TACQOL Manual

Parent Form and Child Form

6-11 years

Leiden Center

for

Child Health and Pediatrics LUMC-TNO

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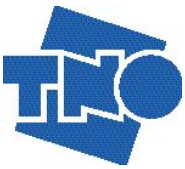

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1 Assessing Health-Related Quality of Life in Children

1.1 The concept of Health-Related Quality of Life

Traditionally, mortality and morbidity have been the most important parameters with which success and failure of medical and preventive interventions have been assessed. Undoubtedly, they will remain essential indicators of the quality of medical care. However, in recent decades, more and more attention has been paid to a third parameter: quality of life. Several factors contributed to this growing interest in quality of life in medical care. First, in western societies at least, many diseases which were once fatal or severely disimpairing can now be cured. So mortality and morbidity rates often do not show differential effects any more. Secondly, many serious medical conditions may perhaps not be cured completely but they have become manageable: with ongoing medical treatment, medication or aid, the life of patients may be preserved, with or without handicaps and / or disabilities. Often, both patients and their environment are satisfied with these medical successes. Sometimes, however, questions arise about the liveability of the remaining life. This is particularly apparent with regard to the elderly and to very young children born with severe medical conditions, disabilities and handicaps. Thirdly, more and more medical conditions may be cured and / or managed, but sometimes such treatment itself is very burdensome for the patient. Furthermore, the treatment may sometimes have serious consequences which the patient must face for the rest of his life. Fourthly, indications exist that Health-Related Quality of Life is an important predictor of (future) medical consumption and that compliance with treatment is greatly improved if treatment is associated with an improvement in Health-Related Quality of Life. Finally, again in Western societies at least, a process of individualisation has taken place, leading to a growing interest in the value of the life of every single human being, as he or she chooses to live.

All these developments resulted in an increase in interest in the quality of life, both in the medical world and outside. The concept of quality of life, however, is often not very clearly defined.

Sometimes the terms Health Status and Health-Related Quality of Life seem to be used as equivalents. Health Status refers to actual problems and limitations in functioning. When measuring Health-Related Quality of Life, this may be deemed insufficient, if not unjustifiable. Health-Related Quality of Life implies the appraisal of one’s health status and primarily by the patient himself [11,12,15,19,50]. This appraisal is related to, but not directly determined by, Health Status. Behavioural factors (adaptation, development of alternative skills), cognitive factors (adaptation of standards, coping), social factors (changes in expectations and demand by significant others) and others (adapted homes, medical devices) are also relevant for the appraisal of functional problems an individual faces. In other words: not every health status problem triggers a bad feeling. Information on the emotional impact of medical conditions may be of great value. Curing health problems is not always possible in conditions such as diabetes mellitus or congenital heart diseases, but negative emotional responses may be prevented or reduced.

Health-Related Quality of Life (HRQoL) is therefore defined in relation to, but clearly distinguished from, the concept of Health Status. HRQoL includes the patient's emotional response to such problems and limitations. In

short, HRQoL is defined as Health Status weighted by people's own emotional responses to Health Status problems they encounter.

In accordance with the literature [1,2,5,7,9,12,13] HRQoL must be assumed to be a multidimensional construct, *i.e.* the evaluation of one's own functioning may vary between domains and the relations between these different evaluations may vary between individuals, groups and moments in time. The literature does not yet provide a consensus concerning the question of which aspects or specific domains should be included in HRQoL questionnaires. However, some domains are more or less commonly mentioned: physical functioning, social functioning and psychological (cognitive, emotional) functioning.

Of course, depending on the medical condition, certain health status problems and the emotional response to such problems may or may not be relevant, *i.e.* they will hardly – or not at all - discriminate between persons or groups of persons. Furthermore, the burden of the medical treatment will vary enormously according to the medical condition. This has led to a discussion about the relative value of generic and disease-specific assessments of Quality of Life. From this discussion, a general rule of thumb emerged: always use generic instruments to enable comparisons between different patient groups, but supplement such generic instruments with disease-specific modules when studying specific groups.

1.2 Measuring Health-Related Quality of Life in children

In recent decades, many efforts have been undertaken to develop reliable and valid instruments for measuring Health-Related Quality of Life. Although based on a variety of theoretical constructs and methodological considerations, many instruments have been presented including the Sickness Impact Profile and the SF 36. They have been used for a variety of purposes: the assessment of Health-Related Quality of Life of individuals, the comparison of relative merits of different treatment for specific diseases, calculations of Quality of Life Adjusted Years and so forth. However, all these instruments were developed, tested and used primarily for the adult population.

In 1994, when TNO Prevention and Health and the Leiden University Medical Center started their collaborative work on Health-Related Quality of Life in children, no commonly used and/or acknowledged instrument for children's Health-Related Quality of Life was available.

Measuring Health-Related Quality of Life in children involves specific problems in addition to the problems associated with Health-Related Quality of Life in general. Health-Related Quality of Life was defined as Health Status weighted by the emotional response of the child itself to Health Status problems it underwent. In general, one may assume that the individual child is the best source of information concerning its own feelings and evaluations. However, children may be lacking in their vocabulary and reading skills. Furthermore, children's cognition is not yet fully developed; up to a certain age their reasoning is to be characterised as concrete, based on rules applied to the specific question at hand only and not on logical rules. One may therefore assume that young children's evaluations will be heavily influenced by recent incidents and that they are less able to

formulate an assessment concerning their functioning in general. Reading skills are not fully developed either. So using paper and pencil questionnaires may be difficult, if not impossible.

Therefore, it may be generally valid to assume that children themselves are the best sources of information concerning their feelings over a given period of time. However, this generalisation may be less relevant and less valid when one wishes to assess such feelings with the use of a short, structured and written questionnaire and for a somewhat longer period of time.

Parents - in general - may be assumed to be well informed about their children's functioning and feelings. This is not to say that they are fully informed. Their perception may be biased by their own feelings and concerns. Children may, willingly or unwillingly, hide some of their thoughts and feelings for their parents. With increasing age, their child will have experiences which their parents have not experienced themselves and which they may not recognise. Children may differ in the degree to which they share their experiences and emotions with their parents and parents will differ in the degree to which they are open to their children’s experiences. Yet, compared to other proxies, such as teachers, doctors, nurses, parents - in general -will have a more extensive and intensive experience with their child, in all sorts of situations. Therefore, it seems wise to use parents as proxies, at least for the youngest children, as long as it is difficult or impossible to use available instruments with children themselves.

1.3 The TACQOL questionnaires: general description

The TNO-AZL Questionnaires for Children's Health-Related Quality of Life (or TACQOL) were constructed to enable a systematic, valid and reliable description of Health-Related Quality of Life of children with chronic diseases aged 6 till 15 by the children themselves or their parents. Health-Related Quality of Life, as assessed by the TACQOL, is defined as children’s health status, weighted by the emotional response of the children themselves to their health status problems.

The questionnaires are designed primarily for research purposes focusing mainly on data aggregated on the group level, for example in clinical trials, evaluative or descriptive studies.

The TACQOL is a generic instrument, measuring general aspects of Health-Related Quality of Life (HRQoL) and thereby enabling comparisons to be made between groups of children with varying chronic diseases. As other generic HRQoL instruments the TACQOL as such is not adapted to capture those aspects of HRQoL which are specific for all different types of chronic conditions and diseases. For a detailed and sensitive assessment of HRQoL in groups of children with specific chronic diseases, more specific instruments are necessary. Specific modules based on the same theoretical assumptions and methodology are now being developed.

The TACQOL is a multidimensional instrument, with 7 scales. The domains covered by the TACQOL are based on a review of the literature, discussions with experts (child psychologists, paediatricians) and statistical testing

(see chapter 2). Table 1.1 presents the TACQOL scales. These scales result in a (group) profile. As HRQoL is seen as a multidimensional construct, no total score is calculated.

Both a Parent Form and Child Form are available. The TACQOL - Parent Form (TACQOL-PF) explicitly asks parents to try and assess their child's feelings with regard to functional problems which their child faces, and not their own feelings (“true proxy”). The TACQOL - PF is designed for (parents of) children in the age group aged between 6 and 15. The TACQOL – CF is for children aged 8-15.

Table 1.1 TACQOL Scales

Label	Scales
BODY	Problems /limitations concerning general physical functioning/complaints
MOTOR	Problems / limitations concerning motor functioning
AUTO	Problems / limitations concerning independent daily functioning
COGNIT	Problems / limitations concerning cognitive functioning and school performances
SOCIAL	Problems / limitations in social contacts, with parents and peers
EMOPOS	The occurrence of positive moods
EMONEG	The occurrence of negative moods

2 Development and evaluation of the TACQOL

2.1 Development of a pilot version

In 1994, TNO Prevention and Health and the Paediatric Department of the Leiden University Medical Center started on the development of a reliable and valid instrument for the assessment of Health-Related Quality of Life in (varying) groups of children (aged 6 till 15) with severe and / or chronic medical conditions.

Based on a review of existing literature, the concept to be measured was defined as Health Status weighted by emotional response to occurring health status problems. This means that our definition complies with the assumption that Quality of Life assessment must imply the appraisal of health status, primarily by the actual patient. [10,11,14,18,19] It was also decided to approach Health-Related Quality of Life as a multi-dimensional concept. Existing literature led us to include the domains: Physical Functioning (symptoms, motor functioning), Social Functioning, Cognition and Emotions. It was decided to add the domain of Autonomy since the instruments target children and Autonomy was considered to be an essential developmental task for children in this age group. Whether or not a satisfying summarising single score could be constructed was considered to be a question which would have to be answered on the base of empirical evidence, depending on the interrelationships between the scale scores representing the domains to be included.

An item pool was created, based on existing literature and discussions with experts (child psychologists, clinical psychologists, paediatricians). An item format like the one presented in table 4.2 was constructed in accordance with the definition of Health-Related Quality of Life and considerations of feasibility. A draft Parent Form and Child Form were then constructed for testing in a pilot study.

2.2 A pilot study among children with severe / chronic conditions and their parents

In the second phase the feasibility and psychometrics of the draft version were tested in a study among about 100 children with severe and / or chronic conditions and their parents. Details of the study have been published elsewhere.[27] The children approached were treated by the Paediatric Department of the Leiden University Medical Hospital and suffered from a variety of serious medical conditions. They were asked to answer the questionnaires while a member of the medical staff or the study team was present.

Data collected were used to evaluate different item and scale scoring systems and to assess the supposed scale structure. Procedures were first tested on the Child Form of the questionnaires. Afterwards, the replicability of these procedures with regard to the Parent Form was checked.

In general, answering the questionnaires met with little difficulty. The time needed was between 10 and 15 minutes. Few data were missing.

In general, the supposed scale structure was reflected in the data. However, the items belonging to the domain of Physical Functioning had to be split into two scales: BODY (containing items with regard to pain and general symptoms) and MOTOR (items with regard to motor functioning). Furthermore, the Emotions scale had to be split into a Positive Emotions scale and a Negative Emotions scale. Clearly, the presence of positive emotions is not dependent on the absence of negative emotions, and vice versa.

The pilot study, using the draft version of the TACQOL, led to minor adaptations of the questionnaires. The final version of the questionnaires was used in a Reference study.

2.3 A Reference Study in a sample of children from the general population

After completion of the pilot study, a new study was started, collecting TACQOL data from a random sample of Dutch children aged 6 - 11 in the general population. Details of this study have been published elsewhere.[25] The aim of the study was twofold:

a reassessment of the psychometric quality of the TACQOL

b (if the first aim was achieved:) collecting reference data in order to enable comparison of TACQOL data of severely / chronically ill children with those of a healthy reference group.

Data were collected with the help of 12 regional Centres for Preventive Youth Health Care (Jeugdgezondheidszorg), all over the Netherlands. They were asked to take a random, stratified sample of 210 children aged 6 till 11 from their registries; equally distributed over three age groups (6/7, 8/9 en 10/11) and within each age group a 50 / 50 ratio between boys and girls.

Parents of all children in the sample were sent a letter explaining the aim of the study and asking them to collaborate and to fill in the TACQOL PF. For children aged 8 and older, a letter to the child and the TACQOL - CF was included as well which the parents were asked to give to their child.

Both the letter to the parents and that to the child stressed that co-operation was voluntary.

After about three weeks, a reminder was sent to those respondents who had not yet returned the questionnaire. Total response was 71% for the parents and 67% for the children. Differences in response between age groups and boys and girls were not substantial. Comparing the percentages of questionnaires received from members of ethnic minorities to similar response rates in representative school-based surveys[6] led to the conclusion that response from those minorities was substantially below that in the population. Appendix III presents some background characteristics of the final sample.

Data entry was done with a programme built with the Blaise system[3], enabling range and routing checking during data entry. Missing data were entered as such, enabling an appraisal of the TACQOL's feasibility in a large scale, postal survey.

