

The role of epilepsy management guidelines in a developing country

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Abstract

India is home to about 10 million people with epilepsy (prevalence of about 1%). The number of Epilepsy Specialists and Neurologists being very small in India, most people with epilepsy are being diagnosed and treated by non-specialists at both primary and secondary care levels. It is obvious that epilepsy management in such situation can be sub-optimal. The Indian Epilepsy Society strongly felt for a need to have its own guidelines for management of epilepsy in India (GEMIND). The guidelines were developed based on a consensus arrived by a group of experts on the good practice parameters relevant to epilepsy treatment in India. The recommendations of the expert group were peer reviewed. The guidelines are parameters of practice and should be considered as guidelines only. The electronic version of GEMIND is now available on the Indian Epilepsy Society-Indian Epilepsy Association website (<http://www.epilepsyindia.org>) and the ILAE website (<http://www.ilae-epilepsy.org>).

Epilepsy is characterized by recurrent unprovoked seizures. As per the WHO, epilepsy is the one of the most common serious brain disorders that affects not only the individual, but also has impacts on the family and the society in general. As per estimates, there may be about 10 million people with epilepsy in India accounting for almost one-fifth of the global figures.

Despite its varied etiology, majority of epilepsy cases can be successfully treated with simple medicines, most often with only one type of drug. Although the treatment of epilepsy in most cases is simple, the drugs very often have to be taken for a long duration. It has been estimated that with proper treatment, 70-80% of people with epilepsy (PWE) can lead normal lives. Unfortunately, in most developing countries 60-90% PWE has been estimated to receive either no treatment or inadequate and inappropriate treatment, most often due to inadequacies in the health care resources and societal stigma. Even for those getting some form of treatment, we have no guidelines at the national level in any country among the developing world.

The need for having 'Guidelines for Epilepsy Management in India' was discussed in the Indian Epilepsy Society General Body Meeting in the annual conference in 2005. Epilepsy being a common condition and the number of Epilepsy Specialists/Neurologists in India is very small, most people with epilepsy in India are being diagnosed and treated by non-specialists in both

primary and secondary care. In such a situation, it is obvious that management can many times be sub-optimal and antiepileptic drugs (AEDs) are not always chosen and used appropriately by clinicians. Certain important and specific areas of concern include initial diagnosis, drug treatment, management of children and pregnant women with epilepsy and management of poorly controlled seizures and status epilepticus with limited resources. Further, it was felt that there remains considerable scope for the development of better epilepsy services at both primary and secondary care level in a developing country like India.

It was finally decided to constitute of a small core group from among members of the Indian Epilepsy Society with Dr Satish Jain as its convener to take up this responsibility of developing the Guidelines for Epilepsy Management in India (GEMIND). The core group had its first meeting on January 12-13, 2008. There were extensive deliberations over two full days. This was followed by a second meeting of an enlarged core group from April 26-27, 2008. The extended core group had a large number of presentations on all aspects of epilepsy in India followed by extensive discussions on each topic. The third and final meeting of the core group was held from August 23-24, 2008. During this meeting each aspect of the recommendations of the core group was again discussed in details with a view to formulate guidelines that should be as

practical and appropriate as possible keeping in mind the resources available to an average primary health care physician in India.

The GEMIND were developed to address specific actual questions posed by the IES appointed Expert Group members. The available evidence based literature pertaining to the questions asked including the available existing guidelines (SIGN¹, NICE², AAN³ and ILAE⁴) were reviewed by the expert group. The GEMIND were developed by arriving at a consensus based on the available literature. The consensus arrived at by the Expert Group was peer reviewed by another group from among the IES members.

The GEMIND are expected to help in improving medical decision making in India, mainly at a general physician level. The guidelines are only to be taken as recommendations for management of epilepsy patients. While using any guidelines for patient care it is important to remember that regardless of overall recommendations for any medical disorder, the individual patient's problems still are the most important factor while deciding on treatment options. Costs, drug availability, ease of use, severity of the medical condition and many other factors play an important role in the decision making. Every physician needs to combine guidelines with his/her own skill, knowledge and experience keeping in mind the needs of the individual patient.

It may be noted that the GEMIND are to be taken as practice parameters by general physicians and should not be regarded as 'standards of epilepsy care' in India. As medical knowledge and diagnostic technology advances, the guidelines will also need to be modified. Since guidelines constitute 'reasonably correct practice parameters', these should be used to formulate and recommend reasonable treatment plans for different clinical situations in regards to management of epilepsy patients in India. It is important to remember that the treating doctor should always make the final decision about the treatment plan keeping in mind the individual patient's problem and the diagnostic and therapeutic options available.

The GEMIND are expected to guide the physicians on providing epilepsy care at mainly the primary and secondary levels of healthcare in India. Printed copies of GEMIND have been distributed free of cost to almost 10,000 physicians all over the country. The electronic version of GEMIND is now available on the IES-IEA website (<http://www.epilepsyindia.org>) and the ILAE website (<http://www.ilae-epilepsy.org>).

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