

Need for a national epilepsy control program

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Abstract

This article briefly outlines the proposed national epilepsy control program. The content of the article is based on four meetings held by invitation of the Ministry of Health. Invitees by ministry – Drs. D. C. Jain, M. Gourie Devi, V. Saxena, S. Jain, P. Satish. Chandra, M. Gupta, K. Bala, V. Puri, K. S. Anand, S. Gulati, S. Johri, P. S. Chandra, M. Behari, K. Radhakrishnan, D. Bachani. Presentations were made by Dr. M. Tripathi. The program will involve all neurologists across the country in teaching and training at state levels and a central monitoring committee.

Key Words

Control, epilepsy, India, national, program

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Section 1

Magnitude of the problem

Epilepsy is one of the most common neurological disorders. It is estimated that there are more than 10 million persons with epilepsy (PWE) in India. Its prevalence is about 1% of our population,^[1] this being higher in the rural (1.9%) as compared with the urban population (0.6%).^[2,3] In the Bangalore Urban Rural Neuro-Epidemiological Survey (BURNs), a task force project supported by the Indian Council of Medical Research (ICMR) covering a population of 102,557, a prevalence rate of 8.8 per 1,000 population was observed, with the rate in rural communities (11.9) being twice that of urban areas (5.7).^[4] Because the prevalence of the disease in rural areas is twice that of the urban areas, there is much need to strengthen epilepsy services in the rural and underserved areas. The burden of epilepsy as estimated using the disability-adjusted life years (DALYs) accounts for 1% of the total burden of disease in the world, excluding that due to social stigma and isolation, which PWE in our country face, this in turn leads to escalation of the disease burden.^[5]

Epilepsy is not benign, especially if not treated. Injury and death can result from poorly treated or untreated epilepsy. Status epilepticus (SE) is a serious and potentially life-threatening complication of epilepsy. Clinicopathological data on 100 patients from a developing country perspective showed that 65% of the patients presented for the first time as SE. Majority of the patients (75%) had generalized convulsive seizures. Patients with prior history of epilepsy (35%) had discontinued treatment in 71.4% cases, resulting in SE.^[6] In a study conducted in Delhi, out of 451 patients, 30 (6.65%) were found to develop SE,^[7] and in another study of 243 patients, it was 84 (38%).^[8]

Mortality in epilepsy

Banerjee *et al* in their study done in Kolkata of 309 incidence and 66 prevalence cases found 20 deaths. Banerjee *et al.*^[9] in Kolkata, 309 incidence and 66 prevalence cases were studied. The annual mortality rate estimated in the study was about 7.63/100,000. The Standardized Mortality Ratio (SMR) was found to be 2.58/100,000. Mortality rate due to SE is reported to be 29%.^[10,11] Sudden death due to the disease varies widely between 2 and 18%.^[12] It is estimated that nearly 2–3 lakh

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Editor Note

This paper by Tripathi *et al* addresses the important issue of coordinated efforts at the national level towards controlling epilepsy. Comments and suggestions on the proposed epilepsy control programme are invited, as it reaches finalization.

patients may die due to epilepsy if they remain untreated. A case-control study design from the US mortality data study on epilepsy showed the association of mental retardation, cerebral palsy, cerebrovascular disease, myocardial ischemia, dementia, foreign body in pharynx and larynx, pneumonia, alcoholism and cirrhosis of liver with epilepsy at the time of death of epilepsy patients.^[13]

Stigma associated with the disease

Stigma is referred to as a severe social disapproval of personal characteristics or beliefs that are against cultural norms. PWE face stigma in many communities. Radhakrishnan *et al.*^[14] studied a total of 1,175 persons. Among these, 31% thought epilepsy to be a hereditary disorder, 27% a form of insanity, 40% were denied employment due to their condition, 11% of the parents did not allow their child to play with children with epilepsy and 55% of the women concealed their epilepsy during marriage negotiations.^[15] Out of those who concealed, 18% were legally divorced and 20% were separated from their spouses because of the disease. These studies reflect different aspects of stigma associated with epilepsy.

