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The Managing Epilepsy Well (MEW) Network: Advancing Epilepsy Self-Management

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Abstract

Epilepsy, a complex spectrum of disorders, affects about 2.9 million people in the U.S. Similar to other chronic disorders, people with epilepsy face challenges related to management of the disorder, its treatment, co-occurring depression, disability, social disadvantages, and stigma. Two national conferences on public health and epilepsy (1997, 2003), and a 2012 Institute of Medicine Report on the public health dimensions of epilepsy highlighted important knowledge gaps and emphasized the need for evidence-based, scalable epilepsy self-management programs. The Centers for Disease Control and Prevention (CDC) translated recommendations on self-management research and dissemination into an applied research program through the Prevention Research Centers Managing Epilepsy Well (MEW) Network. MEW Network objectives are to advance epilepsy self-management research by developing effective interventions that can be broadly disseminated for use in people's homes, healthcare providers' offices, or in community settings. The aim of this report is to provide an update on the MEW Network research pipeline which spans efficacy, effectiveness and dissemination. Many of the interventions use e-health strategies to eliminate barriers to care (e.g., lack of transportation, functional limitations, and stigma). Strengths of this mature research Network are the culture of collaboration, community-based partnerships, e-health methods, and its portfolio of prevention activities which range from efficacy studies engaging hard-to-reach groups, to initiatives focused on provider training and knowledge translation. The MEW Network works with organizations across the country to expand its capacity, help leverage funding and other resources, and enhance the development, dissemination, and sustainability of MEW Network programs and tools. Guided by national initiatives targeting chronic disease or epilepsy burden since 2007, the MEW Network has been responsible for more than 41 scientific journal articles, 2 study reports, 7 book chapters, and 62 presentations and posters. To date, two programs have been adopted and disseminated by the national Epilepsy Foundation (EF), state EF affiliates, and other stakeholders. Recent expansion of the MEW Network membership will help to extend future reach and public health impact.

Targeting the Population Burden of Epilepsy:

Epilepsy is a common neurological condition affecting about 2.9 million people in the United States.¹ Despite treatment advances and improvements in public awareness, people with epilepsy (PWE) experience significant health and social disparities, and stigma—prompting recent renewed public health focus by the Department of Health and Human Services (DHSS).² Because of structural and social barriers (e.g., transportation, stigma), many PWE are unemployed, increasing their risk of social marginalization and economic hardship. To minimize epilepsy burden, the Centers for Disease Control and Prevention (CDC) has supported the Prevention Research Centers Managing Epilepsy Well (MEW) Network, a research practice community dedicated to advancing care approaches that can improve health outcomes in PWE.³ The MEW Network objective is to advance epilepsy self-management research that can be disseminated for public use, consistent with HHS initiatives aimed at improving population health.⁴

Comorbidity, Multi-Morbidity, and Growing Burden:

CDC and others have reported higher rates of comorbidity in PWE, complicating self-management.⁵ PWE are at higher risk of suicide possibly because of under-treated mental illness, sub-optimal self-management, or the synergistic negative effects of psychiatric comorbidity.⁶ Cognitive impairment compounds epilepsy burden.⁷ While self-management is challenging for many, those with low income and of certain racial/ethnic groups face additional barriers related to cultural norms, limited English proficiency, low education and health literacy, and less social support. Psychological distress, is also more common in minorities. The MEW Network has prioritized the mental health needs of PWE since 2009.

Meeting the Gap in Epilepsy Self-Management Research:

Until recently, medical management of epilepsy focused primarily on medication and less on other health behaviors important for seizure control (e.g., sleep, stress reduction). There is a clear need for self-management approaches that are comprehensive, evidence-based, patient-centered, and which can be scaled widely in clinical and community settings.

