

7 Sociocultural History of Epilepsy

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Short Description

Epilepsy is a chronic medical condition with many social aspects, documentations of which exist since earliest historical times. This chapter looks at a selection of topics comprising religion and superstitions, work and mobility, family, and legislation. In the broad public, superstitions and stigma have been slow to react to medical progresses. The many evolutions that modern societies have undergone had also consequences for the life of persons with epilepsy, which can be most clearly seen in the fields of work and mobility. Changes in public perceptions and attitudes occur slowly if at all, and epilepsy specialists and support organizations in several countries have begun to work toward legislations protecting the legitimate interests of patients.

Basic Characteristics

Epileptic seizures on many phylogenetic levels are a possible response of organized neuronal systems, and there is therefore little doubt that epilepsy has been present during the entire development of humankind from prehistory to the present time. It is therefore not surprising to find epilepsy mentioned in early medical texts of many diverse cultures (Temkin 1971).

Epilepsy is also a condition that rarely remains unnoticed in the social environment of the afflicted. Seizures will often occur in whatever public there is, and it is known both from history-taking from witnesses of seizures and from many literary accounts (Wolf 2006) that the unexpected confrontation with a seizure, even in a perfect stranger, often profoundly impresses the terrified observer. Early historical texts show that at a time when societies had become sufficiently organized to need written documents, canonical concepts of epilepsy had often developed and these were frequently religious.

Superstitions, Religious Beliefs, and Concepts of Epilepsy

Religious beliefs are a very important aspect of the life of societies. It is a relatively recent development, and with many restrictions, that they are considered a private matter. In early history, when much still needed to be explained about life, the realm of religious beliefs was large and included matters of health and illness. Hippocrates' polemic against the belief that epilepsy in its variable appearances was sent by gods and should be treated by purifications and

incantations (Hippocrates, around 400 BC) is recognizable in what was documented in a Babylonian cuneiform medical diagnostic series from the middle of the first millennium BC (Kinnier Wilson and Reynolds 1990). This text (entry by Bladin, ► [Medical Aspects of the History of Epilepsy](#), Fig. 6-1) describes multiple seizure types and explains them by the action (the “hand”) of different deities. It therefore would seem that the concept of seizures as sent by gods was widespread in the Mediterranean and Middle East in the first millennium BC.

Hippocrates' rationalist explanation that epilepsy was a disease with natural causes like all other diseases, and its seat was in the brain, was a major landmark for the medical history of epilepsy. However, there is still much ignorance of how profoundly it influenced and changed public views.

Although the idea of diseases sent by different deities was never reconcilable with the monotheistic religions that took over in the following period, the Hippocratic view was not acceptable either to the Christian belief. As is reflected in the story of the epileptic boy in the synoptic gospels (entry by Elzawahry, ► [The Ketogenic Diet in Epilepsies](#), Fig. 253-1), epilepsy was now seen as a possession by evil spirits, which were to be expelled by the Christ (► [Fig. 7-1](#)) and later by his representatives, the priests, in a procedure called exorcism. This view was strictly opposed to natural pathogenic causes such as the influences of moon phases (whence the term “lunatic” for a person with epilepsy). The celestial bodies were created by God and therefore good, and could not become the causes of disease. According to Church Father Origenes who discussed the matter and needed to explain why seizures tended to occur in relation to the lunar cycle, the disease spirits who had entered the sick person's body lured the moon phases and struck accordingly so the blame would not be put upon them but upon the moon (Dölger 1934).

The belief in epilepsy as a possession by evil spirits prevailed throughout the Middle Ages. Numerous works of art depict the epileptic person as someone who is being exorcised, devils leaving the body (► [Fig. 7-2](#)). But even in our modern societies, such beliefs are by no means extinct. In 1976, in Germany, Anneliese Michel, a 23-year-old student who suffered from temporal lobe epilepsy and paranoid psychosis died from starvation when she stopped to eat in a period of repeated exorcisms by two catholic priests who believed in her possession by devils. The case and the consequent lawsuit raised enormous public attention and inspired

two feature films. Even now, some public discussions and an ongoing internet debate including photo and video documentations of her exorcism (http://en.wikipedia.org/wiki/Anneliese_Michel) discuss the medical diagnosis and the assumption of a demoniac possession as two serious alternatives.

