Author’s response to reviews

Title: My husband is not ill; he has memory loss - Caregivers´ perspectives on health care services for persons with dementia

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My husband is not ill; he has memory loss - Caregivers´ perspectives on health care services for persons with dementia

Dear Editor, Elsie Chau Wai Yan,

Thank you for allowing us to review and resubmit our manuscript for possible publication in BMC Geriatrics. We would like to thank the reviewers for pointing out some important aspects. We believe that our review has improved the manuscript substantially, and hope it meets the recommendations from reviewers.

Please find the answers to reviewers’ comments below as a point-by-point response. All changes to the manuscript are indicated in the text by track changes and uploaded as a supplementary file called “Main document_revision110219.docx”.

The new version of the manuscript is submitted as “Manuscript_110219.docx”, and the original manuscript that we have revised is also included for information as “Main document_071118.docx”.

On behalf of the authors,

Randi Granbo
Elisabeth Boulton
Kristin Taraldsen

Authors response to Editor Comments:

BMC Geriatrics operates a policy of open peer review, which means that you will be able to see the names of the reviewers who provided the reports via the online peer review system. We encourage you to also view the reports there, via the action links on the left-hand side of the page, to see the names of the reviewers.

Authors response to Reviewers’ Comments:

Reviewer 1 Doris S.F. Yu: perceived needs of caregivers of persons with dementia on the health care service. In views of the fact that the prevalence of dementia is rising to an epidemic, the topic is of high clinical relevance to inform the development of related health care service. However, the below comments need to be addressed.

Comment 1: The Introduction did not provide with readers with the information about the pattern of health care service utilization among the dementia caregivers. The discussion is only geared towards the impact of stereotyping on help-seeking behaviors. Instead, more comprehensible models have been developed to explain the help-seeking behaviors for caregivers. The authors need to based on such model to discuss the help seeking behaviors of the caregivers and set the direction for this qualitative exploratory study. By the way, to better set the scene for the reader, what is the service utilization among caregivers in the country of origin? As there is a substantial level of paper published to mention the perceived needs and health care service utilization among family caregivers of persons with dementia, the scene setter can be more successful by integrating a brief update of the existing knowledge on the topic. The gap in literature needs to be identified.

Response 1: We thank the reviewer for point this out. We have done several changes:

We have revised the introduction to be more clear about health care service utilization among the dementia caregivers. We have added two paragraphs at pg. 3, line 29 – pg. 4, line 10: “In
Norway, half of the community-dwelling persons with dementia receive home care. Twenty percent of them are users of day care centers, with 1.5 to 2 days spent on average per week. The amount of health care stays relatively constant over time in this group until nursing home admission. The last month before admission to a nursing home, persons with dementia in Norway receive only four hours of home care per week. In contrast, the amount of informal help is estimated to be around 160 hours per month (added two new refs here, number 7 and 8).

Ninty percent of persons with dementia in Norway, receive help from informal caregivers. Decline in activities of daily living, neuropsychiatric symptoms, and living alone are factors associated with increased use of health services. Patients with dementia admitted to nursing homes show better physical health as compared with patients without dementia, indicating admission due to their dementia and not for physical health problems (7, 8).”

Furthermore, we also agree that the discussion should be strengthened. We have done the following changes to the discussion:

- Pg. 13, lines 19-22: Added two new sentences: “They wanted help or support to maintain performance in instrumental ADL functions, rather than services with compensational strategies (for example offering pre-prepared meals instead of supporting the person in the kitchen). This gap might explain the limited usage of health care services, as seen in the Norwegian study of resource use in this population (7).”

- Pg. 13, line 24: Added to the existing sentence a clarification “…, possibly with lower physical abilities”

- Pg. 14, line 1: Clarified by adding “For the spouses, this…”

- Pg. 14, lines 3-4: Added a sentence: “For the daughters, their involvement consisted of providing help instead of being daughters with time for social and pleasant activities.”

- Pg. 14, lines 31- Pg 15, line 1: We have added two sentences and rewritten the following sentence to “Our participants wanted to contribute to improvements in the existing
services. They want to be involved when new servies are developed, and they have serveral suggestions. One suggestion is to involve a…”

- Pg. 15, lines 15-17: We have added a sentence: “Services that meet the needs as they have suggested could improve the services, increase the use of these services, and ultimately support both caregivers and the person with dementia that lives at home.”

Comment 2: On p.4, line 2, it is unclear why the authors specified the ’offspring caregivers”.

Response 2: We agree, we have done two changes. First we changed the sentence in the introduction (Pg. 4, line 14-15), from “both partner and offspring caregivers” to “informal caregivers”. In the methods (Pg. 5, line 3) we changed “informal caregivers” to “informal family caregivers”. Please also see our response to the next comment below.

