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

From: Shahrzad Bazargan-Hejazi" shahrzadbazargan@cdrewu.edu

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

What Motivates Caregivers of Alzheimer Patients: A Qualitative Study

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BMC Palliative Care

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.

While we have not made any changes to authorship but we have changed the corresponding author from “Shahrzad Bazargan-Hejazi” to “Fereshteh Zamani-Alavijeh”

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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1st Reviewer reports:

General points:

1- The authors should proof read and correct some minor grammatical errors (some grammatical errors noted in quotes - these can be corrected without losing the meaning of what is being conveyed)

Authors Response: We edited, and proofread the entire revised version of the manuscript.

2- It is not common to refer to people living with dementia as "Alzheimer's patients", I would generally use the term people living with Alzheimer's disease

Response: The term of "Alzheimer's patients" was changed to " people living with Alzheimer’s Disease or Other Dementias" in the entire manuscript.

1-The introduction provides a short summary of the literature, but it fails to provide a strong argument as to why this study is needed.

The authors touch on positive motivating factors but do not elaborate on what these might be and how they may be associated with good quality care.

Response: We have revised and reorganized the entire Introduction/Background section. We believe this section now meets both reviewers requested revisions.
2. The authors should also discuss if and how motivating factors may differ between health care professionals and family carers.

Response: Done. Added the pertinent text in the introduction, results, and discussion.

3. The authors argue that experiences, perceptions and beliefs cannot be quantified, which is not necessarily true as there are numerous scales developed to assess carer experiences, and thus why a qualitative study is needed.

Response: We toned down the text language as the following and provided the pertinent citations in the body of the manuscript:

However, many of the caregivers’ beliefs, perceptions, and experiences are difficult to quantify (18) because they are influenced by a varying degree of socio-cultural and traditional values, which may deeply influence the individual’s subjective perception of these values. (2, 18)

4. Would understanding better carers’ motivations for caring help develop/tailor interventions to tap into these factors?

Response: Yes. We added the following text in the manuscript:

Introduction: Once we better understand the caregivers’ motives for caring of the people living with ADOD we can develop/tailor interventions to protect the carers’ altruistic motivation and diminish negative aspects of formal and informal caregiving. (19)

Conclusion: It is also important to study how carers’ motivations change as their responsibilities and the work environment evolves.

Also, it is not clear why the authors focussed on people living with AD and not dementia as a more broad diagnosis? Do the authors think that carers of people with AD have different motivating factors to carers of people living with other diagnoses of dementia?

Response: the authors think motivating factors are the same in both groups. we revised the term to people living with Alzheimer's Disease or Other Dementia (ADOD)
Method

1. The methods section is well structured and the following changes would help improve reader understanding:

- Why did the study require bilingual members of the research team if all interviews were conducted in the same language? If the interviews were not conducted in the same language then this needs to be stated and who translated the data. For publication, who translated the quotes to English and were they back-translated to ensure accuracy?

Response: The following texts were added to the method section:

Semi-structured interviews were conducted in Farsi (the predominant and official language in Iran) by one of the study investigators (SZ) at different locations, chosen by the participant.

Furthermore, for publication purposes, SZ and FZ translated the quotes to English, and their translation was back-translated by SHB to ensure accuracy.

The entire manuscript was translated from the original language into English by an authoritative translator, back translated by the SZ and FZ. Different English versions of the draft was produced by all the authors and the final version was edited by one of the bilingual author (SHB) who also is an skillful in qualitative studies.

2. The first sentence of the data analyses section refers to "Alzheimer's and dementia patients" - if the authors recruited people who care for people living with dementia (and did not restrict to those who are for people living with AD) then I would suggest revising the title and the manuscript to reflect this.

Response: Done, for the entire manuscript.

Findings

1- Table 1: what is the difference between occupation and kind of caregiving? Did you recruit professional carers who discussed their experiences of caring for a family member instead of a service user?

Response: The authors corrected the title of column and broke down these demographics into formal and informal caregivers in table 1.
Before you proceed to presenting the themes and corresponding quotes, I would recommend summarising the themes which were identified from the data.

Response: The themes which were identified from the data were summarized as the following: We identified four categories of psychosocial motives based on the caregivers' feedback and experiences. These include 1) Moral, religious, and spiritual motives; 2) Financial motives; 3) Motives to build a social network, and 4) Immoral motives.

