Author's response to reviews

Title: Understanding older women's decision making and coping in the context of breast cancer treatment.

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Author's response to reviews: see over
Dear Mr. Joerg Dirmaier,

Thank you for considering our manuscript for publication in *BMC Medical Informatics and Decision Making*. We are very grateful for the reviewers’ comments and have modified the manuscript accordingly.

Please find below the details of our responses to the reviewers comments.

Yours sincerely,

Kate Lifford, on behalf of the co-authors.

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**Reviewer 1 report:**

The manuscript presents results from a secondary analysis of qualitative interviews with older breast cancer patients. The authors examined decision making and coping mechanisms used by older women as they considered whether to have surgery or primary endocrine therapy. It is a well written report on an understudied topic and would be a contribution to the literature. The tables provide a nice sample of patient quotes illustrating the different aspects of the framework. A few suggestions however to strengthen the manuscript.

Response: We thank this reviewer for their positive review and helpful questions and suggestions. We have addressed each point in detail below and made a number of changes to improve the manuscript.

**Major revisions**

1. In the abstract, intro and methods the authors should clarify that this is a secondary analysis of a data set.

   Response 1. Clarification that this was secondary analysis has been added to these sections (page 2, paragraph 2; page 6, paragraph 1; page 7, paragraph 2)

2. More details about the interviews would be important – was there a structured interview guide? Given that this is secondary analysis, how did the CODE framework influence the interview guide (assuming there was one)? Given that there were two interviewers listed, how were they trained and how was the fidelity of the interview assessed?

   Response 2. We thank the reviewer for raising the question about the influence of the CODE framework on the interview guide as this is important for the interpretation of the results and the potential limitations when drawing conclusions. Further details of the interview guide have been added to the methods section (page 6, paragraph 3), stating that the guide was not built based on the CODE framework specifically. The guide has already been published as supporting information for the paper presenting the primary analysis of the interviews (Burton et al 2014). If the reviewers and editors feel it would benefit the paper we could investigate whether this could be published again as supporting information for the current manuscript. Both interviewers have prior experience of conducting qualitative research and this had been added to the manuscript (page 6, paragraph 3). During the data collection phase of the study the interviewers discussed their interview experiences. However, as no formal process for assessing...
fidelity to the interview was used, we have not included any further details in the manuscript.

3. Please add more details on the coding process, e.g. who coded the interviews? Why were only 20% double coded? How much discrepancy was there between the two coders? Please present results from the analysis of reliability of double coding.

   Response 3. We have clarified in the text that JW conducted the coding (page 7, paragraph 2). As one of the key developers of the CODE framework (Witt et al 2012) she was well qualified for this. Reviewing 20% of the transcripts for their coding was a pragmatic decision (page 7, paragraph 2) and reliability was not calculated as the transcript coding was reviewed rather than blindly double coded.

4. There seem to be inconsistencies with the eligibility criteria. If eligibility criteria were within 5 years – how is it that the range of time from diagnosis is much longer than five years? Also an eligibility criteria is that they were offered both surgery and PET yet they present results that many women were not offered both—how were patients assessed for eligibility? Why were patients who did not meet eligibility included in the data set?

   Response 4. The reviewer has raised a few interesting and important questions here, which we have deliberated upon and discussed both prior to and since receiving this feedback. Patients were assessed for eligibility by site staff (healthcare professionals/research nurses). Time from diagnosis was assessed in varying ways, the majority based on reports from the women themselves during interviews and some based on clinicians’ reports (page 8, paragraph 1), hence the latter might be influenced by recall bias (as suggested in the discussion). While it is unfortunate that some of these women seemed to fall outside of the eligibility criteria, we felt that the specific number of years since the diagnosis and decision was not crucial to our interpretation of the data. We acknowledge that there may be more recall bias, however considering individual differences in recall, anything over 1 year may be difficult to remember, hence excluding the few who reported being diagnosed more than 5 years ago seemed unnecessary.

