Role of the Primary Care Provider

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Key Topics

- Medical Home
- Triple AIM
- Role of the Primary Care Physicians
- Population Health
Needs of Children and Youth with Epilepsy

*May have ramifications beyond seizures, seizure medications, and co-morbid conditions.*

- May be perceived as “different” by their peers
- Significantly less likely to receive care in a medical home, which leads to a higher risk of having unmet needs for care coordination, medical care, and mental health services
- Children and youth from racial and ethnic minorities, as well as lower income families, are disproportionately affected by epilepsy

(National Profile of Childhood Epilepsy and Seizure Disorder)

Source: [https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Coordinating-Center-on-Epilepsy/Pages/Epilepsy0211-2326.aspx](https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Coordinating-Center-on-Epilepsy/Pages/Epilepsy0211-2326.aspx)
Needs of Children and Youth with Epilepsy

Access to high-quality health care would require:

• Improved access to pediatric neurologists
• A collaborative, patient / family-centered, team-based approach to care
• A better informed primary care workforce
• Public education and awareness
• Engagement of numerous stakeholders

(Source: Epilepsy Across the Spectrum: Promoting Health and Understanding)

Source: https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Coordinating-Center-on-Epilepsy/Pages/Epilepsy0211-2326.aspx
What is a Medical Home?

“A family-centered medical home is not a building. It is an approach to providing comprehensive primary care. In a family-centered medical home the pediatric care team works in partnership with a child and a child's family to assure that all of the medical and non-medical needs are met.”

Source: http://www.medicalhomeinfo.org
What is a Medical Home?

“Through this partnership the pediatric care team can help the family/patient access, coordinate, and understand services that are important for the overall health of the child and family, including:

• Specialty care
• Educational services
• Out-of-home care
• Family support
• Other public and private community services.”

Source: http://www.medicalhomeinfo.org
Medical Home

“The American Academy of Pediatrics (AAP) developed the medical home model for delivering primary care that is:

- Accessible,
- Continuous,
- Comprehensive,
- Family-centered,
- Coordinated,
- Compassionate, and
- Culturally effective

- To all children and youth, including children and youth with special health care needs.”

Source: http://www.medicalhomeinfo.org
Triple AIM for Populations

“The IHI Triple Aim is a framework for optimizing health system performance by simultaneously accomplishing three critical objectives, which we call the Triple Aim: improve the health of the population; enhance the patient experience of care (including quality, access, and reliability); and reduce, or at least control, the per capita cost of care.”

- IHI patient experience of desired outcomes:
  - Safe
  - Effective
  - Timely
  - Patient-Centered
  - Equitable
  - Efficient

What Happens When A Child Has A Seizure?

- First seen by Primary Care Provider or Emergency Room
- Referred to Neurologist, Pediatric Neurologist, or Pediatric Epileptologist

_HOWEVER........_
Limited Access to Subspecialists

**CAUSES:**

- Insufficient number of pediatric subspecialists
- Dramatically increasing demand for pediatric care
- Fragmented and inefficient system of pediatric primary and specialty pediatric care
- Inadequate financing of medical education
- Poorly structured payment for clinical care

Limited Access to Subspecialists

RESULTS:

• Lengthy wait times (INSERT LOCAL WAIT TIMES)
• Delays in diagnoses and intervention care can have adverse health outcomes
• Increased family and child stress and anxiety
• Reliance on emergency room services

Primary Care Physician (PCP) is Captain of the Team!

- PCPs know the patient and the family
- PCPs are aware of local and cultural needs
- PCPs are best poised to mitigate anxiety and improve safety
- PCPs often serve as the medical home and/or medical neighborhood and provide continuous, safe, and timely care.
PCP is the Feet on the Ground

Keeping Care Compassionate & Culturally effective

• Better able to understand the local and individual social determinants to health than a specialist can be.
• Specialists often are outside the community, or don’t know the rest of the family even if they are local.
PCP is the Feet on the Ground

*Helps the specialist*

- Understand and partner to mitigate culturally-sensitive opportunities and barriers to care
- Information gateway to local community support, such as the school nurse
  - American Academy of Pediatrics: [http://www.aap.org/epilepsy](http://www.aap.org/epilepsy)
  - Epilepsy foundation of America: [http://www.epilepsy.com](http://www.epilepsy.com)
  - Family Voices: [http://www.familyvoices.org](http://www.familyvoices.org)
  - Parent to Parent: [http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx](http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx)
  - Grupo Vida: [http://www.elgrupovida.org](http://www.elgrupovida.org)
The First Phone Call

Keeping care family centered and accessible

- Seizures are frightening to families and sometimes can be the symptom of a serious medical problem needed emergent or urgent attention. However, for children with self-limited seizures not requiring intervention, they are often sent home from the emergency room with little or no testing and instructions to follow up with their primary care provider.

- Being prepared with answers to commonly asked questions, as well as good family-oriented resources, can go far to reassure a family.

Common questions from parents:

- Why more was not done in the emergency room?
- Why a daily medication was not started?
- What are the chances seizures will happen again?
- What to do if another seizure happens?
The First Visit

*Keeping care: comprehensive and family centered*

- Families should leave the first visit with:
  - Knowledge about basic seizure safety and injury prevention;
  - A written seizure action plan with copies for home, school and all care-givers;
  - A working understanding of what a seizure is and if the child has/might have epilepsy;
  - Medication information;
  - Additional resources, if they are ready, about seizures and epilepsy.
  - In addition the resources already provided, the Child Neurology Society Foundation and American Academy of Neurology have information for patients and families.
    - [http://www.childneurologyfoundation.org/disorders/epilepsy/](http://www.childneurologyfoundation.org/disorders/epilepsy/)
Role of PCP in Managing Seizures

• Either for common or less common management issues, all PCPs will need an efficient, timely and accessible system to obtain decision support at point of care.

• Bolstered by informational support from the pediatric neurology specialist about CYE in general, the PCP should be able to:
  • Discuss seizure safety with the patient and family
  • Develop a seizure action plan and if rescue med needed/ appropriate
  • Provide information about community support resources
  • Identify areas where support is needed for the individual family-including school

Keeping care coordinated, comprehensive, accessible, and efficient
Role of PCP in Managing Seizures

With real time and general informational support from the pediatric neurology specialist, usually the PCP is best placed to efficiently initiate the appropriate evaluation. Examples include:

• Deciding if an EEG or head imaging are needed initially
• What can wait for specialty input
• Determine if a specialty referral is even needed
• Initiate anticonvulsant treatment
• Knowing if and what treatment is appropriate is easier for common disorders.
• A PCP with an interest in epilepsy might draw from a population large enough to become comfortable with common seizure presentations and manage patients who respond well to the initial medication
Role of PCP in Managing Seizures

What experience have the participants had with seizures?

• Does it seem like a common, uncommon or rare topic in their practices?
Seizure Management plan

All caregivers should have the person’s seizure management plan and be trained in the first aid measures used during/after a seizure. The plan should include:

- Seizure type(s) described
  - Warning signs
  - Seizure semiology
  - Typical seizure duration, what defines an emergency
- Rescue medication
  - Length of seizure
  - More than certain number of seizures in certain time
- VNS activation for any seizure
  - Reswipe every 60-90 seconds
- Example:  
Discussion

• What of the material discussed seems most doable? Least? Why or why not?
• Other discussion?