

Measuring health-related quality of life in a child population

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Background: The 56-item TNO AZL Child Quality Of Life (TACQOL) questionnaire was developed to meet the need for a reliable and valid instrument for measuring health-related quality of life (HRQoL) in children. HRQoL was defined as health status in seven domains plus emotional responses to problems in health status. The TACQOL explicitly offers respondents the possibility of differentiating between their functioning and the way they feel about it. The aims of the study were threefold: to evaluate psychometric performance of the TACQOL in the general population, to evaluate the relationship between Parent Forms and Child Forms and to obtain additional information about validity. **Methods:** A random sample of 1,789 parents of 6-11 year olds completed the TACQOL (response rate 71%), as well as 1,159 8-11 year olds themselves (response rate 69%). **Results:** Multiple correspondence analyses showed that item response categories were ordinal and that the TACQOL scales may be regarded as metric. Cronbach's α ranged from 0.65 to 0.84. Only 57% of reported health status problems were associated with negative emotions. Intraclass correlation coefficients between Parents Forms and Child Forms ranged from 0.44 to 0.61. Pearson's correlation coefficients between TACQOL and KINDL ranged from 0.24 to 0.60. Univariate analyses of variance showed that children with chronic diseases and children receiving medical treatment had lower TACQOL scores than healthy children. **Conclusions:** The study showed that with the TACQOL, children's HRQoL can be measured in a reliable and valid way.

Keywords: children, health status, measurement, quality of life

For many decades outcome assessment in medicine has focused on mortality, morbidity and, more recently, on health status.¹⁻⁶ Although necessary and valuable, such outcome measures do not reflect patients' health-related quality of life (HRQoL). In adults, measuring HRQoL was the subject of over 500 articles published up to 1991. These were recently reviewed by Gill and Feinstein.⁷ Of a sample of 75 of them, only 17% included patients' personal views. It has been claimed that HRQoL assessments should provide information about capabilities and well-being and their relevance to the individual concerned.⁸⁻¹⁰ Even if health status is self-reported and, therefore, subjective in nature, the patients' own emotional evaluation of their health status is often not explicitly taken into account. In addition, in utility approaches, preferences for health states are elicited typically from the informed general public and not from the individual patient who has to live with the disease. Only a few attempts have been made to develop reliable generic HRQoL instruments for children, including the

Health Utilities Index,¹¹ the Child Health Questionnaire,¹² the KINDL,¹³ the 16D,¹⁴ and the FS(II)R.¹⁵ None of these instruments explicitly offers respondents the possibility of differentiating between their functioning and the way they feel about it. Related to this issue, HRQoL research in children presents two additional problems: age specificity and the proxy problem. Many existing questionnaires and scoring systems for adults are not applicable to children because they contain domains such as fertility, sexuality and economic independence. For children, even a domain such as independence in daily life (e.g. toilet use, dressing and tying one's own shoe laces) may be inappropriate. Furthermore, who is going to be the one to give an evaluation of the child's HRQoL: the child him/herself or some proxy such as a parent, a nurse, a doctor or a teacher?

The TNO AZL Child Quality Of Life (TACQOL) questionnaire¹⁶⁻¹⁹ was developed to meet the need for a reliable and valid research tool for measuring HRQoL in children. In the literature, it is claimed that HRQoL should be regarded a multidimensional construct, including at least physical, daily living, social and psychological dimensions.²⁰⁻²⁶ In accordance with these claims, the TACQOL covers seven domains: physical complaints and motor functioning (physical), autonomous functioning (daily living), social functioning (social), cognitive functioning and positive moods and negative moods

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(psychological functioning). Items and domains of the TACQOL were chosen on the grounds of results of focus groups with parents, paediatricians and developmental psychologists.^{16,17} HRQoL was defined as health status plus emotional responses to problems in health status or, in other words, as a weighting of health status problems by the emotional impact of such problems. Thus, the TACQOL not only covers health status domains, but also the child's emotional evaluation of reported health status problems. Children's subjective emotional appraisal of their health is explicitly taken into account. The psychometric performance of the questionnaire in a sample of chronically ill children was satisfactory.¹⁶⁻¹⁸

The TACQOL Parent Form (TACQOL PF) questionnaire is completed by parents of children aged 5-15 years. In the PF, parents are asked to answer the questions from the perspective of their child. For children aged 8-15 years, a parallel TACQOL Child Form (TACQOL CF) is available. The aims of the present study were threefold: to evaluate the psychometric performance of the TACQOL PF and CF in the general population, to evaluate the relationship between the TACQOL PF and CF and to obtain information about validity. The study was approved by the TNO Medical Ethics Committee.

