Author’s response to reviews

Title: Palliative care for people with schizophrenia: a qualitative study of an under-serviced group in need

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Author’s response to reviews:

Dear BMC Palliative Care Editorial Office (Dr Pasman),

First, thank you for considering the above article with minor changes. The article has been uploaded, but I neglected to upload the authors responses to the reviewers. My apologies for the inconvenience. Please see below for our response:

Thank you for forwarding the detailed reviewer’s responses to our article entitled ‘Palliative care for people with schizophrenia: a qualitative study of an under-serviced group in need’. We acknowledge and appreciate their advice. Please see our responses and explanation of the changes made below.

Methods

Reviewer 1: The term ‘normative need’ is not clear why it is important to mention this.

Reviewer 2: ‘Normative need’ not clear. How has it been used in the study design.

Response: The concept of normative need is one aspect of Bradshaw’s taxonomy of social need which also includes felt, expressed and comparative needs. In this article we used the opinions of professionals who set a standard (or norm) which relates to their understanding of their patients’ or clients’ needs. It was part of the study design but we believe it will be too complex to explain the whole taxonomy so we have deleted this part of the methods (methods section, page 6, line 24-26 and page 7, line 31-32) and the associated original reference (27). All subsequent references have been adjusted.
Reviewer 1: Reference to a focus group was methodologically confusing. It is a small number and details about the chosen method were missing.

Response: We agree that it was incorrect to call an interview with three people a focus group. The three participants who all worked in the same location were interviewed together due to difficulties in scheduling separate interviews. They were asked the same interview questions, discussed similar cases, all were given the opportunity to contribute and the interview lasted two hours. We deleted reference to a focus group (methods section, page 7, line 12) and replaced the sentence with: ‘Three participants who all worked in the same location were interviewed together. Each participated fully and the interview lasted two hours.’ We have also included this as a limitation in the limitations section (page 21, line 55).

Results

Reviewer 1: A table on characteristics of participants would enlighten the mentioned limitations.

The results could be structured tighter into themes with headings, making them more results than descriptions.

The examples used to illustrate themes are not always strong and may be reconsidered.

Response: We had originally designed a table of characteristics of the participants in order to illustrate the strength of the sampling. This would have been used at the beginning of the results section and would have made it less wordy (page 9, lines 12-43). However, a number of the authors believed that due to the small community setting of the study, including a table of this kind could mean that the participants may easily be identified. In accordance with ethical requirements we had ensured the participants that their data would be treated in confidence. We agree the results section could be better structured with clearer headings. We have revised and reorganised the first domain entitled ‘People with schizophrenia at the end of life: challenges of a vulnerable group. This section (originally page 10, line 16 to page 14, line 12) now focuses on illness, social and health care factors that may affect people with schizophrenia at the end of life. We have also added a figure (Figure 1) to indicate the interrelationship between the factors. We believe the section will now be less descriptive and better reflect the results. Instead of two sub-headings there are now four.

The examples used and quotes used have all been reviewed. Most have been retained, but some have been reorganised to better reflect the new thematic headings and some have been removed (page 13, lines 1 to 17; page 12, lines 47 to 57).

In the second domain entitled ‘Barriers and facilitators to people with schizophrenia receiving palliative care’ we have revised and reorganised the results. The section on page 15, lines 1-45 has been deleted and the point about case-conferencing has been included in a sentence at the end of page 15. Reference to the model used in Western Australia has been deleted as it may be of limited interest to international readers.
Discussion

Reviewer 2: Could the authors add a paragraph to the discussion which discusses which of the findings are specific to people with schizophrenia and which can be translated to people with mental illnesses more generally or to people with other illnesses.

Response: A paragraph has been added in the discussion section on page 21, line 28. The paragraph briefly discusses why we chose to focus on people with schizophrenia for the study and how the findings may be relevant to other groups, eg. people with other severe mental illnesses, intellectual disability or short term psychosis.

Limitations

Reviewer 1: A table of characteristics would enlighten the mentioned limitations in this section.

Response: Please see the explanation above in the results section.

Also, we did not receive an initial email from the journal indicating the editor's decision about the article. This was brought to our attention when a reminder about a final date for revision was sent to the author last week. None of the other authors received a notification either. My apologies if it is now the journal's policy not to send out notifications of decisions.

Thanks for considering our changes and sorry for the inconvenience for sending this in an email.

Kind regards

Professor Beverley McNamara