Report

National Workshop on Public Health Aspects of Epilepsy for Senior Personnel of State Health Departments in India

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The National Workshop on Public health aspects of Epilepsy for senior personnel of State health departments in India sponsored by World Health Organisation was held at National Institute of Mental Health and Neuro Sciences, Bangalore on 29-30 January, 1999. A total of 21 participants and 7 resource persons participated in the workshop. The workshop recognized epilepsy as a public health problem and highlighted the importance of organizing preventive, curative and rehabilitative services for people with epilepsy and need for developing strategies to deliver services in India.

The participants included professionals from diverse fields including Public health, Neurology, Paediatrics and Internal medicine. The participants were drawn from the states of Andhra Pradesh, Goa, Gujarat, Jammu & Kashmir, Karnataka, Kerala, Manipur, Orissa and Uttar Pradesh. The resource persons had wide and rich experience in developing strategies for epilepsy care and services. The resource persons consisted of professionals from NIMHANS, Bangalore; Sri. Chitra Tirunal Institute, Trivandrum; KEM Hospital, Bombay and National Law School, Bangalore. The workshop consisted of 7 lectures on a wide variety of topics with lively interaction between the experts and participants. The participants also gave an' account of status of epilepsy care in their states.

Epilepsy - A public health problem

In the inaugural address, Prof. M. Gourie-Devi, Director - Vice Chancellor, and Professor of Neurology NIMHANS, highlighted the need for the workshop as neurological diseases in general and Epilepsy in particular had emerged as a major public health problem in the last decade. The need for organizing epilepsy care with a focus on prevention, management and continued services in a socio culturally diverse country .like India with limited manpower was emphasized. The recent initiatives by WHO along with DLAE in the form of 'Global Campaign Against Epilepsy - Out of Shadows' was brought to the notice of participants. It was further emphasized that participants along with resource faculty would actively interact on various critical issues in epilepsy care and would help in developing the 'National Epilepsy Control Programme' along with strategies for care.

Need for National Epilepsy Control Programme

In the first session on 'National Epilepsy Control Programme - Concepts and Issues in planning', Prof. Gourie-Devi traced the historical developments in epilepsy management through International initiatives. The importance of Epilepsy as a public health problem as emphasized by World Health Organization. (WHO) was highlighted. A global epidemiological review of epilepsy indicates that nearly 50 million people are suffering from epilepsy, and one-fifth (around 10 million) - live in India. Further, nearly 50% of them are untreated or inadequately treated. In simple terms, epilepsy poses an enormous burden on patients and families as approximately 1 in 100 people are affected with this problem. Epilepsy also poses considerable, problems in the areas of marriage, education, employment, leisure time activities, sports activities and on the overall quality of life. She emphasized the need for planning services for people with epilepsy. With regard to organisation of services, she emphasized that currently for a population of 200,000 at least one neurologist would be necessary. With the existing number of trained neurologists for the whole country being about 500, to reach the optimum number of 5000 neurologists is a far fetched proposition. Hence, there is a need for alternative strategies to be developed in the country. The need for expanding services for people with epilepsy was considered at two levels - namely, 'a top-down approach' of centre to periphery, and the 'bottom-up approach' of periphery to center. In the former approach strengthening of district hospitals ensuring continuous uninterrupted supply of commonly used anti-epileptic drugs and mobile teams to cater to

remote areas are the essential components. While, in the latter, training of people in case detection, diagnosis and management plays a key role. It was highlighted that the training of health professionals at health centre, district level and medical college level Would be different based on the responsibilities assigned to the professionals at various levels of health care.

With regard to the prevention of epilepsy, the estimated relative risk of genetic factors (0.7-5.6), brain injuries (1.4-12.7), febrile convulsion (3.0-14.2), and pyogenic meningitis (7-40) as major risk factors was emphasized. Further, various components under primary prevention, secondary prevention and tertiary prevention were highlighted. It was emphasized that the economic aspects of epilepsy care needs to be ascertained to plan services at various levels.

It was emphasized that there is a paramount and urgent need for 'National Epilepsy Control Programme' and the major objectives of such a programme were put forth. The important aspect was that epilepsy as a major public health problem can be easily identified and diagnosed and in nearly 70-80% seizures can be effectively controlled with one or two available drugs, there by improving the quality of life of these individuals.

Epilepsy care in rural community

Dr.Radhakrishnan, Professor and Head, Department of Neurology, Sri. Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram spoke on rural epilepsy control based on their Kerala experience. He emphasized that for the success of any health policy implementation - availability, acceptability and affordability are the three main principles. Misconceptions about the epilepsy, that it is a life long disorder among the people needs to be removed. He explained the success of rural epilepsy programme in Kerala with high literacy rate and health awareness among the people and stressed the role of epilepsy awareness and education programme.

Large scale rural epidemiological survey undertaken near Thiruvananthapuram between August 1996 to September 1997 using a simple questionnaire with six questions under 3 phase programme yielded an active epilepsy prevalence rate of 4.95/1000 population. Questionnaire used had very high sensitivity of 98.8%. This survey demonstrated a treatment gap of 38% though prevalence and pattern was no different from other parts of the country. While high literacy rate was associated with increased awareness among the people, knowledge, attitude and practice (KAP) study interestingly brought out poor attitude among the Keralites calling for better education programs to change this attitude.

Regarding the treatment, 76% of the rural epilepsy patients in Kerala could be managed with monotherapy and unnecessary use of polypharmacy could be avoided. He also explained that most of the non-compliance in the use of antiepileptic drugs is iatrogenic which requires better and continuing education programme for the primary care physicians. Better doctor patient communication improves compliance.

Diagnosis and management of epilepsy

Dr. P. Satishchandra, Additional Professor of Neurology at NIMHANS while addressing the issues involved in 'diagnosis and management of epilepsy' mentioned that since more than 60-70% of all epilepsy cases in India are Being treated by primary care physicians, general physicians, paediatricians and psychiatrists there is a need to provide training in epilepsy care. He emphasized that epilepsy is essentially a clinical diagnosis based on a good clinical history and description of attack provided by eye witness. He discussed various components of clinical semiology of epilepsy and emphasized the role of EEG and Neuro Imaging. Though these investigations play a very important role in proper identification and management, he stressed the limitation of their availability in a developing country. He narrated various points to differentiate epilepsy from other episodic conditions in both children and adults. Using flow charts, he discussed the approach to epilepsy.

He discussed three aspects of prevention with respect to epilepsy and integrated approach between governmental and non-governmental agencies to tackle such a mammoth problem. Major problem faced at the peripheral hospitals currently is the non-availability of primary drugs. He emphatically mentioned that 'irregular supply of these primary drugs is more dangerous than no supply' and hence it is crucial to ensure regular supply of essential primary drugs such as phenobarbitone and diphenylhydantoin to all health care centres. He concluded by giving the details of programme for district medical officers' which is to be initiated and sought the co-operation and assistance of all the participants in selecting officers for training.

Psychosocial aspects of epilepsy

Dr. Praveena U. Shah, Professor of Neurology, KEM Hospital, Mumbai, discussed at length the various issues related to psychosocial aspects of epilepsy. At the outset, it was mentioned that care for epilepsy patients is extremely rewarding if given at the right time. Patients with epilepsy can be broadly classified as those with good control, partial control and poor control (with associated problems). The key factors responsible for maintaining the quality of life are early diagnosis, proper management and psychosocial acceptance. Further, it was highlighted that a holistic approach aimed at seizure control with good social acceptance and minimum side effects is very much essential for improving the quality of life.

She stressed that there is a need to use wide variety of audio-visual materials to educate large number of individuals including patients, relatives, family doctor, paramedics, employers, public and school children. The various components in relation to education were highlighted in the session. It was further mentioned that "E" is not just epilepsy, but included Education, Enrichment, Encouragement, Employment, Enjoyment, Enlightenment and Empathy. Further, the experience of the team in terms of organizing services through camps, work shops, clinics and the epilepsy cell were highlighted. Epilepsy was considered to .be an important aspect from the employers point of view as majority can be controlled with drugs and in very few cases, it would interfere with their working aspects.

