here, or earlier at the first mention of Medical Aid) provide the reader with a bit more information on what Medical Aid is in South Africa (it connotes different things in different countries).

Medical aid is a local term for health insurance. To avoid confusion for international audiences, I have changed this to “health insurance”, which is also commonly used in South Africa, in the text.

Page 14, line 47. I appreciate that you invoke some literature that examined the experiences of workers here.

There are very few quotes from the Sea Point focus groups and perhaps an over-reliance on quotes from the Khayelitsha FGs. Could you balance this out a bit, please? Or, alternatively, be more explicit about which themes relate to which FGs (most themes appear to relate to the poorer, non-White focus groups- is this the case?)

The most interesting and relevant data emerge out of the Khayelitsha and Lotus River focus groups because these groups are poorer use the public healthcare system which provides a significantly lower level of care than is available in the private sector. We have tried to balance out quotes by inserting more from Lotus River. Sea Point data serves to highlight disparities of
care, but also shows that even in private care geriatrics may struggle to get affordable, age-friendly care. We have inserted a few quotes to this effect. We have also tried to include more quotes from male participants.

Discussion & Conclusion

Overall the discussion is well-written, adequately referenced, and reflective of the results.

Page 20, line 25. The following is more of a 'result', please consider removing from the discussion and adding to the results. "For example, some patients wanted x-rays for diagnostic purposes when they were perceived as unnecessary by doctors, or expected electrocardiograms (ECGs) or blood tests as part of general health checkups, seeing their inability to access these services as denial of care."

Thanks we have moved this to the results section under the “Perceptions of treatment by healthcare workers” heading

There are many references to 'patient-centered care' throughout the paper, but no definition and few references. Please provide a description of what you mean by 'patient-centered care' with additional references to this established body of literature.

We have now included a definition and discussion of patient-centered care in the discussion section.

Barbara B. Cochrane, PhD, RN (Reviewer 3): 1. This manuscript reports on a focus group study of the experience of older individuals' experiences with primary care from three areas of Cape Town, South Africa, representing three levels of income. Strengths of the manuscript include the inclusion of diverse perspectives during data collection and the comprehensive literature reviewed. Weaknesses include limited methodological details or indication of the particular qualitative approach used; confusing/inconsistent flow and terminology in some places; and a
need for citations to support some claims in-text. More detailed comments about these and other considerations are included below.

2. The Abstract "Conclusions" (line 40) are not quite consistent with the Conclusions in-text (page 21). In addition, the Abstract Conclusions indicate that "the paper shows the importance of developing systems ...", but I think it would be more accurate to say that the findings "suggest" this.

Thanks for this comment. We have now used the word “suggest” rather than “show” in the abstract. We have also worked to better align the conclusion section with the conclusion section of the abstract.

3. There should be a design statement at the beginning of the Methods section. To say that the design is "qualitative" is not really sufficient, particularly given there is no citation on page 6 or 7 (or page 8, where the text on line 11 indicates that data were coded "thematically") to indicate which qualitative paradigm (e.g., phenomenology, grounded theory, content analysis only) provided the methodological underpinning for this study. See also #X, #XX.

Thanks for this useful feedback. We used a constructivist grounded theory approach but were hesitant to state this as we did not apply it in a strict sense, in that we did not use a process of theoretical sampling during recruitment or continue to carry out research until theoretical saturation was reached. However, we did not start with a particular theoretical framework and rather allowed the data to speak for itself, we used the principals of coding and constant comparison and did add additional probes to flesh out emerging categories in successive focus groups. We have now explained our approach more in the design statement and added citations from the grounded theory literature.

