

Challenges and Opportunities for Surveillance—the Patient and Family Perspective

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Dimensions of the Epilepsies
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Challenges


➤ Stigma

- Deep historical and cultural roots
 - Laws against marriage
 - Forced sterilization
 - Institutionalization
 - Euthanasia
- Employment discrimination
 - One of the biggest reasons for secrecy

Challenges

- Emotions associated with epilepsy
 - Fear
 - Regarding seizures—when, where, consequences
 - How will people react?
 - Concern for family—how will epilepsy effect my children, is it genetic, etc.
 - Will I die?
 - Shame
 - Societal or cultural
 - Having a seizure at an inopportune time can be embarrassing
 - Lack of control
 - Ashamed of keeping epilepsy a secret

Challenges


- Failure to self-identify as having epilepsy
 - Confusion over terminology (seizure vs. seizure disorder vs. epilepsy)
 - Seizures seen as part of another condition; e.g., seizures as the aftermath of a stroke
 - People with epilepsy don't observe their seizures
 - Children not told they have epilepsy
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Challenges

- People with epilepsy don't tell doctors everything
 - People tell doctors only what they think they need to know
 - Fear of seizures being reported
 - May not know to report side effect, e.g., numbness in toes, rash, etc.
 - May not report self-medication changes
 - May not report self treatment, e.g., supplements
 - Embarrassed to tell doctor


Opportunities

➤ WIIFM—What's In It For Me?

- Identify why someone with epilepsy should participate? What do they get out of it?
 - Consider emotions associated with epilepsy to recruit participants—fear as a motivator
 - People with epilepsy have a strong desire to be rid of their “secret”
 - Altruism—wanting others not to go through what they have experienced
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Opportunities

➤ Identify touchpoints

- Seizures—New onset, intractable, breakthrough
 - Doctor referrals
 - Treatment issues—side effects, surgery, VNS, etc.
 - Employment issues
 - Insurance issues—health insurance, disability
 - Women's issues—pregnancy, hormones, menopause
 - Transportation issues—driving and mass transit
 - School issues
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Opportunities


➤ Identify touchpoints

- Children
 - Explain epilepsy to children, siblings
 - Will my children have epilepsy?
- Volunteer
 - When employment/secretcy not an issue
 - When seizures no longer an issue, e.g., following successful surgery
 - Need help for themselves but don't want to ask
 - To give back to others with epilepsy


Opportunity

- Legislation giving rights to people with disabilities
 - Rehabilitation Act of 1973
 - Americans with Disabilities Act, 1990
 - ADA Amendments Act of 2008
- Technology
 - Internet
 - Medical information available
 - Social Networking
 - Message Boards
 - Anonymity


Opportunities

- Collaboration with organizations researching or surveying comorbid conditions
 - Collaboration with organizations serving or surveying targeted subpopulations
 - Identify trusted members of community to collect data, e.g. Community Health Representatives or Promotores
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Recommendations

- Ensure confidentiality of study participants!!!
 - Consider epilepsy/seizure disorder terminology when writing questions, tagging web pages, journal articles, etc.
 - Think like a marketing director! Identify WIIFM? before recruiting participants. Consider giving participants something, e.g. newsletter, informational brochure, a copy of study results, etc.
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Recommendations

- Identify existing Community Health Representative programs serving racial and ethnic minorities and add epilepsy as a targeted health condition to receive services and for data collection.
 - Add seizure disorder/epilepsy questions to surveillance tools of comorbid conditions and targeted subpopulations.
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On Behalf of People with Epilepsy



Thank You!!!



Epilepsy Foundation of Arizona Camp Candlelight Counselors