Author’s response to reviews

Title: Health related quality of life of Dutch children: psychometric properties of the PedsQL in the Netherlands

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"Health related quality of life of Dutch children: psychometric properties of the PedsQL in the Netherlands"
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To the editor:

Dear Nina Titmus,

Thank you very much for the opportunity to revise our manuscript for possible publication in BMC Pediatrics. After profound editing of the manuscript with valuable advice of the reviewers, the manuscript addresses the comments of the reviewers.

Online we submitted a clean copy of the manuscript and the letter to the reviewers. We appreciate the very useful and comprehensive recommendations for improving the manuscript and hope that we have addressed these recommendations satisfactory.

Yours sincerely,

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1. The Introduction is appropriately succinct given the objective of the study.

   - The authors understand the reviewer’s interest in the translation methodology. The PedsQL was translated into Dutch in a previous study of Bastiaansen et al (2004). This study also provides a description of the translation methodology. No translational activities were undertaken in the current study. On page 4 (Background section) of the initial manuscript Bastiaansen et al (2004) are referenced [13]. To prevent confusion, the authors added on the same page that the PedsQL was not only studied but also translated before.

3. The majority of PedsQL studies have utilized the paper and pencil version. The investigators should incorporate some discussion on the electronic mode of administration, including whether administering the items one at a time on the screen may impact the psychometric properties. Two recent PedsQL internet administration studies may be useful to review and cite (Varni, J.W., Limbers, C.A., Burwinkle, T.M., Bryant, W.P., & Wilson, D.P. (2008). The ePedsQL™ in Type 1 and Type 2 diabetes: Feasibility, reliability, and validity of the Pediatric Quality of Life Inventory™ Internet administration. Diabetes Care, 31, 672-677. Young, N.L., Varni, J.W., Snider, L., McCormick, A., Sawatzky, B., Scott, M., King, G., Hetherington, R., Sear, E., & Nicholas, D. (2009). The Internet is valid and reliable for child-report: An example using the Activities Scale for Kids (ASK) and the Pediatric Quality of Life Inventory (PedsQL). Journal of Clinical Epidemiology, 62, 314-320.)
   - The authors thank the reviewer for this rightly comment and useful references. Some discussion on this matter was added on page 13, it now reads: "Furthermore, it is possible that presenting PedsQL items one at a time on a computer - with missing values not being allowed - could have some psychometric implications. Digital administration of the PedsQL has demonstrated equivalent measurement properties to the paper version [23], yet in the study of Varni et al (2008) each PedsQL scale was depicted on a separate screen and participants had the option to
skip items. The fact that this possibility was lacking in the current study could have forced participants to choose an answer that did not really apply to them. Nonetheless, this probably concerns a minimum of items since Varni et al (2008) also demonstrated similar (low) percentages of missing-item responses of digital and paper version PedsQL™.

4. It would be informative to cite the literature regarding expected age, gender, and parent education/SES differences on generic HRQOL instruments in order to place the results in the context of the larger literature. For example, adolescent girls have been found to have worse emotional functioning in comparison to adolescent boys (see for example, Reinfjell, T., Diseth, T.H., Veenstra, M., & Vikan, A. (2006). Measuring health-related quality of life in young adolescents: Reliability and validity in the Norwegian version of the Pediatric Quality of Life Inventory™ 4.0 (PedsQL™) Generic Core Scales. Health and Quality of Life Outcomes, 4:61.) and socioeconomic status (SES) differences have been found (e.g., Varni, J.W., Burwinkle, T.M., & Seid, M. (2006). The PedsQL™ 4.0 as a school population health measure: Feasibility, reliability, and validity. Quality of Life Research, 15, 203-215.)

- The authors incorporated the suggested literature in the Discussion section: For gender and age the following text was added (p.11): "Regarding the socio-demographic within-group differences, this study demonstrates a gender difference in group 8-12 on the emotional subscale with girls obtaining lower scores than boys. Similar results in adolescent girls have been reported by Reinfjell et al [18]."

SES was not measured in the current study, but the authors did elaborate on employment (p.12): "Findings on parental employment are also notable: having a job had no influence on the child’s HRQOL in our sample. Previous research has shown that children with low socioeconomic status (SES) functioned worse than children from middle SES backgrounds [21]. Employment and SES are not exchangeable, though. Having a job does not necessarily implicate a middle or high SES."

Education was already discussed in the initial manuscript (p.12): "Results of our study indicated a relationship between educational level and PedsQL scores in group 13-18: children of parents with a low education perceived a significant better quality of life. This phenomenon is difficult to explain, since previous research mainly pointed out that high quality of life scores were related to high parental education, or that education had no effect at all [19,20]."
5. The investigators may be overstating when they suggest that the scores obtained in the study are an adequate representation of the general Dutch populations. They will need to bring in additional information to support that the sample characteristics are similar to the population characteristics in the larger Dutch national pediatric population. It is not clear from the procedure section whether probability sampling was conducted. More details are needed to support how representative this sample is of the larger Dutch pediatric population. How many schools were included across how many districts, and the like.

