

**EVALUATION AND MANAGEMENT OF SLEEP PROBLEMS IN CHILDREN WITH NEURODISABILITY: A LITERATURE REVIEW.*****Anum Shumail, Muhammad Zia, Orla Flanagan, Irfan Ahmed.**

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ABSTRACT

This literature review aimed to raise awareness of the current knowledge in the field of sleep disorders, which describes the complex relationship among child's behavior, cognition and neurodevelopmental outcome. Sleep disorders associated with pediatric neurodisabilities and common neurological conditions causing sleep problems in children are discussed briefly in this article. Especial emphasis is given to an evaluation of sleep pattern recognition in children with neurodisabilities. We also summarized a broad range of management plans for child and family/caregivers. Some essential neurological conditions are highlighted as they provide useful insights into how disturbed sleep can impact on the cognitive and behavioral development of a child. Many neurological disorders exist along with sleep disorders such as epilepsy, autism, Cerebral palsy, etc., which carry profound effect on underlying child's cognitive or behavioral pattern. The literature review is based on extensive literature search and author's special interest in sleep disorders and pediatric neurodisabilities.

KEYWORDS: Neurodisabilities, intellectual disability, sleep disruption, epilepsy, Autism, ADHD, Melatonin.**INTRODUCTION**

The prevalence of Sleep problems in the pediatric population is approximately 25%, but if we compare it with children with epilepsy, Autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and other neurological condition, its prevalence is as high as 80%.^[1,2,3] Children with neurodevelopmental disorders (NDDs) (including, include ADHD, autism spectrum disorder, cerebral palsy, Rett syndrome, Angelman syndrome, Williams syndrome and Smith-Magenis syndrome, etc.) reported having disrupted sleep pattern about 70- 80%. Research has proven its adverse effect on daytime behavioral difficulties, cognitive, growth, and neuro-developmental outcome.^[4]

Sleep problems have severe physical, psychological and emotional implications and it is essential to take an appropriate approach in diagnosis and their management. Most Paediatricians do not use a Systematic approach to identify, treat or refer these children with sleep problems. Therefore, only a small percentage of children are identified and treated.^[5]

In history taking, sleep issues are not addressed, or many times parents don't discuss them with their doctor unless specifically asked. The primary requirement for the recognition and correct diagnosis of sleep disorders is careful history taking. In history taking, to avoid sleep disturbances being overlooked, the following fundamental questions should be asked routinely about any child:

Q 1: Does your child have difficulty falling asleep?

Q 2: Does your child remain asleep or wakes up early in the morning?

Q 3: Is your child excessively sleepy/ overactive during the day?

The average sleep times vary with age; however, the systematic review of the literature provided general recommendations for sleep duration at different ages⁽⁶⁾. Newborn infants sleep 16–18 hours per day. After six months of age, healthy infants can sleep for more than six hours at night without a feed. By 18 months of age, sleep patterns usually mature to overnight sleep in addition to one daytime nap. At school age, children

usually sleep approximately 11-12 hours per day. Sleep duration in preadolescent stages are ten hours per day and further reduced to eight hours by sixteen years of age.^[6,7]

Initial screening of sleep problem is an essential step towards timely evaluation and intervention. An example of a mnemonic "BEARS" reminds paediatricians while history taking in the setting of sleep issues in children; which stands for, **B** = bedtime (settling) problems; **E** = excessive daytime sleepiness; **A** = night awakenings; **R** = regularity and duration of sleep; **S** = snoring.^[8]

Paediatric Sleep History: Parents are the usual primary source of information, but children themselves, siblings and teachers may also need to be consulted for the full account. The following aspects should be addressed in sleep complaints:

- Associated medical problems or other triggering factors.
- The pattern of occurrence of sleep disruption.
- Effects on the child and others family members.
- Past and present treatment and their effectiveness.
- Child's 24-hour sleep-wake schedule (table 1) should be described.
- The child's sleep rhythm, i.e., The timing and duration of the overnight sleep phase and any daytime naps and the overall amount of sleep each 24 hours.
- Events that may be of diagnostic significance, e.g., chronic noisy breathing including snoring, Medical and psychiatric history, including past and current treatment.
- Developmental history, including perinatal and neonatal stage, evidence of developmental delay, educational history, adverse experience at school or within the family.
- Social history, including friendships, home and family circumstances and recreational factors which may affect sleep.
- Family history is epilepsy, developmental delay or neuro-metabolic/neuro-psychiatric disorders.
- Sleep hygiene (Table 2) means how far the sleeping environment is satisfactory and whether the organization of the child's activities, especially leading to bedtime is conducive to sleeping well.