Cost of epilepsy (Economic burden)

The treatment of epilepsy involves both direct and indirect costs. Direct cost includes the cost of the hospitalization, treatment, medicines, home care and ancillary services. The indirect costs include loss of time and productivity, the income lost by family members and the foregone leisure time. The cost attributed to pain, suffering and social stigma comes under intangible costs. The direct and the indirect cost of treatment represented 27.1 and 72.9% of the total cost, respectively.^[16]

Krishnan *et al.*^[17] studied 184 patients and found that the annual cost per capita was 27.51 USD. 79.2% of the patients in the study had been given monotherapy, and the first choice of the antiepileptic drug (AED) was phenytoin (PHT) (93%). Radhakrishnan *et al.*^[18] studied 972 outpatients and found the annual cost per capita at about \$47.73. 76.4% patients had been given the monotherapy. The first choice of the AED was Carbamazepine (CBZ) in 44.2%, Valproic acid (VPA) and PHT in 20% cases. Only about 1% were treated with newer AEDs. Two hundred and eighty-five outpatients were studied by Thomas in 2001^[19]; in this study about \$344 was the annual cost of epilepsy per patient. The direct cost was \$93 and the indirect cost was \$251.

Indirect costs increase if the patient does not undergo effective treatment, and a small effort in alleviating the direct costs would bring down the total cost of treatment, including the indirect one.

Table 1: Reasons for unemployment in persons with epilepsy

Reason	Number (%)
Seizure-related falls	34 (29.1)
Fatigue/drowsiness due to AEDs	46 (22.8)
Fear of seizures in workplace	44 (21.8)
Low education because of epilepsy	41 (20.3)
Frequent seizures	36 (17.8)
Denied job because of epilepsy	32 (15.8)
Lack of motivation to do job	32 (15.8)

Unemployment and epilepsy

Many PWE have difficulty getting and retaining jobs. The various reasons for unemployment in PWE in a study from Kerala are summarized in the table given below [Table 1].^[20]

This reiterates that PWE could lead a meaningful life if they were not falling due to seizures at workplace and if employers received education about their problem.

Justification of program

Treatment gap despite availability of medicines in India

Treatment gap in epilepsy is broadly classified into primary and secondary. About 78% of the PWE are affected by this gap.^[21] The treatment gap varies from 50 to 70% among persons with epilepsy.^[22] In a highly literate population of Kerala, a treatment gap of 38% has been found.^[23] Hackett *et al.*^[24] in 1997 found a treatment gap of 50% in Calicut district of Kerala. In the Kuthar valley of south Kashmir, it was 75%.^[25] Sixty-five percent treatment gap was found in the Baruipur block of West Bengal.^[26] A very high treatment gap of 90% was found in West Bengal districts.^[27] More treatment gap in epilepsy results in SE, death, stigma, loss of quality of life and social alienation.

Various reasons have been given for the discontinuation of treatment leading to the treatment gap. Ninety percent of the patients discontinue due to the cost factor, 21% due to unemployment, 20% due to frustration, 21% due to lack of medicines and 10% due to marital disharmony.^[28] Treatment gap has been found to be higher in the rural areas and in the low-income countries as per WHO.

Problems faced by the health care professionals in managing epilepsy in hugely populated rural, underserved, remote areas of India are lack of diagnostic facilities (51.9%), treatment compliance (28.2%), non-availability of new AEDs (17.3%), lack of educational services (17.3%), training (40.4%) and non-availability of epilepsy surgery by 17.3%.^[29]

Affordable treatment is available

Fortunately inexpensive and a good number of AEDs are available in India. Phenobarbitone has been the first choice of treatment in 96% of the developing countries, PHT in 68.2%, CBZ in 42.6% and Valproic Acid in 22.5%.^[30] Sixty percent of the patients remain free from seizures on their first appropriate drug, and prefix an additional 13% on a combination of two drugs. In other words, 70–80% of PWE are controlled with one to two medicines.^[31] Ninety percent of seizure-free patients took only a moderate dose of AEDs.^[32] If a PWE has been properly treated, it would result in a seizure-free good quality of life. The PWE would gain education, which would take care of personal or social stigma- gradually the unnecessary cost of the treatment and burden would be curtailed by providing medication.

