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Epilepsy in Primary Care

Perspectives from a Developing Nation with Special Reference to Rural Areas

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Epilepsy is the most common worldwide neurologic disorder amenable to treatment, if not cure, provided treatment is initiated early and continuously monitored (1). This is feasible in developed countries with their national wealth, organized health care, and availability of health insurance for all. The quality health care includes the all-important critical care medicine and facilities for rehabilitation.

GROUND REALITIES

The situation in developing nations is widely different, with available care of varying standards. Each developing country has its own national priorities, and generally, health is low in the list. Even here, communicable diseases and other health programs head the list, and epilepsy is nowhere in the horizon. We have failed to lobby repeatedly that epilepsy is not a mental illness requiring life-long medication and that in a vast majority, it can be treated effectively to lead to a perfectly normal life and contribute to national productivity and wealth.

Even in the year 2000, India continued to live in villages. Seventy percent of the population is rural, whereas 70% of the medical manpower is urban—the distribution is thus skewed. Prevalence of active epilepsy in India is ~5 per 1,000 in a population of 1 billion. Specialists in neurology total ~500, amounting to 1 for 10,000 subjects with active epilepsy. They are all urban based, as are the tools for investigations, some of which are highly expensive. Facilities for critical care medicine and rehabilitation exist only in large cities. Health insurance is specifically denied for epilepsy. Hence quality health care is but a distant dream except for a lucky few in rural India.

RURAL POOR

The rural poor must depend on the poorly managed governmental Primary Health Units and Centers, besides the private practitioner or alternate systems of medicine. Only phenobarbitone (PB) and phenytoin (PHT) are affordable, and in the absence of health education, compliance with drug regimens is rare. When the response is poor, which is common, a minority attend metropolitan centers, but become disillusioned quickly because the antiepileptic drug (AED) dose must be tailored to individual needs, necessitating frequent follow-up visits and expense, an impractical situation. Thus, early and effective treatment, the core of epilepsy control, is not available for vast majority. The result is uncontrolled epilepsy with its own inherent risks and impact on the quality of life.

The best option in such circumstances is to use the services of trained primary care physicians (PCPs) and paramedical workers (PMWs) and aim at early treatment with PB/PHT with limited investigations, but strict follow-up and health education. This approach has been advocated before (2,3).

THE YELANDUR MODEL

Our experience with a 5-year follow-up of cases treated with PB/PHT in Yelandur in South Karnataka offers additional evidence (4). The Indian Epilepsy Association, Bangalore chapter, teamed up with Karuna Trust, a nongovernmental organization (NGO) in Yelandur taluk, for rural epilepsy control. Trained PMWs surveyed a population of 64,963 individuals in 13,562 households for epilepsy using a door-to-door method (5). Those suspected to have epilepsy were invited to attend the epilepsy clinic at Yelandur, managed by trained PCPs and supervised by a team of six specialists, including three neurologists, all from Bangalore. Here the diagnosis, follow-up, drug dosage, and adverse effects were monitored and supplemented with health education. This included not only drug and life-style compliance, but also inculcated a positive approach to epilepsy in terms of what can be achieved, not what cannot.

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Partial and/or generalized tonic–clonic seizures (GTCSs) account for 85% of all seizure types in epilepsy, with substantial morbidity and mortality. One hundred eighty-five subjects were recruited for therapy with inexpensive PB/PHT with a 5-year follow-up. They had at least two seizures (partial or generalized) in the previous 1 year and were free of clinical evidence of progressive neurologic disease at entry or follow-up. Seventy-five (56%) had a lifetime total (LTT) of >30 GTCSs, and 29 (22%), evidence of brain damage in the form of mental/neurologic handicap. Subjects with absence or myoclonic seizures, for which PB/PHT are ineffective, were not included. Informed consent was obtained from all patients, and their right to opt out of the study was respected throughout. Treatment gap at entry was partial in 36%, absolute in another 43%, and only 21% were taking regular AEDs. Depending on elimination half-lives for PB/PHT, drug compliance was deemed present when the number of missed doses per year did not exceed six. It must be noted that this was not a randomized study comparing the efficacy of PB and PHT. The PMWs helped the patients to maintain a seizure calendar and ascertained the number of missed doses at every home visit, counterchecked by the medical team during the clinic visits. After an initial stabilization period of 3 months, patients were offered either PB or PHT as monotherapy to be taken once daily at night under supervision. In general, PB was the first drug, and PHT was reserved for cases showing poor response at entry to regular PB from elsewhere. Where one drug failed, the other was substituted slowly, and when both were ineffective, dual therapy was resorted to. Ultimately PB was used in 68, PHT in 60, and both in seven.

