PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	The Cancer Patient Experiences Questionnaire (CPEQ): reliability and construct validity following a national survey to assess hospital cancer care from the patient perspective
AUTHORS	Iversen, Hilde; Holmboe, Olaf; Bjertnæs, Øyvind

VERSION 1 - REVIEW

REVIEWER	Karin Bergmark, MD, PhD Jubileumskliniken Sahlgrenska Academy and Sahlgrenska University Hospital 413 45 Gothenburg, Sweden and Department of Oncology-Pathology Karolinska Institutet Karolinska University Hospita 171 76 Stockholm, Sweden No conflicts of interest.
REVIEW RETURNED	11-Jun-2012

THE STUDY	Overall study design: It is not clear how the health care system is organised in Norway. It seems impossible that 400 patients each from 54 hospitals can be representative for the cancer care in a country with a population of 5 million people. Further, the response rate was 52%. Methods: There needs to be examples of questions to understand what the participants have answered. It is not possible from Table 2 to understand parts of the questionnaires. The scoring is not described in sufficient detail.
RESULTS & CONCLUSIONS	The response rate is too low to answer the research question, which affects the credibility.
REPORTING & ETHICS	The first question is not applicable for this kind of article.
GENERAL COMMENTS	1. Why were 400 participants each from 54 hospitals chosen? Is this really reflecting the oncologic health care in Norway? If so, it should be described. But with a population of 5 million people and a health care system that is described to be organised in five regions (reference Wikipedia) it seems odd to describe “cancer patients’ experiences with hospitals” in Norway based on this selection. To my knowledge a large proportion of cancer patients are treated at Radiumhospitalet in Oslo, at least when it comes to radiotherapy, and possibly also at the other university clinics (Bergen, Trondheim, etc.). If these clinics were represented

	by 400 participants as well as very small hospitals, it must involve an uneven representation when it comes to cancer care, mustn't it? 2. With a response rate of 52% it is hard to generalise the findings. 3. It is not well described how the scores were made. Since the mean scores generally are 3.5 to 4.5 one can assume the maximum was 5, is that so? What was the lowest possible score? 0? 1? 4. It is not clear how the questions were asked. For example, in Table 2, "Organisation", point 5, it is reported that "multiple doctors involved was a problem" had a mean score of 3.8. Is that good or bad? What was the phrasing of the question? And (also in Table 2), "Patient safety", it is reported that "information deliberately held back" had a mean score of 4.5. This must mean it is a reverse score, isn't it? As "contradictory information about illness" and "perceived incorrect treatment" with scores 4.7 each. It would be helpful with an appendix with examples of questions.

REVIEWER	Booij, Judith NIVEL
REVIEW RETURNED	01-Jul-2012

GENERAL COMMENTS	Clearly written, it is unfortunate that outcomes of the study (other that quality of the questionnaire) were not given, although I imagine that will be a seperate paper. Why did the authors not use experiences instead of satisfaction?

VERSION 1 – AUTHOR RESPONSE

Reviewer 1

1. Why were 400 participants each from 54 hospitals chosen? Is this really reflecting the oncologic health care in Norway? If so, it should be described. But with a population of 5 million people and a health care system that is described to be organised in five regions (reference Wikipedia) it seems odd to describe "cancer patients' experiences with hospitals" in Norway based on this selection. To my knowledge a large proportion of cancer patients are treated at Radiumhospitalet in Oslo, at least when it comes to radiotherapy, and possibly also at the other university clinics (Bergen, Trondheim, etc.). If these clinics were represented by 400 participants as well as very small hospitals, it must involve an uneven representation when it comes to cancer care, mustn't it?

This is an important issue, but especially when presenting population estimates. The national patient experience surveys have institution level as the main level, since institution results from the surveys are included in the national quality indicator system. Consequently, power calculations have been conducted at the hospital (institution) level, resulting in an appropriate sample size of 400 for each hospital. Individual weights are calculated to adjust for non-response, and these are also related to the size of the hospital populations so that results at higher levels (health enterprise, regions and the nation) take into account differences in hospital size. Therefore, national results are representative of cancer patients' experiences with hospitals in Norway.

In this study we explore psychometric properties of the instrument, and do not make inferences about population estimates. However, we have described this issue better in the Methods, page 8:

"Power calculations have been conducted at the hospital level, resulting in an appropriate sample size of 400 for each hospital. When presenting population estimates, individual weights are used to adjust for non-response. These are also related to the size of the hospital populations so that results at higher levels (health enterprise, regions and the nation) take into account differences in hospital size".

