TNO Prevention and Health

Child Health Division Schipholweg 77-89 P.O. Box 3005 2301 DA Leiden The Netherlands

www.tno.nl

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TACQOL CF 12-15 Manual

Developed by Leiden Center for Child Health and Pediatrics LUMC-TNO

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Authors T. Vogels

J.Bruil H. Koopman M. Fekkes G.H.W. Verrips

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Introduction

This document, serves as a short manual for the TACQOL CF 12-15 (TNO-AZL Child Quality of Life Questionnaire Child Form for children aged 11 till 15). See "TACQOL Manual Parent Form and Child Form 6-11 years" for more detailed information of the development of the TACQOL.

The manual is intended to be used in conjunction with the reference data and data entry forms.

This manual describes the TACQOL CF 12-15 questionnaire and the concepts it wants to measure. It provides information on psychometric properties and instructs users on how to score answers and how to handle data to enable calculation of correct scale scores. Additionally, it provides information on the reference sample.

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T. Vogels

J. Bruil

H. Koopman

M. Fekkes

G.H.W. Verrips

Contents

1	General description of the TACQOL CF 12-15	4
2	Items of the TACQOL CF 12-15	5
3	Scales structure of the TACQOL CF 12-15	6
4	Psychometric properties of the TACQOL CF 12-15	7
5	Naming variables, scoring items and calculating scale scores	11
6	Reference data	14
7	Publications on the TACOOL CF 12 15	15

1 General description of the TACQOL CF 12-15

The TNO-AZL Child Quality of Life Questionnaire Child Form for children aged between 12 and 15 (TACQOL CF 12-15) measures the child's perception of his or her health-related quality of life. The questionnaire was constructed to enable a systematic, valid and reliable description of Health-related Quality of Life. Health-related Quality of Life, as assessed by the TACQOL CF 12-15, was defined as children's health status, weighted by the emotional response of the children themselves to their health status problems. Consequently, the TACQOL CF 12-15 assesses functional problems weighted by the degree to which a child experiences negative emotions to such problems. The TACQOL CF 12-15 can be used to evaluate the impact of illness and treatments on the different domains of young children's lives. The questionnaire is meant for children between 12 and 15 years of age.

Administration of the questionnaire takes approximately 10 minutes.

A more detailed description of the concepts measured and the development of the questionnaire can be found in the manual for the TACQOL 6-11 (Vogels et al, 2000),-

The TACQOL CF 12-15 is derived from the TACQOL CF 8-11. This last questionnaire was originally meant to cover the age range from 8 till 15. However scale structure and reliability proved less satisfactory for the older children between 12 and 15. Therefore, it was decided to adapt the scale structure for the older children, by removing some items from the original Social scale and one scale in its totality (Autonomy). Consult Chapter 3 and 4 for more information.

When comparing with children younger than 12 or when following children during the age range 8 to 15, it is recommended to use the adapted scale structure as presented in this manual. This adapted scale structure was proven to be satisfactory for the younger children as well as for the older children. To facilitate using the instrument in this way, it was decided to keep the original format of the questionnaire. This way the same questionnaire can be administered among all children in the age range between 8 and 15. It is up to the researcher to decide which scale structure – and which syntax and reference data can best be used.

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

It is strongly suggested not to use the TACQOL CF 12-15 for individual diagnostics, e.g. for individual testing or screening. The psychometric properties of the questionnaire do not allow the instrument to be used for decision making on an individual level.

2 Items of the TACQOL CF 12-15

To assess HRQoL as conceptualized, most items consist of two sub questions; the first one assesses the existence of a complaint or functional limitation; the second one assesses the child's reactions to such problems or limitations (see Table 1). The scoring system will be described in paragraph 6.

