Author’s response to reviews

Title: The need for improved cognitive, hearing and vision assessments for older people with cognitive impairment: A qualitative study

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Editor, BMC Geriatrics

Dear Dr Cassady-Cain,

Re: Our submission to BMC Geriatrics - BGTC-D-19-00017 "The need for improved cognitive, hearing and vision assessments for older people with cognitive impairment: A qualitative study"

Thank you for the opportunity to re-submit our manuscript. The reviewers made several important suggestions, all of which we have carefully incorporated into our revised manuscript. We have also made significant changes to the language and writing style, which we believe has
resulted in a much improved manuscript. We have also tightened up the abstract to more accurately reflect the content of the paper.

Finally, please note that we have made some changes to the order of the authors to more accurately reflect the relative contributions of the respective authors. We are in the process to complete the necessary form for this.

We hope you will now find our manuscript ready for publication in BMC Geriatrics. We have outlined our changes point-by-point below and highlighted all changes in the manuscript itself.

Sincerely,

Lucas Wolski and Iracema Leroi

Reviewer reports:

Claudia Jacova (Reviewer 1):

This qualitative study focuses on the experience of persons with dementia (PwD) and their caregivers of hearing, vision, and cognitive assessments. The authors make a good case for the need for such a study: it is clear that sensory and cognitive impairments interact, and all need to be addressed in order to ensure the best possible disease trajectory in neurocognitive disorders. I also appreciated the need for qualitative data, with perspectives obtained from both PwD and their caregivers. Finally, the multisite nature of the study is also a strength.

• Thank you for acknowledging the value of our study and the importance of the multi-site and qualitative aspects of our design.

However, there are also weaknesses that the authors should address to make the manuscript suitable for publication.

• We have worked hard to address all the highlighted issues as well as correct any other concerns that we picked up after our first submission.

The writing is often unclear, and this is not so much a problem of writing in English as it is conveying the themes that the authors have identified.

• We have revised the entire manuscript for clarity of expression to ensure that the themes are informative and accurately reflect the content of each section. *[please note – the line references are no longer accurate due to the changes in the manuscript]*
For example, in describing the results, lines *246 to 250, it is difficult to understand what exactly these themes are.

The headings are not very informative either, for example lines *252-53: here the heading refers to the PwDs knowledge of the assessment, and then specifies differences regarding impairments and the use of corrective devices. What differences are these?

There is a very interesting finding of reluctance among PwDs to have assessments done at their own home. However, this is then mixed with the proper cleaning of what I assume are hearing aids. Lines *368 through 372 are really difficult to understand because there is now mention of training and support services rather than strictly assessments.

- We have reworked this entire section and it now expresses the themes more clearly and any ambiguous statements have been removed [please see entire section, lines 271-455]

There was purposive selection of participants in order to ensure a representative range of sociodemographic characteristics and disease severity. However it is not explained how this was done, particularly given recruitment problems mentioned later on in the manuscript. One of the inclusion criteria was self-reported sensory impairment among PwDs, but in Table 2 one of these participants is described as Not Reported.

- We have more clearly explained how the purposive sub-sample was selected

- Participants were recruited over a three-month period from memory, audiology and vision rehabilitation clinics (community and university-based) at each of the three sites. We undertook a purposive selection of participants from consecutive clinic attendees (between September 2016 and November 2017) to ensure a representative range of sociodemographic characteristic (gender, age, education level) and stage of dementia (mild to moderate). Inclusion criteria for the participants with dementia were: age over 60 years, having an established diagnosis of dementia (due to Alzheimer’s dementia, vascular dementia or a mixed type), in the mild-moderate stage, able to speak and understand the local language of the site, and, have self-reported hearing or a visual impairment severe enough to interfere with their activities of daily living. Older adults having an unstable, acute or current psychiatric or physical condition severe enough to prevent them from participating in the study, as determined by the investigator, as well as complete blindness or severe visual impairment or deafness (profound hearing loss), were excluded from the study. Inclusion criteria for care partners were: age at least 16 years; being the primary person responsible for unpaid support/care for the PwD at least four hours per week in the community; willing to be a co-participant in the study; and able to speak and understand the local language of the site.

