

ORIGINAL ARTICLE

## SLEEP PROBLEMS AMONG CHILDREN WITH NEUROLOGICAL DISORDERS

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### Abstract

A study was conducted to evaluate the extent of sleep problems among children aged between 6 to 15 years old who were followed up at Penang Hospital Paediatric Clinic for various neurological disorders and compared to those with other paediatric illnesses and their healthy siblings.

A parental questionnaire was used to assess sleep problems in 48 children with neurological disorders and compared to 46 of their healthy siblings, 59 children with non-neurological paediatric illnesses and 67 of their healthy siblings. Sleep problems were clustered into five subscales: bedtime difficulties, parental involvement at time of sleep, sleep fragmentation, parasomnias and daytime drowsiness. Children with neurological disorders had significantly more sleep problems than did their siblings, those with non-neurological paediatric illnesses and their healthy siblings ( $p < 0.001$ ). This was particularly so in areas of bedtime difficulties ( $p > 0.001$ ), the amount of parental involvement ( $p < 0.01$ ) and sleep fragmentation ( $p < 0.05$ ) but not parasomnias and daytime drowsiness.

This study confirmed the presence of sleep problems in a heterogeneous group of children with neurological disorders followed up at our clinic. The findings will enable us to target appropriate management strategies to reduce the burden of care for the parents of these children.

**Key words :** *Child; neurological disorder; sleep problems*

### Introduction

Sleep-related problems occur in 20% to 30% of children in the general population.<sup>1</sup> However, difficulty in falling asleep and nightly awakenings are age-dependent and transitory in the majority of the children. Sleep disorders may also complicate certain medical conditions like bronchial asthma, obstructive sleep apnoea and other chronic illnesses.

Studies on sleep problems in children with neurological disorders are limited. Piazza et al<sup>2</sup> reported that up to 88% of children and young adults with mental retardation and severe behaviour disorders had disturbances of sleep such as delays in getting to sleep, frequent night waking or early waking. Quine<sup>3</sup> in a longitudinal study of sleep problems in 200 children with severe mental handicap reported 51% of children had settling problems, 67% of children had waking problems, and 32% of parents said they rarely got enough sleep. Sleep problems are also known to adversely affect the neurological impaired child's communication and academic skills, daytime behaviour and epilepsy.

To date, there is no epidemiological data on sleep disorders among Malaysian children with or without medical or neurological problems. The objective of this study is to evaluate the extent of sleep problems among children aged between 6 to 15 years old followed up at Penang Hospital Paediatric Clinic for various neurological disorders and compared to those with other paediatric illnesses and their healthy siblings.

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## Materials and methods

### *Subjects*

Children with known paediatric or neurological illnesses aged between 6 to 15 years old were recruited from the general paediatric and paediatric neurology clinics at Penang Hospital in the months of February to April, 2000. Two of their healthy siblings if available, one aged older and another aged younger between 6 to 15 years old were selected as controls. We excluded those patients with unclear diagnosis or still waiting for investigations and children who were non-Malaysian. Systematic sampling was used.

### *Study instrument*

Sleep, our outcome measure, was assessed by means of a pretested parental questionnaire (Appendix 1) modified from the Sleep Behaviour Questionnaire (SBQ) developed by Cortesi et al.<sup>4</sup> Although the questionnaire does not establish the formal diagnosis of sleep disorders, it may be used to assess sleep problems. It was specifically designed to assess quantity and quality of sleep as well as reluctance to go to sleep, sleep latency; parental involvement at time of sleep onset, night wakings, co-sleeping; night-time events, daytime drowsiness in different situations, and unrefreshing sleep. Each item was rated on a Likert scale from 1 (never) to 5 (always) by rating how often each item occurred in the last six months. A total sleep behaviour questionnaire (SBQ) score was obtained by computing the sums of all item scores for each particular scale. Thus, the total SBQ scores can range from 24 to 120 with higher scores representing more sleep problems. Sleep problems were also clustered into 5 subscales:—bedtime difficulties, parental involvement at time of sleep, sleep fragmentation, parasomnias and daytime drowsiness.

