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TNO report

PG/JGD 2003.221

TAPQOL-manual

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

Date September 2004

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Copy no
No. of copies
Number of pages 26
Number of appendices 2
Sponsor
Project name
Project number

Introduction

This report is meant as a short manual for the TNO-AZL Preschool Children's Quality of Life questionnaire (TAPQOL). This short manual should be used in conjunction with the reference data and data entry forms.
This short manual describes the TAPQOL questionnaire and the concepts it wants to measure. It provides information on psychometric properties and practical guidelines on how data should be handled and how scale scores should be calculated. In addition, it gives information on the reference sample.
Using the TAPQOL in non-commercial studies is free of charge
Using the TAPQOL in a commercial setting is **not free**.

Leiden, 2004

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Contents

1 General description of the TAPQOL

The TAPQOL measures parent's perceptions of Health-related quality of life in pre-school children. The TAPQOL was constructed to enable a systematic, valid and reliable description of Health-related Quality of Life of preschool children. Health- related Quality of Life, as assessed by the TAPQOL, was defined as children's health status, weighted by the emotional response of the children themselves to their health status problems. Consequently, the TAPQOL assesses functional problems weighted by the degree to which a child shows negative emotions to such problems. The TAPQOL can be used to evaluate the impact of illness and treatments on the different domains of young children's lives, *e.g.* Physical, Social and Psychological. The questionnaire was developed for children between 9 months and 6 years (5 years and 12 months) old.
Usually the TAPQOL will be filled in by one of the parents. It takes approximately 10 minutes to fill in the questionnaire.

The questionnaire is designed primarily for research purposes focusing mainly on data aggregated on the group level, for example in clinical trials, evaluative or descriptive studies. The TAPQOL can not reliably be used as an instrument for individual diagnostics, e.g. for individual testing or screening. In clinical setting it may be used though to guide communication between physician and parents and the child itself.

The TAPQOL is a multidimensional instrument with 43 items covering 12 scales. The domains covered by the TAPQOL are based on a review of the literature, discussions with experts (child psychologists, pediatricians, and parents) and statistical testing. Table 1 presents the TAPQOL scales. These scales result in a profile. As HRQoL is defined as a multidimensional construct, no total score is calculated

Table 1: TAPQOL scales and matching items.

Scale		items
Stomach problems	Measures stomach and intestinal problems.	1, 2, 9
Skin problems	Measures skin problems like eczema, itchiness, and dry skin.	3, 4, 5
Lung problems	Measures difficulties with breathing, lung problems, bronchitis or shortness of breath.	6, 7, 8
Sleeping problems	Measures sleeping problems like being awake or crying or difficulty sleeping during the night	10, 11, 12, 13
Appetite	Measures if the child had a bad appetite, difficulty to eat enough of refused to eat.	14, 15, 16
Problem behavior	Measures difficult and aggressive behavior of the child.	17, 18, 19, 20, 21, 22, 23
Positive mood	Measures positive emotions.	24, 25, 26
Anxiety	Measures if the child was anxious, tense or frightened.	27, 28, 29
Liveliness	Measures if the child was active, lively and energetic.	30, 31, 32
Social functioning (*only for children older than 18 months*)	Measures social contacts with other children, like if the child was at ease with other children	33, 34, 35
Motor functioning (*only for children older than 18 months*)	Measures gross motor problems like difficulties with walking, running, climbing stairs and balance	36, 37, 38, 39
Communication (*only for children older than 18 months*)	Measures communicative skills of the child when compared to children of the same age.	40, 41, 42, 43

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 figure 1). The scoring system will be described in chapter 3.

In the last three months, has your child been ...

Short of breath? □ never □ occasionally □ often

At that time, my child felt:

□ fine □ not so good □ quite bad □ bad

Figure 1: Item example TAPQOL

2 Psychometric properties of the TAPQOL

Psychometric properties of the TAPQOL scales have been evaluated with data from two samples. One sample of preterm children[1] and a sample from the general population as described in chapter 5 and elsewhere[2]. In Table 2 the Cronbach's alphas of the TAPQOL scales are presented for both samples.

Table 2: Cronbach's alpha of the TAPQOL scales for preterm children and general population sample.