   With regards to the criteria of being offered a choice, there is more than one possible explanation for this (page 15, paragraph 1). There might have been an error when reviewing eligibility (and this may also apply to the length of time since diagnosis). Alternatively, the understanding of “offering a choice” might be understood differently among healthcare professionals. For example, for one it may mean that the patient was presented both options equally, asked about their preferences and the two options discussed, however for another it may be that one treatment was recommended but an alternative was mentioned within the discussion (this may be particularly important as there is a need for further guidance on who surgery or PET would be appropriate for). Another alternative for these women not reporting not being offered a choice could be that they do not recall the alternative (and this might be especially so if they were not interested in the alternative) or did not understand that the choice was offered.

5. The results are very difficult to interpret due to the vague wording (e.g. “some patients described difficulty with the decision and others felt pleased they were offered a choice” or “many patients did not perceive they had a choice”). Please report how many patients from
the sample actually supported the themes and results presented. This comment applies to most of the results section and is critical for helping the reader interpret the results.

Response 5. This was a qualitative analysis of a relatively small number of participants. We therefore consider that reporting the specific number of participants reporting each theme would not support the purpose of the study, which was to achieve a rich understanding of older women’s deliberation and coping, rather than sample representativeness. In fact, including precise numbers of participants who reported a particular theme may misrepresent the data, for example in cases where women contradict themselves during interview. We have however added a footnote (which was previously missing in error) to the tables (1, 2 and 3) to explain that the questions that are in bold text represent those that were explored by many women during primary appraisal, (the other questions were explored by fewer women).

6. In the discussion it would be helpful to draw the links more clearly to the need for decision support in this population. The implications written seem so generic that that they are not providing any insight and could have been written without the study (e.g. decision support tool should recognize individual variation in decision making and should have concise easy to understand information). What issues or gaps did the authors find relevant to this population of older women that might help developers? What gaps did they find in the quality of decisions for this population and what are the key information needs of these patients that might differ for younger patients?

Response 6. We agree that the implications seem somewhat generic and have now added further detail to the specific areas to be covered in a DSI (page 15, paragraph 3 and page 16).

Minor revisions

7. In the analysis section – it is not clear what the authors mean by the first sentence “The interviews were analysed using a framework approach.” Perhaps this could be deleted as the next sentence seems to be more relevant?

Response 7. Strictly speaking a “framework analysis” was not used (not all data were coded, only those relevant to the CODE framework, and codes were not added as necessary as the framework was already defined) hence we had used the term “approach”. However, we have made revisions to this section and deleted this unclear sentence and added further detail of the approach we used (page 7, paragraph 2).

8. Please present results on the response rate for the study (how many women were approached for interviews and how many agreed and completed the interview).

Response 8. Due to the data collection methods we unfortunately do not have accurate data on how many women were approached for an interview (page 7, paragraph 3). Study invitation packs were distributed to participating sites and records were not kept in all sites about how many were handed out. We recognised that this is not ideal, however we felt that rather than give an approximation, which will likely be incorrect, we have not reported how many women were invited.
Reviewer 2 report:
Thanks you for the opportunity to review this manuscript describing the findings of a qualitative study exploring how older women engage in decision-making about breast cancer treatments and how they cope with these decisions.

Decision-making and treatment options for women diagnosed with breast cancer at an older age have not been extensively explored. This study represents a novel and important new assessment of the issues confronting women in this age group.

The study was well conceived, the analysis carefully conducted and reported. The manuscript is very clearly and concisely written - in fact the clarity of the presentation could be mistaken for simplicity. However, the authors are presenting a very nuanced analysis of the results.

I do not have any suggestions to improve this report. I look forward to seeing it in print.

Response: We thank this reviewer for their positive comments on our manuscript.

Reviewer 3 report:
The authors report on a well-developed study of decision-making and coping by older women facing breast cancer treatment decisions. They identify a gap in the literature, and use a conceptual model as a guiding framework for a qualitative exploration of issues. Their discussion and conclusions are based on reasonable inferences from the results, and they clearly state the limitations. I see no major compulsory revisions. I was confused enough about the methods that I would like the authors to clarify in a minor essential revision, in very explicit terms, that they re-analyzed data, using the CODE framework, from interviews that had previously underwritten a more grounded or inductive analysis. See below. Finally, I think the authors miss an opportunity to explicitly link their findings to the design of a decision aid. I leave that to their discretion.

Response 1: We thank this reviewer for their positive review of our manuscript and their thoughtful comments and suggestions. We have made a number of changes based on these to improve the manuscript. Details are below.