### *Statistical analysis*

The variables, both the total SBQ scores and the subscales scores were first tested for normality by using K-S and Lilliefors test. Since our variables were not normally distributed and to

achieve this, square root transformation was performed. Homogeneity of variance was assessed by Barlett's test. Analysis of covariance was used with health groups as independent variable and age as covariate. A post-hoc comparison by Scheffe's test was performed for statistically significant data. Categorical data on the demographic characteristics of the health status groups were analysed by Chi-square test. The data were computed and analysed by using STATISTICA statistical package. All results with *p* value less than 0.05 were considered significant.

## Results

The demographic characteristics of the 48 patients with neurological disorders (Neuro), 46 siblings of patients with neurological disorders (Neuro-S), 59 patients with non-neurological paediatric illness (GP) and 67 of their siblings (GP-S) in this study are shown in Table I. There is no significant difference among the health groups in term of gender, mean age and ethnic groups.

For children with neurological disorders, 71% of them had epilepsy as the main diagnosis. Fifteen percent of them had mental retardation or learning disability without epilepsy, 6% had movement disorders and 8% other neurological disorders. The break down of diagnostic categories in the non-neurological group was as follows:— bronchial asthma (24%), haematological illness (24%), oncological illness (15%), cardiovascular disorders (17%), endocrine disorders (8%), renal disorders (3%), and other miscellaneous conditions (9%).

The results of the SBQ scores are given in Table II. For the mean total SBQ score, children with neurological disorder scored the highest, indicating most sleep problems among the health groups ( $p = 0.00001$ ). Post-hoc comparison among the health groups for the mean total SBQ scores is significant between patients with neurological disorders and their siblings ( $p = 0.00002$ ), between patients with neurological

**Table I. Demographic characteristics of the health status group**

	Neuro	Neuro-S	GP	GP-S	<i>p</i> -value
Number	48	46	59	67	
Male	29	27	38	44	0.94
Mean age in yr (SD)	9.7 (2.6)	10.0 (2.8)	9.8 (2.2)	9.8 (2.7)	0.71
Ethnic groups:					
Malay	23	26	37	44	
Chinese	23	18	15	20	
Indian	2	2	7	0	
Others	0	0	0	3	

Neuro: children with neurological disorders  
 Neuro-S: siblings of children with neurological disorders  
 GP: children with non-neurological illnesses  
 GPS: siblings of children with non-neurological illnesses

**Table II. Results of analysis of covariance for the mean total sleep behaviour questionnaire scores, controlled for age**

	Neuro	Neuro-S	GP	GP-S	F value for group effect	<i>p</i> -value
Mean	44.0	34.5	38.4	37.0	8.95	0.00001
(SD)	(11.0)	(7.9)	(8.1)	(9.0)		

\* Higher scores indicate more sleep problems  
 Neuro: children with neurological disorders  
 Neuro-S: siblings of children with neurological disorders  
 GP: children with non-neurological illnesses  
 GPS: siblings of children with non-neurological illnesses

disorders and non-neurological patients ( $p=0.03$ ) and between patients with neurological disorders and siblings of non-neurological patients ( $p=0.001$ ). However, there is no significant difference in the mean total SBQ among other health groups.

As for the subscales scores (Table III), again children with neurological disorder had the highest scores for bedtime difficulties, parental involvement at time of sleep and sleep fragmentation indicating they had the most sleep problems among the health groups in these areas.

However, the scores did not achieve statistical significance among the health groups for parasomnias and daytime drowsiness. Post-hoc comparison is statistically significant between the health groups for the following mean subscales scores only:– bedtime difficulties: 'Neuro' and 'Neuro-S' ( $p=0.002$ ), 'Neuro' and 'GP-S' ( $p=0.02$ ); parental involvement at time of sleep: 'Neuro' and 'Neuro-S' ( $p=0.002$ ), 'Neuro' and 'GP-S' ( $p=0.01$ ); sleep fragmentation: 'Neuro' and 'Neuro-S' ( $p=0.02$ ). Children with neurological disorders also more often shared

