



SNAKE

**SLEEP QUESTIONNAIRE FOR CHILDREN
WITH SEVERE PSYCHOMOTOR
IMPAIRMENTS**

MANUAL

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2014

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Children's and Adolescents' Clinic Datteln
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[Schlafragebogen für Kinder mit **n**eurologischen und anderen **k**omplexen **E**rkrankungen]

Sleep questionnaire for children with neurological and other complex illnesses

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Background

Introduction

Between 25 and 40% of all children and adolescents have a disturbed sleep-wake rhythm (Wiggs et al. 1996). In children with neurological and other complex illnesses, sleep disorders as well as daytime restlessness, caused by the sleep disorders, arise significantly more often, with a prevalence of 50 to 80%. The symptoms are more pronounced, show no spontaneous remission and cause considerable impairment in participation opportunities for the children and in the quality of life of their parents (Didden et al. 2002). In spite of the high prevalence and clinical relevance of persistent sleep disorders and daytime restlessness in these children, these conditions are hardly considered in diagnosis and therapy (Tietze et al. 2012).

Children and adolescents with neurological and other complex illnesses belong to the group of people with severe disabilities. The assessment of their sleep behavior is made more difficult above all by their impaired communicative and cognitive competence. For this reason it is necessary to have the sleep behavior of these children evaluated by their parents or other caregivers (Maas et al. 2011). But to date there have been no third-party observation instruments for children with severe disabilities (Tietze et al. 2012).

With the *Sleep questionnaire for children with neurological and other complex illnesses (SNAKE - Schlaffragebogen für Kinder mit neurologischen und anderen komplexen Erkrankungen)*, a differentiated third-party observation instrument has been developed. It makes possible the reliable and valid reporting of sleep behavior in these children and adolescents (Blankenburg et al. 2013). With such a standardized instrument it is possible to derive necessary and helpful indications for the multidimensional care of this clientele and the evaluation of the course of therapy.

Development and validation of the questionnaire

The item generation of the SNAKE questionnaire was based on the "International Classification of Sleep Disorders" (ICSD; American Academy of Sleep Medicine, 2005). In a further step, the items were compiled from surveys of experts and parents. The factor structure, validity and reliability of SNAKE was investigated within the framework of a multicentric study in Germany of N=224 children and adolescents with neurological and other complex illnesses who were not primarily in treatment for sleep problems. The analyses carried out showed the instrument to have good to very good psychometric characteristics as well as simple and economical applicability (Blankenburg et al. 2013).

To the questionnaire

- 1. Basic concept** With the help of SNAKE, parents assessed the sleep behavior, quality of sleep and daytime behavior of their children during the preceding four-week period. All questions considered the disabilities and special needs of children with neurological and other complex illnesses.

2. Field of application

SNAKE is a third-party observation instrument for children and adolescents with neurological and other complex illnesses, and can be filled out by those close to the children (for example, parents or caregivers). SNAKE is validated for ages 1 to 25 years and is suited to measuring the status and course of therapy.

3. Structure

The SNAKE sleep questionnaire comprises in total **16 sets of questions**. These show **six components** of childhood sleep (see Table 1).

Components I-V record information on the child's sleep based on individual items or simple calculations.

Table 1: Overview of all SNAKE components

I. Sleep conditions	(4g) „How often did your child sleep in your bed at night?“ (4h) „How often did your child sleep in a room with other people?“ (4i) „How often did your child take medication to help him/her sleep“ (7) „How often ... in your child's bedroom? ... were the lights switched on (7a) / ... could noise (e.g., street noise) be heard (7b) / ... was the radio or TV running (7c) / ... was the door open“ (7d)
II. Sleep Onset latency	(2) „How long did it usually take for your child to fall asleep?“ (average sleep onset latency)
III. Length of sleep	(3) „How many hours of sleep did your child actually get at night?“ (length of sleep)
IV. Sleep efficiency	Ratio of total sleep time to time spent in bed: (1) „At what time did you usually put your child to bed at night?“ (bedtime) (11) „At what time did your child usually wake up in the morning?“ (wake up time)
V. Sleep quality	(6) „How would you rate your child's sleep quality overall?“ (sleep quality)
VI. Symptoms and consequences of sleep disorders	see Table 2

Component VI shows symptoms and consequences of sleep disturbances on **5 scales** (see Table 2). A total score can be calculated for each of the individual scales.

