TAAQOL Manual

Leiden Center

for

Child Health and Pediatrics LUMC-TNO

Augustus 2004

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1. Assessing Health-Related Quality of Life

1.1 The concept of Health-Related Quality of Life

Traditionally, mortality and morbidity are the most widely used measures of medical outcome. Due to improved health care and treatment these measures insufficiently capture the full impact of disease and medical interventions. Many diseases are not fatal anymore but may yet have a severe impact on a person's life. During the last decades the improved medical interventions led to a growing interest in assessing functional limitations and well being of patients with several kinds of disease after treatment. Not only medical results should be taken into account, but also the subjective evaluation of the patient should be used to reflect the impact of diseases on the lives of individuals [1,12,13,18]. Gradually, health status and quality of life are developing into standard outcome measures, in addition to mortality and morbidity.

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 [9,11,14,19]. 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 demands by significant others) and other factors (adapted homes, medical devices) are also relevant for the appraisal of functional problems an individual faces. 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) should therefore be 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 [1,3,5,6,7,11,12] HRQoL must be assumed to be a multidimensional construct, as 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 definitive 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 among individuals. 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 The TAAQOL questionnaire: general description

The TNO-AZL Questionnaire for Adult's Health-Related Quality of Life (or TAAQOL) was constructed to enable a systematic, valid and reliable description of Health-Related Quality of Life of people of 16 years and older. Health-Related Quality of Life, as assessed by the TAAQOL, is defined as a person's health status, weighted by the emotional response of the person to his/her health status problems.

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. The TAAQOL should be filled in by the respondents themselves. It takes approximately 10-20 minutes to fill in the questionnaire.

The TAAQOL is a generic instrument, measuring generic aspects of Health-Related Quality of Life (HRQoL) The benefits of a generic measure are that only one instrument is needed among distinct groups and that it allows for comparisons between groups, interventions or conditions. Furthermore, when the general functioning of the patient is being examined, then generic measures are appropriate[16].

The TAAQOL is a multidimensional instrument, with 12 scales. The domains covered by the TAAQOL are based on a review of the literature, discussions with experts (psychologists, medical specialists) and statistical testing (see chapter 2). Table 1.1 presents the TAAQOL scales. These scales result in a profile. As HRQoL is seen as a multidimensional construct, no summary score is calculated. Table 1.2 presents the TAAQOL items for each scale.

Table 1.1 TAAQOL Scales

Label	Scales	n items
Gross motor functioning	Problems /limitations concerning gross motor functioning	4
Fine Motor functioning	Problems /limitations concerning fine motor functioning	4
Cognition	Problems / limitations concerning cognitive functioning	4
Sleep	Problems / limitations concerning sleeping	4
Pain	Problems / limitations concerning pain	4
Social contacts	Problems / limitations in social contacts	4
Daily activities	Problems / limitations concerning independent daily functioning	4
Sex	Problems / limitations concerning sex	2
Vitality	The occurrence of feelings of vitality	4
Happiness	The occurrence of positive moods	4
Depressive mood	The occurrence of depressive moods	4
Anger	The occurrence of angry moods	3

The TAAQOL questionnaire is presented in Appendix I (Dutch version) and Appendix II (English version). The English version is translated according to international guidelines [14].

Table 1.2 Items of the TAAQOL (English version)

GROSS MOTOR FUNCTIONING: *Did you have …*	DAILY ACTIVITIES: *Have you …*
Difficulty walking up the stairs?	Had difficulty with work, study or other day-to-day activities?
Difficulty bending over / kneeling / stooping?	Done less work, studying or other day-to-day activities?
Difficulty walking 500 yards (a couple of streets for example)?	Had problems doing certain types of work, study or other day-to-day-activities?
Difficulty lifting (e.g. carrying shopping)?	Done work, study or other day-to-day activities less conscientiously?
FINE MOTOR FUNCTIONING: *Did you have ….*	SEXUALITY: *Have you …*
Difficulty cutting paper with scissors	Had less sex then previously?
Difficulty fastening the buttons of a blouse / shirt	Found sex less satisfying?
Difficulty opening a can	
Difficulty twisting the lid off a jar	
COGNITION: *Did it happen that …..*	VITALITY: *Did you feel…*
You had difficulty concentrating on what others said?	Energetic
You had difficulty remembering things?	Tired
You had difficulty thinking in a concentrated way?	Fit
Your mind wandered?	Exhausted quickly
SLEEP*: Did it happen that ….*	HAPPINESS: *Did you feel…*
You had difficulty getting to sleep?	Joyful
You slept restlessly	Cheerful
You lay awake a lot at night?	In good spirits
You had a good night's sleep	Happy
PAIN*: Did your have..*	DEPRESSIVE MOODS*: Did you feel…*
Back-ache?	Sad
Pain / tension in neck or shoulders?	Worried
Pain in joints / limbs?	Gloomy
Pain in muscles?	Anxious
SOCIAL CONTACTS*: If you <u>needed it</u>, was it <u>possible</u> for you in the last month to ...*	ANGER*: Did you feel…*
Talk to others in confidence	Angry
Have a nice time with other people	Aggressive
Visit friends	Short-tempered
Have a good talk with others	

1.3 Items of the TAAQOL questionnaires

In order to assess problems and limitations weighted by the emotional response, the TAAQOL 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 (see figure 1.1). Some items, however, are positively phrased, for example 'I had a good talk with others' (see figure 1.2).

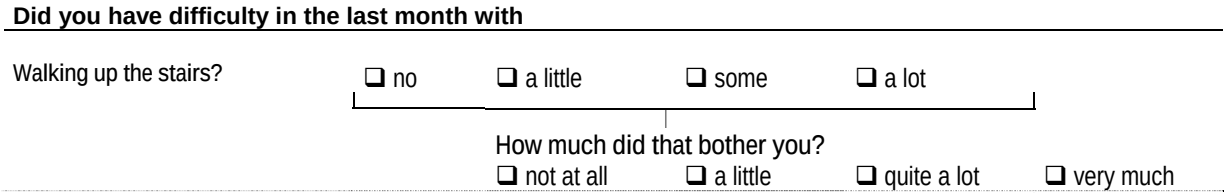

Figure 1.1 Item example (negatively phrased).

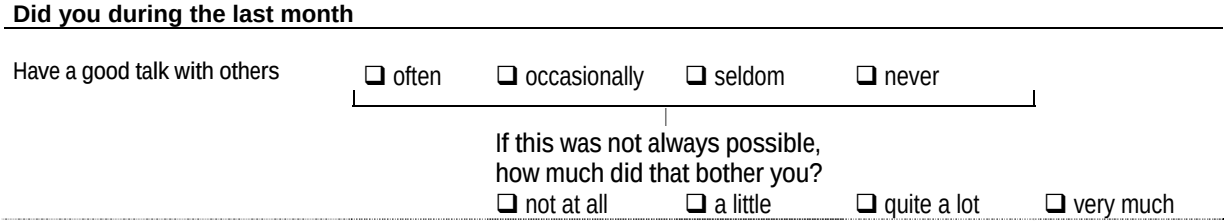

Figure 1.2 Item example (positively phrased).

2 Development and evaluation of the TAAQOL

2.1 Development of a pilot version

In 1995, TNO Prevention and Health and the Paediatric Department of the Leiden University Medical Center started the development of the TAAQOL (TNO AZL ADULT QUALITY OF LIFE)-questionnaire for the assessment of Health-Related Quality of Life in people aged 16 years and older.
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 patient him/herself. [7,8,11,15,16] It was also decided to approach Health-Related Quality of Life as a multi-dimensional concept. Existing literature and discussions with experts led us to include the following 10 domains: Gross motor functioning, Fine Motor functioning, Cognition, Sleep, Pain, Social contacts, Daily activities, Sex, Positive emotions, and Negative emotions.

An item pool was created, with a number of items for each domain, based on existing literature and discussions with experts (psychologists, clinical psychologists, medical doctors). A draft form was constructed for testing in a pilot study. This draft form included 76-items, distributed over the 10 domains.

2.2 A pilot study among a sample from the general population

In the second phase the feasibility and psychometrics of the draft version were tested in a sample aged 16 years and older from the general population. Questionnaires were mailed to a sample of 1471 Dutch households drawn at random from the national telephone registry. A total number of 561 questionnaires were filled in and returned by mail (response rate 38%).

Factor analysis with Varimax rotation, HOMALS, and Reliablity analysis (Cronbach's alpha) were used to evaluate different item and scale scoring systems and to assess the supposed scale structure. In general, the theoretical scale structure was reflected in the data. Reliability analyses led to reduction of the number of items to a final number of 45 items. Factor analysis indicated that the Positive Emotions scale had to be split into a Vitality scale and a Happiness scale, and the Negative Emotions scale had to be split in a Depressive moods scale and an Anger scale. Consequently, the final TAAQOL comprises 12 scales.

2.3 A Reference Study in two samples from the general population

2.3.1 Sample 1

After completion of the pilot study, a new study was started, collecting TAAQOL data from a random sample of Dutch people aged 16 years and older in the general population. The aim of the study was twofold:

a reassessment of the psychometric quality of the TAAQOL,

b (if the first aim was achieved:) collecting reference data in order to enable comparison of TAAQOL data of chronically ill or severely ill patients with those of a reference group.

Questionnaires were mailed to a sample of Dutch households drawn at random from the national telephone registry. As compared to the total adult population in the Netherlands, the national telephone registry includes a somewhat larger percentage of men, and a smaller percentage of individuals in the category 16 to 25 years. In an effort to correct this imbalance, the introductory letter stated that the questionnaire could be completed by any adult member of the household, and a random subset of the introductory letter requested that, if possible, the questionnaire be completed by a member of the household between the ages 15 and 25. Non-respondents were sent a reminder, 2 months and 3 months after the initial mailing.

The survey instrument included the TAAQOL, the SF36[2] and one scale of the Hopkins Symptom Checklist [10,15] (i.e. the scale "psychological functioning"). Respondents were asked to report their age, gender, marital status, education, and ethnicity, and asked to report if they suffered from any of 15 chronic health conditions indicated in a list and use of medical treatment.

A total number of 2800 households were included in the survey. A total of 1771 questionnaires (response rate 63%) were returned.

2.3.2 Sample 2

In addition to sample 1 a second set of data was used for the reassessment of psychometric properties, and the collection of reference data. As part of a study on the HRQoL of patients with multiple sclerosis, a reference group from the general population was included. A random sample of 6.000 Dutch households, drawn at random from the national telephone registry, were sent a questionnaire including the TAAQOL. Respondents were asked to report their age, gender, marital status, education and asked to report if they suffered from any of 15 chronic health conditions indicated in a list and use of medical treatment. Two thirds of the households in the random sample received a letter which stated that the questionnaire preferably should be completed by a woman. The other third of the households received a letter which stated that preferably a man should complete the

questionnaire. This approach was adopted so as to replicate the gender-ratio for MS patients (male : female, 1 : 2) encountered in the sample from the general population.

A total number of 6.000 households were included in the survey. A total of 2.681 questionnaires (response rate 45%) were returned.

2.3.3 Combined total Sample

The TAAQOL scores from sample 1 did not differ significantly from the TAAQOL scores of sample 2. Therefore both samples are combined into one sample. This sample includes a total number of 4.452 respondents, 42 respondents were not included in the analyses because they were younger than 16 years (n=7) or age was missing (n=35). The final sample thus included 4.410 respondents (45% men, 54% women). Age and gender should be included in the analyses as these variables have significant effects on scale scores.

Appendix IV presents some demographic characteristics of the final sample.

2.3.4 Analyses

After data entry, several analyses were done to evaluate the psychometric properties of the final version. The results are presented in chapter 3:

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)[17]. 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 if 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).

b The viability of treating the scale scores (based on the combined-item 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* 3.1.2).

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; 3.2.2; 3.2.3).

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 as distinguished from the concept of health status was assessed by exploring the occurrence of health status problems with and without negative emotional reactions (*cf* 3.3.1).

f Convergent validity was assessed by calculating correlation coefficients with the Dutch versions of the SF-36 and with the "Psychological complaints-scale" of the Hopkins Symptom Checklist (HSCL)([23]), indicating psychological problems (*cf* 3.3.2).

g Criterion validity was assessed by testing the differences in scales scores of people with and without chronic conditions and those who visited a doctor versus those who did not during the last 6 months (*cf* 3.3.3).

3 Psychometric evaluation of the TAAQOL

3.1 Evaluation of the scoring system

3.1.1 Scoring of items

Our definition of HRQoL implies that a single score is 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.

A score of 5 is given when there is no limitation, a score of 4 when there is a limitation (i.e. a little, some, a lot) but when the person is not bothered by the limitation; a score of 3 when there is a limitation and the person is a "a little" bothered, a score of 2 when there is a limitation and the person is "quite a lot" bothered and a score of 1 when there is a limitation and the person is "very much" bothered. This encoding of the scores allows for a weighting of functional problems by their emotional impact (see also the Tacqol manual 6-11, T. Vogels, G.H.W. Verrips, H.M. Koopman, N.C.M. Theunissen, M. Fekkes, R.P. Kamphuis, 1999; par. 3.1.1).

Did you have difficulty in the last month in

Walking up the stairs?	❑ no (5)	❑ a little	❑ some	❑ a lot	
		How much did that bother you?			
		❑ not at all (4)	❑ a little (3)	❑ quite a lot (2)	❑ very much (1)

1 For data-entry values see table 4.1. *These scores will be automatically assigned when the SPSS syntax for calculating the TAAQOL scale-scores, is used. This syntax is described in Appendix 3 and included as file on the CD-rom.*

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In the scales measuring vitality, positive moods, depressive moods and anger, the items measure only the frequency of a specific complaint or limitation during the last month. The items in these domains do not ask for how much the person is bothered, because items in these domains already imply a positive or negative emotional state. In these scales, the scores range from 1 to 4.

In the last month, did you feel ...

Energetic	❑ no (4)	❑ a little (3)	❑ quite (2)	❑ very (1)

1 For data-entry values see table 4.1. *These scores will be automatically assigned when the SPSS syntax for calculating the TAAQOL scale-scores, is used. This syntax is described in Appendix 3 and included as file on the CD-rom.*

To check the assumed ordinality of these scores, a series of homogeneity analyses (HOMALS[17]) was performed, using the categories of the scoring system described above. 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 homogeneity analysis the data were treated as nominal. 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.

Only 4 (1%) of the calculated distances (390) between 2 combined-item scores showed a violation of the assumed ordinality, mainly in the scale measuring pain. These results are very satisfactory.

3.1.2 Calculation of scale scores HOMALS

The TAAQOL contains twelve scales. Crude scale scores are linearly transformed to a 0-100 scale with higher scores indicating better functioning. 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 behavioral 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 TAAQOL 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 are of interval level by definition, based as they are on the calculated Euclidean distances of item categories. Product moment correlation coefficients were calculated between the TAAQOL scale scores and the object quantifications, resulting from the homogeneity analyses. The results are presented in Table 3.1. The figures presented are based on respondents with valid scale-scores on all items of the scale. Correlation coefficients vary between 0.88 and 0.99. TAAQOL 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 3.1 Correlation coefficients (R) between the summed item pair scores and the HOMALS category quantifications

	R	N
Gross motor functioning	.97	4279
Fine Motor functioning	.99	4331
Cognition	.96	4343
Sleep	.92	4321
Pain	.87	4313
Social contacts	1.00	4245
Daily activities	.91	4187
Sex	.96	3829
Vitality	.99	4129
Happiness	.97	4199
Depressive mood	.99	4215
Anger	.99	4234

3.1.3 Missing scale scores

In the calculation of the scale scores one missing combined-item score per scale is allowed for. A missing item score is 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. Less then 3% of all scale scores were missing. The one exception is the scale sexuality with a high number of missing sores. Especially in the older age group these questions might be either too personal, or less relevant.

Table 3.2 Missing scale scores on the TAAQOL by gender and age group

Gender	Men								Women							
Age group	16-25	26-35	36-45	46-55	56-65	66-75	76-85	Total	16-25	26-35	36-45	46-55	56-65	66-75	76-85	Total
Gross motor functioning	0%	1%	1%	1%	2%	2%	4%	1%	1%	1%	1%	1%	3%	8%	9%	2%
Fine Motor functioning	0%	1%	1%	1%	2%	1%	5%	1%	1%	1%	1%	1%	1%	2%	4%	1%
Cognition	0%	1%	0%	1%	1%	1%	1%	1%	1%	1%	1%	0%	2%	1%	7%	1%
Sleep	0%	1%	0%	1%	1%	1%	1%	1%	1%	1%	1%	1%	2%	3%	6%	1%
Pain	0%	0%	0%	1%	1%	2%	5%	1%	1%	1%	1%	1%	1%	3%	6%	1%
Social contacts	1%	0%	1%	1%	2%	5%	8%	2%	1%	1%	1%	1%	2%	5%	7%	2%
Daily activities	1%	0%	1%	1%	2%	10%	11%	2%	1%	1%	2%	3%	4%	13%	22%	4%
Sex	3%	1%	3%	3%	7%	16%	38%	7%	2%	3%	5%	14%	28%	57%	66%	17%
Vitality	1%	1%	1%	1%	3%	6%	7%	2%	1%	1%	2%	3%	10%	11%	17%	5%
Happiness	2%	1%	1%	1%	3%	4%	7%	2%	1%	1%	2%	3%	9%	11%	17%	5%
Depressive mood	1%	1%	1%	1%	2%	4%	5%	2%	1%	1%	2%	2%	9%	10%	15%	4%
Anger	2%	2%	1%	1%	3%	6%	8%	3%	1%	1%	3%	2%	9%	12%	19%	5%
N resp with > 0 missing	6	14	23	22	55	64	34	218	10	29	40	81	112	144	86	502
	5%	4%	6%	6%	15%	24%	46%	11%	4%	5%	8%	20%	37%	61%	73%	21%
N respondents	115	359	395	396	364	262	74	1965	237	554	498	414	303	235	118	2359

3.2 Evaluating the scale structure

3.2.1 Factor structure of the TAAQOL items

In order to investigate the factor structure of the TAAQOL, a principal component analysis with varimax rotation was done on the combined-item scores. The number of scales (12) (par 2.2) was given as a criterion to determine the number of factors to be extracted.

The analysis resulted in a solution explaining 71% of the variance. Table 3.3 presents the factor loadings of the varimax rotated factors of the TAAQOL. The solution reflects the supposed scale structure very well. Factor loadings were rather high, varying between .56 and .87. All 45 items show a higher loading on their own factor than on any of the other factors.

Table 3.3 Factor loadings of TAAQOL combined-item scores on varimax rotated principal components (n = 4410)

