Author’s response to reviews

Title: Important situations that capture moral distress in paediatric oncology

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Author’s response to reviews:

Dear Editor,

We are grateful for the valuable comments on the manuscript (METH-D-19-00179) entitled “Important situations that capture moral distress in paediatric oncology”. We appreciate the opportunity to revise this manuscript and have done our best to respond to the comments and suggestions. We think that this has improved the manuscript and hope that you will be satisfied with our revisions and modifications.

Please see our responses to the reviewers’ comments below.

Phyllis Whitehead (Reviewer 1)
Thank you for your work on this important topic.
ANSWER: Thank you for taking your time to review our manuscript

In abstract please clarify item numbers that you describe.
ANSWER: Thank you for this comment, we agree that this was a bit unclear and have added some information to clarify (Abstract, p.2, line 26.)

Please expand of the cognitive interviews you reference as the rationale for adding the additional items. Describe the methodology and analysis. What year was the MDS-R translated?
ANSWER: We agree with this comment and how now added the years and expanded on the process of cognitive debriefing and hope that this is now more clear. (Background, p. 4, line 78-79 and p. 4, line 85-93.)

Please cite Dr. Corley who developed the MDS and Dr. Hamric, et al who revised the MDS-R.
ANSWER: We apologies for this mistake and have added the references. (Background, p. 3, line 73-74.)

Please explain how you determined a ranking of low, moderate and high score for the MDS-R.
ANSWER: Thank you for this. Unfortunately, this was only a qualitative categorization to avoid repeating the data from the table. However, we have now based the classification on the percentiles of the means of the 21 items from our Swedish study. We have explained this in the analysis and changed some of the categories in the results. (Data analysis, p. 6, line 136-141.)
Please correct your statements on page 3 regarding the clinical dominance of the MDS-R as a weakness.
ANSWER: We are sorry if we misinterpreted the information in the article by Epstein et al where they write that the “MDS-R... contained predominantly clinical situations” (p.115). We have removed this and elaborated on the MMD-HP. (Background, p. 4, line 81-85.)

Please discuss the MMD-HP and how it relates to your items. Are your new items integrated into the MMD-HP? Is there relevance to your items now that the MDS-R has been revised and it is the MMD-HP?
ANSWER: We have added a few sentences in the background and a section in the discussion were we relate our questionnaire and the five items to the MMD-HP. We believe that these items are still relevant to the paediatric oncology setting. (Background, p. 4, line 81-85. Discussion, p. 16, line 332-348. Conclusion, p 17, line 372-373).

Michael Kleinknecht-Dolf, PhD (Reviewer 2):
The abstract is easy to understand and gives generally a good overview of the study. However, a problem statement or a statement about the objectives of the study is missing in the abstract.
ANSWER: Thank you, the aim is now clarified in the abstract. (Abstract, p 2, line 29).

Keywords: Some keywords are not very common (e.g. decide when certain, talk about death). I suggest changing these ones in mesh terms or in keywords used in the common literature of this theme.
ANSWER: Thank you, we have now changed to keywords more used in the literature. (Abstract, p. 3, line 52-53).

The introduction gives an introduction into the theme. However, there is a description of the Swedish paediatric Moral Distress Scale - Revised Instrument missing as well as a description of the intended setting (ambulatory or hospital setting?) and population (who are the mentioned healthcare professionals?) in your study?
ANSWER: We have added information about the target population of the Swedish MDS-R and that the cognitive debriefing was performed with HCP at University hospitals. We have also added a further description of the Swedish paediatric Moral Distress Scale - Revised Instrument. (Background, p.4, line 78-79. Study design, p. 5, line 114-115. Data collection, p.5, line 120-124 and 126-128).

Who were the participants of the described cognitive interviews and in which context seem the five new items to be relevant?
ANSWER: Thank you very much. We have elaborated on the cognitive debriefing and the participants, who were all working in paediatric oncology. (Background, p 4, line 85-88. Discussion, p.16, line 333-334.)

Why do you think, that the same 5 items are relevant for different groups of professionals in the healthcare setting?
ANSWER: Most items in the MDS-R were the same when directed to the different professional groups (RNs, MDs and others). The five added items describe situations that all professional groups encounter. Furthermore, the cognitive debriefing of the Swedish paediatric MDS-R, including the 5 items, was performed with participants from the different groups of professionals (RNs, MDs and NAs). (Background, p.4, line 85-88).
What is the meaning of "experiences of the situations" of research question 3 in the light of the research questions 1 (frequency) and 2 (disturbance)?
ANSWER: Thank you for this comment. We agree and have clarified. (Research questions, p. 5, line 101-108).

