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Clinical sleep services for children: clinical and administrative considerations

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Abstract

Increased recognition of the importance of pediatric sleep medicine, which emphasizes the developmental aspects of sleep and incorporates a number of clinical sleep disorders unique to children and adolescents, has generated considerable interest in expansion of clinical sleep services to meet children's specific needs. This article provides a synopsis of the key points regarding provision of sleep services to children and adolescents as discussed by a panel of pediatric sleep experts at the annual meeting of the Association of Professional Sleep Societies in June, 2000. Essential considerations in establishing a pediatric sleep practice and future directions are provided. © 2002 Elsevier Science B.V. All rights reserved.

Discussants: Judith Owens, MD (co-chair); Jodi A. Mindell, PhD (co-chair); Richard Ferber, MD; Brett Kuhn, PhD; Wallace Mendelson, MD; Carol Rosen, MD; Jerry Rosen, MD; Randi Streisand, PhD.

1. Background

Increased recognition of the importance of pediatric sleep medicine, which emphasizes the developmental aspects of sleep and incorporates a number of clinical sleep disorders unique to children and adolescents, has generated considerable interest in expansion of clinical sleep services to meet children's specific needs. Most sleep centers, however, that have developed such services have done so without the benefit of a model, and no guidelines regarding the structure, organization, and components of clinical pediatric sleep services currently exist. Furthermore, the multidisciplinary nature of the field makes it likely that, in addition to sleep professionals, a number of other disciplines involved in the care of children (including behavioral pediatricians, child psychiatrists, and child psychologists) will become increasingly involved in the development of these services. To address this gap, and to provide an opportunity for health care providers interested in pediatric sleep medicine to share

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information and ideas, a discussion group bringing together a panel of pediatric sleep experts and over 100 attendees was held at the 14th annual Association of Professional Sleep Societies meeting in June, 2000. The following is a synopsis of some of the key points discussed at that meeting, which is intended to provide a springboard for further dialogue and collaboration, as well as to serve as the nidus for the eventual development of practice guidelines for the delivery of clinical sleep services for children.

2. Models for delivery of children's sleep services

As with adult sleep medicine, a number of practice models exist for the provision of children's sleep services and there is significant diversity in the conceptualization of these services. Furthermore, most of these models are the product of what is essentially trial and error over time, and thus represent an evolutionary process rather than preplanned formulations. Nevertheless, the models of service may be grouped into the following four general categories:

Pediatric sleep center. The most traditional model is a free-standing sleep practice that is exclusively dedicated to pediatric patients. Some of these practices also have their own pediatric laboratory, while others refer pediatric patients needing sleep studies to an affiliated adult sleep laboratory.

Pediatric specialist within a general sleep center. A

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second model incorporates a pediatric sleep medicine specialist (usually a physician or psychologist) within the context of a general sleep center. In this model, generally one individual maintains a sleep medicine practice devoted exclusively to children and adolescents and the affiliated sleep laboratory tests both adult and pediatric patients.

Pediatric patients within a general sleep center. The third model is one in which a general sleep specialist sees both adult and pediatric patients. It appears that generally these are sleep specialists trained in adult sleep medicine who also see children and adolescents.

Pediatric sleep practice within a general practice. The final model is the incorporation of pediatric sleep services within a general setting, such as a pediatric center or a department of psychology. This model appears to be more common of psychologists working within a psychology setting.

3. Essential considerations in establishing a pediatric sleep practice

Taken from the discussion, the following are considered to be essential considerations in establishing children's sleep services. Many of these components are not necessarily unique to pediatric sleep, but reflect many of the challenges involved in establishing multidisciplinary clinical services in general.

3.1. Multidisciplinary approach

Ideally, provision of pediatric sleep services involves a multidisciplinary team, which may include pediatrics, family medicine, pulmonary, neurology, psychiatry, psychology, ENT, and pediatric nurse practitioners. An interdisciplinary network of affiliated services, which may also include an outside sleep laboratory, are key to providing comprehensive services. A viable alternative to a centerbased multidisciplinary team is to build a strong referral network of outside providers. However, in a setting where behavioral/psychological services are available only by referral, a comprehensive screening questionnaire is an essential component of the evaluation in order to alert the clinician to the possible need for additional evaluation.

