Author's response to reviews

Title: What matters most to people with multiple myeloma? A qualitative study of views on quality of life.

Authors:

Thomas R Osborne (thomas.osborne@kcl.ac.uk)
Christina Ramsenthaler (christina.ramsenthaler@kcl.ac.uk)
Susanne de Wolf-Linder (susanne.1.de_wolf@kcl.ac.uk)
Stephen A Schey (sschey@nhs.net)
Richard J Siegert (richard.siegert@aut.ac.nz)
Polly M Edmonds (polly.edmonds@nhs.net)
Irene J Higginson (irene.higginson@kcl.ac.uk)

Version: 3
Date: 29 May 2014

Author's response to reviews: see over
Dear Editor,

Re: What matters most to people with multiple myeloma? A qualitative study of views on quality of life.

We are delighted for the opportunity to resubmit this article to the BMC Cancer. Many thanks to the editorial team and external referees for your time and supportive comments, which have helped us to improve the article. I enclose the revised manuscript for your consideration, and a response to the referees’ comments below.

Referee 1 - Discretionary Revisions

1. In the ‘Issues interview’ section, more detail regarding how long the interviews took (average time) would be useful.

We agree and have added this information in the first Results paragraph under ‘Participants’ (Page 9).

2. I am curious as to why the POS was chosen as a comparator when it was not discussed in the 2012 systematic review of quality of life tools in the context of myeloma (Osbourne et al in Eur J Haematology)? While a brief explanation is given for choosing the POS, I am wondering if it was also chosen because of the relatively large percentage of patients in the relapsed/progressive disease phase. A brief expansion on this would provide clarification for readers.

We included the POS to allow exploration of views and preferences towards a tool designed specifically for clinical use (as opposed to use in research). The 2012 systematic review identified no existing questionnaire validated in myeloma that had been designed specifically for clinical application. The EORTC tools were designed specifically for use in research, so we wanted to add a clinical tool as a comparator. The POS also seemed a good choice because it was designed for people with any chronic for progressive condition. We have clarified this in the Methods under ‘Questionnaire Interviews’ (Page 6).

3. In the discussion section ‘views on existing QOL questionnaires’, some very interesting issues are discussed. In particular, some participants’ preference for the EORTC tools over the POS (even though the former has more items). I wonder was that because the EORTC MY24 questions specifically on symptoms common with myeloma (which patients may have felt was more relevant to them)? A brief comment on this would be useful here.
The referee’s comment refers to the Discussion section, but we believe it is referring the Results (under ‘Views on existing QOL questionnaires’, 3rd paragraph). The participant preferences discussed here were intended to be limited to the length of each questionnaire, not the content of the questions. We have attempted to clarify this in the text (Page 12).

Referee 1 - Minor Essential Revisions

4. In the ‘Questionnaire interview’ section, it is stated (line 197) that the questionnaires contained ‘a mixture of open questions, numerical and likert scales’. It is stated later that the POS only has one open question; this sentence should therefore be changed to indicate that only one open question was included.

We agree and have amended this in the text (Page 7)

5. Some brief clarification re EOTC MY24 is needed. It states in the ‘Questionnaire interviews’ section that the MY24 version was used. Some clarification is needed as to why it was decided to use this earlier version and not the revised MY20. Was it because of the findings from the issues interviews which had commenced before the questionnaire interviews?

The MY24 was revised to the MY20 by removal of 4 items due to poor psychometric performance (ceiling effects). There was no suggestion that these 4 items were irrelevant to QOL. We therefore opted to use the MY24 so the importance of these 4 items to QOL could be explored in our study. This was decided at the outset of the study, not in response to the preliminary findings as you suggest. We have clarified these points in the Methods under ‘Questionnaire Interviews’ (Page 6).

6. One minor editing issue to highlight: Methods, page 2, line 52, should read ‘focus group’ at the end of this line.

We agree and have amended this in the text (Page 2).

