

The Presence of Epilepsy on Social Media Platforms - A Systematic Review of Cross Sectional Studies

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Abstract

On December 18th, 2024, 24 papers evaluating social media posts concerning epilepsy and people living with it were found with a search on Web of Science and PubMed. One paper referred to Facebook, two to Instagram, one to Pinterest, two to Reddit, two to TikTok, three to Twitter 'X', and 10 to YouTube. In three papers, the evaluation was not restricted to a special platform but rather to the language of the posts. Misinformation was often found. Perhaps the highest amount of misinformation was found on TikTok, with 55% of videos claiming to show an epileptic seizure rated as showing a psychogenic non-epileptic seizure. The highest amount of derogatory posts was found on Twitter 'X' with 41% of all tweets. More than 40% of the papers focused on YouTube videos. Only four papers used standardized scores to evaluate the posts. According to these scores, only the reliability of videos about cannabidiol oil in the treatment of epilepsy was clearly more than modest. It is an open question how social media posts on epilepsy, or people living with it, should be evaluated.

Keywords: Derogatory comments, YouTube, self presentation, cannabidiol

INTRODUCTION

When taking social media into account, the question arises how people with epilepsy present themselves or are presented without participation in a standardized survey. It will be difficult to analyse this because there is a tremendous amount of data. A study using an advanced machine-learning empowered methodology to analyse open-source digital conversations about epilepsy found 222,000 such conversations, although limiting the search to 12 months and including only conversations originating from US internet protocol addresses.¹ Therefore, studies on the knowledge about epilepsy and attitudes towards people with epilepsy as presented in social media will have to focus on special sources, timeslots, and questions to avoid being overwhelmed by a large amount of data, which is difficult to analyze. In the following review, we will present the studies on epilepsy in social media published until December 18th, 2024, and concerning posts about epilepsy on the platforms Facebook, Instagram, Pinterest, Reddit, TikTok, Twitter 'X', and YouTube. The kinds of posts, the goals, the groups of authors, and the quality of the posts as reported in the papers will be evaluated.

On December 18th, 2024, we launched a Web of Science and a PubMed search with the terms “epilepsy” AND “social media”. We excluded duplicates, papers concerning epilepsy in dogs, studies using social media to post their own survey and studies where social media were only mentioned but not evaluated.

The search yielded 181 results in the Web of Science and 165 in PubMed. After excluding 114 duplicates, the remaining abstracts were screened, and after excluding 208 papers according to the criteria mentioned above, 24 papers were considered as relevant.

EVALUATION OF SINGLE SOCIAL MEDIA PLATFORMS

Evaluation of Facebook

In 2017, a higher number of pages and accounts was found on Facebook than on Twitter 'X' that were related to epilepsy, which just failed to reach significance ($p=0.056$).² Accounts of “non-profit foundations” were most common (47%) followed by “patients and caregiver support groups” (36%). No further evaluation was performed.

Evaluation of Instagram

When Baxendale³ in November 2020 searched for the hashtag #epilepsy on Instagram more than 500,000 posts were found. She analysed the 100 most popular (liked or commented on) memes labelled with this hashtag and classified them into 9 broad categories: Seeking advice, raising awareness, inspirational quotes, celebrations of seizure milestones, living with epilepsy, sharing the diagnosis, experience of seizures, mediation, doctor/patient interactions. She delivers examples of the pictures but does not quantify the occurrence of memes in the different categories. Popoola-Samuel et al.⁴ performed a standardized analysis of 431 posts on Instagram found in December 2022 with the hashtags #seizure, #seizures, #seizureawareness, #seizurefree and #seizuredisorder. Most of them were posted by the health and wellness industry (35.0%), followed by survivors or individuals affected by the disease (32.7%). The content of the posts was classified as true according to the actual definitions of seizures and epilepsy, at 76.8%. No content was regarded as false. All content was evaluated with the Global Quality Score (GQS)⁵, which was developed to evaluate the information on websites about Crohn's disease or ulcerative colitis. This is a five-point Likert scale score with one point for poor quality and five points for excellent quality. On this score, more than half of the posts on Instagram were categorized as not useful or as providing only limited use to the patients. The mean score was 2.26. The reliability of the posts was evaluated with the modified DISCERN score.⁶ This is an abridged version of the original score,⁷ which was developed to evaluate health consumer information for treatment choices for myocardial infarction, endometriosis and chronic fatigue syndrome. In the abridged version, five questions have to be answered with "yes" or "no," resulting in one point for each "yes" and a maximal score of five points if all questions have been answered with "yes." The authors noted that clear aims were formulated in only 39.4% of posts, and that information was presented in a balanced and unbiased manner in only 28.3% of posts. Only 0.5% referred to areas of uncertainty. This resulted in a mean score of 2.11.

Evaluation of Pinterest

In 2017 a study concerning status epilepticus related pins on Pinterest was published.⁸ Fifty-five pins were evaluated, of which 74.5% were based on scientific evidence and delivered accurate information. The purpose was in 67.3% educational. Just 1.8% of posts were negative in tone. However, only 12.7% of posts were used for advocacy purposes.

Evaluation of Reddit

On June 1st, 2022, the 50 most popular posts of adult authors within subreddits pertinent to neurosurgical concerns were identified and then analysed.⁹ In the subreddit "epilepsy", 47 posts were found. About 70% of them were asking for social or health advice. Fifty posts were found in the subreddit "seizures," with 94% of

them asking for social or health advice. Just 27.7% of the posts in the subreddit "epilepsy" and 18% of the posts in the subreddit "seizures" contained treatment-related questions. On October 9th, a similar screening of posts on Reddit was performed; was restricted to patients younger than 18 years, pregnant women, and relatives or close friends of patients younger than 18 years.¹⁰ Here, 50 posts in the subreddit "epilepsy" and 24 in the subreddit "seizures" were selected. Just 17.6% of the posts were from patients younger than 18 years. 33.8% of posts were from relatives or close friends concerned with a patient in middle childhood (i.e. 6-12 years old). This was the largest subgroup of posts. The authors state that they did not find any obvious misinformation in any of the posts.

Evaluation of TikTok

The top 109 videos found with the key word "epilepsy" on TikTok on December 18th, 2022, were evaluated.¹¹ The videos were classified as educational, personal experience, or event. Event videos showed seizures. Of 47 event videos, 26 (55%) were rated as showing psychogenic non-epileptic seizures. However, they had only 39% of the views of the event videos. The event videos showing epileptic seizures were more often viewed. Researchers classified 51 videos as "personal experience," featuring patients and family members describing opinions about epilepsy. They were not regarded as presenting any misinformation. Videos concerning first aid in generalized tonic-clonic seizures apart from a clinical setting were searched for in June 2024 with the search term "seizures first aid".¹² 19 videos were selected. The videos were evaluated with a 21-item checklist, created by the author based on English-language guidelines. The author noticed that the items of his checklist were not sufficiently dealt with in 71.2% of the videos on average. For example, the removal of eyeglasses during the seizure was not mentioned in 94.7% of the videos. Additionally, opening the airways once the seizure ended was missed in 94.7% of the videos. According to the author, 47.4% of the videos contained superfluous instructions. He regarded putting the person on the side as adequate only when the seizure has stopped. Additionally, he found 360 comments containing misinformation.

Evaluation of Twitter 'X'

In 2023, a study analysed all tweets posted in English or Spanish between 2007 and 2023 concerning six neurological diseases.¹³ Epilepsy was in second place in Spanish posts and in third place in English posts. Since further evaluations were performed without distinguishing between the different diseases, no further information is given specific to the tweets concerning epilepsy. This was done by the same authors in a second paper.¹⁴ Here they stated that in 24.18% of the Spanish tweets concerning epilepsy, the disease was trivialized. According to a figure in the paper, the portion trivializing epilepsy was a little bit lower but also well above 20% in English tweets. Epilepsy was regarded as not treatable in 54.45% of the English tweets and in 43.43% as treatable with professional help. From April 15th to April 21st, 2011, Twitter 'X' was searched for tweets concerning "seizure" or "seizures".¹⁵ 1504 tweets were selected for analysis and classified into seven categories (e.g. "Metaphorical", "Informative", "Ridicule/Joke", "Personal Accounts", "Opinion", "Miscellaneous"). 32% were classified as "Metaphorical" describing analogies to "seizure-like" movements. 31% were "Personal accounts" describing personal experience