There is hence an urgent need to formulate a national epilepsy program and the objective of this paper is to stimulate interest in developing such a program at the governmental level subsequent to the meetings held by ministry of health to generate such a program.

Objectives of the program

- To promote public awareness about epilepsy: alleviation of myths and misconceptions, and enhance prevention.
- To reduce the treatment gap of epilepsy in India.
- To build capacity at all levels of human resource for the management of epilepsy.

Strategies

Training

Health workers in the community can be effectively trained to identify PWE and persuade them to seek treatment. Medical officers at Primary Health Care Centers (PHCs), Community Health Care Centers (CHCs) and Physicians at District Hospitals (DH) will be trained for public health aspects, prevention, differential diagnosis and diagnosis of epilepsy. Doctors will receive training by the GEMIND^[33] (Guidelines for epilepsy management in India) formulated by the Indian Epilepsy Society (IES) and ETP (Epilepsy Teaching Program) for physicians. Epilepsy conclaves for postgraduates and neurology practitioners. The training will encompass various aspects of rational management of epilepsy and motivate for a reduction in the treatment gap of epilepsy. A district team will be trained as trainers on all aspects stated (public health aspects, prevention, differential diagnosis and diagnosis of epilepsy, febrile convulsions, etc.) who in turn will provide training to the PHC doctors on essential components. Thus, the emphasis will be to "train the trainers -TOT."^[34] TOT will be done by neurologists from Tertiary Care and State Medical Colleges

having neurologists [Figure 1]. Personnel involved in monitoring and data collection will also be trained in the use of various scales for monitoring change and impact.

Awareness generation

It is possible to prevent many causes of epilepsy in our country.^[35] Intensive health awareness campaigns will be carried out to promote public awareness about epilepsy, its prevention, benefits of treatment, myths and misconceptions, etc. Communication needs assessment will be carried out to understand gaps in knowledge and attitude toward epilepsy and treatment practices. Awareness will be through multimedia, including print and electronic media (film on epilepsy developed by the IES-IEA-18th IEC trust). The railway network, state and central health facilities will be utilised. Messages will be disseminated through advertisements in public places, transportation and street plays. The role of the chapters of the Indian Epilepsy Association (IEA) will be harnessed.

Provision of medicines

After training the medical personnel on dosage schedules and adverse events, a free supply of AEDs will be provided to ensure the management of PWE. First line of drugs will be made available at selected PHCs, CHCs and all District Hospitals. Both first and second line of drugs can be prescribed at Medical Colleges and Tertiary Care Hospitals. Considering the life-threatening implications of SE, training about the management of SE and improving management of SE in emergency rooms,

