

Epidemiology and treatment gap of epilepsy in India

Sir,

Recently, on the basis of four meetings held by invitation of the Ministry of Health, Government of India, Tripathi *et al.*,^[1] have amply justified a proposal for a national epilepsy control program. Within their framework, and in order to make the best use of resources, it is necessary critically to assess the existing gaps in knowledge, research, and treatment and to establish priorities. The following indicates the way forward.

From 1964 onwards, multiple prevalence studies have been carried out in India with a range from 2.5 to 11.9 per 1000 population. A meta-analysis of 26 of these studies reveals a considerable heterogeneity, despite statistical correction.^[2] The heterogeneity is due to differing study methodologies, screening instruments, and definitions. Important issues include uniform case ascertainment, diagnosis, and definitions. In particular, active epilepsy should be defined according to International League Against Epilepsy ILAE criteria.^[3] Inactive epilepsy does not need treatment. Acute symptomatic seizures should not be considered as epilepsy. These need treatment of the underlying condition in their own right and management of seizures may only need to be for a short period. Neurocysticercosis and febrile seizures are probably the commonest examples in India.

There are very few incidence studies from India, and the most recent one suggests an age standardized incidence rate of 27.3/100,000 per year.^[4]

There are no population-based studies on status epilepticus (SE) in India. Hospital data is biased. Nonconvulsive status epilepticus (NCSE) is usually not identified as it requires electroencephalography (EEG) facilities in the intensive care unit (ICU) for diagnosis. In one study 10% of patients with altered mental status had NCSE.^[5] As compared with high income countries, the incidence and mortality rates of SE are likely to be higher in India, due to a higher proportion of central nervous system (CNS) infections, delay in onset to hospitalization, and lack of diagnostic and treatment facilities. Studies from Lucknow, Hyderabad, and Mumbai have amply confirmed this.^[6-8] One way of addressing the long delay to treatment would be to make more widely available the prehospital use of intramuscular or nasal or buccal midazolam.

Adequately designed population-based case control studies of epilepsy in India which focus on the usual risk factors and use imaging and serology for infections such as cysticercosis, are necessary in order to design a suitable prevention program. It will be necessary to know the odds ratio of various risk factors for epilepsy and the attributable risk of these factors. Mortality should not be the only method of assessing outcome.

One also needs to ascertain the rate of remission and relapse. The need for comprehensive epilepsy centers will be clearer once the magnitude of refractory epilepsy is known. These data are currently lacking in India.

The magnitude of epilepsy treatment gap in India ranges from 22% (urban middle income) to 90% (villages).^[9] In order to reduce this gap in the context of limited resources, it would be necessary:

- a. To specify the important cause of gap for a particular community. For example, availability of phenobarbitone versus unwillingness to seek treatment.
- b. Specify the most cost effective resource for a particular situation. For example, train more epileptologists versus train more primary health workers.

These rather extreme examples have been provided to stimulate discussion.

Finally, it should be possible for neurologists and other health care professionals to adopt districts and engage with primary health centre staff and state government health officials to identify patients with epilepsy and treat them with phenobarbitone. In Vasai area, where we have been following up and treating a very small group of 87 patients with active epilepsy since 1986, 77% of patients who are still alive at the end of 26 years have been in seizure remission for a minimum of 5 years (34/44 patients) and with the exception of one patient, are off treatment altogether (unpublished data).

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