Epilepsy and Law

Dr. Joga Rao, Additional Professor at National Law School, Bangalore was invited to discuss 'Legal Issues in epilepsy'. He narrated the judicial understanding of epilepsy as "a neurological disorder marked by disturbed electrical rhythms of the brain and spinal cord and typically manifested by convulsive attacks often with clouding of consciousness" and how the word "clouding of consciousness" has been wrongly interpreted in the judiciary, leading to award 'of -inappropriate judgement to the epileptic individual. He' also explained that epilepsy' has been equated with mental disorders in the Indian law even today and called for joint serious discussions among the legal experts and epidemiologists. He discussed about the lacunae in the Indian legal system with respect to epilepsy and education, driving, marriage and social security. Under the legal parlance, contractual status, civil status, criminal status and constitutional status in Indian law has to relook at epilepsy and calls for change in all these fields. He emphasized that epilepsy patient is a human being and is entitled to 'Right to health' which is a fundamental right of any human being. He debated the pros and cons of making epilepsy as an issue for disability and emphasized the need to look closely into the legal issues in epilepsy while formulating the epilepsy control programme.

District Mental Health Programme - An approach to epilepsy care

Dr. Mohan Isaac, Professor and Head, Department of Psychiatry, NIMHANS, shared his experience of organizing, implementing and evaluating the district mental health programme at Bellary District in Karnataka. Started in 1982 along with National Mental Health Programme, the Bellary District programme has become a model for delivery of mental health services to a large community. There are nearly 500 districts in the country with an average population of 1.5-2 million in different geographical areas. He traced a series of developments starting with the epidemiological studies of mental health problems, development of mental hospitals, general hospital psychiatry units and community models of mental health care.

A series of preliminary activities were undertaken including training of PHC workers, evaluation of trained personnel, implementation of the programmes and training of the trainers. These activities related to development of basic manpower, organizational and monitoring aspects at district and PHC levels. The essential components of the district mental health programme were - (i) training all categories of staff at district and PHC levels, (ii) provision of essential drugs, (iii) simple recording and reporting system, (iv) continuous support and supervision, (v) community participation, and (vi) district psychiatry units. The training of staff included decentralized training, continued on-the-job training and evaluation activities. Necessary care was taken to establish a system of supplying basic antiepileptic drugs in a continuous and uninterrupted manner. Simple records for reporting included patient identification card, simple record books and doctor's case record. The monitoring of the programme was through continuous support and supervision, participation in district level meetings of PHC and constant feedback in both the directions. By generating awareness and sensitization programmes, the support of the district level administrative staff was continuously obtained. Community participation was obtained through education and awareness programmes both in the hospital as well as in the community. The essential intersectoral cooperation with the departments was promoted from the beginning. An important outcome of this model has been that more than 70% of epileptic patients within 5 kms radius of PHC was covered with continuous drug supply, education and supportive programmes. Monitoring the utilization pattern and outcome of the treatment were essential features. He further elaborated that the Bellary model is being currently adopted in about 6 to 8 states in the country with financial support from Government of India.

Strategy for epilepsy care - Need for multiple approaches

In the session on strategies in epilepsy care, Dr. G. Gururaj, Additional Professor and Head, Department of Epidemiology, NIMHANS, while reviewing a number of epidemiological studies on epilepsy, stressed the need for a surveillance system. He mentioned that nearly 30-55% of patients with neurological and psychiatric illnesses seen in NIMHANS satellite clinics had epilepsy and 60-70% of them at first contact had not received any systematic treatment. Experience of managing epilepsy patients has revealed that 60-75% would significantly improve with simple drugs. However, the high drop-out rates varying from 40 to 70% through various studies has been a major cause for concern.

In view of the magnitude of the problem of epilepsy in India a number of strategies had to be developed at the national level to control the problem of epilepsy. Emphasis should be on integration with ongoing programmes and development of new activities. Focus should be on strengthening the role of existing services, personnel and staff at PHC and district levels. A number of new activities where further thrust was required were planning for epilepsy care at state and district levels, development of short term courses for various categories of health personnel including general ‘practitioners, involvement of schools, colleges and the local NGO’s, increasing commitment by professional bodies like Indian Epilepsy Association and Indian Academy of Neurology, increasing the role of private sector, changes to be undertaken in medical education and systematic epilepsy education programmes. Strengthening teaching of epilepsy at medical colleges, establishing advanced centers in epilepsy management and research, operational research for understanding utilization of services and the economic impact were considered as major issues for epilepsy care and management at the national level. It was also mentioned that a district level surveillance system would be appropriate to monitor trend, changes and impact of interventions. The group discussed the importance of these strategies and debated on a number of related issues.