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	Factor 9	Factor 10	Factor 11	Factor 12
Gross motor 1	0,07	0,11	0,17	0,10	0,14	**0,79**	0,09	0,06	0,15	0,15	0,03	0,09
Gross motor 2	0,06	0,08	0,12	0,16	0,10	**0,75**	0,08	0,03	0,34	0,08	0,03	0,06
Gross motor 3	0,05	0,08	0,25	0,04	0,15	**0,77**	0,12	0,07	0,02	0,15	0,01	0,06
Gross motor 4	0,06	0,11	0,28	0,06	0,22	**0,59**	0,04	0,08	0,35	0,14	0,02	0,00
Fine motor 1	0,01	0,05	**0,82**	0,02	0,07	0,08	0,06	0,01	0,06	0,06	0,04	0,04
Fine motor 2	0,05	0,04	**0,80**	0,08	0,11	0,17	0,04	0,02	0,03	0,03	0,06	0,04
Fine motor 3	0,03	0,05	**0,83**	0,05	0,09	0,15	0,09	0,09	0,13	0,06	0,02	-0,01
Fine motor 4	0,06	0,12	**0,73**	0,11	0,07	0,17	0,06	0,05	0,17	0,06	0,01	0,00
Cognition 1	0,09	0,07	0,10	**0,75**	0,10	0,04	0,13	0,06	0,06	0,10	0,10	0,02
Cognition 2	0,07	0,11	0,05	**0,78**	0,08	0,14	0,07	0,06	0,13	0,08	0,05	0,08
Cognition 3	0,12	0,10	0,05	**0,82**	0,17	0,09	0,11	0,14	0,10	0,12	0,04	0,06
Cognition 4	0,14	0,17	0,08	**0,76**	0,15	0,03	0,13	0,16	0,11	0,09	0,06	0,08
Sleep 1	0,08	**0,80**	0,08	0,12	0,06	0,10	0,09	0,11	0,13	0,07	0,03	0,06
Sleep 2	0,10	**0,80**	0,06	0,11	0,09	0,06	0,09	0,15	0,16	0,11	0,07	0,02
Sleep 3	0,11	**0,83**	0,06	0,10	0,10	0,10	0,10	0,13	0,12	0,05	0,04	0,06
Sleep 4	0,12	**0,80**	0,08	0,12	0,13	0,08	0,10	0,11	0,10	0,15	0,05	0,04
Pain 1	0,01	0,11	-0,01	0,09	0,10	0,21	0,09	0,07	**0,70**	0,11	0,03	0,02
Pain 2	0,07	0,17	0,11	0,11	0,09	-0,04	0,07	0,12	**0,71**	0,19	0,03	0,05
Pain 3	0,08	0,11	0,18	0,12	0,11	0,36	0,07	0,07	**0,63**	0,02	0,06	0,01
Pain 4	0,11	0,16	0,21	0,10	0,10	0,22	0,08	0,06	**0,67**	0,09	0,06	0,07
Social 1	0,14	0,11	0,06	0,13	0,03	0,03	**0,73**	0,10	0,11	0,00	0,07	0,11
Social 2	0,30	0,11	0,09	0,11	0,12	0,09	**0,71**	0,15	0,05	0,12	0,07	0,07
Social 3	0,15	0,06	0,08	0,07	0,14	0,13	**0,76**	0,12	0,04	0,13	0,06	0,04
Social 4	0,18	0,12	0,05	0,14	0,08	0,07	**0,82**	0,11	0,10	0,07	0,08	0,11
Daily 1	0,15	0,10	0,10	0,17	**0,72**	0,10	0,09	0,16	0,14	0,21	0,08	0,01
Daily 2	0,12	0,11	0,10	0,10	**0,79**	0,16	0,11	0,10	0,07	0,14	0,03	0,12
Daily 3	0,14	0,10	0,14	0,10	**0,77**	0,21	0,08	0,14	0,17	0,12	0,04	0,08
Daily 4	0,11	0,12	0,09	0,18	**0,74**	0,09	0,12	0,16	0,06	0,12	0,09	0,12
Sex 1	0,12	0,08	0,02	0,10	0,16	0,08	0,13	0,10	0,05	0,08	0,06	**0,87**
Sex 2	0,12	0,09	0,05	0,11	0,11	0,09	0,17	0,14	0,07	0,06	0,04	**0,86**
Vitality 1	0,41	0,09	0,05	0,15	0,17	0,13	0,08	0,00	0,12	**0,67**	0,02	0,03
Vitality 2	0,08	0,19	0,11	0,14	0,21	0,10	0,11	0,24	0,16	**0,71**	0,07	0,06
Vitality 3	0,39	0,14	0,06	0,13	0,19	0,17	0,08	0,04	0,19	**0,69**	0,03	0,07
Vitality 4	0,08	0,13	0,13	0,15	0,19	0,29	0,15	0,21	0,13	**0,65**	0,07	0,09
Depressive 1	0,32	0,19	0,08	0,10	0,18	0,05	0,15	**0,65**	0,04	0,08	0,09	0,10
Depressive 2	0,06	0,13	0,03	0,10	0,07	0,08	0,10	**0,71**	0,13	0,09	0,12	0,09
Depressive 3	0,37	0,14	0,05	0,16	0,18	0,02	0,17	**0,62**	0,04	0,13	0,20	0,05
Depressive 4	0,15	0,14	0,05	0,11	0,15	0,09	0,13	**0,66**	0,09	0,09	0,07	0,07
Happiness 1	**0,80**	0,07	0,03	0,10	0,10	0,05	0,19	0,15	0,05	0,14	0,05	0,03
Happiness 2	**0,78**	0,08	0,02	0,12	0,12	0,04	0,17	0,20	0,08	0,18	0,06	0,03
Happiness 3	**0,76**	0,13	0,06	0,09	0,09	0,05	0,17	0,14	0,05	0,09	0,06	0,13
Happiness 4	**0,82**	0,10	0,05	0,10	0,12	0,06	0,19	0,14	0,07	0,11	0,05	0,08
Anger 1	0,12	0,10	0,02	0,06	0,15	-0,03	0,06	0,45	0,09	0,08	**0,56**	0,02
Anger 2	0,08	0,04	0,07	0,10	0,08	0,01	0,10	0,14	0,06	0,03	**0,83**	0,05
Anger 3	0,05	0,06	0,03	0,08	0,02	0,06	0,07	0,07	0,03	0,04	**0,86**	0,04
% EXPL. VAR	8%	7%	7%	7%	7%	6%	6%	6%	6%	5%	4%	4%

3.2.2 Item scale correlation coefficients

A second evaluation of the supposed scale structure was done by calculating the product moment correlation coefficients between the combined item scores and the scale scores. When calculating correlation coefficients of items with the scale to which they belong, the common 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). In Table 3.4 the results are being presented.

In the TAAQOL, only one item violated the assumption that the corrected item-own scale correlation coefficient should be higher than the remaining item-scale correlation coefficients: ANGER1 shows a slightly higher correlation coefficient with DEPRESSIVENESS. Corrected correlation coefficients were rather high, varying between .50 and .82.

Tables 3.4 TAAQOL: Item – scale and corrected item – scale (bold) correlation coefficients (n = 4410)

	Gross motor	Fine Motor	Cognition	Sleep	Pain	Social	Daily	Sex	Vitality	Depressive	Happiness	Anger
Gross motor 1	**0,77**	0,44	0,31	0,30	0,46	0,29	0,42	0,25	0,46	0,26	0,24	0,13
Gross motor 2	**0,75**	0,42	0,34	0,30	0,55	0,29	0,40	0,23	0,43	0,26	0,22	0,13
Gross motor 3	**0,71**	0,47	0,25	0,26	0,38	0,28	0,41	0,22	0,43	0,24	0,21	0,10
Gross motor 4	**0,70**	0,50	0,29	0,32	0,56	0,28	0,47	0,19	0,46	0,28	0,23	0,14
Fine motor 1	0,39	**0,68**	0,20	0,19	0,28	0,22	0,28	0,13	0,24	0,18	0,14	0,11
Fine motor 2	0,44	**0,69**	0,26	0,21	0,31	0,24	0,32	0,14	0,27	0,22	0,18	0,12
Fine motor 3	0,47	**0,79**	0,25	0,25	0,36	0,27	0,33	0,12	0,29	0,24	0,18	0,14
Fine motor 4	0,48	**0,71**	0,29	0,29	0,40	0,27	0,33	0,14	0,32	0,24	0,20	0,11
Cognition 1	0,25	0,24	**0,64**	0,26	0,27	0,31	0,33	0,21	0,35	0,29	0,28	0,23
Cognition 2	0,33	0,27	**0,70**	0,30	0,35	0,29	0,33	0,24	0,37	0,30	0,26	0,21
Cognition 3	0,31	0,26	**0,79**	0,32	0,33	0,35	0,41	0,26	0,42	0,38	0,32	0,23
Cognition 4	0,28	0,25	**0,73**	0,35	0,34	0,36	0,39	0,27	0,40	0,40	0,33	0,26
Sleep 1	0,31	0,25	0,31	**0,75**	0,38	0,30	0,31	0,22	0,35	0,37	0,27	0,19
Sleep 2	0,28	0,22	0,32	**0,77**	0,39	0,31	0,33	0,21	0,37	0,41	0,30	0,23
Sleep 3	0,30	0,26	0,32	**0,80**	0,39	0,33	0,33	0,24	0,35	0,40	0,31	0,21
Sleep 4	0,31	0,27	0,33	**0,76**	0,38	0,33	0,36	0,24	0,41	0,40	0,33	0,21
Pain 1	0,43	0,23	0,26	0,30	**0,55**	0,24	0,31	0,17	0,35	0,24	0,17	0,15
Pain 2	0,32	0,26	0,29	0,35	**0,54**	0,26	0,30	0,18	0,37	0,30	0,23	0,19
Pain 3	0,55	0,40	0,32	0,35	**0,62**	0,28	0,38	0,18	0,39	0,29	0,23	0,16
Pain 4	0,49	0,39	0,32	0,37	**0,64**	0,29	0,36	0,21	0,41	0,30	0,25	0,18
Social 1	0,22	0,21	0,29	0,29	0,27	**0,62**	0,25	0,28	0,27	0,34	0,35	0,21
Social 2	0,29	0,26	0,34	0,32	0,29	**0,71**	0,36	0,30	0,40	0,43	0,50	0,24
Social 3	0,30	0,25	0,30	0,27	0,28	**0,66**	0,36	0,27	0,36	0,37	0,40	0,21
Social 4	0,29	0,25	0,36	0,34	0,32	**0,77**	0,33	0,31	0,35	0,40	0,43	0,24
Daily 1	0,42	0,32	0,39	0,33	0,39	0,33	**0,72**	0,26	0,51	0,43	0,35	0,26
Daily 2	0,42	0,30	0,33	0,31	0,34	0,33	**0,74**	0,31	0,47	0,38	0,32	0,20
Daily 3	0,49	0,35	0,36	0,34	0,42	0,34	**0,78**	0,30	0,50	0,41	0,35	0,23
Daily 4	0,38	0,31	0,39	0,33	0,33	0,35	**0,71**	0,31	0,46	0,42	0,33	0,26
Sex 1	0,23	0,14	0,27	0,23	0,21	0,31	0,33	**0,72**	0,29	0,31	0,27	0,20
Sex 2	0,25	0,16	0,28	0,25	0,23	0,34	0,31	**0,72**	0,29	0,33	0,29	0,19
Vitality 1	0,36	0,22	0,35	0,29	0,33	0,31	0,41	0,22	**0,67**	0,34	0,53	0,16
Vitality 2	0,41	0,30	0,39	0,40	0,43	0,34	0,49	0,26	**0,68**	0,45	0,38	0,26
Vitality 3	0,43	0,27	0,37	0,36	0,43	0,35	0,48	0,27	**0,75**	0,40	0,54	0,20
Vitality 4	0,53	0,34	0,41	0,37	0,45	0,38	0,51	0,30	**0,68**	0,44	0,38	0,25
Depressive 1	0,26	0,25	0,33	0,40	0,29	0,41	0,41	0,31	0,42	**0,64**	0,52	0,38
Depressive 2	0,21	0,19	0,28	0,32	0,28	0,30	0,31	0,25	0,32	**0,55**	0,30	0,36
Depressive 3	0,23	0,20	0,38	0,37	0,28	0,43	0,42	0,30	0,45	**0,67**	0,56	0,46
Depressive 4	0,25	0,21	0,31	0,34	0,29	0,33	0,37	0,26	0,37	**0,58**	0,36	0,34
Happiness 1	0,22	0,16	0,29	0,28	0,23	0,43	0,33	0,25	0,47	0,47	**0,77**	0,23
Happiness 2	0,24	0,18	0,32	0,31	0,27	0,45	0,37	0,25	0,51	0,51	**0,78**	0,26
Happiness 3	0,24	0,20	0,30	0,32	0,24	0,43	0,33	0,29	0,44	0,45	**0,73**	0,24
Happiness 4	0,24	0,19	0,30	0,31	0,26	0,45	0,36	0,27	0,47	0,47	**0,82**	0,24
Anger 1	0,12	0,12	0,22	0,25	0,20	0,25	0,29	0,18	0,26	0,51	0,29	**0,50**
Anger 2	0,13	0,14	0,24	0,17	0,18	0,23	0,22	0,17	0,20	0,36	0,22	**0,61**
Anger 3	0,12	0,10	0,20	0,15	0,14	0,18	0,15	0,14	0,17	0,29	0,15	**0,56**

3.2.3 Intercorrelations between the scales

Table 3.5 shows the intercorrelations of the subscales.

Table 3.5 Intercorrelations of the subscales of the TAAQOL (n=4410)

	Gross motor	Fine Motor	Cognition	Sleep	Pain	Social	Daily	Sex	Vitality	Depressive	Happiness
FINE MOTOR	0,53										
COGNITION	0,35	0,30									
SLEEP	0,34	0,29	0,37								
PAIN	0,58	0,41	0,38	0,44							
SOCIAL	0,33	0,29	0,39	0,36	0,35						
DAILY	0,50	0,37	0,43	0,38	0,43	0,39					
SEX	0,26	0,16	0,29	0,26	0,23	0,35	0,35				
VITALITY	0,52	0,34	0,46	0,42	0,49	0,42	0,57	0,32			
DEPRESSIVE	0,30	0,27	0,41	0,45	0,36	0,46	0,48	0,35	0,49		
HAPPINESS	0,27	0,21	0,35	0,35	0,28	0,50	0,40	0,31	0,54	0,54	
ANGER	0,15	0,14	0,27	0,24	0,22	0,28	0,28	0,21	0,26	0,49	0,28

On the TAAQOL some subscales have moderate intercorrelation (>.50): GROSS MOTOR and FINE MOTOR; GROSS MOTOR and PAIN; GROSS MOTOR and VITALITY; VITALITY and DAILY ACTIVITIES; HAPPINESS and VITALITY; DEPRESSIVENESS and VITALITY, implying a maximum percentage of shared variance of 34%, indicating uniqueness of the separate scales.

3.2.4 Reliability of the TAAQOL scales

Table 3.6 presents Cronbach's α for the TAAQOL scale scores.

Table 3.6 Cronbach's α of the TAAQOL scales (n=4410)

	Cronbach's α
GROSS MOTOR	.88
FINE MOTOR	.85
COGNITION	.86
SLEEP	.90
PAIN	.78
SOCIAL	.85
DAILY	.88
SEX	.84
VITALITY	.85
DEPRESSIVE	.79
HAPPINESS	.90
ANGER	.72

Cronbach's α varies between 0.72 and 0.90, levels which are deemed sufficient to justify the use of the TAAQOL for studies on groups of patients[3, 14]. 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 TAAQOL scales, should be treated cautiously as possible indicators of change, and 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 TAAQOL 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 3.7 presents the resulting figures.

Table 3.7 Total numbers of problems and numbers of problems with negative emotional reactions , for the TAAQOL scales

	Number of problems	Number of problems with negative emotional reaction	% problems with negative emotional reaction of total number of problems
GROSS MOTOR	4417	3260	74%
FINE MOTOR	1550	995	64%
COGNITION	6135	3842	63%
SLEEP	9130	5853	64%
PAIN	8784	6295	72%
SOCIAL	7304	2666	37%
DAILY	4974	3656	74%
SEX	2346	1480	63%
Total	44640	28047	63%
	N=4410		

Respondents reported a total of 44640 functional problems. However, respondents reported for only 63% of these problems a negative emotional impact on their well-being. Clearly, respondents distinguished between functional problems as such and functional problems with a negative emotional impact. The results in Table 3.7 also indicate that less optimal functioning in some scales has a much higher negative emotional impact then in other scales. For example limitations indicated on items of the scales motor functioning, pain, and daily functioning have a much higher negative emotional impact then limitations indicated on the scale social functioning

3.3.2 Convergent validity: the relationship between the SF-36, HSCL and TAAQOL scales

In order to assess the convergent validity of the TAAQOL, the relationship with the SF-36 and the HSCL-Psychological complaints scales was investigated. The SF-36 has 8 scales (Physical function, Role physical, Bodily pain, General health, Vitality, Social function, Role emotional and Mental health). For the original version, satisfactory psychometric performance was reported [2]. The Hopkins Symptom Checklist (HSCL), a 57-item measure, provides an assessment of psychological and physical discomfort [10],[15]. Apart from an overall scale, two subscales can be derived from this measure, the 'somatic complaints' subscale and the 'psychological complaints' subscale. The last scale is used to assess convergent validity with the TAAQOL subscales on the emotional domain. The 17-item 'psychological complaints'-subscale aims to measure psychological and neurotic complaints such as unpleasant thoughts, outbursts of anger, worrying, and despair.

The Pearson product moment correlation coefficients between the TAAQOL and the SF-36 scales are presented in table 3.8.

Table 3.8 Pearson product moment correlation coefficients between TAAQOL and SF-36 and HSCL- scales (n = 1742)

** Those relationships that we expected are bold.

TAAQOL scales	Gross motor	Fine Motor	Cognition	Sleep	Pain	Social	Daily	Sex	Vitality	Depressive	Happiness	Anger
SF36												
Physical function	**0,83**	0,52	0,37	0,34	0,53	0,39	0,46	0,25	0,58	0,34	0,30	0,16
Role physical	0,56	0,38	0,39	0,36	0,46	0,37	**0,65**	0,31	0,62	0,45	0,38	0,23
Bodily pain	0,59	0,37	0,29	0,38	**0,65**	0,32	0,47	0,22	0,52	0,38	0,31	0,22
General health	0,56	0,41	0,41	0,40	0,50	0,40	0,47	0,30	0,62	0,42	0,41	0,22
Vitality	0,49	0,34	0,48	0,47	0,47	0,47	0,55	0,32	**0,81**	0,55	0,57	0,31
Social function	0,45	0,35	0,39	0,41	0,41	**0,45**	0,56	0,30	0,56	0,56	0,47	0,32
Role emotional	0,25	0,22	0,38	0,34	0,26	0,37	**0,49**	0,26	0,43	0,55	0,42	0,32
Mental health	0,32	0,27	0,46	0,50	0,40	0,52	0,49	0,32	0,57	**0,74**	**0,67**	0,38
HSCL												
Psychological function	0,31	0,30	0,59	0,46	0,40	0,53	0,51	0,30	0,54	**0,70**	**0,53**	0,49

The hypothesized relationships between TAAQOL and SF36/HSCL scales (printed bold) are in general higher than other correlations, indicating convergent validity. The correlation coefficient between TAAQOL GROSS MOTOR and the SF-36 PHYSICAL FUNCTION is high (0.83). These scales are clearly related to each other. However, most scales from the TAAQOL and corresponding SF-36 scales have a correlation coefficient of 0.45 to 0.83 (shared variance = 20% to 69%) indicating both a shared similarity as well as a distinction between the scales.

3.3.3 Criterion validity: effects of chronic illnesses, medical treatment

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 TAAQOL was able to detect such differences, the relationship between TAAQOL scores and two health indicators was assessed:

- Self-reported chronic conditions or diseases, such as allergies, asthma, epilepsy, rheumatism, diabetes and heart conditions. (Table 3.9)
- Self-reported medical consultation in the past six months (consulted a GP or specialist), (Table 3.10)

Scale scores were corrected for age and gender since these two variables have a confounding effect on the scale-scores. A multivariate analysis of variance was conducted with age and gender as covariates

Table 3.9 Results of ANOVA of TAAQOL-scales, by self-reported chronic diseases corrected for age and gender. (n = 4410)

SCALES	Chronic disease No (n = 1918) Yes (n = 2492)	Means	95% CI lower	95% CI Upper	df	F	Prob. F
Gross motor functioning	No	92.2	90.9	93.5	4312	272.5	<.001
	Yes	81.3	80.1	82.4			
Fine Motor functioning	No	97.7	96.9	98.5	4339	75.0	<.001
	Yes	94.1	93.4	94.8			
Cognition	No	86.6	85.3	87.9	4247	93.3	<.001
	Yes	79.9	78.7	81.0			
Sleep	No	79.5	78.0	81.0	4343	134.1	<.001
	Yes	70.3	69.0	71.6			
Pain	No	80.8	79.5	82.2	4340	316.5	<.001
	Yes	68.1	66.8	69.3			
Social contacts	No	86.4	85.3	87.5	4300	55.9	<.001
	Yes	82.0	81.0	83.0			
Daily activities	No	90.3	88.9	91.7	4225	237.8	<.001
	Yes	78.5	77.2	79.8			
Sex	No	88.0	86.4	89.6	3812	62.7	<.001
	Yes	81.3	79.9	82.8			
Vitality	No	70.9	69.5	72.2	4230	274.9	<.001
	Yes	58.9	57.7	60.1			
Happiness	No	67.5	66.3	68.8	4232	55.9	<.001
	Yes	62.5	61.3	63.6			
Depressive mood	No	82.1	80.9	83.3	4254	108.5	<.001
	Yes	75.4	74.3	76.5			
Anger	No	89.8	88.8	90.8	4214	53.3	<.001
	Yes	85.9	85.0	86.8			

Table 3.10 Results of ANOVA of TAAQOL-scales, by self-reported medical consultation corrected for age and sex. (n = 1742)

SCALES	Medical consultation No (n = 699) Yes (n = 979)	Means	95% CI lower	95% CI Upper	df	F	Prob. F
Gross motor functioning	No	90.1	88.0	92.3	1641	91.1	<.001
	Yes	79.8	78.1	81.6			
Fine Motor functioning	No	96.5	95.2	97.8	1651	17.5	<.001
	Yes	93.7	92.6	94.8			
Cognition	No	85.3	83.0	87.7	1657	42.7	<.001
	Yes	77.6	75.7	79.6			
Sleep	No	78.7	76.3	81.3	1656	41.1	<.001
	Yes	70.7	68.6	72.7			
Pain	No	79.0	76.6	81.3	1655	92.6	<.001
	Yes	67.4	65.4	69.3			
Social contacts	No	85.3	83.5	87.2	1645	19.9	<.001
	Yes	81.1	79.5	82.6			
Daily activities	No	90.4	88.0	92.8	1613	110.1	<.001
	Yes	77.5	75.5	79.5			
Sex	No	90.3	87.7	92.9	1504	40.3	<.001
	Yes	81.9	79.7	84.1			
Vitality	No	70.9	68.6	73.2	1642	126.6	<.001
	Yes	57.9	56.0	59.7			
Happiness	No	67.3	65.2	69.5	1636	26.8	<.001
	Yes	61.6	59.9	63.4			
Depressive mood	No	82.5	80.5	84.5	1643	64.3	<.001
	Yes	74.4	72.7	76.0			
Anger	No	90.7	89.0	92.4	1635	41.9	<.001
	Yes	85.2	83.8	86.6			

The two health indicators show a significant relationship with all TAAQOL-scores. There are especially large effect sizes for the scales GROSS MOTOR FUNCTIONING, PAIN, SLEEP, VITALITY, and DAILY ACTIVITIES.

4. Use of the TAAQOL and CD-rom

The TAAQOL CD-rom includes all necessary files for:

1) Using the questionnaire: The CD-rom contains questionnaires in English, German and Dutch. Questionnaires are included as PDF document and can be printed from the CD-rom.

2) Data-entry: The CD-rom includes a SPSS data-entry file.("Data-entry file for TAAQOL questionnaire.sav"). Using this data-entry system allows the use of the syntax file provided to calculate scale scores. Users who want to formulate their own syntax are strongly recommended to name all variables and to score all answer categories according to Table 4.1 of this manual. Otherwise, errors resulting in non comparability are very likely

3) Computing scale-scores: The CD-rom includes a SPSS syntax-file for calculating the TAAQOL scale scores. It is advised to use this file. ("TAAQOL scale construction 45-items.sps"), as doing so reduces the risk of errors substantially.

