Author's response to reviews

Title: The needs of people with dementia living at home: user, carer and professional perspectives

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Author's response to reviews: see over
Dear Editor,

Many thanks for forwarding the referees’ comments for our manuscript “The needs of people with dementia living at home: user, carer and professional perspectives” (MS:1550776711654946) We wish to submit a revised version of the manuscript.

We have made the changes requested by you and both reviewers as follows:

EDITOR

1. Please specify in the manuscript whether consent received was verbal or written.

We have specified in the manuscript the process for gaining consent (pp. 5-6): All participants gave informed consent. Once the interviewer was at the person with dementia’s or carer’s home, they answered any further queries about the Information Sheets and the study and sought informed consent as follows: written consent by signing a Consent Form was required from people with dementia and their carers. In order to achieve this, the interviewer approached them to explain the study again and to inform them about their right to withdraw at anytime. Some people with dementia (11, 7.3%) were unable to provide written consent. When this occurred, the interviewer sought their assent (verbal consent). During this process, the interviewer made sure that he/she had taken as much time and care in explaining the information about this research as simply as possible. The interviewer avoided using long sentences and attempted to reduce any distractions. To find out if the participants have understood the information given, the interviewer observed their ability to ask any relevant questions and also requested the participant to repeat back the information and how it would relate to them. In addition, the interviewer clarified any doubts about the study and reiterated their right to withdraw at anytime.

2. Please note that we are unable to display vertical lines or text within tables, no display merged cells: please re-layout your table without these elements. Tables should be formatted using the Table tool in your word processor. Please ensure the table title is above the table and the legend is below the table. For more information, see the instructions for authors on the journal website.

Tables have been formatted as required.

3. English language have been checked and improved.

REVIEWER 1 (Jill Manthorpe)

1. Add carer to key words

The word “carer” has been added to key words.
2. The opening sentence seems not too backed up by evidence. The references are not to policy and in fact do not refer to older people’s or dementia services. They are also rather dated.

Background (page 3): The opening sentence has been deleted and the references have been updated (References 2 and 3)

3. In referring to Hancock’s study and others where participants live in care homes, it might be better to refer to them as residents.

The words “participants” or “patients” have been replaced by “residents” throughout the manuscript when appropriate.

4. I think there needs to be some re-thinking of the term professionals. It is not clear that the psychiatrists and psychologists were acting in professional roles, or if they were interviewers who had these professional backgrounds (and why these and not others) and, in addition, these are very atypical professionals working with people with dementia. Some discussion of why these professionals were engaged on this task, the potential bias of this approach and the implications of their perspectives would be helpful.

The following text has been added to the Discussion (page 16): The CANE is primarily a clinical based assessment and a strength of this study was that all the researchers (interviewers) were experienced professionals in clinical psychology/old age psychiatry which is likely to improve the clinical validity of the results; previous work has shown that mental health nurses can also make accurate assessments.

5. What is the date of this study? (This needs to be in the text and abstract.)

The date of the study has been added to the Abstract (Method, page 2) and the text (Method, page 4).

6. I think there should be a reference for the claim that in the UK there is often a member of a CMHT for each person with dementia (and possibly a modification of this claim). Does the CMHT provide help and organise care? Only in some instances in my experience as there are eligibility criteria in many cases.

In the Discussion (page 12), the sentence referring to a member of a CMHT organising care for people with dementia in the UK has been rephrased as follows: However, van der Roest et al. [6] and Miranda-Castillo (unpublished data) found that carers reported memory as one of the most frequent unmet need. This may relate to differences in service provision between the countries as in the UK people with dementia often have access to a community mental health team whereas in The Netherlands and in Chile services may be less systematised. Alternatively it may be a result of UK participants being generally recruited from people with dementia known to services so that their memory needs had already been addressed.
7. I think the discussion could say more about the phrase ‘daytime activities’. This is an interesting umbrella term and might be further interrogated in terms of whether this means social interaction, physical activity, activities of daily living and so on. It also has subjective and objective overlaps with perception of isolation, loneliness and normalisation.

The first sentence in the Discussion (page 12) now reads as follows: The current study found that the most common unmet needs reported by carers were similar to those found in The Netherlands by van der Roest et al. [6] and in Chile by Miranda-Castillo (unpublished data), these being daytime activities (understood as any activity that allows the person with dementia to occupy self such as social, stimulation or leisure activities), company and psychological distress.

