

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Experience of living with cancer and comorbid illness: protocol for a qualitative systematic review
AUTHORS	Cavers, Debbie; CunninghamBurley, Sarah; Watson, Eila; Banks, Elspeth; Campbell, Christine

VERSION 1 - REVIEW

REVIEWER	Peter Coventry University of York, UK
REVIEW RETURNED	03-Aug-2016

GENERAL COMMENTS	<p>This is a useful addition to protocols that aim to describe qualitative reviews and in this context it is especially challenging given the novelty of the research area.</p> <p>I do have a couple of substantive points:</p> <p>1. Because the authors have however suggested that there is a 'dearth' of research about the linkages between cancer survivorship and living with long term conditions it seems difficult to maintain that there will be sufficient literature to conduct a meta-ethnographic review with the aim of generating new theoretical insights about 'cancer plus'. So I am not so sure the title which is suggestive of a more conventional review is consistent with the broader aim of a synthesis that draws on meta-ethnography. Perhaps the authors can deal with this tension in the discussion as part of a reflexive section on the pros and cons of narrative based systematic reviews of qual work versus more theory driven reviews using meta-ethnography. I would not think this demands much re-writing but more of a reflection on a contingency plan for the analysis and synthesis if the data does not lend itself to meta-ethnography (and page 8 suggests that only a few studies are likely to be found).</p> <p>2. The other major point I have relates to the links between this review and other work that aims to identify what to do next to inform research and practice. Can the authors be clearer here about the aims of the review - is this about generating theory (possibly), identifying critical research questions for applied studies, and/or applying qual methods to an area that has not been well researched (so here the study also serves as a methodological contribution too). The objective and methods section here could be used to make this clearer.</p> <p>Couple of other things:</p> <p>1. The search phase is used to identify relevant studies and not a sampling frame.</p> <p>2. The three step screening description seems a bit over written. Is this not about screening titles, abstracts and full texts? You can write</p>
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	<p>that in one sentence.</p> <p>3. I didn't follow the idea that a low threshold will be used for inclusion (using patient perspectives to identify LTCs) but also using the Barnett list of LTCs. Isn't the idea of looking at patient views on burden and impact part of the results rather than the screening phase?</p>
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REVIEWER	<p>Mary Wells Professor of Cancer Nursing Research and Practice, NMAHP Research Unit University of Stirling Scotland UK</p> <p>I know four out of five of the authors and collaborate with two of them.</p>
REVIEW RETURNED	16-Aug-2016

