Reviewer's report

Title: 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

Version: 4 Date: 17 October 2008

Reviewer: Michael Erhart

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- Major Compulsory Revisions

1) General: The manuscript addresses an important public health topic. However in its actual form the paper could gain benefit if the authors would try to relate their findings – respectively the issues raised - more closely to the core aim of their work: How can “family oriented support for young carers” be evaluated - respectively are the current HRQoL measures for children appropriate to assess the HRQoL of young carers and thus could serve as outcome criteria’s.
Especially in the results section it would be beneficial if the authors would try to relate or focus more to this question: E.g. are the current conceptions of HRQoL suitable for the situation of young carers? Are the measurement dimensions and items of existing HRQoL measures of relevance for young carers? Are important aspects of young carers situation / and needs omitted? Regarding e.g. the proxy problem it could be stated that especially for young carers the self-reported HRQoL is of relevance; regarding e.g. disease-specific versus generic instruments it could be made clear why generic instruments are warranted for young carers. These issues could be then picked up in the Discussion.

2) Page 2, last 3 lines to page 3 first lines: The authors are searching for an appropriate outcome for “family oriented support of young carers” and focus on individual QoL. Yet from a theoretical point of view there is another perspective possible: Outcomes which address the family system as a whole. Though currently there might be no integrative family outcome available, this issue could be at least discussed: For adults care givers e.g. there are measures available which assess the impact and burden a chronically ill children has on the family e.g. the FABEL questionnaire. It would be helpful to discuss this alternative approach and e.g. tell why (currently) it is not possible to go this way.

3) Page 3, para 2, line 3-6: The first two criteria would lead to a review of existing HRQoL measures for children and adolescents, a sort of review which had been published many times before. Only the third criteria brings in the specific new aspect of this study. 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.

4) Page 5, para 3, line 7-8: Some measures are designed in that way ... eventually it would be helpful to be more specific about this (e.g. different item statement, response choices, number of items and response choices, the use of pictures or symbols ...). 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. Please mention.

5) Page 5, last two lines: Such instruments may or may not be functioning in a comparable way across different cultures and languages, but this could be tested. Thus such instruments may be also applicable in cross-cultural research. 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.

6) Discussion: It would be convenient to also report the dimensions covered by the KINDL and the KIDSCREEN. Eventually it would be helpful to base the decision for the KINDL / KIDSCREEN on the specific aspects covered by the measurement dimensions and indicators of these instruments. E.g. the KIDSCREEN “Autonomy” dimension addresses aspects like “have you had enough time for yourself … ; “have you been able to chose what you want to do in your free-time …” etc. which might be specifically relevant four young carers and which are not covered by instruments like e.g. the PedsQL.

- Minor Essential Revisions

7) Page 1, para 1: This paragraph is confusing: It remains unclear who’s demands and needs / QoL is to be measured? From reading the passage one could also get the impression that the QoL of the children / younger siblings of young carers is to be measured. Thus It would be helpful to shortly introduce the concept of young carers beforehand.

8) Page 4, line 21-23: This point may cause confusion. One crucial aspect has to be clarified beforehand: One the one hand there is the question about the components that constitute HRQoL itself; that is how do e.g. children structure their subjective perception/evaluation/judgement of their health and life situation. On the other hand there is the question about the main determinants of HRQoL: Which factors do influence the HRQoL? HRQoL can be considered a multidimensional concept itself which is multifactor influenced by certain aspects like e.g. health-conditions, social environment etc.

9) Page 5, line 5-6: The issue of international QoL research had not been introduced before. From the actual text it remains unclear why “Therefore, international ... has been carried out”

10) Page 5, para 3, line 1-2: Sentence is somehow awkwardly worded. To summarize, HRQoL can be considered as a latent theoretical concept which cannot be measured directly but only indirectly using indicators. These indicators
are designed to assess the dimensions of HRQoL respectively to measure along the dimensions of HRQoL.

11) Page 4, last paragraph until Page 5, first paragraph: In a stricter sense this paragraph is somehow unrelated to the scope of the actual manuscript. And it is not related to the research questions stated beforehand. The whole paragraph could be either condensed or removed.

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Level of interest: An article of importance in its field

Quality of written English: Needs some language corrections before being published

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:
- I declare that I have no competing interest