Author’s response to reviews

Title: Giving permission to care for people with dementia in residential homes: learning from a realistic synthesis of hearing-related communication’

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Author’s response to reviews:

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Dear Dr Lopez Munoz

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Please find below our responses to the editorial and reviewer comments on this paper. Our responses beneath are in bold and red ink for clarity.

The changes to the manuscript and to Figure 2 have been made with track changes and we have also added marginal comments to indicate where possible the specific reviewer comment that we are responding to.

We trust that we have dealt with all the points raised but would be happy to make any further clarifications if required.

We have submitted the revised manuscript with track changes and the other files.

Yours sincerely

Brian Crosbie
Editorial comments:

1. Please label CMOCs as tables and reference them appropriately within the main manuscript.

All CMOCs have been labelled as tables and referenced appropriately in the text.

- Please rename supplementary files as ‘Additional file X’, and cite explicitly by additional file name in the manuscript e.g. ‘Additional file 1: Fig. S1’. Please ensure that if you have more than one additional file that they are cited in ascending order within the main body of text.

There is one additional file which has been labelled as such and submitted online.

- Please include a "Declarations" section title, consisting of the following sub-sections: Acknowledgments; Funding; Availability of Data and Materials; Authors’ Contributions; Competing interests; Ethics Approval and Consent to Participate. All of these subsections MUST be present.

The declarations have been amended in line as requested.

Reviewer #1:

Overall Comments: The paper is well-written and thought-provoking. It develops a theory using a seldom used 'realistic synthesis' approach to review literature and consider expert opinion concerning the complex situation of the management of hearing-related communication for people living in care facilities who have hearing loss and/or dementia. I enjoyed reading the paper. I have worked on this issue for over three decades and this paper prompted me to think about it in a new way. In particular, I found the CMOC and Figure 2 to be helpful. Nevertheless, the more I thought about these interesting ideas, the more I became convinced that the work as reported in the present paper is not as complete as it could/should be. It has not positioned the work in the most appropriate broader scholarly and health care system context. By starting with a focus on hearing, the literature search and the following realistic synthesis does not seem to connect well to the more mature broader literature on communication in this population and setting.

We thank the reviewer for the positive comments and we have addressed the specific comments beneath. The reviewer has then provided a list of suggestions and we deal with them together.

References: Clearly the authors have covered a wide inter-professional and inter-disciplinary literature, but it still seems to me that the paper overlooks some relevant works (examples listed
below). These works may have been missed because some are very recent and some very old. The older ones may have been missed because the term 'home for the aged' was used to refer to residential care (these terms vary with jurisdiction and have changed over time). More importantly, I suspect that the focus on 'hearing' may have resulted in the broader and highly relevant literature on 'communication' being overlooked. Some authors who have carved out concepts, theories and empirical research regarding communication, health and aging in fields such as speech-language pathology, nursing, socio-linguistics etc. are suggested below.

Work of Marie Savundranayagam (including the Gerontological Society of America documents that provide guidance for communicating with people who have dementia):

https://scholar.google.ca/citations?user=OoVV5IAAAAJ&hl=en

https://www.geron.org/publications/communicating-with-older-adults

Work of JB Orange on communication with people who have dementia: https://scholar.google.ca/citations?user=w5fGIQAAAAJ&hl=en

Work of Jeff Small on communication training for communication partners of people who have dementia: http://audiospeech.ubc.ca/faculty-staff/academic-faculty/jeff-small/

Work of Katherine McGilton on communication between nurses and residents in long-term care: http://katherinemcgilton.com/index.html

Work on audiologic rehabilitation in nursing homes by Ronald L. Schow (see also multiple editions of the text on AR edited by Schow & Nerbonne: https://www.semanticscholar.org/author/Ronald-L-Schow/4724275


We acknowledge there is a broader field of research discussing matters of communication in dementia. However, this really beyond the scope of the research being described in this paper, where we have concentrated specifically on hearing-related communication. We have as suggested made this clearer by removing any reference to 'hearing communication' which obviously suggests a much broader topic than that we have addressed in this review. We have already included two papers by McGilton and one by Schow that are directly relevant to our review, and we have added the suggested reference to the seminal paper by Pichora-Fuller.

Specific Comments:

Abstract: "hearing communication" seems odd. It is common to talk about "speech communication". Probably the most appropriate term would be 'hearing-related communication' (which the authors do use later in the abstract but not throughout the paper). Using 'hearing communication' fits if the focus is on problems arising from hearing loss in a unimodal world. However, for this population in this setting, it seems to be problematic not to accept upfront that communication is multi-modal (hearing, vision, tactile, smell) and that all modalities need to be optimized to enable the person with dementia to connect to their social and physical environment in the most meaningful way. See GSA documents on communication with older adults which foster this more comprehensive approach to communication that would apply to those who have dementia and/or hearing loss.
We acknowledge the multi-faceted nature of communication. Indeed, our study does narrow our focus on hearing-related communication. As mentioned, we have duly amended the text to specify hearing-related communication.