Scale	Number of items	Cronbach's Alpha Pretem children sample N = 109	Cronbach's Alpha General population sample N = 340
Sleeping problems	4	.88	.84
Appetite	3	.79	.76
Lungs problems	3	.83	.84
Stomach problems	3	.66	.51
Skin problems	3	.79	.59
Motor functioning	4	.77	.43
Social functioning	3	.75	.68
Problem behaviour	7	.86	.75
Communication	4	.80	.69
Anxiety	3	.71	.63
Positive mood	3	.82	.77
Liveliness	3	.87	.75

The reliability of most TAPQOL scales was good in the preterm children sample, with Cronbach's alpha ranging from 0.66 to 0.89. Reliability in the general population sample was satisfactory to good for most scales. However, the Cronbach's alpha for the scales relating to "stomach functioning" and "motor functioning" were rather low. This low reliability may have been due to the low prevalence and variance of problems in the general population sample.

For each set of items in a scale, a separate principal component analysis was performed. All these analyses resulted in only one factor being extracted indicating the uni-dimensionality of the scales. All items had a factor loading higher than 0.50. All except two items had a higher corrected correlation with their own scale (item-rest correlation) than with other scales.

On average the correlation coefficients between the TAPQOL scales were low (Table 3). Most correlation coefficients between scales were below 0.30. The correlation between the anxiety scale and the problem behavior scale was the highest, i.e. 0.44.

[1] Theunissen NCM, Veen S, Fekkes M, Koopman HM, Zwinderman KA, Brugman E, Wit JM. Quality of life in preschool children born preterm. Dev Med Child Neurol. 2001;43(7):460-5.

[2] Fekkes M, Theunissen NCM, Brugman E, Veen S, Verrips GHW, Koopman HM, Vogels AGC, WIT JM , Verloove-Vanhorick SP. Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1 to 5 year-old children. *Quality of Life Research*, 2000; 9: 961-72

The results from the principal component analysis and the correlation coefficients support the scale structure and confirm the multi-dimensional definition of HRQoL. This is in accordance with the conventional approach to HRQoL as a multi-dimensional construct.

Table 3: Spearman between ~~inter~~scale correlations coefficients of the TAPQOL scales for the general population sample. N = 340.

Scale	1	2	3	4	5	6	7	8	9	10	11
1 Sleeping	-										
2 Appetite	.19	-									
3 Lungs	.09	.12	-								
4 Stomach	.12	.21	.07	-							
5 Skin	.08	.09	.03	.06	-						
6 Motor functioning	.14	.01	-.02	-.15	.05	-					
7 Social functioning	.09	.04	.06	.02	.04	.10	-				
8 Problem behavior	.20	.19	-.04	.14	.03	.01	.00	-			
9 Communication	.11	.07	.08	-.04	-.04	.14	.21	.15	-		
10 Anxiety	.28	.25	.09	.25	.09	-.04	.11	.44	.15	-	
11 Positive mood	.13	.06	.17	.03	.09	.04	.19	.20	.12	.20	-
12 Liveliness	-.04	.02	.10	-.06	.00	.05	.08	.07	.10	.07	.17

Criterion validity was evaluated by comparing mean scale scores of healthy children (n=251) to those of children born preterm (n=65) and children with some chronic condition (n=62). Results are summarized in table 4. On most TAPQOL scales, the less optimal health condition (i.e., the preterm children and the group with a chronic illness) proved to be related to a significantly lower score. These results demonstrate that the TAPQOL scales can detect differences between healthy and less healthy children.

A more extensive psychometric evaluation of the TAPQOL-scales is described in the following publication:
Fekkes M, Theunissen NCM, Brugman E, Veen S, Verrips GHW, Koopman HM, Vogels AGC, WIT JM , Verloove-Vanhorick SP. Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1 to 5 year- old children. *Quality of Life Research*, 2000; 9: 961-72.

Table 4: Mean TAPQOL scale scores for healthy, preterm (gestational age < 32 weeks) and chronically ill children, standard deviation (SD) and p-value of T-test of for differences of means (p). Higher scores indicate better Health- Related Quality of Life.

