Author’s response to reviews

Title: Palliative care for patients with motor neurone disease and their bereaved carers: a qualitative study

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Manuscript (PCAR-D-18-00173)

Authors

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Dear Editor

I am pleased to resubmit for publication the revised version of manuscript (PCAR-D-18-00173) “Palliative care for patients with Motor Neurone Disease and their bereaved carers: a qualitative study.” We are very grateful to you, the editorial team and the expert reviewers for taking the
time to review our manuscript and for providing valuable and constructive comments. We provide a point-by-point response to each comment below.

Yours Sincerely

Dr Clare Mc Veigh

(Email: clare.mcveigh@qub.ac.uk)

Response to Reviewer 1 Comments:

• Add ‘bereaved carers’ to keywords.

This had been accommodated on Page 2, line 53

• Literature review/background: Indication of origin of international literature and refer specifically to NICE guidelines.

This has been accommodated Page 3, lines 60 -69

• Methods

  • Indicate how many people were approached to take part

Twenty were approached and this is now included on page 5, line 108

• Why a sample of 13? Was this the total number of people who responded positively?

This was the total number of bereaved carers that agreed to partake in the study and participated in a semi structured interview. This information is now included on page 5, lines 118 and 119

• I question the relevance of including participants’ occupations in table.

Thank you for highlighting this. This information has now been removed from table 1 on page 6, line 123

• Where were the interviews conducted?

Conducted in bereaved carers homes and further detail has been added to Page 6, line 128.

• Were they all face to face?
All interviews were face to face, this has been added to Page 6, line 127.

- How long did the interviews last?
  Between 60 -90 minutes and this information has been added to Page 6, lines 128 and 129.

- When were the data collected?
  2015, this information has been added to Page 6, line 128.

- Which approach to thematic analysis was followed?
  King and Horrocks approach, this has been added to Page 7 line 136.

Findings

- I question the inclusion of % in a qualitative study
  Same removed, page 9, line 188

- The findings would be enhanced by a little more interpretation and analysis. Often the analysis consists of a short single sentence supported by a quote, meaning that there is a lack of depth to the analysis.
  Thank you for highlighting this, further interpretation has been added throughout the findings section. Please note, that findings are critically analysed and discussed within the discussion section.

- The introduction to each overarching theme lacks depth
  Each overarching theme has now been introduced in more detail:
  - Page 8, lines 166- 171
  - Page 10, lines 222- 229
  - Page 12, lines 279- 285

- It is slightly confusing that the quotes and sub themes are both presented in italics.
  Interpretative themes are now in italics and bold to provide further clarity and distinction:
  - Page 9, line 173
• P14 line 316 – the comparison with Ganzini et al should emphasise the difference in sample sizes and methodologies between the 2 studies, but I do question the comparison with such a small sample size and the qualitative nature of your study.

Thank you for this suggestion. This comparison has been removed from the discussion section.

Response to Reviewer 2 Comments:

Introduction

• A research question would add clarity.

Research question has been added on Page 4, lines 87-89

Methods

• It would be useful to know what qualitative research approach was adopted and why.

A broad interpretivist approach was adopted. This has now been included and discussed within the methods section on Pages 4 and 5, lines 97-100

• Does the MND register include diagnosis?

Further information on the MND register has been added to the methods section. Please see page 5, lines 110 and 111

• Please insert in the table whether the participant’s family member had received palliative care. It would also be useful to know what type of palliative care was received and for how long. Time since diagnosis to death would also be useful information to include.
Details now included in Table 1 in relation to SPC services and survival from diagnosis, please see Page 6, line 123. Data regarding the length of time which SPC services were received for was not collated.

• How long did the interviews last? Where did they take place? Some examples of questions and prompts needed. One interviewer? Was the interviewer experienced in conducting interviews and/or trained?

See previous response to reviewer 1.

• A section is needed on how quality/rigor was maintained.

Rigor section has been added within the Methods, please see Page 7, lines 148-155

Discussion

• It is not usual to have quotes in the discussion – I would suggest placing these in the findings section.

There are no quotes within the discussion section. All quotes can be found within the findings section.

• Typographical errors

Thank you, these have been addressed throughout the manuscript.

Overall

This study is very similar in design to that of Bentley et al. (2016): Bentley, B. & O'Connor, M. (2016). The end of life experiences of people with Motor Neurone Disease: Family carers' perspectives. Journal of Palliative Medicine, 19(8), 857-862. http://dx.doi.org/10.1089/jpm.2015.0538. The findings are also very similar.

The authors need to present a rationale about why their study was needed. They also need to highlight any novel findings from this study and if/how the findings build upon the previous work.

Thank you for highlighting this. The above paper has now been included in the discussion section, and discussed in relation to the present study (see Pages 14 and 15, lines 322-333). The discussions and conclusion section has also been strengthened to highlight the key findings from the present study.