Reviewer’s report

Title: Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review

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Reviewer: Lutz Goldbeck

Reviewer’s report:

This review is an important one, because so far there are few summaries of the literature on psychosocial aspects of children after open-heart surgery. Due to the improved surgical methods, life expectancy of children with CHD is increasing. Therefore it is necessary to assess outcome not only by somatic parameters, but also in terms of psychological adjustment and quality of life. The merit of this review is the systematic approach, however due to the heterogeneity of samples under study and of psychological outcome measures it is hard to draw any conclusions based on the literature so far. In general, these difficulties are not sufficiently addressed by the authors. Moreover, the developmental perspective (age of the patients at surgical intervention, age at time of assessment) seems not sufficiently considered. The authors failed to include some recently published research papers. Therefore, the review needs some revisions, and the conclusions might be drawn more cautiously.

Major Compulsory Revisions

1. The background information is too short. There is no explanation available why the review was conducted or why it is considered to be necessary at the moment.

2. In general, as the authors state in their discussion, based on the available cross-sectional studies it is almost impossible to distinguish between effects of the disease itself, of the consequences of living with the disease, and of surgery. Therefore it should be clearly justified, why the authors focus on CHD patients after surgical interventions. Moreover, this inclusion criterion is in fact not consequently applied, because according to figure 1 only for at least 50% of the samples under study a history of surgery is required, so this review is in fact based on mixed populations of children with CHD.

3. There are quite a few very specific inclusion and exclusion criteria for selecting papers for this review, but unfortunately there is no description available why particularly those were chosen. The cut-off follow-up period of at least two years after the first surgical intervention seems arbitrary.

4. The approach to examine a variety of risk factors for psychosocial outcome is very important, however the authors select only few factors. Developmental and family aspects of adaptation to chronic conditions and the socio-economical background of the patients are very important. Therefore, age at the time of heart surgery, age at the time of assessment of psychosocial functioning, and family/socio-economical factors should be considered more rigorously. For
example, it would be important not only to report mean ages of the samples under study, but also age ranges or standard deviations.

5. The authors missed to include some studies which would meet their inclusion criteria and provide additional information on QoL:


6. Additionally, in the discussion section a recently developed and validated CHD-specific QoL instrument should be mentioned: the Pediatric Cardiac Quality of Life Inventory (PCQLI) by Marino et al. (Qual Life Res 2008, epub ahead)

7. Besides the overlap with mental retardation due to syndromal/genetic diseases such as Down syndrome, there might be an overlap with a difficult family background, because a considerable proportion of congenital heart defects is due to a fetal alcohol syndrome. Did the authors find any studies regarding this aspect?

8. The type of heart surgery might not be as relevant as the severity of CHD and the impact of surgery regarding correction of heart dysfunction. Again, the association between characteristics of the CHD and method and outcome of surgical intervention requires specific attention.

9. The difference between clinically significant psychological maladjustment and proxy-reported psychological functioning is not clear, both sections refer to studies based on the Achenbach scales, so these are proxy measures according to the authors' definition. Both sections of the results might be better integrated.

10. As QoL was measured differently across studies, the analysis of associations with any risk factors across studies has a very weak methodological basis. The conclusion that QoL is not impaired in children after heart surgery, is for my opinion not justified, due to a probable sample effect of the studies with unclear selection biases. Moreover, disease specific QoL measures have not been applied so far, and a normative approach of comparing QoL of chronic patients with healthy individuals is always restricted to generic QL measures, thus there is a high probability of missing disease-specific problems with these measures.

11. How would the authors distinguish between behavioral symptoms related to the disease or to the consequences of the disease (p 14 first sentence)?

Minor Essential Revisions

12. To me the order of the studies in the tables according to the outcome measure doesn’t make much sense. It is noted, that the studies are grouped by major outcome variables but this is not really the fact. Alden et al. and Bjornstad
et al. both assessed DSM-IV Diagnosis but are not grouped. I would therefore rather prefer a sorting according to the order in the text. This would make the search for a particular study easier.

13. Page 4: When explaining QoL it is said, that the mentioned indices alone are not sufficient but there is no statement concerning what else should be observed instead or additional.

14. Page 5: When mentioning the quality assessment it should be noted, which total score of the quality ranking indicates “high quality”/”low quality” – since those terms are used in the review later.

15. Page 6: When mentioning the data extraction and synthesis it is said, that the heterogeneity of assessment methods did not permit a formal meta-analysis. Was this primarily intended?

16. Page 12, line 7: It is mentioned that some of the studies did not adhere to statistical standards? Which studies? –Unfortunately there is no citation.

17. Page 13. In which way may the parents play a role in the long-term adjustment?

Discretionary Revisions

18. Page 5: For each study there was a quality ranking made. Unfortunately the range and the total mean score are not reported.

19. Page 5: When explaining data extraction it is mentioned that the studies differed significantly with regard of heart defect etc. According to the inclusion criteria this is not very surprising; moreover this is rather a result than a data extraction description.

20. Page 8, line 3-9: Are those findings based on proxy or on self-reports?

21. Page 9: The heading “Risk factors for impaired quality of life” is misleadingly bold (in contrast to risk factors of psychological malfunctioning which is not bold).

22. Page 10, line 13: It must be “is comparable” instead of “compares”.

23. Page 13: As a limitation of the findings it is criticized that the reviewed studies didn’t include patients with chromosomal anomalies although studies which exclusively assessed samples with genetic disorders were explicit excluded from the review. Therefore this is not very surprising.

24. Page 13, line23: What does the superscripted “11” mean?

25. 6th reference: “- -“ The dashes are doubled

26. 14th reference: The square brackets are not necessary.

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**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 interests.