

## Review

# Community Program for Management of Epilepsy

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### ABSTRACT

*Epilepsy is a chronic disorder of the brain that affects people worldwide. It is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized), and is sometimes accompanied by loss of consciousness and control of bowel or bladder function.*

*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%)<sup>1,2</sup>.*

*The disability and psychosocial impact caused by epilepsy in socio-culturally determined traditional societies like India is phenomenal and impose huge economic burden to the individual and the society. Understanding the social and economic impact becomes critically important for effective control and prevention of epilepsy in resource-poor settings like India.*

### Justification of program

#### Treatment gap despite availability of medicines in India

Treatment gap is defined as the number of people with active epilepsy not on treatment or on inadequate treatment, expressed as a percentage of the total number of persons with active epilepsy<sup>4</sup>. Epilepsy treatment gap is a useful indicator for accessibility and quality of epilepsy care and undoubtedly, a very high treatment gap would result in increased disease burden. Treatment gap in epilepsy is broadly classified into primary and secondary. About 78% of the PWE are affected by this gap. The treatment gap varies from 50 to 70% among persons with epilepsy<sup>3</sup>. In a highly literate population of Kerala, a treatment gap of 38% has been found<sup>4</sup>. Hackett et al. in 1997 found a treatment gap of 50% in Calicut district of Kerala<sup>5,6</sup>.

The various causes of treatment gap expressed as median and range were cost of treatment (62%; 11-90%), non-availability of drugs (53%; 18-44%), belief in traditional treatment methods (44%; 6-82%), and superstitions and cultural beliefs (40%; 7-65%).<sup>7</sup> Shortage of skilled manpower, low literacy rates, and long distance from a healthcare facility and other infrastructure problems were other factors responsible for treatment gap. In another systematic review among resource-poor countries, a treatment gap of 64% was reported for Asia with huge urban-rural variations<sup>7,8</sup>.

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%<sup>9</sup>.

#### Integrated Approaches for Epilepsy Prevention, Care, and Rehabilitation Focus on prevention

A significant proportion of epilepsy in India occur due to adverse perinatal events and neonatal infections and majority of the infections that cause epilepsy in developing countries are preventable through improved obstetric and neonatal care, immunization, vector control measures, and improved food hygiene. Thus, active disease surveillance becomes critical for planning appropriate preventive/control measures. Besides several new initiatives in the areas of maternal and child health, control and prevention of childhood infectious diseases, prevention of communicable diseases like malaria and others, many effective solutions to prevent road traffic injuries, work place injuries, and other injuries can significantly contribute for epilepsy prevention. The entire National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases And Stroke (NPCDCS) program can address epilepsy secondary to some metabolic conditions if prevention becomes central focus. Sensitization/orientation of administrators and

professionals in various national programs for prevention and management of epilepsy would go a long way in control of epilepsy during the days to come.

#### **Emphasis on care**

with shortage of specialist manpower and health facilities for epilepsy, there is a need to organize services based on a public health approach model by using existing healthcare facilities.<sup>11</sup> The immediate focus should be on capacity building of various healthcare providers, applying appropriate technology for diagnosis, ensuring uninterrupted drug supply, and creating awareness. In recent years, there is a strong thrust to develop a national epilepsy control program and it is envisaged that India would have a national epilepsy control program in the coming years to close the wide treatment gap<sup>12</sup>.

Various approaches have been attempted by India and other developing countries to deliver epilepsy services in the community with need-based specialized diagnostic techniques and surgical facilities.<sup>[13]</sup> Some of the notable approaches are fixed satellite clinic model of apex institutions<sup>14</sup> camp approach (specialists or trained physicians engaging in rural camps)<sup>15</sup>, mobile clinic approach (single visit by neurologist)<sup>16</sup>, rural approach (integrating epilepsy care in primary healthcare)<sup>17</sup> general practitioners approach (training general practitioners in epilepsy care)<sup>18</sup>. key informant approach (availing services from school teachers and other key leaders of community in identification and education of PWE and their families)<sup>19,20</sup> community health worker approach (for identification, referral, and follow-up)<sup>17</sup> and community-based rehabilitation model<sup>4</sup>.

