PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (**http://bmjopen.bmj.com/site/about/resources/checklist.pdf**) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	The experiences of Australian men diagnosed with advanced prostate cancer: a qualitative study
AUTHORS	Chambers, Suzanne Hyde, Melissa Laurie, Kirstyn Legg, Melissa Frydenberg, Mark Davis, Ian Lowe, Anthony Dunn, Jeff

VERSION 1 – REVIEW

REVIEWER	Nancy Carter School of Nursing, McMaster University, Canada
REVIEW RETURNED	20-Oct-2017

GENERAL COMMENTS	This is a well written and comprehensive manuscript. Methods are clearly described. The presentation of data is done well in text and tables. The choice of quotes from study participants allow in-depth understanding of their experiences. The discussion section includes up to date literature.

REVIEWER	Carol Rivas University College London, UK
REVIEW RETURNED	26-Oct-2017

GENERAL COMMENTS	The paper's key strength lies in the fact that it considers men with advanced prostate cancer. There is limited qualitative data on this group though the paper reveals no great surprises. My main concern is that there are important omissions on approach and the study findings are not well set in the context of existing research. I appreciate there is a limited word count but things have not been said that are critical. Some detailed comments are provided below. Abstract Make clear the participants are from a larger study and in the main text explain how this affects representativeness. Strengths The strengths are described as transferable, valid and reliable but these statements have not been well backed up in the paper and

	moreover I am not clear how a subgroup of a main study equates with these. This seems to be a select and articulate group. Transparent – as claimed – the study is not without as starters a brief description of the larger study sample – while much of this study detail can simply be referenced it is important not to throw the baby out with the bath water Nowhere can I see any evidence that phenomenology was used, beyond the author’s statement that they did so, and Patton is scarcely the person to reference for this approach! Method Describe the particular phenomenological approach/tradition used. Given that you mention this as being a theoretical approach the lack of theory is surprising. See for example http://www.tandfonline.com/doi/full/10.1080/14780887.2011.608466 for guidance. Add detail on the main study group as mentioned above and specify the type of sampling used in main and this study (convenience?) Specify how representative this group is of the men in the main study and the general population – and describe on this basis how transferable the findings are. Critique your own study. Go through COREQ and make sure all points are in fact covered in the paper as they are not. Ironically some of the points not covered are especially relevant to a phenomenological analysis that considers analyst relation to the data. Findings What does ‘men’ mean? All the men, a handful? While qualitative research does not require counts to be used, this is just too vague. It is good to use relative terms at least such as most, many, some, a few. This should be clarified throughout. The regret theme should be reconsidered as: a) it is a biased theme (what about men who show no regret?) and b) there is no evidence presented to show men felt regret; they may have felt other emotions and this seems like forcing the data to fit. The being discounted theme also seems biased if all the men had bad experiences – if they truly did this needs to be unpacked. In terms of support groups, did some men actually like them. Consider ‘deviant’ or appositional viewpoints to get at a richer whole, throughout the analysis and reflect on the impact of your own biases. Under care coordination you state psychosocial support as important yet earlier you state that men did not want such services. Clarify. Discussion Contrast the gap in responses to advanced PCa with other cancers. Is PCa different and why or why not? Contrast with non-advanced PCa. The reference to ageing which the authors seem to suggest is novel with implications and ditto the masculinities comments are the norm in PCa qualitative analysis – ageing references are seen as a form of normalising to cope and there are more papers about PCa and masculinities than any other topic. So the discussion needs to be rewritten and placed better within the context of existing research. The ‘almost’ unique aspect of this study as written is the advanced nature of the disease and not any of the themes. Line 17 of p 24 cite the references to other research and don’t just self-cite but consider the broader literature.

VERSION 1 – AUTHOR RESPONSE

We would like to thank the reviewers for their positive comments about our manuscript and constructive suggestions for improvement. We greatly appreciate advice that the paper is a “well written and comprehensive manuscript with methods clearly described” with a key strength “it considers men with advanced prostate cancer”.

We have addressed suggestions for improvement as outlined below, with changes highlighted in bold in the manuscript.

Reviewer 2

Comment: Make clear the participants are from a larger study and in the main text explain how this affects representativeness. Add detail on the main study group as mentioned above and specify the type of sampling used in main and this study (convenience?) Specify how representative this group is of the men in the main study and the general population – and describe on this basis how transferable the findings are. The strengths are described as transferable, valid and reliable but these statements have not been well backed up in the paper and moreover I am not clear how a subgroup of a main study equates with these. This seems to be a select and articulate group. Transparent – as claimed – the study is not without as starters a brief description of the larger study sample – while much of this study detail can simply be referenced it is important not to throw the baby out with the bath water

Response: Our study focus was to recruit men with advanced prostate cancer, that is hormone resistant or metastatic prostate cancer. The cohort from which these participants were recruited was a national sample that included participants from five different states across Australia. This was a sampling frame that responded to both recruiting men with advanced disease, who are a minority compared to men diagnosed with localised disease, and meets the important purpose of drawing as diverse a sampling frame as is feasible with regards to geography and treatment centre. Within the word limits of this journal we now include more detail on the initial sampling frame (page 4, last paragraph).

