



In centuries past, a priest would cast out the demons that were thought to cause epilepsy.

SOCIOLOGY

Shedding the shame

Plagued by a history of fear and stigma, epilepsy has languished when it comes to research funding.

BY LAUREN GRAVITZ

Throughout history, in almost every culture, epilepsy has been viewed as something to be feared, avoided and concealed. In what is thought to be the earliest written description of the condition, dating from around 1050 BC, the Babylonians referred to it as *miqtu*, or 'the falling disease', and attributed it to ghosts and demons. The ancient Greeks called it 'the sacred disease' and believed that it resulted from divine

intervention. Epilepsy even makes appearances in the Bible, when Jesus heals a boy who suffers from seizures by casting out a 'demon'.

By 400 BC, Greek physician Hippocrates concluded that seizures are hereditary and originate in the brain, yet this view failed to become widely accepted for hundreds of years (see 'Epilepsy's past').

Today, at least in the developed world, the shame and suspicion surrounding epilepsy have eased, but they are far from a distant memory. In an oft-cited editorial in the *British*

*Medical Journal*¹, neurologist Rajendra Kale wrote: "The history of epilepsy can be summarised as 4,000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma."

Over the past century, researchers have made huge gains in the scientific understanding of epilepsy, thanks largely to technologies that allow for a deeper view of the brain's activity, such as the electroencephalogram (EEG) and magnetic resonance imaging (MRI).

Much of the stigma that people with epilepsy endure stems from the alarming nature of the most common type of seizure. These generalized tonic-clonic seizures begin with a loss of consciousness before the convulsions begin. Additional symptoms can include screaming, loss of bladder or bowel control and, on regaining consciousness, confusion and amnesia.

There is another reason for epilepsy's poor reputation. "Part of the mythology around epilepsy has been because it's episodic. That's what led, centuries ago, to the idea that someone was possessed: all of a sudden someone who looks perfectly fine had behaviour that was abnormal," says Gregory Bergey, director of the epilepsy centre at Johns Hopkins University in Baltimore, Maryland. "As we move into the twenty-first century, I'd like to think that this mythology about being possessed has been dispelled. But there are still misconceptions."

BREAKING DOWN BARRIERS

With misconceptions come fear and stigmatization. And the greater the stigma, the poorer the outcome: in people with epilepsy, feelings of shame have been strongly associated with inadequate seizure control, as well as with increased depression, anxiety and isolation.

Although prejudice is a known problem in almost every country, it may be greatest in developing nations, where religious and spiritual beliefs often trump medical understanding of the condition. "In Asia and Africa, families in low-income settings misinterpret what a seizure is, so you have an interpretation problem from the get-go," says Gretchen Birbeck, a neurologist and public-health researcher at the University of Rochester Medical Center in New York. "If someone develops a severe cough that doesn't go away, they recognize they need antibiotics or even a tuberculosis test. In that same family, if someone says something nonsensical, has a seizure and falls to the floor, they tend to think there's a possession or that the person's been cursed. They don't think there's a medical problem."

Misconceptions are not limited to family members. In Nigeria, for instance, at least 16% of health-care workers believe epilepsy is a mental-health disorder rather than a medical one. What's more, 6% of Nigeria's health-care workers believe it is contagious². With these types of mistakes, "patients aren't going to get the right treatment", says Nathalie Jette, a neurologist at the University of Calgary in

Alberta, Canada, who is currently chairing an International League Against Epilepsy task force aimed at assessing stigma in epilepsy.

Incorrect diagnoses are one of the more obvious obstacles to appropriate care, but they are not the only one. Birbeck, who studies epilepsy and other neurological disorders in developing countries, says that even when health-care providers do recognize seizures as a medical problem, family members are often loath to seek treatment. "It casts a pall on the family: if the community realizes that someone in the family has epilepsy, the siblings won't be able to find someone to marry," she says. "So do you take someone to get care or do you hide them at home?"

Even in the developed world, through most of the twentieth century epilepsy remained an affliction that people believed was best kept out of sight. "In civil societies, including the United States, it was felt you could catch epilepsy just by looking at someone having a seizure. So people were sent off to epileptic colonies," says Steven Schachter, a neurologist at Harvard Medical School in Boston, Massachusetts, and past president of the American Epilepsy Society. The last of these colonies closed only about 50 years ago.

Yet the practice may have had some benefit. "The cultural tendency and movement to isolate people with epilepsy may have had a silver lining," Schachter says. "It provided the opportunity to conduct research and move the field forward."