Table 2: SNAKE Component VI scales (symptoms and consequences of sleep disorders)

Scale 1 Disturbances going to sleep	(2) „How long did it usually take for your child to fall asleep?“ (average sleep latency) (4a) „How often did your child resist going to bed (at bedtime)?“ (4b) „How often was your child afraid of falling asleep or of being alone?“ (4c) „How often did your child need your help to fall asleep?“ (4d) „How often did your child have restless sleep and rolling movements while it was falling asleep?“
Scale 2 Disturbances remaining asleep	(5) „How long would you say your child was awake at night on average?“ (average awake time) (4e) „How often did your child wake up during the night?“ (4f) „How often did your child have trouble falling asleep again if awakened?“ (9a) „My child was lying restlessly in his/her bed.“ (9b) „My child was crying and screaming in his/her bed.“
Scale 3	(8c) „How often did your child have a bad sleep because of breathing difficulties?“

Arousal disorders	(10a) „How often did your child snore while he / she was asleep at night?“ (10b) „How often did your child pause between breaths while he / she was asleep at night?“ (10c) „How often did your child tilt his/her head while he / she was asleep at night?“ (10d) „How often did your child grind teeth while he / she was asleep at night?“ (10e) „How often did your child sweat excessively while he / she was asleep at night?“
Scale 4 Daytime sleepiness	(12) „How often did your child fall asleep during the day?“ (13b) „When your child had a bad sleep at night, how often did he / she fall asleep unexpectedly during the day?“ (14) „How many hours did your child sleep during the day in total?“ (day time sleep)
Scale 5 Daytime behaviour disorders	(13a) „When your child had a bad sleep at night, how often did he/she show physical exhaustion during the day?“ (13c) „When your child had a bad sleep at night, how often did he/she become less balanced during the day?“ (13d) „When your child had a bad sleep at night, how often did he/she become restless during the day?“ (13e) „When your child had a bad sleep at night, how often did he/she show aggression during the day?“

Some items aren't assigned to any of the six components and deliver relevant clinical anamnestic information:

- (8a) „How often did your child have a bad sleep because of pain?“;
(8b) „How often did your child have a bad sleep because of epileptic seizure?“;
(15) „How often was your child restless during the day?“.

4. Quality criteria

Reliability

Satisfactory scores for internal consistency (α – Cronbach's Alpha) as well as retest reliability (r_{rt}) within an 8-week interval for the scales of component VI were obtained:

Scales of component VI	Cronbach's α	r_{rt}
Scale 1 - Disturbances going to sleep	$\alpha = .81$	$r_{rt} = .72$
Scale 2 - Disturbances remaining asleep	$\alpha = .85$	$r_{rt} = .86$
Scale 3 - Arousal disorders	$\alpha = .72$	$r_{rt} = .74$
Scale 4 - Daytime sleepiness	$\alpha = .83$	$r_{rt} = .86$
Scale 5 - Daytime behaviour disorders	$\alpha = .86$	$r_{rt} = .74$

Validity

The SNAKE factor structure could be verified in a confirming factor analysis. Good Fit indices (Chi-squared statistics ($\chi^2 = 1.6$); Comparative Fit Index (CFI) = .92; Tucker Lewis Index (TLI) = .93; RMSEA = .53 were shown. Also, the correlations of SNAKE subscales with measurements of comparable subscales of the Sleep Disturbance Scale for Children (SDSC; Bruni et al. 1996) substantiate the convergent validity of the questionnaire (Blankenburg et al. 2013).