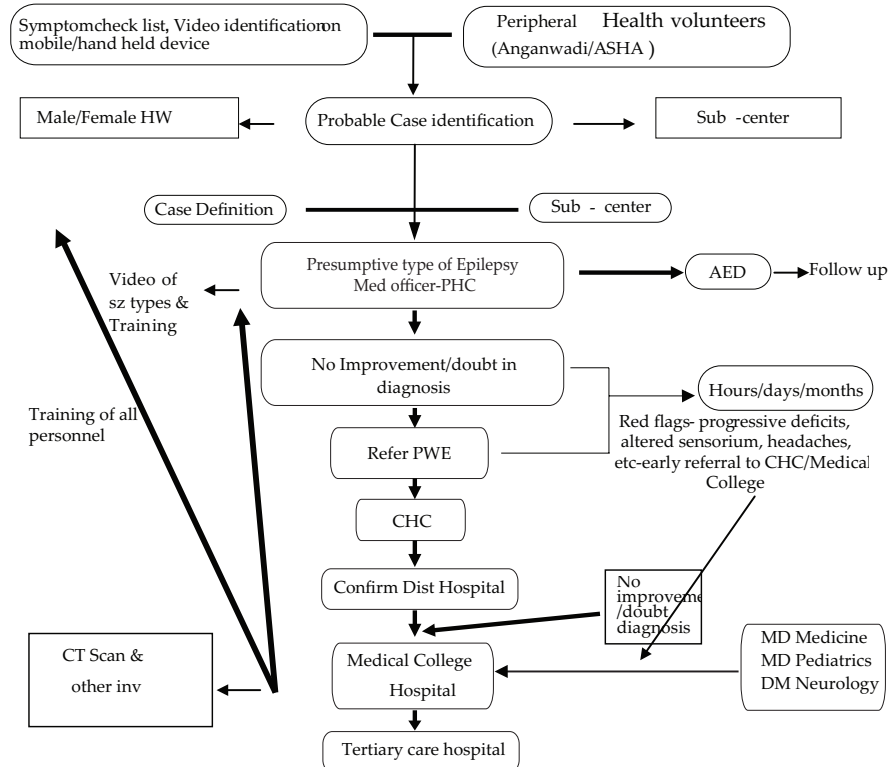


Figure 1: Flow chart for patient follow-up and training Bottom up approach; (*Case definition: Anand et al., Seizures in both adults and children, special populations like women with epilepsy and children will need care by district and medical colleges to address special needs in management).^[36]

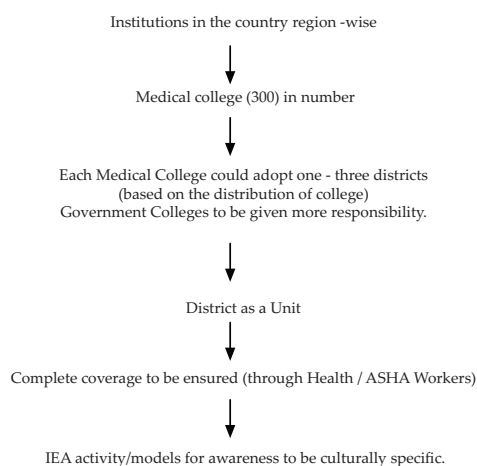


Figure 2: Top down

domiciliary setting and availability of AEDs for SE will be included in the programme especially because of commonness of CNS infections in our country.

Strengthening medical colleges/district hospital

Government Medical Colleges/District Hospitals will be strengthened with portable EEG machines and a Technician (after training workshops carried out by the IES and training courses). Each medical college will cater to four to five districts. The role of the medical colleges will be in diagnosis, management and training for epilepsy. A neurologist and a technician from the medical college will visit the district hospitals periodically for EEG and management of PWE [Figure 2].

Continued identification and follow-up of patients who are drug refractory through a referral system from primary level to secondary/tertiary level hospitals will be developed under the programme. The governments decision to increase the number of postgraduate seats in neurology (as also in all other disciplines) is a step forward in promoting care for people with epilepsy in India. So is the thought of making a years posting in rural areas compulsory.

Medicines to treat epilepsy are not costly and, hence, an approximate cost of the medicines has been provided for in the proposal. There is hence a need to increase the budget allocated to healthcare costs associated with epilepsy in the ensuing 5-year plan.

Programme indicators

The National programme on epilepsy will be monitored and evaluated on the following indicators: Physicians and the doctors at the PHCs, CHCs and District Hospital trained for management of epilepsy.

- Number and characteristics of patients diagnosed and provided AEDs.
- Impact in terms of pre- and post-program monitoring on parameters of employment, marriage, quality of life, injuries and deaths.
- Regular bioavailability study of the medication provided will be done at random intervals.

Continuous monitoring will be necessary at the District, State and Central levels through review meetings and field observations.

There is already a lot of ground work that has been done to develop training modules for nurses, paramedical staff, physicians and neurology residents by the combined efforts of the IES, IEA and the epilepsy trust. A combined partnership between the government and epilepsy bodies in the country will go a long way to reduce treatment gap.

The success of the program will depend on the implementation of trained dedicated personnel determined to bring about a change in the treatment gap and quality of life in PWE.

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