Author's response to reviews

Title: A Comparative Analysis of Computer Based Hospice Palliative Care Datasets in Canada

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Author's response to reviews: see over
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To Whom It May Concern:

February 25, 2008

This letter describes the edits made to MS: 1440149995170147 - ‘A Comparative Analysis of Computer Based Hospice Palliative Care Datasets in Canada’ in order to address the reviewer comments. Aside from the revisions below we have also made editorial revisions to format the manuscript to BioMed Central specifications.

Reviewer #1 – Robin Fansinger

1. The methodology could include a better description and more information on what the seven programs involved in the study were asked to send. It would also be useful to know what services and settings are covered by these different centres, and whether the information submitted covered similar settings of care, e.g. consulting services in an acute care hospital, palliative care units, etc.

EDIT – Page 6 – the methods section has been expanded to describe what data was asked for from the seven centres and what types of care delivery the seven centres represent.

2. The use of the abbreviation hospice palliative care is inconsistently done throughout the manuscript. At times the abbreviation HPC is used, and at other times the full wording is used.

EDIT – we use the full term Hospice Palliative Care during its first reference and then all subsequent references use HPC.

3. In the Methods section the program in Edmonton is incorrectly referred to as the Edmonton Regional Palliative Care Program, when the correct description would be Capital Health Regional Palliative Program, Edmonton. This is also incorrect in the acknowledgements.

EDIT – All references to the Edmonton program have been changed to the Capital Health Regional Palliative Program, Edmonton.

4. In the Introduction the author Gaudette, is incorrectly spelt

EDIT – page 3 – Spelling has been corrected.

Reviewer #2 – Irene Higginson
1. I would advise clarification early on that this is only the computer formats which have been compared

**EDIT** – The title, abstract and introduction all state that we are only comparing computer based data collection. We have added another sentence at the end of the introduction section (page 6) that reiterates that point again. As per the reviewer suggestion we have also emphasized in the abstract and the paper introduction that we are only comparing data element names and definitions and not actual data.

2. I do feel the paper would be much stronger if the authors could look at actual data. If this is not possible I think there should be a much stronger discussion of the issues that may arise in collecting and recording data, in terms of completeness, reliability, and perhaps a recommendation for a further step in collecting such data to assess comparability.

**EDIT** – We agree with the reviewer that comparing actual data is important and that need is forming some of our current research. However we also believe that the key findings from this paper regarding the status of computer based data collection is important.

We have added the following paragraph to the discussion (page 17) to address the issues of collecting and recording data and also to reiterate the value from our study. As per the reviewer suggestion the paragraph also recommended using controlled medical terminologies as a means of collecting data to assess comparability.

‘While we were able to compare the data element names and definitions provided by these HPC centres, we did not have access to the actual patient data collected. Therefore, we were not able determine the extent to which the specified data elements were actually being collected or the completeness or reliability of data collection. Further research is needed that compares the actual data that is collected across different centres and looks at issues of data quality. Research is also needed to map the data elements to formal medical terminologies such as SNOMED-CT as that would enable the formal terminology to act as a standard term to facilitate comparative analysis. Standard terms would also promote better data quality.’

3. There should be some discussion of the potential of data sets to record outcome data

**EDIT**- we have added a sentence on page 15 in the discussion to the potential of recording outcome data, making a reference to Connor’s MDS work in the United States – ‘Part of this MDS should also include HPC outcome data. Examples are the extent of symptom control achieved such as pain and dyspnea as a result of the clinical assessments and interventions provided. Others may include the fulfillment of patients’ wishes such as preferred care settings and support options (Connor et al., 2005).’

4. I found the section on the clinical variability of the data collected especially
interesting. Could the authors expand on this, giving more examples and considering the potential utility of such data? This might link to the outcome data mentioned above.

EDIT - We have added the following paragraph to the discussion of the clinical data on page 13:

Other examples of clinical data elements collected include the Edmonton Symptom Assessment System (ESAS), and Mini-mental State Examination (MMSE), the Palliative Performance Scale (PPS). The type, timing and frequency of assessment being done varied between HPC centres. For instance, The Capital Health Regional Palliative Care Program in Edmonton collects ESAS, MMSE and PPS on a regular basis; whereas the Victoria Hospice routinely collects PPS only.

Reviewer #3 – Grace Johnston
No revisions needed. Paper is ready for publication.

I look forward to a decision on the publication of the manuscript. Please do not hesitate to get in touch with me should you have any other questions about the manuscript

Regards,

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