



Review

Self-management education for children with epilepsy and their caregivers. A scoping review

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ABSTRACT

Self-management education programs have been highly successful in preparing people to manage medical conditions with recurring events. A detailed curriculum for epilepsy patients, and their caretakers, is lacking. Here we assess what is available for patients who have disorders with recurring events and offer an approach to developing a potential self-care curriculum for patients with seizures and their caregivers. Among the anticipated components are a baseline efficacy assessment and training tailored to increasing self-efficacy, medication compliance, and stress management. Those at risk of status epilepticus will also need guidance in preparing a personalized seizure action plan and training in how to decide when rescue medication is appropriate and how to administer the therapy. Peers, as well as professionals, could teach and provide support. To our knowledge, no such programs are currently available in English. We encourage their creation, dissemination, and widespread use.

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1. Introduction

Self-management has been defined as the daily actions that people and their caregivers can take to minimize symptoms and progression of a chronic illness and to minimize the multiple adverse correlates and consequences of the illness [1]. For people with epilepsy, this can include responsibilities for medical care tasks (taking anti-seizure medication as advised, keeping medical-care appointments, avoiding seizure triggers, assisting with remote surveillance [keeping a seizure diary or using a wearable device], participating in shared decision-making), as well as coping with the anxieties and stresses associated with seizure recurrence [2].

A self-management education program has been defined as “an intervention primarily designed to develop the abilities of patients to undertake management of health conditions through education, training, and support to develop patient knowledge, skills or psychological and social resources.” [3] A 2013 Institute of Medicine report strongly promoted self-management interventions for people with epilepsy, and “recommended improving and expanding educational opportunities for patients.” [4] Unfortunately, health-care professionals (HCPs) appear to be inadequately equipped to

provide self-management education, and many had never received postgraduate training in teaching self-management of chronic diseases [5]. Such training is deemed a key element in developing person-centered professional skills that enable HCPs to undertake new roles and successfully facilitate self-management education [5–7].

A recent Cochrane Review of reports of clinical trials “found moderate certainty evidence that one of the educational interventions reduced seizure frequency ... two other educational interventions reduced seizure severity ... The evidence for all other outcomes (drug adherence, knowledge, self-efficacy and self-perception of epilepsy on quality of life) was mixed.” [8] Each of these studies compared patients and caregivers taught a specific self-management program to “usual care” controls. Because none of these studies compared one educational program to another, we do not know if one program achieves its goals better than other programs.

The scoping review of self-management education below covers a diverse range of topics emphasizing what we have learned from those caring for patients with other disorders. We conclude with suggestions about how best to apply what we learned to teach self-management of epilepsy.

The task we posed for this scoping review was to answer the question, “What is in the published literature that would help us prepare guidelines/suggestions/curricula for how best to teach self-management of epilepsy?” We began by reviewing how self-

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management of diabetes mellitus is taught, in large part because the incentives provided by the United States Centers for Medicare & Medicaid Services [9] prompted rapid progression and professionalization. We then extended our focus to other apparently successful efforts for teaching the self-management of asthma, sickle cell disease, cystic fibrosis, congestive heart failure, headache, inflammatory bowel disease, etc.

We saw the need to identify the multiple health-behavior change theories invoked by those explaining why they preferred one approach to the alternatives and decided that readers of our scoping review might want to know more about these theories. What we learned from a study of these theories and how they were implemented allowed us to offer suggestions about how to teach self-management of epilepsy to people with epilepsy and their caregivers.

We provide this scoping review to encourage the design and assessment of self-management programs likely to be successful and to encourage others to support this effort. Our proposed model is based on clinical practice guideline development. We value clinical practice guidelines because they are created by the most knowledgeable based on the best evidence [10,11], subsequently assessed [12,13], and modified as needed [14]. We expect that many providers of epilepsy care would be very grateful for a curriculum that they can modify as needed.

We hope these programs provide a standard that can be modified, updated, and shared. One model of the earliest steps needed is The European Academy of Allergy and Clinical Immunology Task Force on Allergic Diseases in Adolescents and Young Adults, which reviewed “the literature on interventions for improving self-management and well-being in adolescents and young adults with allergic conditions, including asthma, urticaria/angioedema and atopic dermatitis.” [15,16].