Comment 3: On p. 4, line 42, it should be "purposive sample" rather than "'purposeful'. Did the authors maximize the sample variation for this qualitative study? If yes, what are the conditions used to maximize the variation. How to define 'informal caregivers'? Did they have a family relationship with the persons with dementia. How to determine the sample size in this study?

Response 3: We agree and have changed the sentence from «purposeful» to «purposive sample» (Pg. 5, line 3). Furthermore, we added the sentence at the end of the section: “We aimed at including family (both partners and offspring) caregivers and carry out two focus group interviews with 4-6 participants each (16). This number means we could ensure that each participant had the opportunity and time to share experiences from being caregivers and we could collect in depth data.” (Pg. 5, line 9-13). Please also see the response to comment 2 that are relevant for comment 3.

We have also specified in the methods that: “Participants have been caregivers for a prolonged period of time and have..” (Pg. 5, lines 4-5)

Comment 4: The reasons for using focus group interview are less clear. Please justify why focus group was used instead of individual interview.
Response 4: We agree and have added the following to be more clear about this:

We included a sentence at Pg. 6, line 7-9: “Focus groups provide the opportunity for participants to listen to others and refine their own ideas through discussion (23).”

We have added this sentence to strength and weaknesses: Pg. 15, line 22-24: “We experienced that focus group interviews as the method, provided an opportunity for sharing difficult and emotional experiences as caregivers.”

Comment 5: What was the intended group size for the focus group interview? The current group size seems to be lower than the recommendation for maintaining an adequate level of social interaction. Please explain about this.

Response 5: We agree. We have added text and a reference to the methods Pg. 5, line 9-13: “We aimed at including family (both partners and offspring) caregivers and carry out two focus group interviews with 4-6 participants each (16). This number means we could ensure that each participant had the opportunity and time to share experiences from being caregivers and we could collect in depth data”.

Furthermore, we included information about the focus groups we conducted at pg. 5, lines 17-18: “The first focus group included three women and two men spouses, the second group consisted of three women (one spouse and two daughters).”

Please also see the last section of response 4, where we describe a strength with the methods by use of focus group interviews.

Comment 6: What was the interview guide used for the focus group. The information is needed for reader to determine the validity of the study.

Response 6: Yes, we used an interview guide as basis for the focus group interviews, the strategy and the topics are described at Pg. 6, lines 18-23: “We developed a semi-structured interview guide with four themes and a final open question. The themes were: 1) Motivation for joining the
focus group; 2) Perspectives of current health care services; 3) Knowledge of what services the municipality offers to people with dementia; 4) The utility of participation in activities outside the home for people with dementia. Finally, we invited the participants to discuss what services they would prefer for their mothers, husbands or wives.”

Comment 7: On p.6, line 11-18, the authors mentioned that the main themes were presented to a sample of caregivers who had not participated in the focus group. How this sample was recruited and what were the section criteria? Based on what condition they can validate the findings? As the author did not mention whether data saturation has been reached, please explain why a separate sample is needed for audit trail.

Response 7: We thank the reviewer for pointing this out. We have added information in the methods (pg. 7, lines 13-17): “Present at this meeting were informants (n=4) from the focus groups and caregivers (n=3) from the same conversational group for caregivers that wanted to take part although they did not have time for joining the focus group interviews.”

Comment 8: Please explain why a number of quantitative instruments are used in the study the psychometrics of these instruments were not described.

Response 8: We agree that this is not quite clear.

We have moved and revised the quantitative description of the participants from results to Pg. 5 of the methods, and moved the Table with the results from these instruments. We also added information to describe the rationale for using these instruments. Please see under the section “Recruitment and Participants” in the methods (Pg 5, line 14-22), which now is as follows: “We included eight participants, their age ranged from 63 to 83 years (two daughters and six spouses). The first focus group included three women and two male spouses, the second group consisted of three women (one spouse and two daughters). To gain a greater understanding of the participants’ situation, we collected some data on caregiver burden, where Table 1 presents caregiver burden scores from the Hospital Anxiety and Depression Scale (HADS) (16, 17) and the Relatives’ Stress Scale (RSS) (18). Five participants had HADS scores higher than 15, indicating a severe disorder (16, 17). Results on caregivers’ distress show that seven out of eight of the participants were in a high-risk group for psychiatric morbidity, with scores above 30 (19).”
The first section of the results starts now with “Participants’ most explicit reason for taking part in this study was to contribute to a better understanding of needs, in order to improve health care services for home-dwelling people with dementia and their caregivers in the future. Three themes emerged from the analysis: 1) A gap between current health care services and perceived needs; 2) Caregivers’ role is all-consuming; 3) Involvement and participation is necessary for improving services. Table 2 shows the themes and meaning units.” (Pg. 8, lines 1-6)

Comment 9: The Discussion section can be strengthened by discuss the current findings with existing literature. Need to elaborate the implications of the findings to practice and research,

Response 9: We agree, we have done several clarifications in the discussion. Please see response to comment 1 for details. We also have done some changes throughout the manuscript (see all responses) that we think have improved the manuscript. We now think the manuscript is clearer in terms of describing who the participants were and what experiences they had with the health care system, and more importantly what is needed to be changed in order to improve these services.

