PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Are National Cancer Control Indicators for Patient Experiences being met in Regional and Remote Australia? A cross-sectional study of Cancer Survivors who Travelled for Treatment.
AUTHORS	Dunn, Jeff; Goodwin, Belinda; Aitken, Joanne; March, Sonja; Crawford-Williams, Fiona; Ireland, Michael; Ralph, Nicholas; Zajdlewicz, Leah; Rowe, Arlen; Chambers, Suzanne

VERSION 1 – REVIEW

REVIEWER	Mirjam Ekstedt Linnaeus University
REVIEW RETURNED	23-Aug-2020

GENERAL COMMENTS

Thank you for the opportunity to read and review your work.

The present study explored the associations between NCCI factors and health and psychosocial variables for a rural and regional population of cancer patients who are at risk of fragmented or poorly coordinated care. As NCCI items have not been validated for use in research they were subjected to an exploratory factor analysis which yielded a 2-factor solution consisting of the factors: “Communication and patient involvement” and “Provision of information and services”. This instrument was tested against assessments of quality of life (QoL), psychological distress and unmet supportive care needs among a rural and regional cancer population.

The results indicate that patients who report better communication with their health care team and more involvement have better QoL, less stress and anxiety, and lower threat. Patient care experience varies across the NCCI indicators by sociodemographic and clinical factors that likely reflects health care system biases. The authors suggests that the NCCI patient experience indicators have validity and strong potential as a quality assurance tool to lower unmet need in health services and information in the current population. As such the contribution to research is valuable.

The study is cross-sectional but the limitations are taken into consideration and discussed.

The analysis are thoroughly presented and are reliable according to my competence. However the group comparisons in the result section and the table are hard to follow and a statistical review would be valuable.

Minor comments:

	On P 14 line 49 the unit is lacking for the (Median = 211) does the value refer to days? Similarly < 67% is considered as “most patients” although it is slightly more than half of the patients. (Page 18 line 31) There is a need for language check – for example are misspelling such as: “re-contract-ed” and “focussed” on P 7 line 56 or mont instead of month on P 14 line 49.

REVIEWER	Annalisa Trama Fondazione IRCCS Istituto Nazionale dei Tumori, Milan - Italy
REVIEW RETURNED	28-Sep-2020

GENERAL COMMENTS	This is an interesting study aimed at assessing the services experience of cancer patients from regional and remote area in Australia. The authors used available indicators set at policy/planning level and performed a remarkable research. However, some issue and concerns should better addressed and/or explained. Materials and methods The authors should clarify better the role of CCQ and explain what kind of cancer patients stay there. To what extend cancer patients accessing CCQ may or may not represent a selection of cancer patients needing cancer care? The authors should clarify how the non respondents differ from the respondents to assess whether the respondents are representative of the target population. NCCI indicators: please review indicator number 2 it seems a duplicate of indicator number 1. Results the authors should clarify the % of missing information. The time span from the day of diagnosis is large thus, the results reported refer to the baseline questionnaire. However, the baseline questionnaire was administered to pts in different phase of the care pathways. How the time from diagnosis impacted on the missing information? could the author explore difference by time from diagnosis? the authors should expand their analyses to better understand differences by cancers. are those due to the cancer itself? to the type of population (breast and head and neck cancer patients do differ in terms of socio economic level)? to the type of clinics and or organisation available for breast and prostate cancers vs other type of cancers? Discussion The authors should stress the limitation of the study (eg response rate, representativeness of the respondents vs non respondents) The authors should also explain the limits of reporting about the baseline survey results alone. The authors should comment their results in a wider framework. Regional and remote areas do not seem to play a major role compared to other socio, economic and demographic factors. Measuring patient’s experience is relevant. could the author envision a more practical way of doing it vs their research methodology