4) Reference data: The CD-rom includes a SPSS data file with data from a reference group from the general population. ("Reference data TAAQOL 4410 persons SPSS file.sav").This data-file includes the TAAQOL scale scores and demographic characteristics of the reference sample. A (clinical) sample can be compared to the general population sample by simply merging the two data files and analyzing the scale scores. The reference group is also described in paragraph 2.3 and Appendix IV.

4.1 Data-entry, naming of variables and scoring of the items

When data are collected and one wants to create a data-file, it is important that the items are named and scored in the way as described in Table 4.1. A data-entry file is included in the CD-rom.

After data-entry and scoring of the items according to Table 4.1, scale scores can be calculated. Therefore the SPSS –TAAQOL scale core syntax file ("TAAQOL scale construction 45-items.sps") should be used. This file is included in the CD-rom. Using this syntax, scale scores will be linearly transformed to a 0-100 scale with higher scores indicating a better quality of life.

In most scales, items consist of two questions. In these items, the frequency of a specific complaint or limitation is first recorded. In Table 4.1 this is called the "first part of the item". If a problem is reported on the first question, the well being in relation to this problem is assessed. In Table 4.1 this is called the "second part of the item".

Table 4.1 Variable names and scoring of all TAAQOL items for data-entry and SPSS

Item nr:	Naming variable 1st part of item (i.e. frequency)	Scoring 1st part of item	Naming variable 2nd part of item (i.e. bothered by)	Scoring 2nd part of item
1	V1	no=1, a little=2, some=3, a lot =4	R1	not at all=1, a little=2, quite a lot=3, very much=4
2	V2	no=1, a little=2, some=3, a lot =4	R2	not at all=1, a little=2, quite a lot=3, very much=4
3	V3	no=1, a little=2, some=3, a lot =4	R3	not at all=1, a little=2, quite a lot=3, very much=4
4	V4	no=1, a little=2, some=3, a lot =4	R4	not at all=1, a little=2, quite a lot=3, very much=4
5	V5	no=1, a little=2, some=3, a lot =4	R5	not at all=1, a little=2, quite a lot=3, very much=4
6	V6	no=1, a little=2, some=3, a lot =4	R6	not at all=1, a little=2, quite a lot=3, very much=4
7	V7	no=1, a little=2, some=3, a lot =4	R7	not at all=1, a little=2, quite a lot=3, very much=4
8	V8	no=1, a little=2, some=3, a lot =4	R8	not at all=1, a little=2, quite a lot=3, very much=4
9	V9	no=1, a little=2, some=3, a lot =4	R9	not at all=1, a little=2, quite a lot=3, very much=4
10	V10	no=1, a little=2, some=3, a lot =4	R10	not at all=1, a little=2, quite a lot=3, very much=4
11	V11	no=1, a little=2, some=3, a lot =4	R11	not at all=1, a little=2, quite a lot=3, very much=4
12	V12	no=1, a little=2, some=3, a lot =4	R12	not at all=1, a little=2, quite a lot=3, very much=4
13	V13	never=1, occasionally=2, often=3, (almost) always=4	R13	not at all=1, a little=2, quite a lot=3, very much=4
14	V14	never=1, occasionally=2, often=3, (almost) always=4	R14	not at all=1, a little=2, quite a lot=3, very much=4
15	V15	never=1, occasionally=2, often=3, (almost) always=4	R15	not at all=1, a little=2, quite a lot=3, very much=4
16	V16	(almost) always=1, often=2, occasionally=3, never=4	R16	not at all=1, a little=2, quite a lot=3, very much=4
17	V17	never=1, occasionally=2, often=3, (almost) always=4	R17	not at all=1, a little=2, quite a lot=3, very much=4
18	V18	never=1, occasionally=2, often=3, (almost) always=4	R18	not at all=1, a little=2, quite a lot=3, very much=4
19	V19	never=1, occasionally=2, often=3, (almost) always=4	R19	not at all=1, a little=2, quite a lot=3, very much=4
20	V20	never=1, occasionally=2, often=3, (almost) always=4	R20	not at all=1, a little=2, quite a lot=3, very much=4
21	V21	often=1, occasionally=2, seldom=3, never=4	R21	not at all=1, a little=2, quite a lot=3, very much=4
22	V22	often=1, occasionally=2, seldom=3, never=4	R22	not at all=1, a little=2, quite a lot=3, very much=4
23	V23	often=1, occasionally=2, seldom=3, never=4	R23	not at all=1, a little=2, quite a lot=3, very much=4
24	V24	often=1, occasionally=2, seldom=3, never=4	R24	not at all=1, a little=2, quite a lot=3, very much=4
25	V25	no=1, a little=2, some=3, a lot =4	R25	not at all=1, a little=2, quite a lot=3, very much=4
26	V26	no=1, a little=2, some=3, a lot =4	R26	not at all=1, a little=2, quite a lot=3, very much=4
27	V27	no=1, a little=2, some=3, a lot =4	R27	not at all=1, a little=2, quite a lot=3, very much=4
28	V28	no=1, a little=2, some=3, a lot =4	R28	not at all=1, a little=2, quite a lot=3, very much=4
29	V29	no=1, a little=2, some=3, a lot =4	R29	not at all=1, a little=2, quite a lot=3, very much=4
30	V30	no=1, a little=2, some=3, a lot =4	R30	not at all=1, a little=2, quite a lot=3, very much=4
31	V31	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
32	V32	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
33	V33	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
34	V34	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
35	V35	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
36	V36	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
37	V37	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
38	V38	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
39	V39	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
40	V40	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
41	V41	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
42	V42	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
43	V43	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
44	V44	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)
45	V45	no=1, a little=2, quite=3, very =4	(not applicable)	(not applicable)

Caution: A missing assigned value (0, 8, or 9) should be given to all missing answers!!

4.2 Explanation of the item scoring

Eventually, after using the SPSS syntax one single score is given for each pair of items (functional item and the corresponding emotional item) and for each single item in the VITALITY, HAPPINESS, DEPRESSIVE MOODS, AND ANGER 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 ‘a little’, ‘some’ or ‘a lot’ (or: ‘occasionally’, ‘often’, or ‘always’, and in positively phrased items: ‘occasionally’, ‘seldom’ 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 VITALITY, HAPPINESS, DEPRESSIVE MOODS, AND ANGER, no emotional responses are asked. Scores attributed simply reflect the intensity of these emotions (see table 4.4).

Table 4.2 Scoring of items for the scales: GROSSMOTOR FUNCTIONING, FINE MOTOR FUNCTIONING, COGNITION, SLEEP, PAIN, DAILY ACTIVITIES, SEXUALITY. Scores are presented between brackets ( ).

Did you have difficulty in the last month with

Walking up the stairs? ❑ no (5) ❑ a little ❑ some ❑ a lot

How much did that bother you?
❑ not at all (4) ❑ a little (3) ❑ quite a lot (2) ❑ very much (1)

Note: These scores will be automatically assigned when the SPSS syntax for calculating the TAAQOL scale-scores, is used. This syntax is described in Appendix 3 and included as file on the CD-rom.

Table 4.3 Scoring of items for the scale: SOCIAL CONTACTS. Scores are presented between brackets ( ).

Have a good talk with others ❑ often (5) ❑ occasionally ❑ seldom ❑ never

If this was not always possible,
how much did that bother you?
❑ not at all (4) ❑ a little (3) ❑ quite a lot (2) ❑ very much (1)

Note: These scores will be automatically assigned when the SPSS syntax for calculating the TAAQOL scale-scores, is used. This syntax is described in Appendix 3 and included as file on the CD-rom.

Table 4.4 Scoring of items for the scales: VITALITY, HAPPINESS, DEPRESSIVE MOODS, AND ANGER. Scores are presented between brackets ( ).

Scale	Category (Score attributed)	Category (Score attributed)	Category (Score attributed)	Category (Score attributed)
VITALITY				
- Energetic	No (1)	A little (2)	quite (3)	very (4)
- Tired	No (4)	A little (3)	quite (2)	very (1)
- Fit	No (1))	A little (2	quite (3)	Very (4)
- Exhausted quickly	No (4)	A little (3)	quite (2)	Very (1)
HAPPINESS (all items)	No (1)	A little (2)	quite (3)	Very (4)
DEPRESSIVE EMOTIONS (all items)	No (4)	A little (3)	quite (2)	very (1)
ANGER (all items)	No (4)	A little (3)	quite (2)	very (1)

Note: These scores will be automatically assigned when the SPSS syntax for calculating the TAAQOL scale-scores, is used. This syntax is described in Appendix 3 and included as file on the CD-rom.

4.3 Calculating scale scores

Appendix III presents a detailed SPSS program syntax for scoring the item pairs and for calculating the scale scores. ("TAAQOL scale construction 45-items.sps") This syntax is also included on the CD-rom.

Essentially, in order to calculate scale scores for the GROSS MOTOR, FINE MOTOR, COGNITION, SLEEP, PAIN, SOCIAL, DAILY, and SEX scales, the scores of the item pairs are summed for each scale separately. For VITALITY, HAPPINESS, DEPRESSIVE MOODS, and ANGER, the simple item scores are added.

The crude sum scores may range from 0 - 16 for GROSS MOTOR, FINE MOTOR, COGNITION, SLEEP, PAIN, SOCIAL, and DAILY. For SEX the range is 0 - 8. For VITALITY, HAPPINESS and DEPRESSIVE MOODS the range is 0 - 12. And for ANGER the scores vary between 0 and 9.

For all scales the sum-scores are linearly transformed to 0-100 scores. These calculated scale scores are all in the same direction: a low score indicates a lower HRQoL; a high score indicates a higher HRQoL.

Table 4.5 Variable names and variable labels of the final scale scores

Variable name	Label	Description
ngrmot	'gross motoric functioning'.	Problems /limitations concerning gross motor functioning
nfimot.	'fine motoric functioning'	Problems /limitations concerning fine motor functioning
ncogni	'cognitive functioning'.	Problems / limitations concerning cognitive functioning
nslaap	'sleep'.	Problems / limitations concerning sleeping
npijn	'pain'.	Problems / limitations concerning pain
nsoci	'social functioning'.	Problems / limitations in social contacts
nakti	'daily activities'.	Problems / limitations concerning independent daily functioning
nseks	'sexuality'.	Problems / limitations concerning sex
nvita	'vitality'.	The occurrence of feelings of vitality
nposi	'positive emotions'.	The occurrence of positive moods
nsomb	'depressive emotions'.	The occurrence of depressive moods
nagre	'aggressive emotions'	The occurrence of angry moods

Regarding missing values, for each individual scale the following procedure is followed: when one item (-pair) score is missing, the calculated sum score is divided by the number of scored items and then multiplied by the number of scale-items.* When more then one item(pair)-score is missing, the total scale score cannot be calculated and is considered to be missing. The SPSS syntax file on the CD-Rom ensures missing data to be handled correctly ("TAAQOL scale construction 45-items.sps").