Evening

What time is the child's last meal?

What activities typically take place between then and getting ready for bed?

Does he take any sleep medicine?

Going to bed

Who gets the child ready for bed and how? Is it always the same person and done in the same way?

Is there a bedtime routine? If so, what is the sequence of events? Does it include a wind-down period?

What time does he go to bed?

Is he put to bed awake or asleep?

Where and how does he fall asleep (own bed, parent's bed, downstairs, being rocked, nursed or fed, with or without a parent present)?

Does he need a bottle, dummy or any particular object to fall asleep or want someone else to sleep?

Does he express fears about going to bed?

Does he have his own room?

Is the bedroom conducive to sleep or is it a place for entertainment or other arousing experiences?

Does he have any unusual experiences when going off to sleep?

Exactly what happens if he will not go to bed or does not go to sleep readily? Who deals with the problem and how consistently?

Night-time

Does the child wake during the night? When and how often? Does he get up in the night to go to the toilet or have a drink? Is he able to return to sleep quickly or does he need his parents or join them in their bed? If so, what precisely happens, who is involved and what is the result?

Is the child's sleep disturbed in other ways, e.g., restlessness, sleep talking, sleep walking, head banging, teeth grinding, nightmares, or terrified episodes, jerking or convulsive movements or other events of disturbed behavior? How often do these things occur and at what time of night; how long do they last and does he seem awake at the time? What do his parents do?

Does he snore or have difficulty breathing when asleep?

Does he wet the bed?

What is his usual period of continuous sleep?

Waking

What time does the child wake up? For how long has he slept?

Does he wake up spontaneously or have to be woken? Is he challenging to awake? Does he look tired? Is he irritable and in a bad mood?

Does he have any unusual experiences and how does he feel between waking up and getting out of bed?

Daytime

Is the child drowsy or does he sleeps during the day? If he sleeps, can he resist doing so and does he fall asleep when engaged in activities?

What are the number, duration, and timing of naps?

Do his muscles become weak when he laughs or is upset or surprised?

Does he find it difficult to concentrate?

Has his performance at school deteriorated?

Is he overactive, irritable or depressed?

Are there any unusual episodes during the day?

What is the total time spent asleep every 24 hours?

Table 1: Review of child's 24-hour sleep-wake pattern.^[9]

Physical & Mental Examination: This should include particular attention to: Neurological, cardiorespiratory or other diseases that might affect sleep.

Obesity, facial or pharyngeal abnormalities predisposing to upper airway obstruction in particular.

- Overactivity, depression, or other psychiatric disorders likely to affect sleep.
- Evidence of intellectual impairment including signs of specific syndromes relevant to possible sleep disturbances.

Audiovisual recordings, including those obtained by the parent's video recording, can be very informative about nighttime events; mode of onset of a nocturnal episode may be particularly diagnostic.

Actigraphy; Actigraph is an ambulatory device that estimates the sleep-wake patterns and has become popular in pediatric research. Actigraphy provides an objective measure and has gained high popularity due to its ability to measure sleep-wake patterns for extended periods of time (i.e., five or more nights).^[10]

The actigraph devices are involved in the monitoring of body movements by use of small, wristwatch-like movement sensors is another relatively nonintrusive means of collecting objective information about sleep in non-laboratory settings. This device is validated for the estimation of nighttime sleep parameters, but unfortunately, its sleep-onset latency and daytime sleeping validity is limited. Clinical guidelines and research suggest that it is relatively simple to use, and especially beneficial for children, where the details of sleep physiology are not required.^[11]

Polysomnography; (PSG) provides information about the physiological changes that occur during sleep. PSG is

a diagnostic sleep medicine tool during which multiple different physiologic parameters are continuously and simultaneously recorded during sleep period to identify the pattern of sleep and sleep disorders.^[12]

A systematic review of the literature and the American Academy of Neurology (AAN) grading system, support the utility of Polysomnography in pediatric sleep disorder assessment. Most important indications of PSG in Children are as follow.^[13]