We now also in this paragraph comment that the group of men who were interviewed had a similar age range to the sample from which they were drawn and represented four different Australian states. We also have added comment on the educational backgrounds of the men.

In the Discussion we now note that given the involvement of participants across four Australian states with varied sociodemographic backgrounds our data can be considered broadly relevant across the Australian setting (page 13, second paragraph).

We have also added a comment as a limitation that we did not have an ethnically diverse sample and provide a reference to the work of Rivas et al (2016) 1 for this.

Comment: Nowhere can I see any evidence that phenomenology was used, beyond the author’s statement that they did so, and Patton is scarcely the person to reference for this approach! Describe the particular phenomenological approach/tradition used. See http://www.tandfonline.com/doi/full/10.1080/14780887.2011.608466 for guidance.

Response: We have further outlined that our approach was to take an interpretive phenomenological approach and now state this in the Abstract, the last paragraph of the Introduction, and in the first paragraph of the Method. We have revised the references including adding the reference preferred by this Reviewer 2.

Comment: Go through COREQ and make sure all points are in fact covered in the paper as they are not. Ironically some of the points not covered are especially relevant to a phenomenological analysis that considers analyst relation to the data.

Response: We have added more detail on the background and experience in the field of the data coders, and gender, to inform the analyst relation to the data for the reader (last paragraph, page 5). We note that, as outlined in our method, our process of data analysis involved multiple readings of the data, and cross-checking between five authors to minimise bias.

Comment: Findings. What does 'men' mean? All the men, a handful? While qualitative research does not require counts to be used, this is just too vague. It is good to use relative terms at least such as most, many, some, a few. This should be clarified throughout.

Response: We concur that qualitative research does not require counts to be used. In response however we have now clarified in text whether we refer to all men in the study, most men (more than half); many (at least one third); or some (less than one third).

Comment: The regret theme should be reconsidered as: a) it is a biased theme (what about men who show no regret?) and b) there is no evidence presented to show men felt regret; they may have felt other emotions and this seems like forcing the data to fit.

Response: We are unsure why this reviewer has labelled regret as a biased theme and suggests that we have provided no evidence of men reporting regret. In response we now include an additional quote in Table 3 where the man specifically used the word 'regret' (see Table 3); and have now included in text the proportion of men who described regret about either a late diagnosis where the opportunity for cure was missed or where the man made decisions about treatment for which they described not being sufficiently informed. This was most men.

Comment: The being discounted theme also seems biased if all the men had bad experiences – if they truly did this needs to be unpacked.

Response: As requested we now advise that most men described feeling discounted. The basis on which this was described by the men, as outlined in our paper, was linked to their older age and public perceptions of prostate cancer as a cancer men die with not of, and associated controversies about the value of the early detection of prostate cancer. We have added additional quotes to Table 3 to support this theme.

Comment: In terms of support groups, did some men actually like them. Consider 'deviant' or appositional viewpoints to get at a richer whole, throughout the analysis and reflect on the impact of your own biases.

Response: Appositional viewpoints have been described where they occurred.

For example, we describe in the theme about fear/uncertainty about the future that while most men wanted more specific information about what the future held in terms of their time of life left and treatment options, other men did not want to know what the future held and preferred to focus on the present day.

With regards to peer support we note that while most men saw shared experience as an important source of support, some men described barriers such as feeling uncomfortable sharing in a group or not wanting to focus on psychological issues (See page 11).

Comment: Under care coordination you state psychosocial support as important yet earlier you state that men did not want such services. Clarify.

Response: We do not state that men did not want psychosocial services. We report in the theme of masculinities that many men described psychologists and support groups as not being a preferred method of support.

By contrast and as we report, many men did see shared experience in the cancer context (i.e., sharing experiences with other men who have advanced prostate cancer) as helpful. But as we note men did not always describe shared experience as a support group, and again as above there were aspects of peer support not seen as helpful.

With regards to Care Coordination, some men described a number of care aspects, including the provision of psychosocial support, which they thought should be integrated into routine care. As we note in this section of the results, nurses were described as a preferred source of emotional support for some men.

Comment: Contrast the gap in responses to advanced PCa with other cancers. Is PCa different and why or why not? Contrast with non-advanced PCa.

Response: The purpose of this study is to better understand men's experiences of advanced prostate cancer and from this clarify what support services might best meet their needs. A discussion of difference between, for example, men with advanced prostate cancer and women with advanced breast cancer would be very interesting but is beyond the scope and word limit of this paper. Again, we outline in our Introduction the differences between men with advanced vs. localised disease where the treatment methods and outcomes, and hence the illness experience are markedly different. A contrast between these two groups and their supportive care preferences would also be interesting but again outside of scope and word limits.