Scale	Healthy children (n = 251)	Preterm children (n = 65)	Chronically ill children (n = 62)	Significance (p) Healthy vs. preterm children	Significance (p) Healthy vs. chronically ill children
Sleeping	83.1 (±17)	75.9 (±21)	77.2 (±19)	0.004	0.018
Appetite	85.9 (±12)	82.6 (±17)	79.6 (±16)	NS	0.001
Lungs	97.2 (±9)	85.3 (±20)	78.1 (±28)	< 0.001	< 0.001
Stomach	92.6 (±13)	84.2 (±21)	87.6 (±17)	< 0.001	0.013
Skin	92.8 (±10)	90.5 (±15)	88.0 (±13)	NS	0.002
Motor functioning	98.8 (±4)	90.2 (±13)	98.0 (±5)	< 0.001	NS
Social functioning	91.4 (±15)	83.7 (±22)	90.0 (±18)	0.003	NS
Problem behavior	67.7 (±15)	63.7 (±21)	67.0 (±16)	NS	NS
Communication	91.7 (±10)	80.9 (±15)	92.1 (±11)	< 0.001	NS
Anxiety	79.2 (±17)	66.9 (±22)	75.8 (±19)	< 0.001	NS
Positive mood	98.9 (±6)	98.4 (±6)	97.8 (±9)	NS	NS
Liveliness	98.1 (±8)	96.4 (±12)	97.0 (±10)	NS	NS

NS = Not significant (p > .05).

3 Data handling and calculation of scale scores

When a TAPQOL data file is to be created, items should be named and scored as indicated in Table 5. Missing answers should be coded as sysmis or as 9, as this is the missing assigned value in de data entry file.
Otherwise, errors in the calculation of scale scores are likely and the SPSS – TAPQOL 43-tem scale score syntax file cannot be used
After data-entry and scoring of the items in accordance with the guidelines in table 5, scale scores can be calculated. For this end, the SPSS –TAPQOL 43-item scale score syntax file can be used. This. With this syntax scale scores are linearly transformed to a 0-100 scale with higher scores indicating a better quality of life. Consult Appendix A for the syntax and some explanation on the code.

For most scales, items consist of two questions. In these items, the frequency of a specific complaint or limitation is first recorded. In Table 5 this is called the "first part of the item". If such a problem is reported, the well–being of the child in relation to this problem is assessed. In Table 5 this is called the "second part of the item".

Table 5: Variable names and scoring of all TAPQOL 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. well being)	Scoring 2nd part of item
1	V1	never=1, occasionally=2, often=3	R1	fine=1, not so good=2, quite bad=3, bad=4
2	V2	never=1, occasionally=2, often=3	R2	fine=1, not so good=2, quite bad=3, bad=4
3	V3	never=1, occasionally=2, often=3	R3	fine=1, not so good=2, quite bad=3, bad=4
4	V4	never=1, occasionally=2, often=3	R4	fine=1, not so good=2, quite bad=3, bad=4
5	V5	never=1, occasionally=2, often=3	R5	fine=1, not so good=2, quite bad=3, bad=4
6	V6	never=1, occasionally=2, often=3	R6	fine=1, not so good=2, quite bad=3, bad=4
7	V7	never=1, occasionally=2, often=3	R7	fine=1, not so good=2, quite bad=3, bad=4
8	V8	never=1, occasionally=2, often=3	R8	fine=1, not so good=2, quite bad=3, bad=4
9	V9	never=1, occasionally=2, often=3	R9	fine=1, not so good=2, quite bad=3, bad=4
10	V10	never=1, occasionally=2, often=3	R10	fine=1, not so good=2, quite bad=3, bad=4
11	V11	never=1, occasionally=2, often=3	R11	fine=1, not so good=2, quite bad=3, bad=4
12	V12	never=1, occasionally=2, often=3	R12	fine=1, not so good=2, quite bad=3, bad=4
13	V13	never=1, occasionally=2, often=3	R13	fine=1, not so good=2, quite bad=3, bad=4
14	V14	never=1, occasionally=2, often=3	R14	fine=1, not so good=2, quite bad=3, bad=4
15	V15	never=1, occasionally=2, often=3	R15	fine=1, not so good=2, quite bad=3, bad=4
16	V16	never=1, occasionally=2, often=3	R16	fine=1, not so good=2, quite bad=3, bad=4
17	V17	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
18	V18	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
19	V19	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
20	V20	never=1, occasionally=2, often=3	(not applicable)	(not applicable)

