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VIRTUAL ETHNOGRAPHY: WHAT SOCIAL NETWORKS SAY ABOUT EPILEPSY?

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Summary

Epilepsy is a neurological disorder characterized by episodes of sudden and recurrent behavioral changes, known as epileptic seizures. The high prevalence and severity of this disease, especially in individuals who do not have their seizures under control, has caused affected patients to be stigmatized by society in the school and work environment. Currently, with the popularity of social networks and access to information through virtual means, both by patients and curious people, a new way of doing research has emerged, called virtual neography, which consists of the analysis of social media, which emerged as a result of of the need for researchers to approach the online world in their research. Therefore, the objective of the work was to survey publications on social networks about information about epilepsy. For this, three social networks were selected: Instagram, Facebook and Tik Tok, with previously selected descriptors and subsequently the 20 posts that presented greater number of views, likes and shares. Next, an analysis of each post was carried out and we can observe that regarding informative posts about care during a seizure, information about epilepsy with exposure of myths about the disease were the most viewed, liked and shared. In this way, we can conclude that social networks have been acting as an agent to disseminate information about epilepsy behaviors to the community that does not have access to scientific information carried out through traditional methodology.

Key words: Social media. Convulsive crisis. Information and communication technology.

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Abstract
Epilepsy is a neurological disorder characterized by episodes of sudden and recurrent behavioral changes, the so-called epileptic seizures. The high prevalence and severity of this disease, especially in individuals who do not have their seizures under control, has caused affected patients to be stigmatized by society in the school and work environment. Currently, with the popularity of social networks and the access to information through virtual means, both for patients and the curious, a new way of doing research has emerged, the so-called virtual neography, which consists of the analysis of social media. Thus, the goal of this study was to survey the publications on social networks about information about epilepsy, for which three social networks were selected: Instagram, facebook and tik tok, with previously selected descriptors and then the 20 posts that had the highest number of views, likes, and shares were selected. Then the analysis of each post was performed, and we can see that the most viewed, liked, and shared posts were the informative ones about care when a seizure occurs, the information about epilepsy with exposure of myths about the disease. Thus, we can conclude that social networks have been acting as a disseminator of information about epilepsy for the community that does not have access to scientific information through traditional methodology.
Keywords: Social media. Seizure crisis. Information and communication technology.

1. Introduction

Epilepsy is a neurological disorder characterized by episodes of sudden and recurrent behavioral changes, known as epileptic seizures. It is characterized by a long-lasting predisposition to generate seizures due to the transient occurrence of signs or symptoms of excessive or synchronous neuronal activities in the brain, such as unprovoked electrical discharges. It is a chronic disease and its cause can be multifactorial, involving genetic factors and environmental factors, as well as the occurrence of other neurodegenerative diseases (SCHENKEL, 2011; ILAE, 2014).

According to the World Health Organization (WHO) in its 2019 report, epilepsy is one of the most common neurological diseases that affects around 50 million people worldwide. In low-income countries, the incidence is 139 per 100,000 people per year compared to high-income countries, which reach an incidence of 48.9 people. Its distribution has been observed in younger individuals and people over 60 years of age. (EPILEPSY.2019)

Around 70% of epilepsy is treatable with antiepileptic drugs (AEDs), for this it is necessary to carry out an accurate diagnosis and continuous medication administration, since antiepileptic drugs are low cost. Despite the low cost of AEDs, more than 75% of low-income people do not receive the medication and do not have the correct treatment for crises, which can be devastating from a social point of view, as the

Individuals with epilepsy face stigma, discrimination and human rights violations. (WHO, 2017)

Stigma for people with epilepsy who do not have seizure control is a contributor to the poor mental and physical health of patients. Misconceptions and little understanding about epilepsy contribute to the “burden” of the disease and lead to stigma. perception of epilepsy as a form of insanity, ruining people's lives, and being untreatable or contagious. (FERNANDES; LI; LI. 2006).

Controlling epileptic seizures is necessary so that the individual can regain a quality of life. Misconceptions and negative attitudes cause people with epilepsy to feel shame, embarrassment and disgrace. The impact of feeling socially excluded contributes to the physical, psychological and social toll of epilepsy. Stigma can delay adequate healthcare seeking, access to care, healthcare financing, and treatment availability. Institutionalized discrimination in epilepsy affects employment, education, marriage and pregnancy, and driving regulations. (VALENCE,*et al.*, 2006).

