

Epilepsy: History of an Illness in the Consolidation of Stigmas

Ismael Dorado Urbistondo^{1,2,3*} and Rosa Maria Garcia Polo^{2,3}

¹Complutense University of Madrid, Madrid, Spain

²National Association of People with Epilepsy, Spain

³Psychology Center Ismael Dorado, Spain

***Corresponding Author:** Ismael Dorado Urbistondo, Complutense University of Madrid and National Association of People with Epilepsy and Psychology Center Ismael Dorado, Spain.

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Abstract

Epilepsy is one of the illnesses which has been, over its history, surrounded by all sorts of magical and even demonic connotations, because of ignorance, mainly.

Speaking about epilepsy in the 21st century means getting into false myths and stigmas which have caused embarrassment and discrimination all along human history.

Ever since Hippocrates until our very times, moon influences, demonic possessions or brain alterations have provided epilepsy in particular with a special halo of ignorance and false information, thus contributing to social and labour discrimination, as well as hurting patients emotional well-being.

In this article, history of epilepsy is approached from several centuries before Christ to present day, in order to find the foundations of the negative connotations this illness has. It is also explained how, even today, this condition strongly influences patients' emotional and social stability.

We will also see the results from a research performed to review information average citizens have about epilepsy, as well as the direct relationship it has in order to consolidate the stigmas mentioned above.

Keywords: Stigma; Epilepsy; History of Epilepsy

Epilepsy in a globalised world, where the information flow is endless, is still a perfect stranger, and filled with myths. The causes of the illness along history have sometimes been away from science, being close to religion or exorcisms, even magic. Possessed people with the moon as the main cause, mental patients... Actually, this condition is known as the "illness of the thousand names", such as "sacred illness", "morbus hercules" or "morbus comitalis", always making reference to the patient's symptoms or name.

In ancient texts, some references can be already found, perhaps the first ever, which date back to Babylon, around 1800 B.C.

Medicine and doctors themselves were under the protective blanket of the gods. Every single law-breaking action led to an illness. Babylonian medicine was focused on the figure of the pharaoh [1] and its activity ruled by Hammurabi's Code [2]. Epilepsy, along with some other illnesses, such as leprosy, is regarded as an embarrassing illness. On the Code, patients are "forbidden to marry or declare in court", as well as buying epileptic slaves, being returned if they showed symptoms of the illness [3,4].

The link between epilepsy and psychic disorders was described for the first time 2.000 years B.C., when Assyrians wrote the *sakikku* (Book of all Illnesses). In this book, all illnesses are described, as well as the clinical features of epilepsy or *antashube*, meaning "the illness of the falls". The patients were said to suffer from mental disorder breakdowns [5]. The same text explains several clinical aspects where someone starts the breakdown by "screaming, turning their neck, tightening their hands and feet, and passing out" [6-8].

The first reference to brain injury and the link with convulsions appears on Ebers's Papyrus [9], in 1580 B.C. The functioning of the central nervous system is explained, as well as the brain physiology, adding information about pathologies, such as quadriplegia and hemiplegia, apart from epilepsy, described as generalised shaking all over the body [10].

In Ancient Egypt, illness was considered the result of a demonic possession [11]. It was thought to enter the human body through the eyesight, and the treatment was fermented beer, sage, myrrh, malaquite, mustard, and acacia turpentine. Bones were even pierced to allow demons to leave their victim [12].

The ancient Greeks used to think only a god could make people fall down, lose their senses, cause them convulsions, and then bring them back to life, apparently safe and sound [6]. Their belief that it was gods who caused all that made people regard epilepsy as something supernatural.

Hippocrates (400 B.C.), in *morbus pueri*, said it was more common in children, being inherited and infectious, prone to convulsions [22]. He was the first to link epilepsy to a brain pathology, providing it with a more scientific approach, rather than the magical one it always had so far [13]. He inferred this state took place as a result of the "thought organ" becoming flooded with nonchalance, which, in turn, happened because of events having nothing to do with divine events [14].

