

Undercounting epilepsy: Finding the undiagnosed along the border

David M. Labiner, M.D.

Jenny Chong, Ph.D.

The University of Arizona

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Definitions

- ❖ **Seizure: the clinical manifestation of an abnormal and excessive excitation and synchronization of a population of cortical neurons**
 - ❖ **Partial**
 - ❖ **Generalized**
- ❖ **Epilepsy: two or more recurrent seizures unprovoked by systemic or acute neurologic insults**

Epidemiology

❖ ♦ Seizures

- ❖ Incidence: approximately 80/100,000 per year
- ❖ Lifetime prevalence: 9%
(1/3 benign febrile convulsions)

❖ ♦ Epilepsy

- ❖ Incidence: approximately 45/100,000 per year
- ❖ Point prevalence: 0.5-1%

Etiology of Seizures and Epilepsy

- ♦ **Infancy and childhood**
 - Prenatal or birth injury
 - Inborn error of metabolism
 - Congenital malformation
- ♦ **Childhood and adolescence**
 - Idiopathic/genetic syndrome
 - CNS infection
 - Trauma

Etiology - 2

- ♦ **Adolescence and young adult**
 - Head trauma
 - Drug intoxication and withdrawal*
 - ♦ **Older adult**
 - Stroke
 - Brain tumor
 - Acute metabolic disturbances*
 - Neurodegenerative
- *causes of acute symptomatic seizures, not epilepsy**

Current Project

- ❖ Funded by Centers for Disease Control and Prevention
- ❖ October 2005 – September 2008

Community Collaborators

- ❖ Cochise: Chiricahua CHC
- ❖ Santa Cruz: Mariposa CHC
- ❖ Yuma: Regional Center for Border Health and Sunset Medical Center

Specific Aims

- ❖ Aim 1 – Assess the prevalence of epilepsy in non-Hispanic Whites, Hispanics and Native Americans living along the Arizona – Mexico border.
- ❖ Aim 2 – Determine the patterns of health care utilization in non-Hispanic Whites, Hispanics and Native Americans living along the Arizona – Mexico border.

Criteria for inclusion

- Household must be located in Cochise, Santa Cruz, or Yuma Counties
- Participants have lived in area for 6 months or more
- Permission from head of household
- Procedures approved by University IRB

