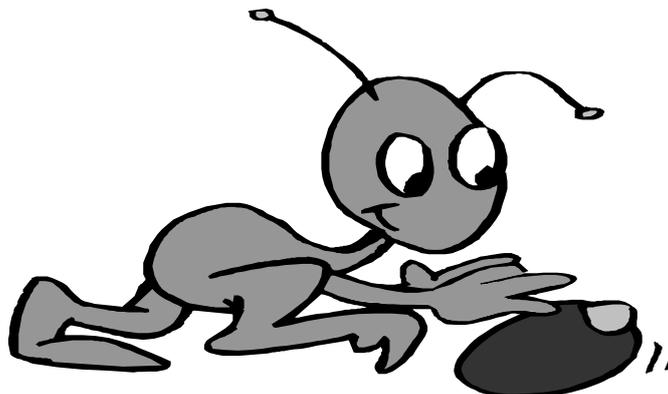


KINDL^R

Questionnaire for Measuring Health-Related Quality of Life in
Children and Adolescents

Revised Version

Manual



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1 Information about the KINDL^R Questionnaire

While most quality of life measures for children have been developed in the English language and then translated in a further, methodologically elaborate step (Ravens-Sieberer and Cieza, 2000), the generic KINDL^R Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents represents a German-language measure (originally developed by Bullinger et al. 1994, revised by Ravens-Sieberer & Bullinger 1998a, 1998b), for use in clinical populations but also with healthy children and adolescents.

The KINDL^R Questionnaire for Children and Adolescents described below was developed and tested with a view to remedying the discrepancy between the urgency of the subject 'Quality of Life in Children and Adolescents' and the lack appropriate measures (Ravens-Sieberer, 2000). In developing it, the goal was to design a short, methodologically suitable and flexible set of instruments which could be completed both by children/adolescents and by their parents, which was available for different age groups and stages of development, which could be used for healthy and ill children (generic approach), which could be extended by means of specific modules (e.g. for different classes of diseases) and which could be used in different types of study, namely: a) epidemiological studies on the situation of children and adolescents in the Federal Republic of Germany, b) clinical studies dealing with the effects of therapeutic measures on the quality of life of acutely and chronically ill children, and c) in rehabilitation, looking into the effects of rehabilitation programmes – and in each case from the perspective of the children and of their parents.

The questionnaire has so far be used and tested in a number of studies over a period of up to three years involving over 3000 healthy and chronically ill children as well as their parents. The psychometric results reveal a high degree of reliability (Cronbach's $\alpha \geq .70$ for most of the sub-scales and samples) and a satisfactory convergent validity of the procedure, beyond which the acceptance of the measure by children and adolescents is high (Ravens-Sieberer, 1998). The questionnaire has been able to distinguish between children with different physical disorders and under different types of strain. Overall, the KINDL^R has proved to be a flexible, modular, psychometrically acceptable method of measuring quality of life in children by means of a central module covering generic aspects in children's quality of life while also measuring the specific burdens associated with diseases in childhood via additional modules. Age-specific versions take into account the changes in the quality of life dimensions in the course of child development.

1.1 Structure of the Questionnaire

The KINDL^R questionnaire satisfies the demand for taking into account progress during child development and the principle of patient-generated data collection by providing different versions of the questionnaire for different age groups and both a self-report version and a proxy version. The common practice of modifying a measure originally designed for adults to make it suitable for children, was avoided here. With the KINDL^R questionnaire an original German-language measure is available that was specifically designed and validated for children. The psychometric testing of the KINDL^R shows that a procedure has been developed that can be used in epidemiological, clinical and rehabilitation research studies; the use of the KINDL^R questionnaire in the context of health care planning is increasingly under discussion.

1.1.1 Self-assessment and external assessment by age groups

Three versions of the KINDL^R questionnaire are available as self-report measures for different age groups:

Kiddy-KINDL ^R for children aged 4 to 6	Kid-KINDL ^R for children aged 7 to 13	Kiddo-KINDL ^R for adolescents aged 14 to 17
<p>Children's Questionnaire Kiddy-KINDL^R Interview</p> 	<p>Children's Questionnaire Kid-KINDL^R</p> 	<p>Children's Questionnaire Kiddo-KINDL^R</p> 

In addition, the questionnaire is available in two proxy versions for parents (3-6-year-olds and 7-17-year-olds):

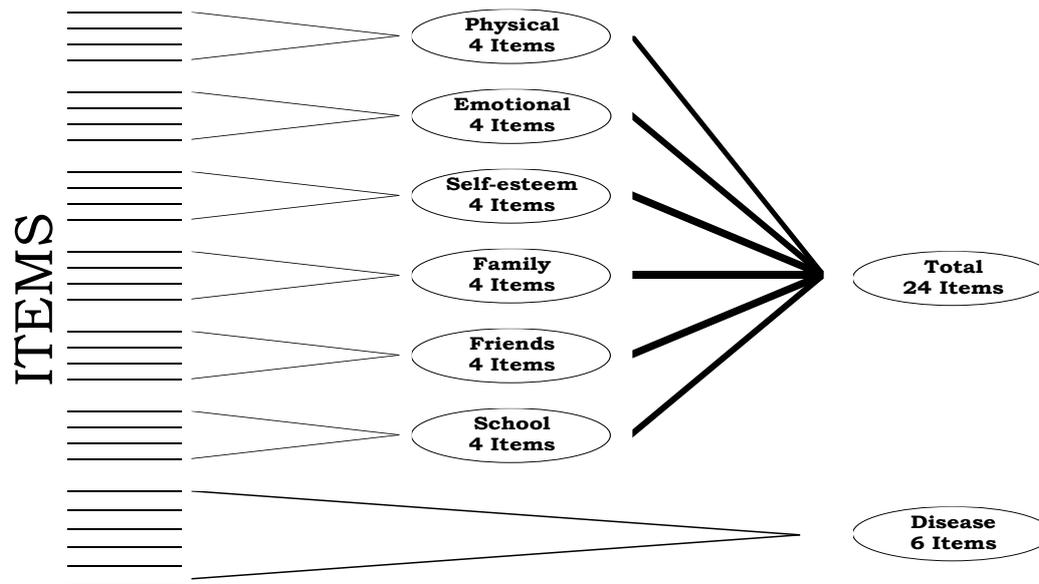
Kiddy-KINDL ^R for Parents of children aged 3 to 6	Kid-/Kiddo-KINDL ^R for parents of children and adolescents aged 7-17
<p>Quality of Life Questionnaire for Children 3 - 6 years Parents' Questionnaire Kindl^R</p> 	<p>Quality of Life Questionnaire for Children 7 - 17 years Parents' Questionnaire Kindl^R</p> 

Furthermore, a **short form of the KINDL^R** (12 items) has been developed, as well as a series of **disease-specific modules** (adiposity, asthma, diabetes, epilepsy, neurodermatitis, oncology and spina bifida). The questionnaire is also available in numerous **languages**, e.g. English, French, Dutch, Russian, Turkish, Italian and Spanish. A **Computer-Assisted Touch Screen version (CAT-Screen)** of the questionnaire is available as well.

