

Epilepsy Services in Rural India- Maharashtra Model of Total Care

Nirmal Surya¹, Hitav Someshwar¹ and Balaji Patil²

¹Epilepsy Foundation India, India

²Eisai Pharmaceuticals India Pvt Ltd, India

Epilepsy is a central nervous system (neurological) disorder in which brain activity becomes abnormal, causing seizures or periods of unusual behavior, sensations, and sometimes loss of consciousness. Epilepsy is a major public health concern affecting people of all races, castes, creeds and genders around the world. It has been estimated that almost 50 million people worldwide are living with epilepsy. Epilepsy seizures are broadly classified as Focal onset, General onset & Unknown onset.

Epilepsy in Rural India

Variable prevalence rate at different times and places has been shown in several studies in India. To interpret the results of earlier studies, which consistently reported lower prevalence rates, temporary trends and increased mortality rates must be seen aside methodological

questions. The prevalence rates of epilepsy between adults and elderly individuals range from 1.2 to 11.9 per 1,000 population, except the study, which indicated a five-year prevalence of 22.2 per 1,000 population in children aged 8-12 years. Some research has shown that active epilepsy has predominantly been identified as the number of people with epilepsy per thousand people at the time of the study. Recent prevalence studies suggest that 80% of these patients live in middle- or lower-income countries, of which 75 % do not receive treatment. The cause of this treatment gap is attributed towards lack of trained staff, poor access to anti-epileptic medicines, stigma related to the condition, poverty and poor access to healthcare. This causes a 3-6 times increase in premature death risk in patients with epilepsy. Approx 110 lakh patients of epilepsy are living in India. (Senthil Amudhan, 2015 Jul-Sep; 18(3):)

Author	Year of publication	Place of study	Sample	Study instrument	Prevalence per1,000	Remarks
Pandey <i>et al.</i> ^[64]	2014	Chandigarh	3,684 children aged 1-18 years	Modified Placencia's screening questionnaires	6.2	6.99 for rural area, 5.48 for urban area, and 4.07 for active epilepsy. ILAE case definition was used
Shah <i>et al.</i> ^[67]	2009	Kashmir	15,218 children aged 6-18 years	A pre-structured questionnaire	3.2	Rural rate was 3.9 and urban rate was 2.96. ILAE case definition was used
Rajshekhara <i>et al.</i> ^[68]	2006	Vellore, Tamil Nadu	50,617 subjects through cluster sampling	Modified WHO protocol	3.8	Prevalence in the urban clusters more than twice that in the rural clusters (6.23 vs 3.04/1,000). NCC is the cause of nearly one-third of all cases in both the urban and rural regions
Srinath <i>et al.</i> ^[69]	2005	Bangalore, Karnataka	2,064 children aged 0-16 years through stratified random sampling	Multiple screening tools	10 (children aged 0-3 years) 7.0 (children aged 4-16 years)	The screening stage was followed by a detailed evaluation stage with use of ICD-10 DCR criteria. The rates were higher for rural followed by slum and urban
Gourie-Devi <i>et al.</i> ^[70]	2004	Bangalore, Karnataka	102,572 through two-stage stratified random sampling	Modified WHO protocol	8.8	The overall age-adjusted rate was 8.3/1,000. The prevalence was 11.9/1,000 for rural areas and 5.7/1,000 for urban areas
Hackett <i>et al.</i> ^[71]	1997	Calicut, Kerala	1,172 children aged 8-12 years through two-stage H-H survey	Modified Rose's screening questionnaires	22.2	Five-year period prevalence was reported
Gourie-Devi <i>et al.</i> ^[72]	1987	Gowribidanur, Karnataka	576,60 subjects through H-H survey	NEPSIG: Modified WHO screening questionnaire	4.6	Screening was followed by clinical examination. The semiurban rate was 2.5/1,000 and rural rate was 5.6/1,000
Mathai ^[74]	1971	Vellore, Tamil Nadu	258,576 subjects through a door-to-door survey	Elaborate checklist on seizure symptoms	8.97	The prevalence was 9.8/1,000 for rural areas and 7.5/1,000 for urban areas
Dube ^[73]	1970	Agra, Uttar Pradesh	29,468 subjects through H-H survey	No objective screening questionnaire	2.3 (active epilepsy) 3.2 (lifetime prevalence)	A team of psychologist, social worker, field investigator, and statistician did the initial screening which was not objective. Suspected cases were confirmed by psychiatrist

WHO = World Health Organization, ICD-10 DCR = International Classification of Diseases, 10th revision, Diagnostic Criteria for Research, ILAE = International League Against Epilepsy, NCC = Neurocysticercosis, H-H = House-to-house

Fig. shows (Adapted from Ann Indian Acad Neurol. 2015 Jul-Sep; 18(3): 263-277)

Psychology and Psychiatry: Open access

Extended Abstract

Open Access

The number of patients of epilepsy are more than the number of cancer and HIV patients, but the funds allotted by the government is less for epilepsy in addition to it no national policy as well in place.

