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*Review*

# Impact of Care Gaps in Epileptic Patients in India—A Review

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**Abstract:** In India, epilepsy is often viewed with superstition, considered a curse rather than a medical condition. Unfortunately, many affected individuals never receive proper medical attention from neurologists, leading them to seek out alternative remedies, including sorcery. Presently, the number of neurologists in India stands at approximately 3000, a concerning figure given the prevalence of epilepsy, which is reported to affect 5.59 to 10 individuals per 1000. This equates to over one million epilepsy patients across the country, representing more than 1% of the total population. Alarmingly, rural areas experience a higher incidence of epilepsy, around 2%, compared to urban centres, where the incidence is approximately 0.5%. This stark contrast underscores the urgent need for improved access to neurological care, particularly in underserved regions. The term "epilepsy" originates from the Greek verb meaning "to seize" or "to get hold of," forming the basis of its etymology. In certain societies, epilepsy is still interpreted as a "penalty for involvement in a forbidden ritual," although perceptions vary among different cultural groups. Individuals diagnosed with epilepsy (PWE) often exhibit behaviours that have led some to speculate about demonic possession or past-life transgressions as causative factors. Consequently, the term "epilepsy" carries diverse social connotations, leading to variations in treatment approaches based on differing perspectives of the condition. Regrettably, some negative attitudes towards epilepsy have fueled stigma, enduring disability, and significant adverse outcomes for those living with the condition. The majority of unreported cases turn to sorcery, exacerbating the already high mortality rates associated with epilepsy disorder and status epilepticus. Various treatment modalities exist for patients with epilepsy to manage their seizures. Given the debilitating and life-altering nature of epilepsy, India offers a range of options including medications (antiepileptic drugs or AEDs), devices, and surgical interventions. When an individual receives a diagnosis of epilepsy (defined as experiencing at least two unprovoked seizures within a short timeframe), life can be dramatically impacted. Several cases highlight the challenges patients face, leading to an increase in Disability Adjusted Life Years (DALY) overall. For newly born infants, constant vigilance from the mother is essential to monitor for any signs of seizure activity around the clock. 1. When a pediatric patient is enrolled in school, their education is often profoundly disrupted. 2. Should the patient be female, her existence would undergo a profound transformation, marked by societal perceptions deeming her as unfortunate and rendering the prospect of marriage untenable. 3. Seizures in young adults precipitate job loss, thereby exacerbating societal burdens. **Conclusion:** There is a pressing need to raise awareness about epilepsy among the general populace of India. Dispelling misconceptions surrounding epilepsy is essential to steer individuals away from reliance on superstition, and instead, encourage them to seek guidance from certified specialists in nervous system disorders. Thankfully, by following the treatment regimen prescribed by a qualified neurologist, patients can significantly increase their chances of living a life free from seizures, thereby enhancing their overall quality of life and personal fulfilment.

**Keywords:** seizures; quality of life; economic burden; psychosocial impact; rehabilitation; stigma; treatment gap

## Introduction

In India, epilepsy is often shrouded in taboo, particularly prevalent among rural communities where a significant portion of patients reside. Many impoverished individuals, grappling with this condition, turn to sorcery in a belief that it is not a medical ailment but rather a manifestation of extraterrestrial influence over their actions. Consequently, there is a notable reluctance among sufferers to seek professional help from neurologists. Current data reveals that one in every 26 individuals will experience epilepsy, making it the fourth most prevalent neurological disorder globally.

Individuals afflicted with epilepsy may encounter a diverse array of side effects, owing to the multifaceted nature of the condition, which encompasses various causes and types of seizures. Beyond epilepsy itself, some individuals may contend with an assortment of seizures or additional medical conditions. These factors play a pivotal role in dictating the severity of the individual's affliction and its ramifications on their daily existence. The manifestation of a seizure is contingent upon the specific type being experienced. Certain seizures may manifest as episodes of staring, while others can induce collapse, tremors, and a loss of consciousness regarding their surroundings. [1,2]

Epilepsy can be caused by a variety of factors that affect an individual's brain. Normally, the cause is a mystery. Majorly may be caused by:

- The terrible cerebrum or head damage.
- Stroke.
- A central nervous system infection.
- Tumors of the brain

## Current Scenario

According to reports, India is home to approximately 10 million individuals with epilepsy (PWE). In our demographic, epilepsy affects roughly 1% of the population.[3] Contrary to urban areas, where the prevalence is lower at 0.6%, rural regions exhibit a higher frequency at 1.9%. [4,5] The Bangalore Metropolitan Rural Neuro-epidemiological Survey (BMRE) revealed a prevalence rate of 8.8 per 1000 individuals, with rural areas displaying a rate twice as high (11.9) as urban locales (5.7). [6] When considering the societal stigma and isolation associated with epilepsy, which exacerbates the burden of the disease, its estimated DALY-based impact accounts for 1% of the global disease burden. [7] This review article provides a comprehensive overview of epilepsy in India, alongside an examination of care gaps and their implications for the condition.

This review encompasses epidemiological evaluations, causal factors, and risk elements associated with epilepsy in India, alongside an examination of the efficacy and demand for epilepsy surgical interventions within the country. It underscores the pressing necessity to enhance epilepsy care across India, particularly given the stark contrast between the estimated 5-6 million individuals grappling with active epilepsy and the limited availability of neurologists, numbering under 2000. This need is particularly acute in rural and marginalized regions, where the prevalence of epilepsy is markedly higher. [3]

## Care Gaps

A significant disparity exists in the treatment of epilepsy, commonly referred to as the treatment gap. This phenomenon delineates the percentage of individuals afflicted with active epilepsy who either lack access to appropriate diagnostic and therapeutic interventions or receive inadequate care, relative to the entire population affected by the condition. This disparity is particularly pronounced in numerous developing nations, where individuals with epilepsy often encounter significant barriers to accessing the comprehensive treatment necessary for managing their condition effectively. [4–7]

The target group was made up of two groups: individuals who are either unable or unwilling to avail themselves of biomedical facilities for diagnosis or treatment, and among those who do, individuals who do not adhere to prescribed AEDs as instructed. This disparity is purportedly influenced by numerous factors, such as limited awareness or availability of AEDs, socioeconomic challenges, societal stigma, deeply ingrained cultural beliefs, deficiencies in healthcare infrastructure, and a shortage of proficient practitioners. Individuals with epilepsy (PWE) often succumb to superstitions and cultural customs, leading them to prefer traditional healers over allopathic physicians for their medical needs. [8–11]

In India, disparities in epilepsy treatment accessibility are evident, with gaps varying from 22% among middle-class urban dwellers to a staggering 90% in rural locales. It is imperative to pinpoint the pivotal factors influencing each community's situation and determine the most efficient allocation of resources to address this discrepancy, particularly in contexts where resources are scarce. [10,12,13]

**Table 1.** Age-specific Bangalore urban & rural prevalence data of epilepsy [3].

| | **Urban** | | **Rural** | |
|---|---|---|---|---|
| **Age range (years)** | **Population** | **Age-specific rate/100,000** | **Population** | **Age-specific rate/100,000** |
| <10 | 11,116 (22) | 495 | 12,303 (24) | 1357 |
| 11-20 | 11,476 (22) | 835 | 11,987 (23) | 1518 |
| 21-30 | 10,762 (21) | 595 | 8788 (17) | 1924 |
| 31-40 | 7883 (15) | 589 | 6719 (13) | 1086 |
| 41-50 | 5116 (10) | 332 | 4907 (10) | 978 |
| 51-60 | 2946 (6) | 339 | 3387 (7) | 886 |
| >60 | 2283 (4) | 350 | 2964 (6) | 641 |
| Total | 51,502 | | 51,055 | |

Adapted from Gourie Devi et aL, 2004(35)

### Disease Knowledge Gaps

Numerous individuals afflicted with epilepsy resort to alternative practices, including sorcery, a phenomenon that can impede their diagnosis and deter them from seeking prompt medical care, owing to the societal stigma associated with the condition. Enhancing public understanding of seizures and epilepsy through educational initiatives stands as one avenue to alleviate this stigma, possibly fostering progress in diagnosis and treatment. Various efficacious public health campaigns have been deployed for diverse ailments. [14]

