

A model for managing epilepsy in a rural community in Africa

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Abstract

As most Malawians with epilepsy consider treatment of seizures to be the domain of traditional healers and attend hospital only when they require treatment for burns which they suffer during fits, steps were taken to encourage people with epilepsy to attend hospital for regular treatment with anticonvulsant drugs. At first only a few patients attended, but within two years 461 had registered at the hospital and two mobile clinics. Publicity was spread through the area action committee, which was organised by the area chief.

The main drug used was phenobarbitone. After treatment was given for six months seizures were fully controlled in 40 (56%) out of 71 patients. A further 20 (28%) had greatly improved. As news of the clinics spread other health units adopted the model, and eventually over 3000 patients with epilepsy were receiving regular treatment at 45 units throughout Malawi.

Introduction

She had suffered much under many physicians, and had spent all that she had, and was nothing bettered but rather grew worse. Mark v, 26.

This sentence might be used to sum up the plight of many people with epilepsy in Third World countries, where management of epilepsy is commonly seen as the prerogative of "traditional healers."¹⁻¹⁰ In Malawi, for example, people with epilepsy spend much time and money travelling from one traditional healer to another in search of help. The epigastric aura experienced by some has given rise to the belief that epilepsy is caused by something like an insect that moves inside the stomach. Traditional healers use a concoction made from roots to induce purging and vomiting. Further roots are carried home by the patient, some to be mixed with porridge and eaten morning and evening, others to be soaked in a clay pot and the water used for bathing. Bathing is done both morning and evening, not at the usual bathing place, but at the rubbish pit.

In addition to the mental anguish experienced by people with epilepsy many suffer from the effects of burns.¹¹⁻¹² Indeed, for the first eight years that I worked in Malawi I encountered patients with epilepsy almost exclusively in the surgical wards, where I had to treat their horrific burns. These burns resulted from falls into the unprotected fires that are used for cooking and warmth. The fires are made of wood laid on stones on the ground, and the person who falls into such a fire during a seizure lies there until he or she awakens or is discovered. Buchanan found that of 100 Malawian adults who were admitted to hospital with burns, 36 had sustained the burns during an epileptic seizure.¹³

Having observed that it was rare for a patient to come to hospital to be treated for epilepsy, I decided to initiate steps to encourage patients with epilepsy to attend hospital for regular treatment.

Model for managing epilepsy

- Publicise availability of treatment
- Educate patients and staff
- Simple regimen with phenobarbitone
- Adequate supplies of drugs
- No charge
- Monthly review clinics
- Patient always sees same health worker
- Mobile clinics

Method

Attempts to publicise the availability of treatment for epilepsy by word of mouth were not at first very fruitful. Then I was invited to speak at a meeting of the area action committee, organised by the area chief and attended by about 100 men representing the villages in the area. When it was mentioned that people suffering from epilepsy should not hesitate to attend hospital to receive help there was loud applause, and after the meeting many expressed their surprise and delight at hearing for the first time that treatment of epilepsy was available at the hospital. Following this fortuitous publicity the number of patients with epilepsy attending the hospital increased dramatically. I interviewed all the patients by using a specially devised questionnaire. In each case a friend who had seen the seizure was also interviewed. Epilepsy was diagnosed on the basis of the history, and seizures were classified using a modified form of the revised classification of the International League Against Epilepsy.¹⁴ There are no facilities for electroencephalography in Malawi.

Only the patients who had had two or more seizures during the preceding year were considered for anti-convulsant treatment. Children with febrile convulsions were considered only if a first degree relative had epilepsy, if the fit was focal, if there was evidence of brain damage, or if tepid sponging, chloroquine, and aspirin had failed to prevent convulsions occurring during a fever.

The choice of drugs was restricted to phenobarbitone and phenytoin, mainly because these were available locally but also because the treatment model was intended to be suitable for use by paramedical staff (medical assistants) and these were the two anti-convulsant drugs with whose use they were most familiar.

All patients were started on treatment with phenobarbitone unless it was specifically contraindicated. The starting dose was 30-60 mg for a child and 60-90 mg for an adult. Treatment was reviewed monthly, and the dose of phenobarbitone adjusted according to response, as evidenced by the degree of seizure control. If seizures continued despite the increased dose treatment was gradually changed to phenytoin. In practice the maximum doses used were 180 mg phenobarbitone

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and 400 mg phenytoin daily. Except in children under 5 a once daily treatment regimen was prescribed. There were no facilities for measuring concentrations of anticonvulsant drugs. Most patients who attend the hospital are subsistence farmers who have no regular income. It was decided, therefore, that anticonvulsant drugs must be supplied free of charge.