MAIN POINTS

- Up to 55% of posts provide misinformations like showing a psychogenic non-epileptic seizure instead of an epileptic seizure.
- Up to 41% of posts are derogatory.
- Only four papers used standardized scores to evaluate the posts.

with having or witnessing a seizure. No other category included more than 12% of the tweeds. 8% of tweeds classified as “Ridicule/Joke” either made fun of seizures of people with epilepsy or joked about the simulation of a seizure. 41% of all tweeds belonging either to the category “Metaphorical” or “Ridicule/Joke” were regarded as derogatory concerning seizures or people with epilepsy. In 2017 a lower number of pages and accounts was found on Twitter ‘X’ than on Facebook related to epilepsy,² which just failed to reach significance ($p=0.056$). Accounts of “non-profit foundations” were most common (80%).

Evaluation of YouTube

Probably in 2008, Lo et al.¹⁶ analysed the top 10 videos, identified by the number of “hits” on YouTube. The videos had been posted in 2005, 2006, and 2007. Eight of these videos were amateur videos, while the other two were professionally produced and posted for educational purposes. The authors evaluated the comments on the videos. The amateur videos were more often commented (i.e., 985 comments on average) than the professional ones (i.e., 159 comments on average). Most comments were not seeking or providing information. The comments for three videos provided information only in a considerable amount (i.e., 30-55%). Most videos were more often commented on sympathetically than derogatorily. There were many more derogatory than sympathetic comments on only two videos. Especially a video with the title “Seizure Caused by VIDEO GAMES!” got nearly 57% derogative comments. A video with the title “Real seizure captured in a crowded mall” had a polarizing effect with 36% derogatory and 34% sympathetic comments. In 2012 Kerson¹⁷ reported about 127 videos found with the search terms “epilepsy” and “seizure” as a controlled presentation of themselves from people with epilepsy or supporting organizations. Out of the videos, 62% were self-narrated or narrated by a related person, and 28% were narrated by medical professionals or support groups. The author cited large parts of the texts accompanying the videos and encouraged readers to have a look at the videos themselves. It was emphasized that the posts allowed people to disclose material that society commonly chooses to hide. It is interpreted as a search for community, which was often answered by sympathetic comments. The question is how the message of the personal post could be appreciated in clinical practice. Brna et al.¹⁸ performed a search on a single day in October 2011 in YouTube using the terms “epilepsy” and “seizures” with the search limits “videos” and “short (<4 min)”. After excluding videos with a lack of relevance, 167 videos, including 5 duplicates, were analysed by four reviewers. The agreement of the reviewers was evaluated with the kappa-type measure¹⁹ and categorized as poor agreement ($k<0.00$), slight agreement ($k=0.00-0.20$), fair agreement ($k=0.21-0.40$), moderate agreement ($k=0.41-0.60$), substantial agreement ($k=0.61-0.80$) and almost perfect agreement ($k=0.81-1.00$). According to this classification there was substantial agreement concerning the age of the shown individuals, moderate agreement for classifying a shown event as epileptic or non-epileptic, but the agreement for classifying an event as “indeterminate” was just slight. The range for classification of a “seizure” video as “non-epileptic seizure” between the reviews was from 25% to 52%. At least three of the reviewers agreed in 28% of the videos for the classification as “non-epileptic seizure”. For the further classification of seizures the agreement was moderate for “generalized

seizures”, fair for “focal seizures” and slight for “unclassified”. In April 2012 a single search was performed in YouTube using the terms “epilepsy” and “seizures”.²⁰ The top 100 results of this search, according to the YouTube algorithm, were further analysed. 44% of the videos presented personal experiences and another 38% were informative or educational. The videos were rated on an accuracy scale, a sympathy scale, and a difficulty scale. 51% of the videos were regarded as accurate, 85% as sympathetic and only 6% as derogatory. On the difficulty scale, only 2% of the videos were rated as using technical language, while all others were regarded as understandable by laypersons. Bhoot et al.²¹ evaluated 59 videos found on YouTube on the 23rd of March 2023 using keywords, such as “epilepsy”, “seizures”, “epilepsy treatment”, “epilepsy prevention”, “epilepsy cause” and “epilepsy cure”. The majority of the videos were concerned with the treatment (i.e., 76.27%) and/or aetiology (i.e., 71.90%) of epilepsy. About half of the videos (i.e., 54.24%) displayed symptoms of epilepsy. The videos were rated with a mean GQS⁵ of 3.3 and a mean modified DISCERN score⁶ of 3.2.