Item nr:	Naming variable 1st part of item (i.e. frequency)	Scoring 1st part of item	Naming variable 2nd part of item (i.e. well being)	Scoring 2nd part of item
21	V21	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
22	V22	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
23	V23	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
24	V24	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
25	V25	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
26	V26	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
27	V27	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
28	V28	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
29	V29	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
30	V30	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
31	V31	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
32	V32	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
33	V33	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
34	V34	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
35	V35	never=1, occasionally=2, often=3	(not applicable)	(not applicable)
36	V36	no=1, yes a little=2, yes a lot=3, cannot walk=4	R36	fine=1, not so good=2, quite bad=3, bad=4
37	V37	no=1, yes a little=2, yes a lot=3, cannot walk=4	R37	fine=1, not so good=2, quite bad=3, bad=4
38	V38	no=1, yes a little=2, yes a lot=3, cannot walk=4	R38	fine=1, not so good=2, quite bad=3, bad=4
39	V39	no=1, yes a little=2, yes a lot=3, cannot walk=4	R39	fine=1, not so good=2, quite bad=3, bad=4
40	V40	never=1, occasionally=2, often=3	R40	fine=1, not so good=2, quite bad=3, bad=4
41	V41	never=1, occasionally=2, often=3	R41	fine=1, not so good=2, quite bad=3, bad=4
42	V42	never=1, occasionally=2, often=3	R42	fine=1, not so good=2, quite bad=3, bad=4
43	V43	never=1, occasionally=2, often=3	R43	fine=1, not so good=2, quite bad=3, bad=4

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

4 Reference data

Reference data were collected via a sample from the general population of children visiting well-baby clinics in the Netherlands in 1997. Periodically, almost all (98%) children aged 0-5 in the Netherlands visit well-baby clinics. During a 6-month period the nurses from six well-baby clinics passed out the questionnaire to the first 100 parents who visited their clinic with a child aged 1-5. All visiting parents were invited to complete a set of questionnaires, except those parents who could not speak Dutch. Almost all parents were willing to fill out the questionnaire. Completed questionnaires were returned by mail.

Response rate in this general population sample was 60% (n =340). The percentage of girls in the sample was 44%. The age of the children ranged from 10 to 60 months: 34% of the children was between 10 and 24 months old, 30% between 24 and 36 months old, 31% between 36 and 48 months old and 5% between 48 and 60 months old. The sample included 62 children with a parent reported chronic illness who had visited the doctor in the last six months. The majority of this group had respiratory problems like asthma (12 children), chronic bronchitis (15 children) and whooping cough (4 children). Thirteen children of this group suffered from allergy problems.

5 Publications

The following studies using the TAPQOL were published:

Fekkes M, Theunissen NCM, Brugman E, Veen S, Verrips GHW, Koopman HM, Vogels AGC, WIT JM , Verloove-Vanhorick SP. Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1 to 5 year- old children. Quality of Life Research, 2000; 9: 961-72.

Theunissen NCM, Veen S, Fekkes M, Koopman HM, Zwinderman KA, Brugman E, Wit JM. Quality of life in preschool children born preterm. Dev Med Child Neurol. 2001;43(7):460-5.

Rovers MM, Krabbe PFM, Straatman H, Ingels K, Wilt GJ van der, Zielhuis GA. Randomised controlled trial of the effect of ventilation tubes (grommets) on quality of life at age 1-2 years. Arch Dis Child, 2001; 84: 45-49.

Sturms LM, Sluis CK van der, Groothoff JW, Eisma WH, Duis HJ ten. The health- related quality of life of pediatric traffic victims. J Trauma 2002; 52: 88-94.

A Explanations and SPSS code calculating TAPQOL scale scores

The variable names assigned to the scales are: stomach skin lungs sleep appetite lively emopos behavior anxiety social motor communi.
In order to use the SPSS syntax that starts on the next, 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 3 and Table 2 of this manual.
2) Missing answers should be coded as 9 (the missing assigned value supposed by the syntax) or sysmis.