MATERIAL AND METHODS

Sample

Twelve GGDs (municipal health services) spread over the Netherlands each selected a random sample of 210 children, stratified by gender and age (6-7, 8-9 and 10-11 years of age), resulting in a sample of 2,520 children. Letters were sent to parents explaining the aims of the study and stressing the parents' right not to participate. If necessary, a reminder was sent after three weeks. The

parent response rate was 71% (n=1,789). No empty returns occurred. The response rate from parents of children aged 8-11 years was somewhat lower than from parents of children aged 6-7 years (67 and 78% respectively). Fourteen percent of parents had not been born in The Netherlands. A recent representative survey suggested that approximately 18% of parents of children in the relevant age groups were not of Dutch origin.²⁷ Ethnic minorities would therefore seem to be somewhat under-represented. Parents of children aged 8-11 years (n=1,680) were asked to have their children complete a questionnaire as well. The response rate from children was 69% (n=1,159) and not related to gender or age.

Questionnaires

The parent questionnaire contained the TACQOL PF as well as questions about demographic details, children's chronic illnesses, common illnesses and medical treatments. The child questionnaire contained the TACQOL CF and the Dutch translation of the German KIND-L. The KIND-L is a generic, multidimensional instrument for children's HRQoL,¹³ measuring four dimensions: physical functioning (body), practical daily functioning (daily), social functioning (social) and psychological functioning (psyche). The KIND-L was translated into Dutch in accordance with internationally agreed guidelines for the translation of HRQoL questionnaires.²⁸ Both the TACQOL PF and the TACQOL CF contain 56 items, covering seven eight-item domains: physical complaints (body), motor functioning (motor), autonomous functioning (auto), cognitive functioning (cognit), social functioning (social), positive moods (emopos) and negative moods (emononeg). The items of the TACQOL PF are presented in table 1.

Table 1 Items of the TNO AZL Child Quality Of Life Parent Form (TACQOL PF)

Body Has your child had/ did your child have	Motor Did your child have difficulty with	Auto Did your child have difficulty with	Cognit Did your child have difficulty with	Social My child was	Emopos My child felt	Emoneg My child felt
Ear aches or sore throats	Running	Going to school on his/her own	Paying attention, concentrating	Able to play or talk happily with other children	Joyful	Sad
Stomach aches or abdominal pain	Walking	Washing him/herself	Understanding schoolwork	Able to stand up for him/herself with other children	Relaxed	Aggressive
Headaches	Standing	Getting dressed on his/her own	Understanding what others said	Other children asked my child to play with them	In good spirits	Angry
Dizzy	Walking downstairs	Going to the lavatory on his/her own	Arithmetic	At ease with other children	Happy	Shorttempered
Felt sick/nauseous	Playing	Eating or drinking on his/her own	Reading	Able to play or talk happily with us, parents	Contented	Worried
Tired	Running or walking long distances	Sports or going out to play on his/her own	Writing	Incommunicative or quiet with us, parents	Cheerful	Jealous
Sleepy	Balance	Doing hobbies on his/her own	Learning	Restless or impatient with us, parents	Enthusiastic	Gloomy
Dozy/lethargic	Doing things handily or quickly	Riding a bicycle	Saying what he/she meant	Defiant with us, parents	Confident	Anxious