The idea of a possession is not restricted to the Christian belief but is also found in other societies, for example, Iran (Vanzan and Paladin 1992), Southeast Asia (Ismail et al. 2005), or Haiti (Carrazana et al. 1999). Induction of epilepsy by witchcraft (e.g., Njamnshi et al. 2009) is a related belief.

In a highly thought-provoking comment Margiad Evans (1909–1954), a writer who suffered from epilepsy (► Fig. 7-3), suggested that this view was not, as commonly believed, created by onlookers of seizures, but by patients themselves, since a seizure could be felt like the invasion of the body by an alien force (Evans 1952).

Another aspect of religion and epilepsy is the hope for a miraculous cure, which made many intractable sufferers of epilepsy – just as with other chronic diseases – undertake a pilgrimage to some holy place like Lourdes or Altötting (► Fig. 7-4). This is not necessarily an indication of a belief in possession but reconcilable with an understanding of epilepsy as a natural disorder originating in the brain (Wolf et al. 2007). It reflects the sick person's pious belief in God as the superhuman healing force who would listen to the intercession of the Saint whom the patient had approached (► Figs. 7-5 and ► 7-6). Superstitions were perhaps more related to magic cures that were in widespread use (Temkin 1971) and made their way even into the household of President George Washington whose stepdaughter had epilepsy (DeToledo et al. 1999).

The counterpart of these superstitions is the belief that persons with epilepsy (PWE) possess supernatural forces. Thus, among the Hmong, a mountain people of Laos, seizures are thought to be evidence that the afflicted have the power to perceive things other people cannot see, and to facilitate entering into trances; PWE in this society (and others) often become shamans (Fadiman 1997).

Work

Concerns about the ability of PWE to work appear very early. In many antique societies, the work force were the slaves, and they would be traded. Both in Assyria (Codex Hammurabi), Egypt, Greece, and probably elsewhere relevant legislation existed (Temkin 1971). If within a set time after a sale (which varied) a slave turned out to have epilepsy, the purchase could be annulled. Plato (► Fig. 7-7) in *Nomoi* (Stephanus edition 916 a,b) stipulates that if somebody sells a slave who has consumption, calculi, uncontrolled micturition, the so-called sacred disease or other generally unapparent disorders of body or soul the buyer – unless he is a physician or a ring master or unless the seller has revealed the fact beforehand – can claim annulment within 6 months,

but within 1 year in the case of the sacred disease. A group of medical experts accepted by both parties has to decide on the matter. If the seller was ignorant of the condition, the purchase will just be annulled and the sales price returned; but if the seller knew, he will have to pay back the double. The details are interesting because both incapacitating and indecent conditions are mentioned and it is not clear to which of the two kinds epilepsy belongs. But the extended observation time for epilepsy clearly indicates that Plato knew of people with infrequent seizures who were on the work market. It is not known what happened to them if they were returned. The case of beautiful Anthia cannot be considered as prototypical who in the Hellenistic novel *Abrokomes and Anthia* by Xenophon of Ephesos is kidnapped and sold to the owner of a brothel in Tarentum. In the earliest reported example of epilepsy malingering she feigns convulsive seizures, thus escapes her horrible fate and is reunited again with her lover.

In many traditional societies, work was and still is organized in and around family-based small workshops where individuals with epilepsy as well as other handicaps would somehow be integrated. In nineteenth century Europe, the development of industrialization fundamentally changed this. PWE increasingly had to compete in a work market, and often were considered unfit for a job out of concerns that seizures could cause accidents and damages to themselves, their work fellows, and their employers. The general understanding was that an “epileptic” was somebody who at any moment unpredictably could get a generalized tonic-clonic seizure that would cause all sorts of problems at work. The quasi-ubiquitous social stigma against epilepsy (Jacoby et al. 2008) had a powerful bearing on the situation, and many PWE on this background found it difficult to earn their living and conduct the independent life that was now considered normal. In the industrialized countries, concern arose especially among people of Protestant denomination with a social commitment, and this resulted in the foundation of a whole series of “epilepsy colonies” (Ewart 1892) in several countries, the first being Bethel in Bielefeld (Germany) in 1867 (► Fig. 7-8). Today many of these colonies have developed into modern and active epilepsy centers, but their original purpose was not to offer treatment but to provide a place to live and work to patients who had become socially incapacitated because of their epilepsy.

