

Measuring health-related quality of life in children: the development of the TACQOL parent form

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Health-related quality of life (HRQoL), conceptualized as patients' own evaluations of their health status, is an important criterion in evaluating health and health care and in the treatment of individual patients. Until now, few systematic attempts have been made to develop instruments to assess the HRQoL of children using such a conceptualization. This article describes the conceptualization and results of a study aiming to develop such an instrument for children aged 6–15 years using their parents as a proxy. The feasibility and psychometric performance of the instrument were evaluated in a study of 77 patients of the paediatric out-patient clinic of Leiden University Hospital. For each of the *a priori*-defined domains, a parent form scale could be constructed with satisfactory reliability and moderate correlations with the other scales. Only some of the parents indicating health status problems also signalled negative reactions to these problems. This is, in our view, a strong argument for the distinction between health status and quality of life (QoL). The correlation coefficients between the parent form and a children's questionnaire were low. Overall, the psychometric performance of the TACQOL parent form looks promising, which suggests that this instrument – with some modifications – can indeed be used to assess group differences in HRQoL in children. The results, however, should be replicated in larger samples, currently under study. The relation between parents' proxy reports on the HRQoL of their children and children's self-reports needs further investigation.

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Introduction

As early as 1948, the World Health Organization defined health as 'a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity'. Nevertheless, since then, for many decades, outcome assessment has been focused on mortality, morbidity and, more recently, also on functional health status. Such outcome measures are of paramount importance in monitoring children's health and in evaluating the effectiveness of children's health care.^{1–8} Although necessary and valuable, these outcome measures do not really reflect patients' 'well-being' properly, in so far as their own, subjective evaluation of their health status is not taken into account. This is also true for preference-based approaches to health-related quality of life (HRQoL), since in such approaches preferences for health states are typically elicited from the informed general public and not from the patient him- or herself. Gill and Feinstein⁹ drew a sample of 75 out of 500 articles focusing on measuring HRQoL of adults. They concluded that only 17% of the articles reviewed included patients' personal views and therefore could be said to evaluate quality of life (QoL), since this is a uniquely personal perception and reflects how individual patients feel about their health status. Such subjective health assessments should provide information about capabilities and well-being and their relevance to the individual concerned.¹⁰ In paediatrics, as in other areas of health care, awareness is growing that medical parameters such as mortality, morbidity and health status are not the only important outcome variables to be considered systematically.^{11,12} Of course, QoL considerations have always been important for the individual paediatrician. Yet, for children, thus far even less attempts have been made

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to develop reliable assessment instruments, independent of the judgement of the individual physician. This is not surprising, since such research in children presents two additional major problems: age specificity and the proxy problem.

Firstly, many of the existing questionnaires and scoring systems for adults are not applicable to children because they contain domains such as fertility, sexuality and economic independence. For very young children, even domains such as independence in daily life (e.g. toilet use, dressing and tying one's own shoe laces) may be inappropriate. To solve this problem, research tools to measure QoL in children should be developed separately for various age groups and may differ considerably from each other.

Secondly, if such a research tool is supposed to measure QoL in a child, who is going to be the one to give his or her evaluation? The child him/herself? Although this is in many ways probably the most valuable opinion, the relevance, reliability and validity of its measurement may be questioned. The dominance of short-term memory, preponderance of recent incidents, absence of a fully developed long-term perspective and language problems may lead to invalid and highly unreliable results. The use of standard questionnaires poses an additional problem as a result of insufficiently developed reading abilities.

Parent opinion is no doubt of great importance; parents are generally quite able to estimate their child's well-being, in respect of the issues mentioned above. Parents, however, may easily over- or underestimate the importance their child attributes to certain aspects of their well-being at a specific point in time; thus, peer-related issues may be far more important to an adolescent than parents have ever thought. Moreover, parents' expectations and previous experiences with the child may well influence their views. Analogous reasoning holds for attending physicians or nurses and teachers, all of whom have their own point of view concerning QoL of a child and will use this as a primary reference guide in forming their evaluation. Valuation studies of health status attributes in the general population have been performed and the data from these studies have been used to weight the quality of these attributes. These scores, however, do not necessarily reflect the patients' well-being, as their valuation of the same attribute may differ markedly from the preferences of the general population. Despite all the difficulties, one cannot avoid measuring children's own evaluation of their health if one wants to measure HRQoL in children. The need to develop proper research tools to measure QoL in children is urgent. In the absence of

such tools, children's well-being is estimated by researchers and attending physicians who use their own personal reference points and their own experience with similar patients as guidelines. Valuable though these estimations may be, they will be hardly comparable between each other and, therefore, do not offer a sound base for evaluations between different physicians, patient groups and so on.