4. In what ways were focus group participants "purposively selected to ensure diversity"? Are you referring to the choice of seniors groups or did you choose specific participants from within the seniors groups (such that, presumably, some were turned some away if they did not add to the diversity of the sample)? With this purposive sampling, how is it that there were so many more females - e.g., does that reflect the membership of the seniors groups from which you recruited?
Purposive sampling was carried out through both the selection of sites and through the selection of participants within groups, but the selection of seniors’ clubs was determined by which NGOs operated in the areas and their willingness to assist. For example, there is only one Seniors’ club in Sea Point and Lotus River, whereas there are many such clubs in Khayelitsha, where the need for support is much higher given the high levels of poverty in the area. In Khayelitsha, we were therefore able to also sample in terms of the kinds of services people received (on-site clinic, healthcare support or no services). The selection of the three different areas was purposive as the neighbourhoods acted as a proxy for income, racial and cultural diversity. Within seniors clubs, we also selected participants to include diversity in terms of other factors that might affect health needs such as living arrangements. We made sure to include as many males as possible, but the lower number of males in the study reflects club membership (the majority of members seniors’ clubs across Cape Town are female, partly because of the larger number of older females and because of club activities) and possibly also because of willingness to participate.

The limited representation of men in the study is obviously a limitation and we have now included this in the limitations section. No one was turned away from the study by our sampling, rather we worked with health social workers at the NGOs, who had a good idea of the socio-economic backgrounds, functional capacity and living arrangements of participants, to help us select appropriate people to approach about participation. In the independent group we did not have this information available and anyone willing to participate was included.

5. The decision/rationale for collecting data via focus groups (rather than interviews, for example) is not stated clearly. In fact, the use of focus groups seems to be introduced incidentally (page 7, line 11), with subsequent text moving on to recruitment strategies and the conduct of the groups. The limitations text on page 9 (lines 8-16) identifies confidentiality concerns related to focus groups, despite their value in "gathering a variety of perspectives and generating debate", but if these points tip the balance in favor of a focus group approach, that rationale should be more clearly linked to the purpose of the study and included earlier in the Methods section. See also #XX.

A discussion on the rationale for using focus groups has now been added at the beginning of the methods section.
6. I think it would be helpful to identify the questions (or a representative sample) that were asked during the focus groups. This would help the reader understand the linkage between the study aim, methods, results, and conclusions. The text on page 7, lines 50-52, just indicates that "broad questions aimed at promoting discussion" were used.

The questions from the focus group guide relevant to the data presented have now been provided in Table 3. The nature of focus groups means that much of the discussion was generated from the responses of participants, as well as additional probing by the facilitator rather than the questions, but hopefully this will provide some indication of what was asked.

7. The Data analysis section on page 8 indicates that findings were presented to community organizations. Was this strategy used to obtain feedback and potentially revise the themes/theory being uncovered (which might be consistent with grounded theory or narrative analysis methods of constant comparison/member checks … see #XX)? If so, what feedback was received and/or revisions made to the reported themes/findings based on this feedback?

Feedback sessions occurred once the first draft of the paper had been developed. This was done via Powerpoint presentations. The purpose of providing feedback to improve the credibility and validity of findings and to disseminate findings to stakeholders to use for advocacy and clinical/community work. We have now provided more information on this process in the text.

8. Characteristics of the populations within the three geographic areas are included. However, I could not find a clear description of the participants in the study. I think such a description (e.g., in table form) would be important to include in the Results, given participants were "purposively selected" to maximize diversity (#XX). Information on gender and overall age range on page 7 was included, but additional information (e.g., living arrangements) could be tabulated for the participants overall without compromising confidentiality (a concern identified on page 8, lines 38-43).

Thanks. We have inserted a table (Table 3) which provides more information on the participants.

9. The study aim, identified on page 6, was "to understand older person's health needs and their experiences of primary healthcare services in their communities." However, the Results section
does not clearly address that aim - at least not initially. The Results on page 9 goes right to a subheading, "Health Service Use". Some introductory text that frames the Results relative to the study aim would be important.

Thanks for this. We have now included a paragraph introducing the results section.

10. The findings reported on page 10, under "Access to services …," are concerning, given the system breakdowns identified. I think a closer link to the data - i.e., 1-2 quotes - would offer more compelling evidence for these findings.

On re-reading this section we realised it was more of a summary of findings explained in sections below. This text has therefore been moved up to the beginning as part of a research summary section recommended by another reviewer. The other sections have been moved around and more sub-sections have been added, as well as more quotes used as supporting evidence.

11. There are some statements/claims that would warrant a supporting citation. For example:

a. Background (page 3, line 13) - while it might seem obvious, a supporting citation would be appropriate regarding how building services and supports are "crucial" for reducing frailty and institutionalization (also note that a period is missing at the end of the sentence).