GENERAL COMMENTS	<p>This paper addresses a very important and topical issue with significant implications for future cancer care. The experiences and needs of patients with cancer and other comorbid conditions are not well researched to date and there is a real need for robust evidence to guide developments in research and practice in this area. This review therefore has the potential to be an extremely useful piece of work and I look forward to reading the results.</p> <p>The overall approach of this review is sound and I would support the publication of the protocol in order to highlight that this important work is being done. However, I think some amendments to the paper are needed in order to enhance its clarity, both conceptually and methodologically. I also think a short section on limitations should be added.</p> <p>I hope that the following suggestions are helpful: -</p> <ol style="list-style-type: none"> 1. To re-write the introduction. Currently this introduces numerous different concepts and issues including experiences, psycho-social support needs, identity, quality of life, access to services, quality of care, patient-centredness, primary care roles, survivorship, without a clear description of what all these mean, why they are all important and how they might relate to each other and to the core focus of the review. At present, the introduction sometimes gives the impression of being a list of important issues rather than a clear rationale for the study. Particular issues are emphasised e.g. identity and psychosocial support, but the rationale for these being central to the topic under investigation is not made explicit. The specific relevance of the review to primary care needs to be clarified. I appreciate that primary care practitioners may well take the main responsibility for managing comorbidities, but think the topic of the review is also highly relevant to those in secondary care. 2. Later on in the paper, further concepts and topics are introduced in the Dimensions of Interest section (p 7) and in Box 1 (search strategy) e.g. health behaviours. Unfortunately this adds somewhat to the slightly confusing introduction. It may be helpful to reduce the number of concepts introduced on the first page and expand the dimensions of interest section so that over-arching concepts and issues to be examined in the review are unpicked and clarified in this section, making links to the search strategy to follow. 3. The research questions could be simplified. I found myself having to read some of them several times. Also - some of the questions are not about the 'lived experience' of people with cancer and other comorbidities, but the rationale for only including qualitative evidence
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	<p>in the review is because the focus is on 'lived experiences'. Later on (page 9 line 31) the authors discuss including literature on 'managing' long term conditions which is different from 'lived experience'. It would be helpful if there was greater consistency throughout the paper.</p> <p>4. Related to the above point, a stronger justification for a qualitative synthesis could be made.</p> <p>5. On page 6 line 19 the authors talk about informing current theory on complex illness but they do not state what this is, whose theory, and why this needs to be added to. I assume they mean that the review will add specific insights on living with cancer and other comorbidities but it would be helpful to state this more explicitly.</p> <p>6. I am intrigued as to where the term 'cancer plus' comes from and I wonder if this would be a helpful or meaningful concept for patients affected. It sounds to me like an 'extra' and I feel that it needs further explanation.</p> <p>7. Although the methodology for the review seems sound, I have some questions and suggestions: -</p> <p>a) Inclusion and exclusion criteria could be tighter. For example, will the search include studies written in non-English language? Is the literature of interest only about people who already had a long term condition and then developed cancer or will it also refer to people who have cancer and then develop long term conditions so that they are living with both. Page 6 suggests that the former is the case.</p> <p>b) could the PRISMA table be annotated so that it is clear how the PRISMA criteria are being addressed in this review?</p> <p>c) will data extraction include details of the sample, demographics, cancer type and comorbidity type(s)? These seem important.</p> <p>d) is the intention necessarily to find one overarching concept as in grounded theory? I don't think this is necessarily possible within a meta-ethnography.</p> <p>e) I think it would be useful to expand the section on meta-ethnography, as the description is very brief and does not really discuss how meta-ethnographies should be reported. The authors may find a paper by France et al helpful http://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-14-119</p> <p>8. Some of the comorbidities listed in Appendix 2 may be difficult to separate from the long term side effects of treatment e.g. hearing loss, which the review intends not to address. It is not entirely clear whether the low threshold to be applied for included conditions will apply to those conditions that are on Barnett et al's list or to others which are not. What exactly is meant by those that are most prevalent? Does this mean the proportion or number within individual studies or the prevalence of conditions across different studies? Presumably the prevalence of conditions will to some extent at least be dependent on the type of cancer studied.</p> <p>9. There are a few typos and some unclear sentences e.g. on page 10 line 18 it says 'abstract screening will be undertaken by DC and another reviewer in adherence to systematic review guidelines' - are there words missing? A careful proof read is recommended.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1

Substantive comments

1. Thank you for this really helpful and thoughtful review. The over ambitious aim of conducting a meta-ethnography is consistent with a concern I have and I fully take this on board. I have introduced

Thomas and Harden's thematic synthesis as an alternative method providing more detailed guidance. In addition, given the resources I have and the likelihood of a small number of papers, I have changed the methods section to reflect the possibility of a narrative synthesis of the extracted review data being more appropriate.

2. Thank you again to both reviewers for encouraging greater clarity about the aims and focus of the review, and how this relates to other work. I have tightened this in the aims and methods section.

Other comments

1. I agree that the aim of the searching phase is to identify relevant articles for the review and have edited this on page 7 accordingly.

2. Although I have kept some of the detail in this section for full transparency, I have edited it heavily to reflect the simplicity of the three step title, abstract and full text screening process (page 9-10).

3. I agree that this section is confusing and I have removed reference to drawing on patients' perspectives of what qualifies as a long term condition (page 6).

Reviewer 2

Thank you to reviewer 2 for the time they have taken to engage with this review and the proposed methodology, it is very much appreciated and I find the comments very constructive and helpful to improving the focus of the review and the quality of its execution. I would like to respond to reviewer 2's points as follows:

1. I can appreciate that introducing such a number of concepts at this stage is unwieldy and although it was intended to reflect the broad and exploratory nature of the review and what we anticipated as being potential issues, I can see that it detracts from the focus and rationale for the study. I have taken the reviewer's comments (points 1 and 2) on board edited the 'introduction' and 'objectives' sections accordingly, to build a clearer picture of how understanding experience of cancer and comorbid illness can provide insights on how services can meet their psychosocial needs.

2. As above, I have expanded the dimensions of interest section to elaborate on different aspects of lived experience to link it more clearly to the search strategy.

3. I have edited the research questions in order to simplify them. In addition, I have made edits to keep a consistent thread throughout the manuscript with regard to a focus on lived experience of cancer and comorbid illness.

4. I have expanded the justification for focusing on qualitative evidence in the proposed synthesis (see Design section, page 5).

5. I agree that the terminology I have used here is misleading and I have adopted reviewer 2's suggested wording. (page 5)

6. I am grateful for the feedback on the term 'cancer plus' and I can see how additional illness is being construed as a bonus. This has been separately brought to my attention and I will give some thought to another way of representing cancer and comorbid illness. In the meantime, I will remove reference to 'cancer plus' from the manuscript.