**Table III. Results of analysis of covariance for sleep behaviour questionnaire subscales scores, controlled for age**

	Neuro mean (SD)	Neuro-S mean (SD)	GP mean (SD)	GP-S mean (SD)	F values for group effect	p-value
Bedtime difficulty	11.0 (4.0)	8.1 (3.9)	9.3 (3.4)	8.9 (3.9)	5.29	0.002
Parent involvement at time of sleep	8.6 (4.5)	5.8 (2.8)	6.9 (3.3)	6.5 (3.9)	5.24	0.002
Sleep fragmentation	8.7 (3.9)	6.7 (2.3)	7.4 (2.5)	7.1 (2.4)	3.89	0.01
Parasomnias	7.3 (2.0)	6.4 (1.5)	6.3 (1.6)	6.7 (1.6)	2.93	0.05
Daytime drowsiness	8.5 (3.3)	7.6 (2.6)	8.6 (3.1)	7.9 (2.6)	1.16	0.32

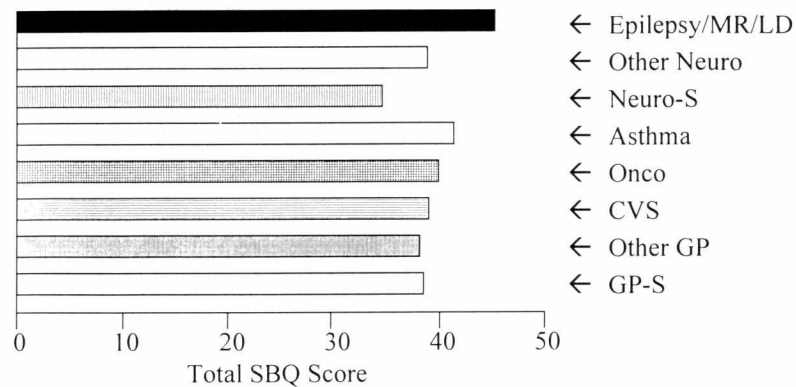
\* Higher scores indicate more sleep problems

Neuro: children with neurological disorders

Neuro-S: siblings of children with neurological disorders

GP: children with non-neurological illnesses

GPS: siblings of children with non-neurological illnesses

**Fig. 1. Mean total sleep behaviour score for various diagnostic categories.**

(SBQ: Sleep Behavioural Questionnaire)

the same room with parents during sleep (41.7%) compared with their siblings (19.6%), children with non-neurological illnesses (20.3%) or their siblings (17.9%).

Comparing the mean total SBQ scores for patients among the various diagnostic categories, children with epilepsy, mental retardation (MR) and learning disabilities (LD) scored the highest indicating most sleep problems, followed by

children with bronchial asthma and oncological disorders (Fig. 1).

### Discussion

Sleep problems in children can be assessed by sleep diary, sleep index score, direct observation in 24 hours schedule, video-polysomnography, sleep questionnaire or a combination of them.<sup>2-6</sup> Our study used a modified sleep

behaviour questionnaire previously validated to evaluate sleep problems in school-age children in the population.<sup>7</sup>

In this pilot study, we found that children with neurological disorders had more sleep problems compared to their siblings, non-neurological paediatric patients and their siblings. They tended to have more bedtime difficulties, i.e. difficulty or reluctance in falling asleep willingly, sleep fragmentation, i.e. disturbed sleep in terms of frequency and duration of night awakening and also more parental involvement throughout the night.

The sleep problems among children with neurological disorder were especially obvious when compared to their own siblings. This reported difference might be exaggerated by their parents who might pay more attention to their ill child than the normal siblings. This is supported by the fact that 41.7% of children with neurological disorders often shared the same room with parents during sleep compared to 19.6% for their siblings. We also found that among our children with non-neurological paediatric illnesses, those with bronchial asthma and oncological disorders also had more sleep problems. This observation was also reported by a previous study that showed children with asthma has significantly more disturbed sleep.<sup>8</sup> However, as our study was not specifically designed to look into the prevalence of sleep problems among children with various paediatric illnesses, the above observation needs to be verified in a larger cross-sectional study.