- The ‘not reported’ point in Table 2 was corrected to read ‘not recorded’; all participants met inclusion/exclusion criteria, which included self-reported hearing and /or vision impairment, which would have been captured at the time of screening and consent.
It would also be important to report disease duration, or time since diagnosis, so that the data can be interpreted more meaningfully.

- This is an important point and one which we have partially addressed in our revision by clarifying that all participants with dementia were in the mild-to-moderate stage of the condition and had clinical symptoms for at least three years' duration. We have added this to the manuscript. Due to the nature of the study design, participants self-reported their diagnoses and thus we were not able to capture accurately duration of symptoms not time since diagnosis and thus did not report it. For this type of qualitative study, which focused on participants' subjective experiences, such information does not contribute much to the interpretation.

The questions used during focus groups and semi structured interviews appear clear in Table 1 but in the text the focus is somewhat different, and centers around the impact of visual, hearing, and cognitive impairments on the lives of PwDs and their caregivers. These two foci are somewhat different.

- We have corrected this issue so that the questions in the text and in Table 1 are fully aligned and tell a consistent story. We have done this by providing more detail of the questions of the interview topic guide in the text and removing table 1 (which became redundant). We believe it is now clearer, as below:

- ‘Content of the guide: The main foci of interest related to the experiences of participants when undergoing cognitive, hearing and/or vision clinical assessments in the recent past, including whether the assessments provided them with sufficient information, and, for care partners specifically, whether the assessment helped them to support the PwD. We were also interested in exploring participants’ (PwD and care partners’) perceptions, knowledge and understanding of the of the clinical assessment process. Additionally issues related to the clinical assessment of cognition, hearing and vision problems in context of comorbidity were also elicited. This was considered to highlight the gap in knowledge, understanding and availability of appropriately validated clinical assessment tools available for PwD and concurrent sensory impairment (Leroi et al. 2018; Pye et al. 2017). The facilitators posed the questions in an open-ended manner, followed by probes to elicit more detailed information, particularly related to barriers and facilitators to effective and informative assessments.’

One of the most significant issues that the authors acknowledge to some extent, is asking PwDs about their perception of the various assessments. It is absolutely important to obtain insight into the experience of persons with dementia, the approach the authors take relies very much on PwDs recall. It might have been much better to interview the patients directly following a specific assessment.

- The Reviewer is entirely correct and makes an important point. Ideally, we should have recruited participants directly following the respective assessments, rather than relying on recall. However, we were unable to adopt this approach since so few PwD in each of the three countries were receiving sensory (particularly hearing) assessments that we would
not have been able to meet our recruitment targets on time. Thus we opted for a pragmatic approach of recruiting people with self-reported problems who had had received such assessments in the past. This is a limitation of our study and one which we have added to the discussions, as below:

• 'There are certain limitations of our study which we must acknowledge. Firstly, we were unable to recruit participants directly following their different assessments, thus, particularly for PwD, they may not have had been able to remember all the details of the assessments they had received. Nonetheless, both PwD and care partners appeared able to express their views in detail and it is likely that the most salient features would have come to the fore.’

Also, the approach appears to treat sensory and cognitive assessments as similar and comparable, but this would have been a very good point to address in the interviews. Are they experienced similarly? Do the perceived weaknesses in one type of assessment apply to other assessments?

• We acknowledge this annotation. Problematically often it is not easy to find suitable participants (especially in this population) that are willing to talk freely and share their experiences in their own words with a bigger audience. Sure, there is a difference in assessing hearing, vision or cognitive problems. In the FGs and SSIs each of the impairments was addressed separately. Unfortunately they weren’t able to figure out all the things that had happened during their individual assessment (due to the cognitive impairment – but even the care partners couldn’t describe what kind of procedures were conducted). Only a few could state what has been done (they had problems to find the right words, due to their cognitive impairment). Besides, participants reported that having hearing problems is perceived differently than having vision problems (e.g. glasses are socially accepted compared to hearing aids). Accordingly PwD rather tend to go to an audiologist and ophthalmologist, than a psychologist or psychiatrist to have their cognition checked.

