Reviewer’s report

Title: Important situations that capture moral distress in paediatric oncolgy

Version: 0 Date: 17 Oct 2019

Reviewer: Michael Kleinknecht-Dolf

Reviewer's report:

Dear authors

Thank you very much for this interesting and clinically important paper. It was a pleasure for me, reading it and so I hope, my considerations about it would be helpful for you. As described in the main text, the aim of this study was to explore the experiences of moral distress in five specific situations of the Swedish MDS-R among healthcare professionals in Swedish paediatric oncology.

Abstract

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.

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.

Background

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?

Who were the participants of the described cognitive interviews and in which context seem the five new items to be relevant?

Why do you think, that the same 5 items are relevant for different groups of professionals in the healthcare setting?

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)?
In addition, please can you give some informations about the experience of moral distress in the healthcare professionals of interest and the differences between them?

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?

Methods
Study design

Please can you give a little bit more informations 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"?

Data collection

Please can you give some more informations 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?

Please can you give some more informations about the instrument (here or in the background), perhaps under the heading "Instrumentation"? What's 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.

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. 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?
Whats 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.

Ethical considerations

Ethical considerations and the ethical approval are described clearly. Please can you made an additional statement, if participation was voluntary.

Results

Participants
How was the response rate for each group and seen in the light of the 6 centers resp. units.

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. It would be helpful, to order the results in line with the research questions.

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.

Whats 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.

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. 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.
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?

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 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.

With kind regards.

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

No

Does the work include the necessary controls?
If not, please specify which controls are required in your comments to the authors.

Unable to assess

Are the conclusions drawn adequately supported by the data shown?
If not, please explain in your comments to the authors.

No

Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

I am able to assess the statistics

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Please indicate the quality of language in the manuscript:

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