Epilepsy Foundation

There are a few NGOs that work in the Epilepsy field. Epilepsy Foundation India is one such NGO that works in this area and is trying to reach ends for the good of epilepsy patients. Established in 2009, this NGO aims to manage patients with epilepsy, spread awareness about epilepsy and train health care workers to provide these patients with better treatment. In 2011, the Epilepsy Foundation together with Maharashtra's National Health Mission Government formed a public-private partnership to identify and treat epileptic patients in Maharashtra's rural districts. The free detection and treatment camps aimed at identifying and treating patients in rural Maharashtra districts, abolishing myths and misconceptions about epilepsy by disseminating awareness through print media, street plays and interactions with social workers, and the last and most important is to train primary health care workers in the diagnosis and treatment of epilepsy to reduce the gap. Through such camps a multidisciplinary team headed by a neurologist travels to various districts of Maharashtra, a team of pediatricians, neurosurgeons, physiotherapists, occupational therapists, speech and language pathologists, clinical psychologists, cognitive therapists, EEG technicians. Epilepsy patients have various co-morbidities or complications that are secondary to complications such as physical, mental, cognitive, cultural, eating, psychological, and emotional disorders. Thus, our model includes a multidisciplinary comprehensive epilepsy care providing a holistic approach for better patient outcome and prognosis. The NGO has made various anti-epileptic medications available through these camps for patients in the rural districts of Maharashtra. Each patient visiting the camp receives three months of free medication for epilepsy and another dose of 3 months of medication is given once again after follow-up. Epilepsy and a further 3-month dose of medication are again administered following follow-up. Social stigma, misconceptions, false beliefs and discrimination against people with epilepsy are the main reason why people in the earlier stages do not seek help. The NGO seeks to educate the public while abolishing the stigma and discrimination against epilepsy by people with epilepsy seeking care early and there are no psychological and emotional disruptions. Educating the public on how to look after people with epilepsy during a seizure outbreak will help avoid problems during seizures. Follow up of patients was a major challenge posed during the early years which was resolved by conducting telemedicine through the government run hospitals and the epilepsy foundation clinic in Mumbai. Rehabilitation services were also provided using telerehabilitation by incorporating family based rehabilitation. Training of healthcare workers happened in various stages. Monthly Sessions for continuing medical education was conducted at the rural hospital on the camp date by a team of neurologist, pediatrician and neurosurgeon for the whole day. These CMEs are accredited 2 points by the Maharashtra medical council. Annually hands on training workshop are organized for management of epilepsy by eminent neurologist and epilepsy specialist, this helps in educating the health care workers to treat epilepsy patients. The NGO organized for training courses through online webinars over a period of 7 days. The NGO also educates and trains members of different NGOs for managing patients during an acute episode of seizure. The NGO and National Health mission government of Maharashtra provides EEG, MRI, CT scan, Blood levels, BERA and any other tests free of costs for patients with epilepsy. The NGO aims to establish ten regional epilepsy centers for regular treatment and

follow-up of patients with epilepsy in various Maharashtra districts. This model has been running successfully since the last 7 years. A total of 69 camps were held, a total of 26137 patients were diagnosed, treated, and given 3 months of free medication. 1724 physiotherapist patients, 2724 occupational therapy patients, 2574 speech therapist patients were assessed and treated. A forensic psychologist found a total of 1896. There were 3340 EEGs, 640 CT scans, 502 drug levels and 118 BERA scans. 150 + Neurologists and pediatricians have rendered their services in these camps. The comprehensive epilepsy camps organized in the rural districts of Maharashtra has helped reduced the treatment gap to 25% in the last 7 years. This has been a successful comprehensive model that has been implemented by Epilepsy Foundation & Government of Maharashtra. We thereby suggest that such a model can be used for different conditions as well. The same model can be used for treating epilepsy in different states of India and other Developing countries.

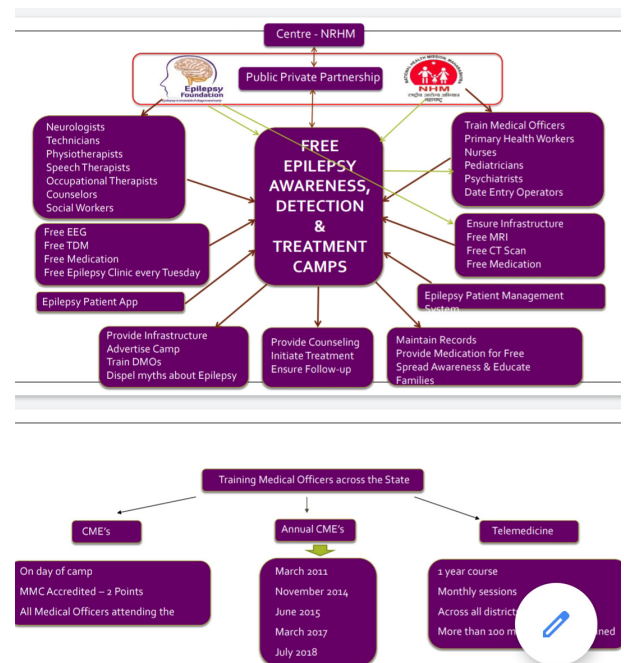


Fig. Epilepsy Awareness, Detection and Treatment camps