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Review Article

Comprehensive Patient Education: A Distant Dream for Indian Epileptic Patients

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Abstract

Epilepsy, a chronic neurological disorder, profoundly impacts an individual's quality of life. Comprehensive patient education is pivotal in empowering patients and their families to manage epilepsy effectively. However, in India, patient education is often fragmented and inadequately delivered, leading many patients to resort to traditional beliefs and practices. This article highlights the critical gaps in patient education for epilepsy in India, underscoring the urgent need for structured and accessible educational interventions.

Recent studies indicate that the prevalence of epilepsy in India ranges from 3.0 to 11.9 per 1000 people. Despite this, government data suggests that actual prevalence rates may be higher.

In reality, epilepsy can be effectively managed with modern medicine. Unfortunately, this awareness is not widespread, particularly in rural areas where most people with epilepsy (PWE) reside, leading to poor living conditions and inadequate access to treatment. Connecting these patients with neurologists and other healthcare professionals is crucial for providing appropriate care. International guidelines emphasize that anti-epileptic drugs (AEDs) can help patients achieve lifelong seizure control, yet these guidelines are not widely implemented in India.

Public health challenges that require a comprehensive and integrated approach. Collaboration among neurologists, public health experts, psychiatrists, psychiatric sociologists, psychiatric nurses, and program managers is essential to improve patient care and rehabilitation for PWE in India. The unmet need for comprehensive patient education is critical in raising awareness about the disease and improving the quality of life for PWE. Education can lead to increased adherence to therapy, reducing the burden and improving outcomes.

Keywords: Seizure; Stigma; People with Epilepsy; Quality of Life; Patient Education

List of Abbreviations: PWE: People with Epilepsy; PVR: Psychosocial and Vocational Rehabilitation; OPD: Out Patient Department; IPHS: Indian Public Health Standards; AEDs: Anti-epilepsy Drugs; PHC: Primary Health Centers; CHC: Community Health Centers; EEG: Electroencephalogram; IEA: International Epilepsy Association; NGOs: Non-Governmental Organizations

Key Message: Epilepsy continues to pose a significant public health challenge in India due to persistent stigmatization, socio-economic disparities, and inadequate patient education. Effective patient education has the potential to enhance therapy adherence and reduce the disease burden.

Introduction

Stigma and discrimination against people with epilepsy (PWE) have persisted for centuries. Historically, epilepsy was often misinterpreted as a spiritual or divine affliction rather than a neurological disorder, leading to the inhumane treatment of individuals with epilepsy. Philosophers such as Hippocrates and Aristotle, as early as the 5th and 4th centuries, recognized the physiological origins of epilepsy, yet the illness continued to be misunderstood and stigmatized. Shockingly, even into the 20th century, individuals with epilepsy were often institutionalized and deprived of basic rights.

In recent years, global attitudes towards epilepsy have improved, with many countries enacting laws to protect the rights of PWE and reduce discrimination. However, a lack of understanding about epilepsy persists in many parts of the world, including India, where stigma remains a significant barrier to raising awareness, providing care, and improving the quality of life for those affected. Addressing this issue requires innovative communication strategies and dedicated research efforts [1,2].

The Role of Education in Epilepsy Management

Effective management of chronic diseases like epilepsy requires more than just information dissemination; it necessitates disorder literacy, which involves interpreting and comprehending information about the disease. Self-empowerment—taking responsibility for self-care, medication adherence, avoidance of triggers, and effective symptom management—is equally crucial. Unfortunately, research on enhancing knowledge about epilepsy and promoting self-empowerment remains limited, with few studies focusing on reducing seizure anxiety and improving patient outcomes [3,4].

In India, the scarcity of outpatient clinics and the absence of dedicated epilepsy nurses or educators result in patients receiving insufficient information during brief interactions with physicians. [5,6] Consequently, PWE and their families lack access to accurate, reliable, and easily understandable information. Education can significantly improve knowledge about epilepsy, boosting self-esteem, self-management skills, and attitudes towards the disease [7,8].

The Indian Context

Limited Resources

India has approximately 3,000 practicing neurologists, leading to a neurologist-to-population ratio of just 0.0002%. The overwhelming number of patients each neurologist must see daily makes it nearly impossible for clinicians to provide adequate counselling or education to every patient experiencing recurrent seizures. The perceptions and treatment of PWE by the public, family members, and society significantly impact their recovery and quality of life. Despite increasing awareness of epilepsy, negative attitudes remain widespread, further complicating the delivery of effective care [9,10].