Comparing the prevalence of sleep problems among children is difficult across studies, as the definition used in previous sleep studies vary and frequently is based on arbitrary categorisation. In contrast to the study on sleep problems in childhood idiopathic epilepsy by Cortesi et al<sup>4</sup> who used a similar sleep behaviour questionnaire, there was no significant difference in parasomnias and daytime drowsiness compared to the controls in our study. We postulate that this was due to the

heterogeneity of our studied population and the possibility that parasomnias are generally uncommon in our population. In many cases, we observed daytime drowsiness even among the controls and this can be attributed to the late sleeping habits or early awakening to go to school. Interestingly, Owen et al<sup>9</sup> found that the increased daily television viewing at bedtime was associated with sleep disturbances and daytime sleepiness in normal school children. Sleep problems among children with neurological disorders can be multifactorial. Functional assessment has shown that sleeping problems were reinforced by parental attention.<sup>10</sup> Undiagnosed seizure disorder was also associated with night time crying.<sup>10</sup> Other researchers<sup>5</sup> pointed out the paramount role of melatonin in maintaining the normal sleep-wake cycle. Pillar et al<sup>11</sup> went on to show that in an institutionalised child with psychomotor retardation, irregular sleep-wake pattern is contributed by abnormal melatonin secretion by measuring serial urinary sulphatoxymelatonin in 24 hours. Hence, treatment options for sleep problems in children with neurological disorders or learning disabilities include behavioural or pharmacological therapies. Piazza et al<sup>12</sup> found that bedtime fading and response cost which consist of systematic delay of bedtime, removal from bed if sleep was not initiated within 15 minutes (response cost) was efficacious. A number of researchers<sup>11,13-15</sup> have also found that melatonin could result in an improvement of sleep pattern. With melatonin, affected children can become less irritable, calmer, socialise better, become more attentive and improve in their cognitive abilities.

The major limitation of this study is possible recall bias as retrospective parental reports can be inaccurate or give an incomplete picture of sleep behaviour in this age group. Owens et al<sup>6</sup> included the self-report of sleep behaviour by the child and teacher's daytime sleepiness questionnaires in an attempt to improve the reliability of their sleep study among school-

aged children. However this is not feasible for most children with neurological disorders or learning disabilities as in the case of our patients. Sleep diary can be used to reduce this bias. However, it is rather tedious and co-operation from parents may not be forthcoming. Although we have pretested our questionnaire and prepared it in two versions i.e. English and Bahasa Malaysia, a few parents still have some difficulties in understanding the questionnaire. This was overcome by further clarification from the authors when the parents handed in the questionnaire. Other possible confounding factors that may have affected our results included socio-economic status and the practice of children sleeping in the same room with their parents among different ethnic groups though using siblings as control mostly eliminated this. Many medications prescribed for children with neurological disorders especially anticonvulsant may also cause sleep problems. This needs to be verified by a larger study that specifically looks into this issue.

### Conclusion

The results of this study confirmed the presence of sleep problems among our children with neurological disorders. A follow-up study is needed to elucidate the probable contributory factors of these sleep problems. Paediatricians managing children with neurological disorders, epilepsy and learning disabilities need to be aware of this phenomenon and should be more proactive to query parents, look into the possible contributory factors and target appropriate management strategies to reduce the burden of care for the parents of these children.