A strength of this mature network is its pipeline that ranges from efficacy studies developing and testing interventions to initiatives focused on improving access and dissemination among healthcare providers and hard-to-reach individuals (Figure 1). The MEW Network works with US organizations to expand its capacity, help leverage funding and other resources, and enhance dissemination and sustainability of programs. The Network has a strong culture of collaboration across sites and with other researchers. Opportunities for interested investigators to collaborate with the Network include interaction at national scientific venues such as the American Epilepsy Society (AES) where the Network is regularly represented, collaboration on Network workgroups, and direct contact with study teams as described in the detailed information and contacts provided on the Network's website.⁸

Brief Overview of Evidence-based Approaches:

The MEW Network has led the way in developing approaches that improve the lives of PWE. Table 1 describes MEW Network studies with information on target population, delivery, content, and evidence base status. In all programs, community engagement provides guidance on cultural, literacy and linguistic considerations, study recruitment and retention. Evidence-based programs include:

- (1) WebEase (Epilepsy Awareness Support and Education) is designed to improve adherence, reduce stress, and improve sleep in PWE. Participants are guided through program modules using a tailored approach and engage in a discussion board, fact sheets, quizzes, and daily polls. Designed to eliminate barriers to care that people with epilepsy face, WebEase is available on-line (<http://www.webease.org>).⁹
- (2) Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) is an 8-week program delivered by telephone or through the internet to groups of PWE with comorbid depression or depressive symptoms. Project UPLIFT combines cognitive behavioral and mindfulness therapies to reduce depression in PWE. Intervention groups are facilitated by a mental health professional or supervised trainee and co-facilitated by a trained peer with epilepsy. The program has been shown to improve depressive symptoms, knowledge and skills, and satisfaction with life.^{10,11}
- (3) PEARLS (Program to Encourage Active Rewarding Lives) is for PWE with depression or dysthymia [8]. This team-based intervention includes doctors, nurses, and social workers, and is delivered by a trained counselor in the client's home.¹²
- (4) HOBSCOTCH (HOMe Based Self-management and COgnitive Training CHanges lives) targets cognitive impairment in epilepsy. HOBSCOTCH combines education about memory strategies and problem solving therapy to improve memory and attention in PWE.¹³
- (5) PACES (Program for Active Consumer Engagement in Epilepsy Self-management) is designed to improve self-management, and cognitive and emotional health in PWE. PACES is delivered in-person in a community setting to groups of 6-8 PWE or over the telephone by a psychologist and a trained peer with epilepsy. PACES has been shown to improve self-management, self-efficacy, depression, and quality of life.¹⁴

New Interventions and Adaptation for Vulnerable Groups:

The MEW Network development pipeline includes new efforts (Table 1, Figure 1) that include a focus on minorities, underserved populations, youth and PWE with comorbid serious mental illnesses (e.g. schizophrenia). The Network is adapting and testing WebEase and Project UPLIFT in African Americans and Project UPLIFT in Hispanics; testing use of mobile technology to improve self-management and quality of life (PAUSE); testing a web-

based group format approach targeting high-risk individuals with negative health events (SMART); and testing an on-line intervention incorporating elements of healthy youth development to promote self-management among adolescents with epilepsy (YESS). A tablet-based decision support system is being tested to assist clinicians in assessing patient self-management behaviors and setting goals for improvement (MINDSET).¹⁵ In all studies, input from PWE or caregivers is solicited to produce programs that integrate patient cultural norms to maximize their appeal, usefulness, and impact. Associated research activities include continued validation of a new epilepsy self-management instrument and an integrated database initiative that will facilitate aggregate secondary data analysis.

Dissemination Efforts:

MEW Network members are committed to public dissemination of evidence-based self-management interventions. The MEW Network collaborates with the national Epilepsy Foundation (EF), its local affiliates and other community partners. For example, EF adopted WebEase to make it freely available on EF's web site. Similarly, with CDC support, EF provides grants to select affiliates to implement Project UPLIFT in some states. The Network uses social media for outreach. In 2015, members participated in an ABC News Twitter Chat generating 15.9 million estimated impressions. Since 2007, the Network has produced 41 articles, 2 study reports, 7 book chapters, and 62 national and international presentations and posters.