I reviewed each patient each month. Thus a caring relationship was established. To ensure that patients would attend on the correct day each patient was given a record card of folded cardboard on which there was a column for recording the date of the next clinic. At review the number of seizures that occurred in the preceding month was recorded in a second column and the drugs supplied were recorded in the third column. The number of tablets to be taken daily was illustrated on the back of the card to help patients who were illiterate.

Much time was spent at the first visit teaching both the patient and the relatives about the cause and treatment of epilepsy. As most had received no education beyond primary school, and many had never been to school, the following simple explanations were used:

(1) Epilepsy is due to a scar on the brain, sometimes caused by meningitis, sometimes following cerebral malaria, sometimes inherited. Treatment aims to stop seizures occurring and allows the scar to heal.

(2) It takes a long time for the scar to heal, and we would not consider reducing, and possibly discontinuing, treatment for at least two years.

(3) Fits will not stop immediately. It takes time for the medicine to work. It may take some months to find the dose of the anticonvulsant drug that best suits a patient, and patients should not become discouraged during this time.

(4) If side effects such as a rash occur the patient must stop taking the drug and report to hospital.

(5) Alcohol should be avoided, but otherwise there are no restrictions regarding diet. (Traditionally certain foods are prohibited.)

Results

After the programme had been going for eight months 11 patients were attending hospital for treatment of epilepsy. Following the publicity about the programme through the area action committee attendances appreciably increased and after a further three months over 70 patients were receiving treatment with anticonvulsant drugs—some walking over 20 miles to attend the clinic.

To help patients who had to come a great distance a monthly review clinic was started at one of the hospital dispensaries, which was 17 miles north. The 20 patients who attended the opening clinic for review were accompanied by 44 new patients. A second mobile clinic was started at another dispensary 11 miles south of the hospital. I reviewed the patients at both mobile clinics and shared transport with the staff who were conducting mobile health clinics for children under 5 years old at the dispensaries.

As news of the epilepsy clinics spread from village to village the number of patients attending the clinics increased, so that two years after the project started 182 patients with epilepsy had registered at the hospital clinic, 192 had registered at one mobile clinic, and 87 had registered at the other—a total of 461 patients. The population within a 20 mile radius of the hospital is roughly 90 000. The average time lapse between the onset of seizures and presentation for "Western" treatment was 6.5 years.

Attrition—Of the 254 patients who entered the programme during its first 18 months, 172 (68%) were still attending six months later.

Attendance—Among the patients due to attend for review each month the attendance varied from 91 to 96% at the hospital clinic and from 71 to 88% at the mobile clinics. The main reasons given for non-attendance were the illness of a child or attendance at a funeral.

Response to treatment—Before starting treatment most patients (406; 88%) had had seizures at least once a month. Table I shows the results of treatment in 71 patients who were followed up for six months or more and in 62 of the same patients who were followed up for one year.

Adverse events during treatment—Table II gives the adverse reactions during drug treatment and the numbers of patients affected. The association of anticonvulsant drugs with the events noted does not necessarily imply causation. Oedema in particular may be due to many factors, including malnutrition. In addition, patients may have continued to take traditional treatments as well as their drugs. One child who developed severe oedema and fever left hospital while still ill and is believed to have died. All other patients made a good recovery when the associated drug was discontinued and they were given the other available anticonvulsant drug.

TABLE I—Response to treatment of 71 patients over six months and of 62 of those patients over one year

Results of follow up	No. (%) of patients followed up for:	
	Six months	One year
No fits	40 (56)	25 (40)
One fit in one year	—	9 (14.5)
Two fits in one year (or one in six months)	9 (13)	8 (13)
Dose took time to adjust (0.1 fit in preceding six months)	8 (11)	5 (8)
Frequent fits reduced (were more than five per month)	3 (4)	6 (10)
Unsatisfactory control	11 (15.5)	9 (14.5)

TABLE II—Adverse events that occurred during treatment with anticonvulsant drugs

Event	No. of patients taking:	
	Phenobarbitone	Phenytoin
Exfoliative dermatitis	2	1
Granulocytopenia	1	—
Urticarial rash	5	4
Oedema (in children only)	4	—
Hypertrophy of gums	—	1
Purulent gingivitis with mouth sores and ulcers	1	—

ADOPTION OF THE MODEL BY OTHER HEALTH UNITS

A description of the epilepsy clinics appeared in a national health extension magazine. After this medical assistants at dispensaries in different parts of Malawi informed me that they had started clinics using the guidelines given in the article and that they were pleased with the response shown. I was then invited to address a council meeting of the body coordinating the work of all church related health units in Malawi to tell of my experience in treating patients with epilepsy. The council members thought that the work described was in keeping with their policy of promoting primary health care and that they would like to encourage further involvement of their units in treating people with epilepsy. It was agreed that financial donors should be sought so that all units could supply anticonvulsant drugs free of charge and a standard epilepsy record card should be printed and supplied to interested units. I was asked to write a guide to the management of epilepsy to be distributed to all units.

One year after these proposals were implemented the results of a questionnaire showed that over 3000

patients with epilepsy were receiving regular treatment at 45 church related health units throughout Malawi.

Discussion

The model presented aims at balancing efficacy with simplicity of use. In Third World countries the doctor to patient ratio tends to be extremely low and much health care is in the hands of paramedicals.¹⁵ Malawi, which has roughly 100 doctors for a population of almost seven million, depends heavily on medical assistants. A further consideration was a shortage of finance.

The model, which was first used at Embangweni Hospital, has proved to be popular with both patients and staff (see box). It requires: (a) Adequate publicity about the availability of treatment. (b) Education of both staff and patients. (c) A simple treatment regimen, based on phenobarbitone. (d) Maintaining an adequate supply of drugs. (e) Treatment without charge. (f) Monthly clinics to review patients. (g) Ensuring that each month the patient is reviewed by the same member of staff. (h) Mobile clinics to make treatment more accessible.

The results of the study suggest that appropriate Western means of treating patients with epilepsy in

rural Africa can be instituted. As the success of treatment in individual patients is seen, the belief that treatment of epilepsy is the prerogative of traditional healers is gradually overcome.

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Research posts and overseas visitors in British gastroenterology departments

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Training for a clinical consultant post often includes a period of research, and the future of some research posts could be jeopardised by the current review of specialty training, which aims to limit the number of trainees.¹ A quota system might reduce opportunities for research by restricting the number of honorary clinical contracts at registrar and senior registrar level. Little information is available about the proportion of trainees who spend time in research posts, the stage of their career at which they do so, the duration or the source of funding of the research, and the contribution of overseas visitors. We present data on honorary contracts and research in gastroenterology.

Method and results

We sent a questionnaire in August 1988 to all members of the British Society of Gastroenterology working in England and Wales, Scotland, and Northern Ireland requesting information about people in their departments holding honorary contracts, with special reference to research posts. By this means an inquiry was made to every university and major district hospital. Lecturers in established training posts in university departments with honorary NHS contracts were excluded from the survey. An additional personal and postal inquiry was made about research experience to all 71 senior registrars in approved training posts in general medicine and gastroenterology during December 1988.

Of the 475 people who replied to the general inquiry, 348 reported that there were no honorary research posts in their departments, 51 reported one or more such posts in medicine, 34 one or more posts in surgery, seven posts in paediatrics, three posts in pathology, one a post in radiotherapy, and one a post in pharmacology. The remaining replies were duplicates or reports from trainees in established posts. Table I

summarises the results for honorary posts in medicine and surgery, and table II gives the sources of funding.

Sixty five of the 123 postgraduates in medicine were visitors from abroad who intended to pursue a career overseas. They came from 23 countries, the largest contingents coming from Australia (13), Greece (five), and India (four). Of the 50 postgraduates in surgery,

TABLE I—Results of general inquiry in 1988 to members of British Society of Gastroenterology concerning people in their departments holding honorary research contracts in medicine and surgery

	Medicine	Surgery
Type of hospital:		
University*	27	14
University associated	4	4
District general	4	1
Type of honorary contract†:		
Senior registrar	2	5
Registrar	90	40
Miscellaneous‡	26	3
Senior house officer	5	2
Career intentions:		
Consultant post in United Kingdom	48	40
Return to country of origin	65	9
Other	7	1
Uncertain	3	
Duration of appointment (years):		
≤1	20	13
2	55	27
3	24	5
>3	17	4
Unknown	7	1
No of clinical sessions/week§:		
0	15	3
1-3	64	24
4-6	34	14
7-11	9	3
Unknown	1	6
Total No	379	143
Mean	3.1	3.2

*Includes Medical Research Council's clinical research centre and post-graduate teaching hospitals.

†Only non-established honorary posts.

‡Includes 22 honorary clinical assistants and seven research fellows.

§Such as outpatient, endoscopy, and other sessions.

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