Reviewer's report

Title: Caregivers' active role in palliative home care - to encourage or to dissuade? A qualitative descriptive study

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Reviewer: Susan E McClement

Reviewer's report:

Comments for Authors

Thank you for the opportunity to review this manuscript. I offer the following evaluative comments which I hope the authors will find helpful.

This qualitative study sought to explore the impact of bereaved family caregivers’ active involvement in medical and physical care on their experiences of the palliative care course of disease.

Unfortunately, the central concepts in this question were not operationally defined. Definitions of the attributes of family caregiver and active involvement would have strengthened the paper. Moreover, these definitions would have provided clarity concerning the inclusion criteria for bereft family members, and the ways in which determination of active involvement in care was discerned.

What is the theoretical framework for this study?

The authors state that it is unclear whether active involvement of family caregivers could be harmful or have a negative effect on their experiences of the palliative course of disease. I am not clear exactly what this means. Does it refer to the psychological and physical health of the family caregivers? If so, research has been conducted examining the issue of caregiver burden in end of life care that indicates whilst the caregiving experience has its rewards, it also has negative effects. That being the case, it is not clear why the authors conducted more qualitative work asking this question. If the authors believe that extant work in the field requires more descriptive work, it would have strengthened the manuscript if a compelling case had been made in that regard.

The setting is well described in this paper.

The sample for this study consisted of 7 spouses of terminally ill cancer patients who had been cared for at home. There is no description of inclusion criteria for family caregivers, save that they be bereft within the past 1-3 years. Contacting family members at this time shows ethical sensitivity, as hopefully issues of acute grief will have begun to be resolved.

It is not clear in the paper how many participants were contacted in total for the study. How many refused? Do we know if there are statistically significant differences in terms of demographic characteristics between participants and
those who did not take part?

There is no mention in the paper of whether or not this study received approval from a Research Ethics Board, and no mention of participants providing written informed consent. That some participants were family members recruited by a physician who had cared for their deceased relative is, in my mind ethically problematic. Despite the benevolent intentions of the researcher, issues of coercion and power differential exist in this instance, and thus an intermediary should have been used to recruit these individuals.

In qualitative research, data collection and analysis occur concurrently. Did this happen in the study? How were differences of opinion regarding the thematic categories that emerged in the data reconciled amongst the research team? The authors identify the use of triangulation within the group of researchers as ensuring the quality of the coding. This needs to be described more fully and issues of rigor as they apply to qualitative research that were used in the study need to be discussed. What were they and what were they intended to achieve? If additional measures to ensure rigor were not part of the study, what do the authors see the impact of this being on the merit of their work?

The conclusions drawn by the authors that their data, based on interviews with 7 family caregivers are “qualitatively representative of experiences among caregivers assisting with palliative care at home” is not defensible. Only spouses were interviewed in this study. There are many other categories of family caregivers whose experiences were not accessed. Therefore, a comprehensive understanding of the impacts of this caregiving cannot be empirically claimed.

Level of interest: An article of limited interest

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests.