EDUCATING PRIMARY HEALTH PRACTITIONERS ABOUT EPILEPSY

Paul M Levisohn MD
Associate Professor of Pediatrics and Neurology
University of Colorado School of Medicine
Co-Chair, Advisory Committee, National Center for Project Access
CME Medical Content Consultant for American Epilepsy Society
Childhood Epilepsy: The Patients

- Epilepsy prevalence in children in developed countries: 3 – 7 / 1000 = 220,000 to 520,000 in US (2009)
  - Approximately 2/3 of childhood onset epilepsy controlled
  - 1/3 medication resistant.

- Associated comorbidities are common
  - Approximately 10% to 20% of I/DD individuals have epilepsy.
  - 35% to 62% of patients with cerebral palsy have active epilepsy.
  - Neurobehavioral disorders common including ADHD, depression.

- Many children with symptomatic epilepsies have persistent seizures.

Childhood Epilepsy: The Providers
Access to Pediatric Neurologists 2009

- Waiting lists for new patients 52.6 days
- Waiting list for return visits 43.6 days
- The supply of child neurologists, as the supply of pediatricians and all physicians, varies geographically.

TRAINING AND EDUCATION OF PEDIATRICIANS

Medical School
Residency
Post-Residency (CME and Maintenance of Certification)
“The education of medical students about epilepsy is often fragmentary and incomplete.”

ACGME Requirements for Pediatrics

- acute major and minor medical problems, including but not limited to respiratory infection . . . seizures . . .

- 4 different 1-month block rotations taken from the following list of pediatric subspecialties or closely allied specialties: (n = 11)
  - Allergy/Immunology
  - Cardiology
  - Endocrinology
  - Genetics
  - Gastroenterology
  - Hematology/Oncology
  - Infectious Diseases
  - Nephrology
  - Neurology
  - Pulmonary
  - Rheumatology

http://www.acgme.org/acWebsite/RRC_320/320_prIndex.asp
Continuing Medical Education and Maintenance of Certification

• **CME:**
  - Self-defined NEEDS
  - GAP analysis
  - OUTCOME:
    - Competence
    - Performance in practice
    - Patient outcomes
    - Knowledge alone is not sufficient

• **MOC requirements:**
  - Part Three: Evidence of cognitive expertise
  - Part Four: Evidence of satisfactory performance in practice.

• **Is care of children with epilepsy a self-defined need?**
RECOMMENDATIONS: OPPORTUNITIES FOR EDUCATION OF PRIMARY CARE PROVIDERS

• Co-management: Project Access - Mississippi
• Medical Home: Care Coordination for Children with Special Health Care Needs
• Continuing medical education
### 1: Co-Management of Patients

**Pediatrician Referrals to Specialists**

<table>
<thead>
<tr>
<th>PCP-reported reason for initial referral to specialists</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help in diagnosis</td>
<td>74</td>
</tr>
<tr>
<td><strong>Help in management</strong></td>
<td><strong>68</strong></td>
</tr>
<tr>
<td>Perform a specialized procedure</td>
<td>16</td>
</tr>
<tr>
<td>Assume care for a problem</td>
<td>8</td>
</tr>
<tr>
<td>Parent request</td>
<td>20</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
</tbody>
</table>

Project Access

- Funded by Maternal and Child Health Bureau / Health Resources and Services Administration
- Three phases focused on improvement in access to care for underserved children and youth with epilepsy.
- Phase II:
  - Four grantees / nine states
  - National Center for Project Access to provide technical assistance, training, evaluation
- Multiple gaps identified in health delivery including
  - Training and education of primary care physicians
    - PCPs see few children with epilepsy
    - Limited access to pediatric neurologists
      - Mississippi Epilepsy Care Improvement Coalition
- Phase III: includes training of care-coordinators
Co-Management: Mississippi Epilepsy Care Improvement Coalition: Training PCPs

