Author's response to reviews

Title: Initial development and psychometric testing of an instrument to measure the quality of children's end-of-life care

Authors:

Kimberley Widger (kim.widger@utoronto.ca)
Ann Tourangeau (ann.tourangeau@utoronto.ca)
Rose Steele (rsteele@yorku.ca)
David Streiner (streiner@mcmaster.ca)

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RESPONSE TO CHRIS FEUDTNER

Thank you for the very detailed review and guidance provided on our manuscript. We believe we have incorporated all of your suggestions (as detailed below), which has improved the paper significantly.

General Comments:

We have reduced the word count to 3911 and removed all references to the thesis on which the paper is based. We have also removed the content about hypothesis testing and provided a rational for not including this aspect in our psychometric testing in the discussion section of the paper.

Specific Comments:

We have removed the specified content from the ABSTRACT and most of it from the BACKGROUND sections. However, based on the feedback of the second reviewer, we added information to the background about proxy reports and challenges with quantifying quality. The phases of the study were expanded to 4 rather than 3 and renamed as suggested.

RESULTS: We provided the number of themes identified across studies and added the number of parents that are represented in the literature review. As the themes did not change in Phase 2 we have provided Appendix A, which details the content of the 5 domains identified in the literature that were refined in Phase 2. We felt that including the specific indicators for both phases would be redundant as there were minimal changes made.

Phase 1 and Phase 2 have been included as separate sections.

We have clarified the recruitment process details including the number of instruments mailed using both opt-in and opt-out methods (see first paragraph of the Phase 4 section on page 12).
We have removed the construct hypothesis testing from the paper except in the discussion section as mentioned above.

DISCUSSION: We have completely re-written the discussion section based on the BMJ article as advised.

RESPONSE TO JULIA DOWNING

Thank you for your review of the paper and specific comments for improvement.

Major Compulsory Revisions

1. We added some information to the background section about proxy reporting and provided additional rationale for seeking the perspectives of bereaved parents.

Minor Essential Revisions

1. We have clarified that parents in the focus groups (now referred to as phase 2) were asked to specifically confirm, challenge, or add to the list of indicators that was identified in the phase 1 literature review.

2. We have clarified the sentence, which now falls into the Phase 3 methods section (page 7), to be clear than some of the parents who took part in phase 2 also took part in Phase 3.