FUNDING GAP

For the most part, however, epilepsy's history of stigma and superstition has done more to slow research than to further it. The disease suffers from a woeful research-funding gap. "Relative to the burden and cost-effectiveness of treatability, epilepsy is incredibly neglected," Birbeck says.

In the United States, 1% of the population has epilepsy at any given time, and 2–4% of the population will have a seizure disorder at some point during their life, making epilepsy the third most common neurological disease, after stroke and Alzheimer's disease. Yet of the six most prevalent neurological conditions, epilepsy ranks fifth in funding from the US National Institutes of Health (NIH) — that level, which equalled about 40% of the funding for stroke in 2011, is decreasing every year³.

In low-income countries, the economic disparity is even more striking. There, the dearth of resources dedicated to treating the disease can be traced to an accident of medical evolution, Birbeck says. When the World Health Organization (WHO) was first established in 1948, it classified all neurological disorders, including epilepsy, as psychiatric disorders. As technologies such as brain scans and EEGs emerged, neurology and psychiatry began to split into separate disciplines. Yet although epilepsy was identified as a physical

and potentially treatable problem in the brain, funding structures at the WHO and other global ministries of health were never rearranged to reflect that new understanding, Birbeck notes. "Global health is modelled off the WHO structure, which has no neurologic section. So, in developing countries, there are psychiatrists but no neurologists," she says.

In the developed world, the misunderstandings associated with epilepsy can also be blamed for a shortage of advocacy; the stigma of the disease has often prevented people who have the disorder and their family members from coming forward to talk about their experiences. This lack of advocacy is directly related to the lack of funding. "If you look across the board at diseases and NIH funding, you're not going to find too many in which there is huge success and great breakthroughs unless there's an advocacy group behind it and a lot of push," says Susan Axelrod, one of the founders of Citizens United for Research in Epilepsy (CURE), an advocacy organization in Chicago, Illinois, that funded about US\$3.5 million of epilepsy research last year.

Despite the fact that patients with epilepsy outnumber patients with Parkinson's disease by about six to one, Parkinson's disease receives much more funding, says Axelrod. For example, the Michael J. Fox Foundation for Parkinson's Research provides about US\$50 million in research funding each year.

Axelrod and others in the field say that they have met public figures who have some form of epilepsy, or who have family members with the disease, but have not gone public because of the negative images associated with it. The early onset of the disorder means that few people have the chance to become powerful advocates.

It is a difficult cycle. Stigma begets lack of advocacy, which begets lack of funding. And researchers are unlikely to choose a field in which little or no grant money is available unless they have a deeply personal reason for doing so. But it is a cycle that many are working to break. CURE, for instance, has partnered with the Howard Hughes Medical Institute to sponsor medical students' internships in epilepsy research laboratories. Also, a growing collection of molecular targets promise enhanced medications in the future (see page S12) and even watch-like devices could help (see page S16).

"We've made some strides," Axelrod says. "I'm not fatalistic. Given how few private resources there are for this disease — and how few spokespeople — I think we're making progress." ■

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1. Kale, R. *Br. Med. J.* **315**, 2–3 (1997).
2. Ekenze, O. S. & Ndukuba, A. C. *Epilepsy Behav.* **26**, 87–90 (2013).
3. Meador, K. J., French, J., Loring, D. W. & Pennell, P. B. *Neurology* **77**, 1305–1307 (2011).

EPILEPSY'S PAST



A brutal cure for epilepsy in the Middle Ages

c. 400 BC Ancient Greek physician Hippocrates advises treatment of epilepsy with diet and drugs.

400–1400 People attribute epilepsy to demonic possession. Physicians treat epilepsy by boring holes in the skull.

c. 1800 Castration or circumcision sometimes used to treat epilepsy.

1886 English surgeon Victor Horsley performs the first epilepsy neurosurgery.

1938 Canadian neurosurgeon Kenneth McKenzie performs the first hemispherectomy for epilepsy, removing half the patient's brain.

1940 US neurosurgeons William van Wagenen and Andrew Akelaitis perform the first corpus callostomy, severing the connection between the brain halves.

1990 Lamotrigine is proved effective against epilepsy with few side effects.

2001 Canadian neurologist Samuel Wiebe publishes clinical trial results showing the benefits of surgery.

2014 Rosalind Picard and her colleagues at the Massachusetts Institute of Technology develop a wrist-worn device that detects seizures.