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 V9 (missing).	Count the number of missing functional complaints
do repeat f1 = V1 V2 V9	Start the repeating statements; use F1 to hold the value of the functional complaints, successively
/f2 = R1 R2 R9	Use F2, to store the value of the emotional reactions, successively
/f3 = VR1 VR2 VR9	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 = P1 to P3.	And finally use F4 to store the value of p1 to p3 successively (created on the run); these are temporary variables to store and recode the values of v1, v2 and v9
compute f4 = f2.	Assign the value of the emotional reactions to f4 (i.e. the temporary variables p1,p2 and p3).
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) 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 temp. variable still be missing, recode to 1
compute f3 = f3+(f4-1).	Then add to the combined variable the value of the temp. variable minus 1
compute stomach = stomach+f3.	Add the value of the combined variable to the scale score
end repeat.	End of repeating statements
If (ni>=1) stomach = 999.	When the no. of missings calculated earlier is larger than allowed, assign 999 to scale score, already defined as missing.
if (ni<1) stomach = 3*stomach/(3-ni).	When the no 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 = stomach.	Ask for Frequencies, to check

Statement	Explanation
missing values VR1 VR2 VR9 (0).	Define 0 as missing in combination items

```
*Below follows the SPSS-syntax for the construction of the TAPQOL scales.
*This is the syntax for the TAPQOL 43-item version.
*It is important that data-entry is always done the following way:
*Frequency of a problem: V1, V2, V3, V4, etc. etc. t/m V43 (Score every item 1, 2, or 3).
*Affective response of the child to a problem: R1, R2, R3, R4, etc. etc. t/m R43 (Score every
item 1, 2, 3, or 4)
*Note: For some questions there are no R-variables!!
*See chapter 3 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: stomach skin lungs sleep appetite lively
emopos behavior anxiety social motor communi.
*Higher scores indicate better quality of life.

** initialize scale scores and some secondary variables.

compute stomach = 0.
compute skin = 0.
compute lungs = 0.
compute sleep = 0.
compute appetite = 0.
compute lively = 0.
compute emopos = 0.
compute behavior = 0.
compute anxiety = 0.
compute social = 0.
compute motor = 0.
compute communi = 0.
compute P1=0.
compute P2=0.
compute P3=0.
compute P4=0.
compute P5=0.
compute P6=0.
compute P7=0.

missing values stomach skin lungs sleep
appetite lively emopos behavior
anxiety social motor communi (999).
execute.

** For each scale the item pairs are coded into a combination item, with
** the name VR1, VR2, VR3, etc.
** The coding of the 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 statement, the rules for missing values are applied.
** These rules allow scales with 4 items to have one itemscore missing,
** whereby scale scores of the other three items are extrapolated to a total scale score.
** The scale 'Behavior' with 7 items is allowed to have two itemscores missing.
** whereby scale scores of the other items are extrapolated to a total scale score.

**
** stomach
**

count ni = V1 V2 V9 (missing).
do repeat f1 = V1 V2 V9
        /f2 = R1 R2 R9
        /f3 = VR1 VR2 VR9
        /f4 = P1 to P3.
compute f4 = f2.
compute f3 = 1.
if missing(f1) f3=0. if
any(f1,2,3) f3 = 2. if
any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
```

```
if missing(f4) f4 = 1.
compute f3 = f3+(f4-1).
compute stomach = stomach+f3.
end repeat.
if (ni>=1) stomach = 999.
freq/var = stomach.
recode VR1 VR2 VR9 (0 = 999).
missing values VR1 VR2 VR9 (999).

**
** skin
**

count ni = V3 V4 V5 (missing).
do repeat f1 = V3 V4 V5
        /f2 = R3 R4 R5
        /f3 = VR3 VR4 VR5
        /f4 = P1 to P3.
compute f4 = f2.
compute f3 = 1.
if missing(f1) f3=0. if
any(f1,2,3) f3 = 2. if
any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 = 1.
compute f3 = f3+(f4-1).
compute skin = skin+f3.
end repeat.
if (ni>=1)skin = 999.
freq/var = skin.
recode VR3 VR4 VR5 (0 = 999).
missing values VR3 VR4 VR5 (999).

**
** lungs
**

count ni = V6 V7 V8 (missing).
do repeat f1 = V6 V7 V8
        /f2 = R6 R7 R8
        /f3 = VR6 VR7 VR8
        /f4 = P1 to P3.
compute f4 = f2.
compute f3 = 1.
if missing(f1) f3=0. if
any(f1,2,3) f3 = 2. if
any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 = 1.
compute f3 = f3+(f4-1).
compute lungs =lungs+f3.
