

Identification of sleep problems by questionnaire in children with severe cerebral palsy

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Research workers: *Dr Yasmin Khan, Consultant Paediatrician in Neurodisability
Jessica Underhill, Research Assistant in Neurodisability
Chailey Heritage Clinical Services*

Background:

Clinical experience suggests that sleep problems occur frequently in children with cerebral palsy. However, there is a lack of research to support this. A number of factors associated with cerebral palsy could affect the sleep of a child with the condition, including pain and orthopaedic problems, spinal curvature, bowel problems, upper airway obstruction, epilepsy, and psychological issues. There are no validated sleep questionnaires that take into account sleep problems in the context of complex disability.

Aims:

1. To develop a questionnaire, applicable to children with cerebral palsy, that gathers information on sleep and the medical factors that may disturb sleep.
2. To evaluate the questionnaire in terms of its reliability over time and its ability to identify differences in sleep between children with and without cerebral palsy.

Method:

- Procedure: A sleep questionnaire with medical section was designed and a comparative study between children with cerebral palsy, aged 2-10 years, and a control group of age-matched able-bodied children conducted. The questionnaire was completed with the children and parents (Time 1) and repeated 1 month later (Time 2). Additionally, each family was asked to complete a sleep diary for one week and this was repeated 1 month later.

- The Questionnaire: The sleep section of the questionnaire was in three parts:

- Bedtime routine;
- Night-time behaviour;
- Breathing quality during sleep.

The medical section identified existing and current medical conditions experienced by the child.

The sleep diary was a subjective record kept by parents of their child's sleep.

Results:

- Participants:

Cerebral Palsy Group – 28 children with cerebral palsy (10 female, 18 male, mean age 6 years, age range 2-10 years).

Control Group – 30 children without physical disabilities (16 female, 14 male, mean age 6 years, age range 2-10 years).

- Reliability over Time: No significant differences for the responses to single questionnaire items between Time 1 and Time 2 (Wilcoxon Tests).
- Sleep Diaries: Provided supportive information for night-time events.
- Medical Section:

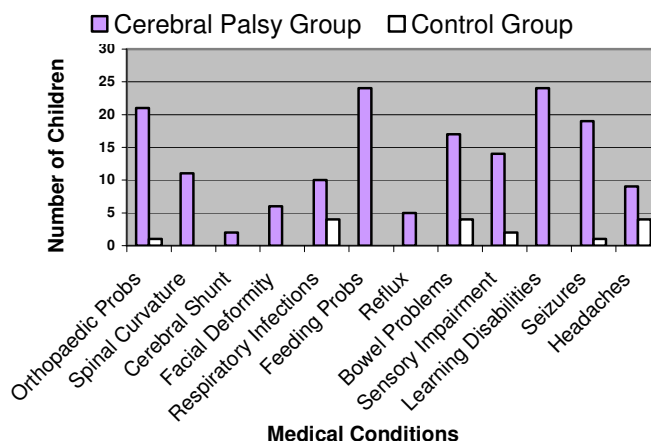


Figure 1: Frequency of children currently experiencing different medical conditions as outlined in the medical section. 14 (50%) of children with cerebral palsy had 4 or more co-existing medical conditions. Interestingly these 14 children also had the highest scores for the Night time Behaviour and the Breathing Quality at Night sections of the questionnaire but did not score highly in the Bedtime Routine section.

- Sleep Sections:

Total scores for each of the three sleep sections were grouped into 3 categories:

- Low - indicating no problem
- Medium – indicating a problem that may need further investigation
- High – indicating a high level problem in need of immediate attention

Section 1 – **Bedtime Routine**:

	Low	Med	High
Cerebral Palsy Group (N=28)	12 (43%)	12 (43%)	4 (14%)
Control Group (N=30)	23 (77%)	6 (20%)	1 (3%)

Table 1: Frequency and % of children scoring in low, medium and high categories for the Bedtime Routine section.

The Bedtime Routine section total scores were significantly higher for children with cerebral palsy indicating a higher frequency of bedtime routine disturbance for this group ($U = 248.5$, two-tailed $p < .01$). Specifically, children with cerebral palsy scored significantly higher for one item in this section:

‘Does your child fall asleep within 20 minutes after going to bed?’ ($U=292$, $p < .01$).

Section 2 – Night Time Behaviour:

	Low	Med	High
Cerebral Palsy Group (N=28)	1 (4%)	21 (75%)	6 (21%)
Control Group (N=30)	22 (73%)	8 (27%)	0 (0%)

Table 1: Frequency and % of children scoring in low, medium and high categories for the Night Time Behaviour section.

The Night Time Behaviour section total scores were significantly higher for children with cerebral palsy indicating a higher frequency of night-time disturbance for this group (U=42, p<.001). Children with cerebral palsy scored significantly higher for the majority of items including:

‘Does your child wake during the night?’ (U=192.5, p<.001).

‘Does your child wake up in pain?’ (U=180, p<.001).

‘Does your child need a change of position at night?’ (U=205, p<.001).

Section 3 – Breathing Quality at Night:

	Low	Med	High
Cerebral Palsy Group (N=28)	19 (68%)	5 (18%)	4 (14%)
Control Group (N=30)	30 (100%)	0 (0%)	0 (0%)

Table 1: Frequency and % of children scoring in low, medium and high categories for the Breathing Quality at Night section.

The Breathing Quality at Night section total scores were significantly higher for children with cerebral palsy indicating poorer breathing quality at night (U=176, p<.001). Children with cerebral palsy scored significantly higher for the majority of items including:

‘Does your child have disturbed breathing during sleep?’ (U=324, p<.05).

‘Does your child snore?’ (U=259.5, p<.01).

‘Is your child’s breathing interrupted by snorts and gasps?’ (U=306, p<.01).

Summary and Conclusions:

- The questionnaire is reliable over time
- Children with cerebral palsy have more disturbed sleep
- Co-existing medical conditions may effect night time disturbance and lead to disturbed breathing at night
- The questionnaire identified differences and similarities in sleep between children with cerebral palsy and children without.

The questionnaire can be used as a tool to identify sleep problems in children with cerebral palsy and guide the clinician towards the appropriate treatment/management options.

*Jessica Underhill
Chailey Heritage Clinical Services
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