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Self-management in epilepsy: Why and how you should incorporate self-management in your practice

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1. Why would clinicians want patients to manage themselves?

Epilepsy presents many challenges for those affected by the disease as well as for family members and providers [1,2]. Epilepsy providers routinely educate and counsel patients on their epilepsy and related health issues. Yet, people with epilepsy spend almost all of their time outside of their doctor's office. Providers cannot support and monitor treatment adherence, mood, or enhance their patients' healthful behaviors, coping skills, and quality of life on a daily basis. Providers may also fail to recognize or treat common co-morbidities such as depression, anxiety, cognitive impairment, and sleep disorders that can adversely affect seizure control and quality of life [3–4]. Often lacking a multidisciplinary team, or having insufficient time in clinical encounters, providers cannot fully address these and related psychosocial needs of their patients with epilepsy [5]. Introducing and encouraging

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access to patients self-management support can address these gaps in care, ultimately transferring “ownership” of care from provider to patient [6,7]. At the individual level, self-management aims to increase patients’ skills and confidence in monitoring symptoms, problem-solving, decision-making, goal-setting, communicating, and adopting healthful behaviors to improve health and quality of life [8–11]. Self-management is a partnership between the patient and provider, incorporating patients’ preferences and goals—making it patient-centered. Self-management also facilitates positive health—inclusive of physical, mental, and social resources that actively promote well-being [12]. Epilepsy self-management domains (e.g., treatment adherence, tracking seizures and medication side effects, stress reduction, sleep, safety, communication) have been extensively reviewed [10,11,13].

At the population-level, the term “self-management support” is used, and includes any grouping of policies, programs, services, and structures that extend across healthcare, social service providers, and communities aimed at assisting individuals in understanding, coping with, and caring for their chronic condition [6]. The Chronic Care Model is an early overarching framework to deliver self-management support [7,14]. Self-management support for people living with chronic conditions such as diabetes, arthritis, and asthma are well-established with standardized program protocols, local provider training programs, multiple federal and local funding streams, community-based delivery partners, and referring providers [6,15–20]. For example, with the growing prevalence of diabetes, a number of evidence-based and professionally accredited (e.g., American Diabetes Association; American Association of Diabetes Educators) diabetes self-management programs are available and implemented in communities across the United States with support from the Centers for Disease Control and Prevention (CDC) and other funders [19]. In 2015, key professional organizations serving people with diabetes issued a joint position statement indicating that diabetes self-management education should be provided to all individuals with diabetes at diagnosis and as needed at different points of care thereafter [21]. State health departments use CDC funding to expand the reach of proven self-management education programs (e.g., Chronic Disease Self-Management Program and the Arthritis Self-Management Program (ASMP)¹) by partnering with community organizations that can embed these programs into their routine operations and sustain them over time [20,22]. The National Asthma Education and Prevention Program Guidelines, supported by CDC and other entities, specify the need to support asthma self-management education for people with asthma [23].

Health transformation (changes in the organization, financing, and delivery of healthcare) has led representatives from health systems, insurers, community-based organizations, and providers to collaborate and make evidence-based self-management programs more widely available to their populations with chronic disease [24,25]. Efforts are underway to use population-level self-management indicators to track how much self-management support occurs for chronic disease at individual, health-care-systems, community, and policy levels (e.g. proportion of health care systems including incentives tied to the delivery of self-

¹The ASMP is endorsed and recommended by the Centers for Disease Control and Prevention, the Arthritis Foundation, and the American College of Rheumatology (<http://patienteducation.stanford.edu/programs/asmp.html>)

management support; proportion of individuals that can articulate setting a health-related self-management goal; proportion of adults who participate in an asthma self-management program) [26–28]. In contrast to other disease groups, systematic implementation of self-management support for people with epilepsy is extremely limited. But, epilepsy self-management programs, tested in randomized control trials with robust study samples, offer substantial promise to improve outcomes and their use could serve as a starting point to augment epilepsy self-management support [29–31].

2. What problems do people with epilepsy have that are amenable to self-management?

Common concerns for people with epilepsy include psychological and emotional effects of epilepsy, cognitive deficits, fatigue, social isolation, unemployment, low income, interpersonal relationship strain, and stigma [1,32–34]. Epilepsy is often compounded by comorbidity, complicating treatment regimens and contributing to worse outcomes [1,35]. Using administrative data, Faught et al. [36] found that about 26% of adults with epilepsy were non-adherent to their medications, increasing their health care utilization. Physicians attribute non-adherence to multiple factors, which sometimes differ from their patients' attributions (e.g., complacency vs. feeling uninformed [37]). Some people with epilepsy report greater confidence with medication adherence, but less so for engaging in other healthful lifestyle behaviors (regular sleep, healthy diet, physical activity, not smoking) conducive to quality of life [38]. More than one-half (58.8%) of participants with epilepsy in a South Carolina needs assessment reported challenges with managing their epilepsy on a daily basis [39]. These factors—forgetfulness, fatigue, feeling uninformed, psychological distress, and other unhealthy behaviors—are amenable to self-management [9]. Evidence-based epilepsy self-management programs can improve confidence, medication adherence, mood, memory, and quality of life [31]. Some of these programs are delivered by Internet or phone, eliminating the barriers of transportation and stigma. Others provide effective, non-pharmacological treatments to reduce depressive symptoms, which may be appealing to some people with epilepsy dealing with substantial polypharmacy burden [31,40].

