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Evaluation of emergency department-based seizure and epilepsy education: Exploring the need for early epilepsy self-management intervention

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Abstract

Many people with epilepsy (PWE) present to the emergency department setting with their first seizure and must wait weeks or months to be seen by a specialized epilepsy provider. The time period between presentation of first seizure and entry into specialized care can be extremely stressful and precarious for PWE and their families. In order to achieve optimal outcomes, epilepsy self-management should be initiated as soon as possible, including in the emergency department setting.

The purpose of this study was to review and evaluate existing epilepsy/seizure-related education materials provided to patients in the emergency room setting to determine the degree to which these materials prepare patients and their families for self-management of epilepsy, or potential epilepsy, during the interim between emergency department discharge and entry into specialized care. Twenty emergency department epilepsy/seizure patient discharge education materials were collected and evaluated using a rubric based on the framework of the Epilepsy Self-Management Scale (AESMMI). Materials were rated on a 0–3 scale based on the degree to which self-management education, resources, and skill building were included.

The mean score of materials reviewed was quite low at just 10.4, with a score of 33 possible. Also concerning is that the materials scored lowest in the domains of social support, stress management, and coping, all of which are extremely important areas for PWE, especially in the early phases of the disease when patients and families are adjusting. Findings highlight the need for development of robust self-management interventions tailored to PWE in the transition period from presentation of first seizure to entry to specialized care.

Keywords

Self-management; Epilepsy; Education; Quality of life; Emergency department

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Declaration of Competing Interest
We declare no conflict of interest.

1. Introduction

The global incidence of epilepsy is 5 million, with up to 71/100,000 people in the United States (US) affected by epilepsy on a yearly basis [1]. Many people with epilepsy (PWE) present to the emergency department for care following the first seizure; other reasons for presentation to the emergency department following first seizure include nonepilepsy-related causes such as alcohol withdrawal, head injury, drug toxicity, and blood sugar abnormalities [2]. Patients in whom epilepsy is suspected who are medically stable and not experiencing status epilepticus are typically discharged and referred to a neurologist, or to their primary care provider who then refers to a neurologist, for follow-up. For patients presenting to the emergency department who are evaluated as potentially having an epilepsy diagnosis, the time between emergency department discharge and seeing a neurologist can be months (>9 months) and can be even longer for PWE who are referred to a primary care provider who then refers to a neurologist [3]. For those patients referred to an epileptologist after initial evaluation by neurology, the wait can be even longer (an additional 4–5 weeks) [4]. The time between presentation of first seizure and entry into specialized care is precarious as PWE and their family members adjust to the diagnosis (or possible diagnosis) of chronic neurological disease, anti-seizure medications, lifestyle modifications, and many other changes (e.g., lack of ability to drive). Those newly diagnosed with epilepsy have described the first year with the disease as lifealtering and note that the time between first seizure and entry into specialized care is particularly stressful [5]. It is imperative that PWE and their loved ones be provided with proper education, resources, and early self-management skills at the time of first seizure presentation to prepare them to manage effectively while waiting for specialty care; these skills can also be honed during this time for use later in their disease course [6].

The Institute of Medicine [6] has stated that self-management is key to achieving desirable outcomes for PWE. Epilepsy self-management has been defined in various ways, but refers to a complex process through which PWE engage, at multiple levels of environments, to manage their epilepsy and associated symptoms and treatments on a daily basis; their self-management is fluid and changes based on current disease status or other life changes [7,8]. More specifically, epilepsy self-management occurs in the following domains: healthcare communication, treatment management, coping, social support, seizure tracking, wellness, and seizure response. Self-management skills in these areas are associated with better outcomes, including seizure frequency and quality of life [9]. Interventions that improve self-management are not merely educational, but provide patients with skill-building and problem-solving opportunities that can be applied to various situations [10]. Patients benefit when self-management education and skills are introduced early and are especially important in the interim between first seizure/diagnosis to specialty care [8].

A review of literature did not yield any studies in which emergency department-based self-management materials were reviewed. Rather, published self-management interventions for PWE are designed to be used after patients have entered epilepsy care. There is a gap in knowledge regarding the type(s) of self-management education and skillbuilding being provided to PWE who present with first seizure in emergency department settings.

The purpose of this study was to review and evaluate existing epilepsy/seizure-related education materials provided to patients in the emergency room setting to determine the degree to which these materials prepare patients and their families for self-management of epilepsy, or potential epilepsy, during the interim between emergency department discharge and entry into specialized care. While patients may experience seizures not related to epilepsy (e.g., alcohol withdrawal), our focus was on materials provided to patients whose seizure(s) are thought to be associated with epilepsy. The results of this study can be used to inform development of an epilepsy self-management education and skill-building intervention tailored to patients in the vulnerable, transitional phase between presentation of first seizure and entry into specialized care.