VERSION 1 – AUTHOR RESPONSE

Reviewer 1:		
Comment	**Response**	**Revision**
On P 14 line 49 the unit is lacking for the (Median = 211) does the value refer to days?	Thank you for noticing this omission. The median value is 211 days.	"days" has been added to the manuscript on page 14.
Similarly < 67% is considered as "most patients" although it is slightly more than half of the patients. (Page 18 line 31)	Thank you, we have revised this sentence.	The manuscript has been changed to "**More than half of the patients** (66.8%) reported that the possible side-effects of their treatment were explained to them in a way they could understand"
There is a need for language check – for example are misspelling such as: "re-contract-ed" and "focussed" on P 7 line 56 or mont instead of month on P 14 line 49.	Thank you for pointing these errors.	These errors have been corrected on page 7 and 14.
Reviewer 2:		
Comment	**Response**	**Revision**
The authors should clarify better the role of CCQ and explain what kind of cancer patients stay there. To what extend cancer patients accessing CCQ may or may not represent a selection of cancer patients needing cancer care?	We have added a more detailed description of the role of CCQ in the methods section. On page 14 of the manuscript, we state that the current sample is representative of the non-metropolitan Queensland cancer population in relation to gender, age and country of birth, as compared to Queensland Cancer Register statistics (available from https://canceralliancegld.health.qld.gov.au/data-access/). There were some differences noted with regard to the prevalence of skin and head and neck cancer in our sample as compared to the population statistics. We also acknowledge in our Discussion that our sample is not representative of metropolitan cancer patients in Queensland who require cancer care.	The following text has been added to the methods section (page 7) "CCQ is a not for profit organization offering a range of services to those affected by cancer, one of those being the accommodation lodges which aim to limit out of pocket expenses for patients. People who are diagnosed with cancer, who are required to travel for their treatment, may receive a referral to stay at one of the CCQ lodges from their healthcare team. Accommodation costs are determined in conjunction with the patient's eligibility for the Queensland government's Patient Travel Subsidy Scheme which is designed to assist in the cost of travel to the nearest specialist medical service that is more than 50km from the patients nearest hospital."
The authors should clarify how the non-respondents differ from the respondents to assess whether the respondents are	Thank you for pointing this out. We have now included a comparison of gender, remoteness, and SES for responders versus non-responders using available data (i.e., names and addresses of non-respondents)	The following text is now included on page 8 of the manuscript. "Based on the available names and addresses of non-respondents it could be estimated that responders and non-responders did not differ

representative of the target population.		significantly according to gender, remoteness, or socio-economic status.”
NCCI indicators: please review indicator number 2 it seems a duplicate of indicator number 1.	We have checked the items and confirm that item 2 is not a duplicate of item 1. The first item reflects whether patients understood their diagnosis while the second reflects receipt of written information. The NCCI indicators we used for this study are available on the Cancer Australia website: https://ncci.canceraustralia.gov.au/psychosocial-care/patient-experience	
1. the authors should clarify the % of missing information. 2. The time span from the day of diagnosis is large thus, the results reported refer to the baseline questionnaire. However, the baseline questionnaire was administered to pts in different phase of the care pathways. How the time from diagnosis impacted on the missing information? could the author explore difference by time from diagnosis?	1. We have now added a column to Supplementary table 1 to specify the % of participants who did not provide a response to each item. This table details the % of data treated as missing for each item within the main analysis. 2. This is a very good point. We have now checked the association between missing responses (including “I don’t remember” or “I don’t recall”) and days since diagnosis. There was one weak association whereby those who were further past diagnosis were less likely to recall/provide a response to the NCCI item “involved in decisions”. This has also been noted in the Supplementary material.	Supplementary Table 1 now includes a “missing %” column and a note about associations with missing responses.
The authors should expand their analyses to better understand differences by cancers. are those due to the cancer itself? to the type of population (breast and head and neck cancer patients do differ in terms of socio economic level)? to the type of clinics and or organisation available for breast and prostate	Thank you for this comment. This is an interesting area of discussion. In order to address the potential for other factors such as SES to explain differences we assessed whether patient experiences differed according to all demographic and area level characteristics (Table 3). Only education was significantly associated with some NCCI items, however, cancer type was not associated with education – therefore it was not identified as a	The following changes have been made in the discussion on page 22: “Notably, breast and prostate cancer patients were more likely to receive clinical nurse support compared to skin and head and neck cancer patients. <u>This may reflect the different resources and services available for specific cancers, for example,</u> the introduction of the specialist nurse role for

cancers vs other type of cancers?	explanation for cancer type differences in patient experience. We suggest that the differences in experience according to cancer type are not likely to be due to the cancer itself (i.e., it's location, morphology, etc.), but rather the resources available for them in the healthcare system. For example, breast and prostate cancer patients may have a different experience compared to skin and head and neck cancer patients as a function of the specialist roles available for those patients. We have emphasised this point now within the discussion.	breast cancer patients, (37) and more recently prostate cancer patients. (38)"
The authors should stress the limitation of the study (eg response rate, representativeness of the respondents vs non respondents) The authors should also explain the limits of reporting about the baseline survey results alone.	We have noted in our Discussion the limitations of our research in regards to generalising our findings to metropolitan populations and the cross-sectional design.	
The authors should comment their results in a wider framework. Regional and remote areas do not seem to play a major role compared to other socio, economic and demographic factors.	Although, not a key focus of the current study, this is a good point to raise given suggestions in the literature that patient experiences may be worse for those living in more remote areas. We have now acknowledged this in the discussion.	The following text has been added to the discussion on page 22 "Despite suggestions than remote living is associated with poorer experiences for cancer survivors, area level factors were not associated with NCCI outcomes. Rather, differences in patient experiences according to cancer were apparent."
Measuring patient's experience is relevant. could the author envision a more practical way of doing it vs their research methodology.	The aim of this research was to measure patient experience using the metric recommended by a key governing body in Australia, however, we agree that there are many other measures of patient experience that warrant examination. This has now been noted in the discussion as an avenue for future research	The following text has been added to the discussion on page 22 "Although the aim of the current research was to assess patient experiences using a metric published by a National governing body, it is important to note that several valid measures of patient experience covering different aspects of patients' care and support

		needs exist and future research will benefit from their inclusion.”