8. In summary, I think that this is an interesting paper in terms of the literature on unmet need and different perception of such. Some further development of the discussion would make this valuable to deliberations about commissioning, e.g. the cuts in resources such as social groups, day centres, and so on that will possibly reduce the option of daytime activities in localities. The paper could also reflect on the advantages of using clinical professionals to assess need and debate whether staff such as community nurses, OTs or social care workers might make other observations.

The following text has been added to the Discussion (page 16): The CANE is primarily a clinical based assessment and a strength of this study was that all the researchers were experienced professional in clinical psychology/old age psychiatry which is likely to improve the clinical validity of the results and previous work has also shown that mental health nurses can also make accurate assessments. Bearing in mind that participants were known to services there are a number of implications for service providers and commissioners. Many people lacked company and daytime activities and also had depressive symptoms suggesting that there should be better provision of social resources such as day centres and possibly more support (or respite provision) for carers (who rated these needs as more common). Lastly, unmet needs for eyesight/hearing were very common, suggesting that better assessment for and/or provision of glasses and hearing aids would have benefitted many people especially as sensory problems have a major impact on communication in people with dementia.

REVIEWER 2

1. The use of an instrument to measure need in different populations is an appropriate methodology to address the question. However the consenting process for involvement in this research needs better description. Were people given any time to consider their involvement or was an instant decision required? The subsequent data collection methods are also glossed over. How did people with dementia complete the instrument – self completion or did advocates get involved? Did the researcher advise the professionals
collecting the data (who were also asked to complete the instrument themselves). How was objectivity ensured?

In the Method (pp. 4-6) we have described in detail the recruitment, consenting and interview processes as follows:

**Recruitment of Participants**
The manager or appropriate member of staff at the recruited center was requested to make a first approach either with people with dementia’s carers or people with dementia themselves (depending on dementia severity and/or living situation) to give them the Information Sheet and to discuss if they were willing to be approached by the interviewer regarding this study. Participants, who had no objection, were contacted by the interviewer by phone and were given more information about the study as required. In addition, details of people who had attended the centre (person with dementia’s name, carer’s name, address, phone, etc) were provided and a letter was sent to the carer and/or the person with dementia including Information Sheets about the study. One week after, the interviewer contacted them by phone, answered any question they might have, explained the study and looked for their willingness to participate. If the potential participant agreed to be involved, the interviewer arranged a day to carry out the interview at their homes.

**Interviews**
Interviews were carried out by experienced professionals: a clinical psychologist (who was the main researcher) and three old age psychiatrists who were trained by MO, one of the authors of the Camberwell Assessment of Need for the Elderly (see description below) to undertake the assessment. Pilot interviews were discussed and agreement in rating criteria was achieved. Meetings with interviewers were scheduled once a month to discuss any difficulties that could have arisen during the interviews. All the interviews with people with dementia were carried out at their homes. Some interviews with carers were undertaken either at the person with dementia’s home, their own home or at a health centre (eg, memory clinic, day hospital).

**Consent Procedure**
The study was carried out in accordance with the latest version of the Helsinki Declaration. Ethical approval was granted by East London & the City HA Research Ethics Committee. All participants gave informed consent. Once the interviewer was at the person with dementia’s or carer’s home, they answered any further queries about the Information Sheets and the study and sought informed consent as follows: written consent by signing a Consent Form was required from people with dementia and their carers. In order to achieve this, the interviewer approached them to explain the study again and to inform them about their right to withdraw at anytime. Some people with dementia (11, 7.3%) were unable to provide written consent. When this occurred, the interviewer sought their assent (verbal consent). During this process, the interviewer made sure that he/she had taken as much time and care in explaining the information about this research as simply as possible. The interviewer avoided using long sentences and attempted to reduce any distractions. To find out if the participants have understood the information given, the interviewer observed their ability to ask any relevant questions and also requested the participant to repeat back the information and how it would relate to them. In addition, the interviewer clarified any doubts about the study and reiterated their right to withdraw at anytime.
In the Measure section (page 7) we have also added the following sentence to the description of the CANE: The CANE is not a self-administered tool. The professional interviewed the person with dementia, listened to their views and rated the user’s section of the CANE. The same procedure was carried out with the carer and finally professionals made their own ratings as a result of the balance between their own, the carer’s and the person with dementia’s perspectives.

2. The socio demographic profile of participants could have been presented more clearly in a table format.

Socio demographic details of participants have been added into Tables 1 and 2.

3. Why there were 152 professional responses and 125 from users and 125 from carers. The numbers of people with dementia who participated is stated as being 152 elsewhere. I thought that the question being posed would require a comparison of responses from the same cohorts. Presumably the 108 comparisons between users and carers were based on dyads? There is some mention of this in the limitations but there is no clear explanation of the numbers available for analysis.

