



## Perspectives on seizure clusters: Gaps in lexicon, awareness, and treatment



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### ABSTRACT

Seizure clusters in epilepsy can result in serious outcomes such as missed work or school, postictal psychosis, emergency room visits, or hospitalizations, and yet they are often not included in discussions between health-care professionals (HCPs) and their patients. The purpose of this paper was to describe and compare consumer (patient and caregivers) and professional understanding of seizure clusters and to describe how consumers and HCPs communicate regarding seizure clusters. We reviewed social media discussion sites to explore consumers' understanding of seizure clusters. We analyzed professional (medical) literature to explore the HCPs' understanding of seizure clusters. Major themes were revealed in one or both groups, including: communication about diagnosis; frequency, duration, and time frame; seizure type and pattern; severity; and self-management. When comparing discussions of professionals and consumers, both consumers and clinicians discussed the definition of seizure clusters. Discussions of HCPs were understandably clinically focused, and consumer discussions reflected the experience of seizure clusters; however, both groups struggled with a common lexicon. Seizure cluster events remain a problem associated with serious outcomes. Herein, we outline the lack of a common understanding and recommend the development of a common lexicon to improve communication regarding seizure clusters.

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### 1. Introduction

The Centers for Disease Control and Prevention estimates that 5.1 million people in the United States have had a diagnosis of epilepsy or a seizure disorder [1]. Epilepsy is an episodic neurological disorder characterized by the spontaneous and unpredictable manifestation of seizures [2]. The unpredictability of seizures, a hallmark of epilepsy, has led many investigators to explore ways to identify and track patterns of seizure occurrence. Haut et al. reported that in addition to overall seizure frequency, the temporal distribution of seizures as either random or predictable events, including clustering, has clinical relevance [3,4]. For instance, a patient who experiences one or two seizures per year may be viewed as having fairly well-controlled disease. However, if the patient experiences a cluster of seizures on

each of those days that require intervention to abort, the condition becomes more serious from both the consumer (includes both patient and caregiver) and health-care professional (HCP) perspectives.

Recognizing patterns of seizure occurrence may be helpful in preventing untoward consequences of seizures that occur in series because seizure clusters lead to frequent emergency rooms visits or hospitalizations [4,5]. When left unchecked, seizure clusters may be associated with postictal psychosis or can potentially proceed to status epilepticus [4,6], a life-threatening neurologic disorder. Increased seizure occurrence in one day is likely to lead to other distressing events, such as lost work, missed school days, and other physical symptoms [7,8]. Despite the potential for poor outcomes in people with epilepsy who also experience seizure clusters, there has been limited research related to seizure clusters or their outcomes.

Seizure clusters, acute repetitive seizures, and serial seizures are not part of the International League Against Epilepsy (ILAE) Commission on Classification and Terminology [9,10]. Interest in testing

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potential treatments for seizure clusters resulted in the US Food and Drug Administration (FDA) convening an advisory panel to define these episodes. The published report from the Peripheral and Central Nervous System Drugs Advisory Committee [11] offered a conceptual definition that was later translated into an operational definition used in clinical trials to evaluate rescue treatments. The conceptual definition offered by the committee stated that acute repetitive seizures are a recognized chronobiological entity that can be defined as a form of seizures that are severe; are a predictable component of the patient's seizure disorder; are historically distinct from the patient's other seizures in type, frequency, severity, or duration; have an onset that is easily recognized by the family and physician; demonstrate patient recovery between seizures; have a consistent component (such as an aura, prodrome, or characteristic single or multiple seizures) that is predictably and temporally linked to subsequent seizures; and are a constellation of seizures variously referred to as cluster, acute repetitive, multiple recurrent, serial, or crescendo seizures.

Building upon the conceptual work of the FDA Advisory Committee on seizure clusters, a consensus statement was provided to offer a simplified operational definition for use in clinical trials. Accordingly, the statement indicated that seizure clusters can occur across multiple seizure types, are a recognizable entity, and contain the following key features: a form of seizure that is severe, has a recognizable onset, is distinct from the patient's usual seizure type and frequency, and demonstrates recovery between seizures [12]. Two decades later, however, the definition of seizure clusters remains unclear.

