News from the CDC: translating epilepsy self-management research to practice

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Epilepsy, which affects about two million persons in the USA, is characterized by recurrent, unprovoked seizures [1]. Many with the condition face significant challenges related to managing treatment, symptoms, disability, lifestyle limitations, depression, and stigma. The Centers for Disease Control and Prevention's (CDC) Epilepsy Program supports activities related to epidemiologic and prevention research, improving care, combating stigma, promoting patient self-management, increasing public awareness and knowledge, and strengthening partnerships. In 2002, promising research on epilepsy self-management began to emerge from CDC's Prevention Research Centers, which led to the development of the Managing Epilepsy Well (MEW) Network (<http://www.sph.emory.edu/ManagingEpilepsyWell/>) [2]. Since 2007, the MEW Network has successfully developed and evaluated several theory-based interventions through telehealth and traditional formats [3]. MEW programs currently available to the public include Epilepsy Awareness Support and Education (WebEase), an on-line self-management program, Using Practice and Learning to Increase Favorable Thoughts (UPLIFT), a telehealth depression treatment program, and Program to Encourage Active Rewarding Lives (PEARLS), a collaborative care home-based depression treatment intervention [3].

WebEase

Designed to address barriers to obtaining care (e.g., lack of transportation, stigma), WebEase is an Internet program based on social cognitive theory, the transtheoretical model, and motivational interviewing [4]. The WebEase program consists of three modules: medication adherence, stress reduction, and sleep management. Participants spend about 2 weeks in each module. In the first week, participants' stage of readiness to change behavior is assessed. They then complete a stage-of-change-appropriate learning module and create a plan and set goals for change or maintenance. In the second week, participants reflect on their progress through stage-tailored queries and motivational interviewing prompts that reinforce desired behavior or that

guide new plans. Content also includes a discussion board, fact sheets, quizzes, and daily polls. Study participants viewed WebEase as useful, acceptable, and easy to use [4]. Participants showed some improvement in self-management, medication adherence, sleep quality, self-efficacy, and social support [4]. Results from a randomized controlled trial found that at follow-up, participants in the treatment group reported higher levels of medication adherence than those in the control group, and subgroup analyses indicated a trend toward significance for the group×time interactions for medication adherence, perceived stress, self-management, and knowledge [5]. An updated version of WebEase will be made available through the Epilepsy Foundation's website by Summer, 2012.

UPLIFT

Project UPLIFT is an 8-week program delivered through the Internet or by telephone to groups of people with epilepsy and comorbid depression [6]. Project UPLIFT combines cognitive behavioral therapy and mindfulness to reduce depressive symptoms; improve life satisfaction and quality of life; increase self-compassion, purpose in life, sleep time and quality; and enhance knowledge and skills related to mindfulness and depression. Intervention groups are co-facilitated by a trained peer with epilepsy and a graduate student, both under the supervision of a licensed, clinical psychologist. A randomized controlled trial found that depressive symptoms decreased significantly, knowledge/skills increased significantly, and other benefits were achieved [6]. With funding from the National Institutes of Health, Project UPLIFT has been modified into a depression prevention intervention—currently undergoing evaluation in a multisite study across the MEW Network. UPLIFT investigators also are developing training sessions for individuals interested in implementing UPLIFT locally.

PEARLS

The PEARLS program is intended for adults with epilepsy who suffer from minor depression, major

depression, and/or dysthymia [7]. PEARLS is an adaptation of an effective home-based depression treatment intervention for older adults [8]. Delivered by a trained counselor in the client's home, PEARLS consists of eight 50-min sessions of problem solving treatment, behavioral activation, and psychiatric consultation. This collaborative care intervention includes a multidisciplinary team of doctors, nurses, and social workers. Research has shown that adults with epilepsy assigned to the PEARLS intervention achieve lower depression severity scores and lower suicidal ideation over 12 to 18 months than patients who receive usual care [7, 9]. PEARLS investigators have developed and offer a 2-day PEARLS training program for providers and administrators to learn about how to use PEARLS methods and implement PEARLS in their communities.

These interventions, along with others that are currently being evaluated, have established the MEW Network as a respected consortium of researchers and stakeholders who are actively addressing key issues affecting the epilepsy community. It is anticipated that opportunities for disseminating network programs throughout local communities will grow as the MEW's collaborative efforts and outreach broaden.

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