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978-1-107-40220-1- Sleep and its Disorders in Children and Adolescents with a Neurodevelopmental Disorder: A Review and Clinical Guide

Gregory Stores

Excerpt

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Introductory remarks

Historical perspectives

The first English textbook of paediatrics, *The Boke of Chyldren*, was published in the mid-sixteenth century. The author was Thomas Phaïre, a lawyer and physician, who wished to draw attention (in fanciful terms by modern standards) to the clinical features, supposed causes, and recommended treatments of various ‘infirmities of children’:

Although (as affirmeth Plinie) there are innumerable passions & diseases, where unto the bodye of man is subiecte, and as well maye chaunce in the young as in the olde: Yet for moste commonly the tender age of children is chefely vexed and greuved with these diseases folowyng (Phaïre, 1545).

He then lists 40 such conditions which include neurological problems such as ‘Swellyng of the head’, ‘The fallyng euill’ (epilepsy), ‘The palsy’ and ‘Gogle-eyes’ (squint). He also discussed the following sleep disturbances: ‘watchyng out of measure’ (sleeplessness or insomnia), ‘terryble dreames and feare in the slepe’ and ‘pyssyng in bedde’. In course of considering ‘watchyng out of measure’ he stressed the importance of sleep:

Slepe is the nourishment & foode of a sucking child, and asmuch requisite as y^e very teate, wherefore wha It is depruiued of the naturall rest, all the hole body falleth in distēper [ill-health or disease].

In addition to his many other high-level accomplishments, Thomas Willis, the seventeenth-century physician and anatomist (who invented the word ‘*neurologia*’ and is credited with being the founder of clinical neuroscience), provided more extensive and detailed accounts of many childhood neurological conditions including various neurodevelopmental disorders.

However, the validity of Willis’s accounts of pathophysiology and treatment is tempered by the highly speculative contemporary notions such as the humoral theory of disease which had persisted from ancient times, and ‘iatrochemistry’ (the theory that disease is the result of chemical reactions involving, for example, ‘*explosions*’, ‘*explosive particles*’ or ‘*spirits*’, and that treatments could be chemical in type) (Williams, 2003). The curious nature of his suggested treatments rivalled Phaïre’s. For instance, he considered that the aims of treatment for limited intelligence were to

purifie and vollarize the Blood and nervous Liquor, together with the Animal Spirits: and also that they may clarifie the Brain and render it more Diaphanous (Willis, 1685, quoted Williams, 2003 p 358).

That said, Willis anticipated modern views about the aetiology of many disorders including intellectual disability, concerning which he distinguished between

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inherited, congenital and acquired causes of ‘stupidity’, differentiating this from ‘folly’ by which he seems to have meant psychiatric disorder (Williams, 2002). One of the many topics on which he lectured and wrote in his book *The London Practice of Physick* was sleep, and he is credited with making early observations of various sleep problems and disorders such as insomnia, nightmares, sleepwalking and even restless legs syndrome (Thorpy, 2000).

Needless to say, concepts, diagnostic methods and treatments have improved since the days of Phaire and Willis who, nevertheless, were well ahead of their time in some respects. Only relatively recently, paediatrics has gradually and sporadically emerged as a branch of medicine in its own right (Still, 1931). Even closer to the present day, as Millichap and Millichap (2009) have described, child neurology has developed to include the subspecialty of neurodevelopmental disability (Painter *et al.*, 2001).

The field of neurodevelopmental disorders has expanded rapidly in recent years with increasing numbers of reports from studies involving many disciplines and medical specialties. This book is concerned with a relatively neglected aspect of the predicament of very many children with a neurodevelopmental disorder, namely, sleep disturbance which can have serious harmful effects on both the child and his family.

It is inappropriate to generalize about sleep disturbance in children with neurodevelopmental disorders because of the many types of sleep disturbance now described and also the wide range of such disorders. For clinical purposes and also research, it is important to avoid reference to ‘mixed groups of children with a mental handicap’, which characterized many earlier sleep studies, and to consider precisely defined sleep disorders in specific subgroups of affected children.

Educational issues

Much knowledge about sleep and its disorders has accumulated in recent times but it remains under-utilized because awareness of these advances by both the general public and professionals remains inadequate. This is especially so regarding aspects of sleep and its disorders in children and adolescents.