Evaluations Focussing on a Special Theme in the Field of Epileptology on YouTube

A search focused on the combination of the term epilepsy with either “Cannabidiol” or “CBD oil” was performed by Silek and Bilgin Topcuoglu²² on 3rd and 4th August 2022. They evaluated 100 videos using the GQS⁵ and the modified version of the DISCERN score.⁶ The mean GQS was 3.21; the mean modified DISCERN score was 3.71. Posts by doctors scored higher than others on both measures [i.e., GQS 3.51 standard deviation (SD) 1.02 vs. 3.01 SD 1.17; DISCERN 3.82 SD 1.02 vs. 3.07 SD 1.12].

Another search focused on the terms “sudden unexpected death in epilepsy” or “SUDEP.”²³ The search was performed on January 9th, 2018, and 113 videos with a view count of at least 100 were found and further evaluated. Most posts were from individual users (51.3%), followed by posts from activist groups (40.7%). Only 8% of the posts were from professional societies. They had mainly an educational focus and were posted on average more than one year later than the posts from the other groups. Overall, there were only 298 comments. Most of them were on the posts of individual users (77.85%), which mainly consisted of tributes to patients who encountered SUDEP and personal experience. There was no evaluation based on one of the established scores.

Vagal nerve stimulation (VNS) for treatment of epilepsy was the focus of a search performed in May 2023 using the terms “VNS for seizures”, “VNS surgery”, and “VNS epilepsy”.²⁴ We looked for videos in English that are not older than 15 years and that have at least 250 views. Fifty one videos were selected and evaluated with the GQS⁵ and the modified DISCERN score.⁶ The results of the GQS are stratified into low quality for 1-2 points, moderate quality for 3 points, and high quality for 4-5 points. According to this classification, 74.5% of the videos were of low quality and only 15.7% were of high quality. The total results of the modified DISCERN score are not reported separately. However, it is stated that the correlation with the GQS was high (i.e., $r=0.807$). 60.8% of the videos shared general information, and 25.5% presented experiences. Only two videos explained the use of magnets to provide additional stimulation. Both videos were rated as being of high quality according to the GQS.

Another survey was conducted concerning paroxysmal episodes in children, with “infantile spasms” and “absence seizures” from the field of epilepsy and “sleep myoclonus” as a phenomenon in the borderland of epilepsy.²⁵ The searches were performed on two dates in July and August 2011. Twenty videos of infantile spasms, 25 of absences, and 22 of sleep myoclonus were rated by all the authors concerning the correlation between the title of the video and the clinical diagnosis on a scale, with 0 points indicating “definitely not”, 1 point for “unlikely”, 2 points for “probable”, and 3 points for “definite”. With mean scores between 1.67 and 1.97, the videos presenting features of epilepsy or sleep myoclonus fall slightly below the classification of probably correctly titled. Especially for infantile spasms, 25% of the videos were rated as definitely showing other conditions. Some absence videos showed absences as part of a more serious epileptic condition, which may lead to unnecessary worries in parents of children with childhood absence epilepsy. Some videos were combined with misleading comments. However, the occurrence and severity of these problems were not quantified.

