

Primary care treatment of epilepsy in Rural Ethiopia

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Abstract

Background: Chronic non-communicable diseases, such as epilepsy, are increasingly recognised as important health care problems in developing countries. Despite cheap effective treatment, the majority of people with epilepsy remain untreated. In northern Gondar, Ethiopia, we have established a treatment program for epilepsy at a primary care level.

Method: Nurse-led clinics were set up at five rural health centers. Nurses from each health center received training in the management of epilepsy at Gondar College of Medical Sciences (GCMS).

Result: Over an 18 month period from April 1998, 813 patients, aged 1-75 years (median age 20) with active epilepsy were registered and started on Phenobarbitone. The duration of epilepsy ranged from 1 month to 50 years (median 4 years) and 87% had not previously been treated with antiepileptic drugs. In only 4% due to an inability to pay for the drugs and more than 90% were unaware that medical treatment existed.

Conclusion: It is possible to provide effective epilepsy treatment using existing health care infrastructure in the country with few additional resources. [*Ethiop.J.Health Dev.* 2002;16(3):235-240]

Introduction

Chronic non-communicable diseases (NCDs) are an increasingly important health care problem in developing countries (1), and neuropsychiatry disorders account for more than a quarter of the global burden of disease(2).

Ethiopia has a population of about 65 million, 85% of whom live in rural areas. In a community based study performed in a rural population of 60,000 in central Ethiopia between 1986 and 1988, epilepsy was the most common cause of neurological disability with a prevalence of 5.2/1000(3). Another study performed in 1998 in a rural population of 25,000 in northwest Ethiopia found a very similar prevalence of 5.3/1000 (Hailu S. Personal communication). Despite the availability, of Phenobarbitone, a cheap and effective treatment, more than 90% of patients

living in rural areas remain untreated(4). Potential reasons for this include cultural factors, lack of awareness of medical treatment and inaccessibility of medical services(5).

Management of infectious diseases at a primary care level is now well established, but a coordinated approach to NCDs at this level does not exist. Over the last 3 years, a program of NCD clinics (epilepsy, diabetes, asthma and cardiac) has been established in rural health centers in the region around Gondar in Northern Ethiopia. In this report we describe one component of this program, the development of nurse-led clinics for the treatment of epilepsy.

Methods

Five health centers in the area surrounding Gondar College of Medical Sciences (GCMS) were selected. Each health center serves a predominantly rural population of about 200,000, and is staffed by health officers and 3-4 nurses. The main function of the health centers is the prevention and treatment of infectious diseases. Before the start of the project, a small

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number of patients with epilepsy were seen and some of the health centers had a limited supply of Phenobarbitone.

One or two nurses from each health center received two weeks training in the diagnosis and management of seizures at GCMS. The training consisted of a series of seminars and practical experience in the hospital epilepsy clinic. The population served by each health center was notified of the development of the clinics through community leaders, community health workers and health center nurses during the course of community work such as vaccination programs.

A physician from GCMS visits each health center on average once per month and sees all possible new cases identified by the nurses. The physician also provides supervision for the nurses whose main responsibilities are patient education and follow-up.

For each new case, the physician takes a history from the patient and a witness, and completes a structured clinical record, which includes basic demographic details, seizure history, risk factors, treatment history, impact of disease and examination findings. Seizure classification is based on the International League Against Epilepsy (ILAE) guidelines for epidemiological studies on epilepsy(6). Seizures are classified according to clinical criteria, without any requirement for electroencephalography (EEG) or neuroimaging. Seizures without any clinical evidence of partial onset were classified as generalized. A follow-up chart was adapted from an example proposed by the World Health Organization and each patient was given a clinic appointment card(7).

If a patient has had two or more unprovoked seizures within two years, treatment is offered. In practice, patients are unlikely to seek help unless their seizures are considerably more frequent than this. The nature of epilepsy, the aim of treatment, importance of compliance and potential adverse effects are discussed with patients and their relatives. First-line treatment is with Phenobarbitone. Before the clinics were

started, it was ensured that there was a regular and adequate supply of Phenobarbitone to each health center. Initially this was externally funded, however, to ensure sustainability, all patients, except those exempted from treatment charges, were asked to pay for their drugs. Phenobarbitone was started at a dose of 50-60mg in adults and 1-2mg/kg in children. Patients were seen monthly until established on maintenance doses and then followed up at 2-3 month intervals.