2. What we have learned from those caring for patients with other disorders

2.1. Assess what is available

If self-management education programs are to be most effective, the programs taught [17,18] and the teaching competencies of healthcare providers [19,20], need to be assessed [21]. Some educational programs begin with an assessment of the student's current level of knowledge and function. Self-management education programs do the same by beginning with an assessment of the level of ‘self-efficacy,’ a person's belief in his/her own ability to perform a behavior required to produce a desired outcome [22], (I can ...”) [23] (“how confident are you in your ability to) [24], which has been offered as an explanation of the level of adherence to health behaviors [25,26].

2.2. Classifications of self-efficacy

Thirty years ago, self-efficacy was classified into three categories: global self-efficacy, domain self-efficacy, and task-specific self-efficacy [27]. We continue to view this classification as helpful, even though others have stated that domains are multi-dimensional (and therefore not specific) [28], efficacy beliefs specific to a particular task or behavior develop/change over time [22], and others see self-efficacy as a continuum [29].

2.3. Generalized self-efficacy

Generalized self-efficacy can be viewed as the person's perception he/she/they can take on any task [30]. The Generalized self-efficacy scale includes statements such as, “I can usually handle

whatever comes my way,” and “It is easy for me to stick to my aims and accomplish my goals.” [31] Scores on this assessment predict health behaviors [32,33], function [34–36], and well-being [37,38].

2.4. Domain-specific efficacy

Those responsible for creating the NIH-Roadmap self-efficacy questionnaires identified five domains: managing daily activities, managing symptoms, managing medications/treatments, managing emotions, and managing social interactions [39]. These validated [23,40] PROMIS (Patient-Reported Outcomes Measurement Information System) self-efficacy measures “are better predictors of mental health, disability, and quality of life than disease severity or diagnosis,” including epilepsy [41]. “Notably, a single domain, self-efficacy for managing emotions predicted all outcomes of mental health, fatigue, physical functioning, and global health.” [41].

Although these instruments were intended to be broad and applicable to a variety of disease states, they are less measures of efficacy (“I am confident I can”) than they are measures of self-management [42] (“I find my efforts to change things”) [43].

2.5. Task-specific efficacy

Minimizing potentially recurring symptoms can require a different set of tasks than are needed to minimize the progression of a disorder without episodic flare-ups. Consequently, medical care teams have created task-specific self-efficacy questionnaires for obesity [44–49], diabetes [50–54], asthma [55–57], heart failure [58,59], arthritis [30,60–62], pain [63–65], chronic obstructive lung disease [66], sickle cell disease [67,68], cystic fibrosis [69], and inflammatory bowel disease [70,71].

2.6. Health-behavior change theories

“Public health and health-promotion interventions that are based on social and behavioral science theories are more effective than those lacking a theoretical base.” [72].

In light of this suggestion, we offer theories favored by different health-behavior psychologists.

a. Health Belief Model

This model has five components (perceived susceptibility; perceived severity; perceived benefits; perceived barriers; and cues to take action) [73]. The contribution of each of these to predict the eventual behavior was found to be smaller than originally assumed [74], prompting diminished prominence/utility [75].

The theory of planned behavior model posits three types of “beliefs,” each with two components: behavioral (attitudes and behavioral intention), normative (subjective norms and social norms), and control (perceived power and perceived behavioral control) [76]. It does have limited predictive validity [75]. In addition, concerns have been raised about the model's ability to assess the falsifiability of hypotheses derived from the theory of planned behaviour [77], prompting others to agree with calling for the “retirement” of the theory of planned behaviour [78–80]. Nevertheless, the theory of planned behavior survives with some investigators continuing to view it as helpful [81].

b. Trans-theoretical model

This model is based on the assumption that individuals go through five stages of behavior change (pre-contemplation, contemplation, preparation, action stage, and maintenance stage) [82]. This has been the source of criticism [83,84], with one critic calling these ‘pseudo stages.’ [85].

c. The self-regulatory model

The self-regulatory model (SRM), also known as the common-sense model is based on the view that cognitive and emotional perceptions of a symptom or diagnosis influence the selection of coping responses and that these responses in turn influence health outcomes. The model incorporates a feedback loop in which the individual monitors her/his/their coping responses and modifies them as needed for discomfort or perception of danger [86,87].