Table 1	Exam	ple of	an item	in the	TACC	OOL	CF	12-15

Pain and symptoms in Try to remember how you					
Have you had earaches	□never	□ occasionally	□often		
or sore throats?					
1		At that time, I	felt: □ notso good	□ quitebad	_l □bad

3 Scales structure of the TACQOL CF 12-15

The TACQOL CF 12-15 is a multidimensional instrument. The paper form consists of 56 items, 44 of which are actually used for the construction of 7 scales. The domains covered by the TACQOL are based on a review of the literature, discussions with experts (child psychologists, pediatricians, and parents) and statistical testing. Table 2 presents the TACQOL CF 12-15 scales. These scales result in a (group) profile. As HRQoL is defined as a multidimensional construct, no total score is calculated.

Table 2 TACOOL CF 12-15 scales and matching items.

Scale	Description	Items	Variable name in
			data entry and
			syntax files
Body *	Measures pain and physical complaints	1 – 8	Cbod
Motor *	Measures locomotor functioning	11-18	Cmot
Cognition *	Measures in cognitive functioning	29-36	Ccog
Peers **	Measures interaction with peers	38-41	Cpeer
Emopos *	Measures the experience of positive emtions	47 49 51 53 55 57 59 61	Cpos
Emoneg *	Measures the experience of negative emtions	48 50 52 54 56 58 60 62	Cneg

^{*}Identical to the correspon-ding TACQOL CF 8-11 scale

^{**} Derived from the TACQOL CF 8-11 Social scale, items referring to parents excluded

4 Psychometric properties of the TACQOL CF 12-15

Psychometric properties of the TACQOL CF 12-15 scales were evaluated using data from the sample from the general population as described in chapter 7. To assess whether the structure found would hold in a sample in which chronic conditions were more prevalent, additional analyses were done on data from a national cohort containing nearly all fourteen years old survivors of children who were born preterm or with a very low birth weight in the Netherlands in 1983. This is the so called POPS-cohort, the Project on Preterm and Small for gestational age children¹.

First aim of the analysis was to check whether the scales and scale structure as defined on the basis of TACQOL CF and PF data, collected among 6-11 year old children², could be replicated in the older sample from the general population.

Six of the original scales could be replicated without any difficulty in this older age group. Two scales, however, could not. The original scale Autonomy could not be replicated with satisfactory reliability and proved to be not independent from the Motor scale. The original scale Social also showed insufficient reliability. The items concerning peer relations however proved to be a reliable subscale, as they were in the younger sample. Similar results were obtained from the analyses using the data from the POPS cohort. It was therefore decided to delete the Autonomy scale from the scale structure for the 12 till 15 age group and to replace the original Social scale with a new scale Peers. This scale consists of only 4 items, whereas the other scales are calculated on the basis of 8 items. Peers scale scores, however, are transformed, so that range, minimum and maximum of this scale are identical to those of the other scales.

In Table 3 the Cronbach's alphas of the TACQOL CF 12-15 scales (calculated on the combination items, when applicable) are presented for the general population sample and for the POPS-cohort.

Table 3 Cronbach's alpha of the TACQOL CF 12-15 scales for general population sample.

Scale	Number	Cronbach's Alpha	Cronbach's Alpha
	of items	General population sample	General population sample
		N = 340	N = 775
Body	8	.74	.77
Motor	8	.73	.80
Cognition	8	.75	.79
Peers	4	.73	.67
Emopos	8	.82	.85
Emoneg	8	.73	.76

¹ Hille ET, den Ouden AL, Saigal S, Wolke D, Lambert M, Whitaker A, Pinto-Martin JA, Hoult L, Meyer R, Feldman JF, Verloove-Vanhorick SP, Paneth N, Behavioural problems in children who weigh 1000 g or less at birth in four countries. Lancet. 2001 May 26;357(9269):1641-3.

² Vogels T, Verrips GHW, Koopman HM, Theunissen NCM, Fekkes M, Kamphuis RP. TACQOL Manual Parent and Child Form, Leiden Center for Child Health and Paediatrics LUMC-TNO. 2000

On average, reliability of the TACQOL CF 12-15 scales in the general population sample was good, with Cronbach's alpha coefficients varying from .73 to .82. In the POPS sample reliability for the Peers scale is somewhat lower than in the general population; all other coefficients were higher.

