

ICARE Member Report: CDC-supported Research on Comorbidities of Epilepsy

- Comorbid conditions of interest
 - Any separate health condition *associated* with epilepsy, especially:
 - Autism
 - Developmental disabilities
 - Other neurologic disorders complicated by epilepsy
 - Depression and anxiety disorders

CDC Epilepsy Comorbidity Research: Aims and Methods

- **Research questions**

- **Public health ‘burden’:**
 - Incidence and prevalence
 - Impact, e.g., disability, quality of life
- **Risk factors and predictors of outcome**
 - Opportunities for prevention
- **Interventions to reduce occurrence or impact**
 - E.g., self management

- **Tools of research**

- **Population-based surveys**
- **Epidemiologic studies of populations**
 - Cross-sectional or cohort
- **Other comparative cohort studies**

CDC Epilepsy Comorbidity Research

Research on Public Health Burden, Risk Factors, and Predictors of Outcome

Surveillance and Epidemiologic Studies

CDC Epilepsy Comorbidity Research: Current studies

- **“Risk Factors of Epilepsy Outcomes:
Comorbidities in Populations with Epilepsy”**
 - Principal Investigator: Anbesaw Selassie, DrPH, Medical University of South Carolina, Charleston, SC
 - Focus/relevance: Prevalence of common comorbid conditions among people with epilepsy (PWI); relation of comorbidities and epilepsy outcomes; healthcare utilization and cost
 - Methods: Retrospective cohort of cases of epilepsy from linked statewide datasets (hospital inpatient, outpatient, office, Medicare, Medicaid), as well as abstracted medical records.
 - Duration: Up to 5 years, commenced September 2011

CDC Epilepsy Comorbidity Research: Current studies

- “Epidemiologic Research and Surveillance in Pediatric Epilepsy”
 - Principal Investigator: Barbara L. Kroner, PhD, RTI International, Rockville, MD
 - Focus/relevance: Incidence and prevalence of epilepsy and comorbidities in children; healthcare utilization, barriers to care; risk factors, and outcomes.
 - Methods: Cohort of 500 children from the two principal pediatric medical centers in Washington DC, followed for two years. Data from administrative sources, medical records reviews, and parent questionnaires..
 - Duration: Up to 5 years, commencing September 2011

CDC Epilepsy Comorbidity Research: Current studies

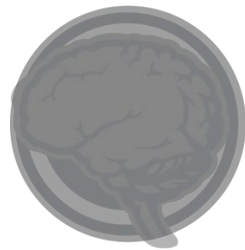
- “Prevalence of Epilepsy and Comorbidities in the U.S. Adult Population”
 - Principal Investigator: Rosemarie Kobau, MPH, Centers for Disease Control, Atlanta, GA
 - Focus/relevance: Prevalence of epilepsy and common comorbidities in the U.S. adult population
 - Methods: Cross-sectional study of epilepsy prevalence, AED use, seizure frequency, access to specialty care, and associated health conditions, using data from the 2010 National Health Interview Survey.
 - Duration: Periodic—biennial or triennial

CDC Epilepsy Comorbidity Research: Current studies

- “Autism and Developmental Disabilities Monitoring (ADDM) Network”
 - Principal Investigator: Marshalyn Yeargin-Allsop, MD, Centers for Disease Control & Prevention, Atlanta, GA
 - Focus/relevance: Prevalence of autism spectrum disorders (ASD), developmental disabilities, and epilepsy in U.S. children
 - Methods: Serial cross-sectional study of prevalence of ASD and comorbidities—including epilepsy—among children aged 4 and 8 years, conducted in 12 communities, based on reviews of health and education records.
 - Duration: Ongoing