The majority of patients who then were admitted to the colonies would not be so now, and the centers' residential departments have been decreasing in size over a long period. The reason is threefold: (1) much fewer patients are resistant to our contemporary therapies, (2) many modern societies have meantime developed a sense of responsibility to integrate their handicapped citizens, including those with epilepsy, and help them to lead a life, which is as normal and rewarding as possible, and (3) much work has been done to develop a more differentiated view of epilepsy as an



Figure 7-1. Jesus Christ cures an epileptic boy. Attributed to the “Third Painter of the Glajor Gospels”, Armenia, 1st quarter of the 14th century. UCLA Digital Library Program. The chain around the boy’s waist seems to refer to the risk of falling into fire and water. In the best-known image of the scene, Raffaello Sanzio’s (1483–1520) Transfiguration of 1520 (Fig. 101-1), the body position seems to indicate that the painter has seen tonic postural seizures



Figure 7-2. Peter Paul Rubens (1577–1640): Saint Ignatius of Loyola exorcising (1617). Wien, Kunsthistorisches Museum. Note the realistic depiction of generalized tonic-clonic seizures including deep cyanosis, which seems to be based upon own observations



Figure 7-3. Margiad Evans (1909–1958)
Photo by Peter North, date unknown

incapacitating condition. A better understanding has developed that there are few jobs, which could not be taken by somebody who has seizures exclusively occurring during sleep or brief focal seizures without impairment of perception and responsiveness.

Vanguard work has been done in Germany by epilepsy specialists together with the incapacity insurances. They agreed on documents defining the availability and possible restrictions of people with different types of seizures and of different frequency for a long list of jobs in the fields of electromechanics, metal work, health care, and pedagogics (Thorbecke and Fraser 2008). If these recommendations are followed, everybody involved is fully insured against possible damages caused by seizures at the workplace. It is hoped that this experience will be followed elsewhere.

In many countries, especially the local chapters of the International Bureau for Epilepsy (IBE) have developed training for job applications to make patients more



Figure 7-4. Ex-voto from the pilgrimage of Altötting (Bavaria) depicting a child with retroversive absence. Photo by Claus Hansmann, Stockdorf

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Figure 7-5. A local epilepsy pilgrimage to the monastery St. Johann in Müstair in the Swiss Alps developed following November 16, 1838, when Katharina Willi, a 23 year old nun was miraculously cured from an undefined, prolonged and seemingly life-threatening disease with rheumatic pains and seizures. This happened after a prayer to the “Chara mamma da Dieu” before an image of the Ascension of St. Mary from 1621 by an unknown artist that had been transferred to the monastery earlier in the same year. With permission from Stiftung Pro Kloster St. Johann, Müstair, Switzerland

successful in being hired into jobs for which they are fully qualified. In spite of all these positive developments, however, excess underemployment of people with epilepsy still exists in many countries.

Mobility

Mobility is the most recent of the issues considered in this chapter, and it is related to the development of modern societies. A job today often depends on the person’s ability to drive a car, be it because the travel from home to workplace with public transport would be cumbersome or just impossible, or be it because the job by itself requires moving around by car, for example, to visit customers or to supervise constructions or other spread activities of the employer. This is one of the reasons why already a single (first) seizure can jeopardize a job.

Fitness to drive today is everywhere one of the most disputed matters related to epilepsy. The regulations vary extremely from country to country, going from the extreme of permanent exclusion even after one seizure to quite liberal regulations. In general terms, the regulations seem to be a good indicator of a country’s prevailing public attitudes toward epilepsy, for example, in cases where the regulations for syncope are much less restrictive than for epilepsy, although the relative risks of both conditions are not essentially different.