The section beginning "the feeling of self-sacrifice…” although does reflect motivating factors relating to morality, this quote also suggests that this individual lacks trust of the care provided in residential/nursing homes.

Response: It is not so much “lack of trust” as is feeling responsible towards the loved ones. We revised this sentence to: this feeling of giving of oneself to facilitate the well-being of a dear one was common among family members who cared for people living with ADOD.

It is not clear what the authors mean by the theme labelled "Iniquitous incentives" - the first quote for this theme doesn't fit well under this label. This quote suggests that there is a forced obligation to take care of elderly in-laws.

Response: We revised term is “immoral motives”.

Yes, in more traditional households in Iran the expectation to take care of the elderly in-laws are common expectations.

Also the final quote of this theme suggests that certain family members (and not family carers per se) take advantage of a person living with dementia for their own financial gains. Therefore this is not necessarily the family carers motivations but that of others.

Response: We decided to delete this quote since it was not directly linked to the participant in this study.
Discussion

1. The discussion is well structured and provides a good in-depth summary of the findings, the implications of these findings for research and clinical practice and the strengths and limitations of this study. The authors reflect on social capital and how professional carers utilise their role to form a social network. It is important for the authors to discuss the implications of these findings for practice. Would facilitating/encouraging social networks of both professional and family carers to form alleviate the burden of caring?

Response: Thank you for offering your thoughtful insight. We added the following text to this section of the manuscript:

It would be of interest to investigate whether facilitating/encouraging social networks of both formal and informal family caregiver alleviate the burden of caring?

Monica Leverton (Reviewer 2): I thank the authors for giving me the opportunity to review this manuscript. The researchers present an important topic, looking at the motivating factors of professional and family caregivers for people living with Alzheimer's disease.

While the topic is important, I feel there are a number of important modifications that would benefit and add strength to the research.

Key words:
1* I would suggest adding 'Alzheimer's disease' as a keyword.

Response:' Done.

Introduction:

*1 In the first paragraph of this paper, the researchers say that Alzheimer's disease is known as the 'unending funeral' (line 15-17). I have not heard or read of this term being used before. Also from reading the paper from which you have cited this term (Lodgson et al., 1999) I cannot see where they have said this anywhere in their paper. I would suggested removing this sentence.

Response: We removed all the text with negative connotation to Alzheimer’s Disease or Other Dementia (ADOD).
2. Furthermore, some sentences could be interpreted as placing blame on people living with dementia and may present an unhelpful negative narrative for those living with the condition - e.g. 'The ongoing and varying demands of caring for these patients are often psychologically, physically, and financially draining (4). Family members and friends, in particular, often voluntarily assume this heavy responsibility'.

Response: This is a very thoughtful observation. We removed all the text with negative connotation to Alzheimer’s Disease or Other Dementia (ADOD).

3. I believe the paper could benefit from bringing in some models of care giver behaviour, where past literature has identified some of the motivators for caregiving behaviour to introduce and support the researchers' findings.

Response: While we have cited some of the previous work but unfortunately we did not set the foundation of this exploratory study on a theoretical framework. We have allotted to this in the limitation section of the manuscript as the following:

Our study also lacked a theoretical framework based on which to suggest strategies to enhance and safeguard altruistic motivation of the caregivers of people living with ADOD and diminish negative aspects of formal and informal caregiving. (19)

4. The rationale for this research is clear, however the paper is missing a research question or specific objective/s.

Response: We added the following to the end of the Background section:

In this study, we attempt to answer the following research question; what are the caregiver’s motives for taking up this role? We aim to explore and describe these motives

Methods:

1. The researchers report using triangulation to enhance the credibility of their data, however it is not clear how or where triangulation of data was used. Triangulation refers to the use of more than one method of data collection and it seems that qualitative interviews was the only method carried out in this study.

Response: This reviewer indeed is right. We did not use triangulation. We corrected this in the text.
Results:

1* I feel the research could be greatly improved by redoing the analysis and separating findings for professionals and family/friend caregivers. The motivations for their care for patients with Alzheimer's disease is likely to differ greatly, with professionals doing so as it is their job and they receive financial income, whereas family caregivers typically do not. The theme of 'financial incentives' applies only to professional caregivers from the examples provided and does not seem to be a specific motivator for caring for someone with Alzheimer's disease. The financial incentive is more so a motivation for working in general.