Studies on epilepsy among Indians have shed light on significant themes, despite encountering potential challenges such as variations in comprehension of questions and the contextual framing of inquiries. These surveys have effectively demonstrated that epilepsy stigma persists universally across different regions, regardless of resources, levels of education, and socioeconomic status. [15]

Regrettably, executing door-to-door surveys proves arduous in numerous areas where epilepsy is burdened by substantial social stigma. Individuals grappling with epilepsy may exhibit hesitancy in divulging their medical background, particularly if they endure intermittent seizures or witness a deterioration in their condition. This reluctance stems from apprehensions surrounding societal judgement and the perception of negligible immediate gains from candidness in their responses. [16,17]

In the domain of neuroscience, particularly within the realm of stroke treatment, there has been notable success in elevating care standards through concerted efforts focused on public awareness, reinforcement of memory, and enhancement of quality. These initiatives have markedly raised the bar for the level of care provided. When crafting public awareness campaigns, it is crucial to gauge the baseline understanding of the subject among the general populace to effectively target and rectify any existing knowledge or awareness gaps. Recent findings indicate that epilepsy and seizures continue to be poorly understood by the public at large. This knowledge deficit could be addressed through educational endeavours directed at individuals living with epilepsy, their families, and wider communities, thereby playing a pivotal role in combating stigma. The correlation between epilepsy education and heightened public awareness, coupled with the reduction of stigma, underscores the substantial impact of endeavours aimed at identifying and rectifying societal misconceptions surrounding this neurological condition.. [18,19]

Recent investigations carried out in developing nations such as Pakistan have corroborated the effectiveness of initiatives aimed at augmenting public consciousness regarding epilepsy, leading to a notable reduction in both the societal stigma surrounding the condition and the treatment disparity. [20] Recent research suggests that individuals afflicted with epilepsy (PWE) require a holistic treatment approach that surpasses mere comprehension of the disorder. The importance of imparting education to individuals with epilepsy cannot be overemphasized. Despite the initiation of the Global Campaign Against Epilepsy in 1997 by the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and the World Health Organization (WHO), subsequent endeavours by the American Epilepsy Society (AES) and the National Institute of Neurological Disorders and Stroke (NINDS) in the United States have established benchmarks for epilepsy research, significantly contributing to global public awareness efforts.. [21].

## Ill Effects on Education

Early-onset epilepsy poses significant obstacles to the developmental trajectories of children, particularly in rural settings where affected individuals often face educational barriers. These impediments take diverse forms, encompassing non-enrollment in educational institutions, challenges in acquiring coping strategies, behavioural issues, drowsiness, diminished attention spans, and academic underachievement. Consequently, affected children encounter discrimination within educational settings, resulting in a decreased likelihood of completing schooling.

A multicenter hospital investigation conducted in India underscored the correlation between epilepsy and unfavourable educational outcomes, demonstrating that 26.1 percent of urban and 38.3 percent of rural patients encountered educational challenges. Notably, Bengali children with epilepsy display pronounced social deficits, evident in their limited engagement in peer activities. Unfortunately, insufficient awareness among educators and peer groups, coupled with parental attitudes, exacerbates academic deficiencies and contributes to elevated dropout rates. [22–25]

## Employment Disruption

Employment prospects frequently hinge upon successful educational attainment and the facilitation of social connections. Nonetheless, persons with epilepsy (PWE) contend with notable impediments to sustaining consistent employment. They confront a myriad of challenges within the workplace milieu, encompassing job insecurity, discriminatory practices, diminished productivity, elevated stress levels, recurrent absenteeism, and eventual dismissal from their roles. [42] Employers often exhibit reticence towards engaging PWE, thereby exacerbating the predicament. The situation is further complicated when PWE endure seizure episodes during work hours, precipitating social ostracism, relegation to lower-wage occupations, and occasionally, outright job termination.