This scale structure was tested by Principal Component Analyses, with VARIMAX Rotation and a given number of components to be extracted: one analysis was run for the combination-items for the scales Body, Motor, Cognition, Peers and one for the items for EMOPS and EMONEG. These two analyses were done separately, because no independence of the EMOPOS and EMONEG scales from the other scales was assumed. All items, except one, fulfilled the criteria specified: a loading of at least .40 on the presupposed factor and no higher loading on other factors than the presupposed factor. The offending items was KM8 (doing things handily) which loaded higher on Cognition.

In the POPS sample, the scales Body and Motor were less independent from each other, with 3 items from the Motor scales (no. 6, 7 and 8) showing higher loadings (> .50) on the Body scale than on the Motor scale.

Tabel 4 presents the product moment correlation coefficients between the scales. Maximum shared variance between scales was found for Body and Cognition and between Body and Motor. No scales, however, share more than 25% of their variance.

Table 4 Inter-scale correlations (Spearman) of the TACQOL CF 12-15 scales for the general population sample (N=340) and POPS sample (n=775).

Scale	Body	Motor	Cognition	Peers	Emopos
General Population					
Motor	.41				
Cognition	.44	.39			
Peers	.17	.25	.25		
Emopos	.29	.24	.32	.33	
Emoneg	.39	.29	.41	.27	.36
POPS					
Motor	.35				
Cognition	.48	.31			
Peers	.20	.22	.28		
Emopos	.34	.25	.41	.38	
Emoneg	.42	.30	.42	.31	.40

The results <u>from</u> the principal component analysis and the correlation coefficients on the data from the general population support the scale structure and confirm the multi-dimensional definition of HRQoL. The results in the POPS sample, however, show that the scales in samples with more chronic conditions, may be interrelated. This is not unexpected and may be explained by some conditions affecting more than one domain simultaneously.

Criterion validity was evaluated by relating health criteria to the TACQOL CF 12-15 scales (see Table 5). The following health criteria were used: a self_-reported chronic illness (last year), a common disease (like the flue) in the last four weeks and having undergone any medical treatment in the last 6 months. In all comparisons, less optimal health was related to a significantly lower score on most of the TACQOL CF 12-15 scales. These results demonstrate that the TACQOL CF 12-15 scales can detect differences between healthy and less healthy children.

Table 5 Mean TACQOL CF 12-15 scale scores for children with vs without chronic condition, common illness and medical treatment from the general population sample; standard deviation and significance of T-test for differences of means. Higher scores indicate better Health-Related Quality of Life

of Life		N	Mean	Std. Deviation	Significance
	Chronic Illness?				
CBOD	No	984	24.16	5.17	<.001
	Yes	336	21.97	5.83	
CMOT	No	986	30.13	2.84	<.001
	Yes	337	28.64	4.15	
CCOG	No	987	27.78	4.01	<.01
	Yes	337	26.96	4.41	
CPEER	No	986	31.17	2.71	n.s.
	Yes	337	30.79	3.53	
CPOS	No	978	13.15	2.72	<.001
	Yes	338	12.54	3.07	
CNEG	No	977	11.80	2.50	<.001
	Yes	338	11.01	2.72	
	Common disease?				
CBOD	No	824	24.80	4.97	<.001
	Yes	496	21.61	5.58	
CMOT	No	826	30.07	3.07	<.001
	Yes	497	29.22	3.57	
CCOG	No	826	27.89	3.98	<.001
	Yes	498	27.04	4.31	
CPEER	No	826	31.15	2.88	n.s.
	Yes	497	30.95	3.05	
CPOS	No	819	13.14	2.79	<.05
	Yes	497	12.76	2.86	
CNEG	No	819	11.84	2.54	<.001
	Yes	496	11.20	2.61	
	Medical treatment?				
CBOD	No	887	24.36	5.10	<.001
	Yes	433	22.04	5.76	
CMOT	No	891	30.19	2.71	<.001
	Yes	432	28.86	4.10	
CCOG	No	891	27.80	3.95	<.01
	Yes	433	27.10	4.44	
CPEER	No	890	31.18	2.78	n.s.
	Yes	433	30.86	3.25	
CPOS	No	887	13.18	2.72	<.001
	Yes	429	12.61	2.99	
CNEG	No	886	11.81	2.47	<.001
	Yes	429	11.16	2.75	

