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Paediatric sleep disorders: the need for multidisciplinary sleep clinics

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Abstract

The field of sleep disorders (SD) medicine crosses the boundaries of many medical specialties and disciplines. This paper aims to highlight the importance of a multidisciplinary approach to the assessment and treatment of SD in children, with particular reference to sleep-disordered breathing (SDB).

The link between SDB and other SD (e.g. various parasomnias, sleep-related anxiety) illustrates the need for a holistic approach to assessment since these co-existing SD can be the most overt symptoms. Further, different approaches to treatment of the various SD are likely to be called for.

Multidisciplinary care becomes particularly pertinent when dealing with clinical groups of children in which an increased prevalence of SD, including SDB, have been noted. Such groups include children with intellectual disabilities and those with neurological or psychiatric conditions. The nature of their basic condition may make it likely that SD will be overlooked with the daytime consequences of the nocturnal disturbance (e.g. cognitive/behavioural problems) misattributed to the underlying condition. *Conclusion*: An ideal national service would include a limited number of specialised sleep centres where a broad and multidisciplinary approach to the recognition, assessment and treatment of children's SD was possible.

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1. Introduction

The term 'sleep disorders' can be used to describe a diverse collection of conditions (over 80 different sleep disorders are listed in the International Classification of Sleep

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Disorders) [1]. Appropriate assessment and/or management of these various conditions cuts across many specialties including paediatrics, psychiatry, neurology, psychology, otorhinolaryngology, dentistry and surgery. Yet, it is common for 'sleep clinics' or 'sleep disorders services' to be organised within a restricted setting, offering clinical services for the treatment of particular types of sleep disorders (e.g. clinics within psychology services focus on psychological approaches to the treatment of sleeplessness; clinics within respiratory services deal with sleep-disordered breathing (SDB)). Such a system is unlikely to be optimally beneficial because different sleep disorders and their causes and daytime effects can be so inter-related. A review of a paediatric sleep clinic in the UK [2] suggested that the most likely explanation for poor outcome at follow-up was not related to the nature or complexity of the sleep disorder, nor to the type of treatment recommended, but rather to poor communication between health professionals involved in the children's care. The existence of multidisciplinary services offering a coordinated, specialised approach to both assessment and management would benefit both the patients and health professionals they consult. Justification for such a view is outlined below, with particular reference to paediatric SDB, by examining four areas where the need for multidisciplinary management is highlighted. These are the relationships between sleep disorders and 1) other wideranging sleep disorders such as the more psychological sleep disorders being associated with the more organic, 2) a range of underlying medical conditions, 3) neuropsychological and social functioning of the patients and their families and, 4) their treatments including the degree of efficacy.

2. Sleep disorders associated with sleep-disordered breathing (SDB)

The association between SDB and a higher incidence of certain other sleep disorders is controversial. Carroll and Loughlin emphasise the lack of good data to support the idea of causality [3]. However, there are numerous reports of difficulty with sleep onset/bedtime, night wakings, sleep terrors, sleepwalking, sleep talking, bruxism, sleep anxiety and enuresis being all more common in children with SDB [4,5]. It is not difficult to see how at least some of these sleep disorders might be caused or at least fuelled by the presence of SDB (for example, arousal disorders such as sleep terrors and sleep walking can be aggravated and triggered by sleep disruption) [6].

SDB in children may not present as overtly as in adults and sometimes associated sleep disturbance (and/or daytime effects of sleep disturbance) can be the most obvious symptom and the reason why the child comes to medical attention in the first place [5,7]. An appreciation of this and the use of thorough and comprehensive history taking followed by further assessments where appropriate [8] is essential in order to avoid overlooking the underlying cause of the child's presenting complaint. Where other sleep disorders coexist with SDB, some might be expected to improve as a result of successful treatment of the SDB although others may persist and need management in their own right. The nature of such treatment would normally be very different to that required for the treatment of SDB and require contributions from different clinical specialties.

Even without conclusive evidence that an association between SDB and these other sleep disorders exists, it is true that sleep disorders can spontaneously occur together

in a child. Assessment and care of sufferers of multiple sleep disorders is best approached in a phased and coordinated manner rather than a fragmented approach where the inter-relationships between the sleep disorders and their treatment might be missed.

3. Underlying conditions associated with SDB

Sleep disturbance, of one sort or another, can be seen to be associated with a number of neurodevelopmental, neurological, paediatric and psychiatric conditions [9]. Conditions which predispose to SDB include Down syndrome, craniofacial syndromes, Fragile X syndrome, the mucopolysaccharidoses, Prader-willi syndrome, cerebral palsy and Arnold-Chiari malformation. The literature suggests that, in amongst the myriad of other problems faced by these children and their families, sleep disturbance may be underrecognised and under-treated not only because health professionals fail to make appropriate enquiries but because parents fail to bring the problems to their attention, considering the sleep disturbance to be untreatable or simply part of the child's basic condition and something they have to tolerate [10]. Failing to recognise and treat sleep disturbance in such children is a serious omission; for example, treating SDB is not only likely to have positive physical effects but also, by improving sleep quality and quantity, to improve other aspects of the child's functioning (eg. cognition, behaviour, quality of life, as discussed below). Identifying and successfully treating the SDB or any other sleep disorders, may be one of the most 'treatable' aspects of the child's condition and have wide-ranging positive effects including upon the parents' mental state and the functioning of the family unit as a whole. There is, therefore, a need to: a) make simple enquiries about the sleep patterns of children with disorders of development and, b) where appropriate, for sleep services to be able to deal with the special issues of assessment and management that might apply in such groups of children, including how the sleep disturbance or its treatment might be impacted upon by other aspects of the child's condition or other interventions they are receiving. The importance of adopting an informed, holistic approach to the care of children whose sleep disturbance exists alongside other intractable conditions is paramount.

