Starting a Pediatric Sleep Program in Your Laboratory

Focus Spring, 2017
Robyn Woidtke MSN-Ed, RN, RPSGT, CCSH
Objectives

1) Compare and contrast pediatric to adult approaches in sleep medicine

2) Describe a "family" approach to care

3) Describe theories of pedagogy and androgogy
KIDS ARE DIFFERENT
So…. you want to study kids?

- Evaluate the need
- Assess your environment
- Assessment of referral sources
- Overcoming objections
- Is it financially feasible
- Assess current capabilities (human resources)
  - What do you have?
  - What do you need?
- Can your HME support pediatrics?
Can the population support the center?

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<td>73.8</td>
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<td>73.9</td>
<td>74.1</td>
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Currently there are only 28 “titled” pediatric sleep centers accredited by the AASM, according to the 2012 AASM Roster of Accredited Sleep Centers

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3459190/
Is there a need?

- 1.2-7% estimated prevalence of sleep disordered breathing (Bixler, 2011)
  - A 2% estimate is ~ 1,500,000
- Insomnia is a frequent complaint
  - Pediatricians rarely address sleep problems
- Research indicates that children who are treated for a sleep problem do better in school
- Few pediatric oriented laboratories
- As the first line therapy, it is estimated that ~ 500,000 adenotonsillectomies (T&A) are performed each year specifically for OSA in children under 15 (Redline, et al., 2011)
Key Point

“The AASM 2011 Practice Parameters on Respiratory Indications for PSG in Children recommends that all children undergoing adenotonsillectomy for sleep disordered breathing have a diagnostic sleep study to establish the diagnosis and determine severity. Currently, it is estimated that fewer than 10% of children have a sleep study prior to surgery”

Owens, Kothare & Sheldon (2012) JCSM
The Growing Obesity Epidemic

- 18% children 6-11; 18% 12-19 (CDC, 2010)
- May be as high as 25%

National Initiative for Children's Healthcare Quality
OSA and Obesity Implications

- Rise in obesity = OSA (1.3-4.6 fold)
- Issues
  - Asthma
  - Low Self-Esteem
  - Poor impulse control
  - Hypertension
  - Insulin resistance
- Sleep disturbances may lead to overweight

Landis & Redline, 2007
Pediatric specific

- 30% of children have a sleep disorder; higher in children with special needs
  - Autism
  - ADHD
  - Parasomnias
  - Trachs
  - Mobility – e.g. Cerebral palsy, weight problems
  - Down Syndrome
  - Abuse – consider Munchausen by proxy syndrome (MBPS)
Special Needs Children

- Difficulty staying asleep and frequent night awakenings
- Trouble falling asleep
- Medical issues may include pain from disease, lung and/or cardiac disease with trouble breathing/fatigue, neuromuscular disorders contributing to sleep-related breathing problems
- 80% have a sleep problem
Audience Participation

- Do you think there is a need?
- What are you seeing in your community?
- Do you think specialized training and certification should be required for technologists?
- Should there be a pediatric lab “accreditation”
See the Pros and Cons

Evaluation and Treatment of Children's Sleep Disorders: A Healthy Debate

Samuel A. Fleishman, M.D., F.A.A.S.M.

PRO: “Not Just Little Adults”: AASM Should Require Pediatric Accreditation for Integrated Sleep Medicine Programs Serving Both Children (0-16 years) and Adults


CON: Specific Pediatric Accreditation Is Not Critical for Integrated Pediatric and Adult Sleep Medicine Programs

David Gozal, M.D.
Assess your current environment

- Size and layout of the current space or planned space
- Adults and peds or just peds?
- Furniture
  - Cribs
  - Beds or appropriate chairs for parents
  - Safety is key, bed rails, chemicals out of reach, wires and cables,
    - Pediatric emergency tools and facilities
Your current environment

- In-patient, out-patient, both
  - Pulmonary function lab currently conducting 4 channel studies?
  - GER?
  - Revenue

- Can you run both adults and peds on the same night?
  - Special nights for kids
  - Responding to referral needs
  - May need to extend lab hours, i.e. start sleep study earlier and run test longer

- What do you do about MSLT?
Is your environment family friendly?

