Title: The experience of palliative patients and their families of a family meeting utilised as an instrument for spiritual and psychosocial care: A qualitative study

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Author's response to reviews: see over
The experience of palliative patients and their families of a family meeting utilised as an instrument for spiritual care: A qualitative study
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EDITOR REQUEST:

Remove list of ethics committees from title page and include in methods – done

Use track changes and leave these visible to aid editors in assessing changes - done

Reviewer's report 1
Title: The experience of palliative patients and their families of a family meeting utilised as an instrument for spiritual care: A qualitative study
Version: 2 Date: 12 November 2010
Reviewer: Peter Strang
Reviewer's report:
Generally, I find this paper interesting and well-written about an important topic. However, there are some structural issues that I would like to comment on:

Major compulsory revisions:
- The research question (aim) is not explicitly defined, even if I understand the aim. This could be clarified.

The focus of the research is clearly stated in the last few lines of the “Background” section on pg 6 the term psychosocial having been added.

“The current study investigated the experience of palliative care patients and their family members, of taking part in a family meeting conducted according to Murphy’s model, for the purpose of facilitating spiritual and psychosocial care.”

- my principal comments are on the definition of "spiritual" in relation to "psychosocial". Although the authors conclude that "spiritual" has many definitions and they choose "the web of relationships that gives coherence to our lives. Religious beliefs may or may not be a part of that web. This web may include relationships with places, things, ourselves, significant others and a power beyond ourselves".
I agree that this is one possible definition, but still the problem is (from a palliative point of view) that we always discuss the 4 dimensions: physical, emotional, social and existential/spiritual.
Most issues, e.g. "relationships" are more or less connected to all 4 dimensions, but still it can be MAINLY a social issue in certain contexts and MAINLY a spiritual in other contexts.
To me, the content and the examples in the Results section are mainly of psychosocial nature (which are important!!) and to a lesser degree spiritual.
Therefore, I have problems with the Title ("spiritual care"), as I read the Results as mainly "Psychosocial care" and just partly "Spiritual care"
Some examples: Theme 1: "relaxed and open atmosphere"
Theme 2: "been given an arena to say things"
Theme 3: "...surprised by... the degree of openness"
Theme 4: "...family bonds had been strengthened"
Theme 5: "informal, relaxed and un-pressured approach..."
Theme 6: "having more than one family meeting..." (would have been desirable)
Theme 7: "should be available to everyone.."

My point is, that for every theme, much of the results are related to important psychosocial issues (and the Murphy Model seems most useful), but I would like to see a crystallisation of the primary spiritual issues. There are definitely such examples also, but they are "diluted" by the psychosocial aspects.

My suggestion would therefore be to try to separate the more typical psychosocial issues from the typical spiritual issues (although I am well aware of the grey-zone).

Reviewer 2 & 3 are correct about the large number of definitions of “spirituality” and that 'meaning' is a common component. The definition we have used does in fact include meaning and has been re-written to express this more clearly pg 4. An explanation of how psychosocial care differs from and overlaps with spiritual care has also been added. Pg 4

The data both in Table 3 and in the text of “Results” has been rearranged into “spiritual impact”, psychosocial impact” and “Both”. As reviewer 2 has pointed out there are lots of shades of grey and this data does not fit easily into these boxes.

An extra section commenting psychosocial outcomes has been added to the discussion pg 24

If you go for that solution, the Title should be "psychosocial and spiritual care" and the spiritual issues should be motivated more in detail in the Discussion.

E.g. "sense of making contribution to research and others (Theme 2)" (=altruism) is meaning-making and in that sense spiritual whereas e.g. Theme 5 Meeting facilitation ("being informal and relaxed") is mainly about communication and in that sense a (psycho)social aspect.

One more example: Theme 2, 2nd para: "...motivated to initiate contact with an estranged grandchild" is mainly a social issues if you focus on re-establishing social bonds, but it may turn out to be an existential/spiritual issue if the underlying cause is guilt (related to man´s freedom to make choices, unethical choices may lead to guilt).

The word “psychosocial” has been included in the title and the abstract has been amended to reflect this change. As indicated above psychosocial issues have been identified in the results and have been referred to in the discussion.

My second main comment is that the experiences of the patients and the family members are mixed. I can see the point that a "family model" is for the whole family. On the other hand even a "family model" may be more suitable for either patients or for family members.

Therefore their experiences should be separated more clearly.

While reviewer 2 is correct in indicating that patients and family members may have different needs and will not necessarily benefit in the same way from a family meeting, to differentiate them too clearly would be to negate the premise that families also function as a system, the whole reason for choosing to use a family meeting.
method. The source of the quotes as being either ‘patient’ or ‘family member’ has been made clearer. Additional quotes have been included to show a greater balance in the reporting of patient and family member views. The fact that family members outnumbered patients by about 3 to 1 needs also to be kept in mind when considering this balance.

I would encourage you to revise the manuscript. I find the manuscript as a whole as interesting and important and methodologically sound.

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**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

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**Reviewer's report 2**

**Title:** The experience of palliative patients and their families of a family meeting utilised as an instrument for spiritual care: A qualitative study

**Version:** 2  **Date:** 22 November 2010

**Reviewer:** Scott Murray

**Reviewer's report:**

Family Meeting Review

1. The question posed by the authors is well defined; that is to investigate the participatory experiences of palliative care patients and significant family members in a family meeting.

2. The methods are appropriate and well described. The tables clearly set out Murphy’s model and the patients’ demographic details.

3. The data generated appear sound and a relevant and adequate amount is given to illustrate the main themes. The themes and sub-themes appear credible and well constructed.

