Author’s response to reviews

Title: What Motivates Informal Caregivers of People with Dementia (PWD): A Qualitative Study

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To: BMC Palliative Care Editorial Office” Marielette.Costoy@springer.com

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Subject: Revised submission to BMC Palliative Care - PCAR-D-19-00008R2

What Motivates Caregivers of Alzheimer Patients: A Qualitative Study

Shakiba Zahed, PhD; Maryam Emami, MD; Shahrzad Bazargan-Hejazi, PhD; Ahmad Ali Eslami, PhD; Majid Barekatain; Fereshteh Zamani, PhD

Dear Editor,

Thank you for giving us the opportunity to revise the above-cited manuscript. We appreciate the thoughtful comments of your reviewers, which have added much value to the current revised version.
In this cover letter we have listed a point-by-point response to each reviewer/editorial point. We also have made sure that the revised version conforms to the journal style. All changes to the manuscript are indicated in the text by yellow highlights.

By resubmitting this manuscript, we confirm that all author details on the revised version are correct, that all authors have agreed to authorship and order of authorship for this manuscript and that all authors have the appropriate permissions and rights to the reported data.

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Technical Comments:

Editor Comments:

BMC Palliative Care 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.

Reviewer reports:

Monica Leverton (Reviewer 2): Response to revisions:

Thank you to the authors for taking my comments on board. I feel satisfied that these have now been addressed and I enjoyed reading the manuscript in its current form.

I have just one minor comment in response to the revisions - My suggestion regarding including some literature on theoretical models of caregiving was intended to benefit the background literature from which to frame the authors’ findings and discussion overall. I do not think it is necessary to highlight as a limitation that there was no theoretical framework from which to suggest strategies to enhance and safeguard altruistic motivations of caregiving, as the manuscript now reads.

Authors Response: Done
Minor typing errors:

Line 22 - there is a mistake in the word carers': "motivating factors presented more so the cares' inner personal perception"

Line 27 = there is a mistake in the word earning: "2) Earng a living and financial independence"

Of Table 1, under educational level formal caregivers, the number of respondents appears to be missing (while the percentage of respondents is 8.4).

Authors Response: This section is omitted. The manuscript has been revised to only focus on informal caregivers' data.

Stephanie Daley (Reviewer 3): General

Along with the first reviewer, I have struggled with the sample including both informal and formal caregivers. I remain unconvinced from the data presented that other than the theme of Moral, Religious and Spiritual motives, that the themes relate equally to both groups.

Personally, I think it would make for a stronger paper to first report the informal caregiver findings in one paper, and then to submit a second paper whereby the formal caregiver findings can be presented, in which the study findings compared to the informal caregiver can be made.

My comments are made on the assumption of the splitting of the findings into two separate papers.

Authors Response: We revised the manuscript to only focus on informal caregivers’ data. In this regard two new in-depth interviews were also added.

Abstract

General - the term people living with Alzheimer's Disease or other Dementia, and the acronym ADOD is not commonly used, and I would suggest sticking to the commonly used People with Dementia (PWD) as one of the first reviewers suggested.

Authors Response: Done
Background

Page 5 Ln 9 - I would use the umbrella term Dementia: Authors Response: Revised accordingly.

Page 5 Ln 21 - care-giving is a worldwide phenomenon - not limited to the US: Authors Response: Revised accordingly.

P5 Ln 26 - responsibility of caregiving by formal caregivers is taken up - not assumed: Authors Response: Revised accordingly.

Methods

Page 6 Ln 26-29 - The analysis in this study does not appear to use grounded theory techniques (and in fact the data analysis techniques do not fit with grounded theory) furthermore I would disagree with the definition of grounded theory given in the text - I would suggest removal of reference to grounded theory. Authors Response: Revised accordingly

Page 6 Ln 46 - should be Female and male - not plural: Authors Response. Revised accordingly

Page 7 Ln 16/17 - an example of the topic areas would be helpful:

Authors Response. Revised accordingly

Findings

As above - need to report the findings from each group in separate publications, but general points as below:

Page 9 - Ln 20 - would not use the term 'dear one' - how do we know it is the dear one? The person might be hated - needs to be a more neutral/descriptive term Authors Response: Done

Page 9 - Ln 33 - should be older people, rather than for older adult Authors Response:this sentence is omitted
Page 9 Ln 41 - why is trained or not trained formal care giver status mentioned for every quote - not sure if you found a difference? If so, would be relevant to discuss further in a separate formal caregiver paper. Authors Response: Revised accordingly.

Page 11 - First paragraph - does social networks apply to informal caregivers - if so, this is not shown in the text adult Authors Response: social networks is omitted.

Page 11 - Paragraph three - the quote from the care giver does not illustrate the theme, unless she is saying that she harms her father-in-law in some way? Authors Response. Revised accordingly.

Page 12 Ln 11, again not sure if the quote illustrates the wider themes as just because that we can say that the motive was immoral because a formal care giver reported stole from the household - there might be other explanations, as this is a proxy report. Authors Response: omitted.

Discussion

General point - how do the four themes fit together and what is their status to each other - For example, for formal caregivers are financial motives stronger than religious motives? Authors Response: themes about formal caregivers is omitted.

P13 Paragraph four - not sure that the safeguarding recommendations, however well meaning, are justified by the data presented. Authors Response: omitted.

Study limitations

How generalizable are findings in other cultures? Particularly those which are secular? Authors Response: We include this as a limitation of the study, which requires further investigation.