After data entry, several analyses were done to assess the psychometric properties of the final version. The results are presented in the following chapter:

a the item scoring system devised in the pilot study was re-evaluated: the assumed ordinality of the scores attributed to the combined answers on questions to health status problems and its corresponding emotional reaction was checked by homogeneity analyses (HOMALS)[22]. This technique may be described as a principal components analysis for nominal data. HOMALS assigns 'category quantifications' to each nominal answer category, in such a way that the first eigen value of the resulting correlation matrix - and the percentage of variance explained – is maximised. HOMALS is also known as a tool for optimal scaling of categorical data and here it is used in order to check of the correct order of categories is found after optimal scaling (*i.e.* quantifying) them. It was supposed that the category quantifications of the combined-item scores should be in line with the assumed ordinality of the item scoring system (*cf* 3.1.1 and 3.1.2).

b The calculation of the scale scores and the viability of treating these scale scores as interval variables was assessed by calculating product moment correlation coefficients between scale scores and the HOMALS dimension scores ('object quantifications'), which are interval variables by definition (*cf* 3.1.3).

c Varimax rotated principal components and (corrected) item rest correlation coefficients were calculated to reassess the assumed factor and scale structure and the independence of the scales (*cf* 3.2.1 and 3.2.2).

d Reliability of the scales was assessed by means of Cronbach's α (*cf* 3.2.4).

e The relevance of the definition of Health-Related Quality of Life was assessed by exploring the occurrence of health status problems with and without negative emotional reactions (*cf* 3.3.1).

f Convergent and divergent validity were assessed by calculating product moment correlation coefficients between the Dutch versions of the KINDL ([8]) and CBCL-based scales([24]), indicating behavioural problems (*cf* 3.3.2 and 3.3.2).

g Criterion validity was assessed by testing the differences in scales scores of children with and without (parent reported) chronic conditions (*cf* 3.3.4).

h The equivalence of the TACQOL PF and TACQOL CF scale scores was assessed by means of product moment correlation coefficients and a multi-trait multi-method analysis using EQS (*cf* 3.3.5).

3 Psychometric evaluation of the TACQOL PF and CF

3.1 Evaluation of the scoring system

The TACQOL - PF and TACQOL - CF scoring system was devised and evaluated in a pilot study among a small sample of children who visited the paediatrician because of a variety of chronic conditions, such as heart conditions, cancer, rheumatism and so on (cf. Vogels et al, 1998). The analyses were replicated on data obtained in the reference study and the results of these replications will be presented here.

3.1.1 Scoring of items

Our definition of HRQoL implies that a single score be attributed to each combination of an item assessing the *prevalence* of a function problem and the corresponding item assessing the *emotional reaction* to such a problem. In theory, on all scales except EMOPOS and EMONEG, 9 different combinations are possible (see table 3.1, left).

Table 3.1 Possible combination of scores of each pair of items and the scoring according to the scoring system

	Possible combinations				Scoring grid			
Occurrence problem / limitation	(very) well	not so well	rather badly	badly	(very) well	not so well	Rather Badly	badly
never	1		*	*	4	*	*	*
sometimes	2	3	4	5	3	2	1	0
often	6	7	8	9	3	2	1	0

* = not applicable

A priori, the weight of each combination on a scale reflecting domain-specific HRQoL is not clear. In order to assess this weight, homogeneity analyses (HOMALS [22]) were performed on the paired items of each scale separately. Using all possible combinations as categories in the analysis, HOMALS scales these categories. The distinction between the answers 'sometimes' and 'often' on the question regarding the frequency of complaints did not result in clear differences in the calculated distance scores. The distinction between never and sometimes/often clearly did, as did the differences between the categories in the items of the scales EMOPOS and EMONEG.

It was therefore decided to score the item pairs using the scoring grid presented in the table 3.1 (right), with scores varying from 0 to 4 and a higher score indicating a higher HRQoL.

For the scales EMOPOS and EMONEG, each item consists of a single question, with 3 categories. The answers were coded in such a way that 0 indicated low HRQoL and 2 a higher HRQoL.

The scores attributed to the (combination of) answers are supposed to be at on ordinal level, *i.e* 4 is an indication of a higher quality of life than 3 and so forth.

To check the assumed ordinality of these scores, a new series of homogeneity analyses was performed, using the categories of the simplified scoring system. We expected these combined categories to behave like ordinal data; *i.e.* the answer scored as 4 should reflect a higher value than the answer scored as 3, 3 higher than 2 and so on. In the analysis, however, the data were treated as being of a nominal level of measurement only. This allowed us to check whether the HOMALS attributed category quantifications were in the required order. For each item, we compared the quantifications of all possible combinations of the combined item scores and counted the number of violations of the assumed ordinality. Table 3.2 presents the number of violations of this assumption.

For the TACQOL – PF, a total of 24 comparisons of the calculated distances between 2 combined-item scores showed a violation of the assumed ordinality. That is 5% of the comparisons made. For the TACQOL – CF, the number of violations was 34; 8% of the total number of comparisons made. Most of the violations concerned comparisons between categories with very low frequencies. Homogeneity analysis is very sensitive for categories with a very low frequency. When violations concerning combined-item scores with a frequency of less then 1% of the sample are disregarded, the number of violations drops to 7 for the TACQOL - PF and 8 for the TACQOL - CF. Clear criteria for evaluating these results are not available, but the results may be deemed very satisfactory.

Table 3.2 Violations of assumed ordinality of category quantification in scoring system

	violations of ordinality comparing all categories		violations of ordinality comparing categories with a prevalence > 1%	
Parent form	n	%	n	%
BODY	4	5%	4	10%
MOTOR	3	4%	0	0%
AUTO	11	17%	3	14%
COGNIT	2	3%	0	0%
SOCIAL	1	1%	0	0%
EMOPOS	3	13%	0	0%
EMONEG	0	0%	0	0%
total	24	6%	7	4%
Child Form				
BODY	4	5%	3	4%
MOTOR	1	1%	0	0%
AUTO	12	17%	2	8%
COGNIT	7	9%	3	8%
SOCIAL	10	13%	0	0%
EMOPOS	0	0%	0	0%
EMONEG	0	0%	0	0%
total	34	8%	8	3%

3.1.2 Calculation of scale scores

The TACQOL contains seven scales. The scale scores are calculated by a simple summation of the (combined) items scores and a simple correction for missing answers (see 3.1.3). The combined-item scores are of an ordinal level of measurements only. Summing ordinal data is common practice in behavioural research. Although common practice, it is a violation of basic measurements principles and should be justified.

An analysis was therefore conducted in order to check if the TACQOL scale scores might be considered as being of interval level of measurement. Homogeneity analysis calculates object quantifications which are comparable to factor scores in principal component analysis. In a fitting HOMALS solution, these object quantifications may be assumed to be interval level scores, based as they are on the calculated Euclidean distances of item categories. Product moment correlation coefficients were calculated between the TACQOL scale scores and the object quantifications, resulting from the homogeneity analyses. The results are presented in table 3.3. The figures presented are based on respondents with valid scale-scores on all TACQOL - PF scales, *c.q.* TACQOL - CF scales.

Correlation coefficients vary between 0.83 and 0.99 (Table 3.3). TACQOL scale scores are therefore nearly identical to a simple linear transformation of the object quantifications. The sum scores may therefore be treated as interval measurements.

Table 3.3 Absolute correlation coefficients between the summed item pair scores and the HOMALS category quantifications (n=1700, resp. n=1094).

	TACQOL – PF	TACQOL – CF
BODY	.94	.98
MOTOR	.93	.93
AUTO	.95	.83
COGNIT	.96	.92
SOCIAL	.87	.91
EMOPOS	.98	.98
EMONEG	.90	.99

3.1.3 Missing scale scores

In the calculation of the scale scores one or two missing combined-item scores are allowed for. They are replaced by the mean value of the non-missing (combined-) item scores. For respondents with more missing combined-item scores per scale, the scale score is assumed to be missing. In the reference study, this procedure resulted in 5% of the respondents having at least one missing scale score on any of the TACQOL PF scales and 2% on any of the TACQOL CF scales (Table 3.4). Only 1% of all scale scores are missing. For most individual scales, the percentage of respondents with at least one scale score missing does not exceed 3%. The one exception is the Cognition scale in the TACQOL PF: in the youngest age group these questions seem difficult or perhaps less relevant and in 6% of the cases no scale score could be calculated.

Table 3.4 Missing scale scores on the TACQOL PF and TACQOL CF, by age and gender

	TACQOL PF							TACQOL CF				
Gender	boys			girls			total[1]	boys		girls		total[1]
age in yrs	6/7	8/9	10/11	6/7	8/9	10/11		8/9	10/11	8/9	10/11	
BODY	1%	0%	1%	0%	0%	0%	0%	0%	1%	0%	0%	0%
MOTOR	1%	0%	1%	0%	0%	0%	0%	0%	1%	0%	0%	1%
AUTO	0%	0%	3%	0%	0%	0%	0%	0%	0%	0%	0%	1%
COGNIT	6%	1%	0%	6%	0%	0%	2%	1%	0%	0%	0%	1%
SOCIAL	1%	0%	0%	0%	1%	0%	0%	0%	0%	1%	0%	1%
EMOPOS	2%	2%	2%	3%	3%	1%	2%	2%	2%	3%	1%	2%
EMONEG	2%	2%	2%	2%	3%	1%	2%	2%	2%	3%	1%	2%
% resp. with >0 missing	8%	3%	4%	8%	3%	5%	5%	4%	2%	2%	1%	2%

	TACQOL PF							TACQOL CF				
Gender	boys			girls			total[1]	boys		girls		total[1]
age in yrs	6/7	8/9	10/11	6/7	8/9	10/11		8/9	10/11	8/9	10/11	
n respondents	327	269	294	325	268	297	1788	261	289	257	293	1122
total % missing scale scores	2%	1%	1%	2%	1%	0%	1%	1%	1%	1%	0%	1%
n scale scores	2289	1883	2058	2275	1876	2079	12516	1827	2023	1799	2051	7854

1 total exceeds sums of age/gender groups as some age or gender data were missing

3.2 Evaluating the scale structure

3.2.1 Factor structure of the TACQOL items

In order to investigate the factor structure of the TACQOL PF and TACQOL CF, a principal component analysis with varimax rotation was done on the combined-item scores. As the scales EMOPOS and EMONEG were not supposed to be independent from the other scales, the items of these scales were not included in the analysis. The number of scales (5) was given as a criterion to determine the number of factors to be extracted.

The analysis resulted in a solution explaining 40% of the variance. The first unrotated principal component explained 17% of the total variance. Table 3.5 presents the factor loadings of the varimax rotated factors of the TACQOL PF. The solution reflects the supposed scale structure fairly well. 35 of a total of 40 items show a higher loading on their own factor than on any of the other factors. One of the items of MOTOR loads somewhat higher on the scale BODY. Two items of Autonomy show a higher loading on MOTOR and two items of the Social scale load higher on the factor BODY.

The same analysis was done for the TACQOL-CF. The analysis resulted in a solution explaining 38% of the variance. The first unrotated principal component accounts for 19% of the variance. Again, the varimax rotated solution (Table 3.6) reflect the supposed scale structure fairly well. Here, 32 of the 40 items show the highest loadings on their own factor. 3 out of a total of 8 items of the Autonomy scale show higher loading on the factor reflecting the MOTOR scale, indicating a clear overlap between these two TACQOL CF scales. The Social scale seems to be rather weak, as 4 out of 8 items show higher loading on other factors. Remarkably, the first 4 items, reflecting aspects of the relationship with the peers, seem to belong together, while the last 4 items, about the relationships with parents, do not.

On the whole, the TACQOL-CF results are highly comparable to those for the TACQOL-PF.

Table 3.5 Factor loadings of TACQOL PF combined-item scores on varimax rotated principal components

ITEM PAIR	factor 1 'Cognit'	factor 2 'MOTOR'	factor 3 'BODY'	factor 4 'Social'	factor 5 'Auto'
BODY1	0.08	0.02	**0.52**	-0.04	-0.02
BODY2	0.04	0.06	**0.62**	0.04	0.06
BODY3	0.03	0.14	**0.56**	0.06	-0.04
BODY4	0.06	0.29	**0.43**	0.01	-0.06
BODY5	0.04	0.07	**0.60**	0.06	-0.01
BODY6	0.09	0.16	**0.60**	0.07	0.20
BODY7	0.11	0.10	**0.55**	0.07	0.14
BODY8	0.06	0.26	**0.40**	0.13	0.06
MOTOR1	0.10	**0.72**	0.14	0.17	0.05
MOTOR2	0.05	**0.77**	0.06	0.01	0.03
MOTOR3	0.02	**0.68**	0.07	0.03	0.06
MOTOR4	-0.00	**0.69**	0.14	0.00	0.04
MOTOR5	-0.04	**0.47**	0.14	0.20	0.27
MOTOR6	0.11	**0.59**	0.27	0.12	0.12
MOTOR7	0.17	**0.53**	0.10	0.10	0.11
MOTOR8	**0.46**	0.41	0.11	0.05	0.14
AUTO1	0.08	0.07	0.06	0.08	**0.60**
AUTO2	0.08	0.07	-0.00	-0.03	**0.74**
AUTO3	0.09	0.12	0.00	-0.11	**0.69**
AUTO4	0.01	0.23	0.05	0.03	**0.43**
AUTO5	-0.00	0.09	0.08	0.11	**0.37**
AUTO6	0.09	**0.48**	0.03	0.25	0.39
AUTO7	0.18	0.30	-0.03	0.14	**0.34**
AUTO8	0.10	**0.46**	0.09	0.01	0.26
COGNIT1	**0.71**	0.09	0.18	0.15	0.05
COGNIT2	**0.81**	0.02	0.08	0.10	-0.03
COGNIT3	**0.62**	0.04	0.13	0.12	0.11
COGNIT4	**0.70**	0.06	0.05	0.08	-0.03
COGNIT5	**0.61**	0.00	0.02	-0.04	0.07
COGNIT6	**0.61**	0.11	-0.02	-0.01	0.11
COGNIT7	**0.82**	0.06	0.06	0.09	0.02
COGNIT8	**0.46**	0.11	0.14	0.10	0.12
SOCIAL1	0.02	0.10	-0.01	**0.81**	0.08
SOCIAL2	0.10	0.13	0.12	**0.57**	0.07
SOCIAL3	0.04	0.04	-0.03	**0.69**	0.05
SOCIAL4	0.10	0.11	-0.02	**0.71**	-0.02
SOCIAL5	0.04	0.05	0.12	**0.44**	0.04
SOCIAL6	0.17	0.08	0.17	**0.36**	0.00
SOCIAL7	0.22	-0.04	**0.28**	0.27	0.26
SOCIAL8	0.14	-0.07	**0.30**	0.20	0.26
% EXPL. VAR.	10%	10%	7%	7%	6%

