

How to approach pediatric sleep medicine in British Columbia: A consensus paper

Communication strategies and a multidisciplinary and interdisciplinary three-level sleep service are needed to ensure effective treatment of the sleep problems affecting many children and their families.

ABSTRACT: Children's sleep problems are currently not a high priority at BC Children's Hospital (BCCH) or at other children's hospitals throughout Canada, nor has sleep been identified as a public health issue, which has to be addressed in a structured way. However, the international literature clearly shows the importance of prevention activities related to pediatric sleep problems, as well as the need to implement sleep services at different levels in the health care system. In order to determine the pediatric sleep medicine needs in BC, the Sleep Research Group at BCCH organized a consensus meeting in June 2007. Participants included members of the clinical research team at BCCH, invited health care professionals, and guest speakers with expertise in pediatric sleep medicine, sleep measurement, and health economics. During the 1-day workshop, participants discussed how the existing gaps in pediatric sleep medicine in BC could be closed and how care for pediatric sleep problems could be delivered at the provincial level. This proposal, based on the published consensus, will form the basis to advocate for improved services in BC.

Some Canadian children's hospitals have sleep labs, but very few have an interdisciplinary sleep service. A concentrated action plan for pediatric sleep information and knowledge distribution has not been implemented in any province. We believe that public health strategies need to be developed in collaboration with national and international organizations, such as the Canadian Sleep Society, the Canadian Paediatric Society, and the American Academy of Sleep Medicine. We also believe that we need a comprehensive interdisciplinary and multidisciplinary sleep service for children in BC.

In order to determine the pediatric sleep medicine needs in BC, the Sleep Research Group at BC Children's

Hospital (BCCH), with the support of the Child and Youth Health Research Network (funded by the Michael Smith Foundation for Health Research) and the Child and Family Research Institute, organized a consensus meeting, Meet the Needs, Close the Gaps, on 25 June 2007, at BCCH. Members of the clinical research team, guest speakers, and health care professionals (see box) met to discuss how the existing pediatric sleep medicine gaps in BC could be closed and how current needs could be met. A summary of this discussion has now been submitted to the decision-makers at the Provincial Health Services Authority, BCCH, and the BC Ministry of Health.

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Background

In recent years, concerns have been expressed worldwide about the increasing number of children and adolescents whose sleep is inadequate (e.g., nonrestorative or disturbed).^{1,2} This problem has been declared a major public health concern and even an epidemic. The growing tendency to sleep less is due to social, technological, and medical changes, including an increased exposure to light at night.³⁻⁵ Demands placed on children's time (e.g., higher academic expectations that require more hours of study) are affecting their sleep. In the US, researchers estimate that 15 million children are affected by inadequate sleep.¹ A Canadian survey also indicates frequent sleep deprivation in children.² In addition, a large group of children with medical and neurological disorders are known to have hard-to-treat chronic sleep disorders.^{6,7} The burden of care for the caregivers of these children may be so heavy that they are forced to request alternate care.⁸

Sleep is a critical restorative brain function, which affects an individual's behavior, intellectual functioning, health, and quality of life. The behavioral manifestations of inadequate sleep include inattentiveness, impulsivity, poor interaction with peers, hyperactivity, aggressiveness, mood difficulties, and depression.⁹ In adolescents, suicide attempts are closely linked with sleep deprivation and depression.¹⁰ Sleep deprivation can result in school failure due to impaired cognitive functioning, verbal performance, abstract reasoning, and memory.¹¹ Persistent sleep difficulties also lead to severe health problems such as high blood pressure, obesity, diabetes, immunological deficits, and cancer.¹²⁻¹⁴ Thus, the costs of inadequate sleep in children and adolescents are huge and compounded by the fact that when children do not sleep their families do

not sleep, or at least have sleep difficulties.¹⁵ While there has been no estimate of what this costs in Canada or BC, it has been estimated that the annual cost of insomnia in the US is close to \$14 billion.¹⁶

Impact not recognized

Despite these profound effects, the sleep disturbances of children are markedly underrecognized and undertreated in BC and many other regions in Canada. This is because of a lack of public awareness of the importance of sleep, a lack of sleep services, and inadequate training of health professionals. Parents often fail to ask for help because they do not realize the serious consequences of their children's sleep difficulties or they perceive that the sleep disturbance is an inevitable part of a neurological or health condition. Yet the vast majority of sleep problems can be adequately treated and the needless suffering of these children and families can be prevented.¹⁷

