Author's response to reviews

Title: A cross-sectional study to compare care needs of individuals with and without dementia in residential homes

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Author's response to reviews: see over
We thank the reviewer for their careful consideration of our manuscript. We feel the suggested revisions have improved the manuscript.

**Required changes**

2. **Pg 8:** Give more specific reliability and validity information. “Generally very high’ is not sufficient when describing reliability. Has the measure been used with the dementia population? If so, what were reliability data (Chronbach’s alpha, etc.)

   We have revised this paragraph:

   ‘The CANE has good content, construct and consensual validity and it demonstrates appropriate criterion validity. Interrater reliability was very good with a Kappa over 0.85 for staff in a study describing older people with mental disorders [12]. The Dutch version showed acceptable construct and criterion validity for use in people with dementia and their proxies [15]. The test-retest reliability in this study was moderate to good for the majority of the CANE items (average Kappa of 0.60) [15].’

3. **Pg 8 at bottom:** Starts a list of operational definitions. These should be reformatted in paragraph format. As written, shows up as a list mid way through paper.

   We have changed this paragraph to:

   ‘We recorded met, unmet and total needs. A met need was recorded when the resident identified a problem but felt there was appropriate help to significantly reduce the need. An unmet need was recorded when the resident identified a problem for which there was insufficient or no help [16]. The total number of needs was the sum of met and unmet needs for each topic.’

4. **Pg 10, Results section:** Include the dementia data within demographic and clinical characteristics—not as a one sentence paragraph. It would be helpful for the reader if the three study groups were specified in this section (proxy group for people with dementia, people without dementia, people with dementia). It would be helpful to summarize the number of respondents for each sub-group. Looking through prior information, I gather that 36 proxies participated, 90 people with diagnosed dementia, and 61 people without dementia. If this could be more clearly laid out for the reader, would be helpful.

   We have revised this paragraph:

   “187 residents participated in the study. 94 participants had a diagnosis of dementia according to medical files (n=90) or cognitive screening (n=4); for 36 people with dementia we relied on proxy-reports. Hence we included 93 participants without evidence of dementia.

   The three study groups did not differ in age, gender and marital status (Table 1.). However, they did differ in (I)ADL functioning and cognitive functioning. Bonferroni post-hoc testing showed that the non-dementia group had better (I)ADL and cognitive functioning than the two dementia groups (residents and relatives). The two dementia groups did not differ from one another in respect to (I)ADL and cognitive functioning. Approximately three quarters of this population was female. Over two thirds of residents were widowed, 19% were married, 2% were divorced and 8% had never married at all (not in table). The mean age of participants was 87 years (range 72-98).”

5. **Pg 11, last sentence bottom of first paragraph:** I believe it is more accurate to state: “...people with dementia who could complete the CANE REPORTED more needs, AND THE PROXIES FOR people with dementia who could not complete the CANE REPORTED the most needs.

   We have added the word ‘reported’ twice.

6. **Somewhere in report—perhaps in summary paragraph:** the authors should indicate whether the hypothesis was supported by the data (see ‘purpose of study’ paragraph, last sentence, pg. 6 where a hypothesis is stated.

   We have revised the first two sentences of the Discussion:
“The aim of this study was to describe the difference in number and type of care needs of persons with and without dementia living in residential care. We compared the total number of needs and unmet needs regarding 24 need topics. Our hypothesis was partly confirmed: people diagnosed with dementia reported more total needs and unmet needs than people without dementia, and within the dementia group proxy’s reported more needs than residents themselves.”

7. Limitations section, pg. 14 could be strengthened in terms of word clarity: “…that the PEOPLE WITH THE MOST NEEDS or WITH ADVANCED DEMENTIA…” “Worst condition” is vague. We have tried to clarify this sentence:

“It is possible that people with the most (unmet) needs and/or most advanced dementia were under-recruited, because they were unable to participate.”