A second test of the criterion-validity was done by comparing handicapped and/or disabled children from the POPS-sample to children without handicap or disability from the same sample. Assessment of handicaps and disability was done on age 5 by pediatrics. The results are shown in table 6. Again, most scales showed significant differences, in the expected direction.

Table 6 Mean TACQOL CF 12-15 scale scores for children with vs without handicap/disability in the POPS sample, standard deviation and significance of T-test of for differences of means (p). Higher scores indicate better Health-Related Quality of Life

	Handicapped/ disabled?	N	Mean	Std. Deviation	Significance
CBOD	No	600	26.8	4.6	n.s.
	Yes	179	26.8	4.3	
CMOT	No	600	30.5	3.0	<.01
	Yes	177	29.6	3.8	
CCOG	No	600	29.0	3.5	<.001
	Yes	179	27.3	4.6	
CPEER	No	600	31.3	2.3	<.001
	Yes	178	30.2	4.0	
CPOS	No	599	14.2	2.5	<.001
	Yes	179	13.1	3.2	
CNEG	No	599	12.7	2.5	<.01
	Yes	179	12.0	2.9	

5 Naming variables, scoring items and calculating scale scores

When a TACQOL CF 12-15 data file is to be created, items should be named and scored as indicated in Table 7. Missing answers should be coded as 9 or sysmis. Deviation from these guidelines will probably result in errors in the calculation of scale scores

For most scales, items consist of two questions. In these items, the frequency of a specific complaint or limitation is first recorded. In Table 2 this is called the "1st part". If such a problem is reported, the well being of the child in relation to this problem is assessed. In Table 7 this is called the "2nd part".

The variable names of the combinations of the first and second part of the items, as calculated in the Syntax are also presented in table 2.

After data-entry and scoring of the items according to table 7, scale scores can be calculated. To this end, the SPSS –TACQOL CF 12-15 syntax file can be used. With this syntax scale scores are computed, with higher scores indicating a better quality of life

Table 7 Variable names and scoring of all TACQOL CF 12-15 items for data-entry and SPSS

