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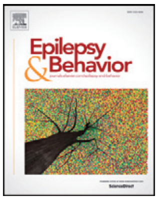

On status epilepticus and pins: A systematic content analysis

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ABSTRACT

Status epilepticus (SE) can be defined as abnormally prolonged, persistent, or recurrent clinical and/or electrographic epileptic activity and, as such, is a challenging medical emergency requiring an aggressive treatment aimed at promptly terminating the seizures. It imposes a relevant clinical burden, both in terms of comorbidity and mortality. In the era of the Web 2.0, most people search the Web to obtain SE-related information. The current investigation aimed at qualitatively characterizing the pins related to SE: Pinterest, "the world's catalog of ideas", is a visual social networking site that enables users to freely upload visual material, to bookmark, and to share it (*repin*). Using SE as a keyword, 192 pins were extracted and analyzed on the basis of their content. Fifty-five were found to meet the inclusion criteria. Fifty-six point four percent of the pins reported at least one cause of SE, the most quoted of which being remote brain injuries (47.3% of the pins); 54.5% and 45.5% of the included pins reported SE symptoms and diagnosis, respectively; 72.7% and 40.0% of pins focused on SE treatment and on prognosis, respectively; and 50.9%, 30.9%, and 40.0% of the pins were intended for physicians, medical/nursing students, and lay people, respectively. Only 12.7% of pins were patient-centered and devoted to fund-raising and advocacy. In the field of neurological diseases, Pinterest, despite being a "pinstructive" tool, is too much overlooked and underused for advocacy purposes. Healthcare workers and stakeholders should be aware of the opportunities offered by Pinterest and exploit this visual social networking site for raising awareness of the life-threatening condition of SE, promoting fund-raising campaigns.

1. Introduction

Status epilepticus (SE) is characterized by abnormally prolonged, persistent, or recurrent clinical and/or electrographic epileptic activity and, as such, is a challenging medical emergency requiring an aggressive treatment aimed at promptly terminating the seizures [1–3]. Its incidence ranges from 10 to 41 cases per 100,000 people, with peaks in children and the elderly [4], and the clinical burden, both in terms of comorbidity and mortality, is relevant [5]. It is a heterogeneous condition and has multiple underlying etiologies. Causes include cerebrovascular or infectious diseases, encephalitis and encephalopathies, neurodegenerative disorders, previous epileptic episodes, low antiepileptic drug levels, alcoholism, drug intoxication or abrupt withdrawal, sleep deprivation, tumors, autoimmune disorders, and metabolic impairments, among others [6]. The treatment of SE is complex and relies on a staged approach [7], with benzodiazepines representing a first-line therapeutic option. In the case of their failure, phenytoin/fosphenytoin, valproic acid, levetiracetam, lacosamide, anesthetics, or barbiturates can be administered [7]. Nonpharmacological management options could be considered for super-refractory cases of SE [8,9], although supporting scientific evidence is poor and scarce.

People increasingly surf the Internet looking for health-related information and use social networks for exchanging information [10,11], leveraging the recent technological achievements. Specifically concerning epilepsy, McNeil et al. [12] conducted a study aimed to explore the way patients suffering from seizures socialize through Twitter. An exploratory 48-hour Twitter search was performed, and 1720 seizure-related tweets were classified according to their content, elaborating a classification scheme that was exploited in a subsequent 7-consecutive-day study in April 2011. Authors analyzed a body of 10,662 tweets and found that 32% of the posts were metaphorical, with only 12% of the posted material being informative and 9% being frankly

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ridiculous. Personal accounts as thematic category accounted for 31% of the online material, whereas 41% of tweets had an explicitly derogatory and highly stigmatizing content. According to the researchers, Twitter, as a social networking site, could be useful in disseminating seizure-related information, but it is sometimes utilized to fuel misconception and stigma, favoring negative attitudes and beliefs towards epilepsy.

Vaidya-Mathur and colleagues [13] performed a study among 141 patients diagnosed with psychogenic nonepileptic seizures (PNES), focusing on the way they socialize with each other and with other people. Patients were administered an *ad hoc* questionnaire designed to assess their preferences in socialization practices, frequency of interpersonal contact, use of social media and networks, and perceived barriers and obstacles to socialization. Surprisingly and contrary to what is commonly thought, the authors found that patients with PNES socialize actively and in a considerable manner. Facebook represented their preferred social networking site. This finding was replicated by a survey carried out by Myers and collaborators [14], with a sample of 1320 consecutive persons with epilepsy.

Myers et al. [15] studied how PNES is portrayed online and found that PNES-related information disseminated by different social networks and sites (namely, Google, Twitter, YouTube, and Instagram) was rich in both professional and patient content, being rather accurate. They concluded that professionals could benefit from social networks in order to reach their audience more effectively.