Referee 2 - Minor essential revisions

7. I was a little confused about the purpose of focus groups, which did not seem to be clearly described other than that they ‘complemented’ the semi-structured interviews (e.g. lines 53 and 130). These were conducted after semi-structured interviews had commenced, therefore were not used to guide development of the semi-structured interview topics and there is no mention of them being used to generate a different type of data through interaction between participants; were they simply a method of triangulation, or were you following the guidelines recommended by Brod? More discussion about their purpose would be useful.

We used individual interviews to offer privacy around sensitive topics and allow greater depth of discussion. We added the focus groups because new or different ideas may have emerged from group interaction. As you point out, this is also a means of methodological triangulation and is recommended best practice when establishing content validity in both new and existing patient reported outcome measures (Brod 2009). We have added more discussion and justification of this in the Methods under ‘Overview of study design’ (Page 4).

(We accept that no additional issues did emerge from the focus groups, and have added further discussion of this point, see comment 12 below)
8. Line 93: I think it would be useful if you describe more about the context of the Wilson and Cleary model (e.g. was it developed for cancer/all diseases etc.), as you draw on it later in the study.

We agree and have added more detail to this paragraph in the Background (Page 3).

9. Line 262: I presume the participants specifically consented to the use verbatim quotations, but it may be useful to say this directly.

We have added confirmation of this in the Methods under ‘Ethical Issues’ (Page 8).

10. Line 268-9: I wondered why so many participants were recruited from Kings College Hospital and so few from Guys Hospital? I’m not sure this was explained, or whether it was important?

The majority of participants were recruited from King’s College Hospital due to earlier Research and Development approval to recruit from this site. We have clarified this in the first Results paragraph under ‘Participants’ (Page 9).

Referee 2 - Discretionary revisions

11. Lines 52/53: I wasn’t sure you needed to present the number of people attending the focus groups in the abstract. I found the number of focus groups/people/topics (issues and questionnaire) somewhat confusing here, although there are typos on this line and it may be clearer when these are corrected.

We have corrected the typos with apologies. We have left the sample sizes in the abstract as we think this improves clarity (Page 2).

12. I was a little surprised that the focus groups with patients did not generate any different insights at all (e.g. lines 282 and 499 onwards). I agree that focus groups are not always needed alongside interviews; these have different purposes and generate different data and the method used should be that which is most appropriate for the research question. However, presenting this as you have gives the impression that the focus groups were slightly worthless afterthoughts and this undermines your study methodology somewhat. You possibly need to argue your case more fully here.

Although no new QOL issues were generated in the patient focus groups, the groups do help to demonstrate that theoretical saturation was reached independently of the chosen interview method (methodological triangulation), which therefore supports the validity of the findings. We have added this justification into the Methods under ‘Overview of study design’ (Page 4), and to the Discussion under ‘Methodological issues and limitations’ (Page 15).

13. Line 321: Do you mean the theoretical model of QOL developed in this study?

Yes. We have clarified this under the heading ‘Development of theoretical model of QOL’ (Page 10).

14. Line 505: you state that no new issues arose in the focus groups, but I presume this relates to the patient meetings, as you present new material from the focus groups with clinical staff.
Yes, this does relate only to the patient focus groups – we have clarified this in the text (Page 15).

15. Incidentally, you only conducted one focus group with clinical staff, but the reason for this was not explained/justified.

This was due to practical considerations. It was challenging to gather a multidisciplinary group away from the clinical service all at once. We have added an explanation in the Methods under ‘Sampling’ (Page 5), and in the Discussion under ‘Methodological issues and limitations’ (Page 15)

I hope you find the changes satisfactory, but please let us know if you have any additional comments.

Yours sincerely,

Dr Thomas Osborne  (corresponding author)

Visiting Research Fellow
Department of Palliative Care, Policy and Rehabilitation
Cicely Saunders Institute, King’s College London
thomas.osborne@kcl.ac.uk