d. Self-determination theory

Self-determination theory posits that humans have three psychological needs, autonomy, competence, and relatedness (also called connection) [88,89]. Self-determination-theory-oriented self-management education programs aim to increase intrinsic motivation as the means to meet these needs [90]. The successes of self-determination theory-informed interventions to improve self-management are attributed to increases in self-determined motivation [90,91].

e. The Capability, Opportunity, Motivation, Behaviour (COM-B) model

The COM-B model identifies the components that might need to be changed for an intervention to be successful. This model has also encountered controversy [92,93]. The 'COM-B system' forms the hub of a 'behavior change wheel' (BCW) that includes nine intervention functions encircled by seven categories of policy that could enable those interventions to occur [94].

f. The Theoretical Domains Framework

To make the use of behavior change theories more accessible to implementation researchers, a group of health psychologists, health psychology theorists, and implementation researchers developed the Theoretical Domains Framework (TDF).

The 2005 version of the TDF integrated 33 psychological theories relevant to behavior change into 128 constructs (component parts of theories) sorted into 12 domains [95]. In 2012, the TDF was revised and validated, and now consists of 84 constructs sorted into 14 domains [96].

In contrast to the many theories that focus on individual factors (e.g., beliefs and motivations), the TDF goes beyond and includes social and environmental factors, allowing it to serve as a planning tool to help identify barriers and facilitators to implementing an intervention. The TDF can also function as an evaluation tool to assess how effective an intervention was at targeting specific behavior determinants and to identify what contributed to the success and/or failure of an intervention [97,98].

The Theoretical Domains Framework (TDF) [95] and the Behaviour Change Wheel (BCW) [94] have been brought together to create a scaffold that

- allows comparisons across reviews
- applies what is known within a systematic review context
- provides a means to accumulate evidence that could potentially be used to understand behavior in similar contexts [99].

g. Use of these health-behavior-change theories

Our encouragement to involve health behavior psychologists in creating and assessing self-management education programs should be tempered with the awareness that a systematic review that assessed 13 digital health interventions designed to encourage health-promoting behaviors in women found "overall weak use of theory, low levels of treatment fidelity, insignificant outcomes, and insufficient description of several interventions to support the assessment of how ... [behavior change theories] were activated [100].

h. Acceptance and implementation

Normalization Process Theory (NPT) explains how characteristics of individuals and systems promote and inhibit the implemen-

tation and sustainment of new interventions [101]. In essence, how is the innovation normalized into what is routine, and what contributes to facilitation, and what are the barriers to normalization [102–104]. This way of finding out what works and what doesn't appears to be helpful [105–107], including the implementation of self-management education programs [108].

Consolidated Framework for Implementation Research (CFIR) describes and categorizes the characteristics of people, institutions, and systems that influence the implementation of an innovation [109]. Normalization Process Theory is sometimes combined with CFIR to identify and explore interactions between agents, processes, and contextual conditions that appear to influence how well innovations are embedded/normalized into routine practices [110].

We encourage those who plan to develop self-management education programs to seek the guidance of carers and those who they care for. This is in keeping with the guidance of others, "Early intervention research continues to highlight the necessity of engaging with and listening to the voices of young people, families and those who work with children and young people." [111].

2.7. Administration of 'rescue' medication

The asthma literature is a good source of how clinicians guide patients and their families in managing a recurrent illness that might require rescue therapy [112–123]. The most important recommendations made are:

- Promote adherence to maintenance therapy
- Help patients and their families recognize deteriorating symptoms (the yellow zone)
- Create and distribute written **action plans** to patients and their families
- Regularly review potential triggers and discuss strategies for managing triggers
- Every healthcare visit should be used as an opportunity to discuss and encourage self-management.

2.8. Vacation-time camps

Summer camps for children with special needs can provide an opportunity for self-management education, as well as for peer-to-peer support, and sometimes respite care for caregivers. This has been documented to varying extents for children with asthma [124,125], burns and their residua [126,127], cancer [128,129], cystic fibrosis [130], diabetes [131], and sickle cell disease [132,133].

The successes of virtual boot camps for training clinicians [134–138], the successes of residential camps, and the limited access of patients to residential camps have prompted the creation of virtual boot camps for patients that appear to achieve the goal of improving self-management [139].