CDC Epilepsy Comorbidity Research

Research on Interventions to Reduce Occurrence or Impact



Managing Epilepsy
Well Network

Cohort Studies

CDC Epilepsy Comorbidity Research: Interventions to Reduce Impact

- **The Managing Epilepsy Well (MEW) Network**
 - **Origin:** in response to Living Well With Epilepsy II Conference recommendations, 2003.
 - **Mission:** to advance and disseminate the science of epilepsy self-management through research conducted in collaboration with network and community stakeholders.
 - **Four collaborating centers:**
 - Emory Univ., Atlanta
 - Univ. of Texas, Houston
 - Univ. of Michigan, Ann Arbor
 - Univ. of Washington, Seattle

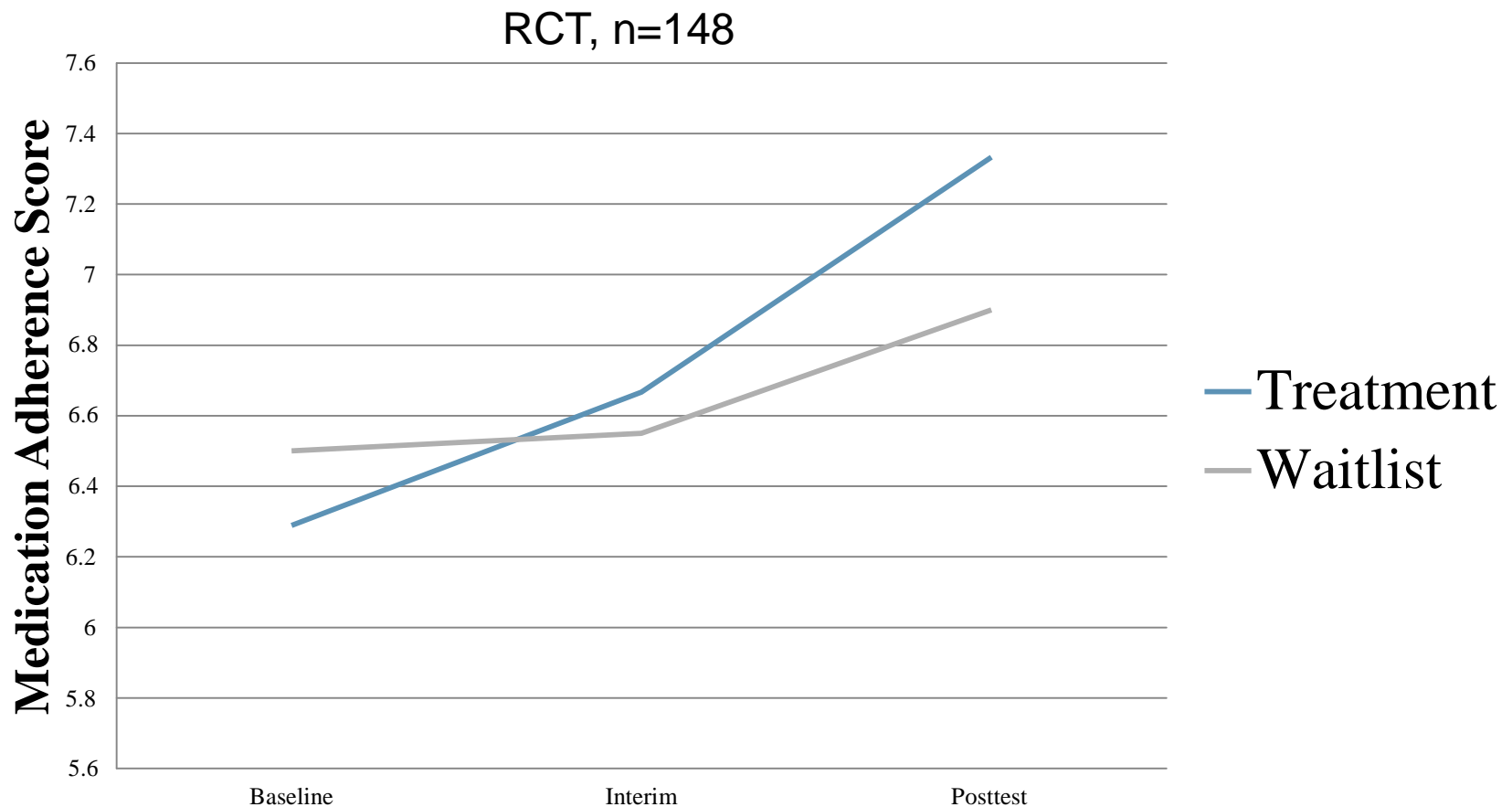


CDC Epilepsy Comorbidity Research: Interventions to Reduce Impact

Selected MEW Network Programs

- **WebEase** (Web Epilepsy Awareness Support and Education)
 - An Internet self-management program to improve medication adherence, stress management and sleep (DiIorio, et al. Health Education Research 2009; 24:185-197; DiIorio, et al. Preventing Chronic Disease 2009; 6:A28.)
- **UPLIFT** (Using Practice and Learning to Increase Favorable Thoughts)
 - An Internet and telephone intervention using cognitive behavioral therapy and mindfulness to treat depression in people with epilepsy