Hippocrates stated: "As regards this 'sacred illness', I don't think it is more sacred than the rest of conditions, but it has a natural origin. To my mind, those who said it was sacred were the same kind of people as the alleged wizards, impostors and charlatans who use the magical and divine arguments to disguise their ignorance when it comes to explain illnesses..." [15].

To Hippocrates, epilepsy represents imbalance of the moods, where indifference outweighs any other kind of mood, thus starting a treatment of diet and drugs [16]. Just like any other illness, epilepsy is considered hereditary, and its source is the brain. A brain overflowing with mood: "when mood runs through our veins, it causes all the symptoms of an attack. The factors triggering so would be the sun, the cold and the winds, causing changes in the brain consistency [17].

In ancient Rome, under the name of *morbus comitialis*, it was agreed that, before an epileptic breakdown, any event would be suspended in order to purify the patient, as well as the place, so as to prevent anybody else's contagion, and the bad luck implied [18].

It would be Quintus Serenus who, in "the moon illness", made a god responsible, as he allegedly used the moon as a means to cause the illness. The epileptic patient became somebody untouchable who possessed the power to capture anybody for the evil, particularly when there was full moon.

With Galenus (130-230 B.C.), the concept of epilepsy adopted a scientific approach again. He described the convulsions, spotting the origin of the illness in the brain [19].

After a great leap forth, now in the Middle Ages, only the Islam maintained the research, unlike the Christian world, monopolised by the Church and its narrow-mindedness. Hippocrates's theories are left aside, getting back to demonic and infernal theories [20].

The epileptic patient is charged with great dishonor, as well as their families, which caused the patient to hide from the rest. The illness is again thought of as infectious [21], with the saliva as infectious agent. It was a world of fear to the supernatural, witchery and such, which was bad luck [20].

Church was the only place to be called for in order to heal epilepsy. Saints were the tool, and trips were arranged to pay them tributes so the patient could be healed by them. Ideally, these trips would be arranged somewhere with Saint Valentine, patron saint of epileptics.

Once more, epilepsy will be the diabolic illness par excellence.

During Renaissance, Charles Le Pois would refer to the brain as the source of epilepsy [22], facing the Church, no less, which still believed in supernatural theories. Actually, the widespread belief of supernatural factors as the cause for epilepsy is reflected in the very name of this disorder: 'epilepsia' comes from the word 'epilambanein', (grab/attack).

Arnaldo de Villanova, in his Practical Medicine Compendium, defines epilepsy as an "occlusion of the main brain ventricles, losing sensitivity and movements; also continuous spasms all over the body" [2]. He also establishes three kinds of epilepsy: The first originates in the brain, whereas the second is the anepilepsy, starting in our veins, arteries, nerves or stomach, later going up to the brain. The third, catalepsy, starts with the patient feeling an alteration of the sensitivity [23].

During this time, healing techniques were completely cruel: Cutting fingers off to inhibit the reflex, tracheotomies, sexual abstinence or trepanations. Samuel Tissot's case (1769) led to the description of the absence breakdown, stating sexual activity, particularly masturbation, as the cause for epilepsy [23].

Victor Horsley, in 1886, improves the trepanation technique, starting the protocol for the surgical treatment of the incurable epilepsy [24].

With Modern Age, great progress is made in aetiology, classification and development of new treatments. In 16th century, the first book about Neurology, *De Cerebri Morbis*, written by Jason Pratensis, Galenus's theories would be brought back [25].

Thomas Willis's theory and research, in 16th century, stated the source of the illness in our brain, also saying epileptic breakdown are the result of a violent chemical reaction. On the same line, John Locke (1676), settles motor convulsive breakdowns as hysterical breakdowns, really [26].

Now in the Contemporary Age, epilepsy as an organic injury in the nervous system is settled in the 19th century.

The French neurologist Jean Martin Charcot (1886), establishes and differentiates several factors of an organic injury from some others with a psychological or hysterical source. Hypnosis was employed to make the symptoms disappear, in a time when epilepsy was considered a psychiatric clinical phenomenon [23].

Fritsch, Hitzig and Luciani's studies in 1870 attribute to epilepsy the excessive cortical motor excitement, replicating his findings by using electrical stimulation on animals.