Recently, a joint research programme on HRQoL in children was set up in The Netherlands by the TNO Institute of Prevention and Health and Leiden University Hospital. The aim of this programme was to develop a generic, i.e. not disease-specific, instrument to assess children's HRQoL. This instrument should be applicable to children in the age group of 6–15 years with different diseases and handicaps, to enable cross-condition comparisons. Furthermore, it should be easy to complete and short. Such practical conditions were considered basic as the questionnaires were to be used as a regular part of standard clinical assessment procedures. As consensus is growing that generic measures of HRQoL should reflect the (affective evaluation of) functioning in different life domains,^{13–15} HRQoL was conceptualized as a complex construct, which cannot be assumed *a priori* to be unidimensional. In view of the difficulties mentioned above, it was thought impossible to develop a reliable and valid questionnaire to be completed by children younger than 8 years themselves. As – in general – parents may be assumed to be among the best sources of information about their children's functioning and emotions, it was decided to focus primarily on the development of a questionnaire for parents, asking them about their children's health status and their children's emotional reactions to health status problems. For children above 8 years, a comparable questionnaire was developed, in order to explore the amenability of such an instrument and its relations with the parent form.

Subjects and methods

Questionnaire and scales

Inspection of existing questionnaires showed no complete consensus about the specific domains to be distinguished, but generally the following domains are considered essential: pain and symptoms, motor functioning, cognitive functioning, social functioning, autonomy (self-efficacy or role functioning) and emotional functioning. These domains were included in the definition of HRQoL to be measured. On the

basis of the existing literature and questionnaires on health status and HRQoL¹³⁻²¹ an inventory of items assessing aspects of health status was made. Based on psychological and clinical experience, 108 health status items were selected, tapping into seven domains of HRQoL: pain and symptoms (body), basic motor functioning (motor), autonomy (auto), cognitive functioning (cognition), social functioning (social), global positive emotional functioning (emo-pos) and global negative emotional functioning (emo-neg). When parents indicated the presence of some health status problem, they were asked to assess the child's emotional reaction. No affective responses were asked regarding global emotional functioning (domains 6 and 7), since this would lead to nonsensical items. Table 1 presents some examples of the items used in the study.

After data collection, the answers to each health status item and its corresponding emotional response item were combined into a new variable indicating no problem, problem without a negative response or problem with a negative response. We supposed that these constructed items were of ordinal measurement level. Correspondence analyses²² confirmed this supposition. On the basis of these constructed variables, items were selected to define scales for the

domains distinguished. Three criteria were used in this selection: the prevalence of health status problems, corrected item subscale correlation coefficients and discrimination values as calculated in the correspondence analysis.⁹ In order to facilitate inter-scale comparisons, it was decided to try and include eight items in each scale.

For children aged 8 years and older, a comparable questionnaire was developed, using the same procedure. Due to difficulties in translating the parent form to items which were comprehensible to children, however, it was not possible to construct exactly identical scales. As a result the scales of the children's questionnaire differ from the parent scales, both in the number of items and content.

The attending paediatricians assessed the severity of disease for each child on a seven-point Likert scale.