Approximately half of adults with epilepsy have at least one other health condition. The most common are depression and anxiety: 23% of adults with epilepsy will experience clinical depression during their lifetime and 20% will suffer from anxiety. Developmental and learning difficulties are experienced by 30%-40% of children with epilepsy and many children with this condition stop attending school. (SCHUBERT R. 2005)

With the popularity of social networks and access to information through virtual means, both by patients and curious people, a new way of doing research has emerged, the so-called virtual neography, which, according to (Santos & Gomes, 2013), netnography (nethnography =net+ethnography), a method predominantly used to analyze social media, which arose due to the need for researchers to approach the online world in their research. (FERRAZ, 2019)

In a virtual scenario, it is necessary for research methods to keep up with reality. This does not mean that the traditional research method should be abandoned, but it needs to be reinvented and reconstruct the processes and techniques of research forms to allow for a better understanding of current facts. (SOARES; STENGE, 2021).

In Brazil, recent studies have analyzed how virtual social networks have been articulated around various pathological conditions. In most cases, these spaces serve as an environment for sharing experiences, emotions and tips, providing support

mutual in the emotional, informational and social spheres. Personal experiences and group exchanges constitute effective ways to deal with these experiences. The virtual nature of these spaces has facilitated openness to others and the construction of social ties that are compromised offline due to stigma and discursive restrictions in relation to these conditions in society. (LEITAN, MICHALAK, BERK; BERK, MURRAY, 2015; BARROS, SERPA JÚNIOR, 2014; MARTINHAGO. 2018.)

Therefore, this study aims to investigate information about epilepsy from basic concepts such as coexistence at school through social networks.

2 Methodology

This is a qualitative study based on virtual ethnographic research as an investigation method. Data collection took place through the researcher's immersion in social networks and the research was carried out in August 2021. (NEERGAARD; OLESEN; ANDERSEN; et al.2009; HINE, 2000).

The social networks selected were Instagram, Facebook and Tiktok. For the searches, it was necessary to select descriptors such as #epilepsy, #criseconvulsiva and # epilepsianaescola and without selection filters for each search.

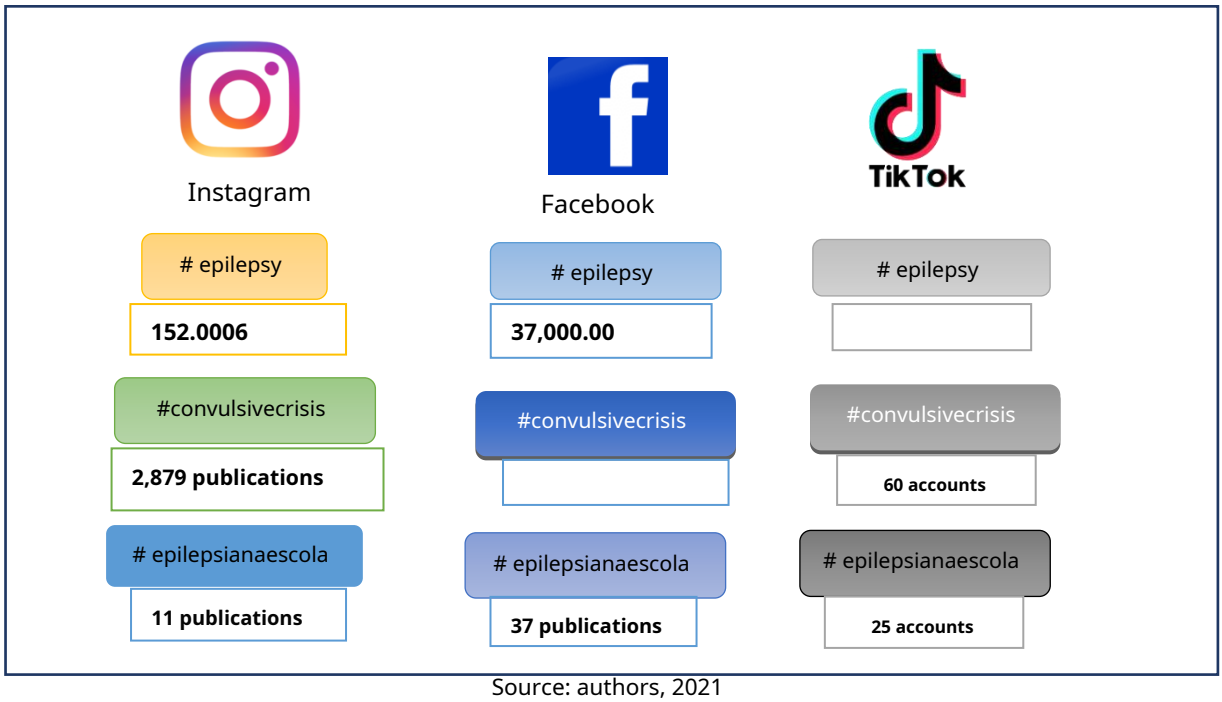
For data analysis, the first twenty publications were used, such as the number of views, the number of likes, the number of shares and the results of each survey were organized in Excel spreadsheets and graphs.