- Indeed, the article would be more complete if the findings were set in the light of the general Dutch population. Therefore, a comparison was made with data from Statistics Netherlands in the Discussion section (p. 10/11): "The PedsQL reference scores obtained in this study are an adequate representation of the general Dutch population. According to Statistics Netherlands [15] in 2008 80.4% (of the total population) were from Dutch origin and 77.9% (of population aged 45-55 years) were employed. These figures are comparable to the socio-demographic data from our study. Furthermore, it is not uncommon [16] to find a large percentage of highly educated parents (48.4%) in the current study, compared to the Dutch working population (33.5%). It is likely that highly educated parents are better aware of the necessity of this type of research, and thus be more willing to participate. During data collection the authors experienced that willingness to take part in the study seemed lower on schools with lower educational levels and higher percentages of migrant children. Possibly, parents not born in the Netherlands experienced language problems and for this reason did not fully understand the information letter to participate in the study. These findings are supported by the fact that there were fewer parents with a high education and Dutch ethnicity in the non-participants group, compared to the group that did participate."

The authors have also included additional information regarding sampling results in the Results section (p. 7): "In total, 891 children from Amsterdam and surrounding regions were approached. They attended four elementary schools (three suburban, one urban), four high schools (one rural, one suburban, two urban) and one school for vocational education (urban)."

6. The types of chronic health conditions identified by the parents should be described. In general, the HRQOL scores for the chronic health condition group are higher than in physician-diagnosed chronic health conditions using the PedsQL, and may not be
representative of the more serious pediatric chronic health conditions in the Netherlands. This should be discussed as a possible limitation.

- **Part of the answer can be found in the initial manuscript as a footnote of Table 2:**
  "Most common chronic health conditions in total Dutch sample were: asthma (36.4%), congenital defect (13.6%), skin disease (6.1%) and migraine (6.1%)."

Moreover, the authors share the reviewer’s concern with respect to serious chronic health conditions. The following text was added to the Discussion section (p.12):

"Another explanation could be that severely ill children did not take part in our study, because they were not present at the time of administration due to illness or that parents did not want to burden them with participation. A further possible reason might be the fact that the presence of a chronic health condition in our sample was determined by the parent and not diagnosed by a physician. Physician-diagnosed chronic health conditions are often stricter than those reported by the parent. Therefore, the 8-12 year old chronic health condition sample in our study might not be completely representative of children with more serious chronic diseases."

**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.
Reviewer 2

Major Compulsory Revisions

1. I’m unclear as to ‘within-group’ difference in this manuscript. The ‘group’ in this study means age group sometime, but healthy vs. chronic disease group some time.
   - In this manuscript ‘group’ always means ‘age group’, unless otherwise specified. The authors hope to have clarified this issue by replacing the term ‘group’ by ‘age group’ in all tables. In the text however, the term ‘group’ was preserved for the benefit of readability. Furthermore, 'within-group differences' refer to 'socio-demographic within-group differences' - this was changed in the manuscript.
   In the current study, healthy and chronic disease samples were always determined per age group. The authors have attempted to clear this up by adding information between brackets in the Statistical analysis section (p.7): "Subsequently, construct validity was determined by t-tests and effect sizes (es), analysing differences in PedsQL scores (per age group) between healthy and chronically ill children..."

2. In Abstract, what’s the denominator of '55.7%', total number of the approached should be reported, or just delete '55.7%'.
   - The authors agree with the reviewer and deleted '55.7%' from the Abstract.

3. What’s definition of 'non-participants'? I didn't find out how 81 non-participants are made up. Why 81 non-participants had 82 parents who completed the questionnaire? (Table 1)
   - The authors can imagine the reviewer’s confusion. Therefore, a footnote was added to Table 1 in which the term 'non-participants' is defined: "Children and parents that refused participation and completed the non-participants form; or children and parents that consented to participation and filled out the socio-demographic questionnaire, but eventually did not complete the PedsQL due to circumstances (e.g. illness, dental visit)."
   The difference between 81 children and 82 parents is caused by missing values.

4. Bonferroni adjusted P value should be indicated in the manuscript.
   - The authors have made the necessary adjustment in the Statistical analysis section (p.7): "...ANOVA with post hoc Bonferroni correction (p<.0167) for age group and education...". Both age group (5-7, 8-12 and 13-18) and education (low, middle and..."
high) consisted of three groups (.05 divided by 3 is .0167). Subsequent alterations were also carried out in the Results section: age on p. 8 and education on p. 9.

Minor Essential Revisions

1. In abstract, The main outcomes, PedsQL total scores, construct validity and effect sizes, can be reported in the result.

   - The authors share the reviewer’s opinion. Therefore, more details were included in the Results section of the Abstract: "PedsQL total scores were 84.18 (group 5-7), 82.11 (group 8-12) and 82.24 (group 13-18)." And: "In the healthy group 5-7, the PedsQL total score was 85.31, whereas the same age group with a chronic health condition scored 78.80. Effect sizes in this group varied from 0.58 to 0.88. With respect to group 13-18, healthy children obtained a PedsQL total score of 83.14 and children suffering from a chronic health condition 77.09. Effect sizes in this group varied from 0.45 to 0.67."

