Strengthen & Enhance Epilepsy Knowledge (SEEK) Training

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Caring for Pediatric Patients with Epilepsy Utilizing Cultural Humility, Family-Centered Care, and Shared Decision-making in a Medical Home Setting

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• We do not intend to discuss an unapproved/investigative use of a commercial product/device in our presentation.
OBJECTIVES

• Describe racial and ethnic disparities and social determinants of health in patients with epilepsy.

• Understand health equity and aspects of cultural competency in providing care.

• Understand barriers to effective communication with families with children and youth with epilepsy (CYE) and how to address them.

• Understand the benefits of a medical home when caring for CYE.
EPILEPSY BACKGROUND

• There are approximately 13.5 million children and youth with special health care needs (CYSHCN) in the United States.¹
  – Included among the CYSHCN are 470,000 children aged birth to 18 years living with epilepsy, the most common childhood neurologic condition in the US.²

• Epilepsy is a brain disorder where a person has recurring seizures.³
  – Seizures are sudden events that cause temporary changes in physical movement, sensation, behavior, or consciousness; they are caused by abnormal electrical and chemical changes in the brain.³
**EPILEPSY BACKGROUND**

- Epilepsy is a condition that requires complex, coordinated systems of primary and specialty care.\(^4\)
  - A lack of awareness of the treatment options by providers can significantly affect a patient’s quality of life.\(^5\)
  - However, only roughly one-third of children with epilepsy have access to comprehensive health care.\(^6\)
  - Nationally, the number of pediatric neurologists is at least 20% below the need, resulting in limited access to care for CYE, especially in rural and medically underserved areas/populations (MUA/Ps).\(^4,7\)
  - Approximately 20% of Americans live in rural areas, while only 9% of the nation's physicians practice in these areas.\(^4\)


Health Equity & Cultural Humility
BASIC EPILEPSY EPIDEMIOLOGY

- ~1% (3.4 million) of the US population has active epilepsy.
- Impacts all racial and ethnic groups.
- Of conditions with adverse outcomes on health and academics in pediatrics, epilepsy is the costliest & 2nd most common.
- Children with epilepsy are more likely to live in poverty and their parents are more likely to report food insecurity.
- Direct yearly healthcare costs can range from $10k-48k per year.

Epilepsy Does Not Discriminate

• **African American & Hispanic** people are nearly 40% of the 3.4 million persons diagnosed with epilepsy in the US.¹

• Approximately **710,000 Hispanic** people are living with epilepsy.²

• Limited data suggest that more than **51,000 Indigenous and Alaska Native people** have active epilepsy.³

• 3 in 200 **Asians in America** have epilepsy.

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Epilepsy and African Americans in America

- More than **578,000 African American, non-Hispanic people** are living with active epilepsy in the US.\(^2\)
- Over **25,000** are diagnosed with seizures or epilepsy each year.
- For many African Americans with epilepsy, access to appropriate care is a critical problem.
- More likely than white Americans to:
  - be **diagnosed with epilepsy in an emergency room** than white Americans.
  - develop epilepsy over a lifetime than white Americans.
  - experience a **medical emergency in which a seizure continues for 5 minutes or more without stopping**.

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Epilepsy Among Hispanic and Latinx/a/o People

• **710,608** Hispanic and Latinx/a/o people in US have active epilepsy.

• Hispanic and Latinx/a/o people are **18.1%** of all people with active epilepsy.

• Community values and attitudes toward epilepsy:
  - Family orientation
  - Over protection, supervision
  - Emotional over-involvement
  - Stigma – person should be hidden


Image Source: Microsoft PowerPoint
Epilepsy Among Asian and Indigenous People

- Research among Asians in America with epilepsy is limited.
- Limited data suggest that more than 51,000 Indigenous and Alaska Native people have active epilepsy.
- However, the data we do have suggests that 255,000 Asians in America have epilepsy — or 3 in every 200.

WHAT IS A “SOCIAL DETERMINANT OF HEALTH”?

- Social determinants of health (SDOH): “particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage.” This includes:
  - Race/Ethnicity
  - Religion
  - Sex/Gender/Sexual orientation
  - Regional/Geographic residence
  - Caregiver’s education
  - Socioeconomic status (SES)/Insurance type
  - English fluency
  - Nativity/Immigration status

Source: Healthy People 2020; US Department of Health and Human Services 2020
Equality vs Equity

- **Equality** equals sharing and division, keeping everyone at the same level. It gives the same thing to all people, regardless of their needs.

- **Equity** demands that individual needs are taken into consideration. It accounts for identities (race, ethnicity, ability, nationality, gender, etc) and circumstances that may otherwise hinder the success of one participant over another.

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SOCIAL DETERMINANTS OF HEALTH IN PEDIATRIC EPILEPSY

• Children and Youth with Epilepsy (CYE):
  – 3-6x more likely to have neurodevelopmental or psychological disorders\(^1,2\)
    ▪ Only 30% receive mental health care\(^1,2\)
  – 4x increased risk of premature death\(^3,4,5\)
  – 55% live in poverty\(^3,4,5\)
  – 32% live in a rural area\(^3,4,5\)
  – 53% have public insurance\(^3,4,5\)
  – 64% have low health literacy\(^3,4,5\)

Sources:
HEALTH LITERACY AND OUTCOMES FOR CYE

• The prevalence of epilepsy is higher in households with lower parental education.¹

• Lower health literacy and education can also lead to decreased access to care and lower adherence to treatment plans. ²

• There are no pediatric studies assessing English proficiency, nativity, or immigration status. ⁴

Sources:
Race/ethnicity are the strongest and most consistently documented social determinants related to epilepsy outcomes.

