



Misconceptions in Epilepsy and its Differentiation from Psychogenic Nonepileptic Events in Pakistan: The Dilemma in Underdeveloped Regions

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Abstract

Epilepsy is a chronic brain disorder characterized by unpredictable seizures, significantly impacting emotional well-being and interpersonal relationships. Despite being a prevalent condition, pervasive myths and misconceptions persist, leading to stigma and societal discrimination. Disparities in epilepsy prevalence exist between affluent and impoverished nations, with higher rates observed in economically disadvantaged regions. In Pakistan, epilepsy affects over 2 million individuals, predominantly in rural areas, yet accurate diagnosis and treatment remain challenging due to limited access to specialized health care facilities and diagnostic tools like video electroencephalogram. Compounding this issue is the misdiagnosis of psychogenic nonepileptic seizures (PNES) as epilepsy, resulting in inappropriate treatments and increased health care costs. Addressing these challenges necessitates a multifaceted approach, including awareness campaigns to dispel myths, improving access to diagnostic tools and specialized care, enhancing health care provider training, and integrating epilepsy management into primary health systems. Collaboration between stakeholders, along with increased research efforts, is vital to ensure equitable access to diagnosis and treatment for epilepsy and PNES, irrespective of geographical location or socioeconomic status.

Keywords

- ▶ epilepsy
- ▶ misdiagnosis
- ▶ Pakistan
- ▶ psychogenic nonepileptic seizures (PNES)

Epilepsy is a neurological disorder that affects people of all genders, ages, and races and the incidence of epilepsy is twice as high in low-income countries as compared to high-income regions, with more than 80% of people living with epilepsy in underdeveloped countries.¹ It is a most common condition but the numerous misconceptions of the disease lead to stigma, a negative thought that can influence patients' social treatment adversely. Certain individuals hold the belief that epilepsy can be inherited, contracted from others, or transmitted through bugs or

saliva. Additionally, some attribute epilepsy to supernatural causes.²

Epidemiological research on children with epilepsy has reported that the prevalence of the disease is higher in underdeveloped countries compared to developed regions and in developing regions, the prevalence rates range from 3.6 to 44/1,000. In contrast, 3.2 to 5.5 out of every 1,000 individuals are reported from developed countries.³ In high-income countries, the rate of epilepsy is usually between 5 and 10 cases per 1,000 people.⁴ However, in low-income

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countries, many more people are affected. For instance, in India, the number of people with epilepsy is much higher than in wealthy countries.⁵ The situation is even more serious in Afghanistan, where between 0.5 and 1% of the population has epilepsy.⁶ It is estimated that around 80% of people who have seizures live in poorer or developing countries.⁷

In Pakistan, we do not have complete information, but it is estimated that over 2 million people have epilepsy, which is about 2% of the population.⁸ The rate of epilepsy in Pakistan is reported to be 9.99 per 1,000 people, and it is more common in rural areas. Some research suggests that as many as 1% of people in Pakistan could have epilepsy.⁹

Psychogenic nonepileptic seizures (PNES) are events that look like epilepsy but are not caused by the same kind of brain activity.¹⁰ Sometimes, people with PNES show brain changes that you would usually see in someone with epilepsy. This is why doctors need to be very careful when diagnosing these conditions. People who have both epilepsy and PNES are often younger or belong to a different gender group than those who only have PNES. It is believed that between 5 and 20% of people diagnosed with epilepsy have PNES, which shows that it is easy to confuse the two conditions.^{11,12} PNES is diagnosed in about 30% of patients who are sent to specialized epilepsy centers. Even with precise diagnostic tests such as video electroencephalogram (EEG), it remains uncommon to misdiagnose an epileptic seizure as PNES. However, when an individual presents with both conditions, clinicians may face challenges in determining the appropriate treatment, particularly in centers specializing in epilepsy management. PNES is notably prevalent in such specialized settings.^{11,12}

In countries like Pakistan, epilepsy is often shrouded in stigma and misinterpretation, sometimes being linked to supernatural causes such as demonic possession or witchcraft. This stigma is exacerbated by the lack of specialized epilepsy clinics and the limited availability of video EEG, which is essential for accurate diagnosis. Consequently, individuals from disadvantaged backgrounds face significant challenges in obtaining proper treatment. A common issue in medical practice is the misdiagnosis of PNES as epilepsy, with a notable percentage of patients referred to tertiary epilepsy centers for refractory epilepsy being diagnosed with PNES—ranging from 10 to 40%.¹³ This misdiagnosis can lead to inappropriate medication use, delayed access to necessary psychological therapy, and increased health care costs.^{9,14} Adding to the complexity, up to 20% of patients with PNES may also have concurrent epilepsy, making accurate diagnosis particularly challenging.¹²

Confronting the issue of epilepsy diagnosis, especially the application of video EEG, demands a comprehensive strategy. A standard digital EEG can cost between 25,000 and 90,000 Pakistani rupees, making it a significant expense, and only a handful of clinics provide this service. Video EEG, which is even more specialized, is offered by just one or two hospitals. This scarcity highlights the procedure's exclusivity and the need for skilled personnel to administer and interpret the tests properly. By overcoming these challenges, the EEG

implementation can be achieved within resource-constrained areas.

Epilepsy is a neurological disorder, whereas PNES are psychogenic in nature. PNES is often misdiagnosed due to its seizure presentation resembling epilepsy. Accurate diagnosis of epilepsy is essential for effective disease management. To address this, health care policymakers should prioritize public awareness campaigns to correct misconceptions about epilepsy and PNES. Additionally, improving access to diagnostic tools like video EEG and utilizing advanced techniques such as positron emission tomography-computed tomography, magnetoencephalography, genetic testing, and innovative surgical approaches (as referenced in studies 13 and 14) is crucial. Training health care providers to differentiate between epilepsy and PNES is vital. Furthermore, establishing more epilepsy clinics with well-equipped staff and offering psychological services for PNES patients can enhance overall care. Advocacy for health policies that integrate epilepsy management into primary health care systems is also important.

Moreover, promoting research to understand the prevalence and factors linked to epilepsy and PNES in disadvantaged areas is essential. Collaboration between governments, nonprofits, and international health agencies can facilitate the pooling of resources and expertise to tackle this global health challenge effectively. These measures can ensure that individuals receive the proper diagnosis and treatment, no matter where they live or their economic situation.

Authors' Contributions

A.K.: Made substantial contributions to the conception and design of the study, and the drafting and revising of the manuscript.

M.A.B.: Made substantial contributions to the design and implementation of the research, and the critical revision of the manuscript.

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Conflict of Interest

None declared.

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