EVALUATION NOT RESTRICTED TO A SINGLE SOCIAL MEDIA PLATFORM

Evaluation Restricted to a Country or not English Language

In a search with the terms “epilepsy” and “seizures” Serbian, Croatian, and Bosnian on the platforms Facebook, YouTube, and Twitter ‘X’ at the end of 2021, over 4000 data points were found, from which 1000 were extracted using a randomized algorithm.²⁶ Accounts from support groups for people with epilepsy were most common (45.4%). The authors distinguished this group from other non-profit foundations with a representation below 5%. The most common topic of the posts and videos was stigmatization (31%). Most posts were seeking and providing information and advice (40%). Only about 5% of posts strengthened psychosocial support according to the classification of the authors. Alsalem²⁷ performed the same search as Karadžić and Ristić²⁶ a year before in Arabic language. He just found 795 pages, accounts, and videos meeting the objectives of his study. Most accounts were from medical and healthcare professionals and institutions (43%) and only 4% from non-profit institutions. People looked for information or advice on many accounts (32%), while only 13% of accounts were providing advice or consultations. The most frequent theme was the definition and classification of epilepsy (21%). On the other hand, 4% of accounts described nutrition treatments of epilepsy and another 6% discussed spiritual explanations and treatment. An internet search restricted to the Polish language and focused on the treatment of epilepsy with cannabidiol was performed on 27th November 2021, and data were obtained for the period of one year.²⁸ Three hundred fourteen texts were analysed. The most common sources were social media (i.e: Facebook, 37 posts; YouTube, 33 posts; Twitter ‘X’, 6 posts). All posts were evaluated with an online version of the original DISCERN score.⁷ In this version, 16 questions have to be answered on a five-point Likert scale. The posts reached an overall score of 26.97, which means a

mean score of 1.7 per post. As can be estimated from a figure in the paper, the mean score for the social media posts was slightly lower. This indicates a rather low quality. But when looking at the original data it is interesting to note that if the scoring had been restricted to the five items of the modified DISCERN score⁶ the result would have been a little bit higher (i.e. 1.95).

Evaluation not Restricted

When performing a qualitative analysis of posts and tweets about epilepsy Meng et al.² extracted the most recent 50 results concerning eight thematic categories of their search without further differentiating between the media platforms Facebook and Twitter ‘X’. They found that most posts provided information (48%), and support was looked for in only 8% of posts. In a sweeping analysis performed for the first two weeks of October 2020 on seven media platforms and world wide web 1,100 posts with the hashtags “epilepsy” or “epileptic”. A sentiment analysis was performed, which revealed that 22% of the posts expressed a negative sentiment. This amount was higher on the World Wide Web and on Twitter ‘X’. The results were published as a conference abstract only.²⁹

DISCUSSION

More than 40% of the papers evaluating social media posts concerning epilepsy and people living with epilepsy focused on YouTube videos. However, the mode of evaluating the social media posts varied significantly between different papers. This is summarized in Table 1. Another problem is the interrater variability, which is taken into consideration in only a few papers (see also Table 1). Some papers mainly focused on the group of authors and their aim in their studies. When looking at the quality of the posts, the results were very different. Perhaps the highest amount of misinformation was found on TikTok with 55% of videos claiming to show an epileptic seizure were rated as showing a psychogenic non-epileptic seizure.¹¹ The highest amount of derogatory posts was found on Twitter ‘X’ with 41% of all tweets. They were classified by the authors¹⁵ as belonging either to the category “Metaphorical” or “Ridicule/Joke”. When a qualitative evaluation of posts is performed, a standardized method should be applied and interrater reliability should be reported. Only four papers used standardized scores to evaluate the posts. According to these scores only the reliability of videos about the cannabidiol oil in treatment of epilepsy²² was clearly more than modest. The results of the evaluation of the posts with two standardized scores are summarized in Table 2 and Table 3. The main limitation of this study is that, due to the high diversity of the evaluations performed in the cited papers, no thorough meta-analysis can be performed. There are more questions than answers after reading the referred studies. What should be evaluated when trying to understand the representation of epilepsy and people living with it on social media platforms? The groups of the authors? The aims of the posts? The quality according to a standardized score? The attitudes of the comments on these posts?