Most recently, Pellock et al. [13] and Haut [4] reviewed the published literature and reported a knowledge gap in defining seizure clusters. Health-care professionals have been using inconsistent terminology to describe these events, including terms such as acute repetitive seizures and cyclical, serial, repetitive, crescendo, and recurrent seizures. To provide appropriate abortive therapy, recognition of seizure clusters is necessary, but the consumers' ability to communicate their experience with seizure clusters to an HCP is challenging because of the lack of clarity surrounding the definition. Further, accurate recognition depends on the ability of consumers and professionals to recognize seizure patterns, including those that are distinct from other seizures in terms of type, frequency, severity, or duration [14]. Lack of recognition of seizure clusters and the subsequent failure of consumers' communication of their existence hinder both accurate seizure tracking and consumers' timely receipt of abortive therapy.

Based on a review of the medical literature and an analysis of social media, the purpose of this paper was to describe and compare consumer and professional understanding of seizure clusters, and to describe how consumers and HCPs communicate regarding seizure clusters.

## 2. Methods

### 2.1. Social media review

Internet discussions were chosen to better describe consumer understanding of seizure clusters. Using this method allowed for a large search of existing data from public websites that reveal real-life descriptions. Websites offering consumer dialogues, such as community forums, were reviewed. Only a few websites provided public community forums allowing users to share experiences and perspectives. Websites of the Epilepsy Foundation, the Lennox–Gastaut Syndrome Foundation, the Tuberous Sclerosis Alliance, the Dravet Syndrome Foundation, Seizure Tracker®, and Patients Like Me were reviewed from August to September 2014 and from December 2014 to January 2015 for accessibility, availability, and the number of posts by consumers pertaining to seizure clusters. The website of the Epilepsy Foundation, [www.epilepsy.com](http://www.epilepsy.com), was selected as the sole source for review of consumer perspectives for further quantitative analysis because at the time of the review, the other patient sites did not offer a sufficient number of posts on the topic to be included. The website of the Epilepsy Foundation had the largest community forum devoted to epilepsy that contained posts about seizure clusters. In addition, this site was the most frequently used for posts referring to seizure clusters using a Google search.

In 2014, [www.epilepsy.com](http://www.epilepsy.com) had 5.5 million unique visitors, with approximately 24% of users visiting its community forums. The majority of users live in the United States (3.5 million unique users), with large representations from other mainly English-speaking countries, such as the United Kingdom (500,000), Canada (280,000), and India (200,000). The [epilepsy.com/connect](http://www.epilepsy.com/connect) section includes a real-time chat room and community forums, where people can post questions, challenges, or personal stories. Registered users of this website respond to each other and provide a rich source of users' perspectives [15].

Using the search engine, the community forums of [epilepsy.com](http://www.epilepsy.com) were examined for posts with the following terms: “acute repetitive seizures”, “ARS”, “acute seizures”, “bouts of seizures”, “clusters”, “cluster seizures”, “Ativan”, and “Diastat”. Table 1 shows the number of posts relating to each search term. Posts were reviewed for content specifically relating to how people define or describe seizure clusters and their perspectives. Ten pages of results for each search term were reviewed. This process included both original posts and any responses to the original posts. The number of responses per search term reviewed ranged from 100 to 250 posts per term. The search terms “clusters”, “cluster seizures”, and “seizure clusters” appeared to be the most consumer-friendly terms based on the relevance of posts found using these terms.

**Table 1**  
Number of responses per search term [15].

Search term	Number of posts	Comments
Acute repetitive seizures	>17,000	<ul style="list-style-type: none"> <li>• High number of posts related to the use of the term “seizures”</li> <li>• Posts that relate to ARS discuss repetitive movements in seizures or acute illnesses that could lead to seizures</li> <li>• Majority unrelated to topic or share experiences only and were excluded</li> <li>• Some relate to community talks or marketing and were excluded</li> </ul>
ARS	240	<ul style="list-style-type: none"> <li>• Majority link to unrelated articles</li> <li>• Most that are relevant share personal experiences</li> </ul>
Clusters, cluster seizures	>16,000	<ul style="list-style-type: none"> <li>• Few ask questions about causes, prevention, or certain treatments, responses not appropriate or correct</li> <li>• Most frequently used term that pertained to topic area</li> <li>• When the term cluster was used alone, usually referred to headaches or migraines and were excluded</li> </ul>
Ativan or lorazepam	>700	<ul style="list-style-type: none"> <li>• Some comments pertaining to doctors not willing to prescribe</li> </ul>
Rectal diazepam	438	<ul style="list-style-type: none"> <li>• Posts included use of diazepam in any form, experiences with rectal diazepam, difficulties affording or using medication in schools, experiences and questions about status epilepticus or cluster</li> </ul>
Diastat	282	<ul style="list-style-type: none"> <li>• Questions or experiences with Diastat, seizure emergencies</li> </ul>

ARS = acute repetitive seizures.

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