In addition, please can you give some information about the experience of moral distress in the healthcare professionals of interest and the differences between them?
ANSWER: Thank you, we have added some information about the differences between professional groups. (Background, p. 3, line 65-70).

What is your idea of the measurement model, why is it useful just to examine this newly 5 items instead of the scale as its whole?
ANSWER: The reason that we examined the 5 in relation to the 21 is that the 5 are new. We hope that, based on this study, decisions can be made if they should be added or not. This has been explained in the aim of the study and we think that it is an improvement. (Aim, page 4, line 97-99).

Methods: Study design
Please can you give a little bit more information about the setting (are these oncology centers hospitals units or ambulatories, or both?), perhaps under the header "setting". To which "original MDS-R" do you refer, when you mention the "original MDS-R"?
ANSWER: Thank you, we have now clarified this (Methods, Study design, p. 5, line 114-115 and 117) (Background, p. 3, line 74. Study design, p. 5, line 117.)

Data collection
Please can you give some more information about the healthcare professionals you have invited to participate (just NA, RN and MD, and how many people of each group? How many units were participating?
ANSWER: Sorry for this mistake, we have now added this information. (Data collection, p. 5, line 120-121 and 123-124.)

Please can you give some more information about the instrument (here or in the background), perhaps under the heading "Instrumentation"? Whats the recall time and how are the response scales look like?
It is unclear, if participation of the healthcare professional was ordered during the joint unit meetings or if it was voluntary. Please, can you made a statement about this.
ANSWER: The information that the respondents were asked to, with no mentioned specified recall time, indicate the disturbance and the frequency on a 5-point Likert scale is now included in the text. The participation was strictly voluntary which is now clarified in the text. (Data collection, p. 6, line 126-128. Ethical considerations, p. 7, line 155-156. Discussion, p 16, line 351).

Data analysis
Please, can you explain, why you have computed a mathematically product of the answers of frequency and the answers of intensity for every item? Conceptually this is questionable, because the intensity of burden is inevitably related with the experience of the frequency of this ethical conflict situation. For a single person, it's not possible, to separate the burden of a certain situation from its frequency, the experience of burden is always inseparable influenced by its frequency. It's possible, that there is a learning effect with every occasion (and perhaps with some supportive interventions, which help additionally to increase the moral resilience), in which the conflict occur, so, the psychological burden will become less intense (see e.g. Rushton, C.H., M. Caldwell, and M. Kurtz, Moral distress: a catalyst in building moral resilience. American Journal of Nursing, 2016. 116(7): p. 40-49) But it's also
possible, that the moral distress increase (see e.g. Epstein, E.G. and A.B. Hamric, Moral distress, moral residue, and the crescendo effect. Journal of Clinical Ethics, 2009. 20(4): p. 330-342). Hence, there seems to be no conceptual or empirical foundation, which support to compute a composite score, therefore it is also statistically not adequate to compute such a mathematically product. Therefore, please can you explain and discuss the rationale behind your methodological considerations doing that. ANSWER: Thank you, we have added some text about this. (Discussion p. 13, line 279-280 and p. 17, line 361-362).

As mentioned in the background section, the measurement model of your scale is not clear. Are these new 5 items potential roots of moral distress, or are these situations, in which persons experiencing moral distress suffer? If this 5 situations describe potential roots of moral distress (formative model), Cronbach's alpha is not an helpful statistic. If they describe situations, in which persons experiencing moral distress (reflective model), why do you separate these 5 items from the whole scale, which is measuring the latent variable moral distress?

ANSWER: We have added some information about the instrument. The five added items describe clinical situations that have been found to generate moral distress among HCP. The reason that we examined the 5 in relation to the 21 is that the 5 are new and we need to determine if they should be included in the instrument. We think that it is of interest to know the frequency, intensity and MDS-R score for each situation. The total MDS-R score has already been published and was calculated on the 21 items to enable comparison with other studies. Cronbach’s alpha has previous been used in the development of this questionnaire already by Corley (1995), and later also by Hamric and Blackhall (2007) and Hamric et al. (2012) to test the reliability. (Data collection, p. 6, line 126-128. Aim, page 4, line 97-99.)