2. Materials and methods

Twenty emergency department epilepsy/seizure patient discharge education materials were collected from health care institutions throughout the US. These materials were collected via the investigators requesting copies of emergency room-based discharge education materials from the facilities. We aimed to have a geographically representative pool of materials, requesting materials from hospitals from all major regions of the US (Midwest, Northwest, West, Southern, and Northeast). We requested materials from both community hospitals and academic institutions. We specifically requested materials given to patients with new-onset seizures, and not those with an established epilepsy diagnosis. All materials were evaluated using a rubric based on the framework of the Epilepsy Self-Management Scale (AESMMI) [11], which measures epilepsy self-management in 11 psychometrically tested domains. Materials were rated on a 0–3 scale based on the degree to which self-management education, resources, and skill building were included, with 0 being not included and 3 being included with details, skills, examples, and resources. The AESMMI is a clinical tool designed to measure the degree to which a person participates in important epilepsy self-management behaviors. We did not use the tool in this way. Rather, we used the psychometrically tested areas of self-management and conceptual definitions of those areas from the AESMMI to determine the degree to which these concepts were reflected in each of the education materials. We chose this tool as the framework for the evaluation rubric due to its extensive development and subsequent psychometric testing, making it a robust representation of the important aspects of epilepsy self-management, which is associated with better epilepsy-related outcomes [11]. Education materials that reflect and support the concepts in the AESMMI are thus more likely to influence self-management in PWE. Materials were further evaluated regarding the degree to which they included aspects important in the transition time between first seizure presentation and entry into specialized care (Web-based epilepsy resources, concrete steps for a neuro referral, explanation and definition of epilepsy/seizures, and concrete steps to follow in the event of a seizure) (See Table 1). Two reviewers (W.M. and R.W.) independently reviewed and scored materials based on the conceptual definitions of each domain in the AESMMI [11]. In the event of reviewer disagreement, the reviewers discussed their scores and came to a consensus about the score. Each set of materials was assigned a total score based on the combination of scores in all domains. Descriptive statistics were performed to determine mean scores and ranges for each set of materials in each of the 11 domains. Frequencies of the presence of

additional content (Web-based resources, etc.) were calculated using SPSS version 27. The institutional IRB determined this study was exempt.

3. Results

The majority of materials (18) were geared generally toward PWE, while two were specific to children. Thirteen of the materials were from community hospitals, while seven were from academic medical centers. Materials represented hospitals in the Midwest (5), Northwest (4), West (2), Southern (4), and Northeastern (5) regions of the US. Out of a maximum score of 33, the mean total score for the materials was 10.4, with a range of 1–20. The mean score for materials from academic centers was 10.9, while that of materials from community hospitals was 10.0. Table 2 displays descriptive statistics per domain evaluated, as well as frequencies of additional content. The domains of stress management and coping were the least well-incorporated into each of the materials, while seizure response was best incorporated. Ten of the 11 domains evaluated had mean scores below 2, and five had mean scores below 1. The majority (95%) of materials reflected an explanation and/or definition of epilepsy and seizures, while 75% included concrete instructions for what to do in case of a seizure. Only 15% of materials included information about Web-based resources, such as the Epilepsy Foundation Website.

4. Discussion

Most PWE present with their first seizure in the emergency department setting and are discharged for follow-up care with a neurologist, which does not happen immediately. During this waiting period, which could last many weeks or even months, patients and their families face significant epilepsy-related challenges; both PWE and their families need support, resources, and self-management skill building during this time period [5,8], especially given that early implementation of self-management skill building is vitally important in any chronic disease [8]. Because the literature lacks any studies in which early and transitional epilepsy self-management education has been studied, we initiated study in this area by reviewing a sample of emergency room-based epilepsy and seizure education materials to determine the degree to which they are aligned with the self-management needs of PWE in the transition phase of diagnosis.

Findings of this study highlight the need for development of robust self-management interventions tailored to PWE in the transition period between presentation of first seizure and entry to specialized care. The mean score of materials reviewed was quite low at just 10.4, with a score of 33 possible. Also concerning is that the materials scored lowest in the domains of social support, stress management, and coping, all of which are extremely important areas for PWE, especially in the early phases of the disease when patients and families are adjusting. Onset of a chronic disease or experience of even one seizure is very stressful, and stress is often a trigger for seizures. Materials provided to PWE and their families in the emergency department setting should thus include education, skillbuilding, and resources aimed at improving social support, stress management, and coping.

