Clarifying the Misperceptions, Misunderstandings and Misinterpretations around epilepsy and mental illness –

Increasing Knowledge and Understanding to Reduce Stigma

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EPILEPSY AND DEPRESSION

What is the relationship?

One important question is whether the neuropathological and neurochemical abnormalities caused by the psychiatric disorder make several neuranatomical structures more vulnerable to endogenous or exogenous insults, which in turn might facilitate the development of the seizure disorder. Andres M. Kanner 2012

- Depressive disorders are the most common psychiatric co-morbidity in patients with epilepsy.

- People with primary depressive disorders have a high risk of developing epilepsy.
More common than you think...

- 1 in 26 people in the United States will develop epilepsy at some point in their lifetime.
- For about 60% of people with epilepsy, the cause is unknown.
- Approximately one third of people with epilepsy live with uncontrollable seizures because no available treatment works for them.
- More than 2.1 million adolescents nationwide are impacted by major depressive episodes.
- Close to 60% of children and adolescents with mental health needs do not receive mental health services.
Misperceptions, Misunderstandings & Misinterpretations

• Psychiatric disorders/epilepsy are not true medical illnesses like heart disease and diabetes.
• Epilepsy/mental health disorders are a product of witchcraft.
• Epilepsy/mental health disorders are contagious.
• People with a mental health disorders/epilepsy can be dangerous and violent.
• Mental health disorders/epilepsy results from a personality weakness or character flaw. People could just snap out of it if they tried hard enough.
• People with epilepsy/mental health disorders shouldn't be in jobs of responsibility and stress.
• Epilepsy/mental health disorders are rare and there aren't many people who live with these.
• People with epilepsy/mental health disorders are physically limited in what they can do.
• With today's medication, epilepsy is largely a solved problem.
STIGMA...

Stigma is a “collection of negative attitudes, beliefs, thoughts, and behaviors that influence the individual, or the general public, to fear, reject, avoid and discriminate against others.”

Gary, 2005, p.980

Stigma manifests in and through social interactions with others.

Precosolido & Martin, 2007

Attitudes, beliefs and stigma about mental health and epilepsy develop during childhood and adolescence.

Wahl, Hanrahan, Lasher & Seayne, 2007
When attitude and behavior change are goals, peers are an integral component of health intervention: stigma reduction efforts should be universal to all and not focused only on those with identified needs.
REDUCING STIGMA

KEY STRATEGY: EDUCATE
Better understanding will cause people to reduce their prejudices and act in a non-discriminatory manner towards individuals who live or have lived with a mental health needs/epilepsy. Education can help to change attitudes, but the magnitude and duration of these changes is limited.

KEY STRATEGY: START EARLY
The youth and young adult years are an opportune time to encourage positive attitudes, reduce stigma and the burden of illness across the life span.

KEY STRATEGY: CONTACT-USE NARRATIVE STORY TELLING
When the general population interacts with a person living with mental health needs/epilepsy as part of an anti-stigma program, there are significant improvements in attitude.

KEY STRATEGY: CONTACT- BE PERSUASIVE
Changes in attitudes resulting from contacts with people who live/have lived with epilepsy/mental health needs are maintained through time and are related to changes in behavior.

KEY STRATEGY: CONTACT- CUSTOMIZE

PROTEST?
Protestation may remove certain messages detrimental to people with mental illness/epilepsy and diminish negative attitudes, but fails to promote more positive attitudes supported by facts. Rebound is possible as protest doesn’t change peoples’ prejudice.
KEY STRATEGY: EDUCATE

Individuals learn more when they see and hear information.

Live storytelling and video presentations conducted together increase engagement and enhance learning.
Reducing stigma among all youth and young adults reforms the culture, within social networks, that embraces discussion of mental health needs and epilepsy, and is inclusive of young people living with complex mental health needs and/or living with epilepsy.

Reach out to children, youth and young adults.
Narrative storytelling by the person living with epilepsy and/or mental health needs influences the listener insofar to elucidate multiple realities so the listener can see, hear, and feel life from a different perspective. After hearing stories the listener is awakened to a new reality and his or her life seems different.

Learn about the audience of focus’ values and life experiences to develop persuasive messages that “SPEAK TO THEM.”
People are naturally storytellers and learn about the world through telling and listening to stories.

People judge the believability of each story through “Good reason.”

Good reason is guided by a person’s culture, character, experiences and values.

People deem a particular story rational when it is comparable to their own lived experiences.

People choose among various stories to construct and reconstruct social reality, an ongoing process.

Storytelling is congruent with existing methods of communication utilized by young people within their social networks – exchanging information about life experiences.

Lerner & Steinberg, 2004
KEY STRATEGY: CUSTOMIZE

First stories are deemed by the listener as true and serve as reference point to judge the truth of other stories.

When attitude and behavior change are goals, peers are an integral component of health intervention: stigma reduction efforts should be universal to all youth and not targeted only to the youth with identified needs.

Telling accurate and developmentally appropriate “first stories” provides an accurate reference point early in life to compare against future potentially inaccurate stories.

When defining stigma reduction messages and planning outreach activities consider your young audiences’ stage of cognitive development.
DISCUSSION
1. Emphasize that being a “real” person comes first, epilepsy and/or a mental illness second.
   Introduce people who are in sustained recovery/ whose seizures are under control, indistinguishable from individuals without psychiatric or epilepsy diagnosis.

2. Use personal stories to broaden others’ ideas about people with epilepsy and/or mental health needs.
   Address challenges, recognition and acceptance, treatment, coping and management skills as well as successes, hopes and dreams.

3. Re-frame mental health needs and epilepsy as brain disorders with a strong biological component.
   This subdues blame and demonstrates that individuals do not have a mental health need and/or epilepsy by choice.

4. Emphasize the link between treatment and positive outcomes.
   Link treatment with recovery and/or control.

5. Promote inclusion so that people can live, learn, work, play, thrive and participate fully.
Misinformation and its correction continued influence and successful debiasing

Can neurobiological pathogenic mechanisms of depression facilitate the development of seizure disorders?

Conceptual Model of Research to Reduce Stigma Related to Mental Disorders in Adolescents
Issues in mental health nursing. 2009 Dec; 30(12)788-795

Strategies to Fight Stigma toward People with Mental Disorders: Perspectives from Different Stakeholders
The Scientific World journal. 2012516358

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Confronting the stigma of epilepsy
Annals of Indian Academy of Neurology. 2011; 14(3)158-163

Mental Health Stigma: Society, Individuals, and the Profession
Journal of social work values and ethics. 2011; 8(2)4-1-4-16

Why stigma matters and why it should be beaten
Stuart H. World Psychiatry. 2005;4(supplement1):6-7
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