### References

1. Ronald ED. The development and disorders of sleep. *Advances in Paediatrics*: Mosby Inc, 1998; 45: 73-89.
2. Piazza CC, Fisher WW, Kahng SW. Sleep patterns in children and young adults with mental retardation and severe behavior disorders. *Dev Med Child Neurol* 1996; 38: 335-44.
3. Quine L. Sleep problems in children with mental handicap. *J Ment Defic Res* 1991; 35: 269-90.
4. Cortesi F, Giannotti F, Ottaviano S. Sleep problems and daytime behavior in childhood idiopathic epilepsy. *Epilepsia* 1999; 40: 1557-65.
5. Jan JE, Espezel H, Appleton RE. The treatment of sleep disorders with melatonin. *Dev Med Child Neurol* 1994; 36: 97-107.
6. Owens JA, Spirito A, McGuinn M, Nobile C. Sleep habits and sleep disturbance in elementary school-aged children. *J Dev Behav Pediatr* 2000; 21: 27-36.
7. Bruni O, Ottaviano S, Guidetti V, et al. The sleep disturbance scale for children (SDSC). Construction and validation of an instrument to evaluate sleep disturbances in childhood and adolescence. *J Sleep Res* 1996; 5: 251-61.
8. Stores G, Ellis AJ, Wiggs L, Crawford C, Thomson A. Sleep and psychological disturbance in nocturnal asthma. *Arch Dis Child* 1998; 78: 413-9.
9. Owen J, Maxim R, McGuinn M, Nobile C, Msall M, Alario A. Television-viewing habits and sleep disturbance in school children. *Pediatrics* 1999; 104: e27.
10. Didden R, Curfs LM, Sikkema SP, de Moor J. Functional assessment and treatment of sleeping problems with developmentally disabled children: six case studies. *J Behav Ther Exp Psychiatry* 1998; 29: 85-97.
11. Pillar G, Etzioni A, Shahar E, Lavie P. Melatonin treatment in an institutionalised child with psychomotor retardation and an irregular sleep-wake pattern. *Arch Dis Child* 1998; 79: 63-4.
12. Piazza CC, Fisher WW, Sherer M. Treatment of multiple sleep problems in children with developmental disabilities: faded bedtime with response cost versus bedtime scheduling. *Dev Med Child Neurol* 1997; 39: 414-8.
13. Jan JE, Freeman R, Fast DK. Melatonin treatment of sleep-wake cycle disorders in children and adolescents. *Dev Med Child Neurol* 1999; 41: 491-500.
14. O'Callaghan FJK, Clarke AA, Hancock E, Hunt A, Osborne JP. Use of melatonin to treat sleep disorders in tuberous sclerosis. *Dev Med Child Neurol* 1999; 41: 123-6.
15. Gordon N. The therapeutics of melatonin: a paediatric perspective. *Brain Dev* 2000; 22: 213-7.

**Appendix 1: Sleeping Behaviour Questionnaire (SBQ)**

- What time does your child go to bed on weeknights? \_\_\_\_\_ (pm)
- What time does your child go to bed on weekend nights? \_\_\_\_\_ (pm)
- How long does it take to fall asleep? \_\_\_\_\_ (minutes)
- Does your child take naps during the day? (Yes) (No)
- If yes, how long? \_\_\_\_\_ (hours/minutes)

Your Child (in the past 6 months)... (please ✓ in the correct column)

	Never	Just at times	Sometimes	Quite often	Always
1 Goes to bed willingly					
2 Falls asleep alone					
3 Falls asleep in his/her own bed					
4 Falls asleep in parent's bed					
5 Wakes up 1–2 times per night					
6 Wakes up 3–4 times per night					
7 Remains awake for less than 30 minutes					
8 Remains awake for more than 30 minutes					
9 Falls asleep again with parent's presence					
10 After nightwaking goes to parent's bed					
11 Wakes up to eat					
12 Shares the bedroom with parents (even if there is another sleeping place)					
13 Sleeps in the parent's bed					
14 Twitches while sleeping or trying to sleep					
15 Wakes up from sleep confused and disorientated					
16 Talks in sleep					
17 Walks in sleep					
18 Wakes up from sleep screaming and terrified (Night terror)					
19 Is refreshed and in a good mood at waking up in the morning					
20 Is sleepy while sitting and/or studying					
21 Is sleepy while watching TV					
22 Is sleepy while sitting and talking to someone					
23 Falls asleep at school					

**SBQ Scoring Instruction**

1. Recode in the opposite direction (5=1)(4=2)(1=5)(2=4) Item 1,2,3,19
2. Factor based scores – complete the sum of items enumerated below:
  - Bedtime difficulties: Item 1,2,3,4
    - sleep latency > or = 30 min score 5
    - < 30 min score 1
  - Sleep fragmentation Item 5,6,7,8,11
  - Parent involvement at time of sleep Item 9,10,12,13
  - Parasomnias Item 14,15,16,17,18
  - Daytime drowsiness Item 19,20,21,22,23
3. Total score: sum of items of each subscale (range 24–120)
4. Higher scores indicate more sleep problems