Hughlings Jackson (1870) rescues Hippocrates's ideas, establishing an organic origin for the illness, and the motor cortex as the source of epileptic breakdowns [27]. He regards the illness as a random excessive discharge of nervous tissue onto the muscle, convulsions depending on grey matter instability [28].

The beginning of the 20th century and the arrival of encephalogram, a breakdown in diagnosis, forecast and treatment. With the work done on the above mentioned Hans Berger and L. Carmichel test, electrical currents in the human encephalon are registered [29].

H Berger developed a great know-how on registering patients under the effects of anaesthetic drugs, morphine, alcohol and analeptics. He described 3 Hz slow waves in absence breakdowns, he managed to register generalized convulsive breakdowns, a coma case [30], thus confirming the existence of irritative activity.

The arrival of techniques such as x-ray and neuroimage allow for the study of brain structures on living patients. Medicines and drugs also experienced great progress, obtaining better and better treatment with lower and lower side effects. Specific classifications about different kinds of epilepsy were accomplished. Diagnosis improved and convulsions started to be controlled [12].

Now in the 21st century, the idea of comorbidity is open again, linking it to different disorders. We mustn't forget Herodotus's theory (480 - 420 B.C.) when he called it "sacred illness [31], declaring that "... it wouldn't be unlikely for the mind to suffer from an illness if the body is not well, either..." .

Depression and anxiety are the most common problems in patients, 20 - 60% of the (González-Pal, Quintana, Fabelo, González and Yopis, 2014) [32].

Research goes on to find something regarding the link between epilepsy and behavioural disorders. It is thought that a number of multi-etiological factors (neurobiological, psychosocial and related to medicines) are capable of influencing the beginning of psychological disorders [33].

There would be some other neurobiological factors, such as the duration of the crisis, starting age, kind of brain injury and breakdown frequency, which may account for the link between epilepsy and a) behavioural disorders and B) the decrease of quality of life.

The study performed in 2014 by González-Pal, Quintana, Fabelo, González and Yopis [32] showed a clear relationship between epilepsy and anxiety, depression, spring fever and hypochondria. Patients would prove to be poorly adaptable, emotionally speaking. Their quality of life and behaviour would be seriously affected. Psychological problems would be importantly conditioned in patients with high-frequency convulsions, influencing their job, family or social relationships negatively.

Precisely the issue of the social circle of the epileptic patient, as well as the existence of old stigmas in society, is something which does not seem to let go. It is still part of our world's reality.

The Spanish dictionary defines the Word "stigma" as a "mark or sign on the body", and also "dishonor, bad reputation" "organic injury or functional disorder indicating hereditary'.

Prejudices are too common for epileptic patients, that is, a "previous and unfavourable opinion about something or somebody unknown".

In the case of epilepsy, the stigma is about the scope of social exclusion suffered by epileptics; this exclusion is based on perception, rather than actual knowledge of epilepsy [34].

Until recently (1970) epileptics were not allowed into bars or theatres. They could not even marry in 18 states. Only in 1980 the last state with this prohibition, declared that fear, and not evidence, was what led to discrimination [35].

Our findings prove that too many people don't even know what epilepsy is. Sometimes they are even affected by it, and they don't know it. One reason might be the fact that, once they were affected during their childhood, they start to feel embarrassed in their pre-teen years, feeling different, and likely to be rejected by society, partly because they may have already been.

Parents, to start with, may think this illness is something to be hidden at any cost, promoting this fear in their child. Even some doctors recommend hiding it, thus making things worse. It is essential to highlight the importance of information and training about this illness, to start preventing ignorance among professionals. They should, instead, be the main support for patients and their families [36].

In 1997 the ILAE, (International League against Epilepsy), the IBE (International Bureau for Epilepsy) and the World Health Organization (WHO) started an ambitious new Project called 'Epilepsy out of the shadows' [37]. Epilepsy is the most common and serious neurological disorder, affecting people of all races, ages, social classes, countries... The consequences are even more serious in developing countries, where 85% of epileptics live, and almost 50 million people have no Access to the right diagnosis or proper treatments [38].

