Author’s response to reviews

Title: Australian integrative oncology services: a mixed-method study exploring the views of cancer survivors.

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Version: 2 Date: 07 Feb 2018

Author’s response to reviews:

Dear Editor and BMC CAM reviewers,

Thank you for the opportunity to resubmit the manuscript Australian integrative oncology services: a mixed-method study exploring the views of cancer survivors BCAM-D-17-01286R1

We sincerely appreciate the reviewers’ comments. Below is our response in point form to each comment. A pdf tracking the changes to the manuscript has also been uploaded.

Your sincerely

Dr Jennifer Hunter

Reviewer reports:

Agnete Egilsdatter Kristoffersen, Phd, MA (Reviewer 1):

Manuscript Review: Australian integrative oncology services: a mixed-method study exploring the views of cancer survivors BCAM-D-17-01286R1
The aim of this study to explore cancer survivors' view and experience with IO in Australia is interesting and valuable. Also, the choice to include CALD groups that are underrepresented in Australian cancer research. As most of the participants (122/150) were Anglo-European/English-speaking Australians, the CALD groups are also underrepresented in this study, as quotations chosen to underline the findings also mainly (27/43) come from Anglo-European/English-speaking Australians.

To bring the view of the CALD groups more to the surface, and to make the result section more accessible, I suggest that the survey data is removed from this paper, and that the differences found between the four groups studied are discussed more in detail in the discussion section.

REPLY: Regarding the comment that the CALD groups were underrepresented. The statistic of 27/43 isn’t entirely correct. Many of the shorter quotes provided in the manuscript narratives are from the CALD focus groups. This in part reflects the shorter, stuttered nature of a group conversation that was often interrupted by the translator. We decided not to cite the source for each short quote as it would interfere with the flow of the sentences in the paragraphs. To increase the proportion of longer quotes that are attributed to CALD focus group participants, some of the shorter quotes have now been extended into longer quotes and other longer quotes from the CALD focus group interviews have been added. Further, if the short quotes were only taken from the CALD focus group discussions, this is now stated in the paragraph.

Respectfully, we disagree with the reviewer’s suggestion not to report the survey results. The aim was to ensure that both the views of cancer survivors from these three CALD groups, along with those from Anglo-European backgrounds were considered. This can only be achieved by reporting all the results from the mixed-method study. We also do not think it is valid to discuss in any further detail, some of the observed differences between the three CALD focus groups, as data saturation was not reached for each CALD group, only for the sample as a whole. This is highlighted when discussing the limitations of the study.

Abstract

Please add the aim of the study into the background section of the abstract.

REPLY: The wording has been changed in the abstract to include the study aim.

Background:

As T&CM seems to be offered both within and outside conventional health care in Australia, it would be useful for international readers to know to what degree T&CM is available for patients within conventional health care and how T&CM is financed.

The prevalence of IO use in Australia should be presented in the background alongside information about where IO is offered, outside or within public health care. I suggest that line 779-783 is moved to the background section.
REPLY: Lines 779-783 have been moved the background section. This is followed by a brief outline of how IO and T&CM services are financed in Australia.

To represent the CALD groups, Arabic, Chinese and Vietnamese populations was chosen. What was the rational for choosing these groups and not for example indigenous Australians?

Some background information on the chosen groups should be placed in the background section.

REPLY: The rational for selecting the three CALD groups reflected the prevalence of these communities in South West Sydney region where the research was located. Although Australian and Torres Strait Islander peoples are also common in this region, these communities were not included due to the logistical constraints of the project. Rather than discussing this in the background, since the decision was pragmatic, the rationale for sampling the three CALD groups has been added to the Methods and is further highlighted when discussing the limitations of the study.

Methods:

The rationale for including the caregivers is not clear and is not part of the aim for the study. Was the caregivers also cancer survivors or are they interviewed as caregivers? If they were not cancer survivors in addition to being caregivers, they must be removed from the analyses or the aim of the study must be adjusted accordingly. A description of how the caregivers were recruited, which ethnic group they belonged to, and their relationship with the patients is also lacking.

REPLY: In the Results: Sample and response rates, an explanation is now given as to why four of the Arabic focus group participants were caregivers. Although their recruitment was unintended, the participants’ caregivers were nevertheless invited to participate in the focus group discussion. Table 1 has also been amended to clarify that all four caregivers participated in the Arabic focus group interview.

Results:

The result section is difficult to access and need to be restructured to be more readable.

Line 238-240 should be moved to line 287 so that the result section start with sample and response rate and participant characteristics.

REPLY: The opening paragraph has been moved to follow Table 3 and has been expanded to address the reviewer’s comments below about subthemes.

Line 254: 3.6 seems like mean and not median. The Median years since diagnosis of the focus group (FG) participants is presented as 8 in the text and 6 in the table. The range is missing for the survey respondents. I also suggest that the range of years (age) is reported both for survey
respondents and FG respondents. I also suggest that there is given information of the gender of the FG participants and a more detailed description of the care-givers (e.g., in which way are they care-givers, gender, age and ethnicity).

