Author’s response to reviews

Title: Experiences of end of life amongst family carers of people with advanced dementia: Longitudinal cohort study with mixed methods

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Author’s response to reviews:

Dear Kee-Lee Chou,

Thank for the opportunity of responding to the two reviewers’ comments to our paper: "Experiences of end of life amongst family carers of people with advanced dementia: Longitudinal cohort study with mixed methods" (BGTC-D-17-00110).

In addition to the comments made by the reviewers, since submitting the review we also identified that the cut-off used was incorrectly applied to the Inventory of Complicated Grief. We have therefore removed the cut-off and replaced it with medians and interquartile ranges.

Reviewer 1:
Comment 1. Did all family caregivers who participated in the study experience the death of older adults with advanced dementia? I assume that authors included caregivers who unexperienced and experienced the death of older adults, seeing figure 1. Authors should not combine those data, because caregiving experience is theoretically heterogeneous between caregivers and bereaved those.

Response: Yes, the paper does include both bereaved and non-bereaved carers. We have restructured Table 2 and revised Figure 1 to make the process of data collection clearer. We feel that one of the unique elements and strengths of this study is that it is one of very few studies that prospectively followed carers of people with advanced dementia for a period of up to nine months and into bereavement if their relative died. Given the severity of dementia, we had anticipated a higher rate of death amongst those with dementia. Due to limits of funding we were unable to extend the data collection beyond the nine month period. However, at the beginning of the study all carers entering the study met the same inclusion criteria. As with all longitudinal studies, the study was aiming to assess changes over time and to examine the experiences of care immediately before death and in the early months after death. In presenting the data all qualitative data is solely from bereaved carers who were interviewed after their relative’s death. For all the pre-death measures we have presented this in Table 2 as both combined data and separate data for those who subsequently experienced death during the study period and those who did not.

Comment 2. Why did they utilize both of qualitative and quantitative data collection? How many participants replied the follow-up survey in 12 caregivers participated in qualitative interviews? I think that those qualitative data cannot apply to the quantitative data. I suggest that authors could use only qualitative data.

Response: We feel that the mix of qualitative and quantitative data strengthens the message of the paper by demonstrating the high levels of psychological morbidity using standardised measures, the level of satisfaction in end of life care services using a validated measure as well as exploring in more depth and from the perspective of the carer their experiences and stories relating to end of life care, psychological wellbeing and adjustment after death. Only carers who experienced their relative’s death could complete the post-death questionnaires. While we acknowledge in the limitations that the sample size post death is small, these quantitative data still provide an indication of mental health for this sample of carers which can help contextualise the qualitative data for these carers. In the research design section we have added the following justification of the mixed methods approach: “This is a mixed methods study with qualitative and quantitative data collected concurrently to enable triangulation of findings (Creswell, 2004). The use of validated measures enabled a standardised way of assessing carers’ mental and health and satisfaction with end of life care. The use of qualitative interviews after death enabled an in-depth exploration of carers’ experiences of end of life care. Combining these two data sources provided a rich and more reliable description of the carer experience at end of life.”

Comment 3. Numbers or selection criteria of participants in each time point is different, regarding Table 2. It does not make a sense.
Response: There is only one set of criteria for participating in the study and therefore at study entry there is only one sample. This is a longitudinal study, so as the study progressed some carers experienced their relative’s death and others did not. We have therefore shown the last assessment while the person was alive or in the study. As we recognise that these two groups differ at the last assessment we have separated their finals assessments in this table. We have restructured Figure 1 to make the process of data collection and the flow of participants through the study clearer. Due to the distressing period in which participants were involved in the study, some were unable to complete all assessments explaining some of the different numbers in the sample over time. However, in checking all the data we did find an error in the flow chart and have corrected this. This mainly related to one participant who consented to participate while their relative was alive but in the time between consenting and having their first assessment their relative died and they moved straight into the post-death sample with no pre-death assessments completed.

Comment 4. How did authors collect quantitative data? Structured interview? Self-administrated survey?

Response: Under design and methods/quantitative analysis we have reworded “At study entry we documented carers’ age…” to: “At study entry we interviewed carers and documented their age…” We have also revised the statement “Self-report measures were repeated at study entry and monthly for up to nine months or until the person with dementia died” to “During a face to face interview, carers were given the option of self-completing the measures or completing them via structured interview.”

Reviewer 2:

Comment 1: I recommend the authors exemplify questions in the interviews on page 7. They wrote "We used a topic guide derived from the literature and our wider programme of work in this field [19] to explore their overall experience of advanced dementia and EOL care including information about dementia progression and EOL received since diagnosis." I read the protocol paper [19], but I could not find examples of questions. Examples will help the readers to imagine interviews.