Minor Essential Revisions
1. In the abstract, the authors should edit the two sentences quote below, as the second is hard to parse. Consider “These included: past experiences of cancer;” etc (separated by semicolons). [“However, a number of considerations which women made throughout the deliberation process were identified. Appraisals related to past experiences of cancer and its treatment, scope for choice, risks, benefits and consequences of treatment, instincts about 45 treatment choice, as well as healthcare professionals’ recommendations.”]

Response 1: We have made this change (page 2, paragraph 3).

2. I would ideally like to see a much clearer and more explicit explanation in the methods of the provenance of the data and the relation of this analysis to that done in citation 3. The reader is referred to citation 3 for methodological details, and then (in results and discussion) told it is a “secondary analysis.” My inference (which the authors need to correct with more explicit explanation) is that they re-analyzed data from the same set of
interviews. This should be stated explicitly. In the original interviews, according to citation 3, those authors used a grounded or inductive approach (which they refer to as framework, although this is a different use of framework than in the current study) to identify three themes: Theme 1—The impact of discovering breast cancer; Theme 2—Treatment decision making; Theme 3—Information—use, preferred content and format. In this study, the authors follow a true framework analysis, bring the Coping in Deliberation model to bear on the previously analyzed data. Overall, I think it would be helpful to the reader to make this much more explicit, concretely something similar to: “Our research team conducted one set of interviews with older patients that generated multiple analyses. The first focused on the need for decision support of these patients, as reported previously [3]. That report identified themes inductively. This report summarizes results from an additional set of analyses from the same interviews. This time the analyses imposed an existing conceptual framework to identify specific coping and decision making strategies that could be targeted in the design of a new decision support intervention.”

Response 2: Based on this comment and that of another reviewer, clarification that this was secondary analysis has been added to the abstract, introduction and methods section. This includes a more detailed section in the methods (page 7, paragraph 2), as suggested, to make it explicit that the interviews were analysed twice and how the analyses varied.

Discretionary Revisions
1. I would ideally like to see more in the discussion about how the CODE categories will inform the content and design of a decision support intervention. I think the authors could draw more explicit connections between the CODE findings and the implications for decision aids. In the effort to provide concrete feedback, I am going to speculate below about ways in which you might incorporate these CODE findings, but I would prefer if you, the authors, could get readers started on this vital process of further interpreting your results:
   a. Based on my interviews with breast cancer patients, younger women often experience breast cancer as going from “immortality to a death sentence” or more generally as a “wake-up call” regarding mortality. Therefore decision aids often serve a useful purpose in showing baseline prognosis, and the absolute benefit of treatments. Younger women essentially need to absorb the vital information that they were not immortal, and (if early stage) their cancer is not necessarily a death sentence. Your data suggests that older women also fear dying of breast cancer (“I shut down... because I thought it was going to kill me”) but also were perhaps more aware of competing threats to their mortality (“at my age, you’ve got to die sometime”), while concerned about quality of life (“worrying about the pain.”) I’m assuming that as you approach design of decision aids, this kind of insight will inform how you present and motivate the use of the decision aid. (Eg, you might design orienting statements such as “Breast cancer can feel like a scary diagnosis, and the treatments may be invasive. At your age, you may be facing other threats to your health. This booklet can help you sort out how aggressively you pursue breast cancer treatment in the context of your other health concerns.”)
   b. I think the finding about prayer is very interesting. In my experience, decision aids don’t tend to highlight and support non-deliberative coping mechanisms. Older patients may be more open to paying attention to decision aids (which may be somewhat unfamiliar,
generationally, as they are rather novel) if they echo, mirror or support existing methods of coping.

c. I’m assuming your eventual decision aid might support older women in conceiving of delegation to their physician as a possibly effective coping strategy. This also strikes me as novel for a decision aid. In general, your findings suggest moving beyond IPDAS criteria to embrace and support existing methods of coping in the content of a decision aid.

Response 3. We thank the reviewer for this overall suggestion as well as their thoughtful, concrete feedback. As a result we have made changes to the discussion to improve it (page 15, paragraph 3 and page 16). For example, how it might be possible to encourage patients to reach their chosen level of involvement in the decision (page 15, paragraph 3), and including the impact of each treatment option on quality of life (page 16 paragraph 2).