Author's response to reviews

Title: Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK.

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Version: 4 Date: 2 June 2009

Author's response to reviews: see over
Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK.

Response to second set of referees comments

We are grateful for the detailed and helpful further comments from two reviewers. We were pleased that the third reviewer, after our changes following the first set of reports, felt the paper should go forward for publication. We have taken each of the comments of the two reviewers and responded to them and now submit a third version of the paper which we feel meets their reservations and incorporates there required and suggested changes. Each change made is detailed below in italicized comments after the reviewer comment.

We hope this new version can now go forward for publication.
Thank you, Neil Small (corresponding author).

Reviewer's report

Title: Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK.
Version: 3 Date: 6 April 2009
Reviewer: Richard Harding

Reviewer’s report:

MINOR ESSENTIAL REVISIONS
Background
1st paragraph
Do you have a reference to the comparison of trajectories CHF/cancer?

*We have added references to Gott et al 2007: Teno et al 2001 and Lunney et al 2003*

You rightly mention that service models have been framed on cancer care- there are several papers published reviewing the models/provision of CHF palliative care in the UK.

*We have changed the wording at the end of para 1 in background and added refs to Johnson and Houghton 2006; Murray et al 2002 and 2005*

Final sentence- it is not so important to write a paper that adds to the literature but to add to knowledge.

*Wording changed to reflect this point*

Results
To assist the reader to know that your 20 respondents were not from a single region you should state where participants were from with respect to your diverse study settings (which is a strength of your study).
Details of where respondents came from included in 1st para of results.

Discussion
It is very important to incorporate the literature on validity of retrospective information collected in bereavement stages in palliative care research.

We continue to make the point that our accounts are of carer views and in that sense are not proxy, they may be carers’ reporting what they think the cared for felt and experienced.
We have added reference to McPherson and Addington-Hall 2003 on proxies – also Higginson et al 1994 and Hinton 1996 on how reports gathered during bereavement can differ from those views expressed during the terminal stage.

Reviewer’s report
Version: 3 Date: 20 April 2009
Reviewer: Amanda J Young
Reviewer’s report:
----------------- - Major Compulsory Revisions
INTRODUCTION:
1. Although this version reads better and the authors have reduced the size of the introduction, there now seems to be a lack of literature about carer’s experience of end of life care.

We have added a sentence in the Background section making the point about the importance of carers but the absence of research in heart failure – to support this we have referred to Grande et al’s 2009 paper identifying gaps in the literature and future priorities for research, we have also added a reference to Clarke et al 2998 specifically about carers in heart failure.

2. There is still limited information about futility, which is discussed at great length in the discussion. Perhaps moving some of this into the introduction so that the reader has some idea about the purpose of the paper.

Extra sentence added to final paragraph of the Background to introduce the consideration of futility that will follow.

DISCUSSION:
1. I would propose moving the Agard study to the futile section of the discussion. Does this study warrant ¾ page though?

Agard section moved as suggested. We have not been able to cut this section and still communicate its main points and its relevance to our paper.
2. Although the discussion is now more clearly focused, I found some parts difficult to follow, particularly page 23 onwards. Possibly use sub sections to help the reader follow your main arguments/conclusions?

*We have reorganized parts of our discussion – moving the Agard study and other aspects of futility and adding linking/signposting sentences on p 23.*

- Minor Essential Revisions
  (Two points related to the aims of the study)
  **ABSTRACT:**
  1. The background section still needs to be more concise, “the study aims to/the aim of this study is to…”or what is lacking in the current literature?

  *This section has been cut to one sentence.*

**INTRODUCTION:**
1. The aim of the paper is still not clearly stated (what is the purpose? what is it assessing?)

  *We have expanded the final paragraph of the Background section to indicate the main themes of the article and capture what it is seeking to assess and how it builds on existing knowledge.*

- Discretionary Revisions
  **ABSTRACT:**
  The discussion section needs more clarity, what do the findings suggest? Possibly, “Our findings suggest that whilst carers use a range of strategies to cope with bereavement there is a need for continued support for vulnerable carers.”

  *We have changed the wording to take on this point.*

The authors very briefly mention depression at the beginning of the results section and again in the conclusion. However, there is no literature in the paper about depression and bereavement, is this a discussion point?

*In the results we have added references to Lloyd Williams and Payne 2002 and 2003 on depression and we have made a discussion point of the need to consider the impact of depression in carers as well as patients.*

- Needs some language corrections before being published:
  1. Page 6 – sentence consideration “(SB) and invited to participate in an interview” rather than invited to complete an interview.

  *changed*
2. Page 6 – “The coding that resulted was” does not sound right possibly, “the final coding from each researcher was compared”

changed

3. Page 8 – sentence consideration “a small number of the people had discussed with their family carer that they would prefer to die rather than survive a crisis and be helpless or immobile.”

changed

4. Page 11 – replace with “The death as an event…”

Changed

5. Page 22 – possibly delete the sentence “But both the increasing number of studies in this area, that we have reported above, and findings in this study..” and replace with “Our findings”

deleted as suggested

6. Page 22 – possibly delete the sentence “But even if discussion well in advance did happen it would not be enough.”

Word change – just deleted “But”

7. Page 22 – reconsider the last sentence on this page possibly consider “due to the progressive nature of heart failure advanced care planning needs to be regularly reviewed…”

We have decided to stick with our original wording.

8. Page 27 – reference 1 date (May 2995) error

Corrected to 2005

9. Page 28 – reference 6 no date

Date added