



## The presentation of seizures and epilepsy in YouTube videos

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### ABSTRACT

We evaluated videos on the social media website, YouTube, containing references to seizures and epilepsy. Of 100 videos, 28% contained an ictal event, and 25% featured a person with epilepsy recounting his or her personal experience. Videos most commonly fell into categories of Personal Experience/Anecdotal (44%) and Informative/Educational (38%). Fifty-one percent of videos were judged as accurate, and 9% were inaccurate; accuracy was not an applicable attribute in the remainder of the videos. Eighty-five percent of videos were sympathetic towards those with seizures or epilepsy, 9% were neutral, and only 6% were derogatory. Ninety-eight percent of videos were thought to be easily understood by a layperson. The user-generated content on YouTube appears to be more sympathetic and accurate compared to other forms of mass media. We are optimistic that with a shifting ratio towards sympathetic content about epilepsy, the amount of stigma towards epilepsy and seizures will continue to lessen.

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### 1. Introduction

Seizures and epilepsy have been sources of drama in the entertainment media for centuries. In early literature, epilepsy was frequently associated with evil. In Milton's *Paradise Lost* from the 17th century, the consequences of leading an unchaste life included "Convulsions, Epilepsies", and Shakespeare associated epilepsy with madness [1]. In contemporary fiction, portrayal of epilepsy has been less negative, frequently describing characters coping with their epilepsy in a sympathetic manner, though the response to their illness is variable, and their fate may be a tragic one [2]. In popular music, madness, horror, and lunacy are found to be associated with epilepsy in song lyrics, though associations with sexual ecstasy and dance euphoria are also present [3].

Baxendale evaluated 62 films featuring seizures or characters with epilepsy and found that, in the newer medium of film, examples of "ancient beliefs" surrounding epilepsy continued to be present including "demonic or divine possession, genius, lunacy, delinquency, and general otherness" [4]. Kerson and Kerson compiled clips of over 200 portrayals of seizures from films and television episodes and noted seven ways in which seizures were used to create drama including evoking specific emotional reactions in the audience and enhancing the voyeuristic experience of the film audience as they watch the

actions of characters watching the actions of those having seizures [5]. The authors make the point that, because of the nature of seizures with their association with loss of control and awareness, seizures will continue to be used by writers and directors for dramatic purposes and will continue to "enthrall" audiences.

One might expect journalistic sources, such as magazines and newspapers, to report a more balanced and less dramatized view of events. This has not been the case, however, with 31% of stories containing errors "of scientific inaccuracy (14%), severe exaggeration of treatment benefits (9%), and exaggerated risks of seizures or bias toward persons with epilepsy (5%)" [6]. A review of nine newspapers focusing on 11 neurologic conditions found that 21% of all stories contained stigmatizing language. Of the 11 neurologic conditions including amyotrophic lateral sclerosis, Alzheimer disease, brain tumors, Creutzfeldt–Jakob disease, dementia, epilepsy, migraine, multiple sclerosis, Parkinson disease, stroke, and traumatic brain injury, epilepsy had the largest percentage of stories judged to be stigmatizing (30%) [7].

The advent of the Internet has given rise to several additional platforms for the depiction of seizures. Social media websites such as Twitter and YouTube differ from the aforementioned forms of media because their user-generated content model allows persons with epilepsy, as well as the greater public, to create and directly comment on seizure-related content. Even in traditional media, content generated by authors who were suspected to have suffered from epilepsy themselves was relatively more realistic in depictions of seizures. Wolf, in his review of the clinical semiologies of seizures described in the literature, listed many examples of authors with epilepsy who described

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seizures accurately and in great detail in their writings [8]. The works of these authors included not only the more commonly recognized generalized convulsion but also auras and complex partial seizures, resulting in more balanced portrayals.

However, recent reports about seizure-related content on social media websites have not been optimistic. McNeil et al. conducted a qualitative content analysis on Twitter status updates (“tweets”), searching for variations on the word “seizure.” They classified seizure-related tweets under the categories of Metaphorical, Informative, Joke/Ridicule, Personal Accounts, Advice-Seeking, Opinion, and Miscellaneous [9]. They found that “41% of ‘seizure(s)’ tweets were either Metaphorical or Joke/Ridicule themes, which were generally derogatory in content.”

YouTube, which allows individuals to easily provide personal video accounts of their seizure experience to large audiences, may become an important source from which the lay public will draw their conceptions of epilepsy. Lo et al. performed a study in which they searched for “seizures” and “epilepsy” on YouTube and then analyzed all the comments on the top ten video “hits” [10]. They coded the comments as derogatory, neutral, or sympathetic as well as information-seeking, neutral, or information-providing. They found that “real life” epilepsy videos had the most favorable empathetic scoring while informative videos had neutral or negative empathy scores and concluded that “video-sharing websites, like YouTube, have the potential to remediate the significant misinformation and persistent stigma surrounding epilepsy.”

