PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Qualitative Analysis of 6961 free-text comments from the first National Cancer Patient Experience Survey in Scotland
AUTHORS	Cunningham, Margaret; Wells, Mary

VERSION 1 - REVIEW

REVIEWER	Claudine Clucas University of Chester, UK
REVIEW RETURNED	08-Jan-2017

GENERAL COMMENTS	The objective is clearly informed by the introduction and the description of the methods is detailed. However, I have a few comments for improvement: The survey does not appear to have measured ethnicity and sexual orientation although these have been shown to affect patient experiences of care. Why these were not measured needs justification. For the quantitative analysis, I am not sure it is justified to merge the categories of student and unemployed/looking for work since some students may be in employment. Also, in table 2, it would be better to present the data for "work full time" and "in full time education" separately since these have a different meaning in terms of employment status. It would be useful to give an indication of whether there were differences in clinical or sociodemographic characteristics between respondents who did not give a comment and respondents who did for each of the seven areas of care. It would be clearer when presenting the results of the quantitative analysis to first present the results relating to the themes derived from the qualitative analysis according to sociodemographic and clinical characteristics since this is the most interesting data. It appears that no differences were found for the overarching themes - this sentence could be clearer. Were associations between the subthemes and sociodemographic and clinical characteristics also examined? Results relating to the proportion of positive to negative comments by tumour group could be reported more clearly - in particular it is not always clear what the reference group is and there is no reference to Table 5 in the paragraph. Also, the chi square results are not presented for gender differences and socioeconomic status. It is interesting that younger people and women felt less positive since this accord with other literature - did the data show differences in reasons given for their experiences or was the difference solely due to them expressing more negative comments (similar content)? There could be more exploration and discussion of reasons for differences in the proportion of positive comments according to clinical and sociodemographic factors, including the role of patient

	expectations of care.

REVIEWER	Hilde Hestad Iversen The Norwegian Institute of Public Health, Norway
REVIEW RETURNED	30-Jan-2017

GENERAL COMMENTS	The objective of this article is to analyse free-text responses from the Scottish Cancer Patient Experience Survey to "understand patients' experiences of care, identify valued aspects and areas for improvement". Seven free-text comment boxes were included in the questionnaire, and 6961 comments from 2663 respondents were analysed using both qualitative and quantitative analysis. The authors concludes that athough the majority of comments were positive, there were a significant number of negative comments and that the results suggest patients would value greater integration of care from services involved in their treatment for cancer. This is a well-written and interesting article, and I appreciate the focus on understanding and analysing qualitative data from a national, large-scale survey. Most patient experience surveys are quantitative in nature, and comments in free-text format are often not addressed when presenting the results. A mixed method approach allows findings to be compared and permits a more complete understanding of the feedback from the patients, and provide useful information for determining specific areas for quality improvement. Closed-ended questions often activate a cultural positivity bias pushing towards the most positive categories, while open-ended questions allow written feedback that can combine extreme positive comments with information and comments eliciting improvement information. Major comments I think two major challenges are related to the current study. The first is that information regarding the analyses conducted are not sufficient to fully interpret the results. The results are comments from seven free-text comment boxes, including seven different questions in seven different sections of the questionnaire. These data were initially analysed separately, before being considered as a whole during the creation of themes. What was this decision based upon? It would be useful to see the number of comments for each of the seven sections. We know that 2,663 left at least one free-text comment, but not the mean number of comments per comment box. How many responded to the first and the seventh for example? How many left comments to all open-ended questions? We know from other studies (and analyses) that respondents do not always answer the specific question, but often give general comments on experiences. I would like to see some reflections regarding this issue. Also, the potential effect on the responses to the closed-ended questions? How were a comprehensive comment that included both positive, negative and neutral experiences analysed? Were all content defined as neutral, or were the comment divided into separate "comments" in further analysis? In the text we are informed that there were no major differences in clinical or sociodemographic characteristics between those respondents who left at least one comment, and all respondents

(results shown in Table 2. What is this conclusion based upon? Also, it would be more interesting to see if there were any differences between those who left comments and those who did not leave any comment at all. There could also be other systematic differences between these groups, for example regarding their health status? Did the questionnaire or data from the hospitals or other health services include information on health status or self-reported health status? Previous studies have shown that this is an important variable when exploring patient experiences.