Response: In the revised version, we analyzed the data based on “formal” and “informal” caregivers. This reviewer is correct. The theme of 'financial incentives' applied to formal caregivers and was not a motivator for informal carers caring for someone living with ADOD. However, the formal caregivers shared the other themes with the informal carers.

2* Adding to this, the findings from the professional caregivers do not seem connected to the focus of the paper which is motivators for caring for patients with Alzheimer's disease.

Response: We agree. In the revised manuscript we deleted this term and instead used “trained” vs. not trained formal and informal caregivers. See also Table 1

3- The theme of 'Developing network of relations' reads as a motivator for working in a residential or nursing home perhaps, rather than a specific motivator for caring for people with Alzheimer's disease. In the discussion, this reads as a reward of the role, not a motivator.

Response: We have revised part of this section as the following:

Social network and social support have protective health quality on the individuals who are embedded in the support group. (47) It also leads to a positive patient-caregiver relationship. (41) It would be of interest to investigate whether facilitating/encouraging social networks of both formal and informal family caregiver alleviate the burden of caring?

In the current study, caregivers allotted to the usability and perceived value of social media that supported their communication with each other, as well as communication with others. In one study, the benefits of having an online platform in enhancing the communication between family members and professional caregivers of dementia patients is reported. (48)
4* The researchers' final theme is immoral motivations/stimuli (different terms are used in the abstract and main body of text)

Response: We have rectified this issue in the revised version.

for caring for patients with Alzheimer's disease. The paper then goes on to conclude that the themes developed can inform future investigators for giving incentives to caregivers. It does not translate how the finding of immoral motivators (such as household theft as described) could then inform a moral way to incentivise caregivers in future.

Response: We have revised the label of this theme to “immoral motives” to inform the readers that all motives are not positive and family caregivers and care services should be aware of possible elderly abuse and safety. We have added the following text in the section:

The finding that a few participants were also driven by an inner desire to take financial advantage of the caregiving situation, points to the needs for strategies that safeguard people living with ADOD against susceptibility to financial exploitation. Other than providing care by the trained formal licensed caregivers, families should closely monitor the process of caregiving. In cases where providing care by an informal caregiver is the only option, the level of the safeguard could be aligned with the patient’s level of vulnerability, nature of relationship between the caregiver and the care receiver, benefits gained by the caregiver, and the level of influence the caregiver has on the care receiver to commit wrongdoing. (49) Several screening tools are available to identify carers’ wrongdoings, but more research is needed to establish their validity and applications for caregivers of people living with ADOD. (50)

5* Overall, the themes developed do not seem congruent for all participants (i.e. family caregivers and professional caregivers). The theme of morality, religion and spirituality is a key motivator and applies to both family and professional caregivers. However, the other three themes lack clarity as to how they apply the focus of the research, specifically the care for people with Alzheimer's disease) as well lacking in congruence between both family and professional caregiver perspectives.

Response: We agree with this reviewer’s comment, however, our aim was to delineate motives behinds our participating caregivers, and certain degree of incongruently was expected based on their specific role. To add some clarity we added the following under the Financial motives: Financial incentives were mostly expressed by formal caregivers who were paid for their service, which is similar to previous studies
6* The interchange of the terms professional and formal caregiving - is there a difference between a professional and formal caregiver? If not, the paper would be easier to read if the terms were kept consistent.

Response: In the revised manuscript we deleted the term professional and instead used “trained” vs. not trained formal and informal caregivers. See also Table 1.

7* Highlight within the text that a table of participant demographics is located at the end of the report. It would also be helpful to break down these demographics into professional and family caregivers.

Response: We broke down these demographics into formal and informal caregivers in table 1. We also revised the Professional caregivers to Trained for Caring of People Living with ADOD with two response categories: Yes and No.

8* It is not clear from the text how the demographics of participants differs for ‘occupation' and 'kind of caregiving’. I had assumed from reading the paper that all professional caregivers by occupation would have been providing professional caregiving while family caregivers would be providing family caregiving. If this is not the case it would be helpful to define the participant groups within the main body of text.

Response: We deleted the term profession and divided the participants to formal and informal caregivers? 12 were Paid Caregivers Direct-Care Workers for People with Alzheimer’s or Other Dementias (formal), and 17 were informal caregivers (Wife, Daughter, Son, Family members, Friend). Of the formal caregivers, nine (75%) had received training regarding caring for people living with ADOD. (Table 1) None of the informal caregivers had such training.