According to ethical guidelines, approval by an ethics committee was not necessary, as this was research carried out on social networks with data open to the public.

2.1 Selection of samples for analysis

From the data obtained, we created a variable to evaluate the 20 most relevant videos from all searches with the descriptors and the criteria used were: number of views, number of likes, number of shares. The posts were then organized into a ranking of interactions from which information about epilepsy was selected.

Figure 1: organization chart of searches on social networks.



Source: authors, 2021

3 Results and discussion

According to the data collected for each descriptor searched on social networks The first twenty posts that had the most views, likes, comments and shares on the social network Facebook, Instagram and Tik Tok were selected. For the social network, tik tok, posts made with the descriptors used did not have the reach of Instagram and Facebook, none of the research carried out presented all the rankings of interactions selected in the research, such as views, likes, comments and shares. Therefore, they were not categorized and selected in the table below.

Table 1. Description of the most relevant posts by topic on the social networks researched in the study.

Channel	Video/poster title	Publication date	Views	Likes	Comments	Shares	Link
Facebook	Procedures correct- crisis convulsive	01.11.18	6.9 thousand	245	27	306	https://www.facebook.com/prof.cassiorossi/videos/186334005577858/.
Facebook	What is a febrile seizure?	05-10-20	585	60	05	12	https://www.facebook.com/402984967134608/posts/792220121544422/ .
Facebook	Epilepsy It is crisis convulsive	13-09-21	90	22	01	06	https://www.facebook.com/100028155909217/posts/868435890771600/.
Facebook	The time has come to resolve all your doubts about epilepsy!	17-08-21	142	09	02	02	https://www.facebook.com/AssociacaoBrasileiradeEpilepsia/videos/985191288934336/
Facebook	Let's go eat The food? # autism # epilepsy	15-09-21	126	17	01	01	https://www.facebook.com/106757011664572/videos/222253729934975/
Facebook	Inside your epilepsy	01-10-21	363	30	11	12	https://www.facebook.com/AssociacaoBrasileiradeEpilepsia/videos/608444920166704/

Facebook	Second walk support for people with epilepsy in American # epilepsy at school	24-09-20	995	70	21	24	https://www.facebook.com/limin.li.311/videos/1557724440937724/
Facebook	I support the cause of epilepsy, 11 February 19 International Day from the epilepsy	06-02-19	377	57	04	22	https://www.facebook.com/limin.li.311/videos/2169748899735272/
Facebook	Epilepsy at life everyday	08-12-20	202	02	01	03	https://www.facebook.com/Sallowillian/videos/430746671295648/
Tik Tok	Epilepsy	07-06-21	Did not inform	1442	63	89	https://vm.tiktok.com/ZM8dc1LAR/
Tik Tok	# epilepsy # treatment	17-07-21	Did not inform	20.0k	1106	529	https://vm.tiktok.com/ZM8RL5Gpj/
Tik Tok	Epileptic seizure	04-10-20	Did not inform	30.9k	157	77	https://vm.tiktok.com/ZM8dcyUW2/
Tik Tok	Absence crisis	26-08-21	Did not inform	14.4k	179	61	https://vm.tiktok.com/ZM8d3SubS/
Tik Tok	Student with epilepsy	15-09-21	Did not inform	64.7k	992	1488	https://vm.tiktok.com/ZM8dEcwjT/

Tik tok	# refractory epilepsy	26-03-21	Did not inform	248.4k	1300	466	https://vm.tiktok.com/ZM8do9y1Y/
Tik Tok	After 13 minutes in a behavioral crisis infantilized	16-05-21	Did not inform	27.5k	66	59	https://vm.tiktok.com/ZM8RLQw6b/
Tik tok	What to do in a convulsive crisis?	13-09-21	Did not inform	5771	54	193	https://vm.tiktok.com/ZM8R68XJN
Tik Tok	Reply to lanne558	07-04-21	Did not inform	6561	145	35	https://vm.tiktok.com/ZM8R6MX1a/
Tik Tok	What to do when a child has a seizure?	10-11-20	Did not inform	5518	94	143	https://vm.tiktok.com/ZM8R6yE1t/
Tik tok	Be careful with hydantal	16-09-21	Did not inform	2687	25	85	https://vm.tiktok.com/ZM8Rjnc5V/
Tik Tok	I look like an earthworm with seizures when I dance.	08-31-21	Did not inform	4116	84	40	https://vm.tiktok.com/ZM8Rj4yt5/

To evaluate the content that was posted on social networks, we initially analyzed the recurring terms in the post titles. From this analysis, we built a word cloud with the 10 most used terms in order to analyze the content published on social networks about epilepsy.