The authors found four overarching themes from analysis of the negative comments; I) Feeling that Individual Needs Are Met, II) Feeling Confident Within the System, III) Processes and IV) Structures. This is a bit confusing. The two first are explained as “key issues which lead to patients having a negative experience of cancer care”, while the two latter are explained as aspects that “can contribute to both these experiences”. Please explain these findings more thoroughly and link them to the descriptions in the methods section. It was not clear to me how the findings correspond to the thematic analysis.
The second main challenge is that the results should be closer tied to the quantitative results and that the setting of the results as part of a quantitative survey could be given more attention. More information would be useful on the association between qualitative and quantitative data. Qualitative comments can help to validate quantitative scores. Previous studies have shown that qualitative data provide a more negative view of patient experiences than quantitative data do, and that high levels of satisfaction from closed-ended questions do not necessarily equate to outstanding care. Did the researchers study the association between the survey scores and the tendency to leave positive/ negative comments?

Few limitations are addressed. The authors describes the process involving different researchers in the qualitative analyses. Quantitative generic patient surveys have a tendency to overestimate patient satisfaction and experiences, but qualitative studies reveals more critical evaluations of healthcare services. However, a range of error sources like social desirability responding is also a threat in qualitative research. The analyses fully depends on the researchers structuring of the responses since the qualitative researcher is part of the process all the way. Another weakness is the subjectivity of the different steps of thematic analysis.

The results described on page 8 and especially in Table 4 describes results that can be hard to categorise because the themes are overlapping. This subject should be addressed in the paper, especially in the discussion section.

We are informed that participants made more positive than negative comments, a ratio of 1:0.78. In the results section we are told that 2,663 left at least one free-text comment, and that in total 6,961 comments were made; 2,528 positive and 1,969 negative. However, according to table 3 and 4 it seems like number of positive comments are 3963, and number of negative comments are 3797. Please explain. In Methods and Results Table 5 it should be described more in detail. What is actually tested?

Minor comments
Page 4, line 34-37. If the development of the instrument has included phases with qualitative and cognitive interviews the

	questionnaire should also be able to provide feedback to the health services on issues that matter to patients. However, quantitative results often have different purposes than qualitative (for example comparing institutions), the latter making further elaboration on different matters possible. The abstract should include information on which health services that was evaluated. In the conclusions the authors states that the majority of comments were positive, however, a ratio of 1:0.78 still means that many have given negative feedback. The manuscript throughout claims to measure "what matters", however, the questions in the survey asks for more detailed elaborations on experiences. On page 10 some of the results are not presented in Table 5. Please comment in the text what results that are presented in tables and the results that are not there.

VERSION 1 – AUTHOR RESPONSE

Reviewer 1 Comments:
- The survey did measure both ethnicity and sexual orientation. Numbers of respondents in these groups have been added to Table 2. The expected counts for responses in these groups were too low to perform chi-squared tests in the quantitative analysis. A comment about this has been added to the Methods section.
- In Table 2, we have not split the data for 'work full time' and 'in full time education'. The numbers for full time education were too small to perform chi-square tests.
- We have split the categories 'in full time education' and 'unemployed looking for work', and instead presented 'in full time education' with 'work full time'. We have altered the wording in the methods section to reflect this change. We have re-run the quantitative analysis to reflect this change, and changed the rows, data and chi-squared results in Table 6. No alterations were made to the narrative of the quantitative analysis as a results of these category changes.
- We have rearranged the order that results are presented in the Quantitative Analysis section so that the results relating to sociodemographic and clinical characteristics are presented first.
- We have removed the paragraph relating to analysis of the overarching themes by clinical and sociodemographic characteristics. The reference group for this analysis was all those participants who had not made a comment which fed into that theme. This analysis did not add any additional insight into understanding the data and the reviewers' comments suggest this part of the analysis was not clear.
- We did not examine associations between the subthemes and sociodemographic and clinical characteristics. We did not have a clear reference group to perform these comparisons.
- We have added a reference to Table 6 in the quantitative analysis paragraph about tumour groups.
- We have added a sentence explaining the reference group for the tumour group analysis. We have also expanded on the explanation of the chi-squared tests in the Methods section.
- We have presented results of the chi-squared tests for gender and socioeconomic status in the text.
- Nothing emerged from the inductive thematic analysis about differences in experience of care as a result of sociodemographic characteristics. Differences identified in the quantitative analysis are a result of differences in quantity of positive and negative comments rather than qualitative differences in the content of comments. We have added a brief comment about this in the Discussion.
- We have added further comments to the Discussion about the proportion of positive comments according to sociodemographic characteristics.