Weighting

The items were scored 0 for no health status problem, 1 for a health status problem without negative emotional responses and 2 for a health status problem with negative emotional responses (c.f Table 1). As the category 'fine' in the emotional response was hardly

Table 1. Some items of the TACQOL parent form as used in this study^a

In the last few weeks ...			
Did your child feel dizzy?	<input type="checkbox"/> No (0)	<input type="checkbox"/> A bit	<input type="checkbox"/> Very much
	↙	↘	↘
		<input type="checkbox"/> How did your child react emotionally?	
		<input type="checkbox"/> He/she felt bad (2)	
		<input type="checkbox"/> No apparent reaction (1)	
		<input type="checkbox"/> He/she felt fine (1)	
Did your child have difficulties keeping their balance?	<input type="checkbox"/> No (0)	<input type="checkbox"/> A bit	<input type="checkbox"/> Very much
	↙	↘	↘
		<input type="checkbox"/> How did your child react emotionally?	
		<input type="checkbox"/> He/she felt bad (2)	
		<input type="checkbox"/> No apparent reaction (1)	
		<input type="checkbox"/> He/she felt fine (1)	
Did your child have difficulties dressing independently?	<input type="checkbox"/> No (0)	<input type="checkbox"/> A bit	<input type="checkbox"/> Very much
	↙	↘	↘
		<input type="checkbox"/> How did your child react emotionally?	
		<input type="checkbox"/> He/she felt bad (2)	
		<input type="checkbox"/> No apparent reaction (1)	
		<input type="checkbox"/> He/she felt fine (1)	

^aThe scores attributed to the paired items are in italics.

used by parents, it was decided to ignore this category. The scores are summed resulting into scale scores ranging from 0 to 16.

Subjects and data collection

The parents of 77 young patients (aged 6–15 years) of the paediatric out-patient clinic of Leiden University Hospital consented to take part in the study. This study was approved by the local ethics committee. The children were treated for various conditions, such as coeliac disease, asthma, congenital heart disease, haemato-oncological problems, juvenile rheumatoid arthritis, diabetes mellitus, etc. The parents completed the parent form of the TACQOL just before consulting the physician about their child. The children's questionnaire was completed by 58 children, aged 8–15 years. A research assistant made sure that the questionnaires were completed independently by the parents and children. Finally, the attending paediatrician filled out a medical information form.

Analysis

The psychometric performance of the TACQOL parent form was evaluated in three ways. Firstly, scales should be reliable, so as to enable the easy detection of differences between individuals and groups. Therefore, Cronbach's α was calculated for each of the seven scales. Secondly, to test for the scale specificity of the items, corrected item-scale correlations were calculated, as well as correlations of each item with all the other scales. Thirdly, the relevance of the distinction between the scales was assessed. This was done by calculating the correlations between scales and by performing a confirmatory factor analysis (principal components and VARIMAX rotation), fitting a five-factor solution to the items of the first five scales (body, motor, auto, cognition and social). The items of the emo-pos and emo-neg scales were excluded from this factor analysis, as no independence of these scales from the other ones was postulated. To evaluate the validity of the distinction between health status and emotional response to problems in health status, the percentages of the respondents indicating no health status problem, those indicating at least one health status problem without negative emotional reactions and those indicating at least one negative emotional reaction to a health status problem were calculated separately for each scale. In order to explore the convergence (if any) between parents', children's and paediatricians' judgements, the parent form scales

were correlated with the paediatricians' judgements on the severity of the disease.

The amenability of the children's questionnaire was evaluated using Cronbach's α . Factor analysis of these data failed due to the matrix not being positive definite. In order to explore the relations with the parent form scores, Pearson's product moment correlation coefficient and intraclass correlation coefficients (ICCs) were calculated. The use of ICCs, in addition to the product moment correlation coefficient, was considered necessary to reveal systematic differences between parents' and children's reports.²⁶ In addition, *t*-tests were performed.

Results

The pilot study showed that it took parents and children 10 min to complete the questionnaire on average. The questionnaire proved to be self-explanatory. Neither parents nor children had difficulty understanding the questions. For each of the domains, a parent form scale could be constructed with satisfactory reliability. Table 2 presents the results of the psychometric evaluation of the resulting scales. A categorical homogeneity analysis largely confirmed the results of the item-rest correlations. These results can be obtained from the authors.