- Rooms appropriately furnished and decorated
- Toys, videos, books etc…
- Parents have appropriate outlets as well
- Do you have the right materials for
  - Parents
  - Age specific
Physical Setting and Needs: Hospital

- Record in the infants normal environment (NICU)
  - nurses often reluctant to relinquish control
  - chaotic, noisy and possibly bright lights
- Usual care and feeding should be maintained
- Understand thermoregulatory requirements (might need to record skin temp)
Referral Sources

- Geographic area
  - Urban vs Rural
- Pediatricians/neonatologists
- Orthodontists/Dentists
- Schools
  - Teachers; school nurses
- Behavioral counselors
- Cranial facial/plastics
- Other
Opportunity!

Use of the ‘BEARS’ sleep screening tool in a pediatric residents' continuity clinic: a pilot study (Owens & Salzellb, 2005)

- 195 (2-12) children had both pre and post BEARS clinic visit
  - 98.7 vs 87.7 had sleep information
  - 92.8 vs 7.2 Snoring
  - 93.9 vs 5.6 EDS

“The BEARS appears to be a user-friendly pediatric sleep screening tool which significantly increases the amount of sleep information recorded as well as the likelihood of identifying sleep problems in the primary care setting.
Administration

- Develop a business case for conducting pediatric sleep studies
  - Include ROI
  - Spin off revenue i.e. surgical procedures
  - GI

- Do not forget to include intangibles
  - PR
  - Community good will
  - May drive adult business
HME Issues

- Does your HME currently deal with pediatric patients?
- Are they aware of the % medicaid
  - Some states are better than others
- Do their RT’s have specialized pediatric training
  - Not unlike the sleep lab 😊
- Revenues for pediatric sleep products and services were expected to reach 30.6 million in 1998, a 6 percent increase from 1997. The market totaled $23.3 million in 1995 (F&S,1999)
Review of 3 Practice Parameters

- American Academy of Pediatrics
- American Academy of Sleep Medicine
- American Academy of Otolaryngology–Head and Neck Surgery (AAO-HNS)
Sleep Studies Indications in Children

- Diagnose SRBD (central and obstructive)
- Titration of positive airway pressure
- Evaluate SRBD treatment effectiveness
- Diagnose PLMD
- Diagnose narcolepsy/ CNS Hypersomnia
- Evaluate unresponsive insomnia
- Evaluate parasomnias and seizures
Clinical Utility of PSG

- Apnea
  - Seizure
  - CNS immaturity
  - GE reflux

Treatment
Clinical Practice Guidelines

RESPIRATORY INDICATIONS FOR POLYSOMNOGRAPHY IN CHILDREN

Practice Parameters for the Respiratory Indications for Polysomnography in Children

R. Nisha Aurora, MD¹; Rochelle S. Zak, MD²; Anoop Karippot, MD³; Carin I. Lamm, MD⁴; Timothy I. Morgenthaler, MD⁵; Sanford H. Auerbach, MD⁶; Sabin R. Bista, MD⁷; Kenneth R. Casey, MD⁷; Susmita Chowdhuri, MD³; David A. Kristo, MD⁸; Kannan Ramar, MD⁹

- 2011


Clinical practice guideline: Polysomnography for sleep-disordered breathing prior to tonsillectomy in children.


Department of Otolaryngology-Head and Neck Surgery, University of Texas Southwestern Medical School, Dallas, Texas, USA.

- 2011
Diagnosis and Management of Childhood Obstructive Sleep Apnea Syndrome
Pediatrics; originally published online August 27, 2012;
DOI: 10.1542/peds.2012-1671

Supercedes 2002
AASM Recommendations for PSG

- PSG performed according to the AASM manual
- Indicated (S)
  - when clinical assessment warrants further testing (S)
  - Considering T&A (G)
  - Infants when there is clinical evidence of SRBD or ALTE (G)
  - Congenital alveolar hypoventilation due to neuromuscular or chest wall deformities (G)
- After T&A to assess for residual
  - Mild OSA if clinical symptoms persist (S)
  - Mod-Severity, obesity, cranial-facial abnormalities, downs syndrome, neurologic disorders
- Titration (S) or on chronic CPAP (G)
- Treated w oral appliance (O)
- Rapid maxillary expansion (O)
- Other
AAO – PSG Recommendations

- Ages 2-18
- NOT
  - Have already undergone tonsillectomy/adenoidectomy
  - Being considered for CPAP
# AAO-Action Statements