Figure 1: Word cloud with the most used terms in social media posts about epilepsy.

Source: authorship, 2021.

Regarding the analysis of publications on Facebook, it was observed that the information disclosed was information that covered everything from what epilepsy is to epileptic seizures and how to behave in the face of a crisis. In the Facebook post in whichthe Prof. Cássio Rossi talks about correct procedures and seizures.

> A seizure is nothing more than an electrical disorder that occurs in the patient's brain, in fact it is a disorder from an electrical point of view where there are exaggerated stimuli that end up causing a lack of consciousness and a generalized body contraction. What should I do when faced with a seizure? Protect the victim so that they do not have secondary injuries such as hitting their head... (ROSSI, 2018).

According to Fisher*et al*(2017) epileptic seizures can be classified essentially focal onset, generalized onset, and unknown onset, defined as hypersynchronous or excessive activities that originate in brain neurons. When these crises do not have a limited period, with continuous crises occurring, they can characterize a situation of*status epilepticus*, which consists of a lasting crisis that takes a longer period of interruption than other crises (YACUBIAN, 2002).

Regarding the procedures we must take in the event of an epileptic seizure, it is important to protect the victim.

> Lateralize the victim's head and make the neck slightly extended, this is enough to free the victim's breathing and prevent them from having an obstruction in their breathing and waiting for the convulsive crisis to pass, which is what will take time to resolve. around a minute. (ROSSI, 2018)

The procedures to be taken during a convulsive crisis are something that should be widely publicized, as it is common to see someone with epileptic seizures and often the people who come to help with incorrect attitudes, which can be harmful to the victim, such as “pulling the tongue” so the patient doesn't choke”, sit on the victim to avoid spasms. These postures can lead to injuries to the victim as the contractions are involuntary and can break or distort some part of the victim's body. Placing your hand in the victim's mouth with the aim of preventing the tongue from choking on saliva is dangerous as it could cause a bite. or injury you are trying to help with.

Another piece of information widely publicized on Facebook was the cannabis-based treatment for seizures. Because the video reports on a mother who has two daughters with monogenetic epilepsy, that is, with an alteration in one gene that causes epilepsy that is difficult to control with drugs (figure 2). The treatment and control of epileptic seizures in patients is extremely important as it is related to quality of life and the drugs available on the market do not control seizures in 30% of patients with epilepsy. Therefore, the search for new pharmacological targets and new drugs that have the ability to reduce crises has increased.

Cannabidiol was used in experimental models to control seizures and later in humans, which has shown success as it controls seizures in approximately 50% of patients tested, and the side effect observed so far has been only drowsiness. However, clinical studies with pharmacokinetics still remain insufficient in terms of ideal doses and identification of drug interactions, which may interfere with treatment or promote toxicity (MATOS *et al*. 2017).

Figure 2: report on cannabis in the treatment of seizures in a network of Facebook.

Source: (17) Watch | Facebook

As for stigma in patients with epilepsy, this behavior is generally more harmful than the condition of having epilepsy itself. Having epilepsy, especially when you do not have control over epileptic seizures, means having your quality of life affected and this condition also impacts the lives of family members.

When analyzing a video published on tik tok with the description of "I look like an earthworm with seizures when I dance." With a high level of reach such as views, likes, comments and shares, it is reinforcing the negative stereotype of someone with a seizure, which is unpleasant for patients.

Epilepsy is one of the chronic diseases that present a higher level of stigma and can have an influence on social relationships, school, employment and emotional aspects. Therefore, the social responsibility of those who share this type of content is extremely important so as not to encourage this type of behavior among Internet users and normalize stigma under any circumstances.

Final considerations

The analysis of publications on social networks about epilepsy addresses various topics ranging from etiology, treatment and information to users of these networks. It is also clear that the number of "communities" supporting patients with epilepsy is large, which forms a network of care and safety for them. What about the type of social network that most

provides information to internet users, we can see that the reach of Tik Tok is much greater than Facebook and Instagram. Therefore, we can conclude that social networks have been acting as an agent to disseminate information about epilepsy behaviors to the community that has not ceased to provide scientific information using traditional methodology.

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