Table 2 shows that Cronbach's α s for the scales vary between 0.71 and 0.89. The scale specificity was good for all but two items, as the item-rest correlation coefficients of all but two items with their own scale were higher than the corresponding item-scale correlations with any other scales. The two offending items were part of the body scale. Both showed slightly higher correlations with the social scale. Forty-three out of 55 items (78%) had a corrected item-scale correlation higher than 0.40 and 35% of the items had an item-rest correlation higher than 0.60. The correlations between the scales were mostly significant but moderate in size, which indicates a limited amount of shared variance, therefore supporting the relevance of the distinction between the scales. The emo-pos and emo-neg scales showed on average the highest correlations with other scales, indicating a relatively high covariance with the other scales. The sign of the correlation coefficients with all scales was as expected, i.e. that negatively valued health status problems go with higher emo-neg scores and with lower emo-pos scores. In order to test the domain structure of the TACQOL, a principal components analysis with VARIMAX rotation was performed on the items of the parent form scales, excluding the emo-pos and emo-neg scale items. A five-factor solution explained

Table 2. Psychometric characteristics of the TACQUOL parent form

	Body	Motor	Auto	Cognition	Social	Emo-pos	Emo-neg
Number of items	8	7	8	8	8	8	8
Cronbach's α	0.71	0.77	0.85	0.87	0.75	0.89	0.80
Number of items with:							
Item-Rest correlation higher than correlations with other scales	6	7	8	8	8	8	8
Item-Rest correlations higher than 0.40	4	5	7	7	6	8	6
Item-Rest correlations higher than 0.60	0	2	4	5	0	6	2
Correlation between scales							
Body	-						
Motor	0.26	-					
Auto	0.39	0.20	-				
Cognition	0.39	0.25	0.39	-			
Social	0.34	0.25	0.37	0.32	-		
Emo-pos	-0.29	-0.19	-0.35	-0.33	-0.55		
Emo-neg	0.50	0.31	0.39	0.21	0.57	-0.41	-

51% of the variance. Table 3 shows that this five-factor solution reproduced the five scale structures very well. All items loaded higher on their own factors than on other factors, except for three items (7.5%). Of all the factor loadings, 50% was above 0.50.

To evaluate the distinction of health status problems *per se* and the affective evaluation of such problems, we distinguished between subjects indicating no problems, those indicating problems without negative responses and those indicating problems with negative responses. Table 4 shows that only 23–30% of parents reporting any health status problems indicated that their child showed negative emotional reactions to these problems. Clearly, only some of the health status problems signalled by parents were, in their perceptions, associated with negative emotional feelings in the child.

The scales for the children's questionnaire were constructed using similar procedures to the TACQOL parent form. Table 5 shows that the Cronbach's α s for the child scales – varying between 0.59 (social) and 0.86 (emo-neg) – were lower than those for the parent scales. The structures of the scales are less sharply defined than those of the parent form, which led to higher interscale interrelations. Three out of eight scales contained only seven items. The sum scores of these scales were weighted so as to be comparable in height with the other scales.

The product moment correlation coefficients between the parent and child scales were very low to

moderate only (Table 5). The ICCs were of the same magnitude as the product moment correlation coefficients. The coefficients suggest some agreement between parents and children when it comes to problems regarding pain and symptoms and motor and cognitive functioning, but hardly any agreement on autonomy and social and global emotional functioning. The *t*-tests resulted in only one significant outcome: parents rated their children's mood slightly more positive than their children themselves did.

The correlation coefficients of the paediatricians' judgements of the severity of disease with the parent form scales were body (0.23), motor (0.24), auto (0.21), cognition (0.07), social (-0.13), emo-pos (-0.11) and emo-neg (0.18). These coefficients suggest that the paediatrician's judgement on the severity of the disease was weakly related to the parents' information with regard to pain and symptoms, motor functioning and autonomy only.

Discussion

The aim of the study was a preliminary psychometric evaluation and validation of the TACQOL, a Dutch questionnaire measuring HRQoL in children, to be completed by parents. The scales show satisfactory reliability. The low interscale correlation coefficients and the high item-rest correlation coefficients indicate the relevance of the assumption that HRQoL is a

Table 3. Rotated factor matrix of TACQOL parent form items (factor loadings)

