Author's response to reviews

Title: After you: Conversations between patients and healthcare professionals in planning for end of life care.

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Author's response to reviews: see over
Please find below our comments (in purple italics) outlining how we have addressed the reviewers/reports. We would like to thank the reviewers for their helpful and constructive comments.

**Title:** After you: Conversations between patients and healthcare professionals in planning for end of life care.  
**Version:** 1  
**Date:** 12 June 2012

**Reviewer report:** H. Roeline W. Pasman

**Reviewer’s report:**  
This is a nice interview study on a relevant topic for BMC Palliative Care with clear research questions, mainly exploring discussions about ACP in a rather pragmatic way as the researchers state themselves.

I have some suggestions to improve the paper, and some parts are not clear to me:

1) (compulsory revision)  
In the first paragraph of the Findings, it is mentioned that the HCP is asked about the patient’s level of understanding of his/her condition and that this varied. It is not clear to me how many patients had a degree of “open awareness” (9? Or more than 9 of which 9 had reported that they had engaged in some level of conversation)? I think some more information about the degree of awareness is useful:  
- for instance an overview of level of awareness of all 18 included cases  
- were the questions to people who were not aware of their situation different from the other interviews? And if yes how? Did this effect the results?  
- the fact that HCPs were asked about the awareness could already be mentioned in the methods section

We have revised this paragraph to clarify:
- **How we are using the term ‘open awareness’**
- **An overview of the level of awareness for all 18 cases including:**
  - How many cancer and heart failure patients demonstrated a degree of open awareness (9 out of 13) and to indicate where this was harder to establish (with the remaining 4 cancer and HF patients)
  - Information relating to levels of ‘open awareness’ for the 5 respondents who were care home residents.
- **The fact that HCPs were asked to brief the researchers about the awareness is moved to the methods section**

With regard to the query about whether the questions to people who were not aware of their situation were different from the other interviews, and if yes how? Did this effect the results?:

We address these points in the new addition which is in the first part of the strengths and limitations section

2)(discretionary revision)  
Findings are now presented in two paragraphs, but the headings of these two paragraphs do not capture the content. In the first paragraph (reflections from
patients and family carers) also views form the HCP are included. I would prefer more content based headings, maybe more or less following the research questions.

We have sought to address this by changing the first sub-heading in the findings section to:
“Issues relating to the initiation of discussions around PPC”

3)(discretionary revision)
I assume that some parts of the Findings section suit better in the discussion paragraph (page 9 “At the time…planning for EOLC”) (page 10 “this may explain in part… relatively better.”) (page 14 “Guidance on ACP… opportunity”)

We felt that the parts referred to on page 9 and 10 were necessary to provide context to the findings but we have moved the section noted on page 14 to the discussion section.

4)(discretionary revision)
In the abstract and methods section it is mentioned that group interviews were held with HCP. It is not clear to me which data in the results come from these group interviews.

We have clarified this in the methods section and elsewhere. The group interview data was primarily drawn upon and reported on in Cox et al, 2011 but also used in the second section of the findings reported on in this paper. This paper draws on data from the HCP follow up interviews which provided another perspective to add to data from patients and relatives and this data is drawn upon in the first section of the findings.

5)(discretionary revision) In the abstract in the findings paragraph it is only mentioned that staff is hesistant to start conversations, but in the results it appears that also patients themselves are hesistant. I would add that finding to the abstract, as it is an important one and also mentioned in the conclusion of the paper.

We have noted this and added this in to the abstract

Reviewer report: Lucy Selman

This is an interesting paper on an important area for end of life care which has been neglected in research up to now. I have some suggestions below to improve the paper.

Abstract: the methods are a little unclear. You state 18 cases and then list numerous people without it being clear that the family members and staff are linked to each patient/case. This is a major strength of the approach and should be made clear. It is also a bit confusing how data were collected from HCPs i.e. through group interviews and then individual follow-up interviews - this needs justifying in the methods section.
We have clarified the connection between the interviews in the abstract. In the methods section we address the point about the different data collected from HCPs and where we draw upon this data.

1. Background: the case for why this study is so important and why advanced care planning needs investigating hasn't really been made. I suggest starting with the importance of and evidence relating to advanced care planning first, including its place in policy, and then discussing your study afterwards in terms of the gaps you are seeking to fill.

We have revised the background section, starting with the importance of and evidence relating to ACP, seeking to emphasise the case for why this study is important and the gap it seeks to address.

The sentence defining advanced care planning in the Discussion belongs in the Background.

We have moved this sentence as suggested.

2. Methods:
   i. Please clarify exactly how all participants were identified and recruited into the study.

   We have added information in the 2nd paragraph of the methods section to clarify this.

   ii. What portions of the topic guide does this paper relate to? It would be useful to ask what questions/topics were explored (some of this is in the Findings section at present).

   Added to the 3rd paragraph of the methods section.

   iii. Again, I think you could make it more clear that you are using a sophisticated case study approach to generate multiple sources of data on one case rather than interviewing groups of patients, carers and staff who are not related.

   We have sought to clarify this point further in outlining how we draw upon the data and the links between the patient cases and the HCP follow up interviews.

3. Analysis:
   i. what theoretical approach did you take to the analysis? comparative analysis is a general technique which fits into many different approaches.

   http://ebn.bmj.com/content/3/3/68.full.

   ii. It sounds like a thematic approach, in which case how was the coding frame developed? how many people took part in the development and the application of the coding frame?

   We have provided more detail to address the point in the methods section (last paragraph).

   iii. The fact that the coding frame had 56 items should be in the Findings section.

   Developing the coding framework was part of our analysis and so we felt this sits better in the section about methods rather than in the findings section.

4. Findings.
i. Where are the demographic characteristics of the participants? This information is essential to judge transferability. Perhaps present in a table together with when they were interviewed.

*We have included a table (Table 4) that provides some demographics of the sample (although not dates they were interviewed since that appeared to complicate the table unnecessarily).*

ii. The findings are presented in quite a descriptive and numerical way. e.g. 'the five participants in the nursing care home appeared least likely to have had..' I wonder whether it would be better to present some of the numerical data on who had and hadn't had PPC discussions at the different services in tables. This could help avoid using language which sounds like you are making statistical generalisations.

*We have attempted to do this in a previous version and found it did not work well; it was also difficult to summarise in a table without providing too much information that could identify individual participants.*

iii. Table 2 - there is nothing in the notes regarding the lack of follow-up at site 4

*We have addressed this point by adding a note – there is also a general note at the end of this table regarding sites where we could not do follow up interviews.*

5. Limitations: please reflect on:
   i. the fact that the sample of health care professionals was self-selected and what implications that might have for your findings.
   ii. the fact that only some cases were followed up.
   iii. more generally, the difference it will have made to the findings that recruitment was delayed at sites 3-5, leaving no time for follow-up. This is a major weakness and should be discussed.
   iv. the fact that some interviews were conducted separately and others joint - what difference would this have made?

*We have now addressed all these points in the limitations section.*

6. Language: throughout, use of terms and abbreviations is not consistent. Please make sure that the first time an abbreviation is used it is stated in full with the abbreviation in brackets, and that throughout the remainder of the text this abbreviation is always used. Examples where this is done incorrectly (often numerous times) are EOLC, PPC, HCPs, GPs. Also, sometimes you use italics for terms and sometimes not.

*This point has been addressed throughout the paper.*