Author’s response to reviews

Title: Important situations that capture moral distress in paediatric oncology

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Author’s response to reviews:

Phyllis Whitehead (Reviewer 1): Thank you for making the corrections from the previous reviews. Great work.
I noticed a couple of grammatical errors that need to be corrected. 1. Line 33 please change "was" to "were" used. 2.Line 358 ...while in the "presents" study...please change to "present".
ANSWER: Thanks for noticing these mistakes, we have changed accordingly.
I would also encourage further research on moral distress to use the Measure of Moral Distress for Health Care Professionals (MMD-HP) instead of the MDS-R (which is now dated). Please add a statement regarding how to integrate your findings of the unique moral distress items for paediatric oncology for further refinement of the MMD-HP not the MDS-R.
ANSWER: We have added some more discussion in relation to MMD-HP (Discussion, line 354-359, p. 16-17) and also a sentence in the conclusion (Conclusions, line 386-388, p.18). However, it is a bit problematic for us that you want us to focus so much on MMD-HP when this study is on the MDS-R. We were recommended to use the paediatric MDS-R, have translated the Swedish paediatric MDS-R to all Nordic languages and are in the middle of data collection. We were not aware that our Swedish data (that was sent to Dr Hamric) would be used to make a new instrument, instead of doing psychometric tests on MDS-R as we were informed.

Michael Kleinknecht-Dolf, PhD (Reviewer 2): Dear authors

Thank you for revising the manuscript. In think, the manuscript gained a lot from the revision. I agree with the implementation of the suggestions. Thank you very much for the benevolent efforts you have made for this. In my opinion, some points that seem important to me in relation with the development of a questionnaire are still not enough explicitly explained:

Background

In the background section, a statement about the conceptual model of measurement you followed is still missing:
According to Hamric, her MDS-R questionnaire is based on a reflective measurement model and its records moral distress as a symptom of certain causes (Hamric, Borchers, &amp; Epstein, 2012). In connection with the further development of the MDS-R to the MMD-HP the authors stated again, that
the questionnaire is based on a reflective measurement model (Epstein, Whitehead, Prompahakul, Thacker, & Hamric, 2019). Is the conception of your questionnaire still in line with this rationale (reflective measurement model for the latent variable moral distress)? In addition, if so, does there exists some hints, that the 21 items in whole does not sufficient asses the latent variable moral distress in the intended setting? Why was the augmentation of the questionnaire with this five items 22 to 26 necessaire to optimize the assessment of the latent variable moral distress?

ANSWER: We think that this is quite confusing because both Hamric and Epstein use the term “root causes” when they describe situations in which persons experience moral distress. Furthermore, they do not use the term you use (reflective measurement model) to describe their model of measurement. We have added a few words in the background about the original MDS-R (Hamric et al 2012) that it describes clinical situations found to generate moral distress (Background, line 75-76, p.4) and have already stated the same about the Swedish version (Method, line 131, p.6). Furthermore, the decision to add the five items is based on empirical data rather than theory. We have added a sentence about this in the background (Background, line 98-99, p.4).

You wrote, there is a 5-Point Likert response scale for both, the frequency as well as for the disturbance. In the light of the definition, that a Likert scale asses the degree of an agreement to a certain statement, the wording of the response scale of your questionnaire is not clear. Please can you explain more explicit the answer categories of your questionnaire.

ANSWER: Thank you, this is now clarified (Data collection, line 133-134, p.6).

Data Analysis

Proof of the psychometric properties of the translated and adapted Swedish MDS-R

To examine the questionnaire's reliability, the statistics of Cronbach's Alpha is described. As mentioned in the first review, Cronbach's Alpha alone is just one statistics to assess the psychometrics of a questionnaire. It is not a test for unidimensionality, its value may also be in an acceptable range by multidimensional scales (Cortina, 1993). Consequently, the statistics of Cronbach's Alpha alone is not an indicator that it is reasonable, building a sum score out of the scores of the individual items. Perhaps, you have done some other statistics? If not, I think, this would be a limitation, which may be eliminated by future research.

ANSWER: We have added a sentence in the discussion (Discussion, line 374-375, p17).

Data Analysis

… Therefore, can you please describe the rationale for the approach that guided your analysis and construction of a composite score out of frequency and disturbance, which was summarized to an overall score? If there is none explicitly, since you have carried out this procedure in concordance with other authors, perhaps it may be a possibility, that you describe this guidance and discuss this procedure critically in the discussion section.

ANSWER: Thank you for your analysis and thoughts on this. We have added a sentence (Data analysis, line 140-141, p.6). Even though we agree with your reasoning, we prefer not to go to deeply into this discussion in this article. However, we have briefly commented this in the discussion (Discussion, line 370-372, p.17)
Reviewer conclusion

I recommend publishing this important and interesting work after a solution or discussion of the mentioned points. The manuscript describes interesting insights in moral distress in the intended setting and is an important contribution to the scientific knowledge about moral distress and its measurement. In my opinion, there are still some revisions or explications necessaire before it is ready to publish. I hope my comments will support doing this revision.

ANSWER: Thank you for all your work in reviewing our manuscript, we hope that these revisions are to your satisfaction.