The community-based rehabilitation model of care had resistance due to categorization of PWE as having disabilities, while the camp approach and satellite clinic model had inherent problems of stigma, difficulty in follow-up, and the failure to ensure uninterrupted supply of drugs. These initial problems can be overcome with community involvement. Though these models could be cost-effective and complementing, no large-scale replication and evaluation studies have been reported till date to examine its cost effectiveness in India.

To circumvent these challenges, a decentralized model of epilepsy care at the district level with two essential parallel and complementary approaches, namely "center to periphery" and second, "periphery to center" was proposed<sup>22</sup>. This model had envisaged the district medical officer as the core person, neurologist as a nodal person, and the primary health center medical officer as

the delivery agent. In line with this, Tripathi *et al.*, have highlighted the complementary bottom up training and case finding model with top down information, education, and communication (IEC) delivery model<sup>23</sup>. National epilepsy network and national epilepsy surgery support activity was proposed to provide proper guidance and support for managing difficult cases and reduce the surgical treatment gap in India<sup>24,25</sup>.

Strengthening and capacity building of primary care settings for managing epilepsy<sup>26</sup>, implementation of telemedicine facilities in managing complicated cases of epilepsy, expanding the scope of surgical interventions and therapeutic drug monitoring, and provision of emergency kits in different settings for management of status epilepticus were suggested for prevention of unnecessary referrals and better utilization of services.

A recent study by Dash *et al.*, has demonstrated the effectiveness of health education in improving drug adherence and self-management skills of PWE with low educational background<sup>27</sup>. This highlighted the importance of including educational program in providing holistic management of PWE, irrespective of their educational status.

While the need for an independent epilepsy control program has been articulated by professionals, there is urgent need for integrating epilepsy prevention, early diagnosis, management, and rehabilitation in the existing programs. As neurological diseases are considered in the larger spectrum of non-communicable diseases and there is a growing elderly population, integrating epilepsy care with the upcoming National Program for Health Care of Elderly (NPHCE) and NPCDCS and in trauma care appears to be some promising strategies in effective reduction of epilepsy burden<sup>28,29</sup>.

#### **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<sup>30</sup>. (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<sup>31</sup>, TOT will be done by neurologists from Tertiary Care and State Medical Colleges having neurologists. 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.<sup>32</sup> 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-18<sup>th</sup> 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, 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

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.

#### **REFERENCES**

1. Sridharan R, Murthy BN. Prevalence and pattern of epilepsy in India. *Epilepsia*. 1999;40:631-6.
2. Leonardi M, Ustun TB. The global burden of epilepsy. *Epilepsia*. 2002;43(Suppl. 6):21-5.