1.1.2 Structure of the scales

The KINDL^R questionnaire consists of 24 Likert-scaled items associated with six dimensions: physical well-being, emotional well-being, self-esteem, family, friends and everyday functioning (school or nursery school/kindergarten). The sub-scales of these six dimensions can be combined to produce a total score.

Figure 1: Structure of the Sub-Scales Included in the KINDL^R Questionnaire



1.1.3 "Disease" module

All versions of the KINDL^R contain an additional sub-scale entitled "Disease", whose items can be completed in case of prolonged illness or hospitalisation. The additional sub-scale consists of a filter question and six items which measure the child's quality of life with respect to his or her illness. In addition, disease-specific modules are available for the illnesses Adiposity, Asthma bronchiale, Diabetes, Epilepsy, Neurodermatitis, Oncology and Spina Bifida.

1.1.4 Kiddy-KINDL^R interview version for children and additional questions for parents

On account of the particular difficulties associated with interviewing young children, the structure of the Kiddy-KINDL^R differs from that of the other questionnaires (Kid/Kiddo). In the self-report version, it only consists of twelve items, two for each dimension. This means that no sub-scale scores can be calculated for the individual dimensions but only a total score. The additional questions on "Disease" are, on the other hand, included in full. The response categories of the Kiddy-KINDL^R cover 3 levels (1 = never, 2 = sometimes, 3 = very often), the children are to be questioned in a face-to-face interview.

The parents' version of the Kiddy-KINDL^R with its 24 items in 6 dimensions corresponds in structure to the parents' version of the KINDL^R for 7 to 17-year-old children and teenagers. However, in order to make up for the potentially lower information content of the self-reported responses by young children, the parents' version of the Kiddy-KINDL^R contains a further 22 items which can be treated as a sub-scale in their own right.

1.2 Structure of the Sub-Scales and Classification of Items

1.2.1 Self-report versions

Kiddy-KINDL^R (4 to 6-year-olds) Children's Version (Interview)	Kid-KINDL^R (7 to 13-year-olds) Children's Version	Kiddo-KINDL^R (14 to 17-year-olds) Teenagers' Version
Physical Well-Being		
1. ... I felt ill 2. ... I had a headache or tummy-ache	1. ... I felt ill 2. ... I had a headache or tummy-ache 3. ... I was tired and worn-out 4. ... I felt strong and full of energy	1. ... I felt ill 2. ... I was in pain 3. ... I was tired and worn-out 4. ... I felt strong and full of energy
Emotional Well-Being		
3. ... I had fun and laughed a lot 4. ... I was bored	5. ... I had fun and laughed a lot 6. ... I was bored 7. ... I felt alone 8. ... I was scared	5. ... I had fun and laughed a lot 6. ... I was bored 7. ... I felt alone 8. ... I felt scared or unsure of myself
Self-Esteem		
5. ... I was proud of myself 6. ... I felt pleased with myself	9. ... I was proud of myself 10. ... I felt on top of the world 11. ... I felt pleased with myself 12. ... I had lots of good ideas	9. ... I was proud of myself 10. ... I felt on top of the world 11. ... I felt pleased with myself 12. ... I had lots of good ideas
Family		
7. ... I got on well with my parents 8. ... I felt fine at home	13. ... I got on well with my parents 14. ... I felt fine at home 15. ... We quarrelled at home 16. ... My parents stopped me from doing certain things	13. ... I got on well with my parents 14. ... I felt fine at home 15. ... We quarrelled at home 16. ... I felt restricted by my parents
Friends		
9. ... I played with friends 10. ... I got along well with my friends	17. ... I played with friends 18. ... Other kids liked me 19. ... I got along well with my friends 20. ... I felt different from other children	17. ... I did things together with my friends 18. ... I was a "success" with my friends 19. ... I got along well with my friends 20. ... I felt different from other people
Everyday Functioning (School or Nursery School/Kindergarten)		
11. ... I coped well with the assignments set in nursery school/kindergarten 12. ... I enjoyed nursery school/kindergarten	21. ... doing my schoolwork was easy 22. ... I enjoyed my lessons 23. ... I worried about my future 24. ... I worried about bad marks or grades	21. ... doing the schoolwork was easy 22. ... I found school interesting 23. ... I worried about my future 24. ... I worried about getting bad marks or grades

Kiddy-KINDL^R (4 to 6-year-olds) Children's Version	Kid-KINDL^R (7 to 13-year-olds) Children's Version	Kiddo-KINDL^R (14 to 17-year-olds) Teenagers' Version
"Disease" Module		
13. Are you staying in hospital just now or do you have some long-term illness? (Filter question)	25. Are you staying in hospital just now or do you have some long-term illness? (Filter question)	25. Are you staying in hospital just now or do you have some long-term illness? (Filter question)
14. ... I was afraid that my illness might get worse	26. ... I was afraid that my illness might get worse	26. ... I was afraid that my illness might get worse
15. ... I was sad because of my illness	27. ... I was sad because of my illness	27. ... I was sad because of my illness
16. ... I was able to cope well with my illness	28. ... I was able to cope well with my illness	28. ... I was able to cope well with my illness
17. ... my parents treated me like a baby because of my illness	29. ... My parents treated me like a baby because of my illness	29. ... My parents treated me like a baby because of my illness
18. ... I avoided others to notice my illness	30. ... I wanted nobody to notice my illness	30. ... I wanted nobody to notice my illness
19. ... I missed something at nursery school/kindergarten because of my illness	31. ... I missed something at school because of my illness	31. ... I missed something at school because of my illness