The overall contribution of the study is somewhat unfocused: the authors call for better communication on the part of health professionals, better education of caregivers, better inclusiveness of patients, but these recommendations seem quite generic and would probably apply to any type of care provided to PwDs and their caregivers. It is difficult to extract from this specific guidelines that may help with future vision, hearing, and cognitive assessments.

• We have now made the recommendations much more specific and more useful in guiding clinical recommendations. These are listed in detail in the Discussion section and are bolstered by relevant references.

The discussion does not provide a lot of connections with existing literature on the subjective experience of assessments among patients. There is a small body of studies on the experience of cognitive screening that the authors should consult. I am not sure whether any studies have been done on the patients' experience of vision and hearing assessments but whether or not, this should be clearly stated.
We have re-examined the literature to address this point and indeed have found little previous reports that tend to capture the subjective experiences of assessments of people with dementia. Molony et. al (2018) for example state that it is important to focus on a person-centered assessment. There is a literature regarding people without dementia and we have now made reference to this to enhance our discussion. Currently there is no findings that reflect upon subjective experiences of PwD with vision or hearing loss that have undergone an assessment.

Andrea Tales (Reviewer 2):

This is a very timely and important area of research. The authors highlight and investigate a very real issue with respect to dementia diagnosis and care.

Thank you for acknowledging the value of our study. We agree that our report is timely and that identifying and assessing hearing and vision impairments in PwD is a significant unmet need that the clinical community needs to address.

There are however several instances where the information in the manuscript lacks clarity and depth. The apparent importance of the findings and thus their impact would be greatly improved by a more in-depth discussion of what was investigated and why and what the findings might mean.

Thank you for pointing this out. We have addressed this issue throughout the manuscript, particularly in the discussion, including the specific points made below. We believe the importance of our findings and their impact is now greater and will be of interest to readers.

Methodology: There is a lack of clarity re. the rationale

We have clarified the rationale for the study more succinctly, in the following way:

‘The primary aim of the EU-funded SENSE-Cog research programme (www.sense-cog.eu) is to explore these and related issues in more depth. This will provide a basis on which to develop a support care intervention for PwD with concurrent hearing and/or vision impairments. … The findings from this study have informed a program of adaptation of assessments tools for people with dual or triple impairment (i.e. Dawes et al.), as well as clinical practice guidelines for clinicians and care workers across the three domains.’

Methodology: There is a lack of clarity re. the organisation and the carrying out of the focus group; the authors mention focus groups but there is a lack of clear information about who was included in each group.
• We have added significantly more detailed about the specific conduct of the Focus Groups and the type of participant in each, to satisfy this point. We believe our Methods are now much improved.

• ‘The facilitators and support team for the PwD all had experience of working with older PwD and sensory impairment, and we aware of the objectives of the study and the research questions. The interviews followed the interview topic guide and were conducted according to Witzels (2000) problem-centred interview methodology. The focus groups (FGs), opted for by all participants in Manchester (n=8 PwD; n=6 care partners) and some participants in Nicosia (n=5 PwD; n=5 care partners). Using the same interview topic guide as the FGs, home-based semi-structured interviews were conducted with a further group in Nicosia (n=3 PwD; n=3 care partners), and Bordeaux (n= 5 PwD; n=5 care partners). The interviews lasted about two and a half hours, following the consent signing process. The facilitators asked participants to introduce themselves, and then explained the purpose of the FG’s/SSIs and explained the conduct of the procedures. Each PwD was supported by a study assistant experienced in working with older adults with dementia. If at any point a participant wanted to leave the room or be with their care partner, this was facilitated. This occurred on one occasion with a single participant at the Manchester site. ‘

Also the authors then discuss dyads...how do these relate to the focus groups and the methodology...this section is rather unclear.