2. Reference the statistical method used (Cronbach’s alpha coefficient)

   - In the current study, data were analysed by means of the statistical program SPSS 16.0.2. Cronbach’s alpha coefficient was calculated by means of this program as well; it is based on average inter item correlation. This is now also depicted in the Statistical analysis section (p.7).

3. Sampling scheme is reported in the procedure section, but the result of sampling is not reported in the result section. It’s very helpful for readers to know if the study result can be generalized to the whole Dutch children population.

   - The authors believe that additional sampling information in the Results section is helpful. For this reason the authors inserted the following (p.7): "In total, 891 children from Amsterdam and surrounding regions were approached. They attended four elementary schools (three suburban, one urban), four high schools (one rural, one suburban, two urban) and one school for vocational education (urban)." See also the answer to subsequent question 4.

4. How does the sample (N=496) distribute by location and percent of migrant children?

   - Reviewer 1 also commented this topic. The Discussion section now elaborates on the comparability of the current study sample and the general Dutch population (p.10/11): "The PedsQL reference scores obtained in this study are an adequate representation of the general Dutch population. According to Statistics
Netherlands [15] in 2008 80.4% (of the total population) were from Dutch origin and 77.9% (of population aged 45-55 years) were employed. These figures are comparable to the socio-demographic data from our study. Furthermore, it is not uncommon [16] to find a large percentage of highly educated parents (48.4%) in the current study, compared to the Dutch working population (33.5%). It is likely that highly educated parents are better aware of the necessity of this type of research, and thus be more willing to participate. During data collection the authors experienced that willingness to take part in the study seemed lower on schools with lower educational levels and higher percentages of migrant children. Possibly, parents not born in the Netherlands experienced language problems and for this reason did not fully understand the information letter to participate in the study. These findings are supported by the fact that there were fewer parents with a high education and Dutch ethnicity in the non-participants group, compared to the group that did participate.

With respect to location the authors refer to the answer on preceding question 3 and page 13 of the Discussion section: "Therefore, we recommend that future research with respect to the PedsQL in the Netherlands should include more regions of the country and incorporate the remaining PedsQL versions."

5. Since no table on “within-group difference”, mean difference +/- sd can be reported in the Results, together with p value.

- Group differences were added to the p values for age, gender, ethnicity (p.8), education and employment (p.9).

Discretionary Revisions

1. Page 9, Para 4, only one child in group 5-7 received psychological care, so it’s not worth to do comparison.

- The authors agree with the reviewer: comparison of one child with a group would not be reliable. Therefore the authors deleted this part from the Results section.

2. In Discussion, PedsQL scores can be compared with other populations.

- This point was emphasized by the first reviewer as well. Besides data already discussed in the initial manuscript (ethnicity and education), discussion on age, gender and employment is now included also.

Age and gender (p.11): "Regarding the socio-demographic within-group differences, this study demonstrates a gender difference in group 8-12 on the emotional
subscale with girls obtaining lower scores than boys. Similar results in adolescent girls have been reported by Reinfjell et al [17]."Employment (p.12): "Findings on parental employment are also notable: having a job had no influence on the child’s HRQOL in our sample. Previous research has shown that children with low socioeconomic status (SES) functioned worse than children from middle SES backgrounds [20]. Employment and SES are not exchangeable, though. Having a job does necessarily implicate a middle or high SES.”

3. This study found a relationship between education level and HRQOL. How is education level associated with parents’ gender, ethnicity and employment status? Adjusting for other demographics, is there still a significant relationship between education and HRQOL?
   - Analyses demonstrated that, when adjusted for ethnicity the effect of education on HRQOL reduced, but a trend remained visible (p=.076). Since parental education still influenced the child’s HRQOL, no further information regarding this issue was added to the manuscript.
   - Covariates parental gender and employment had no effect: HRQOL differences found for education remained significant.

4. Internal consistency coefficients for school function are quite low (0.53-0.62), which might be worth to discuss.
   - Indeed, alpha’s for school functioning were not high. However, as stated in the Discussion section of the initial manuscript, the current findings are still in line with previous PedsQL research (p.11): "The Dutch sample shows the same trend in reliability across subscales as the US [12], however with slightly lower alpha’s. In both samples, the total score appears to be most reliable and subscale school functioning least.” No further discussion was added.

5. A graphic presentation of the results would be very helpful. For example, a figure shows the different PedsQL scale scores by group.
   - The authors understand the reviewer’s point of view, but since it is not common to do this for PedsQL scores (also not by its main researcher Mr. Varni), the authors have not included a graphic presentation.

Thank you for the opportunity and privilege to review your work.

Level of interest: An article of importance in its field
Quality of written English: Needs some language corrections before being Published

Statistical review: Yes, and I have assessed the statistics in my report.

Declaration of competing interests:
I declare that I have no competing interests.