**Table 1. Summary of Action Statements for PSG**

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<thead>
<tr>
<th>Statement</th>
<th>Action</th>
<th>Evidence</th>
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<tr>
<td>1. Indications for PSG</td>
<td>Before performing tonsillectomy, the clinician should refer children with SDB for PSG if they exhibit any of the following: obesity, Down syndrome, craniofacial abnormalities, neuromuscular disorders, sickle cell disease, or mucopolysaccharidoses.</td>
<td>Recommendation based on observational studies with a preponderance of benefit over harm.</td>
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<tr>
<td>2. Advocating for PSG</td>
<td>The clinician should advocate for PSG prior to tonsillectomy for SDB in children without any of the comorbidities listed in statement 1 for whom the need for surgery is uncertain or when there is discordance between tonsillar size on physical examination and the reported severity of SDB.</td>
<td>Recommendation based on observational and case-control studies with a preponderance of benefit over harm.</td>
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<td>3. Communication with anesthesiologist</td>
<td>Clinicians should communicate PSG results to the anesthesiologist prior to the induction of anesthesia for tonsillectomy in a child with SDB.</td>
<td>Recommendation based on observational studies with a preponderance of benefit over harm.</td>
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<tr>
<td>4. Inpatient admission for children with OSA documented in results of PSG</td>
<td>Clinicians should admit children with OSA documented in results of PSG for inpatient, overnight monitoring after tonsillectomy if they are younger than age 3 or have severe OSA (apnea-hypopnea index of 10 or more obstructive events/hour, oxygen saturation nadir less than 80%, or both).</td>
<td>Recommendation based on observational studies with a preponderance of benefit over harm.</td>
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<td>5. Unattended PSG with portable monitoring device</td>
<td>In children for whom PSG is indicated to assess SDB prior to tonsillectomy, clinicians should obtain laboratory-based PSG, when available.</td>
<td>Recommendation based on diagnostic studies with limitations and a preponderance of benefit over harm.</td>
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TABLE 2  Symptoms and Signs of OSAS

History
- Frequent snoring \( \geq 3 \) nights/wk
- Labored breathing during sleep
- Gasps/snoring noises/observed episodes of apnea
- Sleep enuresis (especially secondary enuresis)\(^a\)
- Sleeping in a seated position or with the neck hyperextended
- Cyanosis
- Headaches on awakening
- Daytime sleepiness
- Attention-deficit/hyperactivity disorder
- Learning problems

Physical examination
- Underweight or overweight
- Tonsillar hypertrophy
- Adenoidal facies
- Micrognathia/retrognathia
- High-arched palate
- Failure to thrive
- Hypertension

\(^a\)  Enuresis after at least 6 mo of continence.

TABLE 3  Contraindications for Adenotonsillectomy

Absolute contraindications
- No adenotonsillar tissue (tissue has been surgically removed)

Relative contraindications
- Very small tonsils/adenoid
- Morbid obesity and small tonsils/adenoid
- Bleeding disorder refractory to treatment
- Submucous cleft palate
- Other medical conditions making patient medically unstable for surgery
AAP-Key Action Statements

1: Screening for OSA
- Inquiry to snoring-refer or conduct focused evaluation

2A: Polysomnography
- Based on the symptoms; order PSG or refer to specialist

2B: If PSG not available
- Use other methods to determine diagnosis

3: Adenotonsillectomy
- First line treatment
AAP-Key Action Statements

- 4: High Risk Patients undergoing Adenotonsillectomy
  - Monitor as in-patients postoperatively
- 5/5B: Clinically reassess for persistent signs and symptoms
  - Check for residual symptoms in low and high risk patients
- 6: CPAP
  - Residual symptoms/if surgery not performed
- 7: Weight loss, if appropriate
- 8: Intranasal steroids
  - Mild OSA or where adenotonsillectomy is contraindicated
About Out of Center Testing

Unattended Full-Channel or Limited Channel Portable Monitoring/Home Sleep Test (HST) (CPT codes 95800, 95801, 95806 and HCPCS codes G0398, G0399, G0400):

III. Unattended full-channel or limited channel portable monitoring/home sleep testing (HST), performed out of center as a single night test is proven in patients not previously diagnosed with OSA but with clinical suspicion of OSA (see above) when such testing meets ALL of the following:

A. devices must meet the minimum requirement for limited channel testing measuring heart rate, oxygen saturation, and respiratory analysis; AND

B. patient is an adult;

Health Net, Inc. considers home home/portable sleep studies for the diagnosis of OSA in children (less than 18 years of age) investigational. Limited portable studies, or studies in the home, are not sufficient to exclude OSA in a child with suggestive symptoms, nor can they reliably assess the severity of the disorder which is important in planning treatment. Overnight polysomnography remains the diagnostic "gold standard" in children with OSA.
Staffing Considerations
Staffing issues! Are you ready?