Data were analysed using EPI-INFO version 6.04.

Results

Clinics

The methods used to notify the communities served by the health centers were effective and there was a rapid increase in the number of new patients attending as the news of the clinics spread by word of mouth from patients who had already started and benefited from treatment. Continuity of the supplies of Phenobarbitone was maintained and supplies were sufficient to meet the rapid increase in demand. Since some of the nurses who were trained for the project moved to other posts, it has become necessary to set up an annual training program to maintain at least one trained nurse at each health center. The experience gained through the implementation of the clinics was shared at a meeting with the Zonal Health Bureau. In recognition of the value of the program for both patients and health center staff, a Regional Chronic NCD Office has been established which supports the project and ensures that the health centers have adequate supplies of Phenobarbitone, thus securing the continuity of the Program.

Patients

Between April 1998 and September 1999, 825 patients were evaluated and registered at the five health centers. Twelve had febrile seizures and are not discussed further. Eight hundred thirteen (493 male and 320 female, ratio 1.5:1) had active epilepsy and were started on treatment. The median age on presentation was 20 years (range 1-75 years). Predominance of males was seen in all age groups (Table 1).

Table 1: Distribution of epileptic patients by age group & sex in North Gondar, 1998/99

Age group at diagnosis (years)	Male		Female		Total	
	n	%	n	%	n	%
0-10	94	18.2	54	11.1	148	18.2
11-20	179	37.3	124	25.1	303	37.3
21-30	98	21.3	75	15.1	173	21.3
31-40	53	11.1	37	7.4	90	11.1
41-50	43	9.0	17	3.4	60	7.4
51-60	14	2.9	10	2.0	24	2.9
>60	12	2.5	3	0.6	15	1.8
Total	493	100	320	100	813	100

Seizure history

The duration of epilepsy before diagnosis ranged from 1 month to 50 years (median 4 years). Seven hundred fifty five (93%) patients had tonic-clonic seizures. In 119 of these a history of partial onset was obtained. Other seizure types were rare. Overall, 81% were classified as having generalized seizures and 18% partial seizures (Table 2). Four hundred forty one (54% were experiencing between one and three seizures per month and 271 (33%) were having one or more seizures per week.

Table 2: Seizure type in North Gondar, 1998/99

Seizure Type	No.	%
Generalized	660	81
Tonic-clonic	636	78
Tonic	10	1.2
Atonic	9	1.1
Myoclonic	4	0.6
Absence	1	0.1
Partial	150	18
Secondarily generalized	119	15
Complex partial	28	3.4
Simple partial	3	0.4
Unclassifiable	3	1

Impact of epilepsy

Sixty percent of patients reported one or more significant complications of their epilepsy.

Stigmatization was reported by 198 (24%). One hundred sixty eight (31% of those eligible for marriage) attributed failure of their marriage or inability to find a partner to their epilepsy.

Problems with education were reported by 17%, and problems with employment were reported by 9% of adults. Seventy five (9%) had suffered serious physical injuries as a result of seizures. Minor injuries were reported by 70 patients and overall, 10% had suffered from burns.

Risk Factors

Five hundred seven (69%) had no identifiable risk factors for epilepsy. A family history of seizures in first or second-degree relatives was reported by 192 (24%) patients. A history of previous head injury, intracranial infection or stroke was obtained from 41 (5%). Congenital or perinatal factors were identified in 27 (3.3%). Only 11 (1.4%) patients gave a history of childhood febrile seizures (Table 3).

Table 3: Risk factors for epilepsy in North Gondar 1999/98

Risk factor	No.	%
None	557	69
Family history	192	24
Head injury	26	3.2
Cerebral palsy or learning disability	17	2.1
Intracranial infection	14	1.7
Febrile seizures	11	1.4
Prenatal and neonatal factors	10	1.2
Stroke	1	0.1
Others	11	1.4

Treatment history

The majority (86%) had previously received traditional treatment. Holy water and amulets were the most frequently used traditional remedies. Only 13% had previously been treated with antiepileptic drugs, most commonly Phenobarbitone. Of the 87% who had not previously been treated with antiepileptic drugs, in only 4% was this due to inability to pay for drugs and more than 90% claimed to be unaware that drug treatment existed.