Status of Epilepsy care in some states

A series of presentations were made by the participants from different states highlighting the administrative mechanisms, man power availability and supply of antiepileptic drugs and these are highlighted below:

(i) Andhra Pradesh

The state of Andhra Pradesh with a population of 6.5 million, has 1335 PHC’s, 9 medical colleges, 30 district hospitals along with 157 physicians, 78 pediatricians and 19 neurologists. Epilepsy patients are provided out patient care along with in-patient care as and w-hen necessary. Most of the antiepileptic drugs are available in all the government hospitals. Further, it was mentioned that the institute of mental health at Hyderabad has been selected as a nodal centre under National mental health programme. Currently, training programmes were ongoing lasting for 2 weeks with training of 15-20 doctors in each of the batches,

(ii) Goa

The union territory of Goa with a population of 1.2 million has 5 community health centres, 9 PHC’s with beds and 8 PHC’s without beds. There are 5 taluk level hospitals .and 2 district hospitals. A total of 14 senior health officers, 231 medical officers, 8 physicians, 5 pediatricians and 2 psychiatrists are involved in epilepsy control programme. All the government hospitals provide antiepileptic drugs like phenobarbitone, phenytoin, carbamazepin, and sodium valporate. The drug delivery is free of cost for a period of 15 days at a time to all poor patients.

(iii) Gujarat

The state of Gujarat with a. population of 4.2 million has 945 PHC’s, 178 taluk hospitals and 26 district hospitals along with 60 medical colleges. A total of 1200 district medical officers along with physicians, pediatricians and psychiatrists in 23 medical colleges are involved in epilepsy control programme. The 4 primary drugs mentioned above were available and free drug supply to poor patients for a period of 30 days was followed.

(iv) Jammu and Kashmir

The state of Jammu & Kashmir with a population of 7.7 million has 332 PHC’s, 54 taluk hospitals and 14 district hospitals. 14 district medical officers, 14 physicians and 14 pediatricians are involved in providing services for epilepsy patients. It was mentioned that only phenobarbiton was available in major government hospitals with a free supply for 20 days.

(vii) Manipur

The state of Manipur with a population of 18 lakhs has 20 PHC’s, 4 taluk hospitals and 8 district hospitals. Epilepsy care was currently provided through 8 district medical officers, 440 medical officers, 15 physicians, 14 pediatricians and 5 psychiatrists. Only phenobarbiton was available in the government hospitals with a free supply for a period of 30 days. With a high prevalence of HIV infections in Manipur, there is additional problem of HIV induced seizures.

(vi) Orissa

The state of Orissa with a population of 3.7 million (1998) has 1294 PHC’s, 21 taluk hospitals and 31 district hospitals. A total of 3150 district medical officers along with 86 physicians, 257 pediatricians and 4 psychiatrists are involved in epilepsy control programme. All the anti-epileptic drugs are available in the government hospitals with free supply to poor patients for a period of 2 weeks.

Summary and Recommendations

Intensive discussions followed each of the sessions with participants and the resource persons bringing in a regional and national perspective. The group seriously examined the existing problems and difficulties in the ongoing epilepsy control programme. The following is a summary of the main issues and recommendation for initiating activities at various levels.

1. A review of the epidemiological studies indicate that nearly 8-10 million people have epilepsy in the country at any given point of time. At a district level nearly 15000 - 30000 people are estimated to be suffering from

epilepsy based on population and geographical distribution with local variations.

2. Epilepsy is a significant public health problem in terms of the burden of the disease, nature of illness and its impact on individuals and families.

3. Epilepsy poses significant problem from a sociological perspective in terms of the stigma attached with the illness, with limited opportunities in employment, education, marriage and quality of life.