	Body	Motor	Auto	Cognition	Social
Body					
Throat/ear pain	0.54	-0.16	0.12	0.20	0.01
Stomach pain	0.25	-0.10	0.13	0.33	0.28
Headache	0.53	0.10	0.00	0.15	-0.02
Nausea	0.49	0.06	-0.01	0.27	-0.02
Dizziness	0.33	-0.21	-0.06	0.45	0.25
Tiredness	0.63	0.30	0.06	0.09	0.24
Sleepiness	0.68	0.22	0.22	-0.10	0.01
Drowsiness	0.53	0.26	0.13	-0.05	0.30
Motor					
Walking	0.15	0.73	-0.03	-0.16	-0.00
Running	0.15	0.70	0.14	0.08	0.08
Standing	0.26	0.46	-0.10	-0.19	0.30
Playing	0.14	0.43	0.25	0.08	0.21
Endurance	0.09	0.70	0.14	0.16	-0.05
Sense of balance	-0.07	0.61	0.14	0.17	0.15
Coordination /dexterity	0.02	0.67	-0.15	0.34	-0.02
Autonomy					
Going to school	0.48	-0.02	0.56	0.09	-0.06
Washing him/herself	0.08	0.11	0.77	0.19	0.15
Dressing him/herself	-0.04	0.15	0.77	0.07	0.06
Going to the toilet him/herself	-0.04	-0.01	0.76	0.14	-0.02
Eating and drinking	-0.35	-0.13	0.53	0.10	0.20
Doing sports/playing outside	0.42	0.03	0.58	0.22	0.15
Doing favourite leisure activities	0.20	0.13	0.59	0.09	0.20
Riding bicycle	0.30	0.07	0.79	0.12	-0.01
Cognition					
Concentration	0.08	0.27	0.31	0.65	0.06
Understanding of school subjects	0.20	0.08	0.26	0.78	0.02
Understanding other people	0.00	-0.11	-0.01	0.67	0.10
Arithmetic	-0.09	0.18	0.09	0.63	0.12
Reading	0.01	0.00	0.26	0.81	0.17
Writing	0.12	0.11	0.17	0.74	0.05
Learning	0.22	0.14	0.29	0.79	-0.03
Verbal expression	0.25	0.14	-0.12	0.47	0.05
Social					
Enjoyed playing with other children	0.30	0.05	-0.08	0.06	0.53
Asserted him/herself with other children	0.01	0.29	-0.02	-0.09	0.58
Was popular with other children	0.10	-0.00	0.25	-0.00	0.58
Felt at ease with other children	0.03	0.01	0.02	0.15	0.75
Was introvert	-0.13	0.29	0.24	0.29	0.53
Enjoyed playing with parents	0.00	0.01	0.06	0.16	0.71
Was restless and fidgety	-0.06	0.03	0.31	0.14	0.44
Was rebellious	0.05	0.32	0.37	0.12	0.35

Table 4. Percentages of subjects indicating no health status problems, health status problems without negative evaluations and negatively evaluated health status problems by the TACQOL parent form scale

Percentage of respondents indicating	Body	Motor	Auto	Cognition	Social
1 No health status problems	57	56	57	43	10
2 Health status problems without negative reactions	30	34	30	44	68
3 Health status problems with negative reactions	13	10	13	13	22
4 Total health status problems (groups 2 and 3)	43	44	43	57	90
5 Group 3, as a percentage of group 4	30	24	30	23	25

Table 5. Psychometric characteristics of the childrens' questionnaire

	Body	Motor	Auto	Cognition	Social	Emo-pos	Emo-neg
Number of items	8	7	7	7	8	8	8
Cronbach's α	0.68	0.71	0.61	0.66	0.59	0.81	0.86
Number of items with:							
Item-Rest correlation higher than correlations with other scales	4	3	4	3	4	7	8
Item-Rest correlations higher than 0.40	4	4	3	3	1	7	8
Item-Rest correlations higher than 0.60	1	1	0	1	0	3	4
Correlations between scales							
Body	-						
Motor	0.24		-				
Auto	0.16	0.75	-				
Cognition	0.44	0.39	0.25	-			
Social	0.30	0.16	0.12	0.50	-		
Emo-pos	-0.27	-0.20	-0.06	-0.30	-0.22	-	
Emo-neg	0.57	0.26	0.19	0.56	0.46	-0.39	-
Correlations with corresponding parent form scales							
Product moment correlation coefficient	0.36	0.38	-0.02	0.27	0.04	0.08	0.18
ICC	0.36	0.38	-0.02	0.23	0.04	0.07	0.18
P value of paired t-tests	0.89	0.34	0.12	0.09	0.82	0.04	0.88

complex concept, which, indeed, cannot be adequately represented by a single score. The domain structure of the TACQOL was confirmed by factor analysis of the data of this pilot study. However, the number of respondents was small in relation to the number of items. The construct validation will therefore be replicated in a larger sample study.