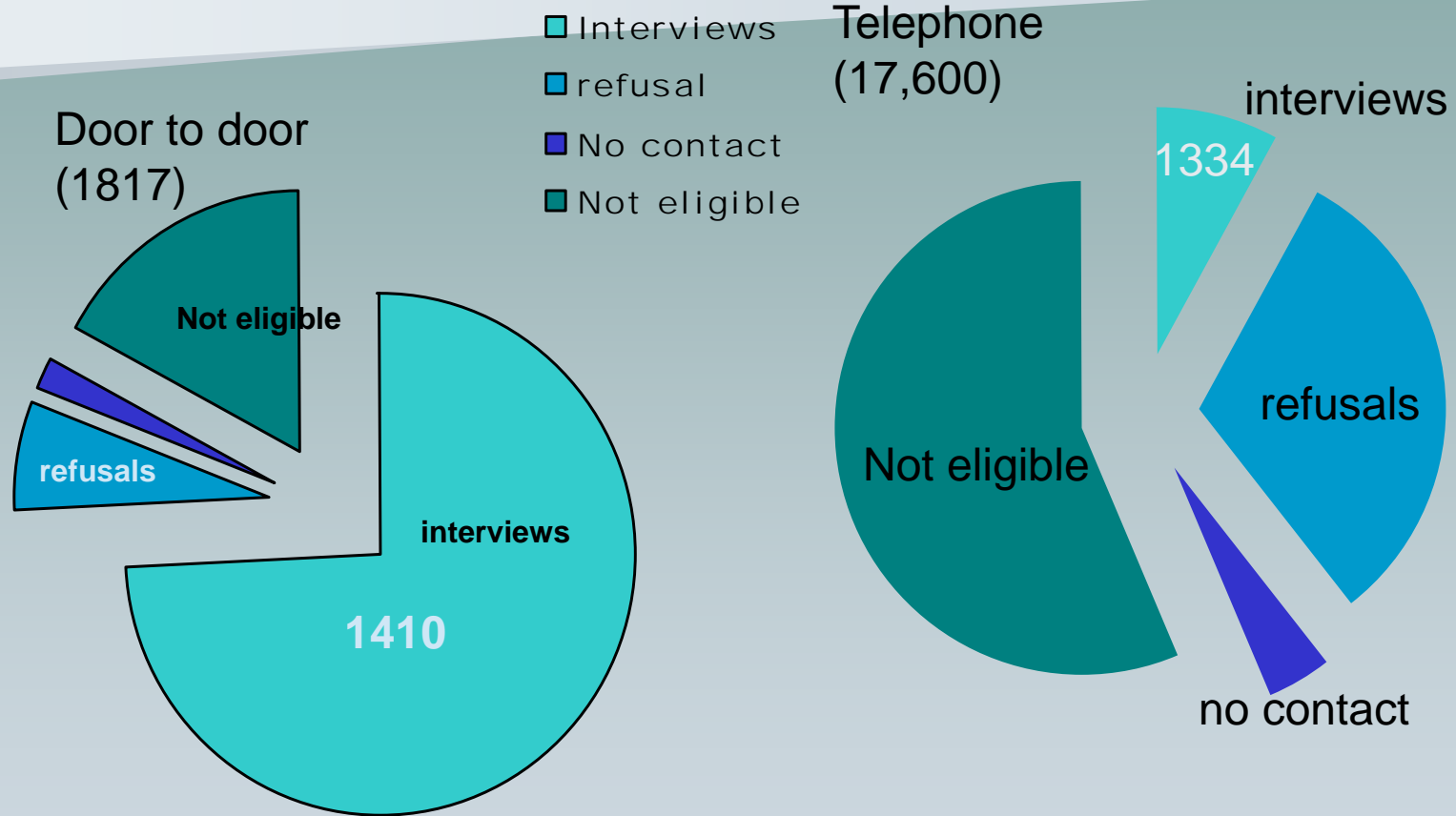
Methodology

- ❖ Two recruitment approaches:
 - ❖ Telephone survey
 - ❖ Interviewers at the University of Arizona called randomly selected household telephones from Cochise, Santa Cruz and Yuma.
 - ❖ Household door-to-door survey
 - ❖ Interviewers attempt to recruit randomly selected households in Arizona border communities of San Luis, Nogales, and Douglas, Arizona.

Survey Procedure

- Obtain demographic and health information of all household residents
- Screen for seizures
- If no seizures, household survey is complete

Recruitment



Screening for epilepsy

- Doctor's diagnosis
- Other people's suspicions
- Seizures that may not be epilepsy related
- Symptoms of seizures

Positive Screens

- ❖ If an individual screens positive for seizures, we invite him or her to see the study neurologist at one of the community health centers or clinic in their county.
- ❖ Study neurologist meets and evaluates the patient, or the survey is used to determine diagnosis.