Lo and coworkers [16] studied the way a video-sharing Web site, such as YouTube, portrays epilepsy. They found that the top 10 videos were being viewed 3200 times daily. Real-life videos were little informative, while videos providing information were characterized by neutral or negative empathy. As such, the authors concluded that YouTube could counteract misinformation and stigma concerning epilepsy.

Brigo et al. [17] exploited a tool that tracks and monitors search queries (Google Trends, GT) and noticed three peaks in epilepsy-related Web searches, coinciding with the public disclosure of celebrities having seizures. The authors demonstrated that most people use search engines to look for terms related to epilepsy to aid self-diagnosis. The authors concluded that fears and worries about epileptic seizures and news stories reporting celebrities with epilepsy seem to be major drivers of the digital behavior.

Brigo and coworkers [18] explored the digital activities related to the Wikipedia page dedicated to epilepsy. They observed a peak in accesses to Wikipedia coinciding with the news of a celebrity having seizure episodes.

All these findings, taken together, seem to confirm the statement by Meng and collaborators [19] that epilepsy is the neurological disorder with the highest media usage: Facebook has, indeed, an impressive number of pages (840 accounts) and users (3 million), higher than Twitter (137 accounts and 274,663 users). Accounts and users are generally foundation and support groups. Media usage has significantly increased throughout the years. Concerning the qualitative analysis of the online material (which included a body of 403 posts and tweets) informing on therapeutics and treatment or providing proper information, correcting common misconceptions and prejudices accounted for 48% of the epilepsy-related posts and tweets, with surgery being mentioned only in 1% of all material.

Regarding SE in particular, we previously demonstrated that most people search the Web to obtain SE-related information [20,21]. Brigo and Trinka [20] and Bragazzi and colleagues utilized [21] a tool that tracks and monitors search queries to explore SE-related digital activities.

The current investigation aimed at qualitatively characterizing the pins related to SE. Among the unique opportunities of the highly dynamic and participatory Web 2.0, Pinterest is a visual social networking site that enables users to freely upload visual material (such as digital images or videos), to collect it on the board (*pin*), to bookmark, to comment on it, and to share it (*repin*). Pinterest, self-defined as “the world's catalog of ideas”, was developed and launched by Evan Sharp, Ben Silbermann, and Paul Sciarra as a closed beta site in March 2010, gained significantly increasing public and media attention in late 2011, and is currently the third most popular social network in the USA behind Facebook and Twitter and ahead of LinkedIn and Google + [22–24].

In the extant scientific literature, scholars have analyzed Pinterest-related activities concerning vaccination [25,26], eating disorders [27–29], concussions [30], dermatological disorders [31,32], infectious diseases [33], and lifestyles such as smoking [34], among others. There is, however, a dearth of studies focusing on the relationship between Pinterest and neurological disorders. Given the increasing volume of SE-related Web activities [20,21] and the popularity of Pinterest [22–24], the current study aimed at systematically describing and analyzing the available pins related to SE.

2. Material and methods

Pinterest was systematically mined using “status epilepticus” as keyword. All pins were downloaded using the Pinterest RESTful Application Programming Interface (API) and analyzed. Pins were characterized on the basis of content (causes of SE, symptoms of SE, prognosis of SE, management and treatment of SE, SE patient-centered, SE onset age), provider, source, tone (neutral/informative, positive, negative), and purpose (clinical, educational, and advocacy).

Two reviewers (GA, GC) independently performed the analysis. Eventual cases of disagreement were solved through consensus or involving a third reviewer expert in neurology and specifically in SE (FB) and an expert in biostatistics and methodology research (NLB).

For further details, the reader is referred to Table 1.

Data were presented as absolute figures and as percentages.

Table 1
Overview of the status epilepticus-related search and content analysis strategy used in the current study.

Items	Details
Pins collection and inclusion	
Used keyword(s)	Status epilepticus
Language filter	None applied
Location filter	None applied
Time filter	None applied
Exclusion criteria	Pins unrelated or nonpertinent with status epilepticus; pins with not enough material for a full review and content analysis
Pins description and analysis	
Content of pins	Causes, symptoms, diagnosis, prognosis, management and treatment, patient-centered content
Level of accuracy and scientific evidence of pins	Scientific evidence-based versus not scientific evidence-based
Provider of pins	Academic provider (scientific societies, scholars, or researchers), commercial provider (profit organizations, pharmaceutical industries), institutional provider (local health unities, hospitals, health authorities, Health Minister), physicians, medical/nursing students, patients organizations or patients, epilepsy organizations and foundations
Source of pins	Academic source (content like scholarly articles, university lectures or presentation), news, blogs and forums, search engines (such as Google, Yahoo), encyclopedia or dictionary (such as Wikipedia), social networks (YouTube)
Intended/designed target of pins	Physician/medical or nursing student, patient, both
Purpose of pins	Clinical, educational, advocacy
Tone of pins	Neutral/informative, positive, negative