Many primary healthcare doctors in India overuse electroencephalograms (EEGs), prescribe AEDs inappropriately and lack the necessary skills to manage AED-resistant epilepsy. This over-reliance on outdated or incorrect practices exacerbates the challenges faced by PWE in receiving appropriate care [11].

Cultural Challenges

In Kerala, a significant portion of the population relies on traditional medical practices to treat epilepsy. Additionally, many PWE attending tertiary hospitals report using complementary and alternative medical (CAM) treatments. Recent studies reveal that a substantial number of patients discontinue epilepsy treatment within a year, primarily due to a lack of understanding of the consequences of stopping treatment [12,13].

Furthermore, nearly one-fifth of the Indian population continues to believe that epilepsy is caused by evil spirits. This pervasive stigma is a major obstacle to effective epilepsy treatment and service utilization. Discriminatory attitudes in society negatively affect education, employment, marriage, and social life for PWE, discouraging them from seeking and maintaining care. These attitudes also lead to reduced availability of healthcare, treatment adherence, and lifestyle guidance, ultimately impacting overall health [14].

Stigma not only affects PWE but also their families, leading to various psychological and social repercussions, including loss of self-esteem, social isolation, and, in severe cases, suicide. Additionally, the side effects of medication can further diminish an individual's quality of life.

Challenges in the Indian Healthcare System

Population Pressure and Policy Reform

India, one of the most populous countries and the third-largest economy globally, has seen significant improvements in health outcomes over the past decade. However, the Indian healthcare system continues to contribute substantially to the global burden of disease [15,16].

The Indian healthcare system is organized into a three-tiered structure, with primary, secondary, and tertiary-level services. These services include: [17,18]

- Primary Level: Focused on rural populations through subcentres, primary health centres (PHCs), and community health centres (CHCs).
- Secondary Level: Provided at district or subdistrict-level hospitals.
- Tertiary Level: Offered at regional or central-level institutions, such as superspecialty hospitals, following Indian Public Health Standards (IPHS).

Communication Gaps

Educating patients from diverse backgrounds and languages presents significant challenges for clinicians. The lack of structured, trained healthcare support staff, such as nurses and counsellors, creates a considerable gap in patient education. There is an urgent need for Psychosocial and Vocational Rehabilitation (PVR) for PWE to enhance their employment opportunities through skill-based approaches in a non-discriminatory context. Raising awareness of epilepsy through audio-visual channels, street plays, and exhi-

bitions—particularly in schools, workplaces, and communities—holds immense potential for improving the lives of PWE. [19].

Lack of Multidisciplinary Approach

A comprehensive team comprising psychologists, social workers, health workers, primary care doctors, and neurologists trained in epilepsy care is essential for improving outcomes. Non-governmental organizations (NGOs) should be actively involved in facilitating the broader integration of PWE into mainstream society [20,21].

Addressing both the demand and supply sides of healthcare is crucial for informing, educating, and motivating individuals and professionals from diverse backgrounds through a multidisciplinary approach.

Unmet needs of Care

The shortage of specialist personnel and health facilities dedicated to epilepsy necessitates structuring services in a public health-oriented manner using existing resources. Priority should be given to building the capacity of healthcare providers, employing appropriate technology for diagnostics, ensuring uninterrupted drug delivery, and raising awareness [22].

Recent years have seen a strong push for establishing a National Epilepsy Control Program in India. This program is expected to bridge the significant treatment gap, addressing communication gaps at nearly every stage of the patient journey (Figure 1).