Target area population

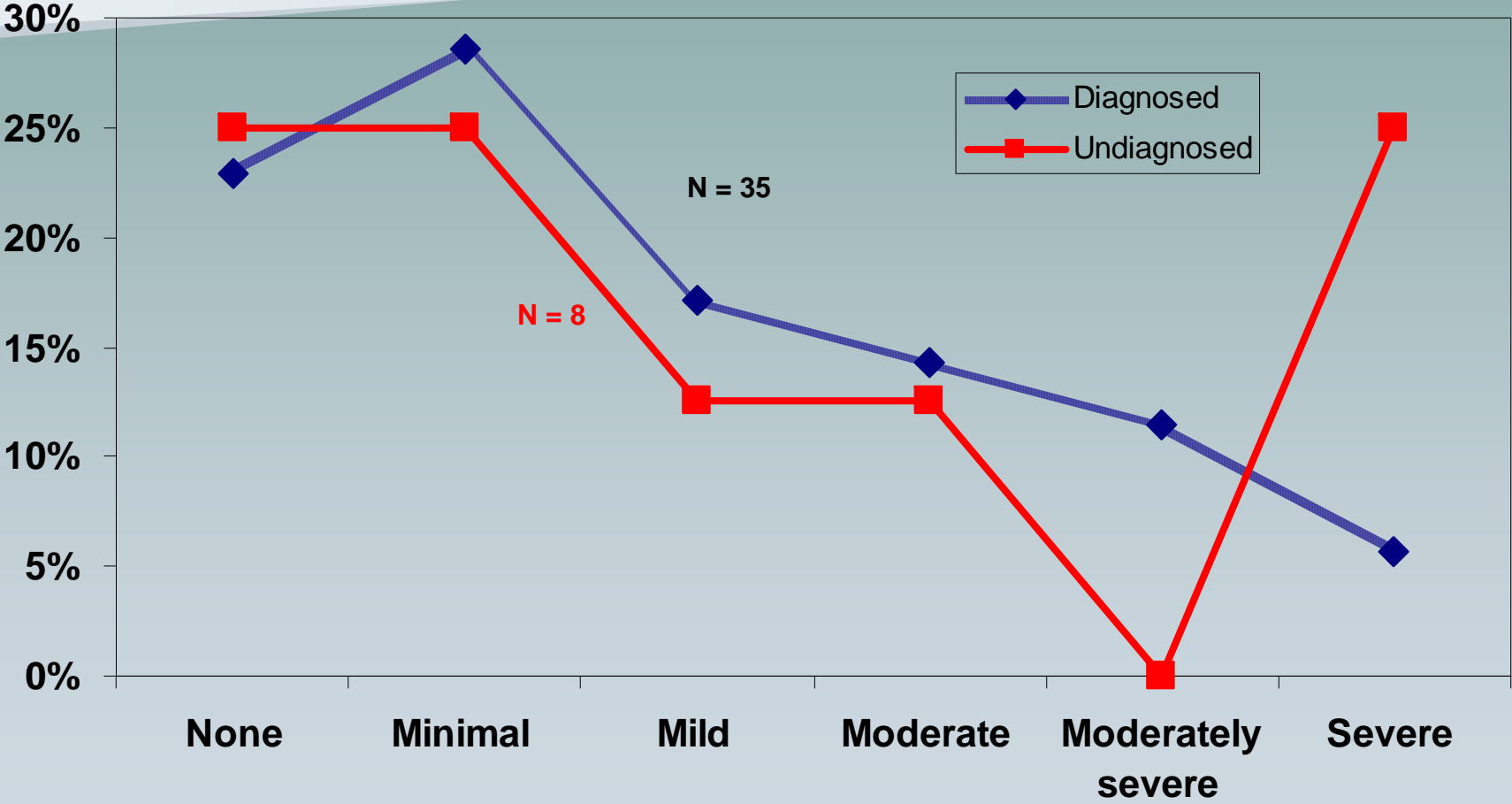
	Study			Census 2000	
	Hispanic	Non Hispanic		Hispanic	Non Hispanic
Cochise	73%	27%		30.7%	69.3%
Santa Cruz	93%	7%		80.8%	19.2%
Yuma	90%	10%		50.5%	49.5%

	No epilepsy	Diagnosed	Undiagnosed
	8022	70	22
Yuma	3465	24	8
Santa Cruz	1575	13	2
Cochise	2981	33	12
% of the diagnosed or undiagnosed that were from door to door			
Yuma		40%	14%
Santa Cruz		31%	0%
Cochise		39%	50%
AVERAGE		38%	32%

	No epilepsy	Diagnosed	Undiagnosed
	8022	70	22
Adult	5902	48	15
Juvenile	3051	18	4
Mean age	32.8 years	36.4 years	38.6 years
Females	53%	63%	77%
Males	47%	37%	23%
Hispanic	84%	63%	71%
Married	40%	41%	41%
> HS Graduate	13%	28%	18%
Employed (FT/PT)	35%	23%	23%

	No epilepsy	Diagnosed	Undiagnosed
	7990	70	22
Migraine	7%	29%	36%
Diabetes	9%	7%	23%
High Blood Pressure	16%	16%	23%
Heart Attack	2%	4%	9%
Angina or CHD	3%	6%	5%
Stroke	1%	10%	18%
Any chronic illness	25%	38%	63%