 - 8 sessions of group delivery of content with trained facilitator with epilepsy under clin.psychologist supervision (Thompson, et al. Epilepsy & Behavior 2010; 19:247-254; Walker et al. Epilepsy & Behavior 2010; 19:239-246.)
- **PEARLS** (Program to Encourage Active Rewarding Lives)
 - A home-based depression treatment intervention for adults with epilepsy and co-morbid depression
 - Chronic care model
 - 8 fifty-minute sessions over 19 weeks then by 5-10 min. by phone
 - Components: Problem-solving treatment; pleasant events scheduling; social & physical activation; psychiatric supervision (Ciechanowski et al. Epilepsy & Behavior 2010; 19:225-231)

Dilorio C, Bamps Y, Escoffery C, Reisinger-Walker E (2011). Results of a Randomized Controlled Trial: Evaluating WebEase, an Online Epilepsy Self-Management Program. *Epilepsy & Behavior*, 22(3): 469-474.



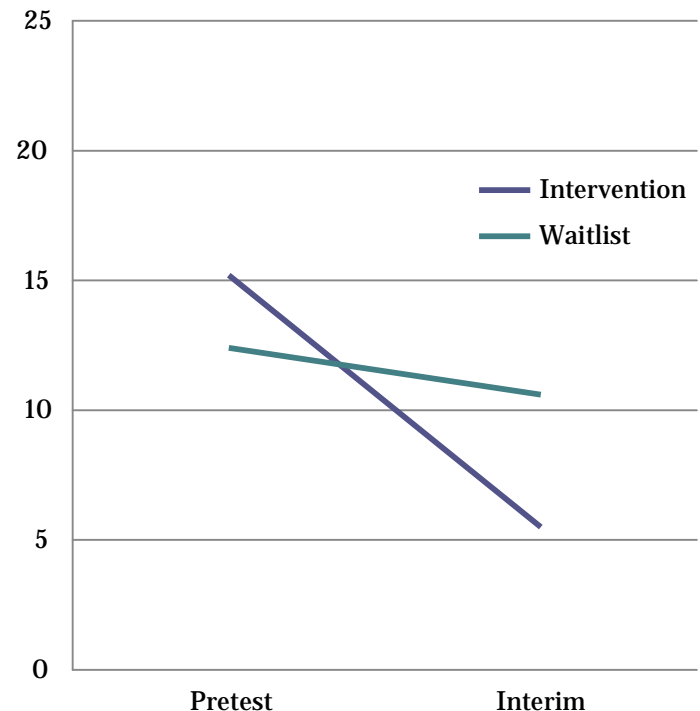
CDC Epilepsy Comorbidity Research: Interventions to Reduce Impact

UPLIFT is Effective in Reducing Depression

- RCT, n=40
- ↓ depressive sx and ↑ knowledge & skills to reduce depression
 - Significant improvement compared to controls
 - Both phone & web interventions
 - Major and minor depressive disorders
 - Effect sustained



Depression: BDI



CDC Epilepsy Comorbidity Research: Interventions to Reduce Impact

PEARLS Improves Depression & Quality of Life

- RCT, n=80
- Significant ↓ depressive sx
- Effect sustained

Ciechanowski P et al. (2010). *Epilepsy & Behavior*, Volume 19(3): 225-231.