Physical examination

Examination of the skull revealed evidence of head injury that antedated the onset of seizures in 17 patients. Cardiovascular examination was abnormal in 20 patients (hypertension,

dysrhythmia or rheumatic valvular heart disease). Splenomegaly, presumed to be related to malaria, was identified in 11 patients.

Discussion

We have shown that it is possible to establish primary care clinics for treatment of epilepsy in rural Ethiopia using existing health care infrastructure and few additional resources. The existence of an affordable treatment, which is effective in the majority of patients, has resulted in the project being supported by both the patients and by the Zonal Health Bureau. Treatment of other NCDs has also been shown to be feasible in a similar setting in South Africa(8).

Although there was a marked increase in the number of patients being treated at the health centers and new cases continue to be registered, it is likely that many people with epilepsy in the community are still not receiving treatment. Assuming a catchment population of 200,000 for each health center and a prevalence of epilepsy of 5/1000, the patients seen so far account for less than 20% of predicted cases. Most of the patients that we have registered have been experiencing frequent tonic-clonic seizures, and it is likely that patients with less frequent and less severe types of seizure are not seeking treatment. It could, however, be argued that the patients most in need are at least receiving treatment. Some patients with disabling epilepsy may still not be receiving treatment. Eventhough the clinics have made treatment more accessible, we have still seen patients who have walked for several days to get to the health centers, and for others traveling to the health centers may not be feasible.

The patients registered at the health centers represent a selected population, but they are nevertheless the largest series of patients with epilepsy reported from Ethiopia(4,5,9,10). The majority of the patients presenting to the clinics were under the age of 30 years and patients over the age of 50 years were rarely seen. This reflects the age structure of the population and is unlikely to be due to major differences in age related incidence. Men in rural Ethiopia are more likely than women to seek medical

treatment when ill and this is a potential explanation for the predominance of males observed in all age groups.

Seizures were classified as partial in only 18% of our patients. In part, this may have been due to the lack of EEG, but cultural factors and language often made it difficult to obtain an accurate account of attacks despite always seeking an account from a witness. A previous study in central Ethiopia found that 20% had seizures of partial onset when clinical criteria alone were used(4). Other studies in Sub-Saharan Africa have found clinical evidence of partial onset in up to 38%(11). When clinical and EEG criteria are used, the proportion with seizures of partial onset tends to increase. In the study from central Ethiopia, when EEG data were used, 26% had seizures with evidence of partial onset(4). Other studies have found a much higher proportion of partial seizures. In a community based study from Nigeria, 55% had partial seizures(12), a rate very similar to that described in the National General Practice Study of Epilepsy (NGPSE) from the UK(13).

There is limited information on risk factors for epilepsy in Ethiopia, but our findings are comparable to those reported by Tekle-Haimanot et. al. (5). We found a family history of epilepsy in 24% compared with 22%. Other risk factors were identified in 11% of patients compared with 14% with the previous study.

It is often assumed that CNS infection is likely to be a common cause of epilepsy in tropical countries, but we obtained a history of previous CNS infection in only 1.7%, a rate very similar to the 2% identified in the NGPSE in the UK(13). In other series from sub-Saharan Africa, a history of previous cerebral infection was reported in 1-8% of cases(5,11,14,15,16). Difficulty of obtaining an accurate medical history and the lack of previous medical records in rural areas make it likely that some patients with epilepsy and a previous cerebral infection are missed. The frequency of previous cerebral infection amongst patients with epilepsy may, however, be lower than expected since, in areas with limited medical facilities, patients with meningitis or encephalitis who are at risk of

subsequently developing epilepsy may not survive the acute infection. In addition, neurocysticercosis, thought to be the most common cerebral infection causing epilepsy in some parts of the world, is unlikely to be relevant in Ethiopia where pork consumption is restricted and there are very few pigs.

A history of previous severe head injury was obtained in 3.2%, but other causes were identified infrequently. Given the age distribution of our patients, it is not surprising that stroke, which is predominantly a disease of older age groups, is found infrequently.

Despite a median duration of epilepsy of 4 years, 87% of our patients had not previously received treatment with antiepileptic drugs. This is comparable to the treatment gap observed in other developing countries (17,18). Although poor access to medical treatment is a factor, more than 90% of the patients who had not been treated with antiepileptic drugs were unaware that treatment existed. In central Ethiopia, Tekle-Haimanot et. al. found that many people living in rural areas believed that epilepsy was due to evil spirits and was potentially contagious (19