1.2.2 Parents' versions

Kiddy-KINDL^R (3 to 6-year-olds) Parents' Version	KINDL^R (7 to 17-year-olds) Parents' Version
Physical Well-Being	
1. ... my child had fun and laughed a lot	1. ... my child felt ill
2. ... my child had a headache or tummy-ache	2. ... my child had a headache or tummy-ache
3. ... my child was tired and worn-out	3. ... my child was tired and worn-out
4. ... my child felt strong and full of energy	4. ... my child felt strong and full of energy
Emotional Well-Being	
5. ... my child had fun and laughed a lot	5. ... my child had fun and laughed a lot
6. ... my child didn't feel much like doing anything	6. ... my child didn't feel much like doing anything
7. ... my child felt alone	7. ... my child felt alone
8. ... my child felt scared or unsure of her-/ himself	8. ... my child felt scared or unsure of itself
Self-Esteem	
9. ... my child was proud of him-/herself	9. ... my child was proud of himself
10. ... my child felt on top of the world	10. ... my child felt on top of the world
11. ... my child felt pleased with him-/ herself	11. ... my child felt pleased with him-/herself
12. ... my child had lots of good ideas	12. ... my child had lots of good ideas
Family	
13. ... my child got on well with us as parents	13. ... my child got on well with us as parents
14. ... my child felt fine at home	14. ... my child felt fine at home
15. ... we quarrelled at home	15. ... we quarrelled at home
16. ... my child felt that I was bossing him/her around	16. ... my child felt that I was bossing him around
Friends	
17. ... my child played with friends	17. ... my child did things together with friends
18. ... my child was liked by other kids	18. ... my child was liked by other kids
19. ... my child got along well with his friends	19. ... my child got along well with his/her friends
20. ... my child felt different from other children	20. ... my child felt different from other children
Everyday Functioning (School or Nursery School/Kindergarten)	
21. ... my child coped well with the assignments set in nursery school/ kindergarten	21. ... my child easily coped with schoolwork
22. ... my child enjoyed the nursery school/ kindergarten	22. ... my child enjoyed the school lessons
23. ... my child looked forward to nursery school/kindergarten	23. ... my child worried about his future
24. ... my child made lots of mistakes when doing minor assignments or homework	24. ... my child was afraid of bad marks or grades

Kiddy-KINDL^R (3 to 6-year-olds) Parents' Version
Additional Items "Kiddy Parents"
25. ... my child was moody and whined a lot 26. ... my child had a healthy appetite 27. ... I managed to show patience and understanding towards my child 28. ... my child felt under pressure 29. ... my child slept soundly 30. ... my child romped around and was very active 31. ... my child kept bursting into tears 32. ... my child was cheerful and in a good mood 33. ... my child was alert and able to concentrate well 34. ... my child was easily distracted and absent- minded 35. ... my child enjoyed being with other children 36. ... I had to give my child a telling-off 37. ... I praised my child 38. ... my child had problems with teachers, kindergarten staff or other child-minders 39. ... my child was nervous and fidgety 40. ... my child was lively and energetic 41. ... my child complained of being in pain 42. ... my child was sociable and out- going 43. ... my child succeeded at everything he set out to do 44. ... my child became dissatisfied easily 45. ... my child cried bitterly 46. ... my child lost his temper quickly

Kiddy-KINDL^R (3 to 6-year-olds) Parents' Version	KINDL^R (7 to 17-year-olds) Parents' Version
"Disease" Module	
47. Is your child staying in hospital just now or does it have a long-term illness? (Filter question)	25. Is your child staying in hospital just now or does it have a long-term illness? (Filter question)
48. ... my child was afraid that the illness might get worse	26. ... my child was afraid that the illness might get worse
49. ... my child was sad because of the illness	27. ... my child was sad because of the illness
50. ... my child was able to cope well with his illness	28. ... my child was able to cope well with his illness
51. ... we treated our child as though he/she were younger, because of the illness	29. ... we treated our child as though he were younger, because of the illness
52. ... my child avoided others to notice his illness	30. ... my child avoided others to notice his illness
53. ... my child missed something at nursery school/ kindergarten because of his illness	31. ... my child missed something at school because of his illness

1.3 Psychometrics

The psychometric tests conducted on the questionnaire and discussed here include the testing of its reliability (internal consistency, i.e. Cronbach's alpha) and validity (factorial validity, convergent validity, discriminant validity and sensitivity).

The first steps in the psychometric calculations consisted of an item analysis and a *reliability analysis* of the KINDL^R questionnaire using the Multitrait Analysis Program of the New England Medical Center at Tufts University in Boston (MAP) (Hays et al., 1988). The MAP program uses Campbell's multitrait approach and permits a confirmatory test of the questionnaire's postulated scale structure. For each item it delivers the magnitude of the correlation between the item and the overall scale (adjusted for overlap) as well as the success statistics for the frequency of cases displaying a higher or significantly higher correlation of an item as compared with the correlation with other scales. These success statistics, also known as scale fit, can take on values between 0% and an optimum 100%, and indicate the *factorial validity* of the questionnaire on an item level. Beyond this, the internal consistency coefficient Cronbach's alpha is given.

The *convergent validation* was done by correlating the sub-scales of the KINDL^R questionnaire with comparable well-being scales. The *discriminant validity* was determined by distinguishing subgroups within the survey population according to criteria that suggested a difference in their quality of life assessment.

The analysis of the psychometric quality of the questionnaire was performed using two samples:

Sample 1

1501 pupils in the fourth and eighth grade completed the short version (12 items) of the KINDL^R in the course of the regular school medical check-ups in Hamburg. The fourth graders (n=918) were an average of 9.7 years old, the eighth grade teenagers (n=583) 14.1 years old. The sample consisted of 48.3 % girls and 51.7 % boys (Ravens-Sieberer et al., 2000a).

Sample 2

1050 children and adolescents from 7 German rehabilitation clinics completed the KINDL^R questionnaire before embarking on a rehabilitation programme. The sample consisted of 50.7 % girls and 49.3 % boys. Their average age was 12.6 years; the sample comprised three diagnostic groups: Bronchial asthma (n=254), Neurodermatitis (n=163) and Obesity (n=633) (Ravens-Sieberer et al., 2000b).

1.3.1 Structure of sub-scales, reliability and factorial validity

The analysis of the data from the KINDL^R questionnaires completed by chronically ill children and adolescents and their parents (Sample 2, n=1050) using the MAP program revealed a good utilisation of the scale width with floor and ceiling effects generally below 10%. The scale fit was above 80% for all sub-scales. The reliability was checked by confirmatory means, Cronbach's alpha as a measure of internal consistency reached values of around $\alpha = .70$ for most sub-scales, while the overall scale displayed a consistency coefficient of over $\alpha = .80$.

