Reviewer's report

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

Version: 1 Date: 6 January 2009

Reviewer: Amanda J Young

Reviewer's report:

- Major Compulsory Revisions

INTRODUCTION:

General points:

1. The introduction includes important and relevant literature but it was difficult to follow. I felt that the introduction needs restructuring (prevalence of heart failure, current issues surrounding heart failure and end of life care, gaps in the research and the aims of the research?).

2. What is currently included in the introduction is relevant but I feel that the authors have missed some important policy documents. For example, the Mental Capacity Act, NICE guidance on heart failure and end of life issues, End of Life Care Strategy, Gold Standards Framework, National Service Framework, information about heart failure resources toolkits and research from Carers UK.

Specific points:

3. It would have been interesting to read, in the opening paragraph, the prevalence of heart failure with some referencing sources.

4. Page 4. The structure of the introduction needs to be addressed. The sentence “In this paper…” should be moved to the end of the introduction.

5. There needs to be a sentence at the end of the introduction to explain the aim/s and objective/s of the research. As it stands this is not clear in the paper.

6. Page 5. The references given for COPD and stroke do not match up.

METHODS:

7. Page 7 and 8. It would have been useful to have a breakdown of the exact number of carer participants legible to be interviewed. For example “All the family carers who had consented to be approached (number consented out of the total number approached, X/542?), and who had been bereaved during the study (X/542?)…”

8. The authors do not mention that this paper describes retrospective proxy accounts of heart failure. I feel that this is important for the reader.

RESULTS:

9. It would have been useful to have a table detailing the demographic details of
the study sample and possibly have a sub section ‘Sample characteristics’.

- Minor Essential Revisions

INTRODUCTION:

10. After reading through the introduction I felt that the authors could have included more relevant research:


Based on this I feel that the authors need to review their literature search.

11. In the discussion the authors describe in detail the discourse of futility. I feel that this needs to be introduced in the introduction section of the paper.

12. Page 4. Some of the information in this paragraph could be moved to the ‘methods’ section (“We will consider two themes…”).

13. The authors mention throughout the paper the lack of professional input during the end of life experience for carers but there is little information about this in the introduction. It would have been interesting to read current research about this. For example, GPs input, experiences and knowledge of end of life care.

METHODS:

14. This paper is a retrospective approach but it is not mentioned in this section of the paper.

15. The interviews covered a number of areas which I feel needs to be more explicit in the findings. For example, satisfaction with care and how care for people with heart conditions could be improved.

RESULTS:

16. The second opening paragraph discusses some important findings from the interviews and I feel that these seem to be more relevant to the aims of the research than some of the points discussed elsewhere in the results.

17. I feel that the authors could include more direct quotes to illustrate the findings and provide more evidence for the reader.

18. Under the second heading “The death itself” the authors have provided an opening paragraph which does not appear under the other two headings. I would
suggest keeping this consistent throughout the results section.

- Discretionary Revisions

INTRODUCTION:

19. The introduction includes important research related to heart failure and end of life care but it was not easy to read. It may be worth having sub sections to make it easier for the reader to read the different areas of concern and /or lack of research.

20. The authors do not mention in the paper the use of retrospective proxy accounts. Although I feel that this is important for the methods section it is at the discretion of the authors to include any research about retrospective studies and end of life accounts’ from proxies.

21. Page 5. The sentence “This study adds to the literature…” seems to read as a discussion point rather than as an introduction sentence. I would suggest moving this sentence to the discussion section or deleting it.

22. Page 5. The authors only provided one reference for the sentence “… but may not fit well with the experiences of people dying from other conditions.” More resource evidence needs to be applied to support this sentence.

RESULTS:

23. I found the results section relevant to the title of the paper but I did not find this section of the paper easy to follow. Although the results section is divided into the three time periods I felt that this could have been more clearly defined and support the opening sentence in the discussion (“this study adds to the literature both on the bereavement experience and on service and support needs relevant to people with heart failure near the end of life”).

A possible suggestion could be:

a. Dying (period leading up to the death)
   i. Carer experience
   ii. Service and support needs
   iii. Any other significant point/s from this section of the interview

b. The death itself
   i. Carer experience
   ii. Service and support needs
   iii. Any other significant point/s from this section of the interview

c. Bereavement
   i. Carer experience
   ii. Service and support needs
   iii. Any other significant point/s from this section of the interview

24. In line with the above, the section on page 13 “Health professionals” could be moved to the end of the opening paragraph of the results section. Alternatively,
rearrange the headings. As the paper stands it does not seem to be in the right place.

DISCUSSION:
25. Page 25. I feel that there could be some evidence to support the claims made in the second paragraph?
26. Page 27. Second paragraph. Unsure of the relevance to the rest of the points in the discussion section?
27. Page 28. The Agard et al study is important and a sentence about policy initiatives could be included here?
28. I feel that more could be discussed about service and support needs as I have interpreted this as one of the aims of the paper?
29. The limitations of the study did not include retrospective proxy accounts.

- Needs some language corrections before being published:
There are some errors in the paper which I feel need to be addressed before the paper can be accepted.
1. Page 5. Sentence structure “There has been some increase in attention paid to certain long term and disabling conditions such as heart failure.”
2. Page 6. Sentence structure “For example, current UK policy prioritises dying at home and home deaths are considered a measure of good end of life care.”
3. Page 8. Sentence structure “These twenty were self-selected therefore from this sub-population from the original study.”
4. Page 10. ‘They had’ instead of they’d.
5. Page 11. Sentence structure “While such a stance is most likely to reflect long held beliefs it also can also help carer and cared for become reconciled to the impending death.”
6. Page 12. ‘he had’ instead of he’d.
7. Page 13. Sentence structure “…reluctantly said she would discuss it if her father ‘approached’ (instead of opened) the subject, although when he did, albeit a little indirectly, she was still not able to respond.”

Level of interest: An article of importance in its field

Quality of written English: Needs some language corrections before being published

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.