* Example for a scale with 4 items. 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: $Sc = 4*(Su/Ni)$; with $Ni \geq 3$.

The SPSS syntax file can only be used when the following assumption regarding coding and variable names need to be met:

1) Variables should be named and scored according to the instructions in chapter 4 and and the SPSS-data entry file and SPSS-syntax file included in this manual

2) Missing answers should be coded as 0,8,9 (the missing assigned value supposed by the syntax).

Experience shows that the code with which combination items are created and scale scores are calculated is difficult to follow. Therefore a brief explanation of the code is given below. However, users are strongly suggested to consult their SPSS-Manual on the DO REPEAT-statement, with which a series of variables can be manipulated without the necessity of repeating each statement for each variable separately.

Statement	**Explanation**
count ni = V1 V2 V3 V4 (missing).	Count the number of missing functional complaints
do repeat f1 = V1 V2 V3 V4	Start the repeating statements; use F1 to hold the value of the functional complaints, successively
/f2 = R1 R2 R3 R4	Use F2, to store the value of the emotional reactions, successively
/f3 = kk1 kk2 kk3 kk4	Use F3 to store the value of the combination items successively; as these do not yet exist they are created when the syntax is run
/f4 = tl1 tl2 tl3 tl4	And finally use F4 to store the value of tl1 to tl4 successively (created on the run); these are temporary variables to store and recode the values of v1, v2 and v3, v4
compute f4 = f2.	Assign the value of the emotional reactions to f4 (i.e. the temporary variables tl1, tl2, tl3, tl4).
compute f3 = 1.	Assign the standard value of 1 to f3 (the combined items) …
If missing(f1) f3=0.	But change into missing when the functional complaint is missing …
If any(f1,2,3,4) f3 = 2.	Or into 2 when there is any negative reaction
If any (f1,1) f4 = 1.	Assume no negative reaction when there is no complaint and assign accordingly to f4 (i.e. temporary variable)
If missing (f1) f4 = 1.	… or when complaint is missing
If missing(f4) f4 = 1.	… should the temporary variable still be missing, recode to 1
compute f3 = f3+(f4-1).	Then add to the combined variable the value of the temporary variable minus 1
compute pgrmot = pgrmot+f3.	Add the value of the combined variable to the scale score
end repeat.	End of repeating statements
If (ni>=1) pgrmot = 99.	When the no. of missing calculated earlier is larger than allowed, assign 999 to scale score, already defined as missing.
if (ni<2) pgrmot = 20 – (4*pgrmot/(4-ni)).	When the number of missing is not greater than allowed, estimate the scale score, on the basis of valid items. (Actually, this statement is not necessary when only one missing is allowed and therefore omitted in the following syntax).
freq/var = pgrmot.	Ask for Frequencies, to check
Freq/var=kk1 to kk4.	Ask for Frequencies, to check
Recode kk1 kk2 kk3 kk4 (0=999).	Recode 0 into 999.
missing values kk1 kk2 kk3 kk4 (999).	Define 999 as missing in combination items

4.4 Comparing mean scores with reference sample from the Dutch population and interpretation of the scale scores

Table 4.6 and 4.7 present the reference sample's means and standard deviations for the TAAQOL scale scores. It should be noted that age and gender have significant effects on the scale scores. The results are therefore not only presented for the total sample, but also for specific age/gender groups.

In Table 4.8 and 4.9, the mean scale-scores of healthy respondents and the mean scale-scores for groups of respondents with a specific chronic illness are presented. These tables give the reader an impression of the differences in mean TAAQOL- scale scores that exist between healthy respondents and several groups of people with a chronic illness.

Table 4.6 TAAQOL: Means and standard deviations (SD) of raw scores in reference sample, men by age

Men	16-25 years			26-35 years			36-45 years			46-55 years			56-65 years			66-75 years			75-90 years		
	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N
GROSS MOTOR	97.7	7.7	115	95.0	14.0	356	92.4	16.2	394	89.2	21.2	391	84.6	21.9	356	78.6	25.5	257	68.8	29.8	90
FINE MOTOR	99.6	2.4	115	99.4	4.0	358	98.5	8.1	393	98.4	8.8	394	97.6	9.3	357	94.0	15.5	259	86.8	20.4	89
COGNITION	86.6	19.5	115	89.4	17.4	357	86.4	21.1	395	85.5	20.9	395	78.0	24.1	360	78.2	22.8	261	70.5	26.3	91
SLEEP	82.6	18.8	115	82.3	21.8	357	78.7	23.1	395	78.7	24.5	395	77.8	25.0	360	75.5	27.0	260	74.2	26.2	91
PAIN	85.5	16.9	115	84.5	17.7	359	77.4	22.3	395	75.6	24.0	394	71.1	24.1	361	72.0	25.4	256	72.1	23.1	89
SOCIAL	89.7	17.5	114	89.8	14.7	359	84.8	17.5	391	85.7	16.3	391	81.8	17.8	358	81.0	19.3	249	79.7	15.9	86
DAILY	82.5	21.2	114	87.8	20.4	359	85.4	22.6	394	86.5	22.8	392	85.6	23.3	357	86.5	23.4	237	79.8	24.7	82
SEX	92.7	16.8	112	87.2	24.1	354	84.6	26.8	385	85.8	25.4	384	75.7	31.3	337	72.2	31.3	220	74.8	31.8	52
VITALITY	71.0	18.8	114	72.9	19.3	356	68.7	21.5	393	69.6	22.6	394	66.7	22.5	352	62.2	24.9	247	56.7	25.9	87
HAPPINESS	73.1	16.9	113	71.5	20.6	356	62.8	20.7	390	63.6	21.3	395	63.1	20.8	355	63.6	20.7	251	61.0	22.0	86
DEPRESSIVE	84.4	14.8	114	84.0	17.3	355	81.5	19.2	394	81.2	19.2	395	81.2	19.5	356	78.9	22.0	251	80.9	19.6	87
ANGER	87.9	17.8	113	88.0	16.9	353	87.5	16.4	390	87.8	17.2	393	86.7	17.9	353	85.8	17.7	246	90.3	16.6	84

Table 4.7 TAAQOL: Means and standard deviations (SD) of scores in reference sample, women by age

Women	16-25 years			26-35 years			36-45 years			46-55 years			56-65 years			66-75 years			75-90 years		
	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N
GROSS MOTOR	91.6	17.1	234	91.6	16.8	553	90.4	18.0	496	83.6	23.9	410	75.9	28.9	294	71.9	28.0	228	51.7	33.0	133
FINE MOTOR	96.8	10.6	236	98.4	6.8	553	96.9	11.8	494	92.7	17.3	412	90.4	19.1	299	88.8	20.6	231	79.5	25.3	140
COGNITION	84.4	21.1	236	86.8	21.7	553	86.3	19.5	493	80.5	25.7	414	78.5	24.1	296	78.7	23.4	233	67.3	27.1	138
SLEEP	73.7	25.0	235	75.9	25.6	552	73.6	24.8	496	65.2	28.9	413	62.9	27.8	297	66.5	26.9	228	60.2	27.9	139
PAIN	77.0	21.2	235	77.1	21.0	552	74.0	21.7	496	66.1	26.7	412	62.6	27.9	300	64.4	26.3	227	58.5	28.9	138
SOCIAL	88.9	17.8	236	88.2	16.9	549	84.7	19.9	491	80.9	20.9	410	78.6	22.3	296	77.4	21.7	223	69.9	23.9	136
DAILY	84.1	22.1	235	84.9	23.2	549	84.9	22.8	489	77.6	30.1	401	79.9	27.6	291	80.0	28.4	205	67.8	35.3	112
SEX	89.3	20.6	231	87.6	22.5	537	89.8	20.5	475	82.5	26.4	356	79.3	29.1	217	84.4	22.3	102	87.8	21.5	48
VITALITY	62.8	22.2	235	64.0	23.1	547	63.5	23.0	490	58.9	26.1	400	58.8	25.3	274	57.0	24.5	209	43.2	27.0	124
HAPPINESS	72.3	20.5	236	71.5	20.6	547	63.8	20.6	487	60.0	22.2	402	59.4	21.9	275	56.2	23.5	209	54.5	25.2	122
DEPRESSIVE	76.4	18.6	236	79.1	20.1	549	76.7	20.2	490	72.2	22.4	406	72.4	23.1	276	72.7	21.4	212	67.1	24.1	125
ANGER	85.0	16.7	236	87.6	16.6	547	87.2	16.1	485	88.1	16.1	404	89.4	16.1	275	90.8	15.3	207	89.4	18.2	120

Table 4.8 TAAQOL: Means and standard deviations (SD) of raw scores in reference sample: men without chronic illnesses and different samples of chronically ill people(Men).

Men	No chronic illnesses 16-55 years			Multiple sclerosis 16-55 years			Back-problems 16-55 years			Asthma 16-55 years			Depression 16-55 years			Arthrose 16-55 years			Heart disease 16-55 years		
	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N
GROSS MOTOR	96.9	10.3	725	50.6	32.2	544	72.5	26.9	134	91.1	19.3	56	85.4	19.4	21	68.1	29.4	51	67.1	32.3	23
FINE MOTOR	99.4	4.2	725	74.9	30.8	566	98.2	6.9	135	98.2	7.3	57	97.0	11.1	21	94.6	17.1	51	96.6	8.2	24
COGNITION	90.3	16.6	727	61.4	32.5	587	81.2	22.4	135	87.4	19.1	57	56.3	28.4	21	82.0	21.8	51	67.4	30.1	24
SLEEP	84.1	19.3	727	63.4	32.5	585	68.0	28.5	135	74.6	27.5	57	59.8	26.5	21	71.6	30.7	51	62.8	33.2	24
PAIN	85.4	16.7	728	65.0	25.9	587	53.2	26.6	134	77.6	23.5	57	63.7	28.1	21	50.5	29.5	50	56.0	30.4	24
SOCIAL	89.0	15.0	723	75.7	23.5	581	81.1	19.6	133	83.9	19.7	57	72.9	20.3	21	82.6	21.5	51	73.7	22.2	24
DAILY	91.1	16.4	726	51.5	33.1	560	70.8	30.1	135	81.8	24.3	56	65.5	26.4	21	68.1	32.2	51	66.0	28.7	24
SEX	89.2	21.9	716	56.0	40.0	537	78.8	29.5	128	84.3	28.0	55	69.6	35.3	21	80.3	32.0	50	69.8	35.5	24
VITALITY	76.0	17.7	723	35.4	25.9	574	56.3	25.0	134	63.8	22.1	56	51.6	22.6	21	53.5	27.3	50	48.6	24.7	24
HAPPINESS	69.6	19.4	719	54.1	23.6	578	59.6	23.4	135	64.5	22.2	56	41.3	17.4	21	58.3	25.2	51	51.0	25.2	24
DEPRESSIVE	85.6	15.4	723	68.3	23.3	580	74.4	21.6	135	80.3	18.7	56	54.8	23.2	21	76.0	23.5	51	64.6	22.4	24
ANGER	89.9	14.4	718	77.9	23.0	575	83.2	22.0	135	87.7	17.3	55	76.7	23.5	21	79.3	25.4	50	74.9	17.5	23

Table 4.9 TAAQOL: Means and standard deviations (SD) of raw scores in reference sample: Women without chronic illnesses and different samples of chronically ill people(Women).