Table 3.6 Factor loadings of TACQOL CF combined-item scores on varimax rotated principal components

ITEM PAIR	factor 1 'COGNIT'	factor 2 'MOTOR'	factor 3 'BODY'	factor 4 'SOCIAL'	factor 5 'AUTO'
BODY1	0.04	0.06	**0.58**	0.01	0.08
BODY2	0.16	0.09	**0.64**	0.03	0.05
BODY3	0.09	0.07	**0.62**	0.00	0.06
BODY4	0.06	0.10	**0.52**	0.11	0.04
BODY5	0.10	0.09	**0.68**	-0.03	0.03
BODY6	0.18	0.14	**0.56**	0.20	0.03
BODY7	0.24	0.12	**0.50**	0.15	-0.04
BODY8	0.18	0.30	**0.51**	0.04	0.05
MOTOR1	0.12	**0.61**	0.21	0.12	0.12
MOTOR2	0.02	**0.53**	0.13	0.17	0.02
MOTOR3	0.07	**0.45**	0.17	0.33	-0.01
MOTOR4	0.02	**0.56**	0.19	0.15	-0.02
MOTOR5	0.01	**0.59**	-0.01	0.04	0.09
MOTOR6	0.14	**0.54**	0.29	0.13	0.15
MOTOR7	0.27	**0.44**	0.11	0.14	0.02
MOTOR8	**0.45**	0.37	0.15	0.07	-0.05
AUTO1	0.04	0.06	0.04	**0.32**	0.10
AUTO2	0.19	0.15	0.02	**0.65**	0.04
AUTO3	0.10	0.16	0.08	**0.69**	0.00
AUTO4	0.04	0.16	0.00	**0.65**	-0.01
AUTO5	-0.00	0.13	0.15	**0.62**	-0.00
AUTO6	0.04	**0.60**	0.06	0.29	0.19
AUTO7	0.30	**0.46**	0.03	0.17	-0.03
AUTO8	0.23	**0.47**	0.04	0.32	0.02
COGNIT1	**0.62**	0.13	0.14	0.16	0.14
COGNIT2	**0.69**	0.07	0.18	0.04	0.07
COGNIT3	**0.55**	0.13	0.07	0.06	0.07
COGNIT4	**0.61**	0.06	0.10	0.06	0.02
COGNIT5	**0.53**	-0.14	0.05	0.05	0.09
COGNIT6	**0.50**	0.12	0.07	0.07	0.07
COGNIT7	**0.70**	0.10	0.11	0.14	0.11
COGNIT8	**0.45**	0.32	0.10	-0.05	0.02
SOCIAL1	0.10	0.02	0.02	-0.01	**0.80**
SOCIAL2	0.18	0.13	0.06	-0.02	**0.46**
SOCIAL3	0.05	0.01	0.05	0.09	**0.71**
SOCIAL4	0.14	0.11	0.02	0.11	**0.72**
SOCIAL5	0.23	**0.28**	0.04	0.02	0.21
SOCIAL6	**0.40**	0.21	0.10	0.04	0.25
SOCIAL7	**0.33**	0.15	0.17	-0.01	0.24
SOCIAL8	**0.28**	0.01	0.14	0.03	0.25
% EXPL. VAR.	10%	9%	8%	6%	6%

3.2.2 Item scale correlation coefficients

A second evaluation of the supposed scale structure was done by calculating the product moment correlation coefficient between the combined item scores and the scale scores. Of course, when calculating correlation coefficients of items with the scale to which they belong, the usual correction was applied: in those cases correlation coefficients with the sum score of the other items belonging to that scale were calculated (item-rest or corrected item scale correlation coefficients). Table 3.7 and 3.8 present the results. The table also includes the EMOPOS and EMONEG items and scales. As these items and scales were not supposed to be independent of the other scales, however, they have not been included in the evaluation. Children with missing values on any of the scales were excluded from the calculations.

In the TACQOL – PF, only two items violated the assumption that the corrected item-own scale correlation coefficient should be higher than the remaining item-scale correlation coefficients: MOTOR8 shows a slightly higher correlation coefficient with Cognition and AUTO8 is correlated with MOTOR. SOCIAL8 is also correlated with EMONEG but as no independency of EMONEG and EMOPOS was assumed this is no violation of the assumptions regarding the scale structure.

In the TACQOL – CF, four items violate the assumption regarding the scale structure. Three of these belong to the Autonomy scale, all showing the highest correlation coefficients with MOTOR. One item of the MOTOR scale shows the highest correlation coefficient with Cognition.

Tables 3.7 TACQOL - PF: Item – scale and corrected item – scale (bold) correlation coefficients .

ITEM PAIR	BODY	MOTOR	AUTO	COGNIT	SOCIAL	EMOPOS	EMONEG
BODY1	**0.36**	0.13	0.07	0.13	0.09	0.12	0.15
BODY2	**0.47**	0.19	0.15	0.15	0.15	0.16	0.20
BODY3	**0.41**	0.23	0.12	0.14	0.17	0.17	0.18
BODY4	**0.34**	0.28	0.13	0.14	0.11	0.15	0.12
BODY5	**0.44**	0.18	0.12	0.14	0.15	0.13	0.19
BODY6	**0.46**	0.34	0.26	0.18	0.24	0.19	0.22
BODY7	**0.39**	0.25	0.18	0.18	0.20	0.14	0.18
BODY8	**0.33**	0.31	0.19	0.13	0.16	0.16	0.12
MOTOR1	0.29	**0.68**	0.36	0.19	0.25	0.29	0.18
MOTOR2	0.22	**0.62**	0.34	0.15	0.17	0.21	0.12
MOTOR3	0.22	**0.51**	0.31	0.12	0.16	0.16	0.10
MOTOR4	0.24	**0.53**	0.28	0.11	0.16	0.23	0.13
MOTOR5	0.24	**0.43**	0.38	0.08	0.26	0.26	0.16
MOTOR6	0.35	**0.59**	0.37	0.20	0.25	0.25	0.22
MOTOR7	0.23	**0.44**	0.30	0.20	0.19	0.13	0.11
MOTOR8	0.23	0.42	0.32	**0.44**	0.25	0.27	0.23
AUTO1	-0.14	-0.18	**0.37**	-0.15	-0.16	-0.13	-0.12
AUTO2	-0.10	-0.21	**0.43**	-0.13	-0.18	-0.09	-0.13
AUTO3	-0.10	-0.24	**0.40**	-0.14	-0.09	-0.07	-0.12
AUTO4	-0.13	-0.25	**0.30**	-0.08	-0.14	-0.10	-0.09
AUTO5	-0.14	-0.17	**0.26**	-0.06	-0.14	-0.10	-0.13
AUTO6	-0.21	-0.47	**0.51**	-0.18	-0.28	-0.22	-0.17
AUTO7	-0.12	-0.34	**0.35**	-0.20	-0.20	-0.20	-0.13
AUTO8	-0.20	**-0.42**	0.34	-0.15	-0.13	-0.14	-0.08
COGNIT1	0.27	0.29	0.21	**0.64**	0.32	0.25	0.26
COGNIT2	0.17	0.19	0.14	**0.72**	0.23	0.23	0.21
COGNIT3	0.19	0.22	0.20	**0.55**	0.28	0.24	0.24
COGNIT4	0.15	0.20	0.13	**0.58**	0.17	0.18	0.16
COGNIT5	0.13	0.13	0.12	**0.49**	0.11	0.13	0.14
COGNIT6	0.12	0.23	0.19	**0.50**	0.17	0.17	0.18
COGNIT7	0.17	0.21	0.17	**0.74**	0.21	0.22	0.20
COGNIT8	0.19	0.23	0.20	**0.41**	0.22	0.21	0.19
SOCIAL1	0.13	0.21	0.23	0.14	**0.47**	0.29	0.18
SOCIAL2	0.19	0.25	0.22	0.20	**0.36**	0.26	0.20
SOCIAL3	0.09	0.15	0.17	0.14	**0.35**	0.25	0.17
SOCIAL4	0.12	0.21	0.17	0.19	**0.37**	0.25	0.14
SOCIAL5	0.12	0.17	0.11	0.14	**0.35**	0.31	0.22
SOCIAL6	0.15	0.20	0.10	0.20	**0.34**	0.31	0.27
SOCIAL7	0.19	0.21	0.20	0.24	**0.46**	0.23	0.42
SOCIAL8	0.18	0.15	0.15	0.17	**0.36**	0.20	0.39
EMOPOS1	0.20	0.24	0.15	0.16	0.30	**0.62**	0.25
EMOPOS2	0.17	0.24	0.13	0.14	0.30	**0.68**	0.25
EMOPOS3	0.17	0.24	0.19	0.23	0.35	**0.60**	0.35
EMOPOS4	0.14	0.24	0.12	0.07	0.24	**0.56**	0.18
EMOPOS5	0.20	0.25	0.18	0.22	0.29	**0.54**	0.31
EMOPOS6	0.19	0.26	0.17	0.22	0.36	**0.70**	0.30
EMOPOS7	0.19	0.25	0.18	0.35	0.31	**0.40**	0.27
EMOPOS8	0.21	0.27	0.15	0.18	0.32	**0.69**	0.28
EMONEG1	0.25	0.15	0.13	0.19	0.30	0.20	**0.42**
EMONEG2	0.17	0.14	0.13	0.13	0.31	0.26	**0.42**
EMONEG2	0.18	0.10	0.06	0.12	0.17	0.13	**0.30**
EMONEG4	0.25	0.20	0.13	0.21	0.34	0.36	**0.47**
EMONEG5	0.10	0.17	0.14	0.21	0.34	0.29	**0.43**
EMONEG6	0.11	0.11	0.10	0.13	0.29	0.16	**0.44**
EMONEG7	0.12	0.11	0.12	0.14	0.27	0.19	**0.39**
EMONEG8	0.23	0.18	0.18	0.20	0.23	0.24	**0.40**

Table 3.8 TACQOL - CF: Item – scale and corrected item – scale (bold) correlation coefficients.

ITEM		MOTOR	AUTO	COGNIT	SOCIAL	EMOPOS	EMONEG
BODY1	**0.41**	0.18	0.15	0.17	0.17	0.10	0.25
BODY2	**0.51**	0.29	0.19	0.27	0.20	0.18	0.29
BODY3	**0.47**	0.26	0.16	0.23	0.17	0.12	0.23
BODY4	**0.40**	0.27	0.17	0.21	0.15	0.16	0.15
BODY5	**0.53**	0.28	0.13	0.22	0.17	0.14	0.26
BODY6	**0.47**	0.36	0.30	0.29	0.23	0.14	0.23
BODY7	**0.43**	0.31	0.26	0.29	0.20	0.13	0.23
BODY8	**0.48**	0.42	0.28	0.31	0.25	0.18	0.25
MOTOR1	0.33	**0.57**	0.42	0.29	0.25	0.21	0.19
MOTOR2	0.22	**0.44**	0.32	0.20	0.17	0.14	0.16
MOTOR3	0.27	**0.42**	0.38	0.22	0.18	0.22	0.21
MOTOR4	0.29	**0.43**	0.39	0.21	0.13	0.21	0.20
MOTOR5	0.14	**0.37**	0.30	0.15	0.16	0.12	0.13
MOTOR6	0.38	**0.52**	0.43	0.31	0.28	0.24	0.24
MOTOR7	0.27	**0.42**	0.36	0.32	0.21	0.14	0.22
MOTOR8	0.31	0.38	0.35	**0.44**	0.24	0.20	0.23
AUTO1	0.08	0.14	**0.20**	0.13	0.09	0.06	0.08
AUTO2	0.16	0.28	**0.43**	0.23	0.19	0.17	0.15
AUTO3	0.19	0.35	**0.46**	0.20	0.16	0.16	0.16
AUTO4	0.12	0.26	**0.39**	0.13	0.08	0.14	0.06
AUTO5	0.20	0.31	**0.36**	0.16	0.12	0.08	0.09
AUTO6	0.23	**0.49**	0.45	0.21	0.26	0.25	0.19
AUTO7	0.18	**0.31**	0.20	0.28	0.23	0.18	0.16
AUTO8	0.22	**0.46**	0.44	0.30	0.22	0.20	0.18
COGNIT1	0.32	0.37	0.31	**0.56**	0.36	0.22	0.33
COGNIT2	0.31	0.32	0.24	**0.60**	0.35	0.23	0.33
COGNIT3	0.22	0.27	0.26	**0.46**	0.29	0.16	0.27
COGNIT4	0.25	0.28	0.22	**0.50**	0.24	0.16	0.27
COGNIT5	0.13	0.11	0.08	**0.38**	0.21	0.12	0.17
COGNIT6	0.21	0.26	0.24	**0.38**	0.25	0.18	0.23
COGNIT7	0.30	0.35	0.29	**0.64**	0.32	0.21	0.30
COGNIT8	0.24	0.36	0.26	**0.39**	0.26	0.16	0.23
SOCIAL1	0.10	0.13	0.09	0.19	**0.43**	0.25	0.19
SOCIAL2	0.14	0.19	0.17	0.22	**0.27**	0.17	0.16
SOCIAL3	0.12	0.14	0.14	0.16	**0.35**	0.21	0.13
SOCIAL4	0.13	0.21	0.19	0.27	**0.42**	0.25	0.20
SOCIAL5	0.16	0.22	0.20	0.22	**0.26**	0.24	0.18
SOCIAL6	0.23	0.28	0.24	**0.37**	0.36	0.27	0.32
SOCIAL7	0.24	0.24	0.21	0.29	**0.39**	0.19	0.38
SOCIAL8	0.18	0.15	0.16	0.24	**0.36**	0.14	0.39
EMOPOS1	0.13	0.19	0.17	0.14	0.30	**0.53**	0.17
EMOPOS2	0.16	0.19	0.20	0.16	0.23	**0.52**	0.14
EMOPOS3	0.15	0.16	0.13	0.22	0.27	**0.46**	0.23
EMOPOS4	0.09	0.14	0.14	0.06	0.14	**0.46**	0.09
EMOPOS5	0.20	0.25	0.22	0.22	0.24	**0.40**	0.21
EMOPOS6	0.13	0.21	0.21	0.17	0.25	**0.59**	0.21
EMOPOS7	0.18	0.23	0.22	0.26	0.23	**0.42**	0.22
EMOPOS8	0.10	0.19	0.18	0.17	0.29	**0.59**	0.21
EMONEG1	0.31	0.22	0.16	0.29	0.31	0.22	**0.50**
EMONEG2	0.20	0.19	0.11	0.22	0.21	0.17	**0.45**
EMONEG2	0.22	0.20	0.12	0.21	0.26	0.07	**0.37**
EMONEG4	0.25	0.21	0.18	0.28	0.34	0.27	**0.47**
EMONEG5	0.24	0.23	0.20	0.27	0.35	0.23	**0.49**
EMONEG6	0.19	0.19	0.15	0.26	0.34	0.20	**0.48**
EMONEG7	0.18	0.16	0.12	0.24	0.22	0.11	**0.42**
EMONEG8	0.28	0.23	0.20	0.30	0.29	0.16	**0.46**

3.2.3 Intercorrelations between the scales

Table 3.9 shows the intercorrelations of the subscales.