Item Var. name nr: 1 st part		Scoring 1 st part	Var. name 2 nd part	2 nd part	Var. name Combination
		Missing answers: 9 or sysmis		Missing answers: 9 or sysmis	
1	K1	never=1, occasionally=2, often=3	KR1	fine=1, not so good=2, quite bad=3, bad=4	Kk1
2	K2	never=1, occasionally=2, often=3	KR2	fine=1, not so good=2, quite bad=3, bad=4	Kk2
3	КЗ	never=1, occasionally=2, often=3	KR3	fine=1, not so good=2, quite bad=3, bad=4	Kk3
4	K4	never=1, occasionally=2, often=3	KR4	fine=1, not so good=2, quite bad=3, bad=4	Kk4
5	K5	never=1, occasionally=2, often=3	KR5	fine=1, not so good=2, quite bad=3, bad=4	Kk5
6	K6	never=1, occasionally=2, often=3	KR6	fine=1, not so good=2, quite bad=3, bad=4	Kk6
7	K7	never=1, occasionally=2, often=3	KR7	fine=1, not so good=2, quite bad=3, bad=4	Kk7
8	K8	never=1, occasionally=2, often=3	KR8	fine=1, not so good=2, quite bad=3, bad=4	Kk8
9	К9	never=1, occasionally=2, often=3	KR9	fine=1, not so good=2, quite bad=3, bad=4	
10	K10	Open question, no label			
11	K11	never=1, occasionally=2, often=3	KR11	fine=1, not so good=2, quite bad=3, bad=4	Km1
12	K12	never=1, occasionally=2, often=3	KR12	fine=1, not so good=2, quite bad=3, bad=4	Km2
13	K13	never=1, occasionally=2, often=3	KR13	fine=1, not so good=2, quite bad=3, bad=4	Km3
14	K14	never=1, occasionally=2, often=3	KR14	fine=1, not so good=2, quite bad=3, bad=4	Km4
15	K15	never=1, occasionally=2, often=3	KR15	fine=1, not so good=2, quite bad=3, bad=4	Km5
16	K16	never=1, occasionally=2, often=3	KR16	fine=1, not so good=2, quite bad=3, bad=4	Km6
17	K17	never=1, occasionally=2, often=3	KR17	fine=1, not so good=2, quite bad=3, bad=4	Km7
18	K18	never=1, occasionally=2, often=3	KR18	fine=1, not so good=2, quite bad=3, bad=4	Km8
19	K19	Open question, no label			
20	K20	never=1, occasionally=2, often=3	KR20	fine=1, not so good=2, quite bad=3, bad=4	
21	K21	never=1, occasionally=2, often=3	KR21	fine=1, not so good=2, quite bad=3, bad=4	

Item	Var. name	Scoring	Var. name	2 nd part	Var. name
nr:	1 st part	1 st part	2 nd part		Combination
					*
22	K22	never=1, occasionally=2, often=3	KR22	fine=1, not so good=2, quite bad=3, bad=4	
23	K23	never=1, occasionally=2, often=3	KR23	fine=1, not so good=2, quite bad=3, bad=4	
24	K24	never=1, occasionally=2, often=3	KR24	fine=1, not so good=2, quite bad=3, bad=4	
25	K25	never=1, occasionally=2, often=3	KR25	fine=1, not so good=2, quite bad=3, bad=4	
26	K26	never=1, occasionally=2, often=3	KR26	fine=1, not so good=2, quite bad=3, bad=4	
27	K27	never=1, occasionally=2, often=3	KR27	fine=1, not so good=2, quite bad=3, bad=4	
28	K28	Open question, no label			
29	K29	never=1, occasionally=2, often=3	KR29	fine=1, not so good=2, quite bad=3, bad=4	Kc1
30	K30	never=1, occasionally=2, often=3	KR30	fine=1, not so good=2, quite bad=3, bad=4	Kc2
31	K31	never=1, occasionally=2, often=3	KR31	fine=1, not so good=2, quite bad=3, bad=4	Kc3
32	K32	never=1, occasionally=2, often=3	KR32	fine=1, not so good=2, quite bad=3, bad=4	Kc4
33	K33	never=1, occasionally=2, often=3	KR33	fine=1, not so good=2, quite bad=3, bad=4	Kc5
34	K34	never=1, occasionally=2, often=3	KR34	fine=1, not so good=2, quite bad=3, bad=4	Kc6
35	K35	never=1, occasionally=2, often=3	KR35	fine=1, not so good=2, quite bad=3, bad=4	Kc7
36	K36	never=1, occasionally=2, often=3	KR36	fine=1, not so good=2, quite bad=3, bad=4	Kc8
37	K37	Open question, no label			
38	K38	never=1, occasionally=2, often=3	KR38	fine=1, not so good=2, quite bad=3, bad=4	Ks1
39	K39	never=1, occasionally=2, often=3	KR39	fine=1, not so good=2, quite bad=3, bad=4	Ks2
40	K40	never=1, occasionally=2, often=3	KR40	fine=1, not so good=2, quite bad=3, bad=4	Ks3
41	K41	never=1, occasionally=2, often=3	KR41	fine=1, not so good=2, quite bad=3, bad=4	Ks4
42	K42	never=1, occasionally=2, often=3	KR42	fine=1, not so good=2, quite bad=3, bad=4	
43	K43	never=1, occasionally=2, often=3	KR43	fine=1, not so good=2, quite bad=3, bad=4	
44	K44	never=1, occasionally=2, often=3	KR43	fine=1, not so good=2, quite bad=3, bad=4	
45	K45	never=1, occasionally=2, often=3	KR43	fine=1, not so good=2, quite bad=3, bad=4	
46	K46	Open question, no label			
47	K47	never=1, occasionally=2, often=3			Not appl.
48	K48	never=1, occasionally=2, often=3			Not appl.
49	K49	never=1, occasionally=2, often=3			Not appl.
50	K50	never=1, occasionally=2, often=3			Not appl.
51	K51	never=1, occasionally=2, often=3			Not appl.
52	K52	never=1, occasionally=2, often=3			Not appl.
53	K53	never=1, occasionally=2, often=3			Not appl.
54	K54	never=1, occasionally=2, often=3			Not appl.
55	K55	never=1, occasionally=2, often=3			Not appl.
56	K56	never=1, occasionally=2, often=3			Not appl.
57	K57	never=1, occasionally=2, often=3			Not appl.
58	K58	never=1, occasionally=2, often=3			Not appl.
59	K59	never=1, occasionally=2, often=3			Not appl.
60	K60	never=1, occasionally=2, often=3			Not appl.
61	K61	never=1, occasionally=2, often=3			Not appl.
62	K62	never=1, occasionally=2, often=3			Not appl.
63	K63	Open question, no label			1