REPLY: 3.6 years is a median, it was calculated using months and then converted into years. The typo in the text has been corrected, the median years since cancer diagnosis was 6, not 8. Ranges have been added. The gender of focus group participants has been added to Table 1. As mentioned previously, details about the four caregivers has been added.

Table 1 has missing text in the lowest row opposite for 6 and 0.3-30. Average age is given for the participants; please specify if this is mean or median age.

REPLY: All rows in Table 1, column 1 now have text. The Average age is the mean.

I find it problematic that information of gender is missing on the survey participants as the pattern of T&CM use is very dependent of gender. Based on the diagnoses it seems like the proportion of men might vary between 3.3 and 34%.

REPLY: The missing data on gender has been acknowledged in the study limitations.

In Table 3 the total number of T&CM users is not mentioned, only the non-users of 7.8% giving 92.2% users of T&CM. I suggest that the total number of users is presented in table 3.

REPLY: The total number and percentage for T&CM use has been added to Table 3.

The themes. In the beginning of the result section (line 238-240), two main theme, 1. Postive perceptions and experience with CAM and 2. Barieres and unmet needs are presented with the sub themes 2.1 Strutural barieres and 2.2 Personal barieres. When the results are presented, theme 1 is first presented with 6 sub themes in line 290-300 (Cancer survival, Side effect, Comorbidities, Positive experience with provider, Hospital based TCM and Would recommend). In the main text seven sub themes are presented as sub headings, leaving Hospital based TCM and Would recommend out and adding three new themes: Perceived positive impact on wellbeing, Downplaying negative outcomes and Positive experiences with IO services. This should be corrected so that the identified themes also represent the sub headings. The same problem in found for theme 2 : Barieres and unmet needs line 394-396 identified the themes: Inadequate service; Lack of funding; Referral pathways; Medical practitioner's attitudes; Lack of information, and Service location as Strutural barieres and further Impairment and disability; Attitudes; Beliefs; Knowledge about TCM, and Available personal resources as Personal barriers in line 396-399. In the main text however, the following themes are used as sub headings: Lack of avalibility of IO services; Difficulties with referral pathways and information; Absence of medical practitioner support; Difficulties with access and Cost of care is used.

REPLY: The presentation of the thematic qualitative analysis now begins by listing the two themes and all their subthemes.
The opening paragraph for Theme 2: barriers and unmet needs has been edited so that the 5 main subthemes are clearly stated along with their relationship to the other two interrelated subthemes, structural and personal barriers.

I also recommend a more structured way to present the data under the sub headings as this varies as the manuscript stands now, starting with data from the surveys some places and only the results from the FG interviews other places.

REPLY: The quantitative and qualitative data were analysed concurrently and are therefore presented concurrently. To help the reader navigate the thematic analysis, following Table 3, a new subtitle has been added - “Thematic results”. This section begins with two paragraphs, each summarising one of the two major themes, their subthemes, and the data sources. The final, third paragraph explains how the mixed method results are presented. This paragraph has been moved from the methods.

The quotations are sometimes labeled with ethnicity and FG, sometimes with nothing and sometimes with just survey.

REPLY: As mentioned previously, the shorter quotes are presented using a narrative style. We decided not to cite the source for each short quote as it would interfere with the flow of the sentences in the paragraphs. Longer quotes are labelled according to the data source. These have been moved to Tables 4 and 5.

I recommend that gender (when known) and age is added, also for the survey participants and specified if care givers are quoted.

REPLY: For quotes from the focus groups, data on gender was accidentally not collected and it is not possible to provide any identifying information about the participants. Firstly, the transcripts were only audio recorded, so we cannot determine who is speaking. Secondly, even if it was possible, providing such information would potentially threaten the confidentiality of individual participants.

For the quotes from survey participants, data on gender was also accidentally not collected. Although age and other characteristics are available, providing such data would be out of place with the information provided from the focus group quotes where only information about the source of the data is provided. Further, it would add little to the overall interpretation of the results.

I think the manuscript would profit from a shorter result section with the findings presented more to the point. Each theme should be presented separately with a clear statement of the main findings, followed by fewer quotations just to illustrate the point.

REPLY: In shortening the length of the results section, we would run the risk of reducing the representation of quotes from CALD groups and would be unable to address earlier recommendations to ensure greater representation in the long quotes. We propose transferring the longer quotes into two tables. In doing so, the results section is considerably shorter.
Discussion

The discussion section is very short compared to the result section. The discussion section would benefit from a more in depth discussion around the findings including a more detailed discussion around strengths and limitation of the studies, comparison to other studies and interpretation of the findings.

REPLY: We have only slightly lengthened the discussion as the paper is already quite lengthy. This has included the addition of more references. We consider that the interpretation of the findings has already been addressed through in-depth presentation of the results.

Conclusion

Due to the highly selected participants in this study, the results should be interpreted with more care and not be generalized to cancer survivals in general.

REPLY: A qualifying statement in the third sentence has been added to the conclusions.