What's the idea of the Mann Whitney U Test? The participants were not independent, because there were working in the same setting, hence you can suppose, that there are unit or center effects. Hence, a multilevel analysis seems to be appropriate, using the participation in a certain healthcare professional group as explaining variable.
ANSWER: Thank you for raising an important point. There could be dependencies between participants within the same unit/centre. However, to avoid parametric modeling of variables that are inherently on an ordinal scale, we have chosen to apply the non-parametric Mann-Whitney U-test. We have added a sentence about this as a possible study limitation. (Discussion, p. 16-17, line 353-357).

Ethical considerations
Ethical considerations and the ethical approval are described clearly. Please can you made an additional statement, if participation was voluntary.
ANSWER: This s now added in the text (Ethical considerations, p. 7, line 155-156).

Results: Participants
How was the response rate for each group and seen in the light of the 6 centers resp. units.
ANSWER: We have now added this information. (Results, participants, page 7, line 163-164).

Results
Please can you make a statement about missings and the handling with them. In the light of the questions mentioned above, the results are difficult to understand and interpret.
ANSWER: We have now added information about missing items. (Data analysis, p. 6, line 135-136. Results, participants, p. 7, line 166).

It would be helpful, to order the results in line with the research questions.
ANSWER: We have reviewed the research questions but since the different questions are answered
intertwined in the results it is difficult fully meet your comment. (Research questions, p. 5, line 101-108.)

Discussion

The discussion of the 5 items of interest is brief and is conducted in the light of other studies. You wrote, "The appropriateness of adding items to validated instruments could be questioned". I agree with you, hence, please can you made an answer to this critic

ANSWER: Thank you for this comment, we have now added some discussion of this issue. (Discussion, p. 12, line 248-252).

What's the clinical relevance of the stated difference between different groups of healthcare professionals. The experience of moral distress depends on context and cultural and consequently also from the professional assignment. Hence, it seems clear, that there exist professional specific differences in the experience of moral distress in certain situations.

ANSWER: We agree that it is clear that differences between professional groups exist however, we think that it is important to know how it differs in order to understand the relevance of the items and ultimately to adapt clinical ethics support.

You use the study of LeBaron et al. (2017) as reference for the idea, that professionals working in countries with limited resources do not experience moral distress in the same way as professionals in countries with more resources. However, there is no such statement in the mentioned article of LeBaron, which content is not about moral distress. Therefore, this statement seems to be a little bit vague to explain the result of item 22 in the light of a systematic scarcity of resources. Perhaps the article Varcoe, C., Rodney, P., & McCormick, J. (2003). Health care relationships in context: an analysis of three ethnographies. Qualitative Health Research, 13(7), 957-973. may be helpful? However, contradictory to these findings of Varcoe et al. are the results of Harrowing et al., which describe, that the nurses in their study suffered under the systematic scarcity of resources (Harrowing, J. N., & Mill, J. (2010). Moral distress among Ugandan nurses providing HIV care: a critical ethnography. International journal of nursing studies, 47(6), 723-731). Hence, the situation is not clear.

ANSWER: Thank you, we agree that our reasoning was not correct and have reformulated and also added one of your suggested references. (Discussion, p. 13, line 272-274.)

Beside the sentence "The appropriateness of adding items to validated instruments could be questioned as it,..." a broader discussion of the methodology as well as a discussion of the study's limitations are missing. It would be helpful, if you can explain some additional thoughts to these two points.

ANSWER: Thank you, we have added some additional thoughts on these issues and hope that it is to your satisfaction. (Discussion, page 12, line 248-252. Discussion, p. 16-17, line 353-362).

Conclusion

The conclusion ends with the statement "Thus, a careful consideration is needed of whether the added items should be included in the original MDS-R, and also whether the reformulated item about not talking about death with a dying child should replace the original item." Hence, what is your conclusion or recommendation in the light of the results of your study?

ANSWER: The end of the conclusion is now changed to reflect our conclusion in the light of the results of our study (Conclusion, page 17, line 370-373).
Reviewer conclusion
I recommend publishing this important and interesting work. The knowledge about the experience of moral distress in the context of paediatric oncology is a contribution to the scientific knowledge about moral distress. Beside this it's also important for the healthcare professionals in this setting to minimize moral distress and to the develop strategies which may support to cope with it.
In my opinion, first there are some major revisions necessaire to give the paper more conceptual and methodological soundness. I hope my comments will support doing this revision.
ANSWER: Thank you for your valuable comment, we do think that it has helped to improve our manuscript.