Table 1: Structure of Sub-Scales and Reliability (children, data transformed 0-100)

Sub-scale	n	No. of items	Mean	Standard deviation	Floor %	Ceiling %	Scale fit %	Internal consistency α
Physical	915	4	70.63	17.31	.1	4.8	87.5	.63
Emotional	915	4	80.31	14.88	.0	9.7	91.7	.68
Self-esteem	915	4	57.88	20.56	.4	1.7	100.0	.75
Family	915	4	77.69	17.13	.0	10.5	100.0	.76
Friends	915	4	71.44	18.25	.3	7.7	91.7	.74
School	915	4	64.56	21.88	.1	3.4	91.7	.64
Total	915	24	70.58	11.94	.0	.0	94.2	.84
Disease module	915	6	77.71	17.96	.0	11.9	91.7	.66

Table 2: Structure of Sub-Scales and Reliability (parents, data transformed 0-100)

	n	No. of items	Mean	Standard deviation	Floor %	Ceiling %	Scale fit %	Internal consistency α
Physical	899	4	64.00	18.44	.0	2.6	83.3	.70
Emotional	899	4	69.44	17.75	.0	4.2	100.0	.76
Self-esteem	899	4	56.06	19.50	.2	2.1	100.0	.77
Family	899	4	79.38	17.75	.1	5.9	100.0	.81
Friends	899	4	67.94	18.13	.0	4.1	87.5	.74
School	899	4	65.63	18.06	.1	3.6	95.8	.62
Total	899	24	56.58	13.15	.0	.0	95.8	.89
Disease module	899	6	69.83	18.88	.0	6.1	88.9	.72

1.3.2 Convergent validity

In terms of convergent validity, the KINDL^R sub-scales were correlated both with the subjective health dimensions of the Child Health Questionnaire (Landgraf et al., 1999) and the SF-36 (Bullinger & Kirchberger, 1998) and with the "Life Satisfaction" questionnaire adapted for children (FLZM; Herschbach & Henrich, 2000). It was found that the KINDL^R total score displayed a high correlation particularly with the "General Well-Being" sub-scale of the Child Health Questionnaires and with the "Vitality" and "Emotional Well-Being" sub-scales of the SF-36 as well as the FLZM ($r > .60$). Since the KINDL^R aims more at the psychosocial than the physical aspects of health-related quality of life, the correlation of the KINDL^R sub-scales with physical aspect of quality of life ("Global Health" and "Physical Activities" scale of the Child Health Questionnaire) are lower, as expected.

Table 3: Convergent Validity (Pearson r)

KINDL ^R sub-scale	CHQ Global health	CHQ General well-being	CHQ Physical activities	SF-36 Vitality	SF-36 Emotional well-being	FLZ Life satisfaction
Physical	.34	.52	.37	.55	.44	.40
Emotional	.26	.59	.31	.48	.56	.45
Self-Esteem	.32	.50	.23	.46	.44	.53
Family	.15	.37	.12	.26	.32	.47
Friends	.19	.48	.37	.42	.41	.46
School	.28	.42	.15	.31	.39	.41
Total	.40	.72	.39	.62	.64	.69
Disease module	.36	.51	.37	.41	.43	.45

1.3.3 Discriminant validity

The initial results of the use of the KINDL^R questionnaire on chronically ill children show that the measure is able to distinguish between differences in the impairment of health-related quality of life in children with different diseases (Asthma, Neurodermatitis, Obesity) both on a sub-scale level and in terms of its total score (see Figure 2).

Table 4: Sub-scale Means for Different Samples

	Physical	Emo-tional	Self-esteem	Family	Friends	School	Total	Disease
Healthy (n=1501)	75.56	83.01	66.6	83.99	78.18	73.13	76.75	
Asthma (n=254)	71.02	82.35	63.68	79.33	76.8	67.34	73.38	82.28
Neurodermatitis (n=163)	74.94	81.44	62.63	80.76	77.72	68.55	74.41	78.29

Obesity (n=633)

70.1

79.28

54.71

76.78

70.84

62.43

68.93

75.45

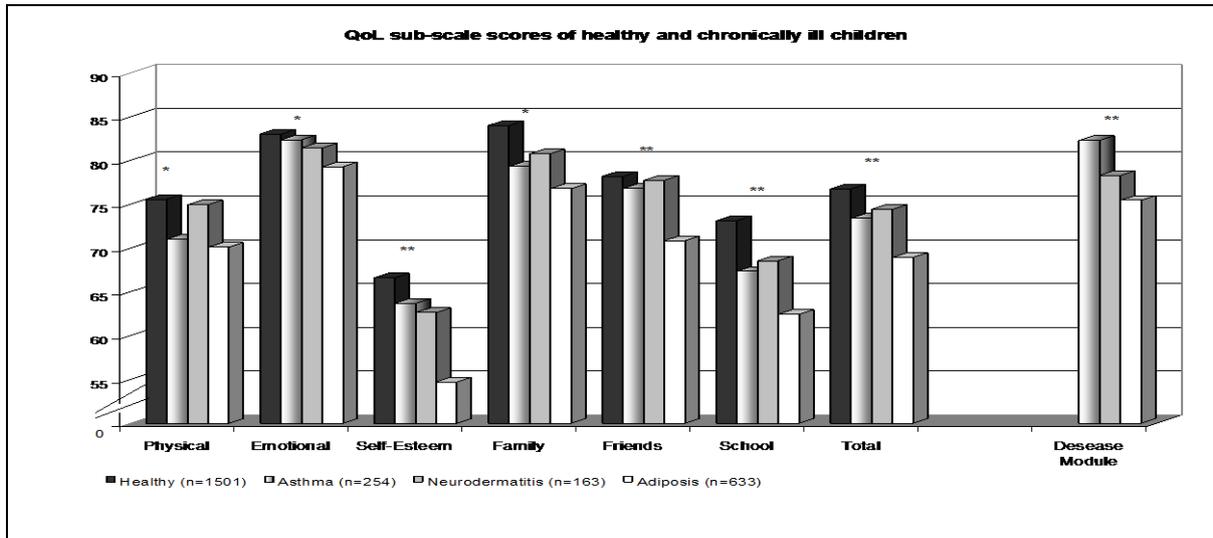


Figure 2: Discriminant Validity of the KINDL^R Questionnaire (*p ≤ .05, **p ≤ .01)

1.3.4 Sensitivity

In a study dealing with the rehabilitation of chronically ill children (cf. Sample 2, Section 1.3) 1050 children completed the KINDL^R questionnaire at the beginning and the end of a six-week in-patient rehabilitation programme.