Health education for parents and prospective parents often pays little regard to sleep. With some commendable exceptions, medical students, specialist trainees (including paediatricians and child psychiatrists, health visitors, child psychologists, and teachers) receive little relevant instruction despite the fact that all come in contact with many young people whose sleep is disturbed, sometimes with serious consequences.

Understanding of children’s sleep problems has improved considerably, certainly since the time of Phaire and Willis, and clinically valuable books are now available, but the attention paid to such problems still tends to lag behind that regarding sleep disturbance in adults. However, a positive sign is that the recent revision of the *International Classification of Sleep Disorders* or ICSD-3 (American Academy of

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Sleep Medicine, 2014) has improved on previous classification schemes by making paediatric aspects an integral part of its accounts of diagnostic issues.

Unfortunately, unlike nutrition and other aspects of basic health care, the topic of sleep and its disorders is neglected in both public health education and professional teaching and training (Colten & Altevogt, 2006). The extent of this neglect can be said to be striking.

Parents would benefit from knowing at least the fundamental facts about sleep, the ways in which it can be disturbed and the effects of this, as well as that, at any age, sleep problems can often be solved or, indeed, prevented (Owens *et al.*, 2011). Rather than trying to accommodate to their children's troublesome sleep, parents would benefit from knowing that unresolved sleep issues can lead to significant learning and behavioural difficulties. Schools do not cover the subject, and teenagers rarely have advice about their sleep despite the frequency with which it is disturbed, with the potentially serious harmful effects discussed later. Consequences of this neglect include parents omitting to mention their children's sleep problems to their doctor, and failing to seek help even for extreme sleep disturbance because they think that the problem is inevitable and cannot be treated (Schreck & Richdale, 2011).

As for professional neglect, it has been found consistently that the amount of time devoted to sleep and its disorders in undergraduate medical student courses is very limited (Peile, 2010). With few exceptions, the situation seems very largely to have remained the same in more recent times and there is little reason to believe that these deficiencies have been made up significantly in higher training. As a result, sleep problems may be overlooked in primary care (Blunden *et al.*, 2004), and relatively few paediatricians are reported to ask about sleep problems (Chervin *et al.*, 2001), or to possess basic knowledge about children's sleep (Owens, 2001). Consequently, many opportunities to help children with sleep problems (and their families) must inevitably continue to be missed (Wiggs & Stores, 1996). The urgent need for improved training in sleep medicine at all levels has been discussed by Strohl (2011).

A similar story can be told for other clinical groups including other medical childcare specialists and nursing staff (although some health visitors have taken the initiative and set up sleep clinics for young children and their parents), and also clinical psychologists (Meltzer *et al.*, 2009). Teachers and educational psychologists will encounter the school problems of children and adolescents whose sleep is inadequate without necessarily realising that this can be the cause (at least in part) of their learning and behaviour problems.

As Owens (2005) emphasized in her introduction to the meeting of the 2003 International Pediatric Sleep Education Task Force, healthcare staff increasingly work with patients and their families of widely different cultural origins. It is necessary, therefore, to be sensitive to the ethnic, socio-economic and cultural context of paediatric sleep disorders regarding their definition, aetiology, recognition, significance, assessment and management, as well as the need for patient and parent educational information. Gellis (2011) has reviewed the findings in studies of the effects of socio-economic status, race and ethnicity on children's sleep.

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Research and clinical practice

An inevitable consequence of this widespread educational neglect is that clinical provision for children with sleep disorders (which often needs to be multidisciplinary in nature) is frequently inadequate. Not surprisingly, research in the field of children's sleep disorders has, for the most part, been limited in both quantity and also quality. The evidence base for many aspects remains limited, often consisting of collective clinical impressions which, nevertheless, can have their value. The review by Kuhn and Elliott (2003) of various treatments for children's sleep disorders in which they graded the evidence in favour of their use, indicates that, in the light of the limited and varied quality of the published research, much remains to be accomplished before many treatments used have their evidence base firmly established. However, that does not justify therapeutic inertia, merely meaning that it is appropriate to be somewhat circumspect about the likely efficacy of treatment in the individual child if only in view of individual differences in response to the treatment chosen.

