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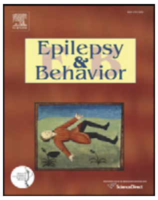

Review

Managing Epilepsy Well: Emerging e-Tools for epilepsy self-management

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ABSTRACT

The Managing Epilepsy Well (MEW) Network was established in 2007 by the Centers for Disease Control and Prevention Epilepsy Program to expand epilepsy self-management research. The network has employed collaborative research strategies to develop, test, and disseminate evidence-based, community-based, and e-Health interventions (e-Tools) for epilepsy self-management for people with epilepsy, caregivers, and health-care providers. Since its inception, MEW Network collaborators have conducted formative studies ($n = 7$) investigating the potential of e-Health to support epilepsy self-management and intervention studies evaluating e-Tools ($n = 5$). The MEW e-Tools (the MEW website, WebEase, UPLIFT, MINDSET, and PEARLS online training) and affiliated e-Tools (Texting 4 Control) are designed to complement self-management practices in each phase of the epilepsy care continuum. These tools exemplify a concerted research agenda, shared methodological principles and models for epilepsy self-management, and a communal knowledge base for implementing e-Health to improve quality of life for people with epilepsy.

1. Introduction

e-Health includes many different electronic, wireless, and mobile devices; resources; and practices that support health and health care [1]. Pivotal reports have noted that e-Health provides an unprecedented opportunity to improve the health of the overall population and to facilitate access to quality and patient-centered health care, especially for the underserved [1,2]. e-Tools represent technological products (e.g., electronic medical records, decision support systems, websites, mobile devices, apps) that support and/or guide tailored health care and health-oriented practices centered on primary goals or outcomes. They have the potential of overcoming barriers to self-management skills training including access (e.g., distance delivery independent of time and location), cost, fidelity (i.e., stand-alone delivery of self-management skills training in a standardized manner), and content (content tailored to patient need and pace of learning) [3]. These tools are already integrated into the daily lives of many people, and e-Tools can be available to support a person with health information, behavior change, and self-management at any necessary moment [4]. The U.S. Department of Health and Human Services (USDHHS) supports a number of initiatives related to e-Health in order to improve population health [1,4–6].

The Centers for Disease Control and Prevention (CDC) Epilepsy Program supported the development of e-Tools as one of several approaches to address the gap in available epilepsy self-management tools and overcome barriers to care that people with epilepsy face (e.g., lack of transportation, stigma) [7]. This is timely given that more than 50% of people with epilepsy have access to the Internet in a variety of settings (i.e., home, work, school, library) [8–10]. The investigation of e-Health applications for epilepsy management lags behind other chronic disease domains (e.g., diabetes, cancer) in terms of number and maturity [11]. A recent review of informatics applications in epilepsy included 68 studies in domains of patient monitoring and prevention, education, and therapy or guideline application [11]. Studies were largely descriptive (describing models, system development, or system installation), with only 17 (25%) being studies of effectiveness (the impact on patient or provider behavior). Further, the majority of published studies involve descriptive or retrospective designs, with only 12 (17%) evaluation studies testing hypotheses in prospective ($n = 8$) or retrospective ($n = 4$) designs [11].

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The CDC Managing Epilepsy Well (MEW) Network has investigated the needs and preferences of people with epilepsy, service providers, and caregivers regarding epilepsy self-management interventions [12–17], including examining access and preferences for e-Health delivery [18,19]. These studies have established e-Tools as a feasible strategy to intervene with this population. The purpose of this report from the field is to describe ongoing research by the MEW Network and its partners that investigates the potential of e-Health to provide self-management support to people with epilepsy.

2. Epilepsy self-management and the CDC Managing Epilepsy Well (MEW) Network

People living with chronic disorders share challenges that include obtaining appropriate care, adhering to complex medication regimens, and making lifestyle adjustments while coping with symptoms, disabilities, and emotional impacts [20]. Self-management, an essential component of the Chronic Care Model (CCM), represents a series of behaviors by which patients participate fully as partners in their health care to better control how their health problems affect their symptoms and lives [20–22]. Epilepsy self-management encompasses specific behaviors related to adhering to treatment and to controlling seizures and their effects and the effects of treatment.