Comment: The reference to ageing which the authors seem to suggest is novel with implications and ditto the masculinities comments are the norm in PCa qualitative analysis – ageing references are seen as a form of normalising to cope and there are more papers about PCa and masculinities than any other topic. So the discussion needs to be rewritten and placed better within the context of existing research.

Response: The purpose of this study, as stated in the Introduction and noted above, was to better understand men's experiences of advanced prostate cancer and from this clarify what support services might best meet their needs. The Discussion is therefore framed around discussing the results in regard to what they tell us about men's preferences for support in this context. Previous studies on the support needs of men with advanced prostate cancer are referenced and it has not been the case that these studies have as a matter of course discussed masculinity. As examples, Carter et al 3 4 who examined advanced prostate cancer supportive care needs from both a patient and health professional perspective does not discuss masculinity. Our study adds to and builds on this work. Similarly, a recent systematic review and qualitative synthesis of men's unmet supportive care needs for all stages of prostate cancer did not identify masculinity as a descriptive theme 5.

We have that we have now added reference to the additional research by Carter et al (2014) 4. As well, we reference a recent comment by Jenkins and Fallowfield (2016) about the critical gap in knowledge about the information needs of men with advanced prostate cancer 6.

Comment: Line 17 of p 24 cite the references to other research and don't just self-cite but consider the broader literature.

Response: Line 17 of p 24 is Figure 1 illustrating our coding structure and so does not include references, hence we are unclear exactly what this comment refers to. We note that we cite our own research where it is needed and relevant. We do focus our references on advanced prostate cancer as this is the focus of this study. As above we have now added reference to the additional research by Carter et al (2014) 4. We have also added reference to the research on ethnicity and the prostate cancer experience by Rivas et al (2016) 1 in the limitations section.

References

1. Rivas C, Matheson L, Nayoan J, et al. Ethnicity and the prostate cancer experience: a qualitative metasynthesis. Psycho-Onc 2016;25(10):1147-56. doi: 10.1002/pon.4222
2. Davidsen AS. Phenomenological Approaches in Psychology and Health Sciences. Qualitative Research in Psychology 2013;10(3):318-39. doi: 10.1080/14780887.2011.608466
3. Carter N, Bryant-Lukosius D, DiCenso A, et al. The supportive care needs of men with advanced prostate cancer. Oncol Nurs Forum 2011;38(2):189-98. doi: 10.1188/11.ONF.189-198
4. Carter N, Miller PA, Murphy BR, et al. Healthcare providers' perspectives of the supportive care needs of men with advanced prostate cancer. Oncol Nurs Forum, 2014:421+.
5. King AJL, Evans M, Moore THM, et al. Prostate cancer and supportive care: a systematic review and qualitative synthesis of men's experiences and unmet needs. Eur J Cancer Care 2015;24(5):618-34. doi: 10.1111/ecc.12286
6. Jenkins V, Fallowfield L, Jenkins VA, et al. No man's land: information needs and resources of men with metastatic castrate resistant prostate cancer. Support Care Cancer 2016;24(11):4471-73. doi: 10.1007/s00520-016-3358-0

VERSION 2 – REVIEW

REVIEWER	Carol Rivas UCL, London UK
REVIEW RETURNED	20-Nov-2017

GENERAL COMMENTS	You have addressed the major concerns thank you.

VERSION 2 – AUTHOR RESPONSE

19th January 2018

Dr Trish Groves
Editor in Chief
BMJ Open

Dear Dr Groves,

Thank you very much for the opportunity to revise and resubmit manuscript bmjopen-2017-019917.R1 entitled: "The experiences of Australian men diagnosed with advanced prostate cancer: a qualitative study".

We appreciate the editors and reviewer advice. We have addressed specific comments from the reviewers and editor as below and believe that this has strengthened the manuscript further. Changes in the text of the manuscript are tracked.

Reviewer 2

You have addressed the major concerns thank you

Response: We thank the reviewer for this comment.

Editor

- For all manuscripts that include details, images, or videos relating to an individual person, written informed consent for the publication of these details must be obtained from that person. The data included in Table 1 of your manuscript contains three identifiers (Age, Marital status, time since diagnosis) and alongside the quotes included in Table 3, mean that the study partcipants are potentially identifiable. Consent for publication is therefore required (see http://authors.bmj.com/submitting-your-paper/patient-consent-and-confidentiality/) in order to publish the data included in Table 1. If consent for publication has not been obtained from all participants please modify the data provided in Table 1 in order to remove one of the three identifiers provided.

Response: Thank you for bringing this to our attention. We have removed marital status from table 1 and reference to this in the legend (See page 17).

- Please revise the title of your manuscript to include the study setting (location).

Response: Thank you for this suggestion. We have revised the title to read ‘The experiences of Australian men diagnosed with advanced prostate cancer: a qualitative study’ (see page 1).

Once again, thank you for the opportunity to revise and resubmit our manuscript and for the helpful guidance from the Reviewers and the Editor. We look forward to your further advice.

Yours Sincerely,

The Authors