Table 3.9 Intercorrelations of the subscales of the TACQOL - PF and TACQOL – CF (n=1700, resp. n=1094).

TACQOL - PF	BODY	MOTOR	AUTO	COGNIT	SOCIAL	EMOPOS
MOTOR	0.39					
AUTO	0.27	0.53				
COGNIT	0.26	0.32	0.26			
SOCIAL	0.27	0.33	0.30	0.32		
EMPOS	0.26	0.35	0.25	0.29	0.44	
EMONEG	0.30	0.25	0.22	0.29	0.48	0.39
TACQOL - CF	BODY	MOTOR	AUTO	COGNIT	SOCIAL	EMOPOS
MOTOR	0.47					
AUTO	0.32	0.61				
COGNIT	0.40	0.46	0.38			
SOCIAL	0.31	0.35	0.32	0.45		
EMPOS	0.23	0.31	0.29	0.28	0.37	
EMONEG	0.38	0.33	0.25	0.42	0.48	0.29

Both on the TACQOL - PF and the TACQOL - CF only two scales share more than 25% of their variance: MOTOR and AUTO, indicating a clear relationship between these scales.

3.2.4 Reliability of the TACQOL scales

Table 3.10 presents Cronbach's α for the TACQOL - PF and TACQOL - CF scale scores. The coefficients are based on respondents with valid scale-scores on all TACQOL - PF scales, c.q. all TACQOL - CF scales.

Table 3.10 Cronbach's α of the TACQOL - PF and TACQOL - CF scales (n=1700, resp. n=1094)

	TACQOL - PF	TACQOL – CF
BODY	.70	.76
MOTOR	.79	.74
AUTO	.69	.66
COGNIT	.84	.79
SOCIAL	.67	.65
EMOPOS	.84	.78
EMONEG	.71	.76

Cronbach's α varies between 0.65 and 0.84, levels which are deemed sufficient to justify the use of the TACQOL for studies on groups of patients. Cronbach's α are not high enough to justify use of the instrument for individual diagnosis. This also means that differences over time in a single patient, as assessed with the TACQOL scales, should be treated cautiously, as possible indicators of change, not as definite proof.

3.3 Validity

3.3.1 Conceptual validity: the distinction between health status problems and emotional response

As stated in paragraph 1.2, the TACQOL defines Health-Related Quality of Life as a concept to be distinguished from Health Status, by including the individuals' emotional responses towards functional problems which they

face. This definition implies the assumption that functional problems may exist without any associated negative feelings. To assess whether this assumption makes sense psychologically, both the total number of problems reported in the questionnaires and the number of problems with any negative emotional response were counted. Table 3.8 presents the resulting figures. The numbers include all respondents for whom all TACQOL - PF and TACQOL - CF scales were available (n=1054).

Table 3.11 Total numbers of problems (NP) and numbers of problems with negative emotional reactions (NPneg), for the TACQOL - PF and TACQOL - CF scales.

	TACQOL – PF			TACQOL – CF		
	NP	NPneg	%NPneg	NP	NPneg	%NPneg
BODY	2886	2191	76%	3721	2960	80%
MOTOR	875	495	57%	1313	791	60%
AUTO	455	208	46%	481	279	58%
COGNIT	2372	968	41%	2416	1116	46%
SOCIAL	1556	775	50%	1480	796	54%
Total	8144	4637	57%	9411	5942	63%
	n=1054			n=1054		

Parents reported a total of 8144 functional problems, 43% percent of which were –in their perception - not associated with any negative emotional reaction in their child. The children themselves reported a total of 9411 problems, with 37% without associated negative emotional reactions. Clearly, both parents and children distinguished between functional problems as such and functional problems with a negative emotional impact.

3.3.2 Convergent validity: the relationship between the KINDL and TACQOL - CF scales

In order to assess the convergent validity of the TACQOL – CF, the relationship with the KINDL scales was investigated. The KINDL is one of the few questionnaires available for the assessment of Health-Related Quality of Life of Children. It is a questionnaire which is intended to be answered by children themselves. The KINDL has 4 scales (Daily, Social, Body and Psyche) and a total scale score. For the original German version, satisfactory psychometric performance was reported.[8] With the co-operation of the German author of the KINDL, the questionnaire was translated into Dutch, using the forward – backward translation procedure recommended by Guillemin et al[15].

The Pearson product moment correlation coefficients between the TACQOL - CF and the KINDL scales are presented in table 3.12.

Table 3.12 Pearson product moment correlation coefficients between TACQOL - CF and KINDL scales

TACQOL -CF	BODY	MOTOR	AUTO	COGNIT	SOCIAL	EMOPOS	EMONEG
KINDL							
DAILY	0.34	0.38	0.29	0.58	0.41	0.43	0.49
SOCIAL	0.25	0.27	0.25	0.33	0.39	0.48	0.37
BODY	0.48	0.39	0.33	0.37	0.33	0.42	0.36
PSYCHE	0.39	0.39	0.34	0.51	0.51	0.48	0.59
KINDL-TOT	0.44	0.44	0.36	0.54	0.49	0.53	0.54

The table reveals low to moderate relationships between the TACQOL - CF and KINDL scales. Maximum shared variance found is 36 between the TACQOL COGNITION scale and the KINDL Daily scale, which is a weak indicator for concurrent validity only. Furthermore, no clear-cut pattern of relations between specific KINDL and TACQOL - CF scales was found. The TACQOL SOCIAL scale is clearly related to the corresponding KINDL scale, but also to KINDL daily and even more to KINDL psyche. COGNIT is related to daily, but also to psyche. TACQOL BODY is related to the corresponding KINDL scale, but shares less than 25% of the variance

Cronbach's α for the KINDL scales were good (between .75 and .80). However, a principal component analysis, with the number of factors to be extracted specified, followed by a varimax rotation, of the Dutch KINDL data revealed some problems with the Dutch version of the KINDL. Almost all items loaded heavily on the first unrotated principal component which explained 25% of the variance, which is 60% of the total variance (42%) explained by the solution. A varimax rotation failed to reproduce the scale structure, as it was reported for German children.[8] Furthermore, correlation coefficients between the KINDL scales were high (interscale-correlation coefficients varying from .53 to .74; mean .62). It might be assumed, therefore, that the Dutch KINDL reflects no specific aspects of HRQoL, but rather well-being in general. This may explain the low to moderate and rather indistinct coefficients reported in table 3.12.

3.3.3 Divergent validity: the relationship between behavioural problems and the TACQOL - PF scales

The concept of HRQoL as defined in the TACQOL scales bears some resemblance to the concept of behavioural problems as they are assessed with the CBCL [24]. Yet the two concepts must be clearly distinguished: the CBCL tries to assess behavioural problems relevant for psychiatric assessment. No substantial relationship between the TACQOL PF scales and CBCL-alike scales were therefore expected.

In order to evaluate the relation of the TACQOL scales with behavioural problems, a selection of CBCL items were included in the parent questionnaires in the Reference Study, although in a different layout and not in the context of the CBCL as such. The items included are those which are part of the CBCL scales Anxiety, Withdrawing Behaviour, Social Problems and Attention Problems. These scales could be reproduced with satisfying reliability, Cronbach's α ranging from 0.66 to 0.83. Pearson's product moment correlation coefficients were calculated between these CBCL based scales and the TACQOL - PF and TACQOL - CF scales. Only data from children for whom all scale scores were available were included. Table 3.13 presents the results.

As hypothesised, the figures indicate the absence of a substantial relationship between the TACQOL - PF and TACQOL - CF scales and behavioural problems as they are assessed by the CBCL. The highest correlation coefficient found was that between Anxiety and EMONEG (-0.30).

Table 3.13 Product moment correlation coefficients between TACQOL - PF and TACQOL - CF scales and the CBCL based scales Withdrawn, Anxiety, Social Problems and Attention problems

	Withdrawn	Anxiety	Social	Attention
Parent Form				

	Withdrawn	Anxiety	Social	Attention
BODY	-0.09	-0.18	-0.08	-0.11
MOTOR	-0.11	-0.19	-0.12	-0.16
AUTO	-0.10	-0.16	-0.12	-0.13
COGNIT	-0.07	-0.14	-0.10	-0.23
SOCIAL	-0.20	-0.29	-0.20	-0.23
EMOPOS	-0.14	-0.24	-0.12	-0.17
EMONEG	-0.16	-0.30	-0.16	-0.22
n=1674				
Child Form				
BODY	-0.09	-0.18	-0.08	-0.11
MOTOR	-0.08	-0.12	-0.09	-0.11
AUTO	-0.10	-0.16	-0.12	-0.13
COGNIT	-0.07	-0.14	-0.10	-0.23
SOCIAL	-0.20	-0.29	-0.20	-0.23
EMOPOS	-0.14	-0.24	-0.12	-0.17
EMONEG	-0.16	-0.30	-0.16	-0.22
n=1076				

3.3.4 Criterion validity: effects of illnesses, medical treatment and chronic conditions

Studies on HRQoL are based on the assumption that health problems may have a negative impact on Health-Related Quality of Life. Consequently, instruments assessing HRQoL should be able to make this impact visible.

To assess whether the TACQOL PF and TACQOL CF were able to detect such differences, the relationship between TACQOL scores and three health indicators was assessed:

- common illnesses, such as flu or colds
- medical treatment in the past few months (consulted a GP or specialist, treatment in a hospital)
- chronic conditions or diseases, such as allergies, asthma, epilepsy, rheumatism, diabetes and heart conditions

Questions concerning these indicators were included in the parent questionnaires in the Reference Study. A large proportion of the sample (71%) had had some common illness during the last month. This was due to an innocent flu outbreak in the winter months during which the data were collected. Nineteen percent of the sample had some chronic condition according to the parents and 45% had undergone some form of medical treatment during the last few months; this mainly involved consulting the GP.

Multivariate analyses of variance using the three indicators and the interactions between the indicators showed no significant effects for the interactions between the indicators. Table 3.14 therefore simply presents the results of simple T-tests for the three indicators separately.

Table 3.14 Results of t-tests of PF and CF-scales, by chronic condition, medical treatment and chronic diseases

		Parents n=1700				Children n=1094			
Chronic condition No/Yes	SCALES	Means	95% CI lower	upper	Prob. t **	Means	95% CI lower	upper	Prob. t **
No	BODY	27.6	27.4	27.8	0.000 *	25.2	24.9	25.6	0.000

Yes		25.3	24.8	25.7		23.4	22.7	24.2	
No	MOTOR	31.0	30.9	31.1	0.000 *	30.0	29.8	30.2	0.000 *
Yes		29.8	29.4	30.2		29.0	28.5	29.5	
No	AUTO	30.9	30.8	31.1	0.000 *	31.3	31.2	31.4	0.003 *
Yes		30.1	29.7	30.4		30.8	30.5	31.1	
No	COGNIT	29.1	28.9	29.3	0.011	28.5	28.3	28.8	0.097
Yes		28.5	28.1	29.0		28.0	27.5	28.6	
No	SOCIAL	30.0	29.9	30.1	0.000 *	29.8	29.6	30.0	0.059 *
Yes		29.3	28.9	29.6		29.3	28.9	29.8	
No	EMOPOS	14.9	14.8	15.0	0.000 *	13.6	13.4	13.8	0.162
Yes		14.2	13.9	14.5		13.3	12.9	13.7	
No	EMONEG	11.6	11.5	11.8	0.000	11.7	11.6	11.9	0.001
Yes		10.8	10.6	11.1		11.0	10.6	11.4	
Common Illness	SCALES	Means	95% CI		Prob. t **	Means	95% CI		Prob. t **
No/Yes			lower	upper			lower	upper	
No	BODY	28.9	28.6	29.2	0.000 *	26.5	26.0	27.1	0.000
Yes		26.4	26.2	26.7		24.2	23.9	24.6	
No	MOTOR	31.0	30.8	31.2	0.026 *	30.1	29.8	30.4	0.040
Yes		30.7	30.5	30.8		29.7	29.5	29.9	
No	AUTO	31.1	31.0	31.3	0.000 *	31.4	31.2	31.6	0.024 *
Yes		30.6	30.5	30.8		31.1	31.0	31.3	
No	COGNIT	29.1	28.8	29.5	0.415	28.7	28.3	29.1	0.255
Yes		29.0	28.7	29.2		28.4	28.1	28.7	
No	SOCIAL	30.2	30.0	30.4	0.001 *	30.0	29.8	30.3	0.008 *
Yes		29.8	29.6	29.9		29.6	29.4	29.8	
No	EMOPOS	14.9	14.8	15.1	0.064	13.8	13.6	14.1	0.013 *
Yes		14.7	14.6	14.9		13.4	13.3	13.6	
No	EMONEG	11.8	11.5	12.0	0.005	11.7	11.4	12.0	0.340
Yes		11.4	11.3	11.5		11.6	11.4	11.8	
Medical. Treatment									
No/Yes									
No	BODY	28.1	27.9	28.3	0.000 *	25.7	25.3	26.1	0.000
Yes		26.0	25.7	26.3		23.9	23.4	24.4	
No	MOTOR	31.2	31.1	31.3	0.000 *	30.3	30.1	30.5	0.000 *
Yes		30.2	30.0	30.5		29.2	28.9	29.5	
No	AUTO	31.2	31.0	31.3	0.000 *	31.5	31.4	31.6	0.000 *
Yes		30.3	30.1	30.5		30.9	30.7	31.1	
No	COGNIT	29.3	29.0	29.5	0.003 *	28.6	28.3	28.9	0.076
Yes		28.7	28.4	29.0		28.2	27.8	28.6	
No	SOCIAL	30.2	30.1	30.3	0.000 *	30.0	29.8	30.2	0.000 *
Yes		29.5	29.3	29.7		29.3	29.0	29.6	
No	EMOPOS	15.0	14.9	15.1	0.000 *	13.7	13.5	13.9	0.021
Yes		14.6	14.4	14.7		13.4	13.4	13.7	
No	EMONEG	11.7	11.6	11.9	0.000 *	11.9	11.7	12.1	0.001
Yes		11.2	11.0	11.4		11.3	11.0	11.5	
*	Not assuming equal variances								
**	Two tailed significance								

