CDC NCCDPHP Epilepsy Program
Select Activities

NINDS, ICARE Meeting
March 24, 2014
Rockville, MD

Rosemarie Kobau, MPH, MAPP
Epilepsy Program
Division of Population Health
Centers for Disease Control and Prevention
NCCDPHP Mission:
To help people and communities prevent chronic diseases and promote health and wellness for all.

NCCDPHP Divisions and Key Programs:
- Cancer Prevention and Control
- Community Health (e.g., REACH)
- Diabetes Translation
- Heart Disease and Stroke Prevention
- Nutrition Physical Activity and Obesity
- Office on Smoking and Health
- Oral Health
- Population Health (e.g., Epilepsy; Arthritis; Healthy Brain Initiative; School Health; Alcohol; COPD; PRCs; HRQOL/WB....)
- Reproductive Health
Four Domains of Chronic Disease Prevention and Health Promotion

- Epidemiology and Surveillance
- Environmental Approaches
- Health System Interventions
- Community-Clinical Linkages
NCCDPHP Epilepsy Program Activities

Epidemiology and Surveillance
- Incidence and Prevalence Studies
- Comorbidity
- Access to Care
- Mortality (SUDEP, Suicide)
- School Policies

Environmental Approaches
(Social environment)
- With EF:
  Educational programs and campaigns in community settings
Community-clinical linkages

- Managing Epilepsy Well Network Programs
  - WebEase
  - PEARLS
  - UPLIFT
  - Professional Training

Health System Interventions/Strategies

- Healthy People 2020 Epilepsy Objective (access to specialty care)
- Cysticercosis screening methods
- Strengthening CMS/CDC partnership to examine state Medicaid authorities, reimbursement for epilepsy self-management
CDC Epilepsy Program Select Research Activity

University of Texas Health Sciences Center (Houston) Prevention Research Center
Principal Investigators: Charles E. Begley, PhD; Ross Shegog, PhD
MINDSET Study Aims

1. Develop a Management Information & Decision Support Epilepsy Tool (“MINDSET”) to provide real-time self-management decision-support to patients and health care providers in neurology clinics.

2. Evaluate usability, feasibility, and efficacy.

**MINDSET Patient/Provider Advisory Group

Patients and clinicians of Kelsey-Seybold, Univ.TX, and the Harris Health System Neurology Clinics**
MINDSET

3 Steps

• Patient data entry

• Provider review

• Patient-Provider discussion
MINDSET log in (staff)

Enters self-management behaviors (13 subdomains)*: Seizures; Medication; Lifestyle…

MINDSET generates on-line report and flags risky behaviors; Patient rates confidence to change risky behavior

Reviews self-management profile: (past behaviors, recommended goals, and behavior change strategies)

*Validated assessment surveys embedded: Epilepsy Self-Mgmt. Scale; Adverse Events Profiles; NDDI-E

Shegog, Begley, Harding et al, 2013
Provider’s Office

HCP

Reviews patient profile & action item checklist

HCP & patient

HCP confirms data with patient and discusses priority self-management goals, and recommended strategies

Shegog, Begley, Harding et al, 2013
Patients reported that MINDSET:

- Helped them to think carefully about their epilepsy
- Can help them to better manage their epilepsy
- Helped them talk to doctor or nurse about their epilepsy
- Delivered credible, useful, and understandable information over multiple visits

Providers reported that MINDSET:

- Minimally disruptive to clinic visits
- Rated favorably for ease of use, thoroughness, and accuracy
- Took more time

Patients and Providers reported that:

- If given the opportunity, they would use MINDSET in the clinic again.
MINDSET Pilot Efficacy Study

**Timeline:** Dec. 2013 – Sept. 2014

**Sites:** Harris Health, Kelsey Seybold, and UT Neurology Clinics

**Sample:** 60 patients with epilepsy (20/site)

**Study Design:** RCT (Treatment vs. Usual Care)

### In each site:

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**Intervention:** MINDSET data entry and risk assessment, Patient/Physician development of Action Plan

**Primary outcome:** Self-management behaviors

**Secondary outcomes:** Symptoms, Psychosocial (Self-efficacy), Patient- Provider Communication
Epilepsy Program Select Research Activity
Epidemiology and Surveillance

Study:
Suicide burden in people with epilepsy using 2003-2010 data from the National Violent Death Reporting System

Goals:
1. Estimate suicide deaths in PWE
2. Examine suicides in PWE by socio-demographic characteristics
3. Examine personal circumstances occurring before death:
   a) physical comorbidities
   b) psychiatric comorbidity/substance/prescription drug abuse
   c) recent stressful life events (e.g., relationship, financial, or school problems)
2003-2010
672 possible cases (history of "epilepsy" or "seizure"--seizure not resulting from suicide method- e.g., drug overdose)
Toxicology results
CDC Injury Center collaboration

Created in 2002
Collects data on violent deaths in 18 states
4 major data sources:
  - Death certificates
  - ME/Coroner reports
  - Law enforcement reports
  - Crime labs

CDC National Violent Death Reporting System (NVDRS)
www.cdc.gov/epilepsy

CDC Epilepsy Program Team

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