• We have removed any mention of dyads since we conducted the Focus Groups for the PwD separately from the care partners, thus the findings did not relate to their dyadic state (as it does in other studies we have conducted). In some cases, our PwD participants had care partners who were also participants, but this was not the case for all participants. Additionally, we added a rationale and citation for the study sample size, although this was not requested by the reviewer: The sample size of the study (n=18 PwD and n=15 care partners) was likely sufficient to capture all emerging themes, as data saturation (rather than ‘theoretical saturation’) was likely to have been reached. According to guidance, if participants are relatively homogeneous (e.g. as in our case, in which participants all fell within a single diagnostic spectrum and had a close age-range), then a purposive sample size approaching 12 will make it possible to ‘render a fairly exhaustive data set’ (Julious, 2005). The sample size also goes in accordance with Bamford and Bruce (2002), who have described a study with fifteen older people with dementia where formal focus group discussions took place with four to nine PwD. In the qualitative context, data saturation is not about the numbers per se, but about the depth of the data (Fusch and Ness 2015).

It would also help clarity if the inclusion and exclusion criteria appeared in the same section.

• We have clarified the inclusion/exclusion criteria for both the participants with dementia and the care partner participants. As below:
Participants were recruited over a three-month period from memory, audiology and vision rehabilitation clinics (community and university-based) at each of the three sites. We undertook a purposive selection of participants from consecutive clinic attendees (between September 2016 and November 2017) to ensure a representative range of socio-demographic characteristic (gender, age, education level) and stage of dementia (mild to moderate). Inclusion criteria for the participants with dementia were: age over 60 years, having and established diagnosis of dementia (due to Alzheimer’s dementia, vascular dementia or a mixed type), in the mild-to-moderate stage, able to speak and understand the local language of the site, and self-reported hearing or a visual impairment severe enough to interfere with their activities of daily living. Older adults having an unstable, acute or current psychiatric or physical condition severe enough to prevent them from participating in the study, as determined by the investigator, as well as complete blindness or severe visual impairment or deafness (profound hearing loss), were excluded from the study. Inclusion criteria for care partners were: age at least 16 years; being the primary person responsible for unpaid support/care for the PwD, at least four hours per week in the community; willing to be a co-participants in the study; and able to speak and understand the local language of the site.

On line 157 the authors state that 'inclusion criteria differed across sites' in what way did they differ?

We have clarified this point and confined the inclusion/exclusion criteria to a single part of the manuscript. We have removed the erroneous statement about differences across site – this was corrected to mean that the sample characteristics differed somewhat across sites.

Line 255...please can you explain and discuss in more detail what is meant by 'couldn't really explain what happened during assessment'

Line 259...what is meant by 'doesn't take the chance of taking further information'..mean? many such points need to be discussed in more detail...as do their potential relevance

Line 306 What does the 'plastic thing' refer to....it's difficult to understand the context for some of the examples given

Line 329 What is the difference between understanding and comprehension...what is the context for this?

Line 421 What do the authors mean buy the statement that 'care partners need to "reach out on their own"'

This is a similar concern as expressed above. We have clarified each of these statements in the manuscript and have revised the entire manuscript for clarity of expression to ensure that the themes are informative and accurately reflect the content of each section.

*[please note – the line references are no longer accurate due to the changes in the manuscript]. Please see the revised excerpt of this section in Reviewer 1 above.*
Is there information about how exactly hearing and vision problems impacted upon cognitive performance...I think there's a great deal of information here that's not perhaps reported at all or in enough depth in the manuscript.

• This is an extremely important point and we thank the Reviewer for raising this; however, addressing this issue goes beyond the specific remit of the study which was to address the experience of hearing, vision and cognitive clinical assessments from the perspective of PwD and their care partners. The nature of the interview schedule did not allow for detailed analyses of how sensory problems might have affected cognitive scores or the performance of cognitive testing. This will be addressed in a subsequent study.