Standardization

Standards in the form of T-scores and percentile ranks for each scale are available for the assessment of the clinical relevance of the questionnaire's results (Appendix 2). The standard scores are based on data of N=224 children and adolescents with neurological and other complex illnesses who were not primarily in treatment due to sleep problems.

Application

1. **Materials**
 - Original questionnaire
 - Evaluation tool (see Appendix 1)
2. **Implementation**

The questionnaire can be filled out by the parents or other caregivers of the child without further instructions. Instructions as to the completion of the questionnaire are at the beginning of each section. Further instructions can be given if necessary.
3. **Evaluation and interpretation**

Components I-V

 - I. Sleep conditions**

Sleep location and sleep disrupting factors of the underlying illness or the surroundings as well as medications are recorded here. Each item is interpreted individually.

limits:

1-2 times a week	satisfactory
≥ 3 times a week	bad
 - II. Onset latency**

The average length of time required to get to sleep (Item 2) indicates the length of the transition from full wakefulness to sleep (time to start of sleep).

limits:

≤ 15 minutes	very good
16-30 minutes	good
31-60 minutes	satisfactory
> 60 minutes	bad
 - III. Length of sleep**

The entire length of sleep (Item 3) can differ from the total number of hours the child has spent in bed.

limits:

≥ 7 hours	very good
6-7 hours	good
5-6 hours	satisfactory
< 5 hours	bad
 - IV. Sleep efficiency**

Sleep efficiency shows the relationship between the entire length of sleep and the time the child has spent in bed. This is calculated using the following formula:

$$\text{sleep efficiency (\%)} = \frac{\text{length of sleep (item 3)}}{\text{wake up time - bedtime (item 11) (item 1)}} \times 100$$

limits:

≥ 85%	very good
75-84%	good
65-74%	satisfactory
< 65%	bad
 - V. Sleep quality**

Sleep quality (Item 6) describes the subjective assessment of the child's sleep relative to quality and well-being on a 4-step numerical scale: "very good – good – satisfactory – poor".

*Component VI
scale scores*

The range of scores of the items assigned to the 5 scales of Component VI is between 1 and 4. The total score of a scale results from the addition of its respective raw scores. Missing scores should be replaced as described in Table 3. The following total range of scores and limits for missing scores result for the individual scales:

Table 3: Component VI scales' range of scores

Scales of component VI	range of values	Handling with missing values
Scale 1 - Disturbances going to sleep	5 - 20	Maximum of one missing value per scale. This is replaced by the average of the scale .
Scale 2 - Disturbances remaining asleep	5 - 20	
Scale 3 - Arousal disorders	6 - 24	Scale calculation is not possible with a missing value.
Scale 4 - Daytime sleepiness	3 - 12	
Scale 5 - Daytime behaviour disorders	4 - 16	

The evaluation tool in Appendix 1 can be used for calculation of scales. The T-scores of the individual scales can be taken from Appendix 2; the percentiles are in Appendix 3.

Assessment

The SNAKE questionnaire constitutes a valid and reliable instrument for the recording of sleep behavior in children and adolescents with neurological and other complex illnesses. The distribution parameters of the available German norm sample provide a rational basis for preliminary diagnostic decisions. With SNAKE a new instrument has been developed that makes possible a comprehensive inquiry into symptoms based on the ICSD.

Source

The SNAKE questionnaire can be referred to at:
The German Paediatric Pain Centre and Paediatric Palliative Care Centre
Children's and Adolescents' Clinic Datteln – University of Witten/Herdecke
www.deutsches-kinderschmerzzentrum.de

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Appendix 1: Evaluation tool for the calculation of SNAKE's 5 scales