- No studies examining racial disparities in long term outcomes

Lower SES: ↓ adherence to medication, ↑ Emergency Department (ED) visits, and ↑ risk of mortality.

Uninsured & public insurance: significant gaps in specialized epilepsy care access and ↑ ED visits.

PEDIATRIC EPILEPSY RESEARCH CONSORTIUM (PERC) SCOPING REVIEW: PRELIMINARY FINDINGS

- Disparities exist but there are limited studies that directly assess disparities in CYE.
- Any disparity results are often underemphasized (ie, hidden in the text or table).
- Race categorized as White/Non-White.
- Health disparities exist within the broader context of structural racism.

**CULTURAL HUMILITY**

- **Cultural Humility**: Listening with the intention of honoring the patient’s beliefs, customs, race/ethnicity, gender identity, sexual orientation, socioeconomic needs, educational background, lived experience, and values.

- Get to know your community: resources, disparities, different populations, languages, and belief systems.

- Don’t assume! ASK about background, religion, and culture to avoid stereotyping.

- Use words and actions to demonstrate your interest in understanding the patient and collaborating on a plan to fit their needs and confirm understanding.

Shared Decision-making in a Medical Home Setting
HOW CAN PEDIATRICIANS HELP?

• Recognize impact of SDOH in CYE and epilepsy outcomes.
• Understand that disparities in health outcomes can be related to the broader context of structural racism.
• Fostering effective communication necessitates an understanding of the SDOH that impact each patient.
• Providing a medical home to help facilitate shared decision making.
• Practicing Cultural Humility.
IMPORTANCE OF A MEDICAL HOME

• **AAP Medical Home** model was developed to improve the delivery of care to children and adolescents with special health care needs.

• The medical home team utilizes Family Centered Care principles and includes patients, families, specialists, primary care physicians (PCPs), and the community.

• Benefits:
  – Foster high quality care and reduce disparities in treatment
  – Coordinate specialists, therapy referrals, hearing/vision screening, education supports, ensure routine health maintenance
  – Transition planning to adult medical care
  – Improve caregiver confidence and decrease ED utilization/readmission

Resident Continuity Clinic as a Medical Home

- Highly rated by patients and families due to more timely service and fewer unmet needs.
- Patients and families appreciate help identifying and accessing resources and helping with paperwork.
- Decreased use of emergency services.
- Increased use of dental services.

**Shared Decision-making in Epilepsy Care**

- Patients that are inadequately informed about treatment and management options reported **higher rates** of dissatisfaction.
- Patients perceive anti-seizure medication (ASM) drug choices and treatment options to be clinician-dominant.
- **Shared decision-making in epilepsy care** = Clinicians and patients discuss treatment options and make decisions **TOGETHER** using the best available evidence.
  - Promotes patient-centered care
  - ↑ patient understanding
  - ↑ adherence to treatment plans

**Shared Decision-Making Tools in Epilepsy Care**

- **Collaborative Deliberation**
  - *Team Talk → Option Talk → Decision Talk*

- **Decision Aids**
  - Variety of formats, help patients and families understand pros and cons of treatments, can facilitate shared decision-making with less face-to-face time
  - Can be reviewed before discussion so patients feel more prepared

- **Option Grids**
  - Single page grid with FAQ’s and 2-3 options in a grid

• Consider that patients may be more likely to adhere to treatment plans if they were involved in the development.

• Managing epilepsy can be especially challenging for patients with other medical conditions and having a medical home to coordinate the various components of health is significantly helpful.

• Shared decision-making is an essential part of providing family-centered care and team-based care within a medical home.

• With shared decision-making, CYE and their family perspectives are valued, and they are included as part of the team in decisions related to treatment plans and management of their health.
SUMMARY

• Epilepsy is a common and costly neurological condition (ie, fiscally, medically, and socially).

• Disparities in epilepsy care exist but are underemphasized and need to be directly investigated.

• Shared decision-making can improve communication, patient satisfaction, and treatment adherence.

• Utilizing the medical home model (such as a resident continuity clinic) can improve coordination, care, and reduce disparities.
REFERENCES


AAP Resources

- National Coordinating Center for Epilepsy
  - Caring for Children and Youth with Epilepsy: What Primary Care Providers Need to Know (webinar series)
  - Managing Pediatric Epilepsy
  - Epilepsy Resources for Health Care Professionals: Shared Decision-Making
- National Resource Center for Patient/Family-Centered Medical Home
ADDITIONAL RESOURCES

• Patient Assistance | Epilepsy Foundation
• Summer Camp | Epilepsy Foundation
• Resources and Seizure Action Plans for Summer Camp | Epilepsy Foundation
• Resource Guide | Support Program for Parents of Teens with Epilepsy | CDC
• You Are Not Alone: Support Program for Parents of Teens with Epilepsy | CDC
• Managing Epilepsy Well Network
**QUESTIONS?**

If you have any questions regarding the presentation, please feel free to contact The National Coordinating Center for Epilepsy (epilepsy@aap.org).