The three health indicators show a significant relationship with most TACQOL - PF scores. MOTOR and EMONEG are not related to common illnesses. On most scales, the relationship with common illnesses is less than that with chronic conditions or medical treatment. In general, the relationships on the PF scales are stronger than those on the CF scales.

3.3.5 Relationship between the TACQOL - PF and the TACQOL - CF

Both the TACQOL-PF and the TACQOL-CF are designed to measure the child's Health-Related Quality of Life. The TACQOL -PF tries to do so by using the parents as proxies; they are not asked to give their own judgements but to assess their children's problems and to indicate whether their child showed a negative emotional reaction towards such problems. Each TACQOL-PF scale should therefore be positively, significantly and substantially correlated to its corresponding TACQOL - CF scale. Table 3.15 shows the means, standard deviations, the significance of the difference, the Product-Moment correlation coefficient and the Intra Class Correlation coefficient of the corresponding scales. The analysis included all children - aged 8 till 11 - for whom both TACQOL-PF and TACQOL-CF data were available.

The table shows that the differences between the CF and PF mean scale scores were significant on all scales, SOCIAL and EMONEG excluded. Compared to their children parent presented a more optimistic view on the scales BODY, MOTOR, COGNITION and EMOPOS and a more pessimistic view on the scales AUTO and EMONEG. The product moment correlation coefficients were all positive and significant, indicating a substantial intercorrelation. Yet the size of the correlation coefficients was limited, indicating a sizeable disagreement between parents and children. Intra Class Correlation Coefficients were generally some points below the product moment correlation coefficients. This can be attributed mainly to the absolute differences between the scores.

Table 3.15 Means and standard deviations of TACQOL - PF and CF; significance of T-test, Product Moment Correlation coefficients (PMC) and Intra Class Correlation Coefficients (ICC) (n=1054)

	Mean	St. dev.	95% CI		Mean	St. dev.	95% CI		P T-test	PMC	ICC
			Lower	Upper			Lower	Upper			
	PF				CF						
BODY	26.9	4.02	26.7	27.2	24.9	5.14	24.6	25.2	0.00	0.61	0.54
MOTOR	30.6	2.75	30.5	30.8	29.8	3.25	29.6	30.0	0.00	0.51	0.48
AUTO	31.3	1.63	31.2	31.4	31.2	1.97	31.1	31.3	0.01	0.47	0.46
COGNIT	28.7	3.90	28.5	29.0	28.5	3.90	28.2	28.7	0.01	0.61	0.61
SOCIAL	29.7	2.63	29.6	29.9	29.7	2.76	29.5	29.9	0.83	0.51	0.51
EMOPOS	14.7	2.13	14.6	14.8	13.6	2.53	13.4	13.7	0.00	0.44	0.39
EMONEG	11.5	2.45	11.4	11.7	11.6	2.71	11.4	11.8	??0.49	0.55	0.55

Theunissen et al. [23] performed a multi-trait multi-method analysis using EQS to assess the degree to which the TACQOL-PF and CF scores may be considered as indicative of an underlying construct of HRQoL. They assessed the degree to which the TACQOL – PF and CF scale scores may be explained by latent scale specific traits, by method (Parent Form or Child Form) or by error. The main results of the EQS analysis are presented in table 3.16. Theunissen et al. concluded that, in general, Children and Parent's scale scores were determined primarily by the scale-specific latent traits and much less by method or error. The results, however, also indicate that the percentage of variance to be attributed to error is substantial and sometimes approximates the proportion of the variance to be attributed to the latent traits. The SOCIAL scale performed weakly, with a large percentage of the variance to be explained by error. On the whole, however, the analysis confirmed convergent validity between corresponding TACQOL-PF and CF scales. Divergent validity between non-corresponding scales was tested in a multi-trait multi-method matrix, assessing whether the mono-trait hetero-method correlation

coefficient was greater than the corresponding hetero-trait hetero-method correlation coefficients. Divergent validity was confirmed for all scales, with the exception of the MOTOR and AUTO scales, which showed overlap. Theunissen et al. concluded that the results do not favour either the TACQOL-PF or the TACQOL-CF as the general best indicator of the child's Health-Related Quality of Life and suggest that is advisable to use both instruments simultaneously.

Table 3.16 Summary of results of an EQS analysis on the TACQOL-PF and CF scales : Percentage of variance explained by latent trait, method and error for the TACQOL-PF and CF scales (source: Theunissen et al. [23])

	Perc. variance explained by					
Scale	Latent trait	method	error	latent trait	method	error
	PF			CF		
BODY	68	8	24	65	14	21
MOTOR	59	10	30	67	24	9
AUTO	41	22	37	38	5	57
COGNIT	42	17	40	54	6	40
SOCIAL	38	30	32	39	21	40
EMOPOS	55	6	39	65	2	32
EMONEG	50	5	45	73	0	26
Total	51	14	35	57	10	32

4 Using the TACQOL

4.1 TACQOL – Parent Form and TACQOL – Child Form

Both a Parent Form and a Child Form are available. Both forms are based on the same concept of Health-Related Quality of Life. Item content is the same, except for some slight and obvious variations in the phrasing of the items (‘you’ vs. ‘your child’).

The TACQOL - Parent Form (TACQOL-PF) explicitly asks parents to try and assess their child's feelings with regard to functional problems which their child faces, and not their own feelings (“true proxy”). The TACQOL - PF is designed for (parents of) children in the age group 6 - 15.

Whenever possible it seems wise to use both the Parent Form and Child Form as supplementary measures.

The TACQOL - Child Form (TACQOL - CF) was constructed for children aged 8 – 15. The TACQOL - CF and TACQOL are identical in design and scale structure.

4.2 Items of the TACQOL questionnaires

Table 4.1 presents the items for the 7 TACQOL -PF scales (English version, translated following the guidelines of Guillemin et al [14]). The child form contains the same items as the Parent Form, with slight adaptations in the phrasing of some items.

In order to assess problems and limitations weighted by the emotional response, the TACQOL first assesses the occurrence of particular functional problems and limitations. If such a problem exists it assesses the degree to which the patient is actually emotionally bothered by that problem. The phrasing of most items implies some problem or limitation. Table 4.2 presents such an item and the way the questions are asked.

Most questions have a negative item content, as in table 4.2. Some items, however, are positively phrased, for example ‘My child was able to play or talk happily with other children’. In these cases, the answers provided are different. The phrasing and the answer categories of positively phrased items on the SOCIAL scale is presented in table 4.3.

Table 4.1 Items of the TAQOL - PF (English version)

BODY	SOCIAL
Has your child had earaches or sore throats?	My child was able to play or talk happily with other children.
Has your child had stomach-aches or abdominal pain?	My child was able to stand up for himself/herself with other children.
Has your child had headaches?	Other children asked my child to play with them.
Has your child been dizzy?	My child was at ease with other children.
Has your child felt sick/nauseous?	My child was able to play or talk happily with us - the parent(s).
Was your child tired?	My child was incommunicative or quiet with us - the parent(s)
Was your child sleepy?	My child was restless or impatient with us – the parent(s)
Was your child dozy/lethargic?	My child was defiant with us - the parent(s)
MOTOR: Did your child have..	POSITIVE EMOTIONS: In recent weeks, my child felt...
difficulty with running?	Joyful
difficulty with walking?	In good spirits
difficulty with standing?	Contented
difficulty walking downstairs?	Enthusiastic
difficulty with playing?	Relaxed
difficulty with running or walking for long periods, with stamina?	Happy
difficulty with balance?	Confident
difficulty with doing things handily or quickly?	Cheerful
AUTONOMY: Did your child have..	NEGATIVE EMOTIONS: In recent weeks, my child felt...
difficulty with going to school on his/her own?	Short-tempered
difficulty washing himself/herself?	Jealous
difficulty getting dressed on his/her own?	Anxious
difficulty going to the lavatory on his/her own?	Sad
difficulty with eating or drinking on his/her own?	Angry
difficulty with sports or going out to play on his/her own?	Worried
difficulty with doing hobbies on his/her own?	Gloomy
difficulty with riding a bicycle?	Aggressive
COGNITION: Did your child have..	
difficulty with paying attention, concentrating?	
difficulty understanding schoolwork?	
difficulty understanding what others said?	
difficulty with arithmetic?	
difficulty with reading?	
difficulty with writing?	
difficulty with learning?	
difficulty in saying what he/she meant?	

Table 4.2 An typical example of a negatively phrased TACQOL item (Parent Form)

Has your child had earaches or sore throats? ❑ never (4) ❑ occasionally ❑ often

At that time, my child felt:
❑ fine (3) ❑ not so good (2) ❑ quite bad (1) ❑ bad (0)

Table 4.3 An example of a positively phrased TACQOL item (Parent Form)

My child was able to play or talk happily with other children ❑ yes (4) ❑ too little ❑ never

At that time, my child felt:
❑ fine (3) ❑ not so good (2) ❑ quite bad (1) ❑ bad (0)

4.3 Scoring items

The scoring procedure is based on the results of the analyses presented in paragraph 3.1

One single score is given for each pair of items (functional item and the corresponding emotional item) and for each single item in the EMOPOS and EMONEG scales. The scoring grid is given in the tables 4.2, 4.3 and 4.4 (in brackets).

When the response to the first part of an item is 'occasionally' or 'often' (in positively phrased items: 'too little' and 'never'), but no response was given on the second part, it is assumed that no negative emotion exists and the item pair is therefore subsequently scored as 3.

For the scales EMOPOS and EMONEG, no emotional responses are asked, as we assumed the distinction between the occurrence of specific emotions and the emotional responses to such emotions to be too subtle to be made in a self-administered and structured questionnaire. Scores attributed simply reflect the frequency with which these emotions occur (see table 4.3).

Table 4.4 Scoring of items in EMOPOS and EMONEG

Scale	Category (Score attributed)	Category (Score attributed)	Category (Score attributed)
EMOPOS	never (0)	occasionally (1)	often (2)
EMONEG	never (2)	occasionally (1)	often (0)

4.4 Calculating scale scores

The scale structure and the procedures for calculating scale scores is based on the results of the analyses based in paragraph 3.1. Appendix I and II presents a detailed SPSS program syntax for scoring the item pairs and for calculating the scale scores.

Essentially, in order to calculate scale scores for the BODY, MOTOR, AUTO, COGNIT and SOCIAL scales, the scores of the item pairs are summed for each scale separately. For EMOPOS and EMONEG, the simple item scores are added. The sum scores may range from 0 to 32 for BODY, MOTOR, COGNIT, AUTO and SOCIAL. For EMOPOS and EMONEG the scores vary between 0 and 16.

The calculated scale scores are all in the same direction: a low score indicates a lower HRQoL; a high score indicates a higher HRQoL.

Regarding missing values, for each individual scale the following procedure should be followed: when less than three item (-pair) scores are missing, the calculated sum score is divided by the number of scored items and then multiplied by eight.[1] When more than 2 items pairs are missing, the total scale score is assumed to be missing.

[1] Assuming that Sc = scale score to be calculated, Su - the sum of the non-missing scored item pairs, Ni = the number of non missing scores, then: $Sc = 8*(Su/Ni)$; with $Ni \geq 6$.

4.5 Comparing frequency distributions with reference data from a random sample of Dutch children

The TACQOL - PF and TACQOL - CF are meant to be used for the assessment of group differences. At present, there is insufficient evidence that the sensitivity and reliability for most scales are sufficient to allow using the instruments for individual assessments. Comparing individual scores with the distribution in the population, therefore, is explicitly not recommended.

However, comparisons on group level are fully justified, as Cronbach's α are between .65 and .84. In order to enable comparison of the distribution of the scale scores of specific groups with the distribution in the reference sample, tables 4.5, 4.6 and 4.7 present the categorised frequency distribution for this sample as a whole and for boys and girls separately. Children from ethnic minorities, while underrepresented in the reference sample, have significantly lower scores. These children were therefore not included in the table.

