Author’s response to reviews

Title: Patients’ experience of communication and handling of symptomatic adverse events in breast cancer patients receiving adjuvant chemotherapy

Authors:

Christina Bæksted (baeksted@cancer.dk)

Aase Nissen (dybedal7@hotmail.com)

Ann Knoop (ann.soegaard.knop@regionh.dk)

Helle Pappot (Helle.pappot@regionh.dk)

Version: 1 Date: 13 Sep 2019

Author’s response to reviews:

Response to reviewer 1:

Reviewer #1: The purpose of the present study was to examine patient-reported experience measure (PREM) regarding communication and handling of side effects/symptoms. I agree that inclusion of patient-reported outcomes of symptomatic toxicities is likely to provide a more sufficient picture of the patient's symptomatic adverse events from cancer treatment possibly leading to better health-related quality of life in cancer patients and better clinical outcomes. Hence it is important to explore patients' experience of communication about and handling of symptomatic toxicities, and am very glad that this study sought to conduct research on this.

1. The article states that 'patient representatives were involved in the development of a PREM questionnaire. More detail regarding this would have been helpful, such as whether patients were involved in choosing the four predefined themes. The adjective 'predefined' implies they weren't and it would be interesting if this is the case to know why.

Response to reviewer:

1. Details on the involvement of patient representatives in the development of the PREM questionnaire have been added in Methods section ‘PREM questionnaire’, page 6. The themes were predefined by the researchers as these themes were identified from the literature.

I thought it was significant that the ePRO questionnaire seemed to help the patients remember their symptoms; this is a clear indicator of its value over conversations about symptoms with nurses.
2. It would also be of value to know more about what the study participants thought of the questionnaire itself.

Response to reviewer:

2. In this study, we did not examine the study participants’ thought of the ePRO questionnaire. We used the same PREM questionnaire for both the intervention arm (ePRO arm) and the usual care arm in the randomized study as we wanted to compare the answers from the two groups. Therefore, we did not include any questions directed at the ePRO questionnaire. However, we have examined the patients’ thought of completing ePRO questionnaire in the clinic in a previous study among prostate cancer patients (Baeksted et al., 2017. Journal of Patient-Reported Outcomes, DOI: 10.1186/s41687-017-0005-6).

I thought it was also significant that participants reported not wanting to bother the nurses with their symptoms and as a patient I can empathize with this. It is also another reason which a questionnaire can be so very helpful, as it take the possibly tired and busy professional out of the process.

3. It would be useful if the sentence 'The questions raised by the patient representatives in the questionnaire might not have been detailed enough to catch possible points of improvement' was unpacked and some idea given as to what possible points of improvement may have been missed.

Response to reviewer:

3. Example of more specific questions that might have revealed possible improvements has now been added to the above mentioned sentence in the Discussion, page 11.

4. Information as to why of the planned 52 interviews, only 22 interviews were completed would be helpful.

Response to reviewer:

4. A possible explanation for why only 22 out of 52 interviews were completed has been added to the Discussion, page 13.

The main conclusion of the study; that the study 'indicates a need for a more comprehensive side effect questionnaire covering more symptoms than the one used as standard procedure today', is very concrete and practical to address. Hopefully there will be further research to meet this indicated need.

Reviewer #2: I thought this was an interesting and succinct article with a clear structure and explicit purpose. I am not qualified to comment on the clinical components of the research or the
findings, but I do have comments on the patient involvement aspects of the paper. Overall, particularly given the focus of this journal, I was really surprised to find so little emphasis on the patient involvement aspect of the research. My specific comments and observations are as follows:

1. You describe the questionnaire being developed "in co-operation" with patients - this seems an odd choice of word to me. Would "in partnership" not more accurately reflect the role and nature of patient involvement?

Response to reviewer:

1. Yes, we agree, ‘co-operation’ has now been replaced with ‘partnership’.

2. How did you decide how you were going to involve patient representatives? Were there limitations to what you were able to do, and how did you manage those?

Response to reviewer:

2. Yes, we did have some limitations regarding time and the fact that it was a national study involving patients across the whole country. Information on the challenges regarding time had been added to the Discussion, page 12, line 11.

3. There is no information about the patient representatives. I was interested to know who they were (women with breast cancer?), where you found them, how you selected them and what their make-up/background was. I think it would reinforce the credibility of your method for patient involvement to be transparent about the practicalities - it's also an opportunity for other researchers to learn from you.

Response to reviewer:

3. Information on the patient representatives has been added to the Methods, page 5 to clarify that the patient representatives were patients with breast cancer receiving adjuvant chemotherapy and were selected by oncology nurses at the oncology departments.

4. I wanted to know more about how you managed the group of patient representatives and how you supported them. Did the group ever meet in person? How did you ensure that they were adequately briefed to carry out the task?

Response to reviewer:

4. The patient representatives did not meet in person, as they were from all different areas of the country. We used this online forum to communicate – here the researcher could make posts and
the patient representatives could communicate with the researcher and each other. All comments from the patient representatives to the posts could be seen by everyone in the group. The researcher contacted each of the patient representative before we started and explained the task and was available by phone and e-mail during the process for any questions or comments. This has now been clarified in the text, Method, page 5-6.

5. My understanding is that the patients' input to the questionnaire design was through an online forum. How did this work in practice? How did you set it up? This seems like it could be a good example of a cost-effective and potentially efficient way of doing patient involvement, so more information and your reflections on how it worked (pros and cons) would be really useful.

Response to reviewer:

5. Information on this online forum has now been added to the Method, page 5.

6. If I've understood correctly, only just over half of the patient reps who you recruited actually got involved in developing the questionnaire. I think it would be useful to understand why. Did you get any feedback from them? With hindsight, is there anything you could or should have done differently? Again, this would be useful material for all of us working in the field of patient and public involvement.

Response to reviewer:

6. Timing of involving the patients in the research process at the same time as they were undergoing active cancer treatment might have influenced this. This has now been elaborated in the Discussion, page 13-14. We chose to involve patients enrolled in the study for which the questionnaire should be developed for. Instead we could have involved patients who had finished their treatment and thereby maybe had more energy to participate. However, we also found it important to involve patients who had the experience of side effects and the completion of side effects questionnaire fresh in mind.

7. Page 11 line 19 ("The questions raised...") - I didn't understand this sentence.

Response to reviewer:

7. The sentence has now been rephrased and hopefully the meaning is now clarified, Discussion page 11.

8. You mention that the involvement of patients "has created a more holistic approach" - how do you know this? I think it's important to explain in practical terms what difference your patient involvement activity made and why. If this is something you are interested in expanding on, I think it would be appropriate to include that in the conclusion.
Response to reviewer:

8. The sentence has been rephrased and now describes that the involvement of patients ensured that the questions were meaningful from the patients’ perspective and especially regarding the response options, Discussion page 12.

In conclusion, I think to provide some more practical detail and reflections on how you involved patients in the questionnaire design would really enhance the value of this paper within this journal.

Response to reviewer:

According to the review comments, more details and reflections on the involvement of patients in the research process have now been added to the manuscript. We hope this has clarified how patients were involved and some of the challenges we faced, e.g. regarding the timing of involving patients.