



HOST

HOLISTIC ASSESMENT OF SLEEP AND DAYLY TROUBLES IN PARENTS OF CHILDREN WITH SEVERE PSYCHOMOTOR IMPAIRMENTS

MANUAL

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Sleep questionnaire for parents of children with neurological and other complex illnesses

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Background

Introduction

Children and adolescents with neurological and other complex illnesses often suffer from persistent sleep disorders. These disorders have a negative effect on the quality of life and opportunities for participation of these children and adolescents as well as their immediate caregivers (Stores & Wiggs 2001; Polimeni et al. 2007; Boergers et al. 2007).

The only questionnaires currently available to assess parents' sleep-related impairment in connection with the sleep disorders of their children are measuring instruments with poor or untested psychometric quality (Tietze 2014).

With the questionnaire on sleep-related problems for parents of children with neurological and other complex illnesses – HOST (**H**olistic assessment of **s**leep and **d**aily **t**roubles in parents of children with severe psychomotor impairment) – an instrument has been developed and validated that makes it possible to record and assess in a differentiated way the effects of these children's and adolescent's sleep disorders on their parents (Tietze 2014). Based on such a standardized instrument it is possible to derive necessary and helpful indications for the multidimensional care of this clientele and for the evaluation of the course of therapy.

Development and Validation

The item generation of the HOST questionnaire was based on the „Pittsburgh Sleep Quality Index“ (PSQI; University of Pittsburgh, Sleep Medicine Institute). In a further step, the items were compiled from surveys of experts and parents. Its factor structure, validity and reliability were examined within the framework of a multicentric study of the parents of 214 children and adolescents with complex psychomotor illnesses in Germany. The analyses carried out showed the instrument to have good to very good psychometric characteristics as well as good and economical applicability (Tietze 2014).

Structure

1. Basic concept

With the help of HOST, parents assess their own sleep behavior over the preceding four-week period. All questions consider the disabilities and special needs of children with neurological and other complex illnesses.

2. Field of application

Assessment of sleep quality in parents of children with neurological and other complex illnesses. The *HOST* questionnaire can also be applied as a re-assessment during treatment.

3. Structure

The HOST questionnaire comprises a total of **12 sets of questions**. These show **five components** of parental sleep behavior (see Table 1).

Components I-III record information about the sleep behavior of parents on the basis of individual items. For Component IV (sleep efficiency), a score is calculated from the individual items.

Table 1: Overview of all HOST components

I. Sleep conditions	(5a) „Did you sleep in a room together with your child?“ (5b) „How often did your partner help you your child’s care during the night?“ (5c) „How often did extended care assist you with your child’s care during the night?“
II. Sleep onset latency	(1) „When have you usually gone to bed?“ (2) „How long has it taken you to fall asleep?“ (average time to fall asleep)
III. Length of sleep	(3) „When have you usually gotten up in the morning?“ (4) „How many hours of sleep did you actually get at night?“
IV. Sleep efficiency	Ratio of total sleep time to time spent in bed
V. Effects of children’s sleep disorders on parents	See Table 2.

Component V shows the effects of the sleep disorders of children and adolescents with complex neurological illnesses on their parents in 4 scales (see Table 2). A total score can be calculated for each of the individual scales.

Table 2: HOST Component V Scales (Effects of children’s sleep disorders on parents)

Scale 1 Sleep Disturbances	„How often did you have trouble sleeping, because you...“ (9a) ... were woken up by your child?“ (9b) ... got up to look after your child?“ (9c) ... had to care for your child at night (e.g. repositioning)?“ (9d) ... were worried that something could happen to your child while sleeping (e.g. seizure, spasm)?“ (10a) „Have your sleep interruptions due to your child’s condition caused insufficient sleep?“
Scale 2 Impairments of physical/ mental functioning	(9e) „How often did you have trouble sleeping, because you worried about your child’s condition concerning the future?“ (10b) „Have your sleep interruptions due to your child’s condition caused increased bad temper or distress?“ (10c) „Have your sleep interruptions due to your child’s condition caused difficulties to keep up enough enthusiasm to get things performed?“ (10d) „Have your sleep interruptions due to your child’s condition caused trouble staying awake while driving, eating meals, or engaging in social activities?“ (10e) „Have your sleep interruptions due to your child’s condition caused a negative mood change?“
Scale 3 Impairments of social functioning	(11a) „Over the years, did a lack of sleep due to your child’s condition restrict your social activities (e.g. meeting friends)?“ (11b) „Over the years, did a lack of sleep due to your child’s condition have a negative impact on your relationship with your partner?“ (11c) „Over the years, did a lack of sleep due to your child’s condition have a negative impact on affection and sex life with your partner?“ (12a) „During the last few years, did the lack of sleep due to your child’s condition and associated stress cause a crisis in your partnership?“
Scale 4 Impairments of working ability	(12b) „During the last few years, did the lack of sleep due to your child’s condition and associated stress cause illness?“ (12c) „During the last few years, did the lack of sleep due to your child’s condition and associated stress cause absence at your work?“

Item (6) „Who primarily took care of your child during the night?“ isn’t assigned to any of the five components and delivers relevant clinical anamnestic information.

4. Quality criteria

Reliability Satisfactory scores for internal consistency (α – Cronbach’s Alpha) as well as retest reliability (r_{tt}) in an 8-week interval are given for the scales of Components V.