In each item, the frequency of occurrence of health status problems is assessed. If such a problem is reported, the emotional reaction of the child to this problem is determined. The reference period is formulated as 'the last few weeks'. For example, the question 'did your child have difficulty concentrating in school', with response categories 'never', 'occasionally' or 'often', is followed (only when the response is 'occasionally' or 'often') by the statement 'at that time, my child felt', with response categories 'fine', 'not so good', 'quite bad' or 'bad'. Items are scored by assigning a value of 4 to the 'never' response, a value of 3 to a 'feeling fine' response, a value of 2 to a 'feeling not so good' response, a value of 1 to a 'feeling quite bad' response and a value of 0 to a 'feeling bad' response. Item scores within a scale are added to a scale score, with a range of 0 to 32. If more than two items are missing in a scale, the scale score is declared missing. In case of one or two missing items, the mean of the non-missing items is imputed. Higher scale scores indicate better HRQoL. No emotional responses to items in the positive or negative mood scales (emopos and emoneg) are assessed since this would lead to nonsensical items. A typical mood item is 'was your child happy', with response categories 'never', 'occasionally' or 'often'. Mood item categories are assigned a value of 0 to 'never', a value of 1 to 'occasionally' and a value of 2 to 'often'. Consequently, emopos and emoneg range from 0 to 16.

Statistical analyses

In coding pairs of questions into single scores, ordinality of response categories was assumed. This assumption was evaluated by calculating category quantifications in multiple correspondence analyses (HOMALS) and, subsequently, counting the number of such quantifications in violation of ordinality. Furthermore, HOMALS provides object quantifications (scale scores) that may be considered metric variables. Pearson correlation coefficients (PCCs) were calculated between scales obtained using such object quantifications, on the one hand and the TACQOL scales obtained by the scoring system presented (e.g. unweighted summation of the item-pairs per scale), on the other. High PCCs would indicate that TACQOL scales may be considered as metric too. The advantage of the TACQOL scoring system above a scoring system based on the HOMALS object quantifications is that the former is independent of sample characteristics.

Mutual independence of the TACQOL scales was evaluated by calculating item-rest and item-scale PCCs, as well as the TACQOL scales PCCs. Cronbach's α was calculated for each scale. The validity of the distinction between health status problems as such and the emotional impact of such problems was evaluated by calculating the total number of problems and the percentage of such problems associated with negative emotional reactions. The relationship between PF and CF was evaluated by calculating intra class correlation coefficients (ICC). Concurrent validity was evaluated by calculating PCCs between the TACQOL scales and the KINDL scales.

Criterion validity was evaluated by relating the TACQOL scores to three dichotomous criteria: any common, non-chronic, illness during a 4 week period prior to testing, any medical treatment in the 6 months prior to testing and any chronic illness. This was done by one-way analyses of variance.

RESULTS

The percentual distributions of the TACQOL scales are presented in *table 2*, along with the percentage of missing items per scale. Scale scores were categorised for ease of interpretation.

Table 2 shows that the percentage of missings was low. TACQOL scale scores were skewed. Cronbach's α ranged from 0.65 to 0.84.

The percentage of ordinality violations was 6% in the TACQOL PF and 7% in the TACQOL CF. Violations occurred mainly in response categories with a prevalence of less than 1%. PCCs between HOMALS object quantification scales and TACQOL scales ranged from 0.89 to 0.95; therefore, TACQOL scales may be considered metric variables.

Over 98% of the item-rest PCCs were higher than PCCs of items with other scales.

The PCCs between TACQOL PF scales ranged from 0.21 to 0.48, with the exception of the PCC between the auto and motor scales (0.61). The PCCs between TACQOL CF scales ranged from 0.22 to 0.48.

Table 3 presents the number of problems perceived and the percentage of such problems associated with negative emotions.

Parents reported a total of 8,144 problems, only 57% of which were associated with negative emotions in their child. Children reported 9,411 problems, 63% of which were associated with negative emotions. Children reported significantly more problems on the body and motor scales than did their parents. Moreover, on all scales but the social scale, children reported more problems associated with negative emotions than did their parents.

Table 4 shows means and 95% confidence intervals for the scale scores, together with ICCs between the TACQOL PF and TACQOL CF scale scores.

Table 4 shows that ICCs between PF and CF scales ranged from 0.44 to 0.61. The magnitude of PF means did not differ very much from CF means.