2.9. Professionalize

When claiming statutory authority to regulate Medicare outpatient coverage of diabetic self-management training accreditation program services in 1997, the Centers for Medicare & Medicaid Services (CMS) announced it would reimburse for "educational and training services furnished ... to an individual with diabetes by a certified provider... to ensure therapy compliance or to provide the individual with necessary skills and knowledge (including skills related to the self-administration of injectable drugs) to participate in the management of the individual's condition ... The American Diabetes Association (ADA) and the American Association of Diabetic Educators (AADE) are the two national DSMT (Dia-

betic Self-Management Training) accreditation organizations approved by CMS to accredit entities that furnish DSMT services.” [9] Among the standards for these service-providing entities are “a multidisciplinary instructional team that . . . includes at least a registered dietitian, as recognized under State law, and a certified diabetes educator (CDE), certified by a qualified organization that has registered with CMS, who have didactic experience and knowledge of diabetes clinical and educational issues.” [140].

CMS has no equivalent standards for epilepsy self-management education, nor does the Institute of Medicine report that examined the public health dimensions of epilepsy [141], nor are we advocating for such standards. Rather, we are calling attention to a professionalization orientation that we have not seen in the epilepsy self-management literature.

2.10. Personalize

Over time, the term ‘*person-centered care*’ [142] has replaced *patient-centered care* [143,144] apparently because ‘*person-centered care*’ is believed to broaden and extend care to the whole life of the person beyond the clinical or medical condition [145]. Both terms are associated with the concept of personalizing self-management options [146–150]. Tools are available to facilitate the personalization process [151,152].

2.11. Partnership

The two-decade-old idea of professional-patient partnership [153] appears to have been relatively dormant until recently. “An increasing number of patients expect and want to play a greater role in their treatment and care decisions.” [154] Recognition of this has led to greater awareness of the need for patient-medical team partnerships [155–161].

The Managing Epilepsy Well website emphasizes that self-management is a team effort. “*Self-management does not mean that people manage their health alone. Self-management requires an active partnership between a person with epilepsy, their family or friends, and their health care provider.*” [162] Care coordinators seem especially well suited to be the link between the PWE and caregivers with the medical care team [163–167].

2.12. Presentation and strengthening the education program

“*Clinicians and educators should consider having multiple components including workshops, one-to-one and group-based learning, mentoring and coaching for optimal program outcomes.*” [168] Over the years, multiple forms of presenting self-management education programs have been considered, including individual (nurse-led [169,170], educator-led [171,172], peer-led [173], pharmacist-led [174,175], or group-based [176,177], in-person [175,178], or remote(virtual) [179,180], as have concerns for patients with specific characteristics (youths vs elderly).

Similarly, consideration has also been given to such post-education supplements as social media [181], devices [182], other digital interventions [183], health coaches [184–188], and peer support [189,190]. We encourage our colleagues to address these options and concerns, especially the issue of training those who will teach/train our patients and their caregivers [191–194].

3. Application of these lessons to the self-management of epilepsy

3.1. Task-specific efficacy

The Epilepsy Self efficacy Scale (ESES) has 33 items that measure different aspects of efficacy in the self-management of epi-

lepsy [195,196]. Thirteen items have the word, ‘medication.’ Others include phrases such as “keep my epilepsy under control” and “avoid situations or activities that make my seizures worse.” Unlike other questionnaires that have a 4- or 5-point Likert scale, the ESES Likert scale has 11 points, ranging from 0, I cannot do at all, to 10, sure I can do.

The Seizure Self-Efficacy Scale for Children (SSES-C) has just 15 items [197]. Nine of them begin with the words, “I can manage my seizure condition.” The last of these concludes with, “because I can handle any problems it can cause.” The 5-point Likert scale ranges from “I’m very unsure I can do that” to “I’m very sure I can do that.”

3.2. Task-specific self-management

The Epilepsy Self-Management Scale (ESMS) is a 38-item scale that assesses epilepsy self-management practices [198]. The 38 items inquire about medication management (n = 10), information management (n = 8), safety management (n = 8), seizure management (n = 6), and lifestyle management (n = 6). A 5-point Likert scale ranges from never, to always. Twelve items are negatively worded (“I would go swimming alone”).

