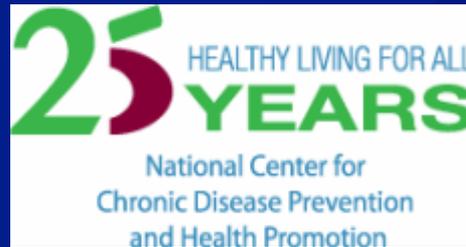


CDC NCCDPHP Epilepsy Program Select Activities

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

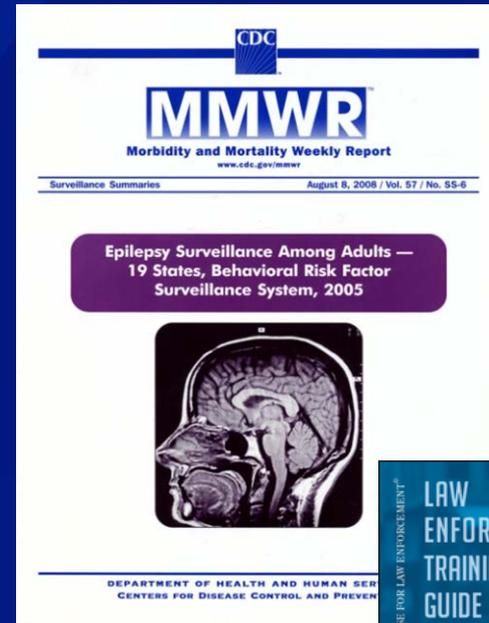
- Epidemiology and Surveillance
- Environmental Approaches
- Health System Interventions
- Community-Clinical Linkages



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



CDC Epilepsy Program Select Research Activity



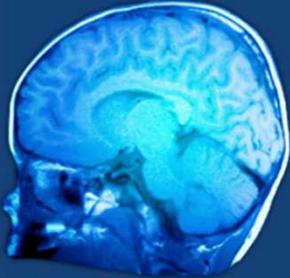
Managing Epilepsy
Well Network

University of Texas Health Sciences Center (Houston) Prevention
Research Center

Principal Investigators: Charles E. Begley, PhD; Ross Shegog, PhD

MINDSET

My Epilepsy My Action Plan About Quit



MINDSET

Management Information &
Decision Support Epilepsy Tool

mind-set
-noun
1. an attitude, disposition, or mood.
2. an intention or inclination.

Previous Next

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

Waiting room

Patient

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)



A screenshot of the MINDSET patient interface. The top navigation bar includes 'MINDSET', 'My Epilepsy', 'My Action Plan', 'About', and 'Quit'. Below the navigation bar, there are tabs for 'My Seizures' and 'Seizure / History'. The main content area displays an 'INSTRUCTION' section: 'Here are some questions about your seizures. Choose the answer that is most correct for you.' Below this is a 'QUESTION' section: 'What type of seizure(s) are you having? Choose all that apply.' There are two columns of buttons representing different seizure types: 'Don't know', 'COMPLEX FOCAL (partial; brief; loss or altered consciousness; auras)', 'TONIC (stiff muscles; loss of consciousness; both sides of brain)', 'MYOCLONIC (repetitive jerking of upper body & extremities; loss of consciousness; both sides of brain)', 'TONIC CLONIC (GRAND MAL) (repetitive jerking; loss of consciousness; both sides of brain; stiff muscles)', 'SIMPLE FOCAL (partial; no loss of consciousness)', 'ABSENCE (PETIT MAL) ("staring spell"; brief; loss of consciousness; both sides of brain; jerking movements)', 'CLONIC (repetitive jerking; loss of consciousness; both sides of brain)', and 'ATONIC (lose muscle tone; involuntary drops/ falls; loss of consciousness; both sides of brain)'. At the bottom, there are 'Previous', 'Next', and 'Go On' buttons.

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

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

Date: ___/___/___

MY ACTION PLAN

RECOGNIZE the need for action. **DISCUSS** how to achieve the action.
 DETERMINE a strategy for achievement. **SET** goals to carry out the strategy.

Have there been any changes to the patient's prescription plan? YES NO
If yes, please fill in new plan in the space provided below

My Prescription Plan			
Name	Type	Dose	Frequency
1.			
2.			
3.			
4.			

Medication Summary

- You reported that in the past two weeks you have missed 3 doses of medication.
- You reported the following *side effects*: BLURRY VISION, UNSTEADINESS, INSOMNIA, LOSS OF APPETITE, and HAIR LOSS.

My Medication Management Goals

Take seizure medication the way the doctor orders it.
Statement: I take seizure medication the way my doctor orders it.
Your Answer: SOMETIMES Your Goal: ALWAYS

- Prioritize taking your AEDs even when your routine is interrupted (e.g. sleeping late or skipping lunch) or your schedule is hectic.

My strategy is:

DO NOT skip doses of seizure medication.
Statement: I skip doses of seizure medication.
Your Answer: Your Goal:

- Use cues to help remember to take your AEDs such as linking them to a certain time of day (e.g. 8 am), with meals (e.g. at breakfast), or with daily activities (e.g. brushing teeth or showering).
- If you miss a dose take it as soon as possible. DO NOT "double up" on doses as this may lead to side effects. Instead, take the next dose as soon as possible, and take the next scheduled dose after an interval of at least 2 hours, often with food to delay the second dose's absorption

My strategy is:

MINDSET Usability/Feasibility Results from Two Field Trials

Shegog, Begley, Harding et al., Epilepsy & Behavior 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:

		Visit 1	Visit 2	Visit 3
R	n=10	X	X	X
	n=10	O	O	O

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

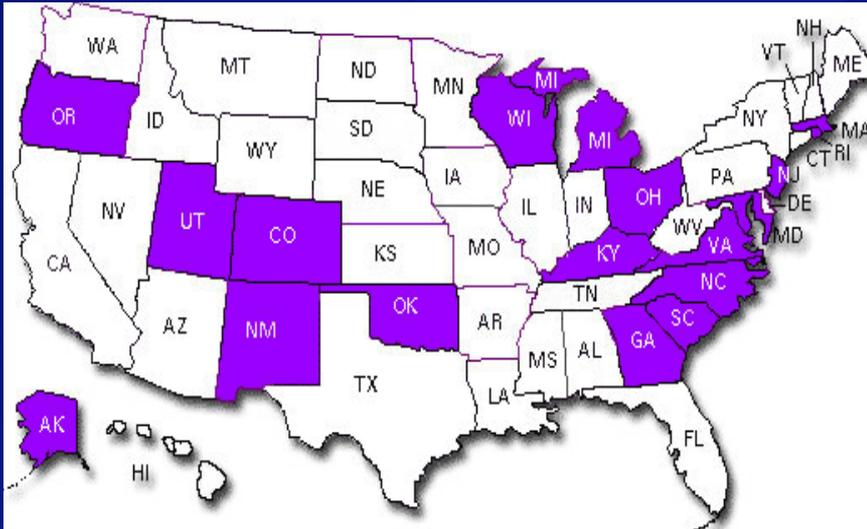
Study:

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)
4. Characterize circumstances of suicide (history of attempts, disclosing intent, leaving a suicide note).

CDC National Violent Death Reporting System (NVDRS)



- 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

- 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

www.cdc.gov/epilepsy

CDC Epilepsy Program Team

- Niu Tian, MD, PhD, Medical Officer
- Margaret Moore, MPH, Public Health Advisor
- Wanjun Cui, PhD, Research Fellow
- Matthew M. Zack, MD, MPH, Senior Medical Officer
- Rosemarie Kobau, MPH, MAPP, Team Lead

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