Action Recommendation:

Building the capacity of epilepsy self-management in communities requires the support of public health, clinical healthcare, social services, and other community partners.¹⁶ As opinion leaders, it is critical for physicians to recommend epilepsy self-management education or evidence-based programs to their patients. The MEW Network is exploring reimbursement strategies that can be used to sustain programs in clinic and community settings. Three major funding models for self-management services have been identified: charitable/government grants and contracts; Medicaid (MCO contracts, waivers and state plan amendments); and private contracts (insurance companies, healthcare providers). It will be critical to have epilepsy stakeholders engaged in the process of identifying and crafting local reimbursement models. It is likely that various strategies need to be explored to fit differing local circumstances and preferences. While the potential gains are great, it will take effort, persistence, and patience to make evidence-based epilepsy self-management available to PWE on a broad population level.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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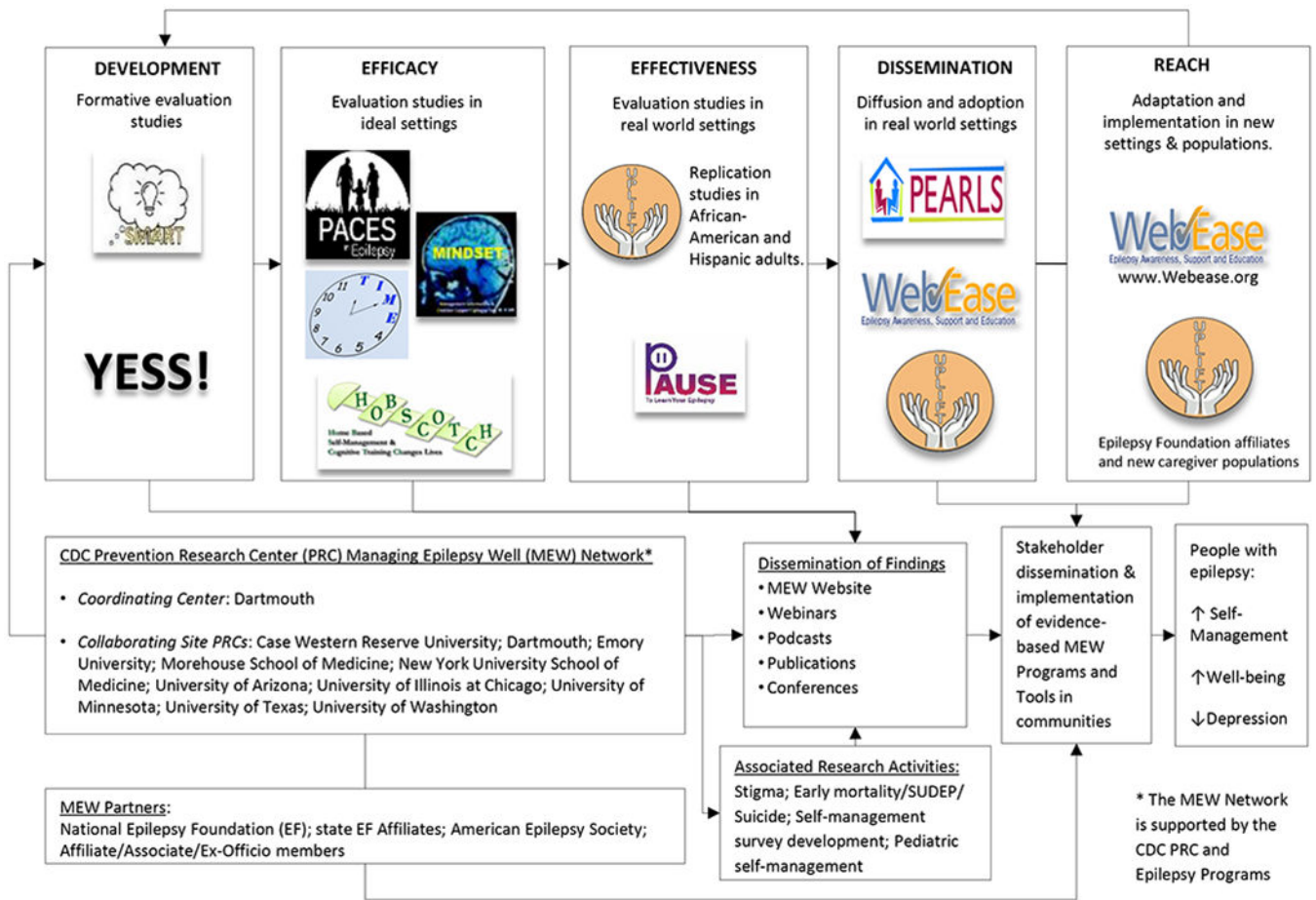


Figure 1.
Managing Epilepsy Well (MEW) Network Interventions & Associated Activities