2. With a response rate of 52% it is hard to generalise the findings.

We agree that potential limitations related to response rate should be emphasized, and we have tried to address this issue in more detail in the Discussion, page 24:

"Another potential limitation is the response rate. In general, postal surveys have lower response rates than other data-collection modes.[4] Non-response bias occurs when the main variables differ systematically between respondents and non-respondents.[28] The response rate (52%) means that almost half of the patients failed to respond; however, it was relatively high compared with previous user experience surveys carried out in Norway.[8–19] Findings from some of these surveys have shown that the low response rates have not caused serious bias.[15, 29–32] The findings from a Norwegian follow-up study involving a hospital population showed that postal respondents and non-respondents had almost the same scores.[32]. These studies indicate that non-response might be of less concern, but uncertainty related to external validity means that more research is needed on the effect of non-response in patient experience surveys on cancer care."

3. It is not well described how the scores were made. Since the mean scores generally are 3.5 to 4.5 one can assume the maximum was 5, is that so? What was the lowest possible score? 0? 1?

We agree that this point should be more clearly presented more in the manuscript. We have included the following text in the Methods, page 7/8:

"Items relating to experiences of care had a five-point scale that range from "not at all" (1) to "a very large extent" (5). Negative items were reverse coded, and a higher score represent a better experience for all items. Scales were transformed to scores ranging from 0 to 100 where 100 is the best possible.

Information on the scale scores are also reported in the text under Table 2 and 4.

4. It is not clear how the questions were asked. For example, in Table 2, "Organisation", point 5, it is reported that "multiple doctors involved was a problem" had a mean score of 3.8. Is that good or bad? What was the phrasing of the question? And (also in Table 2), "Patient safety", it is reported that "information deliberately held back" had a mean score of 4.5. This must mean it is a reverse score, isn't it? As "contradictory information about illness" and "perceived incorrect treatment" with scores 4.7 each. It would be helpful with an appendix with examples of questions.

See point 3 above regarding the score. We suggest that the following examples of questions (including one question from each scale) can be included in the article or in an appendix, but we think maybe the journal wants to have a say on this.

“Did you perceive that the nurses cared about you?”
“Did you have confidence in the doctors’ professional competence?”
“Did you receive sufficient information on treatment options?”
“If you had many doctors, did you experience this as a problem?”
“Did you experience that information was deliberately held back from you?”
“Were your next of kin received well by the staff?”
“Were you satisfied with the cleanliness at the hospital?”

Reviewer 2

Clearly written, it is unfortunate that outcomes of the study (other that quality of the questionnaire) were not given, although I imagine that will be a seperate paper.
Why did the authors not use experiences instead of satisfaction?

We fully agree on the importance of publishing the results, and plan to submit at paper in due course focusing on results from the study.

The study is addressing patient experiences, not patient satisfaction. We have tried to make this point clearer in the revised version, and have included the following text in the Introduction, related to information on the national patient experience survey programme (page 6):

“Due to the aforementioned problems that arise when attempts are made to measure satisfaction, the instruments focus on experiences of the healthcare delivery, not satisfaction”.

VERSION 2 – REVIEW

REVIEWER	Karin Bergmark, MD, PhD Jubileumskliniken Sahlgrenska Academy and Sahlgrenska University Hospital 413 45 Gothenburg, Sweden and Department of Oncology-Pathology Karolinska Institutet Karolinska University Hospita 171 76 Stockholm, Sweden No conflicts of interest.
REVIEW RETURNED	16-Aug-2012

THE STUDY	I am still concerned about the low response rate.
RESULTS & CONCLUSIONS	I am still concerned about the response rate and the representability.
GENERAL COMMENTS	In the revised version of the manuscript it is much easier to understand the findings and make own conclusions. Also the discussion has improved. I am however still concerned about the response rate (52%) and thus how reliable the results are. Two minor questions: 1. Page 2, line 54: What do you mean by "next of kin"?

	Sociodemographic factors? Information to next of kin? Or what? 2. Page 4, line 44: In my opinion, the word "should" is too strong. Could?

VERSION 2 – AUTHOR RESPONSE

Reviewer: Karin Bergmark

1. I am however still concerned about the response rate (52%) and thus how reliable the results are.

In the previous revision we tried to emphasize potential limitations related to the response rate in the Discussion, page 24. In the final sentence on the same page, this concern is further addressed by adding the following:

“........and that the main findings in this study should be replicated in future studies.”

2. Last question (CONSORT etc.) is N/A.

If our interpretation of this comment is correct, and the reviewer asks for checklists included for randomized control trials, we do not understand the relevance. Our study is based on a cross-sectional survey, not a trial.

3. Page 2, line 54: What do you mean by "next of kin"? Sociodemographic factors? Information to next of kin? Or what?

“Next of kin” refers to the items presented in table 2. We have tried to make the content of this scale clearer in the revised version, and the scale is now renamed to “contact with next of kin” throughout the manuscript.

4. Page 4, line 44: In my opinion, the word "should" is too strong. Could?

“Should” is changed to “could”.