• Training program for physicians and NPs to implement co-management model for children with epilepsy
  PHASE 1: 100 children and youth with well-controlled epilepsy
  PHASE 2: additional primary care site in north Mississippi
  PHASE 3: Statewide spread

• Training requires a neurologist familiar with epilepsy care and medical education to:
  1. address the clinical concerns of primary care providers
  2. work within the practice constraints of the PCP
  3. Provide knowledge / skills the primary care providers need
  4. Commitment from medical director, PCPs and administrators
2: **Care Coordination** for Children with Special Health Care Needs: The Medical Home Model

- **Care Coordination**: a process that links children with special health care needs (CSHCN) and their families with appropriate services and resources
  - AAP Criteria for Medical Home
    1) A usual place for sick/well care,
    2) A personal doctor or nurse,
    3) No difficulty in obtaining needed referrals,
    4) **Needed care coordination**,
    5) Family-centered care received.
  - Principal cost driver: percent of care-coordination activities by PCP. **Office-based nurses** prevented emergency department and episodic office visits.

Antonelli RC et al. A Descriptive, Multisite Study of Activities, Personnel Costs, and Outcomes Care Coordination for Children and Youth With Special Health Care Needs *Pediatrics* 122:e209, 2008
3: **CME**: Is Care of Children with Epilepsy a Self-Defined Need for Pediatricians?

- Average number patients with per practitioner = 1546 (pediatric private practice, 1999)
  - Epilepsy prevalence in children in developed countries: 3 – 7 / 1000
  - We can estimate about 4 – 10 patients in average pediatric practice
- Self-assessment of competency by recent graduates of the University of British Columbia pediatric residency training program:
  - 74% of pediatric graduates feel that more of the neurology portion of residency training should be spent on general pediatric behavioral and neurological conditions and would choose to attend CME on these areas.

---

*Hauser WA, Banerjee PN* Epidemiology of Epilepsy in Children in Pellock JM et al. Pediatric Epilepsy Diagnosis and Treatment (3rd Ed). Demos Medical Publishing, NY, 2008
*http://www.childneurologysociety.org/assets/publications/workforce_study_092003.pdf*
Development of Performance Indicators

• Preliminary performance indicators that can be used to assess the primary care management of pediatric epilepsy, based on a review of the available evidence and expert consensus.

• Focus was the management of **uncomplicated epilepsy in primary care**, for children with epilepsy, defined as two or more unprovoked seizures in children ages 0–18 years.

• Consensus on 30 performance indicators:
  • diagnostic strategies and seizure classification 8
  • antiepileptic drug use 9
  • cognitive and behavioral issues 6
  • quality of life 6
  • specialty referrals 3

Is it realistic to expect PCPs to manage even uncomplicated epilepsy?

Provision of Continuing Medical Education

- Should CME be epilepsy specific or focused on co-management of neurologic disorders in general? Or even co-management of chronic illness in general?
- Who should provide CME for Pediatricians and Advanced Practitioners?
  - Specialty specific societies:
    - American Epilepsy Society
    - Child Neurology Society
  - Primary care societies (AAP
    - Medical and Nursing Schools
  - Epilepsy Foundation
    - Training school nurses
    - Project Access: Training in care coordination for CSHCN with epilepsy as model
Recommendations

1. Teaching pediatricians / PCPs:
   - Co-management of chronic illness including uncomplicated epilepsy and associated psychosocial co-morbidities
     - Residency training should focus on common outpatient management of neurologic disorders including epilepsy
     - Training of pediatric PCPs in co-management of CSHCN including epilepsy
     - This may result in improved access to neurologists and other pediatric subspecialists

2. Medical Home: Training care coordinators
   - Coordination of care for CSHCN including active epilepsy and associated medical and psychosocial co-morbidities
     - How much about specific disorders, especially epilepsy, should care coordinators know?
     - Who teaches them?
     - Project Access as demonstration model

3. CME:
   - Define the role of epilepsy-specific CME for primary health care providers:
     - Is it wanted?
     - Is it needed?
     - Is it cost effective?
     - Who should provide it?