Author's response to reviews

Title: The use of health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature

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Author's response to reviews: see over
Dear reviewers,

we are grateful for your recommendations on our manuscript „Health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature“.

We read your reports with reasonable care and best attention. The reports are indeed very adjuvant and helped us to raise the manuscript's quality. We strived to answer all of your recommendations, though some of them sound contradictorily to us.

Subsequent, we will refer to the issues of your reports and describe the related changes to the manuscript.

1) Title

“The title of the manuscript is misleading: it suggests to find literature about young carers. This is not the case” (Grootenhuis 1)

It was not our aim to present literature about young carers but on the use of HRQOL in the population of young carers. Therefore, we corrected the misleading title of the manuscript into:

“The use of health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature”.

2) Abstract

“It would be helpful to shortly introduce the concept of young carers beforehand” (Erhart 7)

We included the requested information into the abstract.

“The aims are not answered in the results section” (Grootenhuis 2)

The aim of the review was to decide whether or not HRQOL could be used as an outcome criterion to evaluate young carers support. We tried to point it out more clearly.

“The inclusion criteria are stated in the results section of the abstract” (Grootenhuis 4)

In the results section of the abstract, there are no inclusion criteria presented but types of instruments that could be chosen for our study.

3) Background

“Frequency and extension of the problem. How many children are the main carer for a disabled adult in Germany” and “Age of affected children” (Rajmil 1,2)

We included prevalence data into the “Background” section.

“I am missing a literature review about the needs of young carers” and “the young carers problems are suddenly presented in the discussion table 1” (Grootenhuis 3, 5)

The problems presented in table 1 are coming from a qualitative study using Grounded Theory approach, carried out by Metzing. This study was the first and onliest research on young carers in Germany. We referred to this study. Nevertheless, we tried to point out in more detail what young carer's problems and needs are. Therefore, we opened a new subsection called “Young Carers in Germany” and included the requested information.
“one cannot do an intervention without knowing the difficulties of these young carers in more detail” (Grootenhuis 5) We do agree to this statement.

4) Aim
“An important additional question is that about the main components of children/adolescents HRQOL. Are these components of relevance for young carers? And if so how far are these young carer specific aspects addressed by the measurement dimensions and indicators of existing HRQOL instruments?” (Erhart 3)
We reformulated the third question addressed to the literature according to this issue. In addition, we opened a new subsection “Relevance of HRQOL dimensions and measurement items for use in young carers” within the “Results” section and tried to answer this issue there.

5) Method
“Selection criteria of abstracts and papers should also be clarified: who and with what criteria included and excluded documents” (Rajmil 5)
We opened the subsections “Inclusion and Exclusion criteria” and “Procedure”, and included the requested information.

6) Results
“[last paragraph of section “Health-related quality of life in children and adolescents”]: This point may cause confusion” [Erhart 8]
We do agree to this statement. Furthermore, we tried to explain that concepts like “peer group”, “family” and “school” are important aspects of the “social domain”.

“The whole paragraph could be either condensed or removed [first paragraph of the section “HRQOL research in children”]” (Erhart 11)
We can understand this recommendation, but we would prefer to keep this paragraph as it shows the process of instrumental development. This is in our opinion important information on HRQOL measure’s validity in general.

“It remains unclear why “Therefore, international … has been carried out”” (Erhart 9)
We tried to make it more clear by saying “Therefore, research … has been carried out in many countries.”

“[First sentence of section “Development of measures”] Sentence is somehow awkwardly worded” (Erhart 10)
The sentence has been reformulated.

“Another possible approach is to identify items which are of relevance across different age groups, respectively which were understood and were functioning in a comparable way across different age groups” (Erhart 4)
We act on this suggestion within the subsection “Development of measures”.

“It is true that from a theoretical point of view these instruments are not favourable if cross-cultural issues come into play. Yet in practice things might be different” (Erhart 5)
We act on this recommendation within the subsection “Development of measures”.

“How many instruments were identifying in the review and which instruments?” (Rajmil 5) and “A review as presented like this should included based on several criteria all measures which are available” (Grootenhuis 4)

We opened a new subsection “Relevance of HRQOL dimensions and measurement items for use in young carers”. There, we state that our search added no further instruments than presented by Solans et al.

7) Discussion

“Yet from a theoretical point of view there is another perspective possible: Outcomes which address the family system as a whole. (...) this issue could be at least discussed” (Erhart 2)

Thank you for this new position. We tried to refer to this within the discussion.

“Eventually it would be helpful to base the decision (...) on the specific aspects covered by the measurement dimensions and indicators of these instruments” (Erhart 6)

We agree to this statement and opened “table 4” which tries to act on your suggestion.

“The approval of Ulrike Ravens-Sieberer does not belong in a scientific manuscript” (Grootenhuis 6)

We excluded this statement.

8) Conclusion

“the interventions goals are presented which do not belong to this manuscript” (Grootenhuis 7)

The service aims have been excluded and the section “Conclusion” has been re-written.

9) Limitations

“The fact that it is not a systematic review and that the authors analized only one database should be included in the limitation section” (Rajmil 4)

We opened the limitation section and included the requested information.

We would like to thank you for your detailed feedbacks. They gave us value information on how to raise the quality of our manuscript. We hope that we clarified all addressed issues, and we hope that you can agree with our corrections within the manuscript.