

Sleep problems in children with developmental disorders

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J R Soc Med 2001;94:177–179

FORUM ON SLEEP & ITS DISORDERS, 6 APRIL 2000

In 1905 Clement Dukes, a school doctor, made the following observation about the effects of sleep loss upon the children in his care¹:

‘... younger pupils are allotted the same number of hours as the seniors for sleep. What this means to the children is lowered vitality, apathy, bloodlessness, diminished growth of the body and brain. It renders the child an easy prey to disease [and] causes slight fainting attacks resembling these cases of epilepsy...’

Although the tone of his remarks may seem over-dramatic it is now well recognized that impaired sleep quantity or quality can have profound effects on daytime mood, behaviour, cognition, general performance and physiology². When sleep disturbance is present in children it impacts not only upon the child’s daytime functioning but also on that of the parents and the family at large; associations between childhood sleep problems and maternal stress, depression, poor marital relationships and even child abuse have been reported^{3,4}.

The negative associations with childhood sleep problems are of particular concern in view of the high prevalence of sleep difficulties. Figures of about 25% of preschool children⁵, 43% of school-age prepubescent children⁶ and 33% of adolescents⁷ are given, and these are likely to be underestimates. The reported rates of sleep disorders in children with developmental disorders are even higher. Rates vary depending upon the criteria used to define a ‘sleep problem’ but examples reported are 49–89% of children with autistic spectrum disorders⁸, 25–50% of children with attention deficit hyperactivity disorder (ADHD)⁹ and 34–86% of children with intellectual disabilities¹⁰.

The sleep problems of children with developmental disorders deserve particular attention not least because of their prevalence but also because of their persistence and severity, the additional stress that they place upon carers, the contribution that sleep disturbance might be making to daytime difficulties with behaviour and cognition and the parents’ ability to cope with them and, fortunately, the

improvements in child and parent functioning that can follow successful treatment¹¹.

SLEEP DISTURBANCE IN CHILDREN WITH DEVELOPMENTAL DISORDERS

The reported sleep abnormalities can be classified into three basic groups: (i) physiological sleep irregularities, such as rapid eye movement (REM) sleep abnormalities, which have been identified across a range of conditions (the clinical significance of these anomalies is often uncertain); (ii) sleep disorders which are more prevalent in particular groups of children, often resulting from their underlying condition—for instance, sleep related breathing disorders are common in children with Down syndrome because of congenitally narrow airways, reduced muscle tone and increased tonsil and adenoid size; (iii) sleep ‘problems’ of unspecified origin which are commonly reported across a range of conditions—notably, difficulty in settling to sleep, night waking, irregular sleep patterns, short-duration sleep and daytime sleepiness. There is also a possible fourth group, in which a sleep disorder is causing or contributing to the ‘primary’ condition. A substantial minority of children with ADHD are reported to have periodic limb movement disorder (PLMD)¹², a condition characterized by stereotypic and repetitive limb movements during sleep which are accompanied by physiological arousal. Sleep quality in PLMD is impaired to such a degree that it shows in daytime behavioural manifestations of sleep disruption—poor concentration, overactive behaviour and impulsivity. After treatment for the PLMD, ADHD symptoms have been reported to diminish or even resolve completely in these cases¹³.

LIMITATIONS OF EXISTING DATA

There are sizeable gaps in our knowledge of sleep disturbance in children with developmental disorders. First, too little attention has been paid to coexisting conditions such as epilepsy^{14,15}—common in certain groups with developmental disorders—that might affect sleep. Secondly, the studies have often been poorly controlled, if controlled at all, for other factors such as age, IQ and current medication that can impact upon sleep patterns. Thirdly, the methods for assessing sleep have varied, ranging from physiological sleep studies conducted in a sleep laboratory to parent report questionnaires. Although

the different methods are all useful and taken together provide more complete understanding, the comparison of results can be difficult. Lastly, very few studies have done more than describe the symptoms or 'sleep problems', when what is needed is analysis of the sleep disorder that underlies the symptoms. This distinction is important since very different sleep disorders can present with similar symptoms, and treatment needs to be based on the disorder. There are just three broad categories of presenting symptoms—sleeplessness, excessive sleepiness and episodic disturbances of behaviour associated with sleep (parasomnias)—but the International Classification of Sleep Disorders¹⁶ lists over eighty underlying sleep disorders each of which can produce one or more of these symptoms. For example, sleeplessness taking the form of difficulty getting to sleep at night may, amongst other things, result from disturbance of the body clock, failure to learn appropriate bedtime behaviour or anxiety. The treatments for these will differ greatly.

WHAT HELP IS BEING PROVIDED TO FAMILIES?