Four of the six KINDL^R sub-scales could be applied both before and after rehabilitation (School and Family had to be omitted because they could not be assessed). For all three groups of chronically ill children (Asthma, Neurodermatitis and Adiposity), significant changes between before and after rehabilitation were apparent, particularly on the KINDL^R dimensions Physical, Self-Esteem, Friends and Total Score, as well as on disease-specific Asthma, Neurodermatitis and Obesity modules and the additional Disease module.

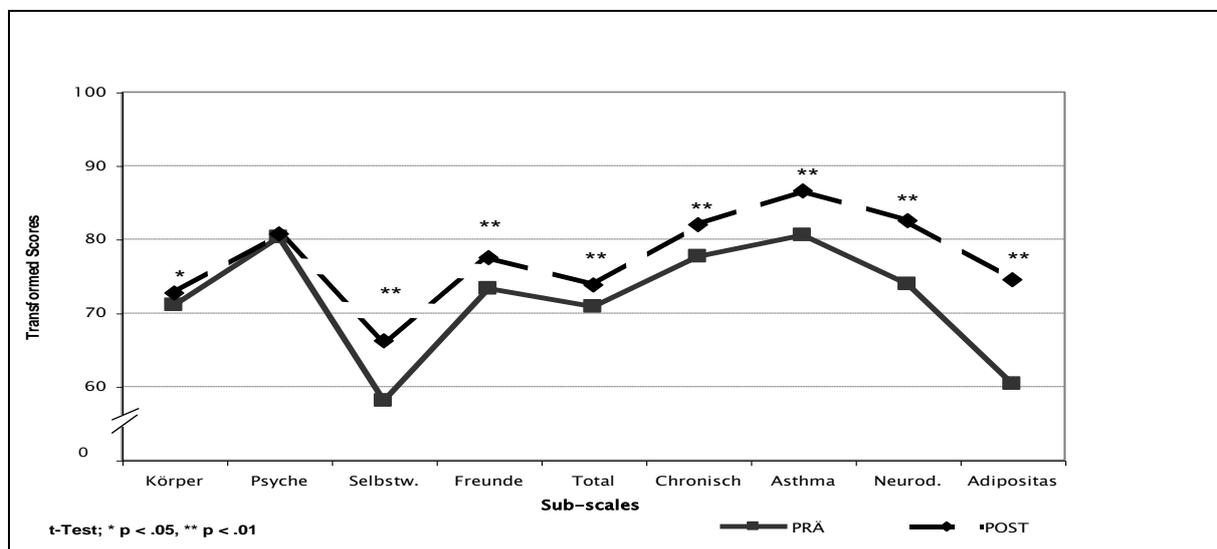


Figure 3: KINDL Sub-Scale Differences by Time of Measurement . T-Test; * $p \leq .05$, ** $p \leq .01$

For the overall group, the Kazis effect size varied between $d=.02$ and $.69$, the changes between before and after rehabilitation were particularly pronounced for the dimension Self-Esteem and also in terms of the Total Score. Looking at the individual diagnostic groups, Asthma and Neurodermatitis displayed effects in the field of the changes in chronic-generic and the asthma-specific module. In the Adiposity group, distinct effects were observed in the field of changes in Self-Esteem, Total Score and the disease-specific obesity module $d=.69$.

Table 5: Strength of Effect $t1 - t2$ (KAZIS effect size)

KINDL sub-scale	No. of items	d total	d asthma	d neurod.	d obesity
Physical	4	.10	.08	.02	.13
Emotional	4	.03	.00	.11	.02
Self-Esteem	4	.40	.14	.12	.56
Family	4				
Friends	4	.23	.18	.20	.26
School	4				
Total	24	.24	.06	.11	.33
Disease module	6	.24	.07	.08	.33
Disease-specific module	12		.51	.50	.82

1.4 Execution

The KINDL^R questionnaire was designed in order to obtain a self-assessment and an external assessment of health-related quality of life in children and adolescents in a wide range of ages and independently of current health status. For each item, the children and teenagers are required to mark the response that comes closest to their own personal experiences.

Parents are asked to complete the KINDL^R questionnaire as proxies, i.e. they are asked to judge the children's quality of life from their own point of view (Ravens-Sieberer et al., a).

In developing the KINDL^R questionnaire, a great deal of emphasis was placed on ensuring that the questions and instructions are straightforward and easy to understand. Both the self-assessment version and the version for external assessment include the necessary instructions for completion and can therefore be answered by children, adolescents and parents without any further assistance from other persons. It is not necessary for a supervisor to be constantly present while the KINDL^R questionnaire is being completed although this may be advisable in the case of children whose reading skills are perhaps not of a necessary standard. In such cases, the KINDL^R questionnaire can be administered in the

form of an interview (face-to-face or by telephone). Experiences and results so far indicate a high practicability of telephone interviews (Bullinger u. Bahner, 1997).

The time needed to complete the KINDL^R questionnaire, as measured empirically in a series of studies, varies between 5 and 15 minutes, depending on the age of the children/teenagers. The average time for completion is 10 minutes, whereby younger children usually require longer to complete the questionnaire. There is no time limit for completing the questionnaire, however for the self-assessed version it is advisable to have the individual questionnaires checked by an authorised person for completeness, since the analysis of the questionnaire may be jeopardised if only a few items are answered.

If both the self-assessment and external assessment versions of the KINDL^R questionnaire are used, it is crucial to ensure that the children/teenagers and parents complete the questionnaires independently of one another!

One means of conducting surveys using the KINDL^R questionnaire, beyond the simple paper-and-pencil questionnaire form, is to include the KINDL^R questionnaire in computer-aided diagnoses and to instruct the children/teenagers on how to enter their own data using a laptop computer. This option is available via the CAT-Screen program (Ravens-Sieberer et al., b). In the long term, the approach of a computer-assisted, multimedia version of the KINDL^R questionnaire would seem sensible particularly in the clinical field, as a routine means of documenting initial and final check-ups (on admission and prior to being discharged) in children and adolescents.