Terminology

Basic terminology in the area of childhood disability can be a source of confusion. For present purposes, 'neurodevelopmental disorder' implies an impairment of the growth and development of the central nervous system. Disorders that are neurodevelopmental in origin, or that have neurodevelopmental consequences when they occur in childhood, can be the result of various pathological processes such as genetic, metabolic, toxic or traumatic.

Childhood 'neuropsychiatric disorders' can be viewed as a subset of neurodevelopmental disorders, characteristically involving prominent psychiatric disturbance arising from neurological dysfunction the precise nature of which might be ill-defined. Children with this type of disorder generally attend child psychiatric services. Autism spectrum disorder, and attention deficit hyperactivity disorder are main examples. Other forms of neurodevelopmental disorder come more readily within the terms of reference of paediatric neurology.

Many children with a neurodevelopmental disorder have an 'intellectual disability'. This (or its equivalent 'learning disability') has been defined in the UK as a significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence), along with a reduced ability to cope independently (impaired social functioning) (Department of Health, 2001). This definition is distinct from 'learning difficulties' which is a general term referring to difficulty learning for various reasons, medical and non-medical. In North America 'learning disability' refers to specific developmental delays such as dyslexia, dyscalculia and dysgraphia. DSM-5 has substituted 'intellectual disability' (or 'intellectual disability disorder') for 'mental retardation' and ICD-11 is likely to do the same (Harris, 2013).

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The term ‘special educational needs’ usually refers to children who have learning disabilities that make it harder for them to learn than most children of the same age. Such children require assistance that may be educational, medical, psychiatric and/or psychological. ‘Children with multiple disabilities’ are defined as having two or more disabling conditions that affect learning or other important life functions. To qualify for special education services each of their disabilities must be so significant that their needs could not be met by special programmes that are designed to address one of the disabilities alone.

Structure and aim of this book

The book consists of four chapters.

Chapter 1 provides an outline of sleep and its disorders in children and adolescents, more detailed accounts of which are provided in books by Mindell and Owens (2010) and Stores (2001).

Chapter 2 considers some special considerations regarding sleep disorders in children with a neurodevelopmental disorder.

Chapter 3 reviews some comorbid conditions capable of contributing to sleep disturbance in children with a neurodevelopmental disorder.

Chapter 4 is the main part of the book. Drawing on the content of previous chapters, it consists of accounts of the sleep disturbance aspects of a range of neurodevelopmental disorders, each considered individually. The accounts are subdivided into three groups:

- neurodevelopmental syndromes
- neuropsychiatric disorders
- other neurodevelopmental disorders.

It is recommended that earlier chapters should have been consulted before Chapter 4 is consulted.

Several boxes, each with a historical/clinical theme, are included in places throughout the text.

Based on a review of the literature, this structure and content of the book aim to provide a useful reference source and clinical guide for paediatricians (including paediatric neurologists and specialists in intellectual disability), child and adolescent psychiatrists, psychologists, primary care staff, nursing staff including health visitors, and others involved with child health, welfare or education, as well as parents. This intended wide appeal illustrates the fact that a multidisciplinary approach to the sleep problems of children with a neurodevelopmental disorder is ideally required. Emphasis throughout is placed on aspects of practical clinical importance. Technical accounts of limited appeal to those who are not specialists in the sleep disorders field have been avoided.

As the book is written for non-specialists in the sleep disorders field, technical abbreviations are kept to a minimum, the main exception being in Chapter 4 where the conventional abbreviation of the name of each neurodevelopmental disorder is used. A list of abbreviations, mainly for technical terms in the sleep

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disorders field that appear in the text, is provided at the rear of the book as this might be helpful when the bibliography is consulted.

At times, purely for convenience, the child is referred to as 'he' or 'his' rather than the female gender. In places, 'child' or 'children' can be taken to include adolescents.

Bibliography

Selected peer-reviewed articles and chapters (and some books) are cited instead of an exhaustive literature review as this would exceed the intended purpose and scope of the book. For the same reason, detailed appraisal of individual publications was not attempted. The fine details of treatment regimes (also being beyond the scope of the book) can be found in the relevant references provided.

Because research in this area is generally limited in terms of the number of studies and sometimes their scientific quality, often conclusions and recommendations can only be provisional and necessarily subject to revision in the light of further study. Frequently, reports only raise clinical possibilities rather than established facts which, nevertheless, are important to consider in assessing and treating the individual child. Ideally, in time, sufficient findings based on well-designed research will become available to allow refinement of available evidence to more adequately guide diagnosis and treatment. Also, hopefully, the literature cited will act as a stimulus to further well-designed investigations.

