

Some facts and figures on epilepsy

At the global level, it is estimated that there are nearly 50 million persons suffering from epilepsy of which three-fourths, i.e. 35 million, are in developing countries. It is estimated that India alone has approximately 8–10 million people suffering from epilepsy.

Epilepsy is a common health problem which carries with it a variety of medical, social, psychological and economic burdens. The impact of the disease is felt, noticed and experienced in all spheres of the patient's life and by the patient's family.

The exact number of people suffering from epilepsy in the South-East Asia Region (SEAR) Member Countries is not known. As per some studies in the Region, it is known that the problem of epilepsy varies from 2–10 per 1000 population. In other words, for every 1000 persons there will be between 2 and 10 persons suffering from epilepsy. Although all these countries collect, compile and publish health statistics, epilepsy is not included, as it is not a notifiable disorder. It is thus difficult to answer the question: "How many are suffering from epilepsy?" However, various hospital-based and community-based studies have reported that it is a commonly encountered problem. Scientists believe that among all neurological conditions, epilepsy is the second commonest condition after headache, in terms of the number of people affected.

Although epilepsy has been recognised since ancient times, a scientific understanding of the problem is recent. In India, the earliest population surveys were carried out by mental health professionals in 1964 in Pondicherry. Neurologists began to study this problem in 1980.

How common is epilepsy in South-East Asia?

India:

Studies from different parts of India reveal that the problem varies from 9/1000 in Bangalore, 5/1000 in Mumbai, 3/1000 near Calcutta to 4/1000 in New Delhi.

Sri Lanka:

In a survey in the Kandy district of Sri Lanka, it was observed that 9 out of 1000 people had epilepsy.

Thailand:

A survey of nearly 3000 people in Thailand revealed that 50 had probable epilepsy.

Bangladesh:

Though there are no national statistics, it is estimated that there are at least 1.5–2.0 million people with epilepsy.

Other SEAR Member Countries:

The problem will be similar in countries such as Bhutan, DPR Korea, Maldives and Nepal as these countries share similar sociocultural and demographic characteristics. If these figures are applied to any local population, it will be possible to know the approximate number of people requiring help in the given geographical area.

The risk of having epilepsy at some point in the average life span of any individual varies between 2% and 5%.

Unlike many other disorders, instances of death directly due to epilepsy are few. However, serious injury can occur during a seizure, such as falling into a well while drawing water, falling down a mountain, falling into a fire while cooking, or automobile accidents while driving. Such accidents during seizures can be fatal. Deaths from epilepsy occur in larger numbers in distant and remote areas as compared to urban areas, probably due to lack of care.

Epilepsy can occur in all age groups and in both genders. There is no substantial gender difference. Younger age groups are much more susceptible to new onset of seizures. Research indicates that the highest number of people with epilepsy are seen in the first twenty years of life, followed by adults and middle-aged individuals. Recent trends suggest an increasing number of elderly people having epilepsy.

The exact difference in the number of cases and the causes of seizures between urban and rural areas is not clearly known. As secondary seizures are related directly to environmental standards and issues, it is possible that the number of cases will be higher in rural areas as compared with urban areas. From a recent study in Bangalore, India, it is known that the problem is nearly 2½ times higher in rural areas as compared with urban areas. The exact reason for this rural–urban difference is not known; lack of facilities for good antenatal/postnatal care, birth injury, malnutrition and childhood infections are probably responsible. Further, as the rural population is greater in the SEAR Member Countries, the burden of epilepsy may be expected to be higher in rural areas, where access to services is limited.

Epilepsy occurs across all sections of society. While there are

no systematic studies on the subject, it is possible that a greater number of people from the lower socioeconomic sections of society will be affected by epilepsy. With improvement in living standards and environmental sanitation, there may be a shift to other strata of society. It remains unclear whether low social status is a cause or an effect of epilepsy.

Treatment gap noticed in selected SEAR Member Countries

- **Yelandur**, South India
78% untreated at first contact
- **Bangalore**, South India
10% (urban) and **24%** (rural) were not on treatment
- **Kashmir**, North India
75% not on treatment at first contact
- **Kandy**, Sri Lanka
50% initiated on treatment for the first time

Treatment gap in SEAR Member Countries

Epilepsy is eminently treatable with simple drugs in a majority of sufferers. However, there is a substantial treatment gap in many SEAR Member Countries. *The treatment gap is the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point of time, expressed as a percentage.* This definition has been developed by the Commission on Developing Countries of the International League against Epilepsy and includes diagnostic and therapeutic deficits. Studies have revealed that in most SEAR Member Countries, nearly 50%–80% of people with epilepsy either do not receive systematic treatment or do not contact any health care institutions. Among those who are on treatment, nearly 40%–70% drop out at various stages of treatment, resulting in the recurrence of seizures.