VERSION 2 – REVIEW

REVIEWER	Mirjam Ekstedt Linnaeus University Sweden
REVIEW RETURNED	27-Nov-2020

GENERAL COMMENTS	The authors have substantially improved the mansucript and I have no further comments

REVIEWER	Trama, Annalisa Fondazione IRCCS Istituto Nazionale dei Tumori, Milan - Italy
REVIEW RETURNED	25-Oct-2020

GENERAL COMMENTS	Thank you for the nice revision of the paper. There few issues in the discussion that deserve minor adjustments. Discussion Tthe author strongly suggest that “… the NCCI patient experience indicators have validity and strong potential as a quality assurance tool”. I would suggest to better contextualise this conclusion since patient experience can be part of quality assurance monitoring, it is not necessarily a quality assurance guarantee The authors showed that patient experiences differed according to cancer hypothesising that health care organisation would play a role. The lower psychological distress may be associated to the different cancer type and therefore with the different capacity to absorb information, take part in decision making, benefit from communications with healthcare professionals? Could the author add references for the “several valid measures of patient experience covering different aspects of patients’ care and support needs exist” mentioned in the discussion? Finally, the Queensland government’s Patient Travel Subsidy Scheme is unique and may largely impact on the patients experience and could contribute to explain the lack of impact of remoteness or SEIFA charachtheristcs. Could the author comment considering also context without this type of subsidy scheme?

VERSION 2 – AUTHOR RESPONSE

Reviewer comments:

1) The author strongly suggest that “… the NCCI patient experience indicators have validity and strong potential as a quality assurance tool”. I would suggest to better contextualise this

conclusion since patient experience can be part of quality assurance monitoring, it is not necessarily a quality assurance guarantee.

This is a good point. We have now amended this sentence to read: "The present study suggests that the NCCI patient experience indicators have validity and potential as a tool for monitoring and benchmarking the quality of cancer care relating specifically to patient understanding and involvement."

2) The authors showed that patient experiences differed according to cancer hypothesising that health care organisation would play a role. The lower psychological distress may be associated to the different cancer type and therefore with the different capacity to absorb information, take part in decision making, benefit from communications with healthcare professionals?

   To address this comment we have included an analysis of variance looking at differences in scores on psychosocial variables across cancer types. In terms of psychological distress we did find that anxiety (F(4) = 3.42, p = .009), physical and daily living (F(4) = 5.02, p < .001) levels were significantly different across cancer types. Post hoc comparisons with a Bonferroni adjustment showed that breast cancer survivors (M = 4.48, SD = 4.10) reported significantly lower levels of anxiety than those in the 'other' cancer group (M = 6.63, SD = 5.94), p = .015. Other significant differences related to physical factors as opposed to psychological distress. These findings are now reported in the manuscript.

   Where we discuss the effect of psychological distress on ability to obtain/retain information, we now refer to the finding about anxiety as an example: "Patients with lower psychological distress have a higher capacity to absorb information, take part in decision making, benefit from communications with healthcare professionals (33,34) and are subsequently more likely to report satisfaction with this element of their care. (35) In fact this may be reflected in the current findings that breast cancer patients in this sample reported both lower levels of anxiety and better patient experiences compared to those with other cancers"

3) Could the author add references for the "several valid measures of patient experience covering different aspects of patients' care and support needs exist" mentioned in the discussion?

   Thank you for pointing out this omission. We have added citations here now.

4) Finally, the Queensland government's Patient Travel Subsidy Scheme is unique and may largely impact on the patients experience and could contribute to explain the lack of impact of remoteness or SEIFA characteristics. Could the author comment considering also context without this type of subsidy scheme?

   We now emphasise and specify the potential impact of sampling bias due to our recruitment method and prescribe caution in interpreting results based on SEIFA in the discussion: "Although regional and remote areas tend to be marked by higher socio-economic disadvantage in Australia (23), the particularly low SES status of this sample may be due to recruiting participants through free or low-cost accommodation services. Low levels of variance in area-level disadvantage in this sample may have impeded the detection of significant effects. These alternative hypotheses should be the subject of future research with samples not in receipt of such services"

Author comment: *Please note that we have also made minor edits to the recruitment figures in Figure 1 and the text to highlight that 10 people who were excluded from this sample consented before it was apparent that they did not have a cancer diagnosis. (i.e., originally we had described them as being ineligible for the research project, however, they were eligible to participate in the research, but not eligible for this study)*