4. Neuropsychological effects of SDB

It is well documented that persistent sleep disturbance has adverse effects on aspects of physical functioning, cognition, behaviour, mood and overall performance at work or school [11]. Pilcher and Huffcutt provide a helpful meta-analysis of the adult research literature which indicates the extent of these deficits; sleep-deprived subjects performed, on average, at the 9th percentile compared to non-sleep-deprived subjects [12]. The reaction of children to sleep loss can, of course, be different to that seen in adults (e.g. they are behaviourally more likely to become 'overactive' rather than show the lethargic and sleepy behaviour which is more typical of adults). It has been suggested that externalising behaviours such as aggressiveness and temper tantrums feature prominently in the

neuropsychological profile of children with SDB [5]. Behavioural and cognitive impairments have been reported to be associated with severity of obstructive sleep apnoea [13].

Recognising and formally assessing the constellation of cognitive and behavioural features associated with SDB is important for a range of reasons, not least because the pattern and features of SDB which are clinically significant are less clear with paediatric populations than with adults [4,7]. Associated neuropsychological profiles are one aspect which should be considered when deciding upon clinical significance and making individual management decisions. As discussed further below, such profiles compared before and after treatment has been implemented can reveal information about the 'efficacy' of treatment and suggest areas of functioning that might need attention in their own right.

Increasingly, as interventions become more sophisticated and successful, it is the relative efficacy of treatments that need to be evaluated. 'Quality of life' is an important but often overlooked aspect to consider. Several components can be included under this term, e.g. disease status, social functioning, functional ability to perform one's tasks, psychological well-being, life satisfaction and domains specific to the disease or treatment under question. A number of instruments have been developed for specifically measuring quality of life for patients with obstructive sleep apnoea [14] including paediatric populations [15]. A key element might be the choice of informant; reports of outcome and preferences for various treatments can vary considerably between patient and health professional, and also between parent and child. It is not difficult to imagine how, for example, the pros and cons of treatment with continuous positive airways pressure (CPAP) might be assigned very differently by the child undergoing treatment and their parent. Identifying such discrepancies and issues underlying them, might ultimately enable one to increase compliance. Carroll and Loughlin suggest that involving behavioural therapists may be a key factor for successful CPAP treatment in some children [16].

5. Treatment issues

The effects of successful treatment for SDB in children (in most cases tonsillectomy or adenoidectomy) on neuropsychological functioning have been reported to be associated with improvements in school performance, behaviour and quality of life [17-19]. Such reports emphasise the importance of identifying and intervening.

However, there is also mention of successful treatment of the SDB not resulting in any improvements in neuropsychological function [20]. The children in the series reported by Brouillette et al. were slightly older than the children in the studies where improvements were found, highlighting the possibility that failure to diagnose and treat early enough might impair children at critical points of development leading to more permanent psychological deficits.

Such results also indicate how evaluation of efficacy of treatment for the sleep disturbance should extend beyond assessment of sleep physiology. It is possible that neuropsychological difficulties that are secondary to the SDB may persist even after the SDB has resolved and that these would need treatment in their own right. A further thought is that deficits that persist after 'successful' treatment might actually indicate that the SDB has not resolved.

6. Conclusions

Paediatric sleep disorders, of one variety or another, are common and to suggest that many cannot be effectively treated at the primary care level would be both unrealistic and impractical. However, in cases of diagnostic dilemma or treatment resistance where the child has particular unexplainable daytime symptoms, multiple sleep disorders, possibly pre-disposing medical conditions or where there is a need for specialised assessments, it would be beneficial to have available specialist sleep disorders clinics with multidisciplinary management of the child. At the very least, an appreciation of the inter-specialty issues associated with the field of paediatric sleep disorders would lead to relevant preliminary enquiries being made and, hopefully, referral to the appropriate specialist(s).

A first step to achieving this is to increase professional training about sleep and its disorders. Recent surveys in the UK suggest that medical students [21] receive very limited teaching (e.g. median times formally allocated commonly being 5 minutes overall, with some specialities, including General Practice receiving a median time of zero minutes!). The same is true of psychologists [22]. Sadly, very similar results have been found elsewhere in Europe and also in North America (see Ref. [21,22]). The current situation needs to change so that the teaching time devoted more accurately reflects the prevalence and seriousness of sleep disorders and their consequences in both children and adults.

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