Scales of Components V	Cronbach’s α	r_{tt}
Scale 1 - Sleep DisturbanceS	$\alpha = .90$	$r_{tt} = .78$
Scale 2 - Impairments of physical/ mental functioning	$\alpha = .91$	$r_{tt} = .69$
Scale 3 - Impairments of social functioning	$\alpha = .85$	$r_{tt} = .88$
Scale 4 - Impairments of working ability	$\alpha = .74$	$r_{tt} = .87$

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Validity The factor structure of the HOST was identified in an exploratory factor analysis. The correlations of HOST subscales with measurements of comparable PSQI subscales (Buysse et al. 1989; Carpenter 1998) substantiate the convergent validity of the questionnaire.

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=214 parents of 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 tools (see Appendix 1)
2. **Implementation** The questionnaire is presented to the parents with instructions as to its completion. Instructions precede each section of the questionnaire, and further instructions can be given if necessary.
3. **Evaluation and Interpretation**

Results of components I-IV

I. Sleep conditions Sleep location and sleep disrupting factors are recorded here. Individual items are scored.

limits:	1-2 times a week	satisfactory
	≥ 3 times a week	bad

II. Sleep 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 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 spent in bed. This is calculated with the following formula:

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

limits:	≥ 85%	very good
	75-84%	good
	65-74%	satisfactory

< 65% bad

Component V scale scores The range of scores of the items assigned to the 4 scales of Component V, as described above, is from 1 to 5. The total score of a scale results from the addition of the raw values of its respective items. The following total ranges of scores result for the individual scales:

Table 3: Component V scales' range of scores and missing values

<i>Scales of Components V</i>	<i>range of values</i>	<i>Handling with missing values</i>
Scale 1 - Sleep Disturbances	5 - 25	Maximum of one missing value per scale. This is replaced by the average of the scale .
Scale 2 - Impairments of physical/ mental functioning	5 - 25	
Scale 3 - Impairments of social functioning	4 - 20	Scale calculation is not possible with a missing value.
Scale 4 - Impairments of working ability	2 - 10	

The analysis tool in Appendix 1 can be used to calculate the scales. The T-scores of the individual scales can be taken from Appendix 2; the percentiles are in Appendix 3.

Assessment

The HOST standardized sleep questionnaire constitutes a valid and reliable instrument for the recognition of impairment of important functions in parents of children with neurological and other complex illnesses. The distribution parameters of the available German norm sample provide a rational basis for preliminary diagnostic decisions. The use of HOST in ongoing studies is necessary in order to record the frequency, manner and consequences of the effects of these children's sleep disorders, as well as to optimize long-term interventions and generate standards of care.

Source

The HOST 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

Reference

Boergers J, Hart C, Owens JA, et al. Child sleep disorders: associations with parental sleep duration and daytime sleepiness. *J Fam Psychol* 2007;21:88–94.

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Appendix 1: Evaluation tools to calculate the 4 HOST scales

Item	Response categories for the item evaluation	Item raw value	At <u>one</u> missing value (mv)	Scale total score	T-Score (Appendix 3)	Percentile rank (Appendix 3)
Scale 1 - Sleep Disturbances						
9a	1 = never; 2 = less than once a week; 3 = once or twice a week; 4 = 3 or 4 times a week; 5 = 5 times or more a week		$mv = \Sigma/4$	Σ	T	PR
9b						
9c						
9d						
10a						
Scale 2 - Impairments of physical/ mental functioning						
9e	1 = never; 2 = less than once a week; 3 = once or twice a week; 4 = 3 or 4 times a week; 5 = 5 times or more a week		$mv = \Sigma/4$	Σ	T	PR
10c						
10d						
10e						
10f						
Scale 3 - Impairments of social functioning						
11a	1 = never agree; 2 = rarely agree; 3 = sometimes agree; 4 = mostly agree; 5 = fully agree		Σ	T	PR	
11b						
11c						
12a						
Scale 4 - Impairments of working ability						
12b	1 = never agree; 2 = rarely agree; 3 = sometimes agree; 4 = mostly agree; 5 = fully agree		Σ	T	PR	
12c						

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

Scale total score	Scale 1 - Sleep Disturbances		Scale 2 - Impairments of physical/ mental functioning		Scale 3 - Impairments of social functioning		Scale 4 - Impairments of working ability	
	T-Score	PR	T-Score	PR	T-Score	PR	T-Score	PR
2							42	0.21
3							47	0.38
4					37	0.10	52	0.58
5	35	0.07	37	0.10	39	0.14	57	0.76
6	37	0.10	39	0.14	41	0.18	62	0.88
7	38	0.12	41	0.18	43	0.24	67	0.96
8	40	0.16	42	0.21	45	0.31	72	0.99
9	41	0.18	44	0.27	47	0.38	77	1.0
10	43	0.24	45	0.31	49	0.46	82	1.0
11	44	0.27	47	0.38	51	0.54		
12	46	0.34	49	0.46	53	0.62		
13	47	0.38	50	0.50	55	0.69		
14	49	0.46	52	0.58	57	0.76		
15	50	0.50	54	0.66	59	0.82		
16	52	0.58	55	0.69	61	0.86		
17	54	0.66	57	0.76	63	0.90		
18	55	0.69	59	0.82	65	0.93		
19	57	0.76	60	0.84	67	0.96		
20	58	0.79	62	0.88	69	0.97		
21	60	0.84	64	0.92				
22	61	0.86	65	0.93				
23	63	0.90	67	0.96				
24	64	0.92	69	0.97				
25	66	0.95	70	0.98				

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

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=214 children with neurological and other complex illnesses (Tietze et al, 2014).

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

T-Score	Scale 1 - Sleep Disturbances	Scale 2 - Impairments of physical/ mental functioning	Scale 3 - Impairments of social functioning	Scale 4 - Impairments of working ability
82				
60				
50				
40				
35				

Note: The normal range is highlighted.