Item	Response categories for the Item evaluation	Item raw value	At one missing value (mv)	Scale total score	T-Score (Appendix 3)	Percentile rank (Appendix 3)
Scale 1 - Disturbances going to sleep						
2	1 = up to 15 minutes; 2 = 16 - 30 minutes; 3 = 31 - 60 minutes; 4 = 61 - 90 minutes n		mv = $\Sigma/4$	Σ	T	PR
4a						
4b	1 = never; 2 = less than once a week; 3 = once or twice a week;					
4c	4 = three or more times a week					
4d						
Scale 2 - Disturbances remaining asleep						
4e	1 = never; 2 = less than once a week; 3 = once or twice a week;		mv = $\Sigma/4$	Σ	T	PR
4f	4 = three or more times a week					
5	1 = never; 2 = 0,2 - 0,9 hours; 3 = 1 - 2 hours; 4 = >2,1 hours					
9a	1 = never; 2 = less than once a week; 3 = once or twice a week;					
9b	4 = three or more times a week					
Scale 3 - Arousal disorders						
8c			mv = $\Sigma/5$	Σ	T	PR
10a						
10b	1 = never; 2 = less than once a week; 3 = once or twice a week;					
10c	4 = three or more times a week					
10d						
10e						
Scale 4 - Daytime sleepiness						
12	1 = never; 2 = less than once a week; 3 = once or twice a week; 4 = three or more times a week		Σ	T	PR	
13b	1 = never; 2 = rarely; 3 = sometimes; 4 = often					
14	1 = never; 2 = 0,1 - 1 hours; 3 = 1,1 - 3 hours; 4 = > 3,1 hours					
Scale 5 - Daytime behaviour disorders						
13a			Σ	T	PR	
13c						
13d	1 = never; 2 = rarely; 3 = sometimes; 4 = often					
13e						

Appendix 2: Distribution parameters (Standards in the form of T-scores and percentile ranges)

Scale total score	Scale 1 - Disturbances going to sleep		Scale 2 - Disturbances remaining asleep		Scale 3 - Arousal disorders		Scale 4 - Daytime sleepiness		Scale 5 - Daytime behaviour disorders	
	T-Score	PR	T-Score	PR	T-Score	PR	T-Score	PR	T-Score	PR
3							37	0,10		
4	36	0,08	34	0,05			41	0,18	36	0,08
5	38	0,12	34	0,05			44	0,27	39	0,14
6	40	0,16	37	0,10	39	0,14	48	0,42	42	0,21
7	43	0,24	39	0,14	41	0,18	51	0,54	45	0,31
8	45	0,31	41	0,18	43	0,24	54	0,66	48	0,42
9	48	0,42	43	0,24	45	0,31	58	0,79	50	0,50
10	50	0,50	45	0,31	48	0,42	61	0,86	53	0,62
11	52	0,58	47	0,38	50	0,50	65	0,93	56	0,73
12	55	0,69	49	0,46	52	0,58	68	0,96	59	0,82
13	57	0,76	52	0,58	54	0,66			61	0,86
14	60	0,84	54	0,66	56	0,73			64	0,92
15	62	0,88	56	0,73	58	0,79			67	0,96
16	65	0,93	58	0,79	60	0,84			70	0,98
17	67	0,96	60	0,84	63	0,90				
18	69	0,97	63	0,90	65	0,93				
19	72	0,99	65	0,93	67	0,96				
20	74	0,99	67	0,96	69	0,97				
21					71	0,98				
22					73	0,99				
23					75	0,99				
24					76	1,0				

T-distribution: mean=50, standard deviation=10; PR: percentile range

The highlighted scores indicate the range of simple standard deviation, thus the normal range.

The calculation of standard scores was made using a random survey of N=224 children with neurological and other complex illnesses (Blankenburg et al. 2013).

Appendix 3: Visualization of the individual's sleep profile.

T-Score	Scale 1 - Disturbances going to sleep	Scale 2 - Disturbances remaining asleep	Scale 3 - Arousal disorders	Scale 4 - Daytime sleepiness	Scale 5 - Daytime behaviour disorders
76					
60					
50					
40					
34					

Note: The normal range is highlighted.