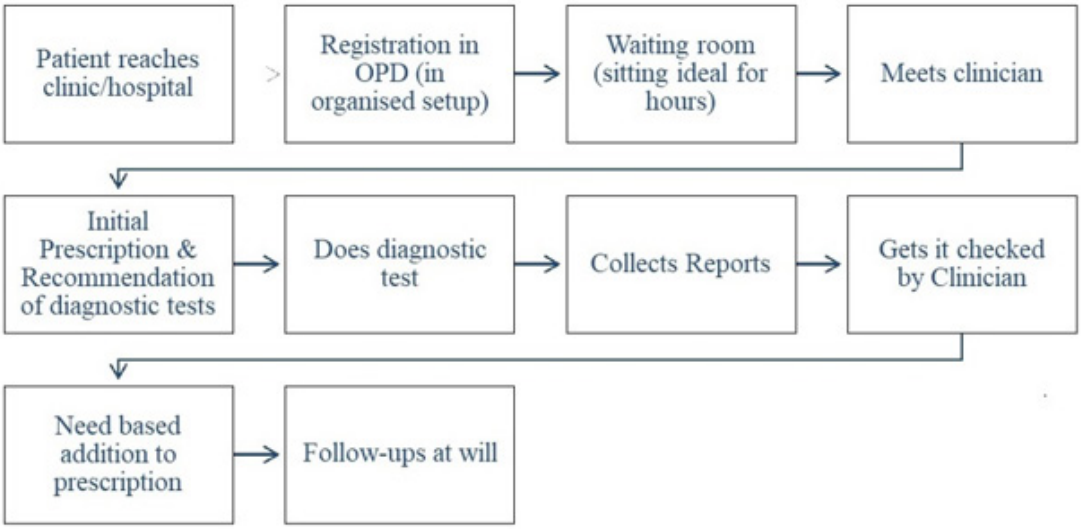

Figure 1: Patient Journey in India.

A shortage of trained staff contributes to poor clinical outcomes, highlighting the need for comprehensive patient education to improve the lives of PWE and their families.

Rehabilitation Gaps

Psychosocial and vocational rehabilitation is a key need for people with epilepsy (PWE) to enhance their chances of employment by using a skill-based method in an environment free from stigma. Raising awareness about epilepsy through audio-visual media, street plays, and exhibitions, particularly in schools, workplaces, and communities, offers a significant opportunity to enhance the quality of life for PWE. There is an urgent need for a team that includes psychologists, social workers, healthcare providers, primary care physicians, and neurologists who are trained in epilepsy care. Greater involvement of non-governmental organizations (NGOs) is also necessary to help integrate PWE more fully into mainstream society. Therefore, addressing both the demand and supply sides is essential to inform, educate, and inspire individuals and professionals from different backgrounds through a multidisciplinary approach. A diploma in epilepsy care, a correspondence course launched by the International Epilepsy Association (IEA), is a positive step toward building this capacity [31,32].

Epilepsy Care in India: Treatment Gaps

The lack of specialist personnel and dedicated health facilities for epilepsy in India necessitates the structuring of services in a manner that utilizes existing public health resources. Prioritizing the capacity building of healthcare providers, employing appropriate technology for diagnostics, ensuring the uninterrupted delivery of medications, and raising public awareness are crucial steps. A National Epilepsy Control Program is anticipated to be implemented in India soon to address the significant treatment gap [23,24].

Discussion

There is an urgent need to develop a comprehensive patient education program for individuals with epilepsy to improve their health outcomes and quality of life. Leveraging the latest advancements in tech-based patient education tools may prove pivotal for PWE [25].

The social stigma associated with epilepsy often prevents individuals from seeking timely medical evaluation. Reducing this stigma is critical, and one of the most effective strategies is increasing public awareness and education about seizures and epilepsy [26,27]. Public health campaigns have proven successful in treating various diseases, particularly in neurology, where stroke care has dramatically improved due to public awareness campaigns, education, and quality improvement measures [28,29].

Understanding the general public's perception of epilepsy through qualitative techniques is essential to direct efforts toward bridging real gaps in knowledge and understanding. Comprehensive patient education is vital to support epileptic patients, enabling them to seek treatment and live a quality life [30].

The community-based rehabilitation model faced resistance because people with epilepsy (PWE) were often categorized as having disabilities. Meanwhile, the camp approach and satellite clinic model had issues like stigma, difficulty in follow-up, and an inability to ensure a constant supply of medications. These initial challenges can be addressed through active community involvement. Although these models may be cost-effective and complementary, there have been no large-scale studies so far to evaluate their cost-effectiveness in India.

To address these challenges, a decentralized model of epilepsy care at the district level was proposed, incorporating two parallel and complementary approaches: "center to periphery" and "periphery to center." In this model, the district medical officer was considered the central figure, the neurologist as the key contact, and the primary health center medical officer as the delivery person.