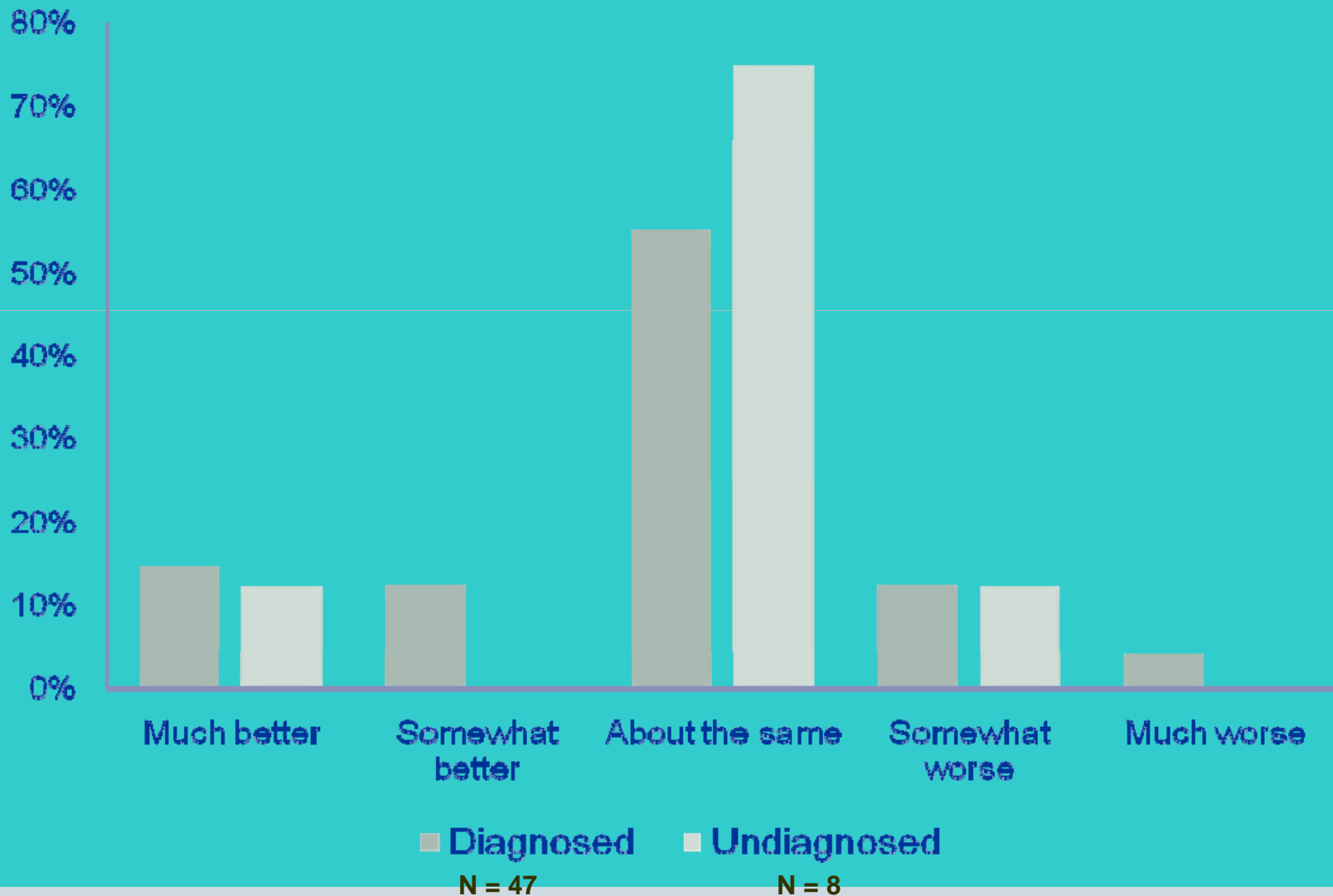
Depression



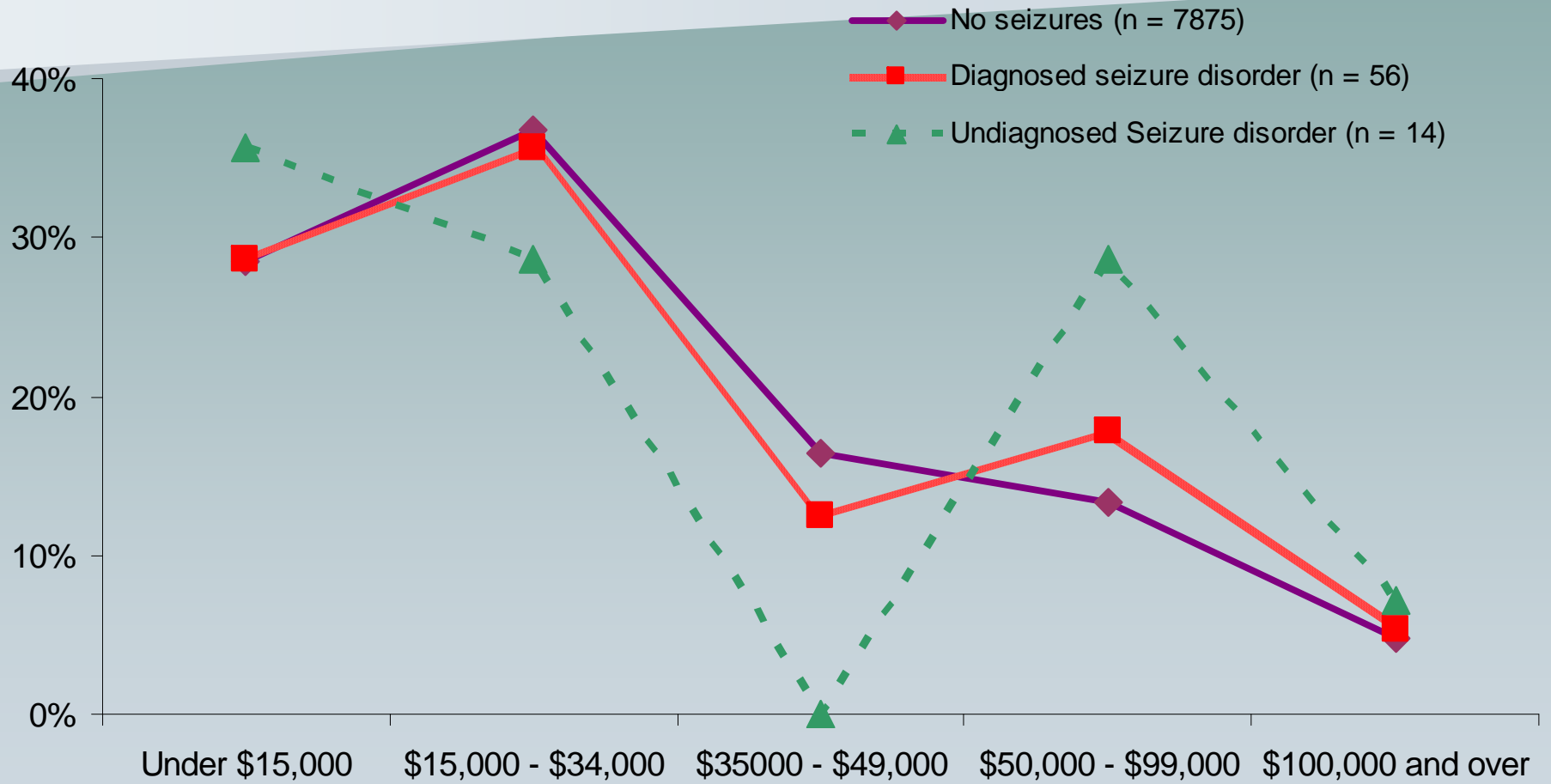
Self Rated General Health



Health compared to 1 year ago



Annual Household Income



Risk Factors (adults)	Diagnosed	Undiagnosed
Total	38	8
Head injury w/ loss of consciousness	29%	50%
Stroke	5%	13%
Brain tumor or brain surgery	10%	
CNS Infection		13%
Arterial venous malformation	3%	
Cysticercosis	3%	
Mental retardation	5%	25%
Learning disability	21%	25%

Seizure characteristics	Diagnosed	Undiagnosed
Total	59	18
Active epilepsy	88%	67%
Epilepsy suspected by others	71%	16%
Seizure not caused by Epilepsy	32%	42%
Seizure caused by a childhood fever	18%	16%
Uncontrolled movements	64%	47%
Unexplained change in mental state	55%	37%
Uncontrollable jerkiness after waking	33%	37%
Other repeated unusual spells	29%	16%

Summary

- Door-to-door recruitment remains a successful technique while telephone surveys have become very difficult
- Undiagnosed individuals identified
- Depression and other chronic medical disorders higher in undiagnosed population
- Hispanics more likely to be undiagnosed than non-Hispanics

Thank you

David M. Labiner, M.D.
labinerd@u.arizona.edu

Jenny Chong, Ph.D.
jchong@u.arizona.edu