1.5 Interpretation and Reference Values

The scores achieved on the individual KINDL^R sub-scales and the KINDL^R total score represent a quantification of the subject's health-related quality of life from the respondent's point of view. There are three ways of interpreting these scores:

First of all, the values within the individual sub-scales can be studied directly. The distance from the possible limits (maximum and minimum achievable values) can give a first indication of a respondent's self-assessment.

The second means of interpretation consists in comparing the sub-scale scores of individuals or populations with the reference values for corresponding age-groups and sexes. This can be done both in terms of the healthy comparison group and, where appropriate, with reference to specific diseases. Here the relative deviation of the measured value from the expected value can be quoted.

In a third possible means of interpretation, changes in the patient's clinical condition can be related to changes in his or her self-reported health status based on clinical measurements and quality of life data collected at the same time.

Until the data from a standard sample is available for the KINDL^R questionnaire, the results of a large sample of Hamburg school children (n = 1501) can be used as a preliminary reference for healthy children (Sample 1, cf. Section 1.3). For the following reference values of the sub-scales transformed to a base of 100, the items missing from the short version have been estimated using regression analysis. The scores for the "Disease" module are based on a sample of chronically ill children (Sample 2, cf. Section 1.3). Here again, the scale has been transformed to a range of 0 to 100.

	Children (7 - 13 years old) n = 918				Adolescents (14 - 17 years old) n=583			
	Girls		Boys		Girls		Boys	
	mean	s.d.	mean	s.d.	mean	s.d.	mean	s.d.
KINDL^R - Total Quality of Life Score -100	76,83	8,63	76,67	8,66	70,78	10,01	73,54	8,83
KINDL^R - Physical Well-being-100	74,43	14,19	76,68	13,03	68,24	17,38	77,18	13,07
KINDL^R - Emotional Well-being -100	83,11	11,33	82,89	10,67	79,41	12,89	79,49	11,80
KINDL^R - Self-Esteem -100	66,68	17,83	66,52	18,95	58,14	19,06	63,27	19,34
KINDL^R - Family -100	84,40	12,85	83,58	13,14	75,51	17,68	79,56	17,05
KINDL^R - Friends -100	78,10	13,78	78,21	12,78	78,06	13,47	78,43	11,96
KINDL^R - School -100	74,10	12,29	72,35	12,88	65,19	13,21	63,58	14,04
KINDL^R - Disease -100	60,56	15,25	64,17	13,75	60,10	14,80	64,91	12,90

2 Analysing the KINDL^R Questionnaire

The following instructions for analysing the six sub-scales that make up the KINDL^R questionnaire and for determining the total score contain general information about the analysis and describe the necessary steps from data entry through to analysis. These steps are the same for all forms – Kiddy, Kid and Kiddo – and for the children’s/teenagers’ and parents’ versions of the KINDL^R questionnaire. Formulas will then be described for summarising the items and for converting the results into sub-scale scores. Finally, the possible ways of dealing with missing data will be dealt with.

As with all standardised instruments, the KINDL^R sub-scales can only be interpreted meaningfully if the contents and the method of analysis are standardised. Changing the content of the questionnaire or the individual steps in its analysis can destroy the reliability and validity of the results. Minor changes can affect the results to a point where comparisons with reference data have to be called into question, and the results of different studies can no longer be compared.

2.1 General Remarks on the Analysis

The KINDL^R questionnaire is analysed by adding the item responses marked on each sub-scale, with certain items being reversed beforehand. Only sub-scales in which less than 30% of the items are missing can be analysed, whereby mean value replacement is used to deal with such missing values. A computerised analysis program exists for the KINDL^R questionnaire, which carries out both item reversal and the summarisation of the sub-scales and their addition (see Chapter 3, Data Analysis).

The items and sub-scales of the KINDL^R questionnaire are calculated such that a higher score corresponds to a higher health-related quality of life. Once the data have been entered, analysis of the items and sub-scales is carried out in four steps:

1. Recoding items. This is necessary for 10 (in certain versions for 11) items.
2. Calculating sub-scale scores by adding the items in each sub-scale (raw scores).
3. Combining these to form a total score; and
4. transformation of the sub-scale scores to values between 0 and 100.

These steps may be conducted using the algorithms presented in this Manual, or else using the in the Data Analysis Files enclosed SPSS statistics package.

2.2 Data Entry

The answers to the items in the KINDL^R questionnaire should be entered exactly as coded in the questionnaire, in other words the number that the respondent has ticked, checked, circled or marked in some other way (raw value). In doing so, the response “never” is always assigned the value 1, the alternative response “all the time” the value 5. Occasionally, there may nevertheless be some confusion as to which number to enter. The following guidelines suggest how the most common coding problems should be dealt with:

- If two possible responses are marked for a single question and these responses are adjacent to one another, then one response is chosen according to a random procedure and entered.
- If two possible responses are marked for a single question and these responses are not adjacent to one another, then the item is coded as a missing value.
- If three or more possible responses are marked for a single question, the item is coded as a missing value.

2.3 Recoding Items

The next step following data entry is to recode the responses. Recoding is the process by which item scores are deduced which will then be used in calculating the sub-scale scores. This process consists of several steps:

1. Values that lie outside the valid range are converted into missing values;
2. Scores are reversed; and
3. Missing values are replaced by specific scores which are estimated for each individual.

2.3.1 Responses outside the valid range

Before the final item scores are assigned, all items should be checked to see whether answers occur that lie outside the possible range. Answers outside the valid range are values which are lower than the minimum score of 1 or higher than the maximum score of 5. Scores outside this range are usually due to errors made during data entry, and should – where possible – be replaced by the correct values by referring to the original questionnaire. If the questionnaire is not available, all values that lie outside the permitted range should be recoded as missing values.

2.3.2 Reversing items

10 (in some cases 11) KINDL^R items are worded in such a way that a higher item score implies a poorer health-related quality of life. Reversing the values of these items is necessary in order to

ensure that higher scores correspond to a higher health-related quality of life for all the KINDL^R items and sub-scales. Chapter 2.5.1 gives details of which items need to be reversed.