One of the challenges when diagnosing pediatric sleep difficulties involves the distinction between physiological and pathological causes. For example, up to 80% of infants younger than 1 year have transient sleep difficulties that are no more than physiological adaptations. In contrast, almost 80% of patients with neurodevelopmental conditions, such as Down syndrome, have pathological sleep difficulties.¹⁸ This unclear physiology/pathology distinction has affected the perceptions of parents and health care professionals about sleep conditions. Pediatric sleep disorders have been and often still are perceived as circumscribed entities, transiently or chronically affecting the well-being of individuals. They are not viewed as a major physiological dysfunction that directly affects physical, neurological, and emotional development, be-

havior, health, and quality of life. Thus, the impact of pathological sleep disorders is often unrecognized and sleep disorders are left untreated, reflecting the slow or inefficient response of health care systems to new knowledge.¹⁹ Together, the social trend toward less sleep, the unclear distinction between physiological and pathological causes of sleep disorders, the slow response of the health care system to new information about sleep medicine, and the great number of misdiagnosed and undiagnosed sleep disorders have resulted in a gaping hole in the health care system.

Information not disseminated

The sleep-related knowledge needed to support efficient and sufficient sleep is not being conveyed successfully to the public. Despite constant media focus on a "sleeplessness epidemic," contradictory information is often presented in an unsystematic fashion. Health-based information about sleep may be resisted by some groups, such as adolescents, who might see prioritizing sleep as "uncool." Similarly, schools and recreational programs for children and adolescents occasionally ignore the needs for sleep hygiene and exacerbate unhealthy attitudes to appropriate sleep. We need a communication strategy that can effectively convey information about sleep and positively influence the sleep perceptions and choices made by health care professionals, public institutions, and the community at large. Speaking of sleep health and the positive effects of restorative sleep rather than of sleep hygiene or sleep disorders would be the first step.

Proposal

For the benefit of all children, and particularly for those who have chronic health problems, we recommend

developing a public-health-based communication strategy, involving stakeholders, and implementing a new provincial medical program, the Interdisciplinary Pediatric Sleep Service Program, based on multidisciplinary public health service concepts.²⁰ These initiatives are essential and long overdue in BC.

Develop communication strategies

A Canadian and, in time, an international web forum are needed so that professionals can share experiences and present relevant overviews. As well, public education activities are needed, such as the Mini Med School series of the Child and Family Research Institute. In addition, complementary communication strategies should be considered, such as the BCCCH/Child Family Research Institute collaboration with the Museum of Anthropology and international partners on the Sleeping and Dreaming in North America exhibition.

Involve stakeholders

The main goals of health care are to inform the public about current understandings and recommendations and to provide patients with a service that is delivered equitably and ethically. To achieve these goals, we need to understand the roles and needs of different health care providers, such as physicians, public health nurses, therapists, and social workers, and to empower them to close the sleep-service-related gaps at the level of care they offer. Patients, professional societies, unions, associations, special interest groups, and the government all have their own visions for health care based on their perceptions and interpretations of existing challenges. The expectations of these stakeholders and strong financial pressures shape the scope and direction of health care

development and will similarly influence our public education activities as well as the suggested sleep program. Therefore, the implementation of this new Interdisciplinary Pediatric Sleep Service Program requires transparent discussions, incentives, and guidelines for every involved group in order to provide a multidisciplinary approach offering service at different levels. Our main aim is to focus on the interests of children and their caregivers as individuals while paying attention to their well-being and quality of life.

In order to involve stakeholders we have created a provincial professional network, which includes the BC Medical Association, the BC Pediatric Society, Child Health BC, and different provincial programs (e.g., the Infant Development Program) as well as teaching institutions (e.g., University of British Columbia, Simon Fraser University, and Thompson Rivers University). We have also started to establish a Canadian professional network through the Canadian Sleep Society and the Canadian Paediatric Society.

Implement three-level service

Clinical evidence¹⁹ and health economic studies²¹ suggest that a “bottom-up” approach is the best way to create a multilevel pyramidal service model that focuses on screening and structured referrals based on algorithms, decision trees, and consensus recommendations. In keeping with the organization of the Canadian health care system, this approach involves medical services at the primary, secondary, and tertiary prevention and care levels: **1. Public education at the primary health care level.** The first level in our pyramidal service model relies on campaigns using appropriate, easily understood language and delivering messages from a patient-centred point

of view. An example would be an information campaign for parents and expectant parents that emphasizes safe and secure sleep practices for infants and reduces the negative association between sleep and sudden infant death. Another example would be knowledge translation by well-known and respected athletes or coaches whom adolescents will listen to and identify with. However, the main target groups for public education will be health care professionals, particularly those who are involved in the management of children with chronic health conditions (e.g., therapists and social workers). A series of workshops will help professionals working with children and their families follow up on sleep difficulties.