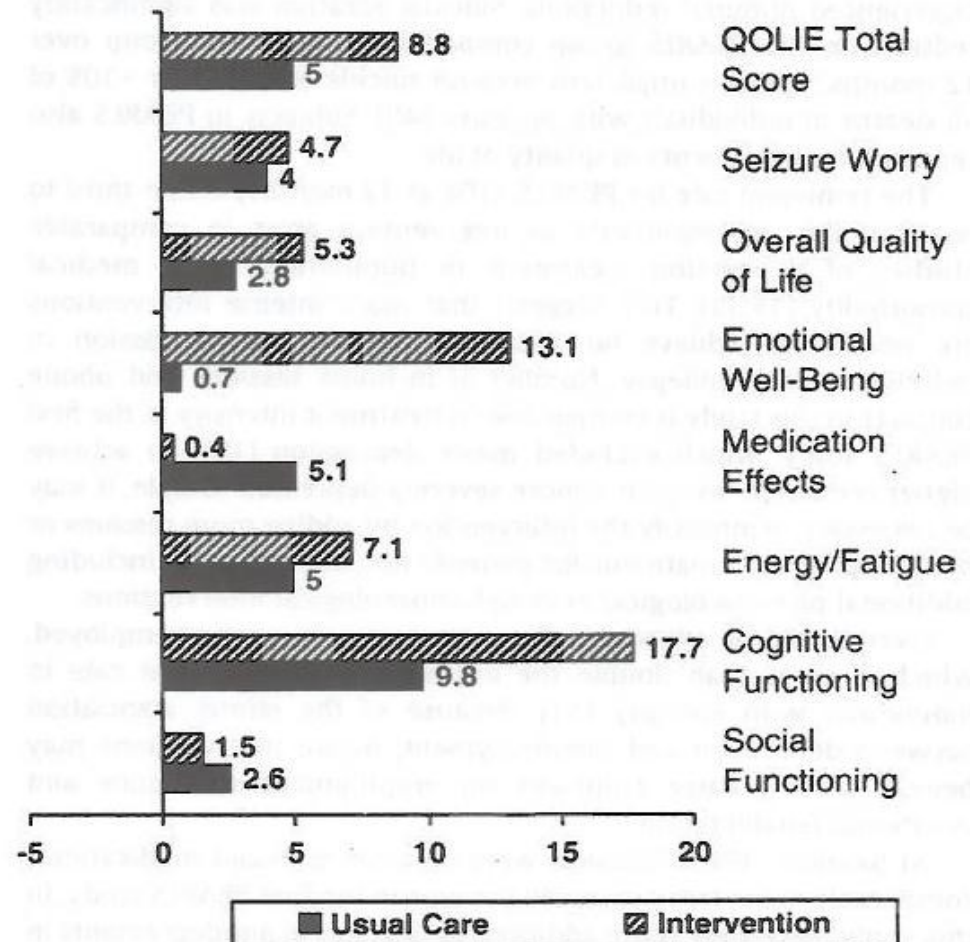


Fig. 3. Change in QOLIE-31 total score and subscale scores from baseline to 12 months (positive change reflects improved quality of life).

Next Steps.....

WebEase

- Launched via EF web site June, 2012
- Smartphone app in development

UPLIFT

- Emory funding for UPLIFT in cystic fibrosis
- UPLIFT CEU training modules in development
- Need implementation sites

PEARLS

- In-person training (Sept. 28, 2012, Seattle, WA)
- On-line training modules in development
- Need implementation sites

END