The patients were generally short and thin. The doses used were far below those generally advocated in the west or even North India. The per diem dose of PB generally did not exceed 45 mg in children and 90 mg in adults, whereas for PHT, the corresponding figures were 150 and 250 mg, respectively. Drug compliance was 67% at 1 year, but thanks to the PMWs, improved to 80, 82, 83, and 84% at each successive follow-up year. The only option for emergencies was oral/rectal diazepam (DZP) solution meant for parenteral use. The specialists verified all data. The study was entirely clinical, because facilities for investigations did not exist.

Analysis of the results was by intention to treat. The outcome measure used was complete remission of all seizure types for $\geq$2 years. Patients were divided into two groups. Group I comprised those with a LTT of $\leq$30 GTCSs and good drug compliance. Group II did not have both. A terminal remission of 2 years was seen in 58, 63, 67, and 66%, respectively, at each successive follow-up year from the second to the fifth. The corresponding figures for group II were 6, 16, 8, and 8%, respectively, the differences being statistically significant. Stepwise multiple logistic regression analysis was used to arrive at predictors of the outcome measure among the following eight clinical variables: gender, age at onset, duration of illness, brain damage, LTT of GTCSs (cut-off point at 30), log of monthly seizure frequency (because of large variations in distribution), assigned drug, and compliance. Only drug compliance and LTT of $\leq$30 GTCSs turned out to be significant predictors. There was not a single instance of death of status epilepticus in a drug-compliant patient and without brain damage. Status was no more frequent with PB compared with PHT in this small series.

Clinical adverse effects with PB were noted in only three (4%) instances and consisted of dullness, hyperkinesis, and somnolence in one each, the last opting for withdrawal from the study. However, adverse effects were noted in 29 (43%) taking PHT: gingival hyperplasia in 24 (36%), ataxia in eight (12%), and both in 3 (5%). Swelling of the gum margins was dependent on dose and duration of exposure and, most important, oral hygiene, which is abysmally poor in rural people. Only three subjects withdrew from the study because of adverse effects with PHT: one with gingival hyperplasia and two with ataxia.

PRACTICAL LESSONS

What are the lessons from this study? Inexpensive PB/PHT minus investigations is quite effective in rural epilepsy control, especially in partial and/or GTCSs, and without the risk of significant adverse effects. We must therefore learn to individualize and not to generalize. Trained PCPs and PMWs can manage this, with a specialist available for help. For 3 years, the local NGO has been running an epilepsy clinic every week, attracting more patients. This approach has helped to establish faith in the rural folk that effective therapy for epilepsy with inexpensive drugs is possible at their doorstep. This is a practical proposition in India and possibly other developing countries with existing resources. All it needs is a sense of commitment and missionary zeal. The essential prerequisites are trained PCPs and PMWs, the latter preferably from the local population; use of inexpensive AEDs; an unbroken drug chain; regular follow-up; and persistent health education. The neurologic fraternity in the country has been repeatedly addressed about revision of the curriculum on epilepsy for the undergraduates (6). Concurrent steps are also being initiated for training in practical epileptology for PCPs and health workers in Karnataka and other states. We always hope that something tangible will emerge.

"Does epilepsy need exclusive diagnosis and treatment facilities? Clearly not" (7). It is not justifiable any longer to withhold peripheral decentralized epilepsy care in rural areas on the grounds that there are not enough

neurologists, or that facilities for investigations are absent. A clinical approach as outlined should suffice now in a vast majority for rural epilepsy control in its early stages. One need not wait for eons to come and deliver us to eternal bliss and happiness!

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