PCCs between TACQOL and KINDL scales ranged from 0.24 to 0.60. PCCs of the four KINDL scales among each other ranged between 0.54 and 0.74.

One-way analyses of variance showed that children with a chronic illness and children who had undergone medical treatment had lower scores on all TACQOL PF and CF scales ($p < 0.001$), except for the cognit scale ($p < 0.01$). Effects sizes ranged from 2 to 7% of the maximum scale range. Differences on the CF scale were in the expected direction, but were only significant ($p < 0.05$) for body, motor, auto and emoneg. Having had a common illness showed small though statistically significant effects on the body, motor, auto and social scales ($p < 0.05$).

DISCUSSION

In this study, HRQoL was defined as health status plus emotional responses to problems in health status, the latter being the way children react to their health status problems emotionally. Children's HRQoL was measured with the TACQOL, a recently developed generic instrument. The aims of the study were to evaluate the psychometric performance of the TACQOL PF and TACQOL CF in the general population, to evaluate the relationship between TACQOL PF and CF and to obtain additional information on validity.

The psychometric performance of both the TACQOL PF and the TACQOL CF was satisfactory. The TACQOL scales were skewed, which is to be expected in a general population. However, the parametric techniques that were applied are quite robust against skewness and have been demonstrated

Table 3 Number of problems perceived (NP) and number (NE) and % (% NE) of such perceived problems associated with negative emotional reactions, by source of information (parents or children), and by TACQOL scale; complete PF/CF (Parent Form/ Child Form) pairs only (8-11-year-olds; n=1,054)

	Parent Form			Child Form		
	NP	NE	% NE	NP	NE	% NE
Body	2,886	2,191	76	3,721	2,960	80
Motor	875	495	57	1,313	791	60
Auto	455	208	46	481	279	58
Cognit	2,372	968	41	2,416	1,116	46
Social	1,556	775	50	1,480	796	54
Total	8,144	4,637	57	9,411	5,942	63

TACQOL: TNO AZL Child Quality Of Life

Table 4 Mean TACQOL PF (Parent Form) and CF (Child Form) scores, 95% confidence interval of mean (95% CI), and class correlation coefficients (ICC) by TACQOL scale; complete PF/CF pairs only (8-11-year-olds; n=1,054)

Scale	Parent Form		Child Form		ICC
	Mean	95% CI	Mean	95% CI	
Body	26.9	26.7-27.2	24.9	24.6-25.2	0.54
Motor	30.6	30.5-30.8	29.8	29.6-30.0	0.48
Cognit	28.7	28.5-29.0	28.5	28.2-28.7	0.61
Auto	31.3	30.8-31.4	31.2	31.1-31.3	0.45
Social	29.7	29.6-29.9	29.7	29.5-29.9	0.51
Emopos	14.7	14.6-14.8	13.6	13.4-13.7	0.39
Emoneg	11.5	11.4-11.7	11.6	11.4-11.8	0.55

TACQOL: TNO AZL Child Quality Of Life

Table 2 Percentage of missing answers, Cronbach's alpha's and categorized percentual distributions of TNO AZL Child Quality Of Life Parent Form (TACQOL PF) (n=1,777) and Child Form (CF) scales (n=1,116)

	Body	Motor	Auto	Cognit	Social	Emopos	Emoneg
Parents							
Percentage of items with missing answers	0.6	0.4	0.4	1.5	0.5	1.4	1.3
Cronbach's α	0.70	0.79	0.69	0.84	0.67	0.84	0.71
Categorised percentual distribution							
0-15 Body to Social	1	0	0	0	0	1	5
16-19 Body to Social	3	1	0	3	0	4	15
20-23 Body to Social	12	2	1	6	2	3	28
24-27 Body to Social	28	5	3	18	9	8	31
28-31 Body to Social	40	29	23	36	57	29	18
32 Body to Social	15	63	73	38	32	55	3
Children							
Percentage of items with missing answers	0.5	0.5	0.5	0.9	0.8	1.1	1.1
Cronbach's α	0.76	0.74	0.66	0.79	0.65	0.78	0.76
Categorised percentual distribution (%)							
0-15 Body to Social	6	1	0	1	0	3	7
16-19 Body to Social	10	1	0	3	1	6	15
20-23 Body to Social	20	4	1	8	2	9	25
24-27 Body to Social	27	10	3	18	12	22	26
28-31 Body to Social	28	41	22	43	51	32	22
32 Body to Social	10	44	74	27	34	29	6