P 3, line 53: "more" compared to what? There are a number of places in the paper where comparative language is used without stating the comparator.

Thank you. We acknowledge this and have amended the wording in various places in the revised version.

Pg 4, line 55: I think the authors need to question the place of hearing aids in care, especially for this population within this setting. Many authors have argued for an ecological approach (consistent with the WHO ICF) within which the use of hearing aids plays a relatively minor role, with more emphasis put on modifying the communication environment (e.g., see work of Mary Beth Jennings: https://www.cjslpa.ca/detail.php?lang=en&ID=137).

We do not think we have over-emphasised the role of hearing aids. They are included as a part of the overall strategy for hearing-related communication but they are not an end in themselves.

P 5, line 25: reference 20 is to palliative care but this important detail is glossed over in the use of the reference in the text. Following the authors own emphasis on the importance of context, they need to be more careful to distinguish between types and degrees of dementia and the presence of comorbidities rather than making potentially misleading over-generalized claims. A principle of aging research is to acknowledge heterogeneity and it would be incorrect to assume that there was a single account for all people who have dementia and/or hearing loss or even that an individual would have the same needs over time.

Although the title of the paper in ref [20] mentions end-of-life, we suggest that all elderly residents with dementia in care homes are in receipt of palliative care and indeed many of them are already in the last year or so of their lives.
We have not distinguished between subtypes of dementia because there is no literature to justify this separation in this group of people. Again, the literature does not tell us much about the different degrees of dementia severity. We fully agree with the last sentence of this comment.

P 5, line 36: It seems that it would be useful to frame the important interactions of person and environment in terms of well-known gerontology theories (e.g., competence-environmental press) or even the WHO ICF. (for a review and general theory see Wahl, H.-W., Iwarsson, S., & Oswald, F (2012). Aging well and the environment: Toward an integrative model and research agenda for the future, The Gerontologist, 52 (3), 306-316.)

We have added this helpful reference (Wahl).

P 5, line 58: The authors state that they used the RAMESES quality and publication standards. However, most readers would not be familiar with RAMESES so it is not very helpful to claim to have complied with an unfamiliar standard, especially since there is no accounting of how exactly the present work was evaluated with respect to the standard. Does the present work meet all the criteria of RAMESES and if so how was this determined? I’m not sure what is actually unique about RAMESES since the elements of literature review and team discussion to develop theory do not seem to be new?

RAMESES is the agreed international quality standard for realist reviews. The first author of the open access RAMESES paper (Wong) is a co-investigator on this study so has provided expert advice on realist methods throughout. The study has adhered to RAMESES guidance. We think reference to the RAMESES paper is probably sufficient as it is open access for any reader wishing to learn more.

P 12. Line 2: See also work of McGilton

As mentioned previously, we have cited two papers by this author.

P 14, line 5: typo "fee" instead of "feel"

Thank you, corrected.
P 16 - it seems to be highly important to also appreciate the complementary use of vision by the high number of residents who will have dual sensory loss.

There aren’t many papers that focus on this, [46] being an exception so as an issue it has not highlighted in our analysis.

P 17 - If the authors want to focus on the concept of "permission" then it seems that this concept warrants its own literature review and a scholarly discussion comparing it to other prevailing concepts in the literature, including pertaining to communication with people who have dementia and/or hearing loss. There is some discussion in the paper about how 'permission' is compatible and likely necessary with the concept of 'patient-centered care'. There is mention of the staff needing to have 'authority'. I suspect that 'responsibility', the converse of 'authority', is also key yet the scope of professional responsibilities (duties) are not examined as carefully as might be useful. I appreciate the proposal of 'permission' as a factor in how health professionals fulfill their roles, but I don't think it is unique to communication with residents who have dementia and/or hearing loss. I wonder if the experience in the local settings where the experts worked may have been overly influenced by somewhat localized organizational challenges in the design of facilities and the delivery of care. Over the last decade, there have been many advances in the design of care facilities around the world and I'm not sure that the local experts were working in settings that are representative of the most modern practices. Perhaps the authors should present their study as a case study of the particular facilities they based their research on and also position the notion of 'permission' in a wider scholarly context including how it maps to the scopes of authority-responsibility for the various professionals? There is an enormous literature about the evolution of the notion of authoritarian vs. equalitarian approaches to clinician-patient communication in the literature on communication, health and aging (see classic works by authors such as Jon Nussbaum, Ellen Ryan, Howard Giles, MaryLee Hummert, Jo Ann Perry).

The reviewer’s comments about permission, authority and responsibility are cogent and worthy of future research. However, the scope, for example of a literature review of the concept of permission, is too wide for the present paper. Presenting our research as a case study would not be a reflection of the research that we have conducted.