2.4 Dealing with Missing Data

In rare cases (1-2% of respondents, or fewer), respondents fail to answer one or several items on a sub-scale. An advantage of sub-scales consisting of several items (like the sub-scales of the KINDL^R) is that a sub-scale score can still be estimated even when some items are missing. The algorithm recommended in the Data Analysis Files replaces each missing value by an estimate made for that specific individual, provided the respondent has answered at least 70% of the items on the sub-scale. This step in the analysis is integrated into the program for data analysis included on the disc.

2.5 Calculation of Sub-Scale Scores

2.5.1 Kid-KINDL^R and Kiddo-KINDL^R

When analysing the KINDL^R questionnaire on the quality of life of children and adolescents in the age range of 7 to 17-year-olds, the following six sub-scale scores can be calculated:

1. Physical Well-being (Items 1 Λ , 2 Λ , 3 Λ , 4)
2. Emotional Well-being (Items 5, 6 Λ , 7 Λ , 8 Λ)
3. Self-esteem (Items 9, 10, 11, 12)
4. Family (Items 13, 14, 15 Λ , 16 Λ)
5. Friends (Items 17, 18, 19, 20 Λ)
6. School (Items 21, 22, 23 Λ , 24 Λ)

A Total Score is formed for all the items. Finally, if necessary an additional sub-scale can be calculated using the six questions in the "Disease" module:

7. Disease (Items 26 Λ , 27 Λ , 28, 29 Λ , 30 Λ , 31 Λ)

The values are as follows:

- 1 = never
- 2 = rarely
- 3 = sometimes
- 4 = often
- 5 = all the time
- Missing value = "blank"

Important! The items marked with a Λ have to be reversed, i.e. 1=5, 2=4, 3=3, 4=2, 5=1. Response value 5 ("all the time") must be the positive end of the item.

!!! Data entered into the data base must always be in the form of raw data!!!

The sub-scale scores can be quoted in various ways. In the SPSS syntax used in the data analysis files, the following quantities are calculated:

- **sum score**
- sub-scale score (corresponding to the mean of the item scores)
- sub-scale score transformed to a range of 0 to 100

2.5.2 Formulae and examples for calculating sub-scale sum scores

Sum score = Sum of sub-scale items

Sub-scale score = $\frac{\text{Sum of sub - scale items}}{\text{Number of sub - scale items}}$

Example: Physical well-being sub-scale score = $\frac{\text{Sum of Items 1, 2, 3, 4}}{4}$

Total sub-scale score = $\frac{\text{Sum of all items}}{24}$

Sub-scales transformed to 100 = $\frac{\text{Sub - scale score - lowest possible score}}{\text{Possible range of raw score}} \times 100$

The calculations described here may be found in the SPSS file "kid_kindl_k.sps" (or the corresponding files for other versions) on the disc for data analysis.

2.5.3 Kiddy-KINDL^R

The calculation of sub-scale scores for the parents' version of the Kiddy KINDL^R is essentially the same as described above for the other KINDL^R versions. However the 22 additional items (Items 25 to 46) form a separate sub-scale known as "Kiddy Parents". Here the following items need to be reversed: 25, 28, 31, 34, 36, 38, 39, 41, 44, 45, 46, 48, 49, 51, 52, 53.

In the self-assessment version of the Kiddy interview, only the total score is calculated, and where necessary the additional sub-scale "Disease".

The values for the children's version are as follows:

1 = never

2 = sometimes

3 = very often

2.6 Contact

If you have any questions about the KINDL^R questionnaire, its short form, the disease-specific modules, translations or the computer questionnaire CAT-Screen, we will be happy to assist you.

You can contact us at the following address:

University Medical Center Hamburg-Eppendorf
Center for Psychosocial Medicine
Department of Child and Adolescent Psychiatry, Psychotherapy and Psychosomatics
Prof. Dr. Ulrike Ravens-Sieberer
Deputy Clinical Director
Head of Research
Research Director "Child-Public-Health"
Martinistr. 52, W 29 (Erikahaus)
D - 20246 Hamburg
Email: ravens-sieberer@uke.de

3 Data Analysis

After sending in the completed KINDL^R user form, we will send you the data analysis files, which allow you to enter and analyse your KINDL^R data simply and in a standardised form.

The data analysis files contain three types of files:

1. SPSS masks for entering KINDL^R data (recognisable by the “.sav” file extension)
2. SPSS syntax files for forming scales (recognisable by the “.sps” file extension)
3. “Read Me” files containing advice on using the SPSS files

Each KINDL^R version has its own SPSS mask and its own syntax file:

Mask	Syntax
Kiddy_Kindl_c_3.sav	kiddy_kindl_c.sps
Kid_Kindl_c_3.sav	kid_kindl_c.sps
Kiddo_Kindl_c_3.sav	kiddo_kindl_c.sps
Kiddy_Kindl_p_3.sav	kiddy_kindl_p.sps
Kid_Kindl_p_3.sav	kid_kindl_p.sps

Parent and children versions may be identified by the ending “_c” (= children) and “_p” (= parents). The ending “_3” indicates that the masks are designed for entering up to three separate time points.

Because of the differences between the Kiddy-KINDL^R and the other KINDL^R versions, there are two “Read Me” files: “Read Me_Kindl” and “Read Me_Kiddy” (see Appendix).

4 Further Reading

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- Herschbach, P., Henrich, G. (2000). Fragen zur Lebenszufriedenheit (FLZ^M). In: U. Ravens-Sieberer, & A. Cieza (Hrsg.). *Lebensqualität und Gesundheitsökonomie in der Medizin - Konzepte, Methoden, Anwendung*. München: Ecomed-Verlag, 98-110.
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- Ravens-Sieberer, U. & Cieza, A. (Hrsg.) (2000). *Lebensqualität und Gesundheitsökonomie in der Medizin - Konzepte, Methoden, Anwendung*. München: Ecomed-Verlag.
- Ravens-Sieberer, U., Görtler, E. & Bullinger, M. (2000a). Subjektive Gesundheit und Gesundheitsverhalten von Kindern und Jugendlichen - Eine Befragung Hamburger Schüler im Rahmen der schulärztlichen Untersuchung. *Gesundheitswesen*, 62, 148-155.
- Ravens-Sieberer, U., Redegeld, M. & Bullinger, M. (2000b). Lebensqualität chronisch kranker Kinder im Verlauf der stationären Rehabilitation. In J. Neuser & J. T. de Bruin (Hrsg.), *Verbindung und Veränderung im Fokus der Medizinischen Psychologie*, 2000 (S. 89). Lengerich: Pabst Science Publishers.
- Ravens-Sieberer, U., Görtler, E., Schwarzmueller, M., Bullinger, M. (in press a). The proxy-by-parent problem - a comparison of direct and circular proxy QoL Ratings with children's self-report. *Quality of Life Research*.
- Ravens-Sieberer, U. Heilmann, M., Wallese, S. (in press b). Assessment of Quality of Life in Young Children with a Computer Assisted Touch Screen Program (Cat-Screen) - Reliability, Validity and Feasibility. *Quality of Life Research*.