The stigma related to epilepsy emanates from the many myths and misconceptions which are being perpetuated. Thus, people with epilepsy do not want to be identified as having epilepsy, and do not come forward to obtain treatment, even in the best of situations.

Knowledge, Attitude and Practice in SEAR Member Countries

There are many studies which use different methods to evaluate knowledge, attitude and practice towards epilepsy, both in the developed and developing countries. The information is usually collected by face-to-face interviews with specific questionnaires. These KAP studies have shown that knowledge is comparable in some developing countries (India and Sri Lanka, where projects have been done) and developed countries. However, the attitude towards epilepsy in India, Indonesia and Sri Lanka is far more negative than it is in developed nations. This is probably related to the prevalent literacy rate and educational status. A contradictory case is

Kerala, a southern Indian state, where despite the high literacy rate, the attitude is extremely poor. Epilepsy is generally believed to be a mental illness there and people object to their children playing with a child with epilepsy.

Comparison of the Responses to Knowledge, Attitude & Practice Inquiry about Epilepsy in Various Countries (%)

	USA	China	North India	Taiwan	South India
Inquiry	1979	1990	1992	1995	2000
Heard or read about it	95	93	92	87	99
Is it an object to play with	6	57	43	18	11
Objection to employment	9	53	-	31	44
Is it mental illness	3	16	15	7	27
Is it hereditary	9	17	18	17	31

Adapted from K. Radhakrishnan *et al. Epilepsia* 2000; 41:1027–1035
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There are reservations about employing people with epilepsy because of the stigma rather than for safety reasons. A significant proportion of the population believe that people with epilepsy cannot pursue their education and gain employment. The educated understand that epilepsy is a treatable condition and that appropriate drugs are available, whereas the uneducated continue to believe that epilepsy is untreatable and is caused by previous bad *karma*. Many people repose their faith in alternative systems of medicine, such as Ayurveda in India and Sri Lanka, and acupuncture in Thailand.

Who treats epilepsy?

Although people in urban areas do contact specialists, family physicians play a major role in providing proper care and direction for people with epilepsy. People contact primary health centres, *taluk* hospitals, district hospitals, nursing homes and tertiary institutions, depending on their accessibility to transportation facilities and socioeconomic factors. An in-depth examination reveals that perception and belief systems of people with epilepsy and their families, availability and accessibility of care, along with utilization of services based on their convenience, often determine their compliance with suggested medication.

Epilepsy is treated by a large number of professionals in the community, for instance, general practitioners, child specialists, obstetricians and neurologists.

Rani was taken to a faith healer for the treatment of epilepsy...

Rani was a beautiful little girl of ten years living in the mountains of Almora district. Unfortunately, she developed epilepsy. Her parents consulted the village leader who said she was possessed by evil spirits and must be immediately taken to a faith healer. Rani and her parents travelled for three days to a remote mountain cave in search of this famous faith healer. The healer tied Rani's feet with a rope and hung her upside down from a tree. Rani cried bitterly but the faith healer explained that the evil spirits would be driven out by her crying. Unfortunately, Rani died after ten minutes of being hung upside down. The faith healer proclaimed it to be the will of God.

Role of faith healer and indigenous systems of medicine

Traditional healers play a major role, as they provide a substantial proportion of care in rural areas. People in Bangladesh and Thailand continue to seek care from faith healers such as "*fakirs*" or "*monks*" before going to a hospital. Patients in Sri Lanka choose to go to a traditional healer, rather than to a modern doctor. These faith healers have strong social and religious connections and they play a very important but negative role in the management of epilepsy. A survey in Sri Lanka revealed that local traditional healers, in spite of the availability of a state-run free health service, were treating nearly 50% of the patients. Epilepsy is also considered an effect of past "*karma*" and 20%–30% of patients and families believe in religious or supernatural powers. In India, it continues to be related to supernatural powers and influences, both in terms of cause and cure. A study in India revealed that 12% believed in this cause, particularly in rural areas. In SEAR Member Countries, practitioners of Ayurvedic, Homoeopathic, Chinese, Siddha and Unani systems are involved to a great extent in epilepsy care. Unfortunately, many unscrupulous healers and manufacturers of indigenous systems of medicine abuse these systems for monetary gains, much to the detriment of the patient.