7. a) I have edited this to include the suggested detail and clarify inclusion criteria. I think there is value in including the perspectives of people diagnosed with cancer before and after a diagnosis of another long term condition and will edit to reflect this. (page 6)

b) I will upload an annotated PRISMA-P checklist

c) I agree these are important characteristics to extract from included studies and I will add more detail to describe extracted information. (page 10)

d) I have taken on board comments from reviewers 1 and 2 about the proposed method to synthesise the findings from the review and I have revised this to include Thomas and Harden's thematic synthesis, and the possibility of producing a narrative summary if more conceptual insights are not possible. I have also clarified that the output is not necessarily just one over-arching concept (now in relation to thematic synthesis as well as meta-ethnography).

e) Thank you. I have followed up on the paper by France and colleagues and reflected further on the appropriateness of using meta-ethnography in this review, as per point d) above and have added a sentence to describe what I propose to report on. (page 11)

8. I have edited the inclusion criteria to limit included conditions to those listed on Barnett et al's list to remove any doubt about which conditions will be included. I take on board that there may be difficulties in separating the cause of the comorbidity reported in the literature. If articles do not clearly state the root of the condition (e.g, congenital deafness versus treatment-related hearing loss), these will be analysed and reported separately in the review findings. I have added this information to the manuscript and I hope it adequately addresses the issue (page 6).

9. Myself and the other authors have proof read the revised manuscript and have attempted to remove any unclear sentences or typos.

VERSION 2 – REVIEW

REVIEWER	Peter Coventry University of York, UK
REVIEW RETURNED	02-Nov-2016

GENERAL COMMENTS	This is a much improved protocol paper that I think will be a very useful resource for researchers who want to engage in a form of qualitative synthesis that goes beyond aggregating existing studies but offers a way to interpret the available evidence to generate questions and hypotheses for future research. I think the authors have done a good job at addressing my chief concern over the tensions of proposing meta-ethnography in the absence of a critical mass of individual studies. The aims are also much more doable and in line with the approach proposed.
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REVIEWER	Mary Wells NMAHP RU University of Stirling UK I know the authors of this paper and collaborate with one of the co-authors
REVIEW RETURNED	10-Nov-2016

GENERAL COMMENTS	The revisions have addressed my comments and improved the manuscript considerably. It is now much clearer. For future reference, it is always helpful to include the reviewers' verbatim comments as well as the author's response to these, as the reviewers' reports are not included on the journal page. I think one small thing needs to be clarified before publication and this is on page 10 within the first data synthesis paragraph. The authors point out that reporting guidance for meta-ethnography is under development and then say 'However, thematic synthesis...lends itself well'. I think the approach of thematic synthesis is reasonable, but the way this is written gives the impression that the author is saying because the reporting guidance isn't available yet, an alternative approach has been chosen in thematic synthesis. I appreciate that reporting guidance does help in clarifying the approach to be used but it isn't essential for conducting a meta-ethnography, as the steps for this are already defined (as described in the first draft of this manuscript). Therefore, I would suggest that the authors provide a brief justification of thematic synthesis as opposed to meta-ethnography. It may be that they want to refer to the reporting guidance under development but I think the issues of reporting are a little different to the issues of conducting a meta-ethnography and would suggest this is clarified. Other than
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that I have no further suggestions.

VERSION 2 – AUTHOR RESPONSE

Reviewer 1

Reviewer Name

Peter Coventry

Institution and Country

University of York, UK

Please state any competing interests or state 'None declared':

None declared

Please leave your comments for the authors below

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THANK YOU FOR YOUR COMMENTS.

Reviewer: 2

Reviewer Name

Mary Wells

Institution and Country

NMAHP RU

University of Stirling

UK

Please state any competing interests or state 'None declared':

I know the authors of this paper and collaborate with one of the co-authors

Please leave your comments for the authors below The revisions have addressed my comments and improved the manuscript considerably. It is now much clearer. For future reference, it is always helpful to include the reviewers' verbatim comments as well as the author's response to these, as the reviewers' reports are not included on the journal page.

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than that I have no further suggestions.

THANK YOU FOR TAKING THE TIME TO READ AND REVIEW MY REVISED MANUSCRIPT. I TAKE YOUR COMMENT ON BOARD ABOUT REPORTING GUIDANCE NOT BEING PROHIBITIVE FOR CONDUCTING A METAETHNOGRAPHY AND HAVE EDITED THE TEXT TO REMOVE THIS IMPLICATION. I HAVE ALSO EMPHASISED WHY A THEMATIC SYNTHESIS MAY BE MORE APPROPRIATE.