Women	No chronic illnesses 16-55 years			Multiple sclerosis 16-55 years			Back-problems 16-55 years			Asthma 16-55 years			Depression 16-55 years			Arthrose 16-55 years			Heart disease 16-55 years		
	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N
GROSS MOTOR	95.5	11.3	739	53.6	30.8	1374	70.2	26.5	206	80.6	25.0	112	76.3	24.9	39	65.3	30.8	96	75.0	28.3	15
FINE MOTOR	98.9	4.4	739	74.4	28.7	1429	91.9	18.5	206	92.7	17.4	113	85.4	22.6	39	86.5	22.5	96	86.3	26.1	15
COGNITION	88.3	19.3	740	61.7	32.2	1452	80.7	25.3	206	79.6	27.5	114	61.3	29.9	39	79.1	26.6	96	60.8	36.4	15
SLEEP	77.6	22.1	741	60.5	30.6	1458	63.3	29.0	207	62.8	30.7	113	47.4	30.4	39	60.9	30.7	96	60.8	34.7	15
PAIN	80.7	18.3	740	58.3	26.5	1449	51.7	25.9	207	66.1	27.6	114	56.9	29.0	39	45.8	30.6	96	57.5	30.9	15
SOCIAL	89.0	15.8	736	75.4	24.6	1435	80.9	21.6	205	80.7	22.5	114	62.3	28.3	39	78.8	21.6	95	72.9	31.8	15
DAILY	89.5	18.4	735	51.7	32.3	1402	72.0	30.2	205	73.5	28.1	112	51.6	32.3	39	70.6	32.2	94	53.8	34.7	15
SEX	91.0	18.9	715	68.1	32.3	1315	81.3	26.4	185	87.3	21.9	105	70.7	32.8	35	81.4	30.4	86	65.2	36.4	14
VITALITY	68.8	20.4	731	34.4	25.2	1429	53.0	26.1	200	52.3	25.6	111	36.3	27.2	39	50.4	27.4	91	36.4	27.1	15
HAPPINESS	70.5	19.8	730	59.2	23.3	1429	60.6	22.0	201	64.5	22.8	112	37.8	23.6	39	59.0	24.1	94	72.2	26.3	15
DEPRESSIVE	80.9	17.5	733	67.0	24.0	1439	70.4	23.8	202	69.8	23.1	113	44.9	25.7	39	71.0	23.4	94	67.8	27.4	15
ANGER	89.4	14.5	731	81.7	21.5	1413	85.7	18.3	200	82.9	20.5	113	73.2	27.6	39	86.5	17.9	94	80.7	26.0	15

5. Discussion

The TAAQOL (TNO AZL ADULT QUALITY OF LIFE) questionnaire is a paper and pencil questionnaire measuring generic Health-Related Quality of Life among (young) adult people. Health-Related Quality of Life is defined as health status weighted by the person'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 TAAQOL questionnaires, the following domains are covered by specific scales: Gross motor functioning, Fine Motor functioning, Cognition, Sleep, Pain, Social contacts, Daily activities, Sex, Vitality, Happiness, Depressive moods, and Anger

Furthermore, Health-Related Quality of Life is defined as a concept that 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 TAAQOL questionnaires assess the occurrence of functional problems, but if such a problem occurs, negative emotional reactions are assessed, too.

The TAAQOL was developed for people aged 16 years and older, and should be filled in by the respondents themselves.

The psychometric performance of the TAAQOL is satisfactory. The TAAQOL scales are skewed, especially in a general population. However, most parametric techniques used in the evaluation of the instruments are quite robust against skew ness, and have been demonstrated to be adequate in analyzing skewed data if sample size is large enough [24].

Cronbach's α ranged from 0.72 to 0.90, which is regarded as very satisfactory for use of the TAAQOL to compare group means. However, when individual scores are of interest, the TAAQOL cannot be used reliably; for use in clinical diagnosis, higher levels of Cronbach's α are mandatory. Furthermore, the stability of the TAAQOL 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, reflect the supposed scale structure perfectly. Correlation coefficients between TAAQOL scales are low to moderate. The construct validity of the TAAQOL may therefore be considered as being good.

Convergent validity has been evaluated by relating TAAQOL scales to SF-36 and HSCL scales. Correlation coefficients were moderate to high, showing a clear relationship between comparable scales. Most scales from the TAAQOL and corresponding SF-36 scales measuring similar constructs have a correlation coefficient of 0.50 to 0.70 (shared variance = 0.25% to 0.49%) indicating both a shared similarity as well as a clear distinction between the scales.

To evaluate criterion validity, the TAAQOL scales were related to two criteria: medical treatment and chronic illnesses. As expected, these criteria had negative effects on the TAAQOL scores, and effect sizes were sometimes very large in terms of the range of the scales.

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. The TAAQOL explicitly offers respondents the possibility to differentiate between their functioning and the way they feel about their functioning. Clearly, the TAAQOL 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

Content

Appendix I

The TAAQOL, Dutch version

Appendix II

The TAAQOL, English version

Appendix III

SPSS code calculating TAAQOL scale scores

Table Variable names and variable labels of the final scale scores

Variable name	Label	Description
ngrmot	'gross motoric functioning'.	Problems /limitations concerning gross motor functioning
nfimot.	'fine motoric functioning'	Problems /limitations concerning fine motor functioning
ncogni	'cognitive functioning'.	Problems / limitations concerning cognitive functioning
nslaap	'sleep'.	Problems / limitations concerning sleeping
npijn	'pain'.	Problems / limitations concerning pain
nsoci	'social functioning'.	Problems / limitations in social contacts
nakti	'daily activities'.	Problems / limitations concerning independent daily functioning
nseks	'sexuality'.	Problems / limitations concerning sex
nvita	'vitality'.	The occurrence of feelings of vitality
nposi	'positive emotions'.	The occurrence of positive moods
nsomb	'depressive emotions'.	The occurrence of depressive moods
nagre	'aggressive emotions'	The occurrence of angry moods

In order to use the SPSS syntax that starts on the next page (and is also included as a SPSS file on the CD-rom), the following assumption regarding coding and variable names need to be met:

1) Variables should be named and scored according to the instructions in paragraph 4.1 and Table 4.1 of this manual.

2) A missing assigned value (0, 8, or 9) should be given for all missing answers.