Table 1. Kinds of evaluation and reported interrater reliability

Platform	References	Kind of evaluation	Interrater reliability
Facebook	Meng et al. ²	Sources	Not applicable
Instagram	Baxendale ³	Categories of aims	Not applicable
Instagram	Popoola-Samuel et al. ⁴	Aims and quality of posts	Not reported
Pinterest	Mahroum et al. ⁸	Sources and aims	Not applicable
Reddit	To et al. ⁹	Categories of aims	Not applicable
Reddit	To et al. ¹⁰	Categories of aims	Not applicable
TikTok	Jiang et al. ¹¹	Sources, aims and reliability	No interrater variability
TikTok	Birkun ¹²	Quality	Not applicable
Twitter	Domingo-Espiñeira ¹³	Sources, aims	Not applicable
Twitter	Domingo-Espiñeira ¹⁴	Themes and aims	Not applicable
Twitter	McNeil et al. ¹⁵	Categories of aims	No interrater variability
Twitter	Meng et al. ²	Sources	Not applicable
YouTube	Lo et al. ¹⁶	Evaluation of comments!	Not applicable
YouTube	Kerson ¹⁷	Hermeneutic	Not applicable
YouTube	Brna et al. ¹⁸	Showing seizures or not	Epileptic seizure k=0.57 Non-epileptic seizure k=0.43 Indeterminate k=0.16
YouTube	Wong et al. ²⁰	Categories, accuracy, difficulty and sympathy of posts	Categories k=0.73 Accuracy k=0.54 Difficulty k=0.49 Sympathy scale 0.30
YouTube	Bhoot et al. ²¹	Popularity, sources, aims, quality	Not applicable
YouTube	Silek and Bilgin Topcuoglu ²²	Quality	DISCERN Cronbach α =0.882 GQS Cronbach α =0.911
YouTube	Rayi et al. ²³	Type of content, sources, comments	Type of content k=0.68
YouTube	Özçelik et al. ²⁴	Categories, quality	GQS k=0.781
YouTube	Borusiak et al. ²⁵	Certainty of diagnosis, quality	Certainty of diagnosis: Infantile spasms k=0.49 Absences k=0.32 Sleep myoclonus k=0.32
Facebook, YouTube, Twitter	Karadžić and Ristić ²⁶	Topics, sources, aims	Not applicable
Facebook, YouTube, Twitter	Alsalem ²⁷	Topics, sources, aims	Not applicable
Facebook, YouTube, Twitter and others	Zakrzewski et al. ²⁸	Quality	Not applicable
Flickr, Instagram, Reddit, Tumblr, Twitter, Vimeo, YouTube, World Wide Web	Gangloff and Hanrahan ²⁹	Sentiment analysis	Not applicable

Cronbach α =measure of interrelatedness with 1.0 marking maximal correlation of results. DISCERN=standardized quality index of consumer health information.^{6,7} k=Kappa-type measure,¹⁹ k<0.00=poor agreement, k=0.00-0.20=slight agreement, k=0.21-0.40=fair agreement (k=0.21-0.40), k=0.41-0.60=moderate agreement, k=0.61-0.80=substantial agreement and k=0.81-1.00=almost perfect agreement.

Twitter 'X', GQS: Global Quality Score⁵

Table 2. Mean scores in GQS⁵

Platform	Score	References
Instagram	2.26	Popoola-Samuel et al. ⁴
YouTube	3.3	Bhoot et al. ²¹
YouTube	3.21	Silek and Bilgin Topcuoglu ²²

Global Quality Score: Five-point Likert scale score with one point for poor quality and five points for excellent quality.
GQS: Global Quality Score

Table 3. Mean scores in DISCERN score

Platform	Score	References
Instagram	2.11 (2.)	Popoola-Samuel et al. ⁴
YouTube	3.2 (2.)	Bhoot et al. ²¹
YouTube - focus on CBD	3.71 (2.)	Silek and Bilgin Topcuoglu ²²
YouTube, Twitter, Facebook - polish - focus on CBD	<1.7 (1.)	Zakrzewski et al. ²⁸

1. Original version.⁷

2. Modified version.⁶

DISCERN=standardized quality index of consumer health information. In the original version (1.), there are 20 items, each scored on a five-point Likert scale, where one represents poor quality and five represents excellent quality. Here, the mean score is given. In the modified version (2.), there are five questions to be answered with "yes" or "no," resulting in one point for each "yes". The range is from 0-5 points, with higher points indicating better quality.

CBD: Cannabidiol, Twitter 'X'

Ethics

Footnotes

Data Availability Statement

The data used in this study can be checked by repeating the Web of science and PubMed research and excluding papers, which were published after December 18th, 2024.

Conflict of Interest: Johannes Rösche received a speaker honorarium from EISAI.

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