P 18 - "causal connections, beyond our analytical claims that certain contexts are related to one or more mechanisms and caused certain outcomes." On the one hand, I find the "CMOC" approach to be attractive insofar as it seems to offer a logical way to guide care planning and evaluation. On the other hand, I have serious doubts that this cause-effect view could actually work, especially for the population and setting in question. It seems that it may be more appropriate to adopt a systems model that acknowledges that there are interactions that may differ dynamically depending on the, possibly moment-to-moment, fluctuations in the person-
environment fit. Processes may be more important than mechanisms. Dynamic adjustment of the system may be more important than somewhat static mechanisms. The over-arching goal of care may be to stabilize the person-environment balance for the person with hearing loss and/or dementia as demands fluctuate due to person and environment issues. How do the CMOCs drive goal-setting or vice versa? How would outcomes be evaluated to determine the success of care?

The reviewer appears to be describing two competing theories of change. Neither can be described as totally right or wrong. A strength of realist methods is that they can cope with a complex and dynamic situation. CMOs can be used in practice by examining what mechanisms contribute to producing desired outcomes. It is important to realise that CMOCs are contingent theories and thus susceptible to being modified in the light of changing evidence.

Pg 19, line 52 "This notion of permissive leadership chimes with McCormack et al (75), looking at person-centred care in general." See comment above about page 17.

See our earlier comment about permission.

Pg 20, line 2 "In addition, we believe this concept is potentially transferable, beyond hearing communication, to other complex care activities within the care home setting." I think the authors have the direction wrong - rather than it being the case that findings about hearing communication may generalize, it seems to me to be more the case that the broader culture of caring over-arches the shaping of the delivery of many forms of care, including hearing care. Indeed, this seems to be consistent with the authors comments about the importance of buy-in by organizational leaders and managers. It may be that communication is integral to multiple relationships in the circle of care. I think the authors could frame their work at a more optimal altitude.

Thank you, we have reworded this.

Figure 2 is key and needs to be explained in a caption.

Yes, we agree and we have added some explanatory text which is in the separately attached file for Figure 2.
Reviewer #2:

This is a well written paper on an important topic. The methods are clearly described, and the authors provide a clear description of how they developed the programme theory. I have some comments which are detailed below.

Thank you.

1. I would have liked some more detail about the content expert group. For example, how many members of the group were there; did they all attend the same meetings or were there separate meetings for different groups; what was the role of people with dementia and their family supporters? The authors say that there were seven meetings of the group (which sounds impressive) but did all members of the group attend all meetings?

Manuscript amended to give more clarity to the makeup of the context expert groups (numbers). And the input of carers within the group.

2. On the whole I think the data extraction and analysis processes are clearly described. However, I would have liked some detail about how the data from the excel spreadsheet (e.g. the salient results) were combined with or informed the data on the CMOs in Nvivo.

We have amended the text accordingly.

3. P5 line 2 - the studies were assessed for 'adequate rigor' - can the authors say how this was defined or judged?

The adequacy of rigor was as judged by the research team in compliance with RAMESES reporting standards. We have added this information to the text.

4. P10 - my understanding is that the authors included 12 papers on staff training that were not specifically hearing related but rather that provided opportunities for transferrable learning. There are clearly many papers that might be relevant to staff training in care homes - what was the criteria for including those 12 papers and not others?

Thank you, we have amended the text accordingly, explaining that there were very few papers specifically related to training about hearing-related communication, so we used reference lists from our core papers to identify a limited number of articles about more general aspects of communication training for dementia.
5. CMOC1 - I did wonder if there were really two ideas combined in CMOC1 - one related to PCC and leadership/modelling of PCC and the other relating to valuing staff. This is more of an observation than a request for a revision but I wonder if there is something about recognising the personhood of the staff as well as of the residents at play here.

Yes, we recognise that this could be divided but to us it appeared that there was a single important process, namely how the management gives permission for PCC to happen.

6. P15 - as supporting evidence the authors use a quote about the role of ‘genuine PCC’. I would have liked something more about this evidence. For example, what did that study mean by genuine PCC and how did it could compel staff to change their behaviour (e.g. what is the mechanism)?

Thank you. This was a slight error on our part in that this extract was not in fact a quote from that paper. We have therefore deleted it.

7. CMO1 and CMO3 both seem to address PCC. Is there unnecessary overlap between the two?

No, in a way this is the same question as comment 5. Our separation is about leadership and permission (CMOC1) on the one hand and staff getting to know the individual (CMOC3) on the other. Emergent properties of these two CMOCs are shown in Figure 2. All the CMOCs are in fact inter-related so that in a sense their boundaries are not hard and fast.

8. In the discussion the authors say that they envisage further work to refine the CMOs. I would have liked some suggestions about what sort of interventions might be developed and tested.

We have added that we think the next step would be a study to test the practical implementation of the five CMOCs.

9. A key argument in the paper is about the importance of permission. The authors refer to ‘their concept of permission’ and say that a previous review alluded to the concept of permission. I think that the previous review (Goodman et al) did more than allude to the concept of permission. It was quite an important part of the programme theory in that review. So the concept of permission in relation to embedding change in care homes is not new.

Text amended accordingly.
10. I noticed a few typos p2 line 1 - should be optimising. P4 line 24-25 doesn't make sense, p19 line 16 should be enable

We have corrected those typos (and a few others) where we have been able to find them.