4. Considering the present situation of services, delivery and mechanisms it was appreciated that there is need for augmenting the existing services along with expansion-and a number of new activities have to be developed.

5. The strategies in expanding services to people with epilepsy should be considered at two levels. The first strategy based on 'top-to-bottom' approach which is a parallel and complementary approach is to establish and strengthen epilepsy services at district hospitals through out patient clinics and mobile teams with adequate availability of antiepileptic drugs. The second approach from periphery to center focuses upon training various categories of health personnel in identification, diagnosis and management with continuous and uninterrupted availability of antiepileptic drugs.

6. Planning, organizing, implementing and evaluating epilepsy services should be undertaken at state and district levels.

7. The activities of primary health centre and its staff in terms of identification, drug distribution, epilepsy education, simple records, reporting mechanisms, monitoring and follow-up should be strengthened to provide better services for epilepsy patients.

8. Since epilepsy interferes with education, marriage, pregnancy, employment, social activities, public awareness and sensitization programmes need to be strengthened. Educational materials should be culture specific and adaptable to the local needs of the people. The materials should focus upon resource materials in local languages, should be appropriate and relevant, use local communication media, to reinforce information, should aim at removing stigma, highlight DO's and DON'Ts and focus on positive aspects of epilepsy.

9. Epilepsy and law was considered an important issue and the impact of law in the areas of marriage, employment and driving was reinforced. It was decided that the existing laws should be modified with awareness programmes for members of the judiciary.

10. Medical education in its present scenario has severe limitations in developing community care doctors to handle epilepsy. It was felt that the importance of socio-cultural and managerial aspects of epilepsy needs to be incorporated into undergraduate teaching programmes.

11. There is a need for establishing advanced centres for epilepsy management and research in the country in selected institutions. These centres should examine the local and regional issues, conduct socio-epidemiological research and provide stale of the art management for epilepsy.

12. The importance of public health research in me area of epilepsy was highlighted and it was felt that operational research focusing on existing health system, services, utilization pattern and drug related issues should be examined.

13. The health economics issues related to epilepsy in terms of direct, indirect and intangible costs needs to be ascertained for understanding several issues.

14. The workshop participants also emphasized the important role of pharmaceutical industries in terms of ensuring continuous, uninterrupted supply and containing cost of drugs for epilepsy patients.

15. With etiology becoming clear that head injuries due to road accidents, falls and violence becoming another major health problem preventive efforts should be initiated at regional and local levels to reduce the problem of epilepsy and head injuries.

16. It was emphasized that epilepsy management and prevention component should be highlighted in the other ongoing national health programmes for tuberculosis, mental health programme, immunization programmes, etc.

17. Schools, colleges, local non-governmental organizations and private sectors should be involved in epilepsy services by their inputs in a number of clinic and out reach' programmes.

18. Various professional bodies like Indian Academy of Neurology, Indian Epilepsy Association and Neurological Society of India along with other professional groups should take up the roles of advocacy, lobbying and developing strategies at local and regional levels.

19. Based on the review of the epilepsy scenario in the country, a National Epilepsy Control Programme (NFCP) needs to be launched with the following objectives:

    a) To make available and accessible, health care to all people with epilepsy (particularly underprivileged and vulnerable population and people in remote territories).

    b) To promote community participation in delivery of integrated, care to people with epilepsy.

    c) To ensure integration of people with epilepsy in various spheres of activity through a comprehensive approach to rehabilitation.

20. The various components requiring inputs and preparatory work to be undertaken for initiating National Epilepsy Control Programme are:

    i) Establish a National control program with a central unit lo guarantee political and operational support for various programme levels,

    ii) Prepare a programme manual: case definition, treatment guidelines, job description of involved personnel,

    iii) Establish recording and reporting system, using standardized material,

    iv) Develop and initiate training programme for health professionals at various levels,

    v) Establish treatment services within existing health services,

    vi) Ensure regular supply of essential antiepileptic drugs,

    vii) Design a plan of supervision of key operations,

    viii) Develop a protocol for monitoring through regular “feed-back” and “feed-forward” mechanisms,

    ix) Prepare a project development plan for NECP with budget, source of funding and responsibilities.