In the Data Analysis section (page 7) the following sentence has been added: All analyses performed to compare the different perspectives on needs were undertaken using the dyads who had complete data on the respective comparison.

The following paragraph has been added to the Results (pp. 8 and 9): Although we tried to interview all people with dementia with the CANE, 27 (17.8%) were unable to understand the questions, so for these participants only carers’ and professionals’ descriptions in the CANE are available. People with dementia in this group were significantly more cognitively impaired (MMSE, M=5.4, s.d. 7.1) than the rest of the sample (M=20.1, s.d. 6.2) (U=116, p<0.01). Also, those who had only carer’s and professional’s descriptions were significantly more functionally impaired (M=3.1, s.d. 1.8) than the rest of the sample (M=6.8, s.d. 3.8) (U=196.5, p<0.01). There were no differences in other person with dementia and carer factors (including demographics, social and clinical variables) between those who had only carers’ and professionals’ descriptions in the CANE and the rest of the sample. In addition, ratings on people with dementia’s needs were obtained only for 125 carers. Fifteen (9.9%) persons with dementia did not have a family carer at all and 12 (7.9%) of them had a carer who did not meet the inclusion criteria.

4. The discussion is largely reliant on a comparison with work conducted in the Netherlands. There are other studies of needs in dementia, and particularly qualitative studies which may have also been brought into the discussion. There is nothing contentious in the discussion or conclusions. The paper may be of interest to the generalist rather than specialist in dementia care.

New and up to date references about needs have been added to the Discussion (references 2, 3 and 15).
The following text has been added to the Discussion (page 16): The CANE is primarily a clinical based assessment and a strength of this study was that all the researchers were experienced professional in clinical psychology/old age psychiatry which is likely to improve the clinical validity of the results and previous work has also shown that mental health nurses can also make accurate assessments. Bearing in mind that participants were known to services there are a number of implications for service providers and commissioners. Many people lacked company and daytime activities and also had depressive symptoms suggesting that there should be better provision of social resources such as day centres and possibly more support (or respite provision) for carers (who rated these needs as more common). Lastly, unmet needs for eyesight/hearing were very common, suggesting that better assessment for and/or provision of glasses and hearing aids would have benefitted many people especially as sensory problems have a major impact on communication in people with dementia.

Discretionary Revisions

1. A more extensive literature review would provide the material for a fuller discussion of the findings.

As mentioned previously, we have added new references and text to the manuscript.

Minor Essential Revisions

1. The paper requires minor editing to improve the use of English in places.

English language have been checked and improved.

2. The authors should also avoid use of the acronym PWD and term patient to describe the person with dementia.

Throughout the manuscript we have replaced the acronym PWD by “person with dementia” or “people with dementia” as appropriate.

Major Compulsory Revisions

1. The authors need to provide a fuller account of the methodology for the reader to have confidence in the findings. This must include a full description of the consenting process for involvement, how people with more advanced dementia were enabled to complete the instrument, how carers were recruited and their views obtained and when professionals completed the instrument.

We have given a full account of the methodology used (see points 1 and 3 above).

2. The questionnaires available for analysis by category of respondent must be clearly presented in tabulated format, including reasons for data not then being used in the analysis.
We included this information in the text (pp. 8 and 9): Although we tried to interview all people with dementia with the CANE, 27 (17.8%) were unable to understand the questions, so for these participants only carers’ and professionals’ descriptions in the CANE are available. People with dementia in this group were significantly more cognitively impaired (MMSE, M=5.4, s.d. 7.1) than the rest of the sample (M=20.1, s.d. 6.2) (U=116, p<0.01). Also, those who had only carer’s and professional’s descriptions were significantly more functionally impaired (M=3.1, s.d. 1.8) than the rest of the sample (M=6.8, s.d. 3.8) (U=196.5, p<0.01). There were no differences in other person with dementia and carer factors (including demographics, social and clinical variables) between those who had only carers’ and professionals’ descriptions in the CANE and the rest of the sample. In addition, ratings on people with dementia’s needs were obtained only for 125 carers. Fifteen (9.9%) persons with dementia did not have a family carer at all and 12 (7.9%) of them had a carer who did not meet the inclusion criteria.

We are grateful to the reviewers for their helpful comments. We hope that the manuscript is now acceptable for publication in BMC Health and Services Research.

Yours sincerely,

Dr. Claudia Miranda-Castillo.