In line with this, Tripathi et al. emphasized the importance of a bottom-up training and case detection approach combined with a top-down information, education, and communication (IEC) strategy [33]. A national epilepsy network and a national epilepsy surgery support program were also proposed to provide proper guidance and support for managing complex cases and to reduce the gap in surgical treatment in India.

To improve the management of epilepsy, it was suggested to strengthen and build capacity in primary care settings, implement telemedicine for managing complicated cases, expand surgical options and therapeutic drug monitoring, and provide emergency kits in various settings to handle status epilepticus [34,35,36]. These measures aim to prevent unnecessary referrals and improve the use of available services [37].

Conclusion

Despite numerous efforts to establish comprehensive patient education for Indian epileptic patients, achieving this goal remains a distant dream. Epilepsy continues to pose a significant public health challenge in India due to persistent stigmatization, socio-economic disparities, and inadequate patient education. Effective patient education has the potential to enhance therapy adherence and reduce the disease burden. This review article aims to serve as a foundation for researchers to conduct extensive studies on patient education and develop comprehensive solutions for delivering effective epilepsy education in India.

Declarations

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Conflict of Interest: None

References

1. de Boer HM (2010) Epilepsy stigma: moving from a global problem to global solutions. Seizure 19(10): 630-6.
2. Shlobin NA, Singh G, Newton CR, Sander JW (2021) Classifying epilepsy pragmatically: Past, present, and future. J Neurol Sci 427: 117515.
3. Austin JK, Huberty TJ (1993) Development of the child attitude toward illness scale. J Pediatr Psychol 18(4): 467–80.
4. Tekle-Haimanot R, Preux PM, Gerard D, Worku DK, Belay HD, et al. (2016) Impact of an educational comic book on epilepsy-related knowledge, awareness, and attitudes among school children in Ethiopia. Epilepsy Behav 61: 218–23.
5. Kim DW, Lee SK, Moon HJ, Jung KY, Chu K, et al. (2017) Surgical treatment of nonlesional neocortical epilepsy: long-term longitudinal study. JAMA Neurol 74(3): 324–31.
6. Yoo H, Kim HS (2015) Development and evaluation of the Empowering a Self-Efficacy (EASE) program for children with epilepsy. J Korean Acad Nurs 45(1): 54-63.
7. Eze CN, Ebuehi OM, Brigo F, OtteWM, Igwe SC (2015) Effect of health education on trainee teachers' knowledge, attitudes, and first aid management of epilepsy: an interventional study. Seizure 33: 46–53.
8. Limotai C, Manmen T, Urai K, Limarun C (2018) A survey of epilepsy knowledge, attitudes and practice in school-aged children in Bangkok, Thailand. Acta Neurol Scand 137(1): 38–43.
9. Al-Dossari KK, Al-Ghamdi S, Al-Zahrani J, Abdulmajeed I, Alotaibi M, et al. (2018) Public knowledge awareness and attitudes toward epilepsy in Al-Kharj Governorate Saudi Arabia. J Family Med Prim Care 7(1): 184-190.
10. Singh H, Aneja S, Unni KE, Seth A, Kumar V (2012) A study of educational underachievement in Indian children with epilepsy. Brain Dev.; 34 (6): 504-10.
11. Iyer RS,Rekha M, Kumar TS, Sarma PS, Radhakrishnan K (2011) Primary care doctors' management behavior with respect to epilepsy in Kerala, southern India. Epilepsy Behav 21: 137–42.

12. Radhakrishnan K, Pandian JD, Santhoshkumar T, Thomas SV, Deetha TD, et al. (2000) Prevalence, knowledge, attitude, and practice of epilepsy in Kerala, South India. Epilepsia.;41:1027–35.

13. Sureka RK, Sureka R (2007) Prevalence of epilepsy in rural Rajasthan - a door-to-door survey. J Assoc Physicians India 55: 741–2.

14. Thomas SV, Koshy S, Nair CR, Sarma SP (2005) Frequent seizures and polytherapy can impair quality of life in persons with epilepsy. Neurol India 53: 46–50.