Haryana M Dhillon (Reviewer 2):

This is an excellent manuscript reporting the results of a mixed methods study conducted amongst cancer survivors who are or have been treated for cancer, about their use during and after anti-cancer treatment. However, there are some questions and recommendations for consideration, these may strengthen the manuscript completely.

How may the sampling strategy in both the qualitative and survey impact the results?

REPLY: A clearer statement about the limited generalisability of the study due to the sampling strategies has been added to the discussion about the limitations of the study.

How were demographics collected in participants requiring an interpreter? Were they translated in written form, or information collected via interview with interpreter?

REPLY: Basic demographics were collected via a simple paper questionnaire that was written in English. The interviewers and translators assisted participants when language was a barrier. This has been added to the Method section - Procedure and instruments.

Survey items: can you specify how many of the 26 questions were closed and how many were open questions?

REPLY: The following information has been added to the description about the survey questionnaire. Open ended questions were used to collect the demographic information; eleven of the close ended questions were followed by an open ended question asking for an explanation to the response; seven multiple choice questions included an open ended option “Other (please
specify)”; and the survey ended with a section for further comments. This has been added to the Method section - Procedure and instruments.

It would be preferable to include the opening statement of the results after the section describing the sample and response rate. Its present location disconnects it from the subsequent results reported.

REPLY: The opening statement about the qualitative analysis has been moved as recommended.

Table 1. Given the small number of participants in the focus groups, reporting percentages should be rounded to the nearest whole number. Use of decimals in this context is not informative.

REPLY: Decimals have been removed

Table 2: the text for long-term treatment, including … is truncated and unreadable.

REPLY: This appears to be a formatting problem with the conversion to pdf. To avoid a repeat, it has been changed from “Long-term treatment, including rehabilitation” to “Long-term treatment / rehabilitation”

Are the quotes in section 'perceived positive impact on side-effects and recovery' all from the Chinese focus group or a mix - it is not possible to tell from what is reported.

REPLY: This has been amended to more clearly demonstrate the source of the quotes.

Page 29/39 line 766: why is there a need to state this is the largest study of its kind? This does not add to the importance or strength of the study - it stands on its own merits. Recommend amending this statement.

REPLY: This statement has been removed.

Page 29/39 line 770: refers to findings aligning with other research, but cites none. Please included citations here.

REPLY: References have been added to support the statements made in the paragraph.

Similarly lines 775-777: are there references further supporting the assertion it is not surprising patients expressed a need for greater IO services.

REPLY: The phrase has been removed.

Page 29/30 line 791-792: the phrasing 'patient affordability' seems odd, this implies the patients are affordable rather than the therapy. Consider rewording.
REPLY: “Patient affordability” has been changed to “affordability”.

Page 31/39 line 836: I am not sure why this statement is included, use of social media networks was not measured as an outcome in the study, it is unclear on what basis the statement was made, particularly as efficiency of recruitment is not reported in via any proportional numbers. Please reconsider the statement.

REPLY: The statement has been removed.

Typos

Page 20/39 line 510: change "were better placed that specialists" to "were better placed than specialists"

Page 23/39 line 617 recommend spelling out asap within the quote Page 26/39 line 696 'complimentary' should be 'complementary'

REPLY: The two typos have been corrected.

Additional file 2:

Question 13 appears to replicate exactly question 12 was this as the survey was sent out or an error in constructing this file?

Also under question 12, text reads 'If yes go to Q18; if NO go to Q22' mean either way questions 13-17 are not answered - please clarify.

REPLY: The survey was constructed in SurveyMonkey and was only answered on-line. A paper copy of the questionnaire was manually created for the purpose of this publication and it is a lot less user-friendly. There is a typo that has now been corrected. Following Q17, participants were skipped to Q23, not Q22 as is currently stated in the paper transcript.

Otherwise, the skip logic for Q11-22 is correct. The logic is as follows:

In Q11, if the participant stated they had used any of T&CM therapies in Q10, then they were asked to answer Q13-17. After which, they were asked to answer Q23-30.

In Q11, if the participant stated they had NOT used any of T&CM therapies in Q10, then they were asked to answer Q12.

In Q12, if the participant also stated they had NOT used any of T&CM products, then they were only asked in Q22 why they had not used any T&CM therapies or products. After which, they were asked to answer Q23-30.
In Q12, if the participant stated they had used T&CM products (but none of the T&CM therapies listed in Q10), then they were asked to answer Q18-21. After which, they were asked to answer Q23-30.

Suzanna Zick (Reviewer 3):

Interesting and nicely done manuscript.

Please revise introduction so you spell out CALD the first time you use it.

REPLY: The first time CALD is used, it is now spelt out in full.

Sociodemographic Table: Fix the heading where text is missing (looks like in a second row that was cut off) that ends with "...including"

REPLY: This appears to be a formatting problem with the conversion to pdf. To avoid a repeat, it has been changed from “Long-term treatment, including rehabilitation” to “Long-term treatment / rehabilitation”