2. Structured knowledge dissemination among professional and associated partners at the secondary health care level. The second level of the pyramidal model relies on subspecialty support and development. Experience has shown that it usually takes up to 15 years, almost a generation, before a new subspecialty is appropriately implemented in the health care system and can provide sufficient service. Therefore, until a pediatric sleep program is fully functioning, every subspecialty will be responsible for sleep problems in their target population.²² Since sleep medicine has recently been accepted as a new subspecialty in the US and in several other countries, we will need national courses and conferences to train and support subspecialists in different fields from all major regions of Canada. In collaboration with various subspecialties, we will continue to develop a pediatric sleep curriculum and will offer a series of pediatric sleep medicine courses to interested professionals.

3. Structured knowledge generation and dissemination among profes-

sionals and associated partners at the tertiary health care level. The third level of the pyramidal model relies on specialists and subspecialists who have an improved understanding of sleep disorders. Pediatricians and pediatric subspecialists will have to pay more attention to the nocturnal phases of various disorders and to the interfaces of nocturnal and diurnal disease connections. They will need to understand certain associations such as the relationship between muscle spasm or gastroesophageal reflux and sleep fragmentation in children with special needs,²³ or between disordered sleep and melatonin deficiency in patients with brain injury.²⁴ The improved understanding of sleep disorders will lead to a more holistic approach, which will have a major effect on the well-being and quality of life of patients and their caregivers. This approach will also decrease the burden and reduce the economic impact of sleep disorders on the health system. Again, depending on the national consensus, a series of specific workshops, with financial support, will be provided to enhance high-quality structured knowledge distribution.

Conclusions

Current international literature clearly shows the importance of implementing pediatric sleep services at different levels in the health care system.²⁵ This and the clinical experience of participants at the consensus meeting indicate that we need to modify the perception of the public and health care professionals about sleep issues by providing information and implementing a multidisciplinary and interdisciplinary three-level sleep service. With the support of several provincial and national organizations, societies, and associations, BCCH plans to take the lead in the creation of a comprehensive sleep program. Adequate

funding will be required for the basic clinical service and for the comprehensive public education program. Funding will also be needed for evaluation of the health, economic, and social impacts of the proposed program, as all new public health services require careful follow-up assessments.

Since quality increases with transparency, our activities will be shared with provincial, national, and international organizations. Whereas pediatric sleep programs exist in some neighboring US states and Canadian provinces, including Washington and Alberta, BCCH has a limited sleep service that cannot adequately serve

Consensus Meeting (Meet the Needs, Close the Gaps)

25 June 2007, BC Children's Hospital

Guest speakers:

Brouillette, Robert T., MD, PhD, Professor, McGill University Health Centre

Kirk, Valerie, MD, Associate Professor, Pediatric Sleep Clinic, Alberta Children's Hospital

Witmans, Manisha, MD, Assistant Professor, Pediatric Sleep Program and Sleep Laboratory, Stollery Children's Hospital, University of Alberta

Invited health care professionals

Collingridge, Alissa, RN, MN, Nurse Practitioner (Complex Care Clinic, BC Children's Hospital [BCCH])

Chow, Carolyn, RN, BSN, Nurse Clinician (Provincial Neuromotor Program, Sunny Hill Health Centre for Children [SHHCC])

Duckworth, Kellie, BSc (Therapy Department, SHHCC)

Duivesteyn, Janice, BSc (Therapy Department, SHHCC)

Fogarty-Ellis, Eileen (Vancouver School Board)

Hall, Wendy, RN, PhD (UBC School of Nursing)

Hunter, Carey (Human Resources Counseling Inc.)

Lee, Vicki, MLIS, Clinical Librarian (SHHCC/BCCH)

McNaughton, Dorothy, BSocSc, PSW (SHHCC)

Penner, Janice, Nurse Clinician/Coordinator (Cleft Palate/Craniofacial Program, BCCH)

Purtzki, Jacqueline, MD, FRCPC, Clinical Assistant Professor (UBC)

Roxborough, Lori, MSc OT/PT Associate Director, Therapy Department (SHHCC)

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Saunders, Roy, MRCP (UK)(Pediatrics), FRCPC, MB, ChB, LRCP, MRCS, Clinical Associate Professor (UBC)

Scott, Lorine, MN NP (F), Nurse Practitioner/Coordinator (Cleft Palate/Craniofacial Program, BCCH)

Smith, Derryck H., MD, Head, (Department of Psychiatry, BCCH)

Wong, Peter, MD, Professor (Division of Neurology, BCCH)

All authors of this article actively contributed in the consensus meeting as speakers and/or moderators.

