An Indian Perspective of the Epilepsies

Developing countries, where ~90% of the people with epilepsy reside, are least equipped to cope with the burden of care of these patients because of an unequal distribution of medical facilities and an inability of a major segment of the population to afford them. Nevertheless, during the last one and one-half decades, considerable progress has been made in the management of people with epilepsy in India. Investigation of facilities such as electroencephalography (EEG), computed tomography (CT) and magnetic resonance imaging (MRI) scans are available in most major cities. Antiepileptic drugs (AEDs), including several of the new ones are widely available. Over 1500 surgeries for medically refractory epilepsy have been performed during the last 10 years, which is several fold more than those undertaken during the previous 50 years.

The burden of epilepsy

Recent community-based surveys have shown that epidemiological indices of epilepsy in India are comparable to those from developed countries, with a prevalence rate of ~5 per 1000 and incidence rate of ~50 per 100,000. With around 1000 neurologists and ~5 million people with epilepsy, in India, there would be approximately 1 neurologist to take care of ~5000 persons with epilepsy. While 70% of the Indian population resides in rural areas, nearly all neurologists practice at or close to big cities and towns. A majority of people with epilepsy in India are therefore managed by primary and secondary care physicians with very little knowledge of the present day management of the epilepsies. In general, patients in India pay for medical care from their own resources. Epidemiological studies from rural parts of India have found that the medical treatment gap among the rural population is around 70%. Lack of medical facilities, failure to diagnose epilepsy, reluctance on the part of the patient and family to accept the diagnosis, and non-availability or non-affordability of AEDs contribute to this enormous treatment gap among the rural population.

Geographically specific epilepsy syndromes

Two epilepsy syndromes, hot water epilepsy and single small enhancing CT lesions in patients presenting with new onset focal seizures, are almost unique to India. The role of an aberrant theroregulatory system sensitive to rapid increases in temperature, coupled to a genetic susceptibility for this disorder is currently being investigated. The majority of patients remit spontaneously within few years, but spontaneous non-reflex seizures may develop in a quarter of patients. Clobazam taken orally 1-2 hours before a hot water bath has been shown to be effective in preventing the reflex seizures.

Single small enhancing lesions

Although cerebral cysticercosis is widely prevalent in several parts of the world, a single cyst seen as a small ring-enhancing CT lesion in patients presenting with new onset focal seizures, occurs almost exclusively in India. Whether this is related to low parasite load or enhanced immune status of the host is uncertain. While the majority of lesions resolve spontaneously within 3 to 6 months without any specific treatment, some may calcify leading to chronic partial epilepsy. Treatment with a single standard AED is recommended for a period of 6 months or till the lesion disappears. The role of cysticidal drugs is controversial; albendazole was not found to be beneficial in one double-blind randomized placebo-controlled study.

Diagnostic facilities

Technical standards of EEG recording and interpretation are generally poor in India because of the lack of qualified technicians and adequately trained electroencephalographers. Widespread availability of MRI in recent years has resulted in its indiscriminate usage. Many of the MRIs performed outside the selected tertiary epilepsy referral centers in India do not conform to the required technical standards and are often performed without proper indication.

Treatment of the epilepsies

Medical treatment

Among the standard AEDs, only phenobarbitone is provided by several pharmaceutical companies among primary and secondary care physicians, whose knowledge about pharmacotherapy of epilepsy is limited. This frequently results in indiscriminate treatment with these expensive AEDs in patients who cannot afford them. Unnecessary AED polypharmacy is widely prevalent. In a study conducted at a tertiary referral center, 58% of the 972 patients referred from primary and secondary care facilities were receiving multiple AEDs simultaneously at the time of referral. More than 95% of these patients were on inadequate dosages of the AEDs. Over the next two years, 72% of them were converted to monotherapy, with better seizure control, fewer side effects and reduced expenditure.

Surgical Treatment

Although the majority of patients with epilepsy are

Epidemiological studies from rural parts of India have found that the medical treatment gap, which is defined as the proportion of persons with active epilepsy in the population who have never received AED treatment, is around 70%

Neurology in India

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responsive to presently available AEDs, nearly 30% of them continue to exhibit recurrent seizures, despite optimal AED therapy, resulting in reduced quality of life and substantially increased risk of morbidity and mortality.7 Epilepsy surgery is a useful option in selected patients with AED-resistant focal epilepsies.

The first epilepsy surgery in India was performed in 1951 by Dr Jacob Chandy at the Christian Medical College, Vellore.8 During the last 10 years, there has been a revival of interest in the surgical treatment of epilepsies, with a few major centers regularly performing epilepsy surgery. Over 850 epilepsy surgeries have been undertaken at the R. Madhavan Nayar Center for Comprehensive Epilepsy Care, Trivandrum, during the last 12 years, nearly three-quarters of them for refractory temporal lobe epilepsy. The majority of patients are selected for surgery based on non-invasive selection strategies at an affordable cost without compromising patient safety and seizure outcome.9

Those medically refractory epilepsy patients who are not candidates for resective epilepsy surgery, can be offered vagal nerve stimulation or a ketogenic diet. While the cost of vagus nerve stimulation can be afforded only by a minority of patients, there are very few centres in the country practicing ketogenic dietary treatment.

Some social issues
Misunderstanding and lack of knowledge about epilepsy and the resultant discrimination against people with epilepsy are still widely prevalent in India as in any other developing country. Since it is difficult for a woman with epilepsy to get married, parents often conceal the history of epilepsy at the time of marriage negotiations.10 Preliminary data from the Kerala Registry of Epilepsy and Pregnancy revealed that nearly two-thirds of the women were not receiving folic acid supplementation at the time of conception and congenital fetal malformations occurred at a frequency of about 13%.11

Conclusions
While tremendous progress in diagnosis and treatment of persons with epilepsy has been made in India in recent years, the distribution of epilepsy care is lopsided and concentrated in urban areas. More equitable distribution of services can be achieved by establishing more comprehensive epilepsy programs in different parts of the country to reduce the medical and surgical treatment gap, and to educate the public and primary health care providers about recent trends in the management of epilepsies.

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