



Editorial

‘Untreated epilepsy’ – A conspiracy of silence?



Is there anyone working in the field of epilepsy who is not aware of ‘untreated epilepsy’? This is mostly a rhetorical question. Why then, does untreated epilepsy remain an elephant in the room? *Untreated* epilepsy is a loaded term. It implies that we are aware of epilepsy in our communities and that we have failed in our responsibility of providing treatment for it. Tossing around the more sanitized term – ‘treatment gap’ – shifts responsibility from doctors to nobody in particular. We discuss treatment gap ad nauseam. However, not much changes.

As is widely known, epilepsy is one of those noncommunicable diseases whose burden is largely borne by countries with a lack of resources. Of the 50 million patients with epilepsy, about 40 million are in middle- and low-income countries. Of these 40 million, up to 70% remain untreated! Untreated epilepsy is an entity for which we have reasonably effective treatment. Yet, a large majority of the patients do not get the benefit of treatment. This could simply be a matter of chance or a case of an as yet unfinished agenda on the part of the medical community. Or is this a more deliberate error of omission?

The three requirements for an effective community epilepsy primary care program are epilepsy literacy in patients, competent doctors, and easily available and affordable antiepileptic medication. In a country like India, there are a handful of epileptologists and about 2500 neurologists. How can such few doctors take care of 10 million patients with epilepsy in the country? It is the rural, poor populations that end up being the least served. Primary epilepsy care providers are urgently needed in very large numbers. With training, most health professionals could potentially be enlisted for this job. Such an initiative is likely to encounter challenges, and resistance from specialists to divest epilepsy care to nonspecialists is one of them.

What determines the likelihood of a medical entity attaining a ‘preferred’ status along with all the perks that such a status brings? For some reason, autism, HIV, and, more recently, ALS have generated popular interest along with millions of dollars. Why could not epilepsy ever catch the popular imagination? Is the sight of a hapless patient with untreated epilepsy repeatedly and unexpectedly falling down, convulsing, sustaining injuries, getting burnt, or even dying not worthy of our attention? I do not think we are so insensitive. However, to my mind, the problem stems from the fact that not many people who matter actually get to see a convulsion! Policy makers, health planners, and funders should all be shown videos of real patients, preferably in real-life situations, having seizures. I think this could clarify the seriousness of the condition far better than any other form of communication.

We have come a long way from the time when patients with epilepsy would be treated with sedating doses of bromide and phenobarbitone. Antiepileptic drugs with very few side effects and varying modes of action are now available. Newer drugs and devices continue to be researched and appear in the market at regular intervals. These are meant for the 20–30% patients with epilepsy who respond suboptimally to the available drugs. This is also where the commercial interests of big pharmaceutical companies lie. First-line drugs like phenytoin, carbamazepine, and sodium valproate that would form the mainstay of treatment in poor populations with untreated epilepsy are not likely to result in exponential business growths. Which pharmaceutical company would be seriously invested in mass producing tons of first-line antiepileptic drugs and selling them to patients in poor countries at a low cost? Could governments or the WHO play a role in this?

Epilepsy is discussed in scores of neurology as well as epilepsy meetings held all over the world every year. Scientific programs include wide ranging topics including complex molecular and genetic bases of seizures, designer drugs, simulation models for predicting seizures, and elegant surgical techniques that border on sci-fi for patients with medically refractory seizures! Ironically, there is hardly any meeting where the scourge of untreated epilepsy is given any prominence. The problem that is a reality for at least 70% of patients with epilepsy worldwide seems to fall in everybody’s blind spot. Exhibitors will not derive any benefit from untreated patients and are unlikely to show any interest in this aspect of epilepsy. Teasing out the logistics of epilepsy primary care may not be intellectually stimulating for academia either. But some reconciliatory middle ground needs to be worked out.

Who is charged with ensuring that patients with epilepsy are not deprived of treatment? Should this responsibility lie with governments, nongovernmental organizations, national and international epilepsy associations, doctors, and/or pharmaceutical companies? If patients in large numbers still remain untreated, then why do we not introspect and see where we have gone wrong? Millions of patients with epilepsy can be made seizure-free with relatively inexpensive treatment. Why are we not moving to correct this situation?

Epilepsy also needs more heroes. Everyone wants to rally around a recognized face in the name of a cause. Which Indian film actor, cricketer, politician, musician, or academician has epilepsy? I do not know. Do you? In most societies, epilepsy is only talked about in hushed tones. In most societies, epilepsy is heavily stigmatized. One carefully keeps epilepsy under wraps and makes no mention of it in public. This silence suits everyone. There is no public outrage against governments or systems that have abandoned patients.

There is no demand for access to affordable treatment by patients or caregivers. Millions of patients suffer in silence while no one is held accountable.

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EPILEPSY IN DEVELOPING COUNTRIES: PERSPECTIVES FROM INDIA

India, with a population of 1.2 billion, has an estimated 12 million persons with epilepsy (PWE). As 70% of Indians are agrarian, more PWE live in villages and small towns than in big cities. However, most doctors and hospitals providing epilepsy care are concentrated in a few large metropolitan cities. This sets the stage for many of the ills that plague epilepsy care in India.