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all regions of BC. This deficiency must be remedied. As health professionals in one of the last provinces to implement such a program in Canada, we will have an opportunity to learn from others as we close the gaps in pediatric sleep medicine in British Columbia.

Competing interests

None declared.

References

1. Smaldone A, Honig JC, Byrne MW. Sleepless in America: Inadequate sleep and relationships to health and well-being of our nation's children. *Pediatrics* 2007;119(suppl 1):S29-S37.
2. Gibson ES, Powles AC, Thabane L, et al. "Sleepiness" is serious in adolescence: Two surveys of 3235 Canadian students. *BMC Public Health* 2006;6:116.
3. Jenni OG, O'Connor BB. Children's sleep: An interplay between culture and biology. *Pediatrics* 2005;115(1 suppl):204-216.
4. Owens JA. Introduction: Culture and sleep in children. *Pediatrics* 2005;115(1 suppl):201-203.
5. Iglowstein I, Jenni OG, Molinari L, et al. Sleep duration from infancy to adolescence: Reference values and generational trends. *Pediatrics* 2003;111:302-307.
6. Zucconi M, Bruni O. Sleep disorders in children with neurologic diseases. *Semin Pediatr Neurol* 2001;8:258-275.
7. Didden R, Korzilius H, van Aperlo B, et al. Sleep problems and daytime problem behaviours in children with intellectual disability. *J Intellect Disabil Res* 2002;46(Pt 7):537-547.
8. Espezel H, Jan JE, O'Donnell ME, et al. The use of melatonin to treat sleep-wake-rhythm disorders in children who are visually impaired. *J Vis Impair Blind* 1996;90:43-50.
9. Archbold KH, Pituch KJ, Panahi P, et al. Symptoms of sleep disturbances among children at two general pediatric clinics. *J Pediatr* 2002;140:97-102.
10. Liu X. Sleep and adolescent suicidal behavior. *Sleep* 2004;27:1351-1358.
11. Durmer JS, Dinges DF. Neurocognitive consequences of sleep deprivation. *Semin Neurol* 2005;25:117-129.
12. Barthlen GM, Stacy C. Dysnomias, parasomnias, and sleep disorders associated with medical and psychiatric diseases. *Mt Sinai J Med* 1994;61:139-159.
13. Gupta NK, Mueller WH, Chan W, et al. Is obesity associated with poor sleep quality in adolescents? *Am J Hum Biol* 2002;14:762-768.
14. Chasens ER. Obstructive sleep apnea, daytime sleepiness, and type 2 diabetes. *Diabetes Educ* 2007;33:475-482.
15. Meltzer LJ, Mindell JA. Relationship between child sleep disturbances and maternal sleep, mood, and parenting stress: A pilot study. *J Fam Psychol* 2007;21:67-73.
16. Walsh JK. Clinical and socioeconomic correlates of insomnia. *J Clin Psychiatry* 2004;65(suppl 8):13-19.
17. Mindell JA, Owens JA. *A Clinical Guide to Pediatric Sleep: Diagnosis and Management of Sleep Problems*. Philadelphia: Lippincott Williams and Wilkins; 2003.
18. Dyken ME, Lin-Dyken DC, Poulton S, et al. Prospective polysomnographic analysis of obstructive sleep apnea in down syndrome. *Arch Pediatr Adolesc Med* 2003;157:655-660.
19. Miller AR, Recsky MA, Armstrong RW. Responding to the needs of children with chronic health conditions in an era of health services reform. *CMAJ* 2004;171:1366-1367.
20. Government of British Columbia. The challenge of chronic disease management in British Columbia. 2003. www.health.gov.bc.ca/cdm/practitioners/challenge.pdf (accessed 17 October 2008).
21. Peacock S, Ruta D, Mitton C, et al. Using economics to set pragmatic and ethical priorities. *BMJ* 2006;332:482-485.
22. Ipsiroglu OS, Saletu B. [Sleep medicine between science and clinical practice—how long can we avoid the issue?] *Wien Klin Wochenschr* 2001;113:217-218. German.
23. McCarty SF, Gaebler-Spira D, Harvey RL. Improvement of sleep apnea in a patient with cerebral palsy. *Am J Phys Med Rehabil* 2001;80:540-542.
24. Wasdell MB, Jan JE, Bomben MM, et al. A randomized, placebo-controlled trial of controlled release melatonin treatment of delayed sleep phase syndrome and impaired sleep maintenance in children with neurodevelopmental disabilities. *J Pineal Res* 2008;44:57-64.
25. Krakow B. An emerging interdisciplinary sleep medicine perspective on the high prevalence of co-morbid sleep-disordered breathing and insomnia. *Sleep Med* 2004;5:431-433. **BCMJ**