Reviewer's report

Title: Socio-Demographic and clinical factors associated with health related quality of life in children of the Middle East with beta-thalassemia

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Reviewer: Luigi Mazzone

Reviewer's report:

This paper deals with a theme of potentially substantial clinical interest investigating the associations between sociodemographic and clinical factors and the quality of life in children with thalassemia living in Middle Eastern countries, as well as the differences in quality of life between children and their parent-proxies.

A point of strength of this research, as compared to other studies investigating the quality of life, is the combining child self and parent proxy-reports to evaluate health, functioning, abilities and emotions in children.

Furthermore, this is a well-written paper, and the statistical analysis performed is suitable.

However, this study has some limitations that the authors should clarify in order to further improve the manuscript.

The authors refer to several studies on the quality of life in children with thalassaemia in the introduction. More details about the studies should be included, given that they differ with this study with respect to both participants’ characteristics and time of examination. Such details may help convincing the reader about the contribution given by the present study.

A bit more information about the medical aspects and burdensome nature of the illness, I feel, would help. I would consider carefully also whether or not to relate findings to other illness groups.

I was wondering why the authors did not recruit a control group of healthy subjects.

The subjects originally came from countries of the Middle East (i.e. Kurdistan, Palestine, Libya, Iraq and Syria) and therefore spoke different languages; so I was wondering if the PedsQS was validated in original language (all questionnaire in arabic language?) of these countries.

Even if the Pediatric Quality of Life Inventory is a good questionnaire to investigate the quality of life and it is “sensitive to cognitive development”, the authors did not complete a real cognitive or psychological evaluation with normative scale, which would have been helpful in order to avoid confounding factor (i.e. cognitive, psychological or psychiatric problems in parents or children) that could have influenced the results. Please include and discuss this aspect among the limitations of the study.
The authors stated that when they compared the level of agreement between child self and parent proxy-ratings, it was found that parents tended to slightly underestimate their child’s HRQoL. I was wondering if there were differences according to gender, age and socioeconomic status to try to better explain this result or if differences were also found in different populations (i.e. in Italian patients or in the patients of other Countries of Middle East).

It is generally accepted that β-thalassaemia may cause psychosocial imbalance and increased risk of psychosocial and behavioral problems in thalassaemic patients and their parents. Thalassaemic subjects have been described by most authors as distressed from their illness itself and from iron chelation, and frequently having maladaptive coping strategies. A psychosocial support to reduce emotional distress, to improve the compliance to chelation, and to strengthen coping strategies for a better integration in daily life has indeed been indicated. For instance, Aydinok and al. (2005) suggested that the frequency of psychopathology is higher in thalassaemics in comparison with normal population. For this reason, thalassaemic patients and their parents need a lifelong psychological support for prevention of mental health issues. In the conclusion section the authors should suggest therapy strategies (i.e. cognitive-behavioral therapy, Mazzone et al. 2009) that other reports showed to have a good effect on the compliance to chelation therapy.

**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.