- Pediatric skill set?
- Tech to patient ratio
  - Age and acuity dependent
- May be able to conduct some daytime studies
  - Appropriate?
  - Other competing obligations, i.e. clinic
Pediatric Sleep Technologist

- Have specific training for this population
- Apply concepts of normal growth and development
  - psychosocial development, cognitive abilities
- Be knowledgeable about illnesses or conditions unique to various age groups
  - childhood OSA vs adult OSA
- Employees versed in infant/child CPR
Pediatric Sleep Technologist

- Must enjoy working with infants and children
- PATIENCE is a virtue every pediatric sleep technologist must possess
- Feel comfortable and confident in their abilities
  - parents sense inexperience
- Be firm, yet sensitive to the parents situation
- Familiar with sleep/wake behaviors
  - repetitive motor, sucking and transitional objects
Staffing Requirements

- 1 day shift FTE dedicated to pediatrics
- Evening and/or night technicians with pediatric experience
- Staffing ratio will vary upon the age of the child and census, may be 1:1
Pediatric Program Coordinator Day

- Coordination of visits with and by other specialties (Craniofacial, Pulmonary, Genetics, ADHD)
  - Care Coordination is a HOT BUTTON
- Follow-up: may be extensive
  - Surgical referrals
  - CPAP titration, mask fitting
  - Psychosocial
  - Social services
- Phone calls to and from parents are frequent and often lengthy
Pediatric Program Coordinator Day

- Participates in community awareness programs
  - Schools/PTA
  - Churches
  - Other
- Research endeavors
- Training of new technologists, fellows
- Marketing the program to referral sources

If competent in *sleep technology*
- Daytime PSG for premies/newborns (if appropriate)
- Scoring records
Reimbursement

- Varies from carrier to carrier
  - Usually covered
  - % insured varied and may be geographic
- Lots of Medicaid
  - Covered for certain dx and if the patient qualifies
- Uninsured
Things to consider: Performing PSG on Infants

- Daytime nap recording for preterm infants and newborns (4-6 hours recording time)
- Overnight recordings for older infants with diurnal sleep rhythms
- A minimum of 1 sleep cycle (50-60 minutes) is recommended in the young infant, but ≥ 2-3 cycles are preferred
- Hook-up before feeding, sleep well after feeding
Timing of Recording
Developmental Factors

- Post-conceptional age (PCA)
  - Quiet sleep: 39% at term
  - Active sleep: 60% at 34 weeks, 50% at term
  - At 3 months, REM sleep onsets may disappear (range of normal, 50% at 3 mos.)
- Circadian influence important after 1 month
- Age of child should be considered
Now that the hard work is done.....

Let’s take care of patients
The referrals are coming in…

- Family centered approach is very important to the success of the sleep laboratory

- The “Sleep Team” consists of
  - Parent (s)
  - Child
  - Sleep Center Staff
    - Physician
    - Technologist
      - Day and Night
    - Ancillary staff

Zaremba et al Journal of Clinical Sleep Medicine, 2005
Don’t Forget!!!!

Not only do we care for the patient, we must consider parents, siblings and extended family members!
The “Family” Patient

All children should be assessed for general physical and emotional health, as well as family stability

Family history is very important!
The “Family” Patient

- Perception
  - parents
  - child
- Disorder vs. Problem
- “Buy in”
  - parents
  - child
Family Education: Pre-Study

- Parents may be sleep-deprived, stressed, anxious and/or fearful, may feel powerless
- Assess parents’ level of understanding
  - Language
  - Reading
- All procedures should be fully explained prior to onset of the study and during the study as needed
  - Photos may be helpful
Identify roles for the family

- What are the parents expected to do?
  - How can you make their experience positive?
  - Understand that the parents are the “experts” on their child
  - Staff is open to suggestions by the parents to ease the ‘trauma” of the sleep center experience
  - You must “tell” or them what you need them to do
    - “Your job is to ………..
  - You must “engage” their support

Zaremba et al Journal of Clinical Sleep Medicine, 2005
Identify roles for the family