3. How can self-management techniques be put into your practice?

Epilepsy self-management can be conceptualized along a three stepped-care continuum, used to model health services for depression and other chronic mental health conditions (Table 1) [41–43]. Stepped care is intuitively practical for clinicians—first, one begins by asking patients about their self-management awareness and needs, and if necessary, recommending the lowest effort/least burdensome interventions (e.g., an on-line self-management program). Then one moves onto more complex or intensive approaches as clinically indicated (Table 1). The CDC Prevention Research Centers' Managing Epilepsy Well (MEW) Network has advanced epilepsy self-management research including providing professional training and patient education [31]. Out of the MEW Network research, six evidence-based programs are available to provide self-management support to people with epilepsy with different levels of self-management need [31]. Some of these programs are delivered by web, phone, or in-person, thereby eliminating barriers to care: HOBSCOTCH,

PACES, PEARLS, UPLIFT, TIME and WebEase with several other programs under development [31].² Each program is unique in addressing important self-management domains in adults with epilepsy (Table 1) and has been reviewed [31,44,45]. For example, HOBSCOTCH is a telephone-based program that can help improve memory and quality of life in adults with epilepsy [45]. PACES consists of weekly group meetings during which participants discuss topics (e.g., stress management, social participation, assertive communication) and set goals that are personally meaningful [47]. WebEase, a free on-line program, seeks to improve medication adherence, sleep quality, and stress management using proven behavioral science methods that account for people's confidence in and readiness for behavior change [48]. UPLIFT and PEARLS eliminate barriers to mental health care, by delivering effective depression treatment in the patient's home, by telephone (UPLIFT), or in person (PEARLS) [49,50]. TIME reduces symptoms of depression in adults with epilepsy and serious mental illness such as schizophrenia and bipolar disorder [51]. To extend these programs' reach, the Epilepsy Foundation (EF) has facilitated delivery of WebEase to all adults with epilepsy, by hosting it on the EF website (www.webease.org). WebEase Flyers for patients and providers are available on the CDC Epilepsy Program website (www.cdc.gov/epilepsy). The CDC and EF have facilitated delivery of UPLIFT to adults with epilepsy and comorbid depression in Colorado, Connecticut, Delaware, Florida, Illinois, Michigan, and New York. The CDC and EF provide other opportunities to support implementation of MEW Network evidence-based programs for interested groups.

Physician champions for self-management are critical; if an arthritis self-management program was recommended by a health care provider, patients were 19 times more likely to participate in the program than without that recommendation [52]. While motivating patients may be a challenge and dependent upon multiple factors (e.g., patient knowledge, motivation, confidence, social support), and patient adherence might vary for numerous reasons (e.g., inconvenience, expense) [9], proven self-management strategies (e.g., goal-setting; motivational interviewing; action plans; phone-delivery and other structured interventions) address such challenges and facilitate health-enhancing behaviors [6]. Use of validated assessment tools can assist providers in identifying patients who would benefit from epilepsy self-management support [53,54]. By promoting self-management, a provider becomes a partner in shared health decision-making—aligning patient and provider goals. To address challenges in integrating self-management support in clinical practice, the US Health and Human Services Education and Training Resources on Multiple Chronic Conditions (MCC) for the Healthcare Workforce is a new set of training materials for healthcare professionals focused on improving the care for adults with chronic disease, especially those with multiple chronic conditions such as epilepsy [55]. The HHS initiative recognizes UPLIFT and PEARLS in its inventory of evidence-based programs for adults with epilepsy and MCC [56]. The HHS curriculum includes a Self-Management Support module that provides an overview of strategies that can be implemented by health care

²HOBSCOTCH (Home Based Self-management and Cognitive Training Changes Lives); PACES (Program for Active Consumer Engagement in Epilepsy Self-management); PEARLS (Program to Encourage Active Rewarding Lives); UPLIFT (Using Practice and Learning to Increase Favorable Thoughts); TIME (Targeted Self-Management for Epilepsy and Mental Illness); WebEase (Epilepsy Awareness Support and Education).

providers in their practice to improve the quality of care of persons with chronic conditions (Fig. 1) [55].