Another aspect of mobility is air travel, which has enormously increased in modern societies both for business and for leisure. Some jobs require frequent air traveling, including long distance flights, whereas being able to take holidays in remote countries is a matter of life quality. The typical concern of airlines is the occurrence of seizures or even of status epilepticus during flight. Airline policies vary greatly (Mumford and Warlow 1995) and include perfectly reasonable requests like traveling with a companion but also others such as increasing the antiepileptic drug (AED) dose before the flight that is not based on any evidence. Some companies even do not seem to accept passengers with a diagnosis of epilepsy which, again, may mostly be due to prejudice and stigma. The actual risks related to air travel have been little investigated. There is no indication that the flight in itself produces any specific risks, but especially travel to substantially different time zones may cause disturbances of sleep, which could trigger seizures in disposed patients; a slight increase of seizure frequency has been reported mostly in patients with a high baseline frequency, whereas the risk of relapse in a seizure-free patient seems to be extremely low (Trevorrow 2006). The subject is still relatively new and obviously needs both further research and further discussions to develop fully rational regulations.



Figure 7-6. São José de Ribamar is a local saint with exceptional powers in the seaside port of the same name in the state of Maranhão in the North of Brazil. Numerous ex-votos dedicated to him witness of his miraculous help in illness, tempest at sea and other adversities. Ex-votos are for sale both in the church and in a nearby shop specialized in objects of devotion. Asked about the correct ex-voto for epilepsy both the sexton in the church and the staff of the shop without hesitation recommended a waxen model of a head or, in case of small children, of a whole body. (a) The saint's grotto and statue (author's photo). (b) The church dedicated to the Saint (source: wikimedia commons). (c) Waxen models for sale as ex-votos in the church (author's photo)

Family

One of the questions many societies were concerned about was the fitness of persons with epilepsy to have their own family, and epilepsy was a legal obstacle to marriage until 1969 in Finland, and until 1999 in India (D'Souza 2004) when this legislation was abandoned due to the political action of specialists.

Such laws seem not have been ancient laws, although there were traditions that found unwise for a person with epilepsy to marry (Temkin 1971). The reasons probably were that epilepsy was frequently hereditary, especially in societies where consanguineous marriages were common, or that it was considered contagious. For men, another reason may have been the economic uncertainties that often were connected with epilepsy. Would they manage to feed a wife

and children? The story of the epileptic Marquis d'Harville, a character in *The mysteries of Paris*, Eugène Sue's social critical novel of 1834, who is twice rejected as a bridegroom in spite of his perfectly good social standing, probably reflects typical attitudes in the elevated levels of French (or European) early nineteenth century society.

But it seems that first with the advent of the eugenics movement in the late nineteenth century, and starting with the Connecticut marriage law of 1896 (<http://www.bio-medicine.org/biology-definition/Eugenics>) the matter of fitness for marriage of people with epilepsy moved from the private to the societal sphere, and it was now clearly the aspect of reproduction of people with diseases considered hereditary that prevailed. This can clearly be seen in the legislation of Nazi Germany, which did not subsume the matter under

marital law but on July 14, 1933 created a separate “Law for the prevention of progeny of sufferers from hereditary diseases” (<http://www.documentarchiv.de/ns/erbk-nws.html>) that was considered a major step forward by many international eugenicists (Allen 2002). It enforced the sterilization of people with, among others, “hereditary falling sickness” but did not forbid them to marry. If people were happy to be married to a person with whom they could not have children it was their own business.