end repeat.
if (ni>=1)lungs = 999.
freq/var = lungs.
recode VR6 VR7 VR8 (0 = 999).
missing values VR6 VR7 VR8 (999).

**
** sleep
**

count ni = V10 V11 V12 V13(missing).
do repeat f1 = V10 V11 V12 V13
        /f2 = R10 R11 R12 R13
        /f3 = VR10 VR11 VR12 VR13
```

```
        /f4 = P1 to P4.
compute f4 = f2.
compute f3 = 1.
if missing(f1) f3=0. if
any(f1,2,3) f3 = 2. if
any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 = 1.
compute f3 = f3+(f4-1).
compute sleep = sleep +f3.
end repeat.
if (ni>1)sleep = 999.
if (ni<2) sleep = 4*sleep/(4-ni).
freq/var = sleep.
recode VR10 VR11 VR12 VR13 (0 = 999).
missing values VR10 VR11 VR12 VR13 (999).

**
** appetite
**

count ni = V14 V15 V16 (missing).
do repeat f1 = V14 V15 V16
        /f2 = R14 R15 R16
        /f3 = VR14 VR15 VR16
        /f4 = P1 to P3.
compute f4 = f2.
compute f3 = 1.
if missing(f1) f3=0. if
any(f1,2,3) f3 = 2. if
any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 = 1.
compute f3 = f3+(f4-1).
compute appetite =appetite+f3.
end repeat.
if (ni>=1)appetite = 999.
freq/var = appetite.
recode VR14 VR15 VR16 (0 = 999).
missing values VR14 VR15 VR16 (999).

**
** lively
**

count ni = V30 V31 V32 (missing).
do repeat f1 = V30 V31 V32.
if not missing(f1) lively = lively+f1.
end repeat.
if (ni >=1) lively = 999.
freq/var = lively.

**
** emopos
**

count ni = V24 V25 V26 (missing).
do repeat f1 = V24 V25 V26 .
if not missing(f1) emopos = emopos+f1.
end repeat.
if (ni >=1) emopos = 999.
freq/var = emopos.

**
** behavior
```

```
**

count ni = V17 V18 V19 V20 V21 V22 V23 (missing).
do repeat f1 = V17 V18 V19 V20 V21 V22 V23 .
if not missing(f1) behavior = behavior+f1.
end repeat.
if (ni >2) behavior= 999.
if (ni<3) behavior = 7*behavior/(7-ni).
freq/var = behavior.

**
** anxiety
**

count ni = V27 V28 V29 (missing).
do repeat f1 = V27 V28 V29 .
if not missing(f1) anxiety = anxiety+f1.
end repeat.
if (ni >=1) anxiety = 999.
freq/var = anxiety.

**
** social
**

count ni = V33 V34 V35 (missing).
do repeat f1 = V33 V34 V35 .
if not missing(f1) social = social+f1.
end repeat.
if (ni >=1) social = 999.
freq/var = social.

**
** motor
**

count ni = V36 V37 V38 V39(missing).
do repeat f1 = V36 V37 V38 V39
        /f2 = R36 R37 R38 R39
        /f3 = VR36 VR37 VR38 VR39
        /f4 = P1 to P4.
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 motor = motor +f3.
end repeat.
if (ni>1) motor = 999.
if (ni<2) motor = 4*motor/(4-ni).
freq/var = motor .
recode VR36 VR37 VR38 VR39 (0 = 999).
missing values VR36 VR37 VR38 VR39 (999).

**
** communi
**

count ni = V40 V41 V42 V43(missing).
do repeat f1 = V40 V41 V42 V43
        /f2 = R40 R41 R42 R43
        /f3 = VR40 VR41 VR42 VR43
```

```
        /f4 = P1 to P4.
compute f4 = f2.
compute f3 = 1.
if missing(f1) f3=0. if
any(f1,2,3) f3 = 2. if
any (f1,1) f4 = 1.
if missing (f1) f4 = 1.
if missing(f4) f4 = 1.
compute f3 = f3+(f4-1).
compute communi = communi +f3.
end repeat.
if (ni>1)communi = 999.
if (ni<2) communi = 4*communi/(4-ni).
freq/var = communi.
recode VR40 VR41 VR42 VR43 (0 = 999).
missing values VR40 VR41 VR42 VR43 (999).

*** transformation to 0-100 scales with higher scores indicating better quality of life.

COMPUTE stomach    = 100-((stomach-3)/0.12) .
COMPUTE skin    = 100-((skin-3)/0.12) .
COMPUTE lungs = 100-((lungs-3)/0.12) .
COMPUTE sleep= 100-((sleep-4)/0.16) .
COMPUTE appetite = 100-((appetite-3)/0.12) .
COMPUTE lively = (lively-3)/0.06 .
COMPUTE emopos = (emopos-3)/0.06 .
COMPUTE behavior = 100-((behavior-7)/0.14) .
COMPUTE anxiety = 100-((anxiety-3)/0.06) .
COMPUTE social = (social-3)/0.06 .
COMPUTE motor = 100-((motor-4)/0.16) .
COMPUTE communi = 100-((communi-4)/0.16).

variable labels stomach 'TAPQOL scale stomach problems'.
variable labels skin 'TAPQOL scale skin problems'.
variable labels lungs 'TAPQOL scale lung problems'
variable labels sleep 'TAPQOL scale sleeping'.
variable labels appetite 'TAPQOL scale appetite'.
variable labels lively 'TAPQOL scale liveliness'.
variable labels emopos 'TAPQOL scale positive mood'.
variable labels behavior 'TAPQOL scale problem behavior'.
variable labels anxiety 'TAPQOL scale anxiety'.
variable labels social 'TAPQOL scale social functioning'.
variable labels motor 'TAPQOL scale motor functioning'.
variable labels communi 'TAPQOL scale communication'.

FREQUENCIES
  VARIABLES= stomach skin lungs sleep appetite lively emopos
behavior anxiety social motor communi
  /STATISTICS=STDDEV VARIANCE MINIMUM MAXIMUM MEAN .
```