There are still people who think an epileptic patient has no autonomy or can't start a family. In a survey, almost 38% were reluctant to have a relationship with an epileptic patient. It is not a magical or incurable illness, it is just chronic, just like many other illnesses, but without diminishing autonomy or other skills we may need.

Social exclusion and stigmas reach one of their peaks when we find out some children are rejected at some schools because of epilepsy. For adults, finding a partner to live with, or a job to live on becomes an oddisey, even when there's no good reason for it.

In the survey, one can see how people with a certain education do not seem to have any prejudices against epileptic patient, whereas people with a low educational level are wary of them (Novoa and Cabello, 2013) [39].

In order to set the degree of knowledge regarding epilepsy, a survey was conducted in 2017, with the following results.

Patients and Method

This is a cross study with specific questions for 84 patients of the Psychology Centre *Ismael Dorado*, attending the office during 2016 - 2017.

Subjects: Patients with at least a basic educational level, without epilepsy or a relative suffering from it.

Instrument: 8 questions, with two kinds: Yes/No questions, and a last question with two alternative answers, Psychologist/Neurologist, reflecting the most common stigmas among people who ignore this condition. The questions were the following:

1. Is epilepsy infectious?
2. Is epilepsy a mental illness?
3. Can patients swallow their own tongue during a crisis?
4. Is it necessary to hold the patient tight during a crisis?
5. Are epileptics violent?
6. Has epilepsy got a treatment?
7. Does the epileptic patient have a lower IQ then the rest?
8. Are you afraid of sharing your life/space with an epileptic person?
9. Is a psychologist/neurologist necessary?

Results

In the first question (Is epilepsy infectious?), 56 participants answered affirmatively, whereas 28 of them did negatively.

In the second question, (Is epilepsy a mental illness?), 51 participants answered affirmatively, whereas 33 of them did negatively.

In the third question, (Can patients swallow their own tongue during a crisis?), 80 participants answered affirmatively, whereas 4 of them did negatively.

In the fourth question, (Is it necessary to hold the patient tight during a crisis?), 80 participants answered affirmatively, whereas 4 of them did negatively.

In the fifth question, (Are epileptics violent?) 51 participants answered affirmatively, whereas 33 of them did negatively.

In the sixth question, (Has epilepsy got a treatment?), 17 participants answered affirmatively, whereas 67 of them did negatively.

In the seventh question, (Does the epileptic patient have a lower IQ than the rest?), 54 participants answered affirmatively, whereas 30 of them did negatively.

In the eighth question, (Are you afraid of sharing your life/space with an epileptic person?) 74 participants answered affirmatively, whereas 10 of them did negatively.

In the ninth question, (Is a psychologist/neurologist necessary?), 44 participants answered affirmatively, whereas 40 of them did negatively.

Discussion

Epilepsy patients do not have a low IQ level or any kind of psychological disorder. However, even today, people diagnosed with epilepsy live completely stigmatized, often having to hide their condition.

Between 300.000 and 400.000 people in Spain are thought to suffer from any kind of epilepsy, and 20000 new cases are estimated to be detected every year. Besides, around 70% of patients have managed to slow down the frequency of breakdowns, even giving up their medication after few years.

Stigmas are still clearly visible, all of them based on violence, ignorance, fear to coexistence with them or mental illness.

Conclusion

As we can see, there are plenty of false myths associated with the right way to act before an epileptic breakdown. We must forget the idea of "not to introduce anything inside the patient's mouth"; we must wait for the breakdown to end, remove any dangerous objects around if they have fainted, and, as soon as the breakdown seems to be over, -usually less than two minutes- lie them down sideways so they can breathe properly. We must not hold them tight so we don't hurt them.

As we can see, the stigma comes from three sources: a) ignorance, b) prejudice and c) discrimination.

Really hard work must be done, should we be interested in changing this situation. Educating people and spreading these ideas from an early age is the right choice, as our little beloved ones are sometimes nothing but the reflection of their parents' lack of knowledge.

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