Reviewer 2 Comments:
- We have expanded on our description of our approach to the qualitative analysis, to explain why we

decided to consider the data as a whole during the creation of themes.
- We have added a table (Table 3) which gives the number of comments for each of the seven comment boxes, broken down by first order code.
- We have included a paragraph in the Discussion to reflect on the effect of closed ended questions on the content of comment box answers.
- We have added some detail to the Methods section to explain how we coded comments which had positive, negative and neutral content.
- Table 2 has been modified to include information about respondents, and non-respondents.
- The data from the survey did not include any additional information about health status or self-reported health status. One closed-ended question in the survey asked 'Which of the following applies?' with the following options (i) my cancer has been taken out/treated without any sign of further problem; (ii)my cancer was taken out/treated without any sign of further problem, but has since come back/spread to other parts of my body; (iii) none of the above options apply to my type of cancer; (iv) I would prefer not to say; (v) I don't know. However, 976 people did not know, or did not reply to this question, and of those who did reply, 103 ticked that there cancer had since come back, with the remaining participants ticking option (i). There was therefore insufficient responses or variation in responses to use this question as a measure of health status. We have included this as a limitation in the Discussion.
- We have added further detail to the Methods section to explain how we arrived at the themes from the thematic analysis. We have added a figure to the Negative Comments section within the Findings to better illustrate the themes, and have provided some additional detail about how the themes emerged from the analysis.
- We did not have access to most of the quantitative data measured in the survey, therefore we were limited in the analysis we could do to compare the qualitative and quantitative survey results. We have commented on this as a limitation in the Discussion section. We have added some comments to the Discussion about the differences between overall experience of care as measured in the closed-ended questions and qualitative descriptions of patient experience.
- We have added limitations to the Discussion section in line with the reviewer's helpful suggestions.
- We have added an explanation about quotes to the Methods section of the paper. In order to preserve the context of the quote, the full wording of the comment is given, even though comments may have had several second order codes applied to them and therefore be representative of a number of different sub-themes.
- We have provided an explanation to the Methods section that counts refer to number of comments within a sub-theme, and that comments could contribute to more than one sub-theme.
- We have provided a more detailed explanation of the chi-squared tests carried out as part of the quantitative analysis in the Methods section.
- We have added clarification to the point about usefulness of quantitative data in the Introduction (to clinical staff).
- We have added 'across all Health Boards' to the setting and participants section of the Abstract.
- We have noted the ratio of positive to negative comments in the Discussion.
- We have changed our wording in the two sentences which talk about what matters to patients.
- We have presented results in the Results section for analysis not presented in Table 6.

Following revisions, we have re-numbered tables and references as required.
In summary, we would like to thank the Reviewers for their very helpful and constructive comments and we have amended the paper to fully incorporate the extremely useful recommendations. We believe that the paper is significantly improved as a result, and trust that it is now acceptable for publication in BMJ Open.

VERSION 2 – REVIEW

REVIEWER	Dr Claudine Clucas University of Chester, UK
REVIEW RETURNED	03-Mar-2017

GENERAL COMMENTS	This revised version of the manuscript is clearer and the discussion is stronger.

REVIEWER	Hilde Hestad Iversen Norwegian Institute of Public Health, Norway
REVIEW RETURNED	17-Mar-2017

GENERAL COMMENTS	In my previous review I suggested major revisions. In my opinion, major challenges were related to the description/presentation of the qualitative analyses and the results. I was very pleased that the revised manuscript addressed my concerns in a thorough manner, and I think that the paper had improved significantly. It is a pity that the authors did not have access to quantitative data, if tied together the study could have been even more interesting.