- Obstructive sleep apnea syndrome (OSAS),
- Post-adenotonsillectomy to assess residual symptoms,
- Preoperative adenotonsillectomy assessment for moderate to severe OSAS,
- Obesity and craniofacial anomalies that obstruct the upper airway,
- Neurologic disorders (e.g., Down syndrome, Prader-Willi syndrome, and myelomeningocele),
- Positive airway pressure (PAP) titration in children with obstructive sleep apnea syndrome,
- Congenital central alveolar hypoventilation syndrome,
- Sleep-related hypoventilation due to neuromuscular disorders or chest wall deformities,
- Selected cases of primary sleep apnea of infancy,
- Sleep-related breathing disorder in infants,
- Apparent life-threatening event (ALTE),
- Monitoring of chronic PAP support, after treatment of children for OSAS, to determine whether additional treatment is necessary,
- Noninvasive positive pressure ventilation (NIPPV) titration in children with other sleep-related breathing disorders,
- Children on mechanical ventilation may get benefit from a periodic evaluation with polysomnography to adjust ventilator settings,
- Children treated with tracheostomy for sleep related breathing disorders benefit from polysomnography as part of an assessment before decannulation,
- Miscellaneous uses are; chronic asthma, cystic fibrosis, pulmonary hypertension, bronchopulmonary dysplasia, or chest wall abnormality such as kyphoscoliosis.

Primary indications are excessive daytime sleepiness and measurement of multiple latency tests (MSLT), which measures the time a child, takes to fall asleep in a standardized condition, investigations of complex parasomnias and to check the response to treatment.

Standard PSG involves recording EEG, EOG, and EMG from which necessary measures of NREM sleep, REM sleep, and sleep continuity can be made. PSG can be extended to include a range of respiratory measures (for sleep-related breathing problems), additional EEG channels if nocturnal epilepsy is suspected, or anterior tibialis EMG recording for detection of periodic limb movement in sleep.^[12,14,15]

Other helpful Investigations: Depends sleep disorder being considered, further laboratory investigations may be appropriate.

These include.^[16,17]

Overnight oximetry (Overnight SpO₂ trace).

- Limited channel polysomnography.
- Hematological, biochemical and endocrine studies especially in children who appear tired and lethargic.
- Urine analysis in cases of enuresis.
- Toxicology screen if substance abuse is suspected.
- Special EEG monitoring for possible epilepsy.
- Otolaryngological evaluation in case of snoring during sleep.
- Children with Down syndrome and other neuro-disabilities.
- Developmental assessment if the learning disability is suspected.

Treatment of sleep disorders

General principles

The mainstay of management of sleep problems in children with neurodisabilities is similar to that of typically developing children.^[18]

As with all childhood sleep problems, management decisions need to be based on the careful assessment of the individual child. Behavioral therapy is quite successful in treating sleep disturbances in children with neurodisabilities.^[19,20]

Common strategies used are: *Maintaining good sleep hygiene, Sleep scheduling, Bedtime routine plus gradual distancing of parents, Extinction, Bedtime fading, Chronotherapy, and medications.*^[19,20,21,22,27]

Sleep hygiene means how far the sleeping environment is satisfactory and whether the organization of child's daily activities (especially leading to bedtime) are conducive to sleeping well. Improvement in sleep hygiene is the first step in the management of these children. It is defined as a set of sleep-related behavior that exposes persons to activities and cues that prepare them for and promote proper sleep^{23, 24, 25}. Essential features of sleep hygiene are mentioned below:

Table 2: Sleeping environment should be facilitative for sleep

- Familiar settings
- Comfortable bed
- Correct temperature
- Darkened, quiet room
- Non-stimulation
- No negative association (e.g., punishment)

Encourage

- Bedtime routine
- A consistent bedtime and waking up times
- Going to bed only when tired

- Thinking about problems and plans before going to bed
- Falling asleep without parents
- Regular daily exercise, exposure to sunlight

Avoid

- Overexcitement at bedtime
- Late evening exercise
- Caffeine-containing drinks late in the day
- Smoking and excessive alcohol (teenagers)
- Large meals late at night
- Excessive or late napping during the day
- Too much time awake in bed

Sleep scheduling & scheduled awakening:

Establishment of a strict bedtime routine is recommended to the parents of young children, especially those with sleep difficulties.^[25]

Sleep scheduling consists of enforcing a regular schedule for putting the person in bed in the evening, waking in the morning and daytime naps according to age and development of a child. For night waking, no specific interventions are required except keeping him or her in bed. Despite all the challenges every attempt should be made to maintain sleep/wake regularity and adapt sleep schedule to individual needs.^[26,27,28]

Sleep practices and Bedtime routine: Children with neurodevelopmental disorders are easily over stimulated because their brain has difficulties processing extra information. Therefore bedtime activities must be planned very carefully and choosing them should be based on their stimulating or calming influence. Any unexpected event, pain, anxiety, seizure, heavy meal, hunger bright light, cold or heat, bathing with too many toys and playing with siblings are often over exciting. Similarly, a favorite television program, quiet bath, small snack, familiar blanket, pleasant sound, rhythmic, repetitive low-frequency movements, soft music and gentle touching seems to have calming influence on all children.^[29]

Extinction or Extinction-based behavioral sleep

intervention: This is a type of sleep behavioral intervention for young children involve extinction procedures where parents must ignore their child's cries for a period.