3.2. Financial issues

As with all medical and psychological specialties, billing issues and establishment of reimbursement codes are paramount to obtaining and maintaining financial stability. Given that pediatric sleep services inherently require the provision of behavioral treatments, reimbursement issues with many insurance providers can be difficult, especially if a psychologist is providing these services. Across the board, all discussants who involved a psychologist in their practice commented on the difficulties with reimbursement issues. In some settings, it may be advantageous to bill all appointments under medical codes (using the International Classification for Sleep Disorders codes), with a physician co-signing with a psychologist. Some additional strategies for improving reimbursement include billing for follow-up patient phone calls and outside telephone consultations, and billing for a multicomponent evaluation. Furthermore, it should be noted that although a pediatric sleep clinic often generates only modest clinical revenues, these clinics often serve as the primary referral source for overnight sleep studies which do generate considerable income for an institution.

3.3. Overnight sleep studies

Although a detailed discussion of the factors involved in setting up and maintaining a pediatric sleep laboratory as a component of the clinical sleep service was clearly beyond the scope of this discussion group, all participants acknowledged the importance of a collaborative affiliation with one or more sleep laboratories for overnight sleep studies. If this facility is part of an adult sleep laboratory within one's own or another institution, the set-up (technicians, accommodations for parents, etc) of the laboratory must be able to accommodate the unique needs of children in a range of ages (note: The American Academy of Sleep Medicine offers an excellent video entitled 'KIDSzzzSleep: Your Child's Overnight Sleep Study'). If patients are referred to an affiliated laboratory, mechanisms for scheduling sleep studies, orienting patients, provision of necessary information to the technical staff, and prompt feedback of results to the sleep clinic, referring and/or primary care physician, and family need to be established.

3.4. Population and referral base

The multidisciplinary nature of children's sleep services increases the likelihood that each specific practice will have its own unique population that is often a reflection of individual interest and expertise (e.g. sleep issues of medically complex children, infant/toddler behavioral issues, sleep disordered breathing). However, given the biopsychosocial nature of sleep problems and the high percentage of dual and triple diagnoses, especially comorbid behavioral issues, pediatric sleep specialists and pediatric sleep centers should be prepared to assess and treat a wide spectrum of disorders across a range of ages and developmental levels. In the process of establishing a pediatric sleep service, as well as of increasing the level of an existing service, there are multiple means of developing, maintaining, and expanding referral sources. These include presentation of grand rounds and local CME lectures, giving talks to parent and school groups in the area, and encouraging local media coverage of pediatric sleep issues, as well as direct mail solicitation of local pediatric providers.

3.5. Training

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Many pediatric sleep clinics function within an academic setting and thus provide an opportunity to involve trainees in the provision of clinical sleep services. The level of training and range of disciplines which may be appropriate for this type of collaboration are broad, and include: medical students; pediatric, family medicine, and psychiatry residents; fellows in ambulatory pediatrics, behavior and development, sleep medicine, adult and child neurology, adult and pediatric pulmonology, and child psychiatry; clinical psychology graduate students, interns, and post-doctoral fellows; and nursing and nurse practitioner students. In a multidisciplinary pediatric sleep clinic, involvement of faculty as providers facilitates recruitment of trainees from the corresponding disciplines, but it is also often possible to recruit training program directors or even individual trainees who would be interested in establishing a relationship if one does not already exist. The educational, clinical, and research-related advantages of such a collaboration are mutually beneficial and include the provision of a unique educational experience that is often not found within the context of a standard training program, potential expansion of the magnitude and scope of clinical service delivery, and enhanced capacity for developing and implementing clinical research projects. In addition, the exposure of trainees to the field of pediatric sleep medicine has directly led, in a number of instances, to the subsequent successful establishment by those trainees of pediatric clinical services at new sites around the country.

The provision of an optimal educational experience for trainees, however, does involve some planning and additional work on the part of the faculty involved and is a process which should be tailored to the types and levels of trainees involved. A syllabus of basic readings in pediatric sleep medicine should be provided and brief didactic sessions on a variety of specific topics presented in the clinical setting may be helpful. Trainees should also receive instruction in conducting the clinical pediatric sleep interview, and in the format and content of reports. Exposure to the sleep laboratory and overnight sleep studies is also highly desirable. The scheduling of appointments in the clinic should take into account the need for additional time for supervision of trainees, and thus the efficiency of the clinic may be somewhat compromised. In general, it is preferable for trainees to structure their clinical involvement within a block of time (3-4 month rotation) to optimize both continuity and exposure to a variety of pediatric sleep disorders.

3.6. Administrative support

As with many other types of medical and psychological services, there are multiple administrative issues involved in providing sleep services for children; these include scheduling of appointments, billing, typing of reports, and contact with third party payers. Some practices employ their own designated secretaries, typists, and billing coordinators, whereas others share these needs with other services, such as pediatrics, pulmonary, psychology, or an adult sleep center. Some also hire an independent bill collection agency.