Response: The reference to the protocol paper in this sentence was not aiming to provide example questions but to describe our wider programme of work. We have followed this statement with the following: “A subset of questions focused on the care provided to the person with dementia such as “What support or services did [the person with dementia] receive towards the end?” Questions also explored physical, psychological, spiritual and social needs and “how well were they dealt with by hospital/nursing home staff?” Another set of questions explored communication about end of life care such as “Did any staff (GP, Consultant, nursing home staff etc) talk to you about what might have happened to [the person with dementia] in the future?” “Did anyone discuss with you what the course of [person with dementia’s] illness was likely to be?” and “Was there any information regarding [the person with dementia’s] illness/care you found difficult to understand?” A further set of questions explored carers’ personal reaction to their relative’s illness, end of life care and their bereavement, for example: “How did you find
dealing with [the person with dementia’s] illness” and “Have you had any help or support with your bereavement?”

Mixed methods design: numerous comments: Comment 2: Was the design convergent or sequential mixed methods design? Please clarify each period of quantitative and qualitative data analysis; Comment 3: Prevention confirmation bias: When bridging the quantitative and qualitative components of this type of research, accounting for confirmation bias is critical. One analytic process has a critical impact on the other. For example, researchers may conduct qualitative analysis so that it corresponds to findings from quantitative analysis. Please explain how the authors eliminated the biases. Comment 5: Is there any discrepancy between quantitative and qualitative findings? The authors wrote "While carers often described how well they coped with their relative's dementia and dying, there were also many accounts that supported the quantitative findings of high levels of grief and distress.” on page 18. They also wrote "Two carers who had not moved their relative from what they perceived as a poor quality care home, reported the lowest satisfaction on the SWC-EOLD and experienced complicated grief after death.” on the same page. Is there any gap between quantitative and qualitative results? The gap might be especially important results which can be found by mixed methods approaches.

Response: In the study design section we have added “This is a mixed methods study with qualitative and quantitative data collected concurrently to enable triangulation of findings (Creswell, 2004). The use of validated measures enabled a standardised way of assessing carers’ mental and health and satisfaction with end of life care. The use of qualitative interviews after death enabled an in-depth exploration of carers’ experiences of end of life care. Combining these two data sources provided a rich and more reliable description of the carer experience at end of life.”

At the beginning of the data analysis section we have added: “In this mixed methods study we analysed the quantitative and qualitative data independently with a statistician analysing the quantitative data (VV) and qualitative researchers analysing the qualitative interviews (KM, NK, SD and JH). We gave equal weighting to both sources of data and the point of integration was during interpretation and final write-up of results (Creswell, 2004). This approach aimed to reduce the impact of confirmation bias in analysing the two data sources. In the results section we present the quantitative data as stand-alone findings but for the qualitative data we have reflected on quantitative findings that either contradict or support the qualitative findings when evident.”

In modifying Figure 1 we have also included the analysis of data in the flowchart of the study to help clarify and illustrate when and how the data was analysed and then combined.

In the ‘strengths and weaknesses’ section of the discussion we have added: “This study used a mixed methods approach with equal importance attributed to qualitative and quantitative findings. Both data types were collected from one longitudinal study, analysed independently and then combined at the point of interpretation and write up to minimise confirmation bias.” The paragraph under the subheading “carer mental health” in the discussion section also explores the potential divergence of carers reporting high levels of emotional distress while also reporting
in qualitative interviews coping quite well. However, no substantial differences between the two sets of data were evident.

Methods: Comment 4: I recommend the following sentences be written in Methods section: page 9 (Data were collected between May 2012 and December 2014) and page 10 (Thirteen carers (37%) were bereaved during the observation period … relative had died shortly after the nine month study observation period.)

Response: We have reworded the first statement to: “Quantitative and qualitative data were collected concurrently between May 2012 and December 2014”. We have clarified and corrected the second sentence to state: “One carer did not complete any pre-death assessments as their relative died between the time the carer consented and their first assessment was completed – they therefore only have the 2 and 7 month post death assessments. Twelve carers (34%) were bereaved during the observation period and completed measures at 2 months (n=11) and 7 months (n=9) after the death. Ten of these carers also completed a qualitative in-depth interview 2 months after the death. Another two carers completed qualitative interviews two months after their relative’s death, however, they have no post death quantitative data as their relative died shortly after the 9 month study period and therefore they are included in ‘non-bereaved’ at final assessment in Table 2”.

Comment 6: Some references were not followed with submission guidelines of BMC Geriatrics.

Response: We have reviewed the reference list to ensure that no references list more than 6 authors.