Extinction-based behavioral sleep intervention techniques comprise of, unmodified extinction, graduated extinction, and extinction with parent presence. After the bedtime routine, the parents leave the room and could re-enter the room and encourage the child to sleep at an interval of 3 or 5 minutes. These intervals were extended on subsequent nights.^[27,30,31,32]

Bedtime fading: Bedtime fading is a strategy whereby the person is sent initially to bed at a relatively late time, i.e., a time at which rapid sleep onset is highly probable,

and then at the gradually earlier time. Throughout the fading, the person is not allowed to sleep outside the prescribed sleep time.^[32,33]

Chronotherapy: The primary regularizing agents of the circadian rhythm are light is melatonin. Light is the most potent agent of circadian rhythms. Timely exposure to bright light can be used in the treatment of circadian rhythm sleep disorders. In addition, timed administration of melatonin, either alone or in combination with light therapy has been shown to be useful in the treatment of the following circadian rhythm sleep disorders.^[34,35,36]

This strategy was initially employed with adults of average intelligence who had delayed sleep phase insomnia. During the implementation of the strategy, participants were exposed to 27-hour day in a laboratory setting. This was done by delaying scheduled bedtime and wake times by 3 hours per day until the approximate clock hours desired were reached. Through the use of chronotherapy, the sleep of involved individual improved and required shorter intervals to fall asleep after being put in bed. On follow up these positive changes were maintained when the patients were sent home from the hospital.^[34,35,36,37]

Abbreviations Used

ASD	Autism spectrum disorder
ADHD	Attention deficit hyperactivity disorder
NDDs	Neurodevelopmental disorders
OSAS	Obstructive sleep apnea syndrome
PSG	Polysomnography
EEG	electroencephalography
EOG	electrooculography
EMG	electromyography
ECG	Electrocardiography
NREM	Non-rapid eye movement sleep
REM	Rapid eye movement sleep

Melatonin

Systematic review and meta-analysis provide sufficient evidence that melatonin decreases sleep onset latency, increases total sleep time and improves overall sleep quality in children. Melatonin (N-acetyl-5-methoxy-tryptamine) is an endogenous hormone secreted by the pineal gland. It is synthesized from tryptophan which is first converted to serotonin, then to N-acetylserotonin and finally to Melatonin.^[38,39,40]

Antihistamines

Due to a potential for rapid tolerance and minimal effectiveness in inducing sleep, the use of antihistamine in insomnia patients is not recommended. It may adversely affect sleep quality, and cause residual drowsiness.^[41]

Clonidine

Clonidine is alpha-2 receptor agonist, has a role in severe sleeplessness that has failed to respond to behavioral and social measures. Clinical Global Impressions-Severity (CGI-S) scores for parents were significantly reduced after clonidine use in comparison with baseline, indicating a reported decrease in insomnia severity.^[40,41,42,43]

Benzodiazepines: Sedative medications like benzodiazepine have been shown to be useful in the short-term treatment of insomnia in young children, although these agents have not been approved by US Food and Drug authority for pediatric insomnia. Short-acting benzodiazepines may have a role in the brief treatment of pediatric insomnia associated with an anxiety or mood disorder, psychosis, aggression;

however, tachyphylaxis and risk of misuse preclude the long-term use of benzodiazepines for the treatment of insomnia in children.^[41,42]

Care of the affected Families

The psychological effects of a child's sleep disorder on other family members should not be overlooked. Parents might be severely affected by the condition of their child or by persistently disrupted sleep caused by the child's sleep disturbance. Depression, impaired parent-child relationships and parenting skills, marital disharmony and under-functioning at work are all possible consequences. Other children in the family may also suffer.^[44,45,46]

Psychiatric consultation: Sleep disturbances in children and adults may be an early sign of serious mental illness before more definite evidence develops, and many psychotropic medications have affect on sleep. It is worth having close liaison with pediatric psychiatric services while managing sleep problems in children.^[47,48,49]

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