3.7. Leadership

As with most clinical endeavors (especially those that may not be in well-established disciplines), the need for an individual to assume a leadership position in the delivery of pediatric sleep services is key. This individual, depending upon the nature and scope of the clinical services, may be responsible for coordinating administrative and financial issues, establishing and maintaining collaborative relationships with other disciplines and clinical services, as well as referral sources, supervising training efforts, and overseeing clinical research projects. Perhaps the most important role, however, is to maintain visibility and a presence within the context of the setting (e.g. academic institution, hospital, multispecialty clinic facility) in which the clinic functions in order to justify and preserve the services provided in the current climate of health care cutbacks.

3.8. Triage issues

In order to function smoothly, any multidisciplinary pediatric sleep center must establish a triage system to direct specific patients to the appropriate provider in the clinic (e.g. pulmonologist – sleep disordered breathing). Various sleep centers have solved this problem in different ways. For example, some centers hold a brief meeting at the beginning of clinic and triage according to the presenting complaint. Initial information about the referral concern may be obtained by a secretary or nurse practitioner during a brief phone intake and/or through review of information on an intake packet which families are required to complete prior to the scheduled appointment.

3.9. Logistics of visit

Issues that need to be considered in scheduling patients include: (1) the amount of time the family will be at the center; (2) the average duration of both intake and follow-up appointments (note that initial visits are often lengthy as both assessment and treatment occur during the same visit); (3) the number of trainees and staff seeing each patient and whether that process will occur concurrently or sequentially (e.g. one discussant recommended the inclusion of a nurse practitioner at all intake visits to enable that individual to handle the majority of follow-up phone calls); and (4) the inclusion of information or tours of the sleep laboratory for children and adolescents who require an overnight polysomnogram.

3.10. Follow-ups

The final issue that needs to be addressed is how followup contacts and appointments will be handled. Some clinics require all follow-ups to be patient visits, whereas others utilize phone follow-ups exclusively or in addition to clinic visits. Furthermore, in some clinics, the majority of followups are handled by a nurse practitioner or fellow rather than by the primary physician/psychologist. In addition, as part of the implementation of a behavioral plan, many services schedule regular phone 'check-ins' with patients.

4. Future directions

Clearly, the development of children's sleep services is still a relatively new endeavor in the field of clinical sleep medicine, and thus, the continued expansion of such services, as well as the establishment of standardized guidelines for their delivery, form the logical next step. However, it would appear from the breadth and diversity of solutions that both the discussants and the audience had developed, that it will be a challenge to achieve some degree of consensus. A number of factors have likely contributed to the multiplicity of approaches; these include the numerous specialties, primarily medical and behavioral, that are involved in the field of pediatric sleep; the relative lack of empirical data supporting specific treatment outcomes, and until recently, the relative dearth of opportunities for ongoing dialogue and sharing of ideas among pediatric sleep specialists.

In order to begin to accomplish these goals, a number of complimentary processes need to take place. First, a comprehensive list of individuals/centers who currently offer clinical sleep services for children (or who are interested in doing so in the future), as well as the nature of those services, needs to be developed. The first step in developing such a database has been a recent survey by the authors of basic information (including contact information, affiliation, specialty, percentage and numbers of patients seen within pediatric sleep, and research interests) for approximately 100 individuals/centers across the country, which currently provide sleep services for children. This database is intended to serve as an ongoing and expanding resource for clinical referrals, as well as the basis for further exchange of ideas. In addition, a more active role for the Pediatric Section of the American Academy of Sleep Medicine (AASM) could provide a forum for ongoing dialogue, and might also offer the opportunity for further discussion with adult sleep centers. Third, some consensus needs to be reached about the minimal requirements for the delivery of pediatric sleep services and practice guidelines developed by a group of pediatric sleep experts. The development of a special task force through the AASM to establish guidelines for clinical sleep services for children would be an important step in formalizing the mechanism through which such a discussion would take place. Presentation and dissemination of well-established pediatric sleep service delivery systems that work should be encouraged, as well as ongoing feedback that would further refine these systems. Additionally, monitoring mechanisms need to be established in order to ensure quality of care in the provision of pediatric sleep services. Finally, further research on the efficacy of a variety of treatments, ranging from behavioral management strategies to indications for adenotonsillectomy for obstructive sleep apnea, as well as on clinical outcomes is clearly necessary.

This short note is intended to stimulate an ongoing discussion on provision of children's sleep services. Those individuals who are interested in continuing this dialogue are invited to join 'pedsleep', an ongoing e-mail discussion list that is moderated by Dr Avi Sadeh (contact Dr Sadeh at sadeh@post.tau.ac.il), contact the authors directly, or join the Pediatric Section of the American Academy of Sleep Medicine.