Author's response to reviews

Title: Perceived Benefits and Barriers to Exercise for Recently Treated Patients with Multiple Myeloma: A Qualitative Study

Authors:

Melinda J Craike (melinda.craike@deakin.edu.au)
Kaye Hose (myeloma@leukaemia.org.au)
Kerry S Courneya (Kerry.Courneya@ualberta.ca)
Simon J Harrison (Simon.Harrison@petermac.org)
Patricia M Livingston (Trish.Livingston@deakin.edu.au)

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Perceived Benefits and Barriers to Exercise for Recently Treated Patients with Multiple Myeloma: A Qualitative Study

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3 April, 2013

Dear The Biomed Central Editorial Team

Re: MS: 1957577890856926 Perceived Benefits and Barriers to Exercise for Recently Treated Patients with Multiple Myeloma: A Qualitative Study

Thank you for consideration of our manuscript for publication in your journal. We could like to thank the reviewers for their considered and helpful comments. We have reviewed the manuscript according to your reviewer’s comments. We have addressed each of the reviewer’s comments below. We have also made some minor editorial changes throughout the manuscript. A copy of the amended manuscript with track changes and a clean copy are attached.

Thank you again and we look forward to hearing from you in due course.

Regards

Melinda Craike

Reviewer # 1

**Major Compulsory Revisions:**

1) Please report how many patients were written down for participation. How was the response rate? How many interviews could be completed and how many not?

This was an exploratory qualitative study that aimed to examine the perceived benefits and barriers to participation for patients with multiple myeloma. The sample was a selected using a purposive sampling technique and it was not an aim of the study to be representative of the broader multiple myeloma patient population. Patients initially self-assessed their eligibility and were later screened to confirm eligibility. Due to the nature of patient selection (ie a patient database where eligibility could not be confirmed) we are not able to report the number of eligible patients who received the initial mail out. A response rate can therefore not be calculated. However, as stated, a purposive sampling technique was used and we do not see this as a limitation to the study validity.

We have included that we used a purposive sampling technique in the ‘Research Participants’ section (p. 6)

Also, the small sample and potential lack of representativeness of the sample has been reported as a study limitation (p. 28).

We have included information relating to the number of people who responded to the mail out and the number of interviews that were completed and reasons for non-completion in the Sample and Clinical Characteristics section (p. 10).
2) It is crucial that detailed information on the stem cell transplant modality is missing. There are different treatment options (e.g.: autologous HSCT, tandem autologous HSCT and allogeneic HSCT). In particular for the allo setting major complications could be expected with regard to GvHD and other transplant-related complications. The complications may have a major impact on physical activity behavior.

Patients treated for multiple myeloma in Australia are treated with autologous stem cell transplant. Tandem and allogeneic SCT are not routinely offered to Australian patients. To clarify this in the manuscript, we have replaced ‘Stem Cell Transplant (SCT)’ with ‘Autologous Stem Cell Transplant (ASCT)’ throughout the manuscript.

3) Mandatory: More subgroup data/percentage data! E.g. page 13: “Almost all respondents felt that physical activity was beneficial to them. These benefits were reported as predominantly related to their recovery from treatment and coping with symptoms of MM as well as psychological benefits.” Please report percentage data here and review all sections in the manuscript and fill in quantitative data.

Qualitative research describes and explains the participants’ experiences, behaviours, interactions and social contexts without the use of statistical procedures or quantification. As such, many qualitative researchers reject the use of numerical data in their studies and it is convention in qualitative research not to include percentages of respondents. Furthermore, the open ended nature of questions and answers is not conducive to quantifying responses.

Our paper includes quantification of data where we believe that it is appropriate, ie from the data collected through the questionnaire, however adding percentages to the narrative qualitative data will not add to its interpretation and will detract from our emphasis explanation of the main themes in a contextual and in-depth manner. We refer the reviewer to published papers of similar studies by two of the authors [1], and other authors [2, 3]

4) Please report on the influence of the variable “time since treatment completion” on the current physical activity behavior and the change between pre- and post-treatment (page 11). Further parameters like treatment, region and level of education should be taken into account.

The authors agree that it is important to examine the influence of variables including time since treatment, treatment type, region and level of education on physical activity behavior. However, this was not an aim of this study and this type of analysis is not appropriate given the study design and small sample size.

Given the small sample size, it is not appropriate to present statistical analyses relating to differences in physical activity by time since treatment, treatment type, locality and level of education. A multivariate analysis is required to examine the statistical significance and relative influence of demographic and treatment characteristics on physical activity participation. Presenting descriptive statistics on the influence of treatment type, locality, age and length of time since treatment is likely to be misleading as there may be interaction effects of these factors, which
requires a multivariate analysis (for example, younger people are more likely to have ASCT and this might explain the relationship between treatment and physical activity participation).

5) Page 24: I think a RCT is not the right way to get more insight into the physical activity behavior of MM patients. A bigger quantitative and systematic survey (with regard to include also inactive MM patients) is need.

We have amended this section as requested (p. 28)

Minor Essential Revisions:

6) The sections on page 8: “As a way of validating the codes, three interviews were independently coded to check the interpretations of the coder and validate the themes. There was agreement between both coders as to the dominant themes and their interpretation of the meaning from the ideas represented in the interviews.” Remains uncertain with regard to the numbers of coders and interviewers. Please write more clear sentences.

The number of coders and interviewer has been clarified on pages 7-9.

7) Page 8: Remove the sentence “The sample group was younger than the overall population of MM patients, whose mean age at diagnosis is 70 years [1].” This should be mentioned in the discussion part.