Beginning of the SPSS syntax:

```
*Below follows the SPSS-syntax for the construction of the TAAQOL scales.
*It is important that data-entry is always done the following way:
*Frequency of a problem: V1, V2, V3, V4, etc. etc. t/m V45 (Score every item 1, 2, 3, or 4).
*Second part of every item, i.e. "How much did that bother you?": R1, R2, R3, R4, etc. etc., R28, R29, R30 (Score every item 1, 2, 3, or 4)
*Note: For questions 31 and higher there are no R-variables!!
*See paragraph 4.1 of the manual for details on naming of variables and assigning values.
*The following syntax constructs scales and transforms scale scores to a 0-100 score.
*The variable names assigned to the scales are: ngrmot 'gross motoric functioning', nfimot 'fine motoric functioning', ncogni 'cognitive functioning',
*nslaap 'sleep', npijn 'pain', nsoci 'social functioning', nakti 'daily activities', nseks 'sexuality', nvita 'vitality',
*nposi 'positive emotions', nsomb 'depressive emotions', nagre 'aggressive emotions'.
*Higher scores indicate better quality of life.




** initialize scale scores and some secondary variables.


missing values r1 r2 r3 r4 r5 r6 r7 r8 r9 r10 r11 r12 r13 r14 r15
  r16 r17 r18 r19 r20 r21 r22 r23 r24 r25 r26 r27 r28 r29 r30
  v1 v2 v3 v4 v5 v6 v7 v8 v9
  v10 v11 v12 v13 v14 v15 v16 v17 v18 v19 v20 v21 v22 v23 v24 v25 v26 v27 v28 v29 v30
  v31 v32 v33 v34 v35 v36 v37 v38 v39 v40 v41 v42 v43 v44 v45 (0,8,9).

compute v31_b = v31.
compute v33_b = v33.
compute v35_b = v35.
compute v37_b = v37.
compute v42_b = v42.
compute v44_b = v44.

recode  v31_b v33_b v35_b v37_b v42_b v44_b (1=4) (2=3) (3=2) (4=1).



compute pgrmot = 0.
compute pfimot = 0.
compute pcogni = 0.
compute pslaap = 0.
compute ppijn = 0.
compute psoci = 0.
compute pakti = 0.
compute pseks = 0.
compute pvita = 0.
compute pposi = 0.
compute psomb = 0.
compute pagre = 0.

compute t1=0.
compute t2=0.
compute t3=0.
compute t4=0.
compute t5=0.
```

```
compute t6=0.
compute t7=0.
compute t8=0.
compute t9=0.
compute t10=0.
compute t11=0.
compute t12=0.


missing values pgrmot to pagre (99).
execute.



** for each scale the item pairs are coded into a combination item, with
**the name kkx with x referring to the itemnumber.
**The coding of the combined item pairs is handled using a DO REPEAT statement
**(see SPSS-manual); at the same time the scale score is calculated.
**After the DO REPEAT statements, the rules for missing values (see paragraph 4.4) are applied.




**
** pgrmot
**

COMPUTE PGRMOT = 0.

count ni = v1 v2 v3 v4 (missing).
do repeat  f1 = v1 v2 v3 v4
        /f2 = r1 r2 r3 r4
        /f3 = kk1 kk2 kk3 kk4
        /f4 = t1 t2 t3 t4.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3,4) f3 =  2.
if any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute pgrmot =  pgrmot+f3.
end repeat.
if (ni>1) pgrmot =  99.
if (ni<2) pgrmot = 20 - (4*pgrmot/(4-ni)).
freq/var =  pgrmot.
freq/var=kk1 to kk4.
recode kk1 kk2 kk3 kk4 (0 = 999).
MISSING VALUES kk1 kk2 kk3 kk4 (999).



**
** pfimot
**


count ni = v5 v6 v7 v8 (missing).
do repeat  f1 = v5 v6 v7 v8
        /f2 = r5 r6 r7 r8
```

```
        /f3 = kk5 kk6 kk7 kk8
        /f4 = t1 t2 t3 t4.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3,4) f3 =  2.
if any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute pfimot =  pfimot+f3.
end repeat.
if (ni>1) pfimot =  99.
if (ni<2) pfimot = 20 - (4*pfimot/(4-ni)).
freq/var =  pfimot.
freq/var=kk5 to kk8.
recode kk5 kk6 kk7 kk8 (0 = 999).
MISSING VALUES kk5 kk6 kk7 kk8 (999).


**
** pcogni
**

count ni = v9 v10 v11 v12 (missing).
do repeat  f1 = v9 v10 v11 v12
        /f2 = r9 r10 r11 r12
        /f3 = kk9 kk10 kk11 kk12
        /f4 = t1 t2 t3 t4.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3,4) f3 =  2.
if any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute pcogni =  pcogni+f3.
end repeat.
if (ni>1) pcogni =  99.
if (ni<2) pcogni = 20 - (4*pcogni/(4-ni)).
freq/var =  pcogni.
freq/var=kk9 to kk12.
recode kk9 kk10 kk11 kk12 (0 = 999).
MISSING VALUES kk9 kk10 kk11 kk12 (999).


**
** pslaap
**


count ni = v13 v14 v15 v16 (missing).
do repeat  f1 = v13 v14 v15 v16
        /f2 = r13 r14 r15 r16
        /f3 = kk13 kk14 kk15 kk16
        /f4 = t1 t2 t3 t4.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3,4) f3 =  2.
if any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
```

```
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute pslaap =  pslaap+f3.
end repeat.
if (ni>1) pslaap =  99.
if (ni<2) pslaap = 20 - (4*pslaap/(4-ni)).
freq/var =  pslaap.
freq/var=kk13 to kk16.
recode kk13 kk14 kk15 kk16 (0 = 999).
MISSING VALUES kk13 kk14 kk15 kk16 (999).


**
** ppijn
**


count ni = v17 v18 v19 v20 (missing).
do repeat  f1 = v17 v18 v19 v20
        /f2 = r17 r18 r19 r20
        /f3 = kk17 kk18 kk19 kk20
        /f4 = t1 t2 t3 t4.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3,4) f3 =  2.
if any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute ppijn =  ppijn+f3.
end repeat.
if (ni>1) ppijn =  99.
if (ni<2) ppijn = 20 - (4*ppijn/(4-ni)).
freq/var =  ppijn.
freq/var=kk17 to kk20.
recode kk17 kk18 kk19 kk20 (0 = 999).
MISSING VALUES kk17 kk18 kk19 kk20 (999).



**
** psoci
**


count ni = v21 v22 v23 v24 (missing).
do repeat  f1 = v21 v22 v23 v24
        /f2 = r21 r22 r23 r24
        /f3 = kk21 kk22 kk23 kk24
        /f4 = t1 t2 t3 t4.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3,4) f3 =  2.
if any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute psoci =  psoci+f3.
end repeat.
if (ni>1) psoci =  99.
if (ni<2) psoci = 20 - (4*psoci/(4-ni)).
```

```
freq/var =  psoci.
freq/var=kk21 to kk24.
recode kk21 kk22 kk23 kk24 (0 = 999).
MISSING VALUES kk21 kk22 kk23 kk24 (999).



**
** pakti
**

count ni = v25 v26 v27 v28 (missing).
do repeat  f1 = v25 v26 v27 v28
        /f2 = r25 r26 r27 r28
        /f3 = kk25 kk26 kk27 kk28
        /f4 = t1 t2 t3 t4.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3,4) f3 =  2.
if any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute pakti =  pakti+f3.
end repeat.
if (ni>1) pakti =  99.
if (ni<2) pakti = 20 - (4*pakti/(4-ni)).
freq/var =  pakti.
freq/var=kk25 to kk28.
recode kk25 kk26 kk27 kk28 (0 = 999).
MISSING VALUES kk25 kk26 kk27 kk28 (999).



**
** pseks
**

count ni = v29 v30(missing).
do repeat  f1 = v29 v30
        /f2 = r29 r30
        /f3 = kk29 kk30
        /f4 = t1 t2.
compute f4 = f2.
compute f3 =  1.
if missing(f1) f3=0.
if any(f1,2,3,4) f3 =  2.
if any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 =  1.
compute f3 =  f3+(f4-1).
compute pseks =  pseks+f3.
end repeat.
if (ni>0) pseks =  99.
if (ni<1) pseks = 10 - (2*pseks/(2-ni)).
freq/var =  pseks.
freq/var=kk29 kk30.
recode kk29 kk30 (0 = 999).
MISSING VALUES kk29 kk30 (999).
```

```
**
** pvita
**


count ni = v31_b v32 v33_b v34 (missing).
do repeat  f1 = v31_b v32 v33_b v34.
if not missing(f1) pvita = pvita+f1.
end repeat.
if (ni>1) pvita =  99.
if (ni<2) pvita = 16 - (4*pvita/(4-ni)).
freq/var =  pvita.



**
** pposi
**


count ni = v35_b v37_b v42_b v44_b (missing).
do repeat  f1 = v35_b v37_b v42_b v44_b.
if not missing(f1) pposi = pposi+f1.
end repeat.
if (ni>1) pposi =  99.
if (ni<2) pposi = 16 - (4*pposi/(4-ni)).
freq/var =  pposi.



**
** psomb
**


count ni = v36 v39 v40 v45 (missing).
do repeat  f1 = v36 v39 v40 v45.
if not missing(f1) psomb = psomb+f1.
end repeat.
if (ni>1) psomb =  99.
if (ni<2) psomb = 16 - (4*psomb/(4-ni)).
freq/var =  psomb.



**
** pagre
**


count ni = v38 v41 v43 (missing).
do repeat  f1 = v38 v41 v43.
if not missing(f1) pagre = pagre+f1.
end repeat.
if (ni>0) pagre =  99.
if (ni<1) pagre = 12 - (3*pagre/(3-ni)).
freq/var =  pagre.
```

```
compute ngrmot = (100/16)*pgrmot.
compute nfimot = (100/16)*pfimot.
compute ncogni = (100/16)*pcogni.
compute nslaap = (100/16)*pslaap.
compute npijn = (100/16)*ppijn.
compute nsoci = (100/16)*psoci.
compute nakti = (100/16)*pakti.
compute nseks = (100/8)*pseks.
compute nvita = (100/12)*pvita.
compute nposi = (100/12)*pposi.
compute nsomb = (100/12)*psomb.
compute nagre = (100/9)*pagre.


Variable labels ngrmot 'gross motoric functioning'.
Variable labels nfimot 'fine motoric functioning'.
Variable labels ncogni 'cognitive functioning'.
Variable labels nslaap 'sleep'.
Variable labels npijn 'pain'.
Variable labels nsoci 'social functioning'.
Variable labels nakti 'daily activities'.
Variable labels nseks 'sexuality'.
Variable labels nvita 'vitality'.
Variable labels nposi 'positive emotions'.
Variable labels nsomb 'depressive emotions'.
Variable labels nagre 'aggressive emotions'.
```

End of the spss syntax.

Appendix IV

Sample characteristics of the Reference data (N=4410).

Characteristic[1]	Category	Men	Women	Total
		N (%)	N (%)	N
Total		1990 (45%)	2396 (54%)	4386
Marital status	Married	1384 (70%)	1349 (57%)	2733
	Living together (not married)	164 (8%)	274 (12%)	438
	Single	371 (19%)	681 (29%)	1052
	Living with parents	64 (3%)	74 (3%)	138
Highest education[2]	Lower	801 (4-%)	1206 (51%)	2007
	Intermediate	515 (26%)	593 (25%)	1108
	Higher	581 (29%)	474 (20%)	1055
	Other	87 (4%)	111 (5%)	198
Chronic illnesses[3]	Asthma	125 (7%)	185 (8%)	310
	Epilepsy	20 (1%)	15 (1%)	35
	Arthritis	53 (3%)	99 (4%)	152
	Back-problems	242 (13%)	344 (15%)	586
	Heart disease	132 (7%)	65 (3%)	197
	Diabetes mellitus	73 (4%)	50 (2%)	123
	Stomach/Intestinal problems	76 (4%)	128 (6%)	204
	Arthrosis	161 (9%)	330 (15%)	491
	Cancer	40 (2%)	50 (2%)	90

[1] because of missing data, the total number do not add up to 100%

[2] Lower educational level-elementary education, MAVO (general secondary education-junior level), VBO (lower vocational education); intermediate educational level=HAVO/VWO (general secondary education-senior level) and MBO (vocational education-junior level); higher educational level=HBO (vocational education-senior level) and WO (university education)

[3] self-reported chronic illness

Appendix V

Variables in the reference dataset on the CD-Rom

Variable	Categories	Question
Age	Continuous in years	Age was obtained by asking the date of birth and the date the questionnaire was filled out and subsequently calculating the difference between the two dates. Both questions are on the first page of the TAAQOL.
Gender	1 = Male 2 = Female	"Are you male or female?". Question is on the first page of the TAAQOL.
Born	□ [1] Netherlands □ [2] Suriname □ [3] Turkey □ [4] Morocco □ [5] Other, i.e. …… For the reference data-file the categories were grouped into three categories, i.e. 1 = Born in the Netherlands 2 = Born in another Western country 3 = Born in another non-Western country	"In which country were you born?" only available for sample 1
Educat	□ [1] None (Geen) □ [2] Elementary school (Basisschool) □ [3] Lower vocational education (LBO) □ [4] General secondary education-junior level (Mavo/Mulo) □ [5] Vocational education medium level (MBO) □ [6] General secondary education senior level (HAVO) □ [7] General secondary education senior level (VWO/HBS) □ [8] Vocational education senior level/College (HBO) □ [9] College/University (Universiteit) □ Other …… For the reference data-file the categories were grouped into three levels of education, i.e. 1: 1-4: Lower educational level (none/elementary school/secondary lower vocational) 2: 5-7: Intermediate educational level (secondary medium/high vocational) 3: 8-9: Higher educational level (College/University) 4: Other	"What is your highest completed education?"
Marital	□ [1] Married □ [2] Living together (not married) □ [3] Single □ [4] Living with parents	"With whom you are currently living?"
Religion	□ [1] No religion □ [2] Roman Catholic □ [3] Reformed □ [4] Dutch reformed □ [5] Islamitic □ [6] Other, i.e. ……	"Do you have a religion?"

Chronic diseases: Astma Bronchit Allergy Reuma Heart Diabetes Bowel Artrosi Back Epileps Cancer Hearing Depres Other_di	a) Asthma b) Chronic bronchitis c) Allergies d) Rheumatism e) Heart-disease f) Diabetes g) Chronic stomach/ intestinal problems h) Arthritis i) Back problems j) Epilepsy k) Cancer l) Hearing-problems m) Depression n)Another chronic disease i.e. …… Note: For the reference data-file the items Asthma and Chronic bronchitis were combined into one variable: asthma.	□ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes □ No □ Yes	"Did you have one of the following diseases during the last 12 months?"