The distinction between existing problems and emotional reactions towards such problems seems to

be very relevant, in as much as most parents signalling a problem do not report associated negative emotional feelings in their child. In other words, HRQoL of children is not necessarily reduced when health problems occur. This phenomenon is the ultimate argument for assessing HRQoL as a concept, in distinction from health status.

As expected, the children's questionnaire performed less well than the TACQOL parent form,

even though the children's questionnaire was used only among children aged 8 years and older. The children's scales showed less reliability and higher interscale correlation coefficients. This may indicate that children's evaluations of their functioning – or their reporting it in a questionnaire – is more diffuse, less consistent and more heavily influenced by single experiences, while parents give information based on a more structured and generalized perception. If this is true, the lack of substantive correlations between the scales of the parent form and those of the children's questionnaire comes as no surprise. Furthermore, some problems in functioning and some negative emotional evaluations may be more easily detectable for parents than other factors. Similar partial discrepancies between information from questionnaires for parents and children have been reported, both with regard to HRQoL of adults²³ and in other fields, for example with regard to psychopathology among children.^{23,24} Yet these inconsistencies should be investigated and validated in other studies. For that to be possible, children's questionnaires with better psychometric characteristics should be developed.

If the discrepancy between the information obtained from parents and that from children is validated as an indication of a real discrepancy and not just as an artefact due to specific characteristics of the measurement, such findings would underscore the importance of not only using information given by the children themselves, but also seeking information from parents regarding their children's HRQoL. This should also have consequences for clinical practice with regard to communication with the child and their parents and for the (non-medical) support of children with health problems. At the same time, such discrepancies call for studies investigating the mechanisms by which parents and children come to different assessments of a child's HRQoL. Some though limited correlation coefficients were found with physicians' assessments of the severity of disease. These findings suggest that physicians tend to agree in their assessment of the medical severity of disease and that this judgement coincides to some extent with the body and motor scales. The lack of substantive correlation coefficients between this assessment and the other scales suggests either that their assessment seems to be less influenced by problems in other domains or that the physicians' assessments may vary considerably. This is just what we assumed to be the case and forms the main reason for efforts to develop a reliable questionnaire.

This preliminary study was performed with a first version of the TACQOL and with a small number of

children. The psychometric evaluation showed satisfactory characteristics, but also indicated room for improvement. The results of the study led to some adaptations in the response formats of the TACQOL parent form, enabling the respondents to give a more differentiated response. This could result in higher scale variances and therefore in better opportunities for assessing relationships with other variables. Furthermore, adapted versions of the children's questionnaire have been developed, completely in line with the TACQOL parents form, thereby enabling better studies on the relationship between parents' and children's perceptions. These questionnaires are now being used in several studies with larger numbers of both sick and healthy children.

The weighting of items is a point which deserves more attention. In the scoring method used until now, a scale score of 2 may mean two things: either the subject reported two health status problems, but no negative reaction or the subject reported one problem with an associated negative response. In other words, a health status problem without a negative reaction has half the weight of a health status problem with a negative reaction. Other weightings may be more valid. A valuation study in which various populations will be asked to judge the severity of different health states may provide at least a partial answer to this question.

Overall, the psychometric performance of the TACQOL parent form looks promising, which suggests that this measure can indeed be used to assess group differences in children's HRQoL, for example in studies evaluating the effects of different treatments. Whether it can be used to evaluate differences at an individual level remains, as yet, to be ascertained.

The concept of HRQoL as a combination of health status problems and their affective evaluation has interesting and important implications. Curing health problems is not always possible in conditions such as diabetes mellitus or congenital heart disease, but negative emotional feelings resulting from these conditions may be prevented or reduced. In the area of chronic diseases in children in particular, psychosocial care forms an essential part of health care, which might well have to be offered during all of their lives.

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