^{*} When empty: not used in scale construction; Not appl.: scale scores not based on combined items.

In paragraphs 2 and 7 the items and their scoring system are described. However, scale scores, for all scales except CPOS and CBEG, are not based on the original questions, but on the combination of the first en second part of the items. Table 8 presents the scoring system of these combination items.

Items on a scale are summed; then scale scores are linearly transformed with 0 indicating minimal HRQoL and 32 indicating maximal HRQoL.

Table 8 Example of an item in the TACOOL CF 12-15

Pain and symptoms i	n recent weeks			
Try to remember how you				
Have you had earaches or sore throats?	□never □occasionally 1	√ □ often		ı
1	At that time,	I felt:		-
	□ fine 2	\Box not so good 3	□ quite bad 4	□ bad 5

Figure 2. Scoring system of combination-items, used in calculating scale scores

6 Reference data

Reference Data were collected with the help of the Leiden University Medical Center, the Amsterdam Academic Medical Center and 8 regional Centers for Preventive Youth Health Care (Jeugdgezondheidszorg) all over the Netherlands. The Centers for Preventive Youth Health Care were asked to take a random, stratified sample of 212 children aged 12 till 15 from their registries; equally distributed over two age groups (12/13 and 14/15) and within each age group a 50 / 50 ratio between boys and girls.

Questionnaires were sent to the adolescents, accompanied by an introductory letter stressing the right not to participate. If necessary, a reminder was sent after three weeks. Respondents received a small present as an incentive for their participation. Total response was 78%. The mean age of the resulting sample was 14.0 years old (range 12-15 years), and 52.4% were girls (47.6% boys). The majority (95.2%) of the subjects was born in the Netherlands, as were their mothers (88%) and fathers (88%). Twenty-one percent of adolescents reported a chronic health condition. The most common chronic illnesses were migraine (7.0%), asthma (5.8%), and back problems (4.8%).

7 Publications on the TACQOL CF 12 15

Verrips GHW., Vogels AGC, Den Ouden AL, Paneth N, Verloove-Vanhorick SP, Measuring Health-related quality of life in adolescents: agreement between raters and between methods of administration, Child Care Health Dev. 2000,26(6);457-69