As requested, this sentence has been deleted and moved to the discussion section (p. 28)

8) Page 9 (f): The n and % number in the same brackets looks a bit confusing. Sort them better by using a semicolon instead of a comma.

Done

Discretionary Revisions:

9) Write 2-12 month instead of two-12 month (consequent spelling)

Done

10) Page 8: “In the final stage,….” should be a new paragraph or the paragraph above should be removed

We have not made this a separate paragraph as there is only one sentence preceding this statement and we do not feel that this warrants a separate paragraph.

11) Word count for all sections, table count and line count is missing

This information has been added to the title page
Reviewer #2

Major compulsory revisions

I felt the data in this paper was potentially very interesting and of interest. However the paper would benefit from considerable reviewing on several levels. The abstract needs to include more detail. It would benefit from including the place and year of the data collection, and that the data was collected over the telephone. The abstract should also mention the grounded theory approach was used as this is stated further on in the methods section of the paper. The abstract also includes the abbreviations SCT without explaining the meaning. It is not very clear in the abstract if this is an intervention study.

Thank you to the reviewer for these positive comments. The abstract has been substantially amended with the changes suggested (p. 2). Dates of data collection and location have also been added to the Methods section of the manuscript (p. 7).

Overall the paper could benefit from far greater depth of detail. It would have more impact if fear quotes were given but more details about the context surrounding each quote. The quotes do not benefit from being listed with simply dotted lines separating them.

In the results section, we have reduced the number of quotes and added more detail in each section.

Under the section entitled measures. It is not clear if the interviews were done on the telephone. Surely it would be helpful if the grounded theory approach was mentioned here? Table 1 could be omitted as it was not very informative – this could be included in the text.

The words ‘telephone interview’ have been added to this section. We have also clarified the process of the questionnaire administration in the procedure section (p.7).

Table 1 has been deleted and information included in the text (p. 8).

The grounded theory approach has been added to the measures section (p. 8).

Some detail on the difference between the treatments of MM would help for those readers not familiar with the illness.

We have added a paragraph (paragraph 2) in the ‘Background’ section that describes the differences in the treatments of MM (p. 4).

In the results section the unit of measurement is needed for physical activity e.g what determines if the activity is vigorous, moderate or mild?
The ‘Measures’ section includes details of the physical activity measurement, including examples of light, moderate and vigorous intensity physical activity (pp 7-8). The physical activity measurement were self-completed by participants prior to the interviews, therefore the participants themselves determined what the intensity of their physical activity was depending on their own perceptions.

The paper would benefit from using fewer quotes and giving more context around fewer quotes rather than a list of quotes - of which not all were very illuminating. Some of the quotes did not seem to fit well under the subtitles given, but this may be resolved using fewer quotes and reorganising the subsections.

In the Results section, the number of quotes has been reduced and more detail regarding each subsection has been included.

The authors need to be careful of the use of "all" referring to the participants in a qualitative analysis. In particular the authors stated that "all" the participants enjoyed being physically active when a previous quote contracted this.

This has been noted and in the context of enjoyment the sentence now begins with ‘Most of the participants...’ (p. 18).

The section entitled Perceived Barriers to Physical Activity would benefit from having subsections with more detail e.g. fatigue. As stated previously fewer quotes would improve the paper. The authors should also give each quote a form of individual identification e.g. a number, or pseudonym in addition to the detail given this would enable the reader to see if the quotes are being used from the same person.

We have provided more details in each of the subsections of the section entitled Perceived Barriers to Physical Activity (p. 19). Following each quote in brackets we have included a participant pseudonyms as well as details about the participant.

In the section entitled "Low self motivation" the first list of dialogue from the transcript does not appear to comply from an interview using a grounded theory approach, it appears the interviewee is asking a leading question and suggesting the participant may lack motivation rather that the participant mentioning this unprompted.

In this conversation thread, the feelings that the participant could not be bothered or could not get going were raised by the participant. The interviewer then paraphrased what the interviewee was saying to clarify the point that the interviewee was making.
Similarly the second list of dialogue seems to merge the difference of lack of motivation and lack of interest in physical activity. This difference should be explained in more detail.

We have explained this difference in more detail (p. 21).

The discussion would benefit from a comparison of activity levels with the same age groups in the general population.

In the discussion we have added information relating to a comparison of activity levels of other cancer survivors as we believe that this provides a more meaningful comparator group than older adults in the general population (p. 23).

Also please could the authors confirm if it is possible to use a grounded theory approach using interviews by telephone.

Grounded theory is a process for the discovery of theory from data obtained from social research[4]. It refers to a research philosophy as well as a method of data analysis (the constant comparison method). Telephone interviews are an accepted way of gathering interview data in qualitative research and have been used in many qualitative studies that use grounded theory (e.g.,[5-7]). We have not found any evidence that this method is contrary to using a grounded theory approach.

Paragraph six in the discussion is unclear. The meaning of "instrumental" values is not clear and would benefit from some explanation.

We have re written this paragraph for clarification (p. 25).

The section on limitations should also include telephone interviews as a potential limitation to the data collected.

We have not included the telephone interviews as a potential limitation of the study. The interviewer in our study was very experienced at conducting telephone interviews and establishing rapport over the telephone. As discussed above, telephone interviews are an accepted way of gathering interview data in qualitative research and have been used in many qualitative studies (e.g.,[5-7]). We therefore do not believe that conducting interviews over the telephone was a limitation of the study.

References


7. Mottram A: 'They are marvellous with you whilst you are in but the aftercare is rubbish': A grounded theory study of patients' and their carers' experiences after discharge following day surgery. *Journal of Clinical Nursing* 2011, 20(21-22):3143-3151.