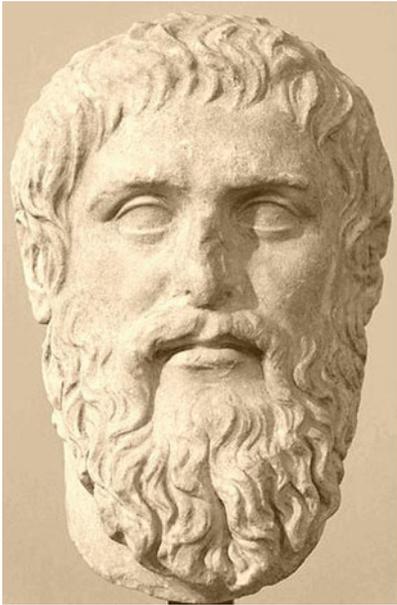


Figure 7-7. Plato. Musei Capitolini, source: wikimedia commons

About 100 years after the introduction of the first laws excluding PWE from matrimony, this legislation seems largely to have disappeared again and remained, thus, not more than a footnote in the sociocultural history of epilepsy. This, however, does not mean that there is no issue. Legislation is one aspect, public attitudes another, and quite different. Opinion polls that have been used in many countries to assess public knowledge of and attitudes about epilepsy often comprise the question if the person would allow their child to marry a person with epilepsy. These reveal substantially variable degrees of acceptance/rejection. Thus, in Jordan only 11% of the responders agreed although 71% thought that people with epilepsy could have children (Daoud et al. 2007). In the USA already in 1979 only 18% objected to having an in-law with seizures whereas in 1988 in China 87% objected, and in Hungary the objection rate between 1994 and 2000 fell from 53% to 41% (Mirnics et al. 2001). This response clearly demonstrates that regarding this question (a) enormous cultural differences exist, and (b) the public can be educated to some extent, reducing prejudices and discrimination.

Not many data are available about actual marriage rates of people with epilepsy, but where they were investigated (Canada, India, Japan, and Korea) they were found reduced, and divorce rates increased (Kim 2007; Pennell and Thompson, 2009). In Asia, most patients who got married did not disclose their condition before marriage. The same did the above-mentioned literary character Marquis d’Harville who remained silent about his epilepsy the third time he proposed, and was successful. He had learnt the lesson.

Again, however, longitudinal investigations indicate historical changes in recent times. In Canada in 1949, both men and women with epilepsy had a marriage rate of 33% as compared with an expected of 57% for men and 60% for



Figure 7-8. View from Bethel in the early 20th century. The patients lived and worked in small houses with the families of deacons who also taught them a handcraft. Courtesy Hauptarchiv der v. Bodelschwingschen Anstalten Bethel

women. Thirty years later, among the patients seen at the same center, the marriage rate of men had remained the same whereas the marriage rate of women had risen to 58%, not much below average (Dansky et al. 1980). The authors believe that the difference was there because, notwithstanding the progress in medical and social care that had happened in the interval, men had still to cope with the problems of employment in addition to their illness. This hypothesis was not investigated. However, it is safe to conclude that more than one impediment works against marriage of PWE, and that these respond differently to changes in society.

Legislation

As said above, some of the earliest historical documents regarding epilepsy are juridical, and many legal aspects have already been touched. Other areas of life that have legal implications include duty of care, informed consent, involvement in research, social interactions, insurance, recreational pursuits, and privacy (Beran 2008). Of these, health, accident, and life insurance seem to be areas where many PWE still are often exposed to unfair treatment. Insurances represent a contractual relationship between insurer and insured, and there is thus no imperative to force an insurer to cover certain risks. However, epilepsy support organizations in some countries where disability acts exist have tried to use their antidiscrimination aspects to improve insurance conditions for PWE.

Disabilities acts and similar specific legislation to protect people with handicaps have been implemented in an increasing number of countries. In principle, epilepsy is covered by these. However, epilepsy organizations in some countries found general disabilities laws insufficient for some of the typical issues related to epilepsy and have taken initiatives to obtain specific legislation. Thus, a “National Epilepsy Law” was passed by the Argentinian parliament in 2009. It is anti-discriminatory and protective and especially addresses the issues of work, education, medical care, and the implementation of a specific epilepsy program with the Ministry of Health (<http://www.cefundepi.org.ar/ley.htm>). Also in Columbia and probably other countries, legislation specifically protecting PWE is on its way.

Conclusion

There is certainly some truth in Rajendra Kale’s *bonmot* “the history of epilepsy can be summarized as 4000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma” (Kale 1997). Studying the sociocultural history of epilepsy can leave us with the impression that with respect to this condition two parallel worlds exist, one of science and medical care where enormous progress has been made, and another one of superstitions, which has been quite resistant to learning from the

numerous initiatives of public information and education. Initiatives of epilepsy organizations to take steps toward specific legislation protecting the legitimate interests of PWE are therefore timely. But it is also evident that the profound transformations that modern societies have undergone also have changed the life conditions of people with epilepsy, mostly to the better.

Related Topics

- ▶ Psychosocial Impact of Epilepsy in Children and Family
- ▶ Quality of Life in People with Epilepsy
- ▶ Stigma and Discrimination in Epilepsy
- ▶ The Impact of Epilepsy on Women

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