4. The manuscript does adhere to relevant standards for reporting.

5. The discussion is clear, discusses study methodological limitations, and the conclusions very modest.

6. The limitations of the work are clearly stated including the need for more research in a wider more heterogeneous group.

7. The authors do refer to two other papers that they have published from this thesis.

8. The title and abstract clearly summarise the study.

9. The writing is very clear and excellently set out.

Discretionary revisions include:

Refer to any previous studies of family meetings being studied, or clearly state this is the first

The use of family meetings in Palliative care and how this one differs from other has been discussed more fully. See pg 5 of document.

Little more detail about next study needed in this area

A little more detail has been added see pg 27 of document
Reviewer's report 3
Title: The experience of palliative patients and their families of a family meeting utilised as an instrument for spiritual care: A qualitative study
Version: 2 Date: 30 November 2010
Reviewer: Irene J Higginson
Reviewer's report:
This paper uses a qualitative study to describe the family meeting as an instrument for spiritual care. The authors set out in the background and define spirituality as ‘the web of relationships that gives coherence to our lives’. They use a family meeting (a common practice in many aspects of health care) to improve this issue and have studied this informed by the methods of hermeneutic phenomenology – which seeks to reveal and convey deep insight and understanding of the concealed meanings of experiences based on observation and interpretation.
In general the paper is well written and interesting. Many of the aspects of the methods are clear.

The authors definition of spirituality is somewhat narrow – see perhaps the recent critique in the nursing literature - J Clin Nurs. 2009 Jun;18(12):1666-73. A critical view of how nursing has defined spirituality. Clarke J. More common definitions set out spirituality as ‘a search for meaning, which may or may not include belief in a higher power’ (see chapter by Speck P in Management of Advanced Disease, or Kearney and Mount in Handbook of Psychiatry in Palliative Medicine). I wonder if focussing on the web of relationships would be seen by many in the spiritual field as being too restrictive and lacking the concept of ‘meaning’ which pervade many definitions. This questions the title and the approach and needs discussion.

Reviewer 3 is correct about the large number of definitions of “spirituality” and that ‘meaning’ is a common component. The definition we have used does in fact include meaning and has been re-written to express this more clearly pg 4. Rather than being too narrow it could be argued (as reflected in reviewer 2 comments for instance) that our definition is too broad encompassing some commonality with psychosocial for example. Some more recent references have been included.

‘Psychosocial’ has been included in the title.

Some of the references and literature on definitions and concepts is rather old and would benefit from updating with some of the newer literature and models, such as those published in Soc Sci Med.

As indicated above some more recent references have been added.

The methods of reporting hermeneutic (or interpretative) phenomenology have
much criticised in the literature. Guidelines for reporting such studies are available. In general these include: assessing the credibility, fittingness, auditability and confirmability (see J Adv Nurs. 2006 Jul;55(2):215-29. Critical appraisal of rigour in interpretive phenomenological nursing research. de Witt L, Ploeg J.). The paper needs to assess its ability to stand up to these criteria. In this regard aspects of the method are missing – for example it would be usual to see two coders of the qualitative themes, or at least one checking another – this is not apparent in the text. This is especially important as it gives credibility to the themes identified. It is not clear how the quotes were chosen. In general in qualitative research it is important to look not only at confirmatory but also deviant cases as these often provide important information – how were these handled by the authors?

It is true that guidelines (more than one) are available for assessing rigour and credibility in qualitative data. A section has been added summarising measures taken to ensure rigour as they were utilised in this study and have been duly referenced. See pg 11. As indicated in the text they are available in more detail in an article already published relating to the methodology used in this study. One item of significance is the reviewers comment about inter-rater reliability in relation to coding. Not all qualitative research methodology experts agree with the view expressed by this reviewer. It is also not consistent with the understanding of hermeneutic phenomenology which is utilised in this study and has been explained in more detail as indicated below both in this paper and in one already published which is referred to in the text. There were not many “deviant” cases but where they occurred they have been recorded in the results.

In addition it would be helpful for the broad range of readers of BMC journals (and this reviewer) to see the authors definition of hermeneutic phenomenology and a rationale of why they chose this particular approach rather than other qualitative approaches.

A definition of hermeneutic phenomenology has been included and the reason for choosing this form of phenomenology as opposed to others has been given.(pg 7-8)

Of the 66 patients offered the family meeting only 12 eventually accepted it, most because of refusals. This brings into question the acceptability of the family meeting in this context. This point needs greater discussion.

We believe that this has already been discussed both in this article and the already published one which is referred to.

The family meeting is now reported quite widely. Their purpose is seen more broadly that that in this paper – e.g. for information sharing (Palliat Med. 2009 Mar;23(2):150-7. Family meetings in palliative care: are they effective? Hudson P, Thomas T, Quinn K, Aranda S.) – and there is also evaluative studies on training staff to conduct the family meetings (Palliat Support Care. 2009;7(2):171-9. Conducting family meetings in palliative care: themes, techniques, and preliminary evaluation of a communication skills module. Gueguen JA, Bylund CL, Brown RF, Levin TT, Kissane DW.). Therefore it would be helpful if this paper could consider more specifically its own contribution to the
literature, where is it adding value? I would have thought examining the role of the family meeting in providing spiritual support – would be valuable – as opposed to the other roles which are more restrictive. While the same themes might emerge it would help the readers to put it into a wider context.

The use of family meetings in palliative care is discussed more fully on pg 5, including how this one differs in its focus to others which have been reported.

Level of interest: An article of limited interest
Quality of written English: Acceptable
Statistical review: No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests: I have no competing interests