In our present study, we expanded upon the research of Lo et al. [10] by classifying YouTube video content rather than the comments about the videos. We used categories similar to those created by McNeil et al. [9] to classify tweets and also to judge the accuracy, level of sympathy, and difficulty level of the videos. We hypothesized that, because YouTube allows user-generated content, and in particular, allows those with epilepsy to share their personal accounts, the content on YouTube may be more sympathetic towards those with epilepsy in comparison to traditional media.

## 2. Methods

### 2.1. Study sample and selection

Using the same search protocol as Lo et al. [10], a single search was performed in YouTube in April 2012 using the terms “epilepsy” and “seizures,” with the results sorted by relevance. Although the algorithm for results sorting by relevance is not stated on the YouTube website, this sorting method was used in this study because it is the default sorting method for YouTube users. In addition, when this search was performed with videos sorted by view count, the results were less relevant; the top hits consisted of popular music videos containing warnings about the risk of triggering photosensitive epilepsy upon their viewing.

A new account was created in YouTube on a computer that was signed out of all related services and had a cleared web browser and Flash Player cache and removed cookies so that the search would not be biased in any way. The top 100 videos from the above search were added to a playlist such that the same list of videos could be reviewed by both reviewers in the same sequence.

For the purposes of this study, videos were excluded and not numbered among the top 100 results if the video was not primarily in the English language; used a definition of the word “seizure” that did not pertain to the phenomenon of sudden, transient episodes suggestive of hypersynchronous cerebral activity (e.g., the “seizure” of cocaine shipments by authorities); or used the word “seizure” in such a manner that the intended meaning is unclear (e.g., an instrumental free-form song entitled “Seizure” with no videographic basis from which the intended meaning could be inferred).

### 2.2. General information extracted from videos

The top 100 videos were then analyzed in order. For each video, collected data included the view count, inclusion or absence of specific events characterized as seizures, category of the central figure of the video (adult human, human child, animal, or inanimate), whether the central figure was the uploader of the video or not (based on the video description), and category of video production as amateur or professional. No judgment was made about whether events appeared to be epileptic or nonepileptic in nature based on the fact that the general public would be unlikely to make that differentiation upon viewing the video.

The same definition of amateur versus professional video was applied from the Lo et al. study [10]: “Amateur videos were those in which the individuals in the videos were poorly lit; the filming was obviously done with a home video camera; and there was ‘camera shake.’ On the other hand, professional videos appeared to be filmed with high-resolution video cameras mounted on stable tripods, were professionally staged in terms of lighting and make-up, and had more elaborate sets for filming.”

### 2.3. Video classification

Then, two reviewers (V.W. and M.S., both clinical neurophysiology fellows with a specific interest in epilepsy at the time of video review) independently analyzed the 100 videos on two separate days in April 2012. The reviewers independently assigned each video to one of eight categories based on video content with the use of the video description if necessary (Table 1). These categories were adapted from those used by the McNeil et al. study [9]. Each video was assigned to only one category.

The two independent reviewers also rated each video on a 5-point scale regarding the accuracy of information regarding seizures or epilepsy (Accuracy Scale) and the overall positive (sympathetic) or negative (derogatory) impression suggested by the video regarding seizures or epilepsy (Sympathy Scale), as well as the difficulty level of the video on a 4-point scale (Difficulty Scale). With the Accuracy Scale, if the video contained no educational information or contained only anecdotal information (e.g., “valproate made me see red spots”), then it was rated 0. If the information was inaccurate, then the rating was  $-1$  (slightly inaccurate) or  $-2$  (very inaccurate), whereas accurate information was rated  $+1$  or  $+2$ .

With the Sympathy Scale, the videos were rated based on whether the video was sympathetic towards persons with epilepsy, with 0 as neutral,  $+1$  or  $+2$  as sympathetic, and  $-1$  or  $-2$  as unsympathetic or derogatory.

Lastly, the difficulty level was rated on a 0-to-3 scale. A rating of 0 was used for videos that were not directly conveying any information

**Table 1**  
Video classification categories.

Category	Description
Personal Experience/ Anecdotal	An account of someone who has seizures or epilepsy; may or may not be a personal account
Advice-Seeking	A video posted for the purpose of asking the YouTube audience for their advice
Informative/Educational	An educational video posted expressly to convey information about seizures and epilepsy
Advertisement	A video posted for advertising medications, devices, procedures, clinical trials, or epilepsy centers
Opinion	A video posted that voices an opinion for the purpose of persuading others
Entertainment/Popular Culture	A video that uses the concepts of seizures or epilepsy as sources of entertainment
Joke/Ridicule	A video that uses the concepts of seizures or epilepsy as the source of a joke or ridicule
Oblique Reference	A video in which there is only a peripheral reference to seizures or epilepsy

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