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Advocating for health care insurance for people with epilepsy living in India

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Opinion

Epilepsy is a common neurological disorder worldwide. A 2017 systematic review and meta-analysis of international studies revealed an annual cumulative incidence of epilepsy of 67.77 per 100,000 persons (95% CI 56.69-81.03) and incidence rate of 61.44 per 100,000 person-years (95% CI 50.75-74.38).[1] Multiple studies have documented that the lifetime prevalence, and incidence rate of epilepsy is higher in low to middle income countries. India, the seventh largest country by area with a population of 1.425 billion is now the most populous country in the world having surpassed China in 2023.[2] The global burden of epilepsy is very high and a big chunk of this resides in India. It is estimated that nearly 12 million people with epilepsy (PWE) reside in India; contributing to nearly one-sixth of the global burden.[3]

The Global Cost of Epilepsy Task Force determined that the total cost of epilepsy, applying per person costs to the estimated 52.51 million people in the world with epilepsy and adjusting for the treatment gap, was $119.27 billion.[4] The economic burden of epilepsy in India in 2001 was determined to be in the range of INR 68.75 billion (USD, 1.7 billion).[5] Factoring in inflation likely this number today is much higher. In the same study, the annual cost of epilepsy per patient was determined to be INR 13,755 (USD, 344). Epilepsy patients incur direct costs (cost of medical consultations including cost of travel, laboratory and radiology costs) as well as indirect costs (cost due to loss of productivity and disability).[5]

In the United States most epilepsy patients are covered by commercial insurance plans. This is health insurance administered and provided by private (non-governmental) entities. Medicare, a federal government program funded by Social Security and Medicare taxes and in part by the federal budget provides coverage for epilepsy patients older than 65 years. Patients with limited income and resources are covered by Medicaid (a joint federal and state program). Veteran epilepsy patients may receive their care at VA hospitals and other locations within its system. A small number of Americans with epilepsy are uninsured and pay out of pocket for their care. Most commercial insurance plans and Medicare beneficiaries have coverage for both inpatient and outpatient epilepsy care and may also opt-in for prescription drug benefits provided by a stand-alone prescription drug plan. The Affordable Care Act, a comprehensive health care reform act enacted in March 2010, has helped get more Americans with epilepsy coverage.

As compared to the United States, coverage options for PWE living in India are dismal. Epilepsy is currently not covered by any health insurance plan in India. Further there are no government benefits such as disability which PWE can avail of. In India most insurers currently have an insert in the policy stating a permanent exclusion for epilepsy. If mental illnesses, psychological and certain hereditary disorders are determined to have caused epilepsy, some health insurance plans might cover the subsequent treatment expenses. In the United States during the COVID-19 public health emergency, insurers also covered telehealth services providing PWE living in remote areas access to specialist care. No such provision was available to PWE in India.

Given the burden of epilepsy in India, it is imperative that we advocate for comprehensive health insurance coverage for our patients. All PWE should have access to quality health care that is affordable, accessible, physician-directed, patient-centered, inclusive and equitable. We also need to strongly oppose and counter efforts to cut or limit insurance coverage for PWE. Since for the vast majority of PWE, anti-seizure medications are the most common and cost-effective treatment for controlling or reducing seizures, timely, affordable access to prescription medications within all insurance plans should be available. Telehealth coverage will help bring specialist care to PWE residing in villages and small towns across India. In spite of comprehensive insurance coverage disparities in epilepsy care persist in the United States and social determinants of health like socioeconomic status, race, ethnicity, age, gender, education level and geography negatively impact access to epilepsy care. In India these disparities are even more glaring and that is our call to action.

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Conflicts of interest

The author declares no conflicts of interest.

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