8. Same section as #8: THE study sample MAY HAVE BEEN LESS DISABLED than the overall POPULATION of residents. THUS OUR FINDINGS MAY HAVE UNDERESTIMATED the number of UNMET NEEDS. HOWEVER WE ATTEMPTED TO ADDRESS THIS BY SEEKING PROXY PARTICIPANTS.

Revised accordingly.

9. #9 above: I’m not really sure if the authors feel they underestimated the number of unmet needs—not sure what their point is. Would be helpful to know if the 3 groups were representative of the proportion of people without a dementia dx, with dementia and able to participate, and requiring proxy responders. Also, this seems to be a place to talk about the proxy responders and how accurate their responses may have been. You reference proxy responses earlier in your lit. What are implications for your study r/t proxy responders.

10. Pg 14 2nd paragraph. Could it be that people with dementia may not be able to recognize that they have unmet needs? If so, could this have created under-reporting of unmet needs for this group?

11. Pg 15, last sentence: Could it also be that people with dementia may not remember the care provided? (in relationship to unmet needs)

We feel the textual revision has clarified this section. We address the use of proxy reports later in the discussion:

“There are no studies that compare the needs of persons with and without dementia in residential homes. In line with some studies [11-14] relatives reported more needs than residents themselves, whereas residents and relatives reported similar rates of objective physical and cognitive functioning. A number of reasons could underlie this difference: people with dementia may not recall having certain needs or may have forgotten some of the services that have been provided. Alternatively, they may not want to complain or they may not be aware of the services that they can ask for. On the other hand, families may overestimate the needs of their relative with dementia or may not be aware of the services delivered.”

12. Pg 16, the conclusion is a summary of the findings. This section needs to be broadened to place the conclusions within the broader context of these populations. What is the significance of this study’s findings to the populations in their settings?

We have revised the Conclusion:

“This first study to explore care needs in the residential care setting emphasises the importance of carefully establishing care needs for people with dementia. Relatives reported more needs than people with dementia themselves and this difference was not accounted for by actual differences in physical and cognitive functioning. Staff in residential care may want to consider discussing care needs with both the individual themselves and their families and integrate these reports with their own impression of the individual. The low number of unmet needs amongst people with no
diagnosis of dementia may be due to appropriate care provided by the residential care facilities or a tendency of residents to attune their needs to the available resources. 

13. TABLE #1: The proxy respondents appear to be called ‘carers.’ In the paper, the setting is described as assisted living settings and the proxies are described as family members. I suggest that the label ‘carer’ in Table #1 be re-worded as ‘proxy.’ Also, given the mean age of the proxies, they appear to be spouses. They are also the oldest group of respondents which is a bit surprising.

We have revised the wording for Tables 1 and 2.

Minor edits (changes in CAPS):

a. Pg 4 line 3: ...on average they also LIVE LONGER.

b. Pg 4, 3rd line from bottom: ...consequences INCLUDING UNDER-REPORTED CARE NEEDS because of

c. Pg 5, line 4: Therefore, care PROVIDERS should
d. Pg 5, lines 5-6: ...care, UNMET NEEDS MOST BE IDENTIFIED

e. Pg 5, line 1: ...staff and relatives AS WELL AS high agreement

f. Pg. 6, 2nd paragraph: put aim (purpose?) of student in past tense as it is completed. Currently written in present tense

g. Pg 8: Needs some editing in terms of paragraphs—what content goes within what paragraph.

h. Pg 8: line 3-4: needs include DIAGNOSED PHYSICAL AILMENTS AS WELL AS FUNCTIONAL PROBLEMS SUCH AS managing....

i. Pg 8: Give reliability and validity information. “Generally very high” is not sufficient when describing reliability. Has the measure been used with the dementia population?

j. Pg 8 at bottom: There is a list of operational definitions. These should be in paragraph format. As written, shows up as a list mid way through paper.

Revised accordingly.