The MEW Network was established in 2007 with support from the Centers for Disease Control and Prevention (CDC)'s Epilepsy Program and Prevention Research Centers (PRCs) Program to enhance behavioral and social science research of people living with epilepsy [23]. The Network's mission is to “advance the science related to epilepsy self-management by facilitating and implementing research, conducting research in collaboration with network and community stakeholders, and broadly disseminating the findings of research” [23,24]. The Network defines epilepsy self-management as the sum of processes a person uses to optimize seizure control, to minimize the effects of having a seizure disorder, and to maximize quality of life in partnership with their health-care provider. This shifts the focus from seizure control to that of ‘optimization’ with quality of life as one of the goals [25,26]. This definition recognizes that self-management may not necessarily lead to complete seizure control but can still result in a reduction in seizure frequency, improvements in self-efficacy and coping skills, and improvements in other health and quality-of-life outcomes for people with epilepsy. The MEW definition focuses on three primary behavioral domains: 1) treatment management, 2) seizure management, and 3) lifestyle management [25,27–30]. The MEW Network has been actively involved in formative studies investigating the potential of traditional community-based and e-Health programs to support self-management and trials to develop and evaluate e-Health interventions (henceforth, referred to as e-Tools) to overcome recruitment barriers (i.e., participant travel, transportation) that limited earlier CDC-supported studies of traditional face-to-face and group-based interventions [30].

3. Self-management e-Health for people with epilepsy: MEW formative studies

The MEW Network studies have investigated the needs and preferences of people with epilepsy, service providers, and caregivers regarding epilepsy self-management interventions [12–17] and, more specifically, to examine access and preference for e-Health delivery [18,19]. These studies have indicated the need for expanded efforts to develop a broad array of self-management interventions and have established e-Tools as a feasible strategy to intervene with this population.

3.1. MEW Network key informant interviews on self-management interventions

Through key informant interviews with epilepsy clinical, academic, and human service professionals ($n = 101$), MEW investigators have examined challenges of individuals with epilepsy, their caregivers, and service providers in meeting desired patient outcomes [14]. Emerging concerns included lack of convincing evaluations of self-management interventions, insufficient research describing the elements of management that are shared versus unique to individual patients [14], a tendency for clinical professionals to take too narrow an approach to epilepsy care [15], and failure to recognize the way the condition affects all aspects of functioning [15]. These factors represent antecedents to care plans and impact services that can be inadequate for the range and intensity of problems that patients face [15]. Survey studies of epilepsy care and self-management of people with epilepsy from socioeconomically diverse urban populations ($n = 437$ and $n = 238$, respectively) have provided similar conclusions; that is, too few programs exist in general and too few evidence-based programs are available to practitioners, community agencies, and families [12,13]. Epilepsy education is particularly overlooked for people with comorbid conditions and developmental disabilities, those with intractable and refractory epilepsy, low-income patients, and those from diverse racial and ethnic backgrounds [12,13].

3.2. Evidence of potential for e-Health self-management interventions

MEW investigators assessed computer and Internet use among adults with epilepsy (≥18 years) and their caregivers ($n = 183$) in a cross-sectional study [19] through an online and a paper survey distributed at two epilepsy clinics. Most participants in the online and clinic groups had access to computers and the Internet (95% and 60%, respectively) and used the Internet to find health information (99% and 57%, respectively). Participants reported searching for general information on epilepsy (43%), medication (30%), specific types of epilepsy (23%), and treatment (20%). Most reported that they likely would use an Internet-based self-management program to help control their epilepsy.

A mailed consumer-based needs assessment survey of adults with epilepsy (≥18 years) in the Pacific Northwest ($n = 165$) informed the design of an in-person self-management program and included questions about delivery modalities such as e-Health [16,17]. Though the potential for e-Tool applications was seen in the survey results, a majority of patients expressed a preference for an in-person (individual or group) program delivery, as opposed to a distance delivery (phone or Internet). The findings reinforced the importance of consumer input and needs assessment regarding program design and that a range of delivery options for interventions, including in-person delivery, may have to be considered.

Even when individuals with epilepsy are able to access and use e-Tools for self-management, there is also concern that such tools may elicit seizure events in photosensitive patients. The MEW investigators examined the incidence of computer-associated seizure events in adult patients with epilepsy (18–75 years, $n = 320$) during a longitudinal study conducting three computer-based assessments. Fourteen seizure events were documented, occurring during 1.6% of all completed assessments. Possible precipitating factors for seizure events included hunger, fatigue, stress, and medication changes. Participants reported that computer use could have triggered their seizures in only two instances, suggesting that the use of computer-based strategies for self-management intervention is not contraindicated, if judiciously prescribed.

The MEW formative studies have reinforced the promise of self-management e-Tools to be accessible, desirable, and largely safe for adults with epilepsy while also reinforcing the importance of collaboration with patients in the formative and predissemination stages [31].

4. Self-management e-Tools for people with epilepsy: MEW intervention studies

The MEW intervention studies have been conducted to develop, implement, evaluate, and disseminate innovative e-Tools for individuals