Author’s response to reviews

Title: Factor Structure of the Quality of Children's Palliative Care Instrument when Completed by Parents of Children with Cancer

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Author’s response to reviews:

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Dear Dr. Miyashita

Thank you for your consideration of our manuscript, “Factor Structure of the Quality of Children’s Palliative Care Instrument when Completed by Parents of Children with Cancer”, for publication in BMC Palliative Care.

We appreciate the feedback from the reviewers and have responded to each of their points below and revised the manuscript accordingly. We thank them for their time in helping to improve the quality of our manuscript.

This manuscript has not been published elsewhere, is being submitted only to BMC Palliative Care, and it will not be submitted elsewhere while under consideration. All authors have participated in study conception or design; analysis or interpretation of data; and drafting or revising of the manuscript. All authors have approved the manuscript as submitted.

Thank you for considering our manuscript and we look forward to hearing from you.
RESPONSE TO REVIEWS

Eva Bergstraesser (Reviewer 1):

1) Methods - The instrument was developed out of the existing QCECI; however, the process is described only briefly. The selection of items seems to be based on the selection of three of the authors only. Pretesting was only performed with one parent who completed the score before the instrument was used in the main sample. As the goal of this new instrument is very different to the prior one, this pretesting might not be rigid enough. The authors should give reasons for this procedure.

RESPONSE: Item selection was completed by three of the authors, however, decisions were based on relevance of the items to experiences throughout the illness trajectory; the overall goals of the larger study; psychometric testing and feedback from respondents on the original instrument. We added a new second paragraph and restructured what is now the third paragraph to be clearer about our rational for revising the instrument and the information used to revise the instrument. We added information about the role of the lead author in development of the original instrument and how feedback from parents involved in the original development were incorporated into the revisions. While additional pre-testing may have been ideal, the timeline of the larger study did not allow for it. We believe that the process to develop the QCPCI and the subsequent testing described in this paper are an important step forward in the field of PPC research.

2) Confirmatory factor analysis instead of exploratory factor analysis was chosen. This decision should be explained briefly.

RESPONSE: We added a rationale for using CFA in the data analysis section: “We chose Confirmatory Factor Analysis (CFA), using Mplus (version 7), to confirm the four-factor structure of the revised instrument since we had clear expectations about the number of subscales and how the items should load onto the factors based on the Exploratory Factory Analysis (EFA) used in the original development of the QCECI.10 CFA includes more stringent criteria than EFA11,12 for determining whether selected domains/subscales fit together as expected to comprise a larger scale thus we felt CFA was more appropriate for this step in instrument development and assessment.”

3) Methods - It is mentioned (Data collection line 29-31) that data collection occurred before and after an educational intervention, however this intervention is not described throughout the manuscript. This Intervention also occurs in the discussion (4th page line 31: The primary objective of our study was to assess the impact of an educational intervention,...). If this would be the primary goal, the title of the paper would be misleading, and again, the educational intervention is not described.

RESPONSE: We have added information to the background about the intervention that was used in the
larger study: “In this project we delivered the Education in Palliative and End-of-Life Care for Pediatrics (EPEC®-Pediatrics) curriculum to health professionals and sought to assess the quality of PPC before and after the educational intervention.” The manuscript with the details of the larger study is now published thus we have updated the reference list. We have referred to the “larger study” throughout the manuscript more consistently (e.g., last sentence in background; 3rd paragraph under Instrument; data collection line 29-31; discussion 4th page) to distinguish it from the subanalysis presented in this paper which is focused on psychometric testing. We have also revised the sentence in the discussion (4th page) to indicate that the overall objective of the larger study was to assess the impact of the educational intervention rather than calling it the primary goal. Our title (revised as suggested by reviewer 2) reflects the subanalysis that is the focus of the manuscript which we believe is appropriate.

4) Methods - Probably related to the educational interventions the structure of the study is not clear. What was the reason to choose two data collection periods?
RESPONSE: As noted above, we have indicated in the background that we sought to assess the quality of PPC both before and after the educational intervention. We have also clarified in the data analysis section that data were collected before and after implementation of the educational intervention.

5) Methods - To mix data from two time points (data analysis line 45) to increase the sample size for assessing psychometric properties seems to be risky. The argumentation for this step is rather short and should be more detailed. Was the sample of two time points homogeneous enough to allow this step?
RESPONSE: The two sample were homogeneous in terms of all background variable (e.g., age of ill child, cancer type, marital status, family income) except time since diagnosis which was shorter (11 vs. 8 months; p=0.01) at post-test. We have added this information to the data analysis section to increase the evidence for combining the two samples.

6) Methods - Data analysis - The authors refer to a submitted manuscript for further information on data analysis. This is not reasonable - please either describe data analysis or refer to an accepted manuscript.
RESPONSE: We have added more information about the analysis (as noted in the response to item #5 above) and have updated the reference to our now published manuscript with the full details of the larger study.

Minor points
1) Results - line 51 - "Approximately 580 families were approached…" - please provide an exact number.
RESPONSE: We revised the sentence to indicate there were 579 families approached.

2) Results, confirmatory factor analysis - line 53 - instead of Table 2 - it should be Table 3 if I got it correctly.
RESPONSE: Thank you for catching this error. We have changed the line to refer to Table 3.

3) Just a remark - the very small group of CNS tumors is surprising - the authors could comment on this briefly.
RESPONSE: Our best guess is that children being treated for a CNS tumor may come in to the clinic or hospital less frequently than a child with something like leukemia (our largest group)
thus would have had fewer opportunities to be approached to participate in the study. We have
not added any comments to the manuscript on this point given our uncertainty as to the cause
and we are not sure where this information would fit in the manuscript.

Julia Downing (Reviewer 2):
This is an interesting study and an important one as we need to be able to measure the quality of
children's palliative care throughout the disease spectrum. It is a well written paper but would benefit
from defining the population in the title i.e. with parents of children with cancer - so that it is clear from
the outset the population within which the tool is being tested.
RESPONSE: We have changed the title to: “Factor Structure of the Quality of Children’s Palliative
Care Instrument when Completed by Parents of Children with Cancer”