Epilepsy: Sources of Stigma and Campaign Efforts

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Background

- Gallup polls showed steady improvement in attitudes toward epilepsy in US from 1950 to 1980 (Caveness & Gallup, 1980, *Epilepsia, 21:509-518)*
- 1987 Gallup poll showed that despite better awareness (LaMartina, 1989, *J Epilepsy, 2: 45-48)*
  - Two-thirds would put something in someone's mouth during a seizure
  - One-third thought less of people with epilepsy and their families
  - One-sixth thought you could identify people with epilepsy by looking at them

Dimensions of Epilepsy Stigma

- Centers for Disease Control and Prevention developed an instrument to measure attitudes toward people with epilepsy – Attitudes and Beliefs About Living with Epilepsy (ABLE)
- Four dimensions were identified:
  - Negative stereotypes (not as smart, should not marry)
  - Risk and safety concerns (not let their child ride in car if driver has epilepsy, not hire a babysitter with epilepsy)
  - Work and role expectations (not able to cope with everyday life, not as successful at work as others)
  - Personal fear and social avoidance (feel nervous around people with epilepsy, would not date a person with epilepsy)

Dimensions of Epilepsy Stigma

- Mean scores reflected that respondents were:
  - Least likely to agree with negative stereotypes
  - Most likely to agree with risk and safety concerns
  - Moderate agreement on work and role expectations and personal fear and social avoidance (DiIorio et al., 2004, *Epilepsy & Behavior: 5, 965-975)*
- Current research is underway to explore changes between 2005 and 2013 on two ABLE factors:
  - Work and role expectations
  - Personal fear and social avoidance

Campaign Strategies

- Since 2000 the Epilepsy Foundation has conducted yearly, multifaceted campaigns to increase awareness and public education about epilepsy.
- Groups with the lowest awareness, most negative perceptions, or most negative attitudes were targeted.
    - Youth: Teens, tweens, and young adults
    - Ethnic/minority groups: African-American, Hispanic-American, and Asian-American
- Methods: mass media such as television, radio, print; DVDs, internet; social media; celebrity endorsement

(Price et al., in press, *Epilepsy & Behavior)*

Most Successful Campaign
2001-2004 *Entitled To Respect*

- Main goals were to increase teen's awareness of epilepsy and to increase self-esteem among teens with epilepsy
- Teens were targeted first. Then, it was extended to tweens and African-American youth as *Get the Word Out*.
- Prior to launch a survey of 20,000 teens from multiple states showed
  - Two-thirds had no or limited familiarity with epilepsy
  - Two-thirds did not know what to do if someone had a seizure
  - Almost half were not sure if epilepsy was contagious
  - Less than one-third would date a person with epilepsy

(Austin et al., 2002, *Epilepsy & Behavior, 3: 368-375)*

Most Successful Campaign
2001-2004 *Entitled To Respect*

- Message: *"Youth with epilepsy are entitled to respect just like everybody else."*
- The awareness and educational campaign focused on outreach through teen media channels and support of the popular music group *NSYNC
    - *E2R* campaign messages included public service radio messages with music from *NSYNC's recently released CD.
    - The Epilepsy Foundation's webpage was linked to *NSYNC's website and 6 other sites popular with teens.
    - Other methods included television, posters, brochures, and contests.

Post-Campaign Survey

- Results showed improvement with Latino and Hispanic youth improving the most
  - Lack of awareness decreased from two-thirds to less than one-fourth
  - Knowledge that epilepsy was not contagious increased from one-half to two-thirds
  - More teens were informed that people with epilepsy could work and drive
- Areas that did not improve
  - Continued high levels of uncertainty and misinformation on first aid response to seizures
  - Youth with epilepsy continued to be perceived as being less popular by their peers

Regular Education and Outreach Efforts

- The Epilepsy Foundation has ongoing efforts to educate specific groups through their national affiliate network. Specifically targeted are:
    - School nurses, child and adult day care workers, first responders, law enforcement personnel, middle and high school students, and parents of children with epilepsy
    - These programs on seizure recognition and response are regularly evaluated. For example, school nurses show increased confidence to handle seizures after training. (Austin et al., 2010, *Journal of School Nursing, 26: 420-429*)

IOM Committee Recommendations

- In 2012 IOM released a report, *Epilepsy Across the Spectrum: Promoting Health and Understanding,* on the public health dimensions of epilepsy.
- The committee had two formal recommendations
  - Informing the media to improve awareness and eliminate stigma (e.g., promote accurate TV storylines and depictions of epilepsy)
  - Coordinate public awareness efforts (e.g., developing shared messages among stakeholders)
- The committee also developed eight key messages with accurate information about epilepsy to help reduce stigma.

Challenges

- Epilepsy is a spectrum disorder with a wide range of severity, seizure types, and co-occurring conditions. Goals can vary and messages can appear to conflict.

- Campaigns are not evaluated for change because of cost. Most evaluations focus on process outcomes such as campaign reach. (Price et al., in press, *Epilepsy & Behavior)*

- Two studies in 1981 and 2006 each found that about half of respondents believed that violence is possible or likely during a seizure. (Collins et al., *Epilepsy & Behavior, 10, 69-76)*

- Common myths such as putting something in someone's mouth during a seizure and calling an ambulance for a seizure persist despite years of educational campaigns about proper response to seizures.