A recent meta-analysis of randomized controlled trials of the effectiveness of self-care interventions in chronic illness prompted the authors of the report to conclude that “self-care interventions are modestly effective in improving outcomes.” [199] Nevertheless, self-management education programs for epilepsy appear to increase the child’s or parent’s knowledge and understanding of epilepsy [200–211], medication adherence [202,208], reported ability to cope [204,206], child’s health-related quality of life [201,203,208–211], and parent’s (or other caregiver’s) self-perception of competence [200,201,203,208,212] known as self-efficacy [22,32]. These programs also reduce anxiety/fears [206,207,209–213], seizure recurrence [207,210], emergency dept visits [206,210], and school absences [206,210].

3.3. Seizure action plans and administration of ‘rescue’ medication

For most children, seizures are self-limited, and last less than a minute. For some, a single seizure can be followed by a second seizure. The term “seizure cluster” has been variously defined [214]. Currently, the accepted definition of a cluster is two seizures in a six-hour interval [215,216].

Compared to children who have single seizures, those who have seizure clusters are at increased risk of dying [217], and of “status epilepticus” (now defined as “a seizure with 5 minutes or more of continuous clinical and/or electrographic seizure activity or recurrent seizure activity without recovery between seizures.”) [218,219], which can result in cognition-perception limitations [220].

The International League Against Epilepsy (ILAE) [218] and the American Epilepsy Society (AES) [221] recommend treating a continuous tonic-clonic seizure after five minutes. Those who care for children with a prolonged seizure or a seizure cluster are encouraged to administer ‘rescue’ medications at home and to arrange for the same at school [222]. Unfortunately, these rescue medications are underutilized [223–229]. This may, in part, reflect the difficulties caregivers and school staff have recognizing and responding to clinical deterioration [230]. It might also reflect the lack of a seizure action plan [231,232], which should include “guidelines on how to respond during a seizure.” [233,234].

An assessment of how well parents would administer the rescue medication rectally found that 97 % of the 60 observations had at least one handling error, as did 58 % of the 24 assessments of administering via the buccal [235]. This prompted the authors to conclude that rescue administration, whether via the rectal or buccal route, is “a highly error-prone process.” Caregivers should “be

Table 1

Self-management education can be provided in different settings and by people with different perspectives and backgrounds.

Settings		
In-person [240]	Group [241,242]	
Remote [243,244]	mHealth [245–247]	
Presenter/follow-up support		
Educator [248,249]	Nurse [250,251]	Community health worker [252–254]
Medical assistant [255,256]	Team [257,258]	Case manager [259]
Health coach [260,261]	Peer coach [262,263]	Pharmacist [175,264]

regularly and intensively trained ...[using models or] dolls ... to identify high-risk handling errors.” [235] Others, too, have recommended “simulation with mannequins.” [236].

Indeed, families/caregivers would like to have seizure action plans that are individualized, and they would like to have more rescue therapy training than they were given [237]. Compared to caregivers who did not receive a seizure action plan, those who did were more comfortable regarding seizure care and missed fewer appointments [238].

3.4. What's missing

We believe training modules that can be shared/exported are needed [203,208,239]. These self-management education modules have been evaluated in Germany and Turkey, but we know of no comparable evaluation in a primarily English-speaking country. We want to encourage our most knowledgeable and capable colleagues to come together to decide how best to provide potentially modifiable, modular, self-management programs in English for children and adolescents with epilepsy, and their caregivers.

We are not aware of any sharable program that prepares caregivers to administer rescue medication comfortably.

We offer Table 1 as a set of options for consideration when planning, designing, implementing, and supporting a self-management education program.

3.5. The future

We envision a future in which the most knowledgeable design and test self-management education programs that are most likely to be successful. These educational/motivational programs will provide personalization options and allow modification. These programs will be worthy of sharing and will become standard until improved.

4. Conclusion

- Educating children and adolescents with epilepsy (and their caregivers) to manage their epilepsy well requires educational and motivational programs that are probably not yet available in English.
- Educators and health-behavior psychologists are likely to contribute to the design of the most appropriate self-management education programs.
- Because one size does not fit all, the best self-management education programs will allow personalization.
- Access to professionally-developed self-management education programs (with a menu of standardized curricula and options to individualize) is likely to be helpful to many people with epilepsy.

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