It should be noted that both age and gender have small but significant effects on TACQOL scale scores. Appendix IV, therefore, presents (categorised) frequency distributions for the TACQOL - PF and CF scales for age and gender groups separately.

Table 4.5 Percentages of categorised TACQOL scores; reference sample; Boys and Girls, all ages

	Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	SCORES	EMOPOS	EMONEG
Boys and Girls	Parent Form								
	0-15	1%	0%	0%	0%	0%	*0-5*	0%	1%
	16-19	3%	1%	0%	3%	1%	*6-7*	1%	3%
	20-23	12%	2%	1%	5%	2%	*8-9*	4%	15%
	24-27	29%	5%	4%	18%	9%	*10-11*	3%	28%
	28,29	21%	7%	6%	13%	18%	*12-13*	8%	32%
	30,31	19%	22%	17%	22%	39%	*14-15*	29%	18%
	32	15%	64%	73%	38%	32%	*16*	56%	3%
	n=	1618	1618	1618	1618	1618	1618	1618	1618
	Child Form								
	0-15	5%	1%	0%	1%	0%	*0-5*	0%	2%
	16-19	10%	1%	0%	3%	1%	*6-7*	3%	5%
	20-23	20%	4%	1%	7%	2%	*8-9*	5%	15%
	24-27	27%	10%	3%	18%	12%	*10-11*	9%	24%
	28,29	15%	13%	5%	20%	18%	*12-13*	22%	26%
	30,31	13%	28%	17%	24%	33%	*14-15*	31%	22%
	32	10%	44%	73%	28%	34%	*16*	30%	6%
	n=	1048	1048	1048	1048	1048		1048	1048

Table 4.6 Percentages of categorised TACQOL scores; reference sample; Boys, all ages

		Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	SCORES	EMOPOS	EMONEG
Boys	Parent Form									
		0-15	1%	0%	0%	0%	0%	*0-5*	0%	2%
		16-19	4%	1%	0%	3%	1%	*6-7*	1%	3%
		20-23	10%	2%	1%	7%	3%	*8-9*	4%	17%
		24-27	26%	5%	4%	18%	11%	*10-11*	3%	26%
		28,29	21%	6%	6%	14%	17%	*12-13*	8%	31%
		30,31	20%	24%	17%	23%	38%	*14-15*	30%	18%
		32	19%	62%	73%	35%	30%	*16*	55%	4%
		n=	807	807	807	807	807	807	807	807
	Child Form									
		0-15	4%	1%	0%	1%	0%	*0-5*	0%	2%
		16-19	9%	1%	0%	2%	1%	*6-7*	3%	5%
		20-23	20%	3%	1%	7%	2%	*8-9*	5%	16%
		24-27	27%	10%	3%	19%	12%	*10-11*	10%	22%
		28,29	16%	11%	5%	20%	19%	*12-13*	23%	25%
		30,31	14%	31%	17%	25%	34%	*14-15*	32%	23%
		32	10%	44%	75%	26%	33%	*16*	27%	6%
		n=	513	513	513	513	513		513	513

Table 4.7 Percentages of categorised TACQOL scores; reference sample; Girls, all ages

		Scores	BODY	MOTOR	Auto	Cognit	Social	Scores	EMOPOS	EMONEG
Girls	Parent Form									
		0-15	1%	0%	0%	0%	0%	*0-5*	0%	1%
		16-19	3%	1%	0%	3%	0%	*6-7*	1%	3%
		20-23	14%	1%	1%	4%	2%	*8-9*	3%	14%
		24-27	31%	5%	3%	18%	7%	*10-11*	3%	30%
		28,29	21%	9%	5%	13%	18%	*12-13*	8%	32%
		30,31	19%	19%	18%	20%	39%	*14-15*	29%	18%
		32	12%	65%	73%	42%	33%	*16*	57%	3%
		n=	804	804	804	804	804		804	804
	Child Form									
		0-15	6%	1%	1%	1%	0%	0-5	0%	1%
		16-19	10%	1%	0%	4%	1%	6-7	2%	5%
		20-23	20%	4%	1%	7%	2%	8-9	6%	14%
		24-27	28%	9%	4%	17%	12%	10-11	9%	27%
		28,29	15%	14%	6%	19%	17%	12-13	20%	26%
		30,31	13%	25%	17%	22%	31%	14-15	31%	22%
		32	9%	45%	72%	30%	36%	16	32%	5%
		n=	519	519	519	519	519		519	519

4.6 Comparing mean scores with reference sample of Dutch children

Table 4.8 and 4.9 present the reference sample's means and standard deviations for the TACQOL scale scores. It should be noted that age and gender have small but significant effects on the scale scores. The table therefore not only presents overall figures, but also figures for specific age/gender groups.

The means of the TACQOL scale scores vary in the reference group. One may expect similar differences in other studies to occur. Such differences should not necessarily be interpreted as indicating differences in domain-specific HRQoL. The absolute scale scores are – in a way – meaningless. TACQOL scale scores must be interpreted in relation to either the reference group, other specific samples or in relation to earlier or later measurements in the same group.

Using the data in the tables, t-tests may be used to test for significant differences with the reference sample from Dutch children.

Table 4.8 TACQOL - PF: Means and standard deviations of raw scores in reference sample, by age and sex

	Mean	Std. Dev.	N	Mean	Std. Dev.	N
All ages	Boys and Girls					
BODY	27.21	3.88	1618			
MOTOR	30.79	2.56	1618			
AUTO	31.25	1.68	1618			
COGNIT	29.07	3.70	1618			
SOCIAL	29.87	2.47	1618			
EMOPOS	14.86	1.98	1618			
EMONEG	11.533	2.38	1618			
All ages	Boys			Girls		
BODY	27.53	3.91	807	26.88	3.82	804
MOTOR	30.78	2.54	807	30.79	2.59	804
AUTO	31.22	1.75	807	31.28	1.61	804
COGNIT	28.87	3.80	807	29.25	3.61	804
SOCIAL	29.72	2.62	807	30.02	2.32	804
EMOPOS	14.77	2.10	807	14.94	1.85	804
EMONEG	11.46	2.49	807	11.60	2.27	804
Age 6/7	Boys			Girls		
BODY	27.91	3.77	287	27.26	3.73	280
MOTOR	30.87	2.52	287	31.22	1.74	280
AUTO	30.99	1.97	287	31.13	1.65	280
COGNIT	29.16	3.58	287	30.17	2.81	280
SOCIAL	29.96	2.39	287	30.32	1.88	280
EMOPOS	14.92	2.03	287	15.25	1.40	280
EMONEG	11.29	2.37	287	11.71	2.12	280
Age 8/9	Boys			Girls		
BODY	27.38	3.77	247	26.68	3.92	246
MOTOR	30.77	2.54	247	30.72	2.86	246
AUTO	31.13	1.78	247	31.30	1.63	246
COGNIT	28.50	3.86	247	28.61	4.06	246
SOCIAL	29.39	2.81	247	29.98	2.28	246
EMOPOS	14.81	1.94	247	14.84	1.99	246
EMONEG	11.25	2.67	247	11.47	2.29	246
Age 10/11	Boys			Girls		
BODY	27.28	4.16	273	26.68	3.81	278
MOTOR	30.70	2.57	273	30.42	2.98	278
AUTO	31.53	1.41	273	31.41	1.56	278
COGNIT	28.91	3.94	273	28.89	3.74	278
SOCIAL	29.76	2.64	273	29.74	2.69	278
EMOPOS	14.57	2.29	273	14.73	2.07	278
EMONEG	11.83	2.42	273	11.59	2.39	278

Table 4.9 TACQOL - CF: Means and standard deviations of raw scores in reference sample, by age and sex

	Mean	Std. Dev.	N	Mean	Std. Dev.	N
All ages	Boys and Girls					
BODY	25.00	5.10	1048			
MOTOR	29.81	3.23	1048			
AUTO	31.20	1.97	1048			
COGNIT	28.49	3.90	1048			
SOCIAL	29.72	2.76	1048			
EMOPOS	13.60	2.50	1048			
EMONEG	11.64	2.68	1048			
All ages	Boys			Girls		
BODY	25.28	4.92	513	27.80	5.22	519
MOTOR	29.94	3.07	513	29.73	3.38	519
AUTO	31.33	1.53	513	31.06	2.33	519
COGNIT	28.59	3.37	513	28.48	4.04	519
SOCIAL	29.74	2.66	513	29.70	2.83	519
EMOPOS	13.51	2.54	513	13.68	2.47	519
EMONEG	11.61	2.76	513	11.65	2.60	519
Age 8 /9	Boys			Girls		
BODY	25.28	4.80	240	24.87	5.25	242
MOTOR	29.84	3.20	240	29.75	3.57	242
AUTO	31.13	1.82	240	30.80	2.83	242
COGNIT	28.61	3.60	240	28.24	4.36	242
SOCIAL	29.62	2.95	240	29.65	2.89	242
EMOPOS	13.39	2.61	240	13.48	2.49	242
EMONEG	11.55	2.88	240	11.50	2.63	242
Age 10/11	Boys			Girls		
BODY	25.27	5.03	273	24.73	5.20	277
MOTOR	30.02	2.94	273	29.71	3.20	277
AUTO	31.50	1.21	273	31.29	1.75	277
COGNIT	28.57	3.73	273	28.69	3.74	277
SOCIAL	29.85	2.37	273	29.75	2.79	277
EMOPOS	13.62	2.47	273	13.85	2.44	277
EMONEG	11.67	2.65	273	11.78	2.58	277

4.7 Comparing mean scores with reference sample of Dutch children without chronic conditions or diseases

Under certain circumstances, it may be desirable to compare TACQOL scores, not with the sample in the reference study as a whole, but only with the children without chronic condition or disease. Tables 4.10 and 4.11 therefore present means and standard deviations from the random sample, after exclusion of children with (parent reported) chronic conditions. Again, children with any missing score and children from ethnic minorities were also excluded. To test for significance of group differences, again, t-tests may be used, using the data presented in the table.

Again, absolute TACQOL scale scores must be interpreted with caution. TACQOL scale scores must be interpreted in relation to either the reference group, other specific samples or in relation to earlier or later measurements in the same group.

Table 4.10 TACQOL - PF: Means and standard deviations of raw scores in reference sample: children without chronic illnesses, by age and sex

	Mean	Std.Dev.	N	Mean	Std.Dev.	N
Overall						
BODY	27.60	3.69	1318			
MOTOR	31.00	2.27	1318			
AUTO	31.35	1.56	1318			
COGNIT	29.16	3.70	1318			
SOCIAL	29.99	2.32	1318			
EMOPOS	14.98	1.80	1318			
EMONEG	11.68	2.34	1318			
All ages	Boys			Girls		
BODY	27.92	3.78	654	27.29	3.58	657
MOTOR	30.98	2.26	654	31.03	2.28	657
AUTO	31.28	1.68	654	31.41	1.44	657
COGNIT	28.97	3.80	654	29.33	3.60	657
SOCIAL	29.86	2.43	654	30.12	2.20	657
EMOPOS	14.86	1.94	654	15.09	1.65	657
EMONEG	11.63	2.43	654	11.71	2.25	657
Age 6/7	Boys			Girls		
BODY	28.45	3.63	232	27.62	3.38	227
MOTOR	31.09	2.44	232	31.41	1.52	227
AUTO	31.05	1.97	232	31.23	2.70	227
COGNIT	29.31	3.66	232	30.29	2.70	227
SOCIAL	30.13	2.13	232	30.45	1.76	227
EMOPOS	15.07	1.84	232	15.39	1.09	227
EMONEG	11.54	2.29	232	11.81	2.16	227
Age 8/9	Boys			Girls		
BODY	27.59	3.74	201	27.21	3.74	203
MOTOR	30.85	2.42	201	31.00	2.44	203
AUTO	31.14	1.78	201	31.46	1.44	203
COGNIT	28.47	3.92	201	28.56	4.16	203
SOCIAL	29.44	2.73	201	30.06	2.16	203
EMOPOS	14.88	1.82	201	14.94	1.82	203
EMONEG	11.37	2.59	201	11.58	2.29	203
Age 10/11	Boys			Girls		
BODY	27.68	3.92	221	27.02	3.62	227
MOTOR	30.98	1.88	221	30.66	2.69	227
AUTO	31.66	1.07	221	31.54	1.33	227
COGNIT	31.23	1.54	221	29.06	3.64	227
SOCIAL	29.96	2.40	221	29.84	2.58	227
EMOPOS	14.62	2.13	221	14.91	1.91	227
EMONEG	11.97	2.39	221	11.73	2.31	227

Table 4.11 TACQOL - CF: Means and standard deviations of raw scores in reference sample: children without chronic illnesses, by age and sex

	Mean	Std.Dev.	N	Mean	Std.Dev.	N
	Boys and Girls					
All ages						
BODY	25.30	5.04	860			
MOTOR	29.99	3.15	860			
AUTO	31.29	1.86	860			
COGNIT	28.54	3.93	860			
SOCIAL	29.77	2.67	860			
EMOPOS	13.62	2.49	860			
EMONEG	11.74	2.67	860			
All ages	Boys			Girls		
BODY	25.54	4.81	418	25.17	5.18	426
MOTOR	30.12	2.89	418	19.92	3.36	426
AUTO	31.38	1.50	418	31.18	2.18	426
COGNIT	28.66	3.59	418	28.53	4.15	426
SOCIAL	29.82	2.50	418	29.75	2.78	426
EMOPOS	13.48	2.54	418	13.75	2.45	426
EMONEG	11.69	2.72	418	11.78	2.63	426
Age 8/9	Boys			Girls		
BODY	25.52	4.66	198	25.30	5.30	198
MOTOR	30.00	3.07	198	30.01	3.47	198
AUTO	31.16	1.81	198	31.06	2.58	198
COGNIT	28.71	3.54	198	28.14	4.54	198
SOCIAL	29.74	2.69	198	29.64	2.91	198
EMOPOS	13.38	2.64	198	13.49	2.56	198
EMONEG	11.62	2.79	198	11.64	2.65	198
Age 10/11	Boys			Girls		
BODY	25.55	4.96	220	25.05	5.08	228
MOTOR	30.23	2.71	220	29.85	3.28	228
AUTO	31.59	1.12	220	31.32	1.74	228
COGNIT	28.62	3.64	220	28.88	3.74	228
SOCIAL	29.89	2.31	220	29.85	2.68	228
EMOPOS	13.57	2.45	220	13.99	2.32	228
EMONEG	11.76	2.66	220	11.89	2.61	228

5. Discussion

The TACQOL - PF and CF are paper and pencil questionnaires measuring generic, i.e. not disease-specific, Health-Related Quality of Life among children. Health-Related Quality of Life is defined as health status weighted by the child's emotional response to problems in health status.