Untreated epilepsy. Reported estimates of treatment gap between the north and south of India and also between rural and urban populations vary (table e-1 on the *Neurology*[®] Web site at Neurology.org). For the most neglected regions, a treatment gap of up to 90% has been reported. While untreated epilepsy suggests failure of the health care system, it also constitutes low-lying fruit, where it would be cost-effective to seek out, diagnose, and initiate antiepileptic drug (AED) treatment in drug-naïve patients. We know that if patients previously unexposed to AEDs are treated, at least half of them are expected to become seizure-free. In other words, the number needed to treat for such patients is 2. There are few other entities in neurology where outcome with treatment is expected to be so good. India is a young nation with more than two-thirds of the population below age 35 years. Improving treatment options and availability will empower PWE to not only improve their own lives but also participate in and contribute to society.

Consequences of untreated epilepsy. Active epilepsy with frequent seizures is dangerous, depressing, and disabling. While medical consequences of seizures are recognized more easily, the social, economic, psychological, personal, and professional fallout often escape attention. If a child has epilepsy, there is a high probability of him or her dropping out of school. Young PWE are often discriminated against when seeking employment, forcing them to remain financially dependent on family, friends, or society. Acceptance and fulfillment in a marital relationship is frequently denied to a PWE, more so if the PWE is

a woman. Stigmatization against PWE in society is widespread, deep-rooted, and pervasive. Seizures in untreated patients are often generalized and may lead to injuries and mutilation (figure). The severe disability associated with active epilepsy and frequent ongoing seizures is often forgotten or overlooked even by experts in the field.¹

What causes the treatment gap? Illiteracy, poor health awareness in general, and cultural acceptance of alternative, mostly unscientific, systems of therapy have been advanced as reasons for the treatment gap. While these may have been correct in the past and may still be true to some extent today, most Indian villages have urbanized to varying extents and information technology has made inroads in many previously insulated communities. In a survey of 200 rural PWE, all knew that epilepsy was a medical condition and 97% believed they would benefit from modern medicine.² Increasingly, the only reason that patients cite for not ever having taken treatment in spite of having had active epilepsy for decades is lack of access to a doctor. The poignancy of this bottleneck is further exaggerated because of the willingness and ability of thousands of these untreated patients to buy and consume AEDs if only they could get a prescription. While patients often know that medicines can help them, lack of information about the details of treatment, especially that treatment generally has to be continued for years, leads to a secondary treatment gap where a PWE prematurely stops treatment and loses seizure control.

Deficit in primary care. Why is it so difficult for patients in most of rural and semiurban India to consult a doctor? On paper, there is a hierarchy of functional government-run facilities responsible for primary health care needs at various levels, including villages. On the ground, however, these services are inconsistent and patchy, and there is in effect no reliable, uniform primary health care system present throughout the country. There are regional disparities, nonuniformity of available resources between states, and varying degrees of participation from public and private sectors. The cost of health

Supplemental data
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Figure **Mutilation seen in untreated epilepsy patients in the community**



Untreated epilepsy with frequent generalized seizures leads to frequent injuries, mutilation, and disability. Burns, loss of digits, loss of limbs, and dental injuries are seen in these patients.

care is largely borne by individuals and out-of-pocket health spending is currently 86%. These intricacies culminate in a tentative primary care that is not available to many. The reality for a PWE in a village is often to rely on the village quack who peddles an assortment of “remedies,” not because the PWE knows no better but more often because he or she can find no better.

The silver lining. In spite of so many problems, there is also some respite for Indian patients seeking epilepsy treatment. Most AEDs are not only available widely, easily, and consistently in the market, but there are Indian “branded generics” that are competitively priced and well within reach of the majority. Of the first-line drugs, which still form the mainstay of AED usage in India, carbamazepine, phenytoin, and valproic acid at mean adult doses would cost between \$3 and \$6 for a month’s therapy. Newer drugs are somewhat more expensive, with levetiracetam, topiramate, zonisamide, and lacosamide priced at between \$8

and \$10 for a month’s treatment. However, as the newer AEDs are generally only used as add-on therapy, the total cost of treatment when they have to be used may be out of reach of many Indian patients.

Burden of preventable epilepsy. Epilepsy need not be as big a problem as it is. In a study where 500 PWE were classified, almost 60% of patients had epilepsy due to neurocysticercosis or birth hypoxia, both of which may be prevented by improving sanitation and reducing the practice of unsupervised home deliveries, which is decreasing but still found in many rural communities. It has been demonstrated that there is a direct correlation between the prevalence of cysticercosis and epilepsy in communities. If epilepsy due to head trauma and other CNS infections is also added, India could reduce its epilepsy disease burden considerably. This, of course, requires longer term planning and actions extending far beyond the health care system.

What can be done? How can the epilepsy treatment gap in India be narrowed? For any meaningful change, there has to be an emphatic departure from the status quo and existing systems of dispensation have to be radically rethought and restructured. There is unlikely to be a numerical reconciliation anytime soon, between the number of neurologists or even physicians, practicing in India and the number that is actually needed. In the face of this extreme shortage of trained personnel who have traditionally treated epilepsy, the answer may lie in smarter triaging of patients to ensure that skill is not wasted and is used in the order that it is needed. An epileptologist or even a neurologist need not see every PWE. Primary care in epilepsy has to be nurtured, revived, and strengthened. The epilepsy workforce can be quickly expanded with previously unused health personnel including nurses³ and paramedics. Applications of technology are being tested, for example prediagnostic screening for epilepsy at the community level using a phone app⁴ and remotely following up patients who are on AEDs using mobile phones. These practices have to prove their worth and then find acceptance among both patients and the medical fraternity while other ways to use technology innovatively have to be pursued. Mobile outreach clinics have also been tried and shown to have a role.⁵

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