- Depending on the age of the child
  - Ask them to help
  - Understand their limitations
    - Don’t ask them to do something that they cannot!
  - Ask them what they want their “job” to be
    - Kids respond to being a “good helper”

- Adolescents may not want to engage at all
  - Sometimes more difficult than the younger school age child
Have the parents bring

- Transitional object
  - special blanket
  - toy
  - musical animal
- Special foods or drinks (including formula)
- Books (for the child and parent)
- If appropriate, audio tapes
Understanding the Parental Conflict

- Parents wish to do the best for their child
- Parents do not want to see their child in distress
- May be in denial that a problem exists
- May be sleep deprived due to
  - Sleeplessness of child
  - Other issues at home; other children; job, spouse
  - Their own sleep disorder

Sleep deprivation can lead to poor coping mechanisms
Things you didn’t know you would have to deal with!

- Irate parents
- Parents in denial
- Dysfunctional family units
  - Divorce
  - Mental illness
  - Lack of support systems
- Language barriers
- Teaching teenage parents

Everything you can think of……
Preparation for the Sleep Study

- Systematic and individualized preparation
  - One size does not fit all
- Thorough explanations for each component of the sleep lab visit
  - Photos and daytime visits to the center are very helpful for all
- If OSA is suspect, schedule “fitting and acclimatization” sessions
- Role playing, depending on the age can help to ease the stress of coming to the lab
  - Putting electrodes onto a doll
Family Education: Post-Study

- Explain the course of events regarding interpretation and results
- Ask the parents and, if appropriate the child, if they have any questions or concerns they may not ask!
- Depending on diagnosis and SOP’s initiate plan of care and follow-up
  - May need referrals
We have diagnosed them, now what?

- Training and education is time consuming
  - Will depend on the reason for coming to the sleep center
- Each stage of development requires own set of age matched tools for learning
- When is the patient/family ready to accept therapy?
  - CPAP
  - Meds for apnea i.e. methylzanthines
  - Meds for narcolepsy
  - Parents in limit setting
Learning and Training Needs

- Different than adults
- Requires knowledge relating to learning principles
- May be working with parents who are children themselves
- Assessment will likely be ongoing
# Adult versus Child Learning

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<th>Andrology</th>
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<tr>
<td>Subject Centered</td>
<td>Problem Centered</td>
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<tr>
<td>Dependant Learners</td>
<td>Independent Learners</td>
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<tr>
<td>Inexperienced Learners</td>
<td>Experienced Learners</td>
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<tr>
<td>Teacher Prescribed Content</td>
<td>Learner Prescribed Content</td>
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<tr>
<td>Learners Grouped by Age Level or Ability</td>
<td>Learners Grouped by Interest or Needs</td>
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<tr>
<td>Learning for the Future</td>
<td>Learning for the Now</td>
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<tr>
<td>Learners Subordinate to the Teacher</td>
<td>Learners Equal to the Teacher</td>
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<tr>
<td>Rigid, Traditional Structure</td>
<td>Flexible, Alternative Structure</td>
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<tr>
<td>Passive Learners</td>
<td>Active Learners</td>
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Tools for Learning

- Various teaching methods
  - Lecture
  - Group discussion
  - One-on-one
  - Demonstration
  - Gaming
  - Simulation
The Child as a Learner

- Drawing and Painting
  - requires little direction
  - have the child explain their work
  - used to clarify misconceptions
The Child as a Learner

- Dramatic Play
  - assignation of roles
  - have the child administer the treatment to a doll or puppet
  - Supervision and active participation required
Adaptation and Assessment

- Play therapy can be used to assess the child's perception of the situation
- Plan age related activities
- May need to alter/add activities depending on stage of therapy
- Ask them if they understand
  - Have them repeat or demonstrate back
  - Encourage questions
General Principles

- Give positive reinforcement
- Project an attitude of acceptance and sensitivity
- Be organized and give direction as needed
- Elicit and give feedback
- Use questions
- Know who you are teaching
- Use repetition and pacing
- Summarize important points

Bastable, Essentials of Patient Education, 2006
Summary

- Preparation is key to success
- Evaluate existing resources
  - Develop networks for referral
  - Nice to have a “Pediatric Sleep Case Manager”
- Ensure technologists have proper training in pediatrics
- Engage the family support system
- Develop alliances with referrals to and from the sleep center
The End