B Variables in the reference file

The reference file contains the TAPQOL scale scores and the extra variables, presented below.

Variable name	**Description and categories**	**Based on the following question**
Age	Age when filling in questionnaire, in years	Age of the child 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 TAPQOL.
Gender	1 = Boy 2 = Girl	"Is the child in question a boy or a girl?". Question is on the first page of the TAPQOL.
Chronic diseases: Astma Bronchit Allergy Epilepsi Reuma Back Eye Heart Diabetes Bowel Hearing Growth Other_di name_di	Experienced chronic condition during the last year? All: 1 = No 2 = Yes	"Did your child have one of the following diseases during the last year?"
gp	1 = No 2 = Yes	"Has your child visited or been treated by a general practitioner during the last 6 months?"
Speciali	1 = No 2 = Yes	"Has your child visited or been treated by a specialist doctor during the last 6 months?"
Medic	1 = No 2 = Yes	"Did your child use medication during the last 6 months?"
Hospital	1 = No 2 = Yes	"Has your child stayed in a hospital during the last year?"
day_hosp	Number of days in hospital	"How many days did your child stay in the hospital during the last year?"=
Operate	1 = No 2 = Yes	"Did your child undergo any operations during the last 6

Variable name	Description and categories	Based on the following question
		months?"
Educ_mom	Educational level mother: 1 = Lower educational level (none/elementary school/secondary lower vocational) (categories 1 till 4 in question) 2 = Intermediate educational level (secondary medium/high vocational) (categories 5 till 7 in question) 3 = Higher educational level (College/University) (categories 8 till in question)	"What is the highest completed education of the mother?" 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)
Educ_dad	Educational level father 1 = Lower educational level (none/elementary school/secondary lower vocational) (categories 1 till 4 in question) 2 = Intermediate educational level (secondary medium/high vocational) (categories 5 till 7 in question) 3 = Higher educational level (College/University) (categories 8 till in question)	"What is the highest completed education of the father?"
Born_mom	Country of Origin mother 1= Netherlands 2 = Suriname 3 = Turkey 4 = Morocco 5 = Other	"What is the country of origin of the mother?"
Born_dad	Country of Origin father 1= Netherlands 2 = Suriname 3 = Turkey 4 = Morocco 5 = Other,	"What is the country of origin of the father?"
Proxi	Who answered questionnaire? 1 = Mother 2 = Adoptive/surrogate/stepmother 3 = Other female caretaker 4 = Adoptive/surrogate/stepfather 5 = Other male caretaker	"Who filled out the questionnaire?"