3. Pahl K, de Boer HM. Atlas: epilepsy care in the world. Geneva: WHO; 2005. *Epilepsy and rights*; pp. 72-3.
4. Ray BK, Bhattacharya S, Kundu TN, Saha SP, Das SK. Epidemiology of Epilepsy- Indian perspective. *J Indian Med Assoc.* 2002;100:322-6.
5. Gourie Devi M, Satishchandra P, Gururaj G. Epilepsy control program in India-A district model. *Epilepsia.* 2003;44:58-62.
6. Radhakrishnan K, Pandian JD, Santhoshkumar T, Thomas SV, Deetha TD, Sarma PS, et al. Prevalence, knowledge, attitude, and practice of epilepsy in Kerala, South India. *Epilepsia.* 2000;41:1027-35.
7. Hackett RJ, Hackett L, Bhakta P. The prevalence and associated factors of epilepsy in children in Calicut District, Kerala, India. *Acta Paediatr.* 1997;86:1257-60.
8. Mbuba CK, Ngugi AK, Newton CR, Carter JA. The epilepsy treatment gap in developing countries: A systematic review of the magnitude, causes, and intervention strategies. *Epilepsia* 2008;49:1491-503.
9. Neligan A, Sander JW. The treatment gap in epilepsy: A global perspective. *Epileptology [Internet]*
10. Atlas of Epilepsy care in the world. Geneva WHO, IBE, ILAE. 2005
11. Tripathi M, Jain DC, Devi MG, Jain S, Saxena V, Chandra PS, et al. Need for a national epilepsy control program. *Ann Indian Acad Neurol* 2012;15:89-93.
12. Jain S, Chandra PS. Delivery of health care and socioeconomic issues -India. In: Engel J Jr, Pedley TA, editors. *Epilepsy: A Comprehensive Textbook.* 2<sup>nd</sup> ed. Philadelphia: Lippincott-Raven; 2008; 2:2885-2889.
13. Reddy GN, Channabasavanna SM, Gourie-Devi M, Das BS, Prabhu GG, Shariff IA, et al. Extension of the mental health services by satellite clinics as a model. *NIMHANS J* 1986;4:71-5.
14. Kapur RL, Chandrashekar CR, Shamasundar C, Isaac MK, Parthasarathy R, Shetty S. Extension of mental health service through psychiatric camps: A new approach. *Indian J Psychiatry* 1982;24:237-41.
15. Bigelow J, Singh V, Singh M. Medication adherence in patients with epilepsy after a single neurologist visit in rural India. *Epilepsy Behav* 2013;29:412-5.
16. Mani KS, Rangan G, Srinivas HV, Srinidharan VS, Subbakrishna DK. Epilepsy control with phenobarbital or phenytoin in rural south India: The Yelandur study. *Lancet* 2001;357:1316-20.
17. Averis AK. Epilepsy management: The general practitioner's perspective. *Seizure* 1997; 6:81-5.
18. Feksi AT, Kaamugisha J, Gatiti S, Sander JW, Shorvon SD. A comprehensive community epilepsy programme: The Nakuru project. *Epilepsy Res* 1991;8:252-9.
19. Feksi AT, Kaamugisha J, Sander JW, Gatiti S, Shorvon SD. Comprehensive primary health care antiepileptic drug treatment programme in rural and semi-urban Kenya. ICBERG (International Community-based Epilepsy Research Group). *Lancet* 1991;337:406-9.
20. Pal DK, Das T, Sengupta S. Comparison of key informant and survey methods for ascertainment of childhood epilepsy in West Bengal, India. *Int J Epidemiol* 1998;27:672-676.
21. Meinardi H, Scott RA, Reis R, Sander JW, ILAE Commission on the Developing World. The treatment gap in epilepsy: The current situation and ways forward. *Epilepsia* 2001;42:136-149.
22. Gourie-Devi M, Satishchandra P, Gururaj G. Epilepsy control program in India: A district model. *Epilepsia* 2003;44:58-62.
23. Tripathi M, Jain DC, Devi MG, Jain S, Saxena V, Chandra PS, et al. Need for a national epilepsy control program. *Ann Indian Acad Neurol* 2012;15:89-93.
24. Radhakrishnan K, Rathore C, Rao MB. National epilepsy surgery support activity. *Ann Indian Acad Neurol* 2014;17:S132-3.
25. Rathore C, Rao MB, Radhakrishnan K. National epilepsy surgery program: Realistic goals and pragmatic solutions. *Neurol India* 2014;62:124-9.
26. Jeyashree K, Sinha S, Patro BK. Pathway to care of epilepsy patients: Exploratory study from an urban slum in Northern India. *Ann Indian Acad Neurol* 2013;16:357-60.
27. Dash D, Sebastian TM, Aggarwal M, Tripathi M. Impact of health education on drug adherence and self-care in people with epilepsy with low education. *Epilepsy Behav* 2015;44:213-7.
28. National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) | National Health Portal [Internet].
29. Operational Guidelines for NPHCE: Ministry of Health and Family Welfare [Internet].
30. Guidelines for the management of epilepsy in India. Indian epilepsy society. Indian epilepsy association-18<sup>th</sup> International Epilepsy congress trust. 2008. [Last accessed on 2011 Nov 20]. Available from: <http://www.epilepsyindia.org/gemind-main.asp>.
31. Gourie-Devi M, Satishchandra P, Gururaj G. Epilepsy Control Program in India: A District Model. *Epilepsia.* 2003;44(Suppl 1):58-62.