Materials scored highest related to seizure safety and first aid, which is unsurprising given the emergency department setting and the nature of the goals of the emergency department. However, none of the materials reviewed included any concrete steps for contacting the next provider, whether it be a PCP, neurologist, or epileptologist. While it is possible this could be given to patients separately, outside of their seizure-related materials, ensuring that patients and families have this information is vital. The US healthcare system is extremely complex, with entry into care being a significant obstacle for many [12]. Lack of clear, concrete directions about next steps could worsen this obstacle for people with a possible diagnosis of epilepsy. Based on the materials reviewed, we could not adequately evaluate the degree to which patients and families were provided with concrete steps for neurology referral.

The emergency department is not an environment that lends itself to the delivery of well-developed, patient-centered self-management interventions. The emergency department is hectic, fast-paced, and a triage/initial treatment area for patients; it is not designed for in-depth patient education or training. It is thus not practical to consider developing self-management interventions for those in the transition phase of an epilepsy diagnosis that is designed to be implemented in the emergency department environment. Rather, the use of theory-based, patient-centered interventions tailored to this transition time can be developed in a Web-based, sustainable, scalable format; such interventions could be *provided* in the emergency department to patients with a referral to specialized epilepsy care without emergency department nurses, physicians, and other providers being responsible for their full implementation.

Web-based self-management interventions have been used with success in epilepsy and other chronic diseases [13–15], and this format has multiple advantages: it is sustainable, scalable, easily updated, and user friendly. Other interventions have been successful using this Web-based format with the epilepsy population. For example, the Personalized Internet Assisted Underserved Self-Management of Epilepsy (PAUSE) intervention, delivered to underserved populations via the Web, has been shown to significantly improve both self-management and quality of life in PWE [16]. Similarly, Web Epilepsy Awareness, Support, and Education (WebEASE), a completely online intervention, has improved both self-efficacy and self-management in PWE, while also demonstrating improvements in medication adherence, stress management, and epilepsy knowledge [17]. A Web-based intervention aimed at providing initial self-management skills and epilepsy-related resources to patients and families in the transition phase of epilepsy diagnosis could be of great benefit. Based on our results, there is an urgent need for such an intervention; our findings can be used to directly inform the development of this type of intervention. This intervention should be developed to reflect important areas of self-management, such as those depicted in the well-tested AESMMI [11], and can be provided to patients in the emergency department setting and accessed by them throughout their disease course, including the vulnerable time between seizure presentation in an emergency department setting and entry into specialized care.

The current study is not without limitations. First, we used convenience sampling to request the emergency room materials from hospitals throughout the US. A future study on this

topic should gather a sample of education materials that could be confirmed as representative of all regions and types of hospitals. For example, we did not evaluate materials from any extremely rural hospitals, which should be included in a follow-up study. Second, our sample size of materials was also modest. A follow-up study would benefit from inclusion of a larger number of education materials.

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Table 1

Education evaluation rubric.

	0	1	2	3
Self-Management Content				
SM: treatment management				
SM: healthcare communication				
SM: coping				
SM: social support				
SM: seizure tracking				
SM: wellness				
SM: seizure response				
SM: safety				
SM: medication adherence				
SM: proactivity				
SM: stress management				
Other Content				
	YES	NO		
Web-based epilepsy resources				
Concrete steps for neuro referral				
Explanation/definition of epilepsy/seizures				
Concrete instructions for what to do in case of seizure				

0 = not included.

1 = Included but without details, skills, examples, or resources.

2 = Included with details but lacking skills, examples, or resources.

3 = Included with details, skills, examples, and resources.

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Table 2

Domain scores (minimum possible = 0, maximum possible = 3).

Domain	Mean (range)
SM: treatment management	1 (0–2)
SM: healthcare communication	1.57 (0–2)
SM: coping	0.29 (0–1)
SM: social support	0.43 (0–1)
SM: seizure tracking	1.4 (0–2)
SM: wellness	0.5 (0–3)
SM: seizure response	2 (0–3)
SM: safety	1.7 (0–3)
SM: medication adherence	1 (0–3)
SM: proactivity	0.86 (0–3)
SM: stress management	0.29 (0–2)
Frequency of Presence of Other Content (out of 20)	
Web-based epilepsy resources	3 (15%)
Concrete steps for neuro referral	0 (0%)
Explanation/definition of epilepsy/seizures	19 (95%)
Concrete instructions for what to do in case of seizure	15 (75%)

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