Engaging nontraditional health providers (NTHP), (e.g., community health workers [CHW], navigators, health educators/coaches) to deliver self-management support is another evidence-based practice that may also meet gaps associated with provider shortages [57]. One study demonstrated that structured physician counseling followed by a 10-min booster call from a health educator addressing patient's needs and progress produced meaningful increases in healthful behavior change in a high-risk group of adults [53,58]. The Institute of Medicine noted that NTHP can be a valuable asset in epilepsy care [1]. The Centers for Medicare and Medicaid Services expanded payment for services provided by non-licensed providers. States are mobilizing partners (e.g., community colleges, nonprofits, health systems) to train NTHP on chronic disease management, and to integrate NTHP in healthcare teams. There are few data on NTHP to deliver self-management for PWE, but their use in other vulnerable populations offer promise for epilepsy [57].

For example, a trained NTHP, following a provider's recommendation, can assist a patient in accessing and registering for a program such as WebEASE. This could then be followed up with structured coaching by phone to facilitate self-management goal attainment. Currently NTHP are being trained at the University of Texas to help adults with epilepsy use MINDSET (Management and Information Decision Support for Epilepsy Tool), another promising MEW Network intervention designed to facilitate self-management assessment and the selection of goals and strategies for improvement [59]. In this case, the NTHPs follow-up with phone calls to check in on patients' progress and to provide supportive coaching and access to informational support, if necessary. Evaluation of this model is underway. Depending on local availability of other epilepsy self-management programs, the NTHP could help a patient to access other evidence-based self-management programs (e.g., Chronic Disease Self-Management Program) or community resources [6].

Finally, patients with epilepsy and severe intellectual and developmental impairment may not be able to self-manage their disorder. In these cases, caregivers (e.g., parents, spouses, partners, family, and friends) might be more heavily involved in disease-management support. Given their own burden, caregivers should be recognized and supported with similar resources [60]. Less is known about effective self-management of pediatric epilepsy [61], but family-management models offer helpful frameworks [62]. Epilepsy self-management approaches sustained with grant funding are limited, and there is an urgent need to expand the effectiveness and reach of evidence-based programs to increase payers' willingness to implement such programs.

4. Conclusion

Self-management plays an important part in comprehensive epilepsy care, with the goal of increased knowledge, better self-care, healthier behaviors, and improved outcomes [1]. Epilepsy self-management extends beyond the clinic into the patient's home and community, and ultimately is a synergistic partnership between a patient and their provider. Chronic disease models demonstrate that effective self-management programs and supports can be

implemented in clinical and community settings [1,6,9,63–65]. In response to the Institute of Medicine’s recommendations calling for the promotion of evidence-based epilepsy self-management programs, we hope to engage epilepsy providers to serve as epilepsy self-management education disseminators and self-management program adopters. Clinicians play a key role in informing and motivating patients to engage in these programs. The programs are structured so that very little direct participation is required from clinicians, and the programs have been shown to be effective in prospective randomized trials [31]. Providers and other stakeholders can partner with groups such as the MEW Network and EF to implement epilepsy self-management in communities throughout the United States. As evidenced by this commentary, a robust evidence-base of epilepsy self-management is accumulating [31]. To supplement this emerging science, developing consensus-based guidelines for the behavioral management of epilepsy that is informed by expert clinical opinion, and patient and stakeholder experience and preference, might further advance the field. Moreover, self-management support could become a criterion for a Level 4 National Association of Epilepsy Centers designation [66], thereby facilitating program delivery. In a rapidly changing health care world increasingly characterized by new models of care, an increasing number of insured patients, professional shortages, and virtual care delivery, self-management needs to play a larger role in achieving better health for persons with epilepsy.

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Applying Self-Management Support in Practice



Source: U.S. Department of Health and Human Services. Multiple Chronic Conditions Initiative. Education and Training Curriculum on Multiple Chronic Conditions. Washington, DC. June 2015. Self-Management Support: Module 2

Fig. 1.
Applying self-management support in practice.

Table 1

3-Tiered Health Promotion Approach* (HPA) Model for Individuals with Epilepsy.

HPAs	Epilepsy self-management model examples
<p><i>Universal</i></p> <ul style="list-style-type: none"> • All patients • Minimally invasive • Easily disseminated 	WebEase (targets medication adherence, stress; delivered on-line) [48]
<p><i>Selected</i></p> <ul style="list-style-type: none"> • Target those at risk for: <ul style="list-style-type: none"> ○ poorly controlled epilepsy ○ comorbid depression ○ cognitive impairment • Identification often based on demographic or clinical variables • Individually or group-tailored • Tailored for specific populations (Hispanic, African-American, rural) 	<p>HOBSCOTCH (targets memory; delivered by phone) [46] PACES (targets medical, cognitive, and psychosocial adjustment; delivered in groups and by phone) [47]</p> <p>UPLIFT (targets depression; delivered by phone) [49]</p>
<p>Indicated</p> <ul style="list-style-type: none"> • Target those known to be at very high risk (severe mental illness) • Highly tailored and of greater intensity 	<p>PEARLS (targets depression); delivered in-home [50] TIME (targets serious mental illness); delivered in groups and by phone [51]</p>

*References no. [41–43].