When children with developmental disorders have sleep disturbance, they are far from certain to receive treatment. Wiggs and Stores¹⁷ report that of 124 children with severe intellectual disabilities and current or past sleep problems only 47% had received treatment and the percentage was only slightly higher (54%) in 61 children with autism and sleep problems (unpublished). These figures, of course, say nothing about the quality or success of the treatment. Why is treatment not routinely provided? One reason is that doctors¹⁸ and psychologists^{19,20} lack professional training in sleep disorders; such training as they do receive is limited in time and scope. Secondly, parents of children with associated conditions may hesitate to seek advice. Among reasons suggested by parents are that sleep problems are longstanding¹⁷ and thus part of 'normal' life, that parents (and professionals) view them as an inevitable and insoluble aspect of the underlying condition³ and that previous experience has been negative—the offer of hypnotic medication when this was not wanted, or inappropriately devised behavioural programmes^{17,21}. Professionals involved in the care of these children must be capable of assessing, recognizing and diagnosing sleep disorders. This should be with a view to implementing treatment themselves or guiding the parents of affected children to other agencies providing treatment.

ASSESSMENT OF SLEEP PATTERNS

Stores provides a helpful framework for structuring the assessment of sleep in young people²². He emphasizes the importance of a careful sleep history along with the developmental, medical, psychological and family history.

Detailed review of the child's 24 hour sleep–wake pattern is recommended to identify factors that are causing or perpetuating sleep problems. Options for further investigation²³ then include the use of sleep diaries in which parents systematically record information, questionnaires (for screening purposes or to provide detailed information about specific aspects of sleep), video recordings, monitoring of body movements (which can detect basic sleep–wake patterns) and polysomnography (PSG), either in a laboratory or in the child's home. Objective recordings may be helpful when information is lacking or of doubtful veracity, and also for assessment of the few sleep disorders where features of the PSG form part of the formal diagnostic requirement (e.g. narcolepsy, obstructive sleep apnoea). However, clinical enquiries and systematic sleep diary information will in many instances be sufficient for basic assessment.

TREATMENT

Treatments for sleep disorders include adjustment of environmental and lifestyle factors, behavioural techniques to help the child learn good sleep habits or unlearn bad ones, cognitive therapy, chronotherapy (altering sleep timing to re-set the body clock), physical measures such as use of bright light to alter sleep times or nasal continuous positive airways pressure to aid breathing during sleep, surgery (e.g. removal of tonsils and adenoids if they are causing obstruction) and pharmacological approaches (such as sedatives, stimulants and melatonin). Detailed advice can be found elsewhere: Stores²³ provides an overview of management strategies, and other reviews advise on specific disorders such as autism⁸, ADHD⁹ and intellectual disabilities²⁴. Wiggs and France¹¹ also review behavioural treatments for sleep problems in children with coexisting physical, psychological and intellectual disabilities.

Although detailed management guidelines cannot be offered here, some general conclusions can be drawn. First, there is much need for further research, not only because of the deficiencies outlined earlier but also because much of the existing work focuses on sleeplessness while other types of sleep problem are neglected.

Secondly, various behavioural treatments and chronotherapy have been reported successful across a range of conditions, even where the sleep problem is longstanding and severe. A gradual approach, where the new behaviour is taught in small steps, may be more practical and acceptable to parents than an acute intervention, especially in children with developmental disorders. In the absence of studies addressing relative efficacy, the choice of technique should generally be guided by parental preference.

Thirdly, pharmacological management may have a place in the management of some sleep disorders. For example,

clonidine and imipramine have been reported useful in children with ADHD, and melatonin has been found helpful for children with disorders of the sleep-wake cycle (although the uncertainties and concerns surrounding the use of melatonin in children must be weighed up carefully in each case²⁵). In general, sedative medication has a very limited role in the management of children's sleeplessness since the clinical effects are slight and not well maintained; hangover daytime effects are common and parents are often resistant²⁶.

Lastly, an argument for treating sleep problems in children with developmental disorders is that the benefits apply not only to the affected child but also to the family as a whole.

THE FUTURE

The high rate of sleep problems in these 'special' populations suggests that enquiries about basic sleep-wake patterns should form part of routine history-taking, especially where features of the child's daytime behaviour or mood are suggestive of disturbed sleep. Where appropriate, extended assessment should be performed with a view to diagnosing and treating the underlying sleep disorder. Treatment decisions need to be based not only on the type of sleep disorder but also, within reason, on the family's preferences and abilities.

Undeniably, randomized controlled trials of interventions (or combinations of interventions) are needed. Ideally these would include homogeneous groups of children whose sleep disorder and basic condition are tightly defined. Confounders would be controlled for, or at least documented. To achieve sufficient numbers, such trials might have to be multicentre. Until data from such studies are available the most practical and quickest way to gain treatment efficacy data may be carefully designed and well documented single case experiments.

In view of the widespread nature of the sleep disorders and the good response to behavioural treatments, another aspect to consider is prevention. A potentially useful area for future research is evaluation of advice to new parents on how to encourage good sleep habits and deal with the most common sleep disorders. If effective methods could be identified the development of longstanding and severe sleep disorders might be prevented and so too the alarming negative factors with which they are associated.

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