5 Appendix

1. "Read Me_Kindl" File

Dear KINDL^R User,

In our data analysis files we have included a template for a KINDL^R database (children and parents, different age versions) and a data analysis file for the KINDL^R questionnaire. The calculations can be done using the SPSS program suite.

Please pay special attention to the following points:

The following comments concern the Kid-KINDL^R (for children between the ages of 7 and 13) and the Kiddo-KINDL^R (for adolescents between the ages of 14 and 17). **If you are using the Kiddy-KINDL^R (for children between the ages of 3/4 and 6) please refer to the corresponding 'Read Me' file.**

The file 'kid_kindl_c.sav' can be used to enter all the Kid-KINDL^R data supplied by children. Analogously, the file 'kid_kindl_p.sav' is for the parents' data. The Kiddo-KINDL^R data of adolescents can be entered into the file 'kiddo_kindl_c.sav'. For all SPSS files on this disc, the files for the child/adolescent versions can be identified by a "_c" (= children), while the parents' versions bear an "_p" (= parents).

!!! Data entered into the data base must always be in the form of raw data !!!

The values of the KINDL^R items are as follows: 1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = all the time, "blank" is treated as a missing value.

The values of all the other variables are recorded in the SPSS file.

Further important variables in the file are:

- 'id' = identification number (five digits), beginning with a „9“ for children, with a „7“ for parents. Apart from this, children and parents must have the same ID number so that data sets can subsequently be assigned to each other in pairs!
- 'sex' = sex (1=boy, 2=girl)
- 'name' = name of the child
- 'age' = age at the time point in question (enter years and months as decimal figures: age = years + (months/12), e.g. 8 years and 6 months = 8.5)

The parents' version has the following additional variables:

- **'parent'** = parent completing questionnaire
(1=mother, 2=father, 3=both together, 4=other)
- **'pare_2'** = completing parent, other details (text field)

The instructions for reversing the raw scores are to be found in the analysis files 'kid_kindl_c.sps', 'kid_kindl_p.sps', and 'kiddo_kindl_c.sps', as are the commands for forming scales.

The program file 'kid_kindl_c.sps' also shows how six sub-scales and a total score can be formed. Forming sub-scales is carried out in an analogous way to the psychometric testing of the 24-item KINDL.

The six sub-scales correspond to the arrangement in the questionnaire:

- Physical well-being (Items 1 to 4)
- Emotional well-being (Items 5 to 8)
- Self-esteem (Items 9 to 12)
- Family (Items 13 to 16)
- Friends (Items 17 to 20)
- School (Items 21 to 24)

In addition, where necessary an additional sub-scale can be formed from the six questions in the "Disease" module (Items 26 to 31).

For each sub-scale, the results are calculated in three forms: a summed score, a mean score and finally a score transformed to a scale of 0 to 100.

If you have any questions about data analysis, please do not hesitate to contact us at (Tel: +49 - 40 - 7410 - 57377).

Yours sincerely

Dr. Ulrike Ravens-Sieberer M.P.H.

2. "Read Me_Kiddy" File

Dear KINDL^R User,

In our data analysis files we have included a template for a Kiddy-KINDL^R database (children and parents) and a data analysis file for the KINDL^R questionnaire. The calculations can be done using the SPSS program suite.

Please pay special attention to the following points:

The file 'kiddy_kindl_c.sav' can be used to enter all the Kiddy-KINDL^R data supplied by children. Analogously, the file 'kiddy_kindl_p.sav' is for the parents' data. For all SPSS files on this disc, the files for the child/adolescent versions can be identified by a "_c" (= children), while the parents' versions bear an "_p" (= parents).

!!! Data entered into the data base must always be in the form of raw data !!!

The values of the Kiddy-KINDL^R items are as follows:

1 = never, 2 = sometimes, 3 = very often.

For the parents' version, the following values apply:

1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = all the time.

"Blank" is treated as a missing value.

The values of all the other variables are recorded in the SPSS file.

Further important variables in the file are:

- **'id'** Identification number (five digits), beginning with a „9“ for children, with a „7“ for parents. Apart from this, children and parents must have the same ID number so that data sets can subsequently be assigned to each other in pairs!
- **'sex'** sex (1=girl, 2=boy)
- **'name'** name of the child
- **'age'** age at the time point in question (enter years and months as decimal figures: age = years + (months/12), e.g. 8 years and 6 months = 8.5)

The parents' version has the following additional variables:

- **'parent'** parent completing questionnaire (1=mother, 2=father, 3=both together, 4=other)
- **'pare_'** completing parent, other details (text field)

The instructions for reversing the raw scores are to be found in the analysis files 'kiddy_kindl_c.sps' and 'kiddy_kindl_p.sps', as are the commands for forming scales.

The program file 'kiddy_kindl_c.sps' also shows how a total score can be formed from the twelve items in the children's version. In the parents' version, on the other hand, ('kiddy_kindl_p.sps') six sub-scales can be formed. Forming sub-scales is carried out in an analogous way to the psychometric testing of the 24-item KINDL.

The six sub-scales correspond to the arrangement in the questionnaire:

1. Physical well-being (Items 1 to 4)
2. Emotional well-being (Items 5 to 8)
3. Self-esteem (Items 9 to 12)
4. Family (Items 13 to 16)
5. Friends (Items 17 to 20)
6. School (Items 21 to 24)

In addition, a specific sub-scale for parents of children up to the age of 7 is formed: Kiddy Parents (Items 25 to 46).

Finally, where necessary an additional sub-scale can be formed from the six questions in the "Disease" module (children: Items 14 to 19; parents: 48 to 53).

For each sub-scale, the results are calculated in three forms: a summed score, a mean score and finally a score transformed to a scale of 0 to 100.

If you have any questions about data analysis, please do not hesitate to contact us at (Tel: +49 - 40 - 7410 - 57377).

Yours sincerely

Dr. Ulrike Ravens-Sieberer M.P.H.