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General outline of sleep and its disorders in children and adolescents

Basic aspects of the neurobiology of sleep

The nature of sleep

Sleep does not simply consist of the shutdown of daytime activities. The onset of sleep, waking up, and the two distinct types of sleep described shortly all involve complex brain mechanisms the modern view of which has been described by Brown *et al.* (2012). The most fundamental clinical aspect of sleep is that it is an essential part of existence in the sense that without it survival is not possible. If kept awake continuously long-term, experimental animals undergo profound deterioration in their basic bodily processes and they die.

Lesser degrees of sleep loss, and also poor quality (broken) sleep, can have serious harmful psychological and even physical effects. Without regular periods of rest, animals are unable to function properly in many ways.

In humans and related species sleep has very distinctive characteristics compared with other states of relative inactivity. Brain activity of hibernating animals is generally depressed as part of an overall slowing of bodily processes. The same is true in coma, or when unconscious. Sleep is different. For example, it is possible to be roused from sleep but, more especially, sleep shows specific patterns of brain and other physiological activity.

Interesting inter-species differences have been described. Duration of sleep within each 24 hour period varies from about 3 hours in a horse to almost 20 hours in bats. An adult human holds a mid-way position at an average of 7–8 hours. These differences are perhaps partly explained by differing vulnerability to attack by predators, although other possible explanations have been suggested.

Humans usually sleep at night in a bed; hamsters, for example, also sleep in their beds but during the day. Some animals, such as cattle and horses, can sleep standing upright; others, such as leopards, may sleep in a tree. Dolphins, and some other sea-dwelling mammals which need to be awake enough to breathe intermittently at the surface, and some other species, sleep in one half of their brain at a time, switching from one hemisphere to the other at intervals of minutes to hours ('inter-hemispheric sleep'). Roosting birds are able to sleep while maintaining their balance on a perch. Fish and reptiles also sleep or, at least, rest regularly in a way similar to sleep.

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10 Chapter 1 General outline of childhood sleep disorders**The functions of sleep**

As already mentioned, sleep is necessary for survival. Sleep can also be seen as particularly important as adult human beings spend about one-third of their life asleep and children much more than that. By early school age the average child has spent more time asleep than eating, playing, exploring his environment or interacting with others.

There has been much debate about the function of sleep. Clearly, there is no single explanation. Sleep serves many different, related functions, the balance between them changing during the course of development and possibly varying from one species to another.

Different theories have emphasized mental and bodily restoration and recovery during sleep, or the laying down of memories in the brain so that learning from experience is possible. Others have speculated that dreaming is essential for the working out of possibly deep-seated emotional problems and conflicts. On the physical side, basic functions requiring adequate sleep include growth, resistance to infection and possibly the process of repair following injury or other damage to body tissues, and various other metabolic processes. Inadequate or poor quality sleep in humans can cause potentially profound psychological and physical changes which can be reversed if sleep is restored to normal.

Types of sleep

There are two very different types of sleep: non-rapid eye movement (NREM) sleep and rapid eye movement (REM) sleep. It seems that a balance between these two types is required to function well.

NREM sleep

In adults this type of sleep makes up about 75% of sleep. It is divided into four levels of increasing depth, called stages, each of which has its own characteristic brain activity as recorded by the electroencephalogram (EEG). Stages 1 and 2 are relatively light sleep; stages 3 and 4 are deep sleep from which it is especially difficult to waken. Most deep sleep (also called slow wave sleep) occurs in the first 3 hours of overnight sleep. At this depth of sleep sleepwalking and related disorders occur. Fragments of dreams can occur in NREM sleep.

REM sleep

Needless to say, the main feature of REM sleep that makes it different from NREM sleep is prominent eye movements. Because most dreaming occurs during this type of sleep, it is also called 'dreaming sleep'. Compared with the 25% by age 2 and afterwards, REM sleep takes up at least 50% of sleep in newborns (and more than this before birth) suggesting that it is particularly important for early brain development. It appears to play some part in memory although the details are unclear. In infants, 'active' sleep is the precursor of REM sleep and 'quiet' sleep is the precursor of NREM sleep. Otherwise, sleep at this age is of 'indeterminate' type.