to be adequate in analysing skewed data if sample size is large enough.²⁹

Cronbach's α ranged from 0.65 to 0.84, which is regarded as satisfactory for use of the TACQOL in comparing groups.³⁰⁻³² However, when the value of a scale for an individual is of interest, the TACQOL cannot be used safely; for use in the clinical situation much higher levels of Cronbach's α are mandatory. In addition, the stability of the TACQOL, as well as sensitivity to change, still need to be ascertained.

The validity of the scale structure, i.e. the domains that were distinguished, is supported by the finding that item rest PCCs were almost always higher than PCCs for items from other scales. Furthermore, PCCs between TACQOL scales were low to moderate. The construct validity of the TACQOL is therefore good.

PF scales were moderately correlated to CF scales. This implies that, at an individual level, a parent differed considerably from their child in their judgement about the child's HRQoL. This is a common finding that has been described extensively in the literature on proxy ratings.³³⁻³⁵ In commenting on this phenomenon, Saigal et al.³⁶ state that "the viewpoint of those who have to live with a certain health state is what matters". As no golden standard exists and both parents' and children's opinions may be valuable in evaluating treatment effects, it seems best to obtain both parents' and children's evaluations whenever possible. As PF and CF scale means did not differ greatly, at a group level the TACQOL PF may be regarded as a satisfactory proxy for the TACQOL CF. The relationship between TACQOL PF and TACQOL CF has been studied in detail elsewhere.¹⁹

Concurrent validity was evaluated by relating TACQOL CF scales to KINDL scales. PCCs were low. This held true even for scales intended to measure comparable concepts. The lack of relations between the TACQOL and the KINDL may partly be caused by a different time frame: the last weeks for the TACQOL and the last week for the KINDL. In addition, since the PCCs between the KINDL scales were high, the Dutch KINDL scales may predominantly reflect a single quality of life dimension. In contrast, the TACQOL CF scales were only moderately interrelated, indicating high domain specificity, with each domain only moderately related to a common, single quality of life factor. If these findings are replicated in future research on concurrent validity of the TACQOL CF and the Dutch KINDL, the TACQOL CF may be more consistent with a multidimensional definition of HRQoL than the Dutch KINDL.

To evaluate criterion validity, the TACQOL scales were related to three criteria: common illnesses, medical treatment and chronic illnesses. As expected, these criteria had negative effects on the TACQOL PF and CF scores, although effect sizes were not very large. As has been reported in the literature, children's HRQoL may be influenced by other factors than their health status. For instance, Saigal et al.³⁷ found that even severely handicapped children rated their health status as highly as healthy controls did. At the same time, parents may

underestimate both the prevalence and emotional impact of health status problems.¹⁹

The validity of the distinction between health status and HRQoL was supported by the finding that only approximately half of the health status problems reported were associated with negative emotional reactions in the children. The TACQOL explicitly offers respondents the possibility of differentiating between their functioning and the way they feel about their functioning. The possibility that patients have a health problem but do not feel bad about it may bias patients' self-reporting in typical health status questionnaires. Patients may wish to incorporate the fact that they do not feel bad about a certain health status problem by rating their health status problem as less severe than a proxy rater such as a doctor, parent or spouse would. This mechanism may explain the often reported lack of difference between patients and healthy controls in self-reported health status.^{37,38} If it matters how children feel about their functioning rather than how they are functioning,⁷ measuring health status alone does not provide all the relevant information. Clearly, the present study has shown that 'subjectivity can be made scientific'.⁸ With the TACQOL, HRQoL in children can be measured in a reliable and valid way. The instrument may therefore be suitable for evaluating the effects of medical intervention in chronically ill children. Curing health problems is often impossible in chronic diseases such as diabetes mellitus or congenital heart disease, but negative emotional feelings resulting from these diseases may be prevented or reduced.

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