Reviewer 2, Xue Bai (Reviewer 2): This manuscript entitled "My husband is not ill; he has memory loss - Caregivers' perspectives on health care services for persons with dementia" examined informal caregivers' perspectives and perceived needs related to health care services/activities for older adults with dementia. Using a qualitative method, the authors found that the current health care services do not meet the needs of either the persons with dementia or their caregivers. The topic itself is very interesting and worth investigation, but there is still room for improvement before it can reach the publication standard of BMC Geriatrics. The authors may want to make revisions with reference to the following comments and suggestions:

Comment 1: In the "Background" section, the authors may want to elaborate more on "caregiver burden" in paragraph 2.

Moreover, in paragraph 3, rather than simply claim that "A multinational review of interventions to reduce dementia-caregiver burden found that most of these interventions have been unsuccessful", the authors should explain what the main types of interventions were included for review, and to what extent and based on what standard, they were seen as unsuccessful.
Similarly, it is unclear what "multicomponent intervention design" refers to.

Response 1: We agree. Please see the response to comment 1 from reviewer 1 above. Furthermore, we have rewritten the «multinational review…» part by adding the description of intervention types. We have changed the sentence into: “Educational interventions and/or support can, however, reduce caregiver burden, especially if the support is given at the onset of care” (Pg. 3, line 20-22)

Comment 2: In the "Methods" section, although the authors tried to provide reasons why focus group not individual in-depth interviews were used for data collection, the rationale remains unclear.

Were all the participants primary caregivers for their family member with dementia? Based on what criteria, the participants were formed into two focus groups? How long was each focus group interview?

If both spousal and children caregivers were included, would the sample size (n= 8) be too small to make meaningful conclusions?

Factors such as the how long the participants have been taking care of the dementia person, the severity level of dementia should also be taken into consideration.

Response 2: We agree that the rationale for using focus group interview as the methods need more explanation. Please see the response to the comments from reviewer 1 above. Most importantly we have included a sentence at Pg. 6, line 7-9: “Focus groups provide the opportunity for participants to listen to others and refine their own ideas through discussion (23).” We have also added this sentence to strength and weaknesses: Pg. 15, line 22-24: “We experienced that focus group interviews as the method, provided an opportunity for sharing difficult and emotional experiences as caregivers.”

Please also note that we have added a sentence in the discussion “Seven of them were caregivers for relatively physically fit persons, and they received limited help from the health care system. They all wanted..” (Pg. 13, lines 13-14).
Comment 3: The results section is generally clear, but the findings seem to be simple and superficial. Whether there are any different experiences/perspectives between working caregivers and retired ones, between male and female caregivers, between experienced and inexperienced caregivers have not been analysed and discussed.

Response 3: We agree that the results are not very clear, and have done some minor changes to be more clear about different experiences. The following changes have been made:

• Pg. 9, line 15: “one of them” changed to “one of the spouses”

• Pg. 9, lines 16-19: moved the last sentence earlier in this section and revised the sentence into:
  “One of the male spouses explained that it was….”

• Pg. 10, lines 22-26: changed/added some words to the section, which now says: “The participants felt that most of the health carers did not have any consideration towards the person’s unique identity and personality. One spouse (FS69) said: “My husband is not ill - he has short term memory loss.” As soon as the diagnosis of ‘dementia’ is given, focus seemed to be on the disease. The participants felt, like one of the daughters explained, that nobody was interested in “the person behind the dementia” (D63).”

• Pg. 11, lines 14-17: Changed the sentence to “Participants who lived together with a person with dementia talked about….One of the spouses…..”

• Pg. 11, line 18: Changed the sentence to “Some of the spouses…..”

We have also changed the word “caregivers”/”informants” to “participants in the results to be quite clear.

We have changed “Despite limitations…” to “Despite experiencing limitations…” (Pg. 9, lines 18-19).

Comment 4: If more detailed comparisons had been made between different types of informal caregivers, and taking into consideration the severity level of dementia, the authors could then provide meaningful policy and service suggestions to design and implement tailored programs for informal caregivers and patients with dementia.

Response 4: We agree, and we think the revised version of the manuscript now are more clear about the participants in this study, the results, and what is needed in existing and new developed
services for this group of health care receivers. Please see the revised version and the responses
to all comments for details.