Health-Related Quality of Life is conceptualised as a multi-dimensional concept, covering various life domains. The quality of life on one domain may vary, independently from that on other domains. In the TACQOL questionnaires, the following domains are covered by specific scales: BODY (assessing the emotional impact of physical complaints), MOTOR (motoric functioning), Auto (Autonomy), Cognit (cognition), Social (interaction with parents and peers). Furthermore, two scales covering general mood are included: EMOPOS (Positive emotions) and EMONEG (Negative Emotions).

Furthermore, Health-Related Quality of Life is approached as a concept which is related but not identical to the concept of Health Status. Health Status is based essentially on problems in functioning. These problems may however vary in their impact on a person's well-being and it is essentially this impact which is referred to when the concept of Health-Related Quality of Life is used. Therefore, the TACQOL questionnaires assess the occurrence of functional problems, but does not stop there: if such a problem occurs, negative emotional reactions are assessed, too.

The TACQOL-CF (child form) was developed for children aged 8-15. The TACQOL-PF (parent form) may be used in order to assess Health-Related Quality of Life among children aged 6-15, using the parents as source of information.

The psychometric performance of both the TACQOL - PF and the TACQOL - CF is satisfactory. The TACQOL scales are skewed, especially in a general population. However, most parametric techniques used in the evaluation of the instruments are quite robust against skewness, and have been demonstrated to be adequate in analysing skewed data if sample size is large enough [25].

Cronbach's α ranged from 0.65 to 0.84, which is regarded as satisfactory for use of the TACQOL to compare group means [3,15,16]. However, when individual scores are of interest, the TACQOL cannot be used safely; for use in clinical diagnosis, much higher levels of Cronbach's α are mandatory. Furthermore, the stability of the TACQOL and its sensitivity to change need to be ascertained.

The validity of the scale structure -i.e. the scales that are distinguished - is supported by the finding that corrected item – own scale correlation coefficients are almost always higher than correlation coefficients with other scales. Furthermore, principal component analyses, followed by varimax rotation, generally reflect the supposed scale structure fairly well. Finally, correlation coefficients between TACQOL scales are low to moderate. The construct validity of the TACQOL may therefore be considered as being good, with the exception of two clearly overlapping scales on the TACQOL -CF: Auto and MOTOR.

PF scales are significantly and substantially correlated to CF scales, but the resulting scores are clearly not identical. This implies that, on an individual level, a parent may differ considerably from his or her child when judging the child's HRQoL. This is a common finding that has been described extensively in the literature on proxy ratings [19, 22]. As no gold 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, on a group level the TACQOL - PF may be regarded as a satisfactory proxy for the TACQOL - CF. However, the simultaneous administration of both scales is recommended whenever possible since TACQOL - PF and CF clearly supplement each other and each questionnaire is a valid approximation of the child's 'true' Health-Related Quality of Life.

Convergent validity has been evaluated by relating TACQOL - CF scales to KINDL scales. Product moment correlation coefficients were low and are rather indistinct, showing no clear relations between comparable scales. The lack of relations between the TACQOL and the KINDL may partly be caused by a different time frame: recent weeks for the TACQOL, and the last week for the KINDL**.** Furthermore, since the product moment correlation coefficients between the KINDL scales were high, the Dutch KINDL scales may predominantly reflect a single quality of life dimension. By 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 KIND-L, the TACQOL - CF may be more consistent with a multi-dimensional definition of HRQoL.

As for divergent validity: the relationship between four CBCL-based scales with the TACQOL scales was assessed. The items of the TACQOL scales bear some resemblance to those in the CBCL. Yet the concepts measured in both instruments must be clearly distinguished: the CBCL tries to assess behavioural problems which are relevant for psychiatric assessment. The TACQOL pretends to measure functional health status problems, weighted by their emotional impact. As expected, all correlation coefficients between CBCL and TACQOL scores were low, indicating divergent validity.

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 in terms of the range of the scales. As has been reported in the literature, children's HRQoL may be influenced by other factors than their health status alone. Coping, adaptation of behavioural patterns, internal standards and external expectations all may have their influence on how health and health status affect Quality of Life. For instance, Saigal et al. found that even severely handicapped children rated their health status as highly as did healthy controls[37].

The validity of the distinction between health status and HRQoL was supported by the finding that only about half of the health status problems reported were associated with negative emotional reactions in the children. The TACQOL explicitly offers respondents the possibility to differentiate 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, a parent or a spouse would. If it matters how children feel about their functioning rather than how they are functioning, measuring health status alone does not provide all relevant information. Clearly, the TACQOL allows for a reliable and valid measurement of Health-Related Quality of Life, intrinsically subjective as the concept of Health-Related Quality of Life may be.

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Appendices

Appendix I

Explanation of the SPSS code calculating TACQOL scale scores

The variable names assigned to the scales are: BODY, MOTOR, AUTO, COGNIT, SOCIAL, EMOPOS, EMONEG.

The syntax presented on the next page, is also included on the CD-ROM. In order to use the SPSS syntax it is essential that the following assumptions regarding coding and variable names be met:

1) Variables should be named and scored according to the instructions in this manual and the syntax supplied on the CD Rom.

2) Missing answers should be coded as 9, as this is the missing assigned value supposed by the syntax.

The syntax in which combination items are created and scale scores are calculated proves to be difficult for many users. Therefore a short explanation is given below. Users are strongly suggested to consult their SPSS manual on the DO REPEAT statement, with which manipulation on series of variables can be performed, without the necessity to repeat all statements for each variable separately.

Table 1 Explanation of syntax used to create combination items and to calculate scale scores

SPSS statement	**Explanation**
count ni=k29 k30 k31 k32 k33 k34 k35 k36 (missing).	Count number of missing functional items
do repeat f1=k29 k30 k31 k32 k33 k34 k35 k36	Start do repeat manipulations; F1 is assigned the value of the functional complaint
/f2=kr29 kr30 kr31 kr32 kr33 kr34 kr35 kr36	F2 is assigned the value of the emotional reaction
/f3= kc1 kc2 kc3 kc4 kc5 kc6 kc7 kc8	F3 is assigned the value of the combination items; as they do not yet exist the kc1 … kc8 variables are created when the syntax is run.
/f4=r1 to r8.	F4 is assigned the value of r1 … r8; as they do not yet existed they are created on the run; r1 to r8 are temporary variables, to store the value of the emotional reaction and then being recoded.
compute f4=f2.	Store the value of the emotional reaction in r1 .. r8.
compute f3=1.	Assign the standard value of 1 to the combination item,

SPSS statement	Explanation
if missing(f1) f3=0.	But change into 0, when functional complaint is missing
if any(f1,2,3) f3=2.	And change into 2 when there is a complaint (sometimes or often)
if missing(f4) f4=1.	Recode the temporary variable with the value of the emotional reaction into 1, when missing (meaning: no negative reaction is assumed)
compute f3=f3+(f4-1).	Then ad the value of r1 .. r8 minus 1 to the combination item
compute ccog=ccog+f3.	And add the combination item to the variable storing the scale score.
end repeat.	End of the repeating statements.
if (ni>2) ccog=99.	If more than 25% of items is missing, scale score is assigned 99, already defined as missing.
if (ni<3) ccog=40-8*ccog/(8-ni).	If less then 25% is missing, scale score is adapted to no of valid answers and transformed with 0 indicating minimal HRQoL and 32 indicating maximal HRQoL
freq/var=ccog.	
Missing values kc1 kc2 kc3 kc4 kc5 kc6 kc7 kc8 (0).	In combination items, o is defined as missing.

Appendix II

SPSS code calculating TACQOL scores

```
**
** Computation TACQOL CF 8-11 scales
**

*************************************************************************************************************
**
This syntax will work properly only if all variables have been named according to the
names in the de_tacqol_CF 6-11.sav file and if missing answers have been coded with a 9 or as
sysmis.
*************************************************************************************************************
**

*************************************************************************************************************
**
Those interested in comparing children between 6 to 11 and children between 12 and 15 or those
interesting children through the age range from 6 till 15 are advised to use the syntax file CF 12 -
15_scales.sps.
That syntax computes different scale scores which are found applicable among the younger children
as well.
*************************************************************************************************************
**

*************************************************************************************************************
**
NB: adapt the path in the following line to where you saved your de_tacqol_CF 6-11.sav file.
*************************************************************************************************************
**

get file = "d:\dat\nkvl\de_tacqol_CF 6-11.sav".


**Initialize scale values

compute cbod = 0.
compute cmot = 0.
compute caut = 0.
compute ccog = 0.
compute csoc = 0.
compute cpos = 0.
compute cneg = 0.
missing values cbod to cneg (99).

** Initialize temporary variables r1 to r8

compute r1=0.
compute r2=0.
compute r3=0.
compute r4=0.
compute r5=0.
compute r6=0.
compute r7=0.
compute r8=0.

execute.


**
** cbod
**
```

```
count ni = k1 k2 k3 k4 k5 k6 k7 k8 (missing).
do repeat  f1 = k1 k2 k3 k4 k5 k6 k7 k8
          /f2 = kr1 kr2 kr3 kr4 kr5 kr6 kr7 kr8
          /f3 = kb1 kb2 kb3 kb4 kb5 kb6 kb7 kb8
          /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute cbod =  cbod+f3.
end repeat.
if (ni>2) cbod =  99.
if (ni<3) cbod = 40-8*cbod/(8-ni).
freq/var =  cbod.
missing values kb1 kb2 kb3 kb4 kb5 kb6 kb7 kb8(0).
execute.

**
** cmot
**

count ni =  k11 k12 k13 k14 k15 k16 k17 k18 (missing).
do repeat  f1 =  k11 k12 k13 k14 k15 k16 k17 k18
          /f2 =  kr11 kr12 kr13 kr14 kr15 kr16 kr17 kr18
          /f3 =  km1 km2 km3 km4 km5 km6 km7 km8
          /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute cmot =  cmot+f3.
end repeat.
if (ni>2) cmot =  99.
if (ni<3) cmot = 40-8*cmot/(8-ni).
freq/var =  cmot.
missing values km1 km2 km3 km4 km5 km6 km7 km8 (0).
execute.

**
** caut
**

count ni =  k20 k21 k22 k23 k24 k25 k26 k27 (missing).
do repeat  f1 =  k20 k21 k22 k23 k24 k25 k26 k27
          /f2 =  kr20 kr21 kr22 kr23 kr24 kr25 kr26 kr27
          /f3 =  kz1 kz2 kz3 kz4 kz5 kz6 kz7 kz8
          /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute caut =  caut+f3.
end repeat.
if (ni>2) caut =  99.
```

```
if (ni<3) caut = 40-8*caut/(8-ni).
freq/var =  caut.
missing values kz1 kz2 kz3 kz4 kz5 kz6 kz7 kz8(0).
execute.

**
** ccog
**

count ni =  k29 k30 k31 k32 k33 k34 k35 k36 (missing).
do repeat  f1 =  k29 k30 k31 k32 k33 k34 k35 k36
         /f2 =  kr29 kr30 kr31 kr32 kr33 kr34 kr35 kr36
         /f3 =  kc1 kc2 kc3 kc4 kc5 kc6 kc7 kc8
         /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute ccog =  ccog+f3.
end repeat.
if (ni>2) ccog =  99.
if (ni<3) ccog = 40-8*ccog/(8-ni).
freq/var =  ccog.
missing values kc1 kc2 kc3 kc4 kc5 kc6 kc7 kc8 (0).
execute.

**
** csoc
**

count ni =  k38 k39 k40 k41 k42 k43 k44 k45 (missing).
do repeat  f1 =  k38 k39 k40 k41 k42 k43 k44 k45
         /f2 =  kr38 kr39 kr40 kr41 kr42 kr43 kr44 kr45
         /f3 =  ks1 ks2 ks3 ks4 ks5 ks6 ks7 ks8
         /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute csoc =  csoc+f3.
end repeat.
if (ni>2) csoc =  99.
if (ni<3) csoc = 40-8*csoc/(8-ni).
freq/var =  csoc.
missing values ks1 ks2 ks3 ks4 ks5 ks6 ks7 ks8 (0).
execute.

**
** cpos
**

count ni =  k47 k49 k51 k53 k55 k57 k59 k61 (missing).
do repeat f1 =  k47 k49 k51 k53 k55 k57 k59 k61.
if not missing(f1) cpos =  cpos+f1.
end repeat.
```

```
if ni < 3 cpos =  8*cpos/(8-ni)-8.
if ni > 2 cpos =  99.
freq/var =  cpos.

**
** cneg
**

count ni =  k48 k50 k52 k54 k56 k58 k60 k62 (missing).
do repeat f1 =   k48 k50 k52 k54 k56 k58 k60 k62.
if not missing(f1) cneg =  cneg+f1.
end repeat.
if ni < 3 cneg =  24-8*cneg/(8-ni).
if ni > 2 cneg =  99.

freq/var =  cneg.
```

```
**
** Computation TACQOL PF 6-11 scales
**

*************************************************************************************************************
**This syntax will work properly only if all variables have been named according to the names in the
de_tacqol_CF 6-11.sav file and if missing answers have been coded with a 9 or as sysmis.
*************************************************************************************************************
**

*************************************************************************************************************
**
NB: Adapt the path in the following line to where you saved your de_tacqol_PF 6-11.sav file.
*************************************************************************************************************
**


get file = "d:\dat\nkvl\de_tacqol_PF6-11.sav".


**Initialize scale values

compute pbod = 0.
compute pmot = 0.
compute paut = 0.
compute pcog = 0.
compute psoc = 0.
compute ppos = 0.
compute pneg = 0.
missing values pbod to pneg (99).

** Initialize temporary variables r1 to r8

compute r1=0.
compute r2=0.
compute r3=0.
compute r4=0.
compute r5=0.
compute r6=0.
compute r7=0.
compute r8=0.

execute.


**
** pbod
**

count ni = o1 o2 o3 o4 o5 o6 o7 o8 (missing).
do repeat  f1 = o1 o2 o3 o4 o5 o6 o7 o8
        /f2 = or1 or2 or3 or4 or5 or6 or7 or8
        /f3 = ob1 ob2 ob3 ob4 ob5 ob6 ob7 ob8
        /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
```

```
compute f3 =  f3+(f4-1).
compute pbod =  pbod+f3.
end repeat.
if (ni>2) pbod =  99.
if (ni<3) pbod = 40-8*pbod/(8-ni).
freq/var =  pbod.
missing values ob1 ob2 ob3 ob4 ob5 ob6 ob7 ob8(0).
execute.

**
** pmot
**

count ni =  o11 o12 o13 o14 o15 o16 o17 o18 (missing).
do repeat  f1 =  o11 o12 o13 o14 o15 o16 o17 o18
        /f2 =  or11 or12 or13 or14 or15 or16 or17 or18
        /f3 =  om1 om2 om3 om4 om5 om6 om7 om8
        /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute pmot =  pmot+f3.
end repeat.
if (ni>2) pmot =  99.
if (ni<3) pmot = 40-8*pmot/(8-ni).
freq/var =  pmot.
missing values om1 om2 om3 om4 om5 om6 om7 om8 (0).
execute.

**
** paut
**

count ni =  o20 o21 o22 o23 o24 o25 o26 o27 (missing).
do repeat  f1 =  o20 o21 o22 o23 o24 o25 o26 o27
        /f2 =  or20 or21 or22 or23 or24 or25 or26 or27
        /f3 =  oz1 oz2 oz3 oz4 oz5 oz6 oz7 oz8
        /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute paut =  paut+f3.
end repeat.
if (ni>2) paut =  99.
if (ni<3) paut = 40-8*paut/(8-ni).
freq/var =  paut.
missing values oz1 oz2 oz3 oz4 oz5 oz6 oz7 oz8 (0).
execute.

**
** pcog
**

count ni =  o29 o30 o31 o32 o33 o34 o35 o36 (missing).
```

```
do repeat  f1 =  o29 o30 o31 o32 o33 o34 o35 o36
         /f2 =  or29 or30 or31 or32 or33 or34 or35 or36
         /f3 =  oc1 oc2 oc3 oc4 oc5 oc6 oc7 oc8
         /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute pcog =  pcog+f3.
end repeat.
if (ni>2) pcog =  99.
if (ni<3) pcog = 40-8*pcog/(8-ni).
freq/var =  pcog.
missing values oc1 oc2 oc3 oc4 oc5 oc6 oc7 oc8 (0).

**
** psoc
**

count ni =  o38 o39 o40 o41 o42 o43 o44 o45 (missing).
do repeat  f1 =  o38 o39 o40 o41 o42 o43 o44 o45
         /f2 =  or38 or39 or40 or41 or42 or43 or44 or45
         /f3 =  os1 os2 os3 os4 os5 os6 os7 os8
         /f4 = r1 to r8.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3) f3 =  2.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute psoc =  psoc+f3.
end repeat.
if (ni>2) psoc =  99.
if (ni<3) psoc = 40-8*psoc/(8-ni).
freq/var =  psoc.
missing values os1 os2 os3 os4 os5 os6 os7 os8 (0).
execute.

**
** ppos
**

count ni =  o47 o49 o51 o53 o55 o57 o59 o61 (missing).
do repeat f1 =  o47 o49 o51 o53 o55 o57 o59 o61.
if not missing(f1) ppos =  ppos+f1.
end repeat.

if ni < 3 ppos =  8*ppos/(8-ni)-8.
if ni > 2 ppos =  99.
freq/var =  ppos.

**
** pneg
**

count ni =  o48 o50 o52 o54 o56 o58 o60 o62 (missing).
do repeat f1 =   o48 o50 o52 o54 o56 o58 o60 o62.
if not missing(f1) pneg =  pneg+f1.
```

```
end repeat.
if ni < 3 pneg =  24-8*pneg/(8-ni).
if ni > 2 pneg =  99.
freq/var =  pneg.
```