A study conducted in Kerala unveiled that 58% of individuals afflicted with epilepsy, in contrast to 19% of the general populace, were without employment due to work-related mishaps induced by seizures, educational deficits, and fatigue stemming from the use of antiepileptic drugs (AEDs). Furthermore, over a quarter of epilepsy patients reported enduring substandard work performance and bleak employment prospects for a span exceeding three years. Amongst those under AED treatment, 20.6% were without employment, while 5.7% had lost their jobs, with a notably higher proportion observed among individuals who had ceased their medication, as documented by Das et al. [24,26,27]

## Marriage a Distant Dream

Despite the legislative amendments expunging “epilepsy” from the Hindu Marriage Act of 1955 and the Special Marriage Act, the enduring stigma associated with the condition persists, particularly concerning matrimonial affairs. Issues concerning reproductive health and child-rearing for women, alongside employment prospects and financial security for men, have emerged as prominent considerations within the framework of marriage. Agarwal et al.'s study elucidates that individuals afflicted with epilepsy (PWE) exhibit a diminished propensity for marriage vis-à-vis the general populace, encounter delayed marriage onset, especially among females, and confront an elevated incidence of divorce. [28]

In numerous regions of India, the disclosure of epilepsy among individuals (PWE) before marriage is frequently withheld due to apprehensions that it might compromise matrimonial negotiations. Santosh et al. reported that approximately 55% of epileptic patients opt to conceal their condition during matrimonial discussions. However, divulging the condition often results in escalated dowry demands or even termination of engagements. Marital unions may encounter strain or dissolution upon the revelation of epilepsy. Studies indicate that 18% of individuals who concealed their epilepsy during matrimonial proceedings ultimately underwent a divorce, while 20% resorted to living apart, and 45% grappled with mental health adversities. The occurrence of epilepsy within matrimonial bonds has been linked with unfavourable treatment outcomes, as noted by Das et al. Furthermore, apprehensions regarding progeny with epilepsy or other health complications frequently deter pregnancy post-marriage. Acknowledging the discrimination encountered by epileptic individuals, the Indian judiciary has decreed that epilepsy should not be conflated with mental illness. Consequently, the practice of divorcing individuals due to epilepsy has been vehemently denounced, owing to the advocacy endeavours of the Indian Epilepsy Association (IEA). [24,29–31]

## The Burden of Making Ends Meet

Epilepsy imposes a considerable financial burden on individuals afflicted with the condition (referred to as PWE) and their families. Economic disparities exacerbate the vulnerability of those with limited financial resources, as they encounter barriers to accessing high-quality medical care. Moreover, the disruption in the supply of free antiepileptic drugs (AEDs) in publicly funded institutions worsens the situation, placing added financial strain on individuals who must cover expenses associated with transportation and, at times, forego wages to procure essential medications.

Indirect costs encompass a broad spectrum, encompassing the loss of time, income, and productivity for both the affected individual and their family. Intangible expenses, though challenging to quantify, include personal distress, social stigma, and emotional suffering. Assessing indirect costs is complex due to inherent challenges in accounting for variables such as time away from employment, reduced productivity resulting from disability and premature mortality, and missed opportunities arising from early disengagement from educational or occupational pursuits.

Furthermore, numerous investigations overlook the direct and intangible expenses linked with accessing pre-treatment aid, managing concurrent ailments, and mitigating the adverse effects of antiepileptic drugs (AEDs). Consequently, it is anticipated that the genuine economic ramifications of epilepsy surpass prevailing estimations, emphasizing the necessity for a thorough comprehension and focused interventions to mitigate the financial strain on individuals affected by epilepsy and their families. [32,33]

**Table 2.** Epidemiology of epilepsy in India [3].

| Place, period | Investigators | Population sample | Prevalence rate per 1000 | Remarks |
|---|---|---|---|---|
| Vellore study, 1969 | Mathai | 258,576 (20%) | 9.78 (R) 7.48 (U) 8.97 | No validation survey |
| Severe Mental Morbidity Survey | Psychiatrists | 35,000 x 4 centers | 1.28-6.95 | Wide discrepancies in figures over the four centers |
| Gauribidanur study, 1982-1984 | M. Gourie-Devi, NIMHANS | 57,660 | 5.6 (R) 2.5 (U) | Systematic random sample modified WHO questionnaire |
| Urban Parsi study Bombay, 1985(39) | Bharucha | 14,010 | 4.7 (U) | WHO protocol, the particular community |
| Rural Kashmir, 1986(40) | Kaul | 63,645 | 2.47 (R) | WHO protocol |

| | | | | |
|---|---|---|---|---|
| Vasai study Bombay, 1996 | Bharucha | 16,325 | 4.8 (R) | WHO protocol |
| Rural Bengal, 1989 | S. K. Das | 37,286 | 3.06 (R) | WHO questionnaire Age-specific rates given |
| Rural Haryana, 1993 | AIIMS, Delhi | 8595 | 5.58 (R) | Epilepsy + FS |
| Yelandur study, 1991-1995(37) | K. S. Mani | 64,963 | 3.91-4.63 | Tribal population included modified ICEBERG questionnaire Incidence rate 4.93/100,000 |
| BURN, 1992-1995(36) | M. Gourie-Devi P.Satishchandra | 1,02,557 | 5.6 (U) 11.0 (R) 8.8 | Modified WHO questionnaire; TG: 50% |
| SCTIMST, Kerala 1996(38) | Radhakrishna et al. | 2,38,102 | 4.9-5.4 (R) | Separate questionnaire for epilepsy |
| Kolkata, 2003-2004(41) | S. K. Das | 52,377 | 5.57-7.63 (U) | NIMHANS questionnaire age-adjusted rates |

## Hampering Overall Quality of Life

Prejudiced societal attitudes exert profound effects not only on interpersonal dynamics encompassing matrimonial propositions, betrothals, and romantic liaisons but also impede the engagement of individuals with epilepsy (PWE) with healthcare services and impel non-adherence to treatment modalities. This impediment entails a delay in accessing medical interventions, non-compliance with therapeutic protocols, and reluctance to adopt essential lifestyle adjustments pivotal for holistic well-being. Moreover, the stigma associated with epilepsy engenders a deleterious impact on the quality of life for afflicted individuals and their kin. Familial responses to epilepsy often encompass a spectrum of emotional states including avoidance, culpability, apprehension, despondency, angst, perplexity, and desolation. [43] These emotional responses can precipitate significant psychosocial ramifications such as diminished self-assurance, withdrawal from social interactions, strained familial bonds, and, in severe instances, contemplation of self-inflicted harm. Additionally, the adverse effects of pharmacotherapy may exacerbate the overall detriment to the quality of life. [34]

## Conclusion

Epilepsy persists as a highly stigmatized condition, presenting formidable hurdles in accessing treatment and achieving a satisfactory quality of life for individuals affected by it, termed persons with epilepsy (PWE). Despite the array of Antiepileptic Drugs (AEDs) available, a substantial treatment gap persists, estimated between 50% to 70%. This disparity may arise from various factors, encompassing cultural stigma, deficiencies in healthcare infrastructure, inadequate education, ingrained beliefs, and socioeconomic constraints. Discrepancies in the management of chronic epilepsy may result from healthcare providers prescribing costly AEDs, diagnostic inaccuracies, ineffective therapeutic approaches, and suboptimal treatment adherence. A comprehensive approach to addressing epilepsy necessitates a multifaceted strategy, encompassing the enhancement of individuals' knowledge, attitudes, and behaviours. Furthermore, extensive research efforts are imperative to augment public awareness, optimize patient care, and destigmatize epilepsy, thereby empowering individuals to perceive it as a manageable condition and seek effective long-term treatment.

## Declarations

**Authors' contributions:** Rajesh Pandita drafted, and edited the manuscript, and Dr. Rachna Patel helped in reviewing. All authors read and approved the final manuscript.

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**Availability of supporting data:** Not applicable

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## List of Abbreviations

| | |
|---|---|
| **DALY** | Disability Adjusted Life Years |
| **AEDs** | Antiepileptic Drugs |
| **PWE** | People with Epilepsy |
| **ILAE** | International League Against Epilepsy |
| **AES** | American Epilepsy Society |
| **DM** | Doctorate of Medicine |
| **IBE** | International Bureau for Epilepsy |
| **NINDS** | National Institute of Neurological Disorders and Stroke |

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