15. S RP, Ramesh R, Rachel P, Chanda R, Satish N, Mohan VR, et al. (2012) Quality of life among people with epilepsy: A cross-sectional study from rural southern India. Natl Med J India 25: 261–4.

16. Kumari P, Ram D, Haque Nizamie S, Goyal N (2009) Stigma and quality of life in individuals with epilepsy: A preliminary report. Epilepsy Behav 15: 358–61.

17. Nehra A, Singla S, Bajpai S, Malviya S, Padma V, et al. (2014) Inverse relationship between stigma and quality of life in India: Is epilepsy a disabling neurological condition? Epilepsy Behav 39: 116–25.

18. Patel V, Parikh R, Nandraj S, Balasubramaniam P, Narayan K, et al. (2015) Assuring health coverage for all in India. Lancet 386: 2422–35.

19. Sinha R, Pati S (2017) Addressing the escalating burden of chronic diseases in India: Need for strengthening primary care. J Family Med Prim Care 6(4): 701-708.

20. Amudhan S, Mani K, Rai SK, Pandav CS, Krishnan A (2013) Effectiveness of demand and supply side interventions in promoting institutional deliveries - A quasi-experimental trial from rural north India. Int J Epidemiol 42: 769–80.

21. Gourie-Devi M, Satishchandra P, Gururaj G (2003) Epilepsy control program in India: A district model. Epilepsia 44: 58–62.

22. Tripathi M, Jain DC, Devi MG, Jain S, Saxena V, Chandra PS, et al. (2012) Need for a national epilepsy control program. Ann Indian Acad Neurol 15: 89–93.

23. Marcus C (2014) Strategies for improving the quality of verbal patient and family education: a review of the literature and creation of the EDUCATE model. Health Psychol Behav Med 2(1): 482-495.

24. Ma XP, Li YP, Yang R, Zhou D, Li JM (2021) Challenges of patients with epilepsy and measures for improving epilepsy care in western China: A qualitative study. Epilepsy Res 178: 106788.

25. Bray JE, Mosley I, Bailey M, Barger B, Bladin C (2011) Stroke public awareness campaigns have increased ambulance dispatches for stroke in Melbourne, Australia. Stoke 42: 2154–7.

26. Steriade C (2021) Closing the Diagnostic Gap in Epilepsy: Recognizing More Than Just Motor Seizures. Epilepsy Curr 21(3):173-174.

27. Wakefield MA, Loken B, Hornik RC (2010) Use of mass media campaigns to change health behaviour. Lancet 376:1261–71.

28. Pandita R, Patel R (2023) A scoping review in Indian post-stroke patients. Scripta Medica 54(4): 413-8.

29. Kalilani L, Faught E, Kim H, Burudpakdee C, Seetasith A, Laranjo S, et al. (2019) Assessment and effect of a gap between new-onset epilepsy diagnosis and treatment in the US. Neurology 92: e2197–e2208.

30. Pandita R, Patel R (2024) Impact of Care Gaps in Epileptic Patients in India—A Review. Preprints.

31. Amudhan S, Mani K, Rai SK, Pandav CS, Krishnan A (2013) Effectiveness of demand and supply side interventions in promoting institutional deliveries - A quasi-experimental trial from rural north India. Int J Epidemiol 42: 769–80.

32. Amudhan S, Gururaj G, Satishchandra P (2015) Epilepsy in India II: Impact, burden, and need for a multisectoral public health response. Annals of Indian Academy of Neurology 18(4): 369–381.

33. Tripathi M, Jain DC, Devi MG, Jain S, Saxena V, et al. (2012) Need for a national epilepsy control program. Ann Indian Acad Neurol 15: 89–93.

34. Gourie-Devi M, Satishchandra P, Gururaj G (2003) Epilepsy control program in India: A district model. Epilepsia 44: 58–62.

35. Rathore C, Rao MB, Radhakrishnan K (2014) National epilepsy surgery program: Realistic goals and pragmatic solutions. Neurol India 62:124–9.

36. Rathore C, Rao MB, Radhakrishnan K (2014) National epilepsy surgery program: Realistic goals and pragmatic solutions. Neurol India 62: 124–9.

37. Jeyashree K, Sinha S, Patro BK (2013) Pathway to care of epilepsy patients: Exploratory study from an urban slum in Northern India. Ann Indian Acad Neurol 16: 357–60.