Thanks a reference has been inserted.

b. The Data Analysis text on page 8 indicates that data were coded using open-coding and then re-coded thematically. No citation is offered to support this approach, and analytic strategies for qualitative studies (and the meaning of terms like open-coding and thematic coding) can differ somewhat depending on the specific qualitative approach (and its philosophical/methodological underpinnings). See also #XX.

Thanks. Please see earlier response regarding the use of a grounded theory approach.
12. The use of some terms might confound a reader's understanding of the research report. A key term that is unclear (for this reviewer from the US) is the use of "coloured" people - which is not an acceptable descriptor in our country. I think it would be important to offer an appropriate context and definition for the use of this term. A few other examples of questions about terminology:

We understand your concern here. In South Africa, the term ‘coloured’ refers to the ethnic and cultural group made of persons of mixed-race, Khoi or Asian descent. The term emerged as a result of apartheid classification system, but is still commonly used today and is not considered to be pejorative. ‘Cape Coloureds’ are the largest population group in the Western Cape, the province where the study was carried out. The term connotes a specific cultural identity and set of demographic characteristics to the other large population groups (black African, white and Indian). We have added an endnote clarifying this, but don’t think it is appropriate to use another term.

a. Participants in this study are community-dwelling older adults, and the interviews did not occur in the clinical setting. Therefore, it is confusing to identify participants as "patients" in some places (e.g., Abstract line 38; page 4, line 1).

We have changed the word “patients” to “participants” where appropriate in the text.

b. The Abstract "Results" (line 29) indicate that services in lower-income areas were *significantly* less responsive. For this qualitative report, I would recommend a different choice of terms than "significantly," which has a clear statistical meaning in research.

Thanks for this. We agree and have changed the wording to “much less responsive”

c. The statement on page 4 (lines 1-8) addresses individual and "supply side" factors influencing health care access. The meaning of "social capital" and "human capital" (e.g., how they differ from other factors listed) are unclear. The reference cited to support this statement does not fully address these factors (nor does it use these terms).
We have inserted references that refer more directly to social capital and described its influence. Human capital may in fact not be an appropriate term and it has been removed.

d. What is the referent for "non-NGO group" on page 7 (line 16)? I'm assuming the text refers to the focus group in Khayelitsha (not run by the four Cape Town-based organizations), but its characterization as a non-NGO group is unclear (e.g., not all organizations are NGOs, but are you saying that the Cape Town-based organizations *are* NGOs?). Although "NGO" is a well-known acronym, it still should be defined the first time it is included.

Thanks. Non-NGO is indeed unclear. We have now used the full-term non-governmental organisation in the text. We have now referred to the “non-NGO” group as the members of the independent seniors’ club in the text.

13. The flow of text is a little confusing. For example:

a. The "Setting" (page 6) is described before the Methods section.

b. "Limitations of approach" is included on page 8 of the Methods section, rather than the Discussion where such considerations are usually addressed.

This section has been moved to the discussion

c. Some of the text included under Results (e.g., page 14, lines 36-44 [note that three citation numbers are included here]) links study findings to other literature, which would be more appropriate for the Discussion section. If you have included this information as "Results" to convey elements of constant comparative analysis (e.g., an approach used in grounded theory), then I think the Methods text should indicate that a grounded theory approach was used and that data analysis involved constant comparison. See also #XX.

Yes, as noted in responses a grounded theory approach was used.
The Conclusions section on page 21 seems to focus on "Implications". For example, the text identifies the need to "increase the number of healthcare workers to address demand-side challenges to care." However, there is insufficient evidence provided to support such policy change at this point (e.g., considerations are more complex than just participant perceptions). See also #XX.

The severe shortage of healthcare workers and its effect on healthcare service delivery is one of the largest limitations on the provision of adequate and responsive care to all groups in South Africa, but older persons in particular. Further discussion related to this has been provided.

14. The formatting of references is not consistent and - in particular - the source information is sometimes limited, which presents a challenge for the reader who might want to confirm or understand more about a reference.

Thanks. This has been addressed.