Appendix III

Sample Characteristics of the Reference Study

Characteristic	Category	Boys	Girls	Total
		%	%	%
total		50	50	100
Age group	6/7 years	37	37	37
	8/9 years	30	30	30
	10/11 years	33	33	33
Legal status parents	married	93	93	93
	divorced	5	4	4
	one parent family	2	3	3
Father born in	Netherlands	92	91	91
	Surinam	1	1	1
	Dutch Antilles	1	1	1
	Turkey	1	2	2
	Morocco	1	1	1
	Other	4	4	4
Highest education father	Primary or less	7	6	6
	Secundary, lower vocational	19	24	22
	Secundary, general, medium level	14	13	14
	Secondary, general high level / pre-academic	7	10	9
	Post secundary education	46	40	43
Mother born in	Netherlands	92	93	92
	Surinam	2	1	2
	Dutch Antilles	0	1	1
	Turkey	1	2	1
	Morocco	1	1	1
	Other	4	3	4
Highest education mother	Primary or less	6	6	6
	Secundary, lower vocational	22	21	22
	Secundary, general, medium level	20	25	23
	Secondary, general high level / pre-academic	13	14	14
	Post secundary education	39	33	36

Due to the stratified sample, the boy / girl ratio in the sample is 50/50. In the Dutch population aged 5-14, this ratio is 51/49 [29]. The distribution by age in the population shows a overrepresentation of the youngest group and a under-representation of the second category, when compared to the distribution in the same age population (34% / 33% / 33%, for boys and girls [29]).

The authors do not know national figures of legal status of parents, which are truly comparable. As for country of birth of parents, in a representative survey[6, 27] among pupils aged 12-18 in Dutch secondary education, parents of 18% of the pupils were not born in the Netherlands. As the percentage of children from ethnic minorities is increasing, the percentage in age group 6-11 may be assumed to be higher. So, with 8%, children from ethnic minorities in the study sample are clearly underrepresented. Also, the level of education in the study is less then that in the survey mentioned. However, for parents born in the Netherlands, educational level is similar.

Appendix IV

Frequency distribution (categorised) TACQOL–PF and CF Scales

Table V.1 Percentages of categorised TACQOL-PF scale scores Boys, aged 6-7

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage									
	0-15	1%	1%	0%	0%	0%	0-5	0%	1%
	16-19	3%	0%	0%	3%	0%	6-7	1%	4%
	20-23	8%	1%	1%	6%	3%	8-9	4%	21%
	24-27	24%	6%	5%	17%	7%	10-11	1%	26%
	28,29	22%	6%	7%	14%	14%	12-13	7%	29%
	30,31	21%	22%	23%	20%	45%	14-15	29%	18%
	32	20%	65%	64%	40%	30%	16	59%	2%
	n=	287	287	287	287	287		287	287

Table V.2 Percentages of categorised TACQOL-PF scale scores; Boys, aged 8 - 9

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage									
	0-15	0%	0%	0%	0%	0%	0-5	0%	3%
	16-19	2%	0%	0%	3%	0%	6-7	1%	3%
	20-23	11%	4%	0%	9%	3%	8-9	4%	16%
	24-27	29%	4%	4%	19%	15%	10-11	2%	28%
	28,29	19%	4%	8%	14%	20%	12-13	9%	33%
	30,31	21%	26%	17%	26%	34%	14-15	32%	14%
	32	17%	62%	70%	29%	28%	16	52%	4%
	n=	247	247	247	247	247		247	247

Table V.3 Percentages of categorised TACQOL-PF scale scores; Boys, aged 10/11

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage									
	0-15	0%	0%	0%	1%	0%	0-5	0%	1%
	16-19	6%	1%	0%	4%	1%	6-7	1%	3%
	20-23	11%	1%	1%	5%	2%	8-9	5%	13%
	24-27	25%	6%	2%	17%	13%	10-11	6%	24%
	28,29	21%	8%	3%	13%	17%	12-13	8%	32%
	30,31	18%	25%	11%	24%	35%	14-15	27%	22%
	32	19%	60%	84%	37%	33%	16	53%	5%
	n=	273	273	273	273	273		273	273

Table V.4 Percentages of categorised TACQOL-CF scale scores, Boys, aged 8 - 9

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage	0-15	4%	1%	0%	0%	0%	0-5	1%	2%
	16-19	8%	1%	0%	3%	1%	6-7	3%	7%
	20-23	23%	3%	2%	7%	2%	8-9	5%	16%
	24-27	26%	11%	3%	15%	13%	10-11	10%	21%
	28,29	17%	11%	6%	26%	17%	12-13	25%	25%
	30,31	14%	32%	20%	25%	33%	14-15	31%	21%
	32	9%	42%	69%	24%	33%	16	26%	7%
	n=	240	240	240	240	240		240	240

Table V.5 Percentages of categorised TACQOL-CF scale scores; Boys, aged 10/11

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage	0-15	4%	1%	0%	1%	0%	0-5	0%	2%
	16-19	10%	0%	0%	2%	0%	6-7	3%	3%
	20-23	18%	3%	0%	7%	2%	8-9	5%	17%
	24-27	28%	9%	2%	23%	11%	10-11	10%	23%
	28,29	16%	11%	4%	15%	20%	12-13	21%	25%
	30,31	13%	30%	14%	25%	35%	14-15	33%	25%
	32	11%	45%	80%	28%	32%	16	29%	5%
	n=	273	273	273	273	273		273	283

Table V.6 Percentages of categorised TACQOL-PF scale scores; Girls, aged 6 till 7

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage									
	0-15	1%	0%	0%	0%	0%	0-5	0%	1%
	16-19	2%	0%	0%	1%	0%	6-7	0%	2%
	20-23	12%	1%	0%	1%	1%	8-9	2%	10%
	24-27	27%	6%	4%	13%	6%	10-11	2%	32%
	28,29	25%	5%	8%	12%	15%	12-13	5%	36%
	30,31	21%	14%	19%	20%	41%	14-15	30%	16%
	32	12%	74%	69%	53%	37%	16	62%	3%
	n=	270	270	270	270	270		270	270

Table V.7 Percentages of categorised TACQOL-PF scale scores; Girls, aged 8 till 9

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage									
	0-15	1%	1%	0%	1%	0%	0-5	0%	0%
	16-19	3%	1%	0%	4%	0%	6-7	1%	3%
	20-23	15%	2%	1%	5%	2%	8-9	4%	17%
	24-27	32%	2%	3%	22%	9%	10-11	3%	29%
	28,29	20%	10%	5%	15%	19%	12-13	9%	30%
	30,31	17%	24%	18%	20%	39%	14-15	30%	17%
	32	12%	60%	74%	34%	32%	16	55%	4%
	n=	259	259	259	259	259		259	259

Table V.8 Percentages of categorised TACQOL-PF scale scores; Girls, aged 10 till 11

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage									
	0-15	1%	0%	0%	0%	0%	0-5	0%	1%
	16-19	3%	2%	0%	4%	1%	6-7	1%	4%
	20-23	15%	1%	1%	7%	3%	8-9	5%	14%
	24-27	35%	6%	2%	19%	7%	10-11	3%	30%
	28,29	18%	12%	3%	13%	22%	12-13	10%	28%
	30,31	18%	19%	16%	21%	37%	14-15	27%	21%
	32	12%	60%	78%	37%	31%	16	54%	3%
	n=	278	278	278	278	278		278	278

Table V.9 Percentages of categorised TACQOL-CF scale scores; Girls, aged 8 till 9

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage	0-15	6%	1%	1%	1%	0%	0-5	0%	2%
	16-19	10%	2%	0%	5%	1%	6-7	2%	5%
	20-23	19%	4%	2%	8%	3%	8-9	8%	16%
	24-27	26%	10%	4%	15%	13%	10-11	8%	28%
	28,29	15%	10%	7%	21%	15%	12-13	23%	24%
	30,31	14%	25%	17%	19%	35%	14-15	34%	21%
	32	9%	48%	69%	31%	33%	16	25%	5%
	n=	242	242	242	242	242		242	242

Table V.10 Percentages of categorised TACQOL-CF scale scores; Girls, aged 10 till 11

	Cat. of Scores	BODY	MOTOR	AUTO	COGNIT	SOCIAL	Cat. of Scores	EMOPOS	EMONEG
Percentage	0-15	5%	1%	0%	0%	0%	0-5	0%	1%
	16-19	11%	0%	0%	3%	1%	6-7	3%	5%
	20-23	20%	5%	0%	6%	2%	8-9	4%	13%
	24-27	29%	9%	3%	18%	12%	10-11	10%	25%
	28,29	14%	18%	4%	17%	20%	12-13	18%	27%
	30,31	12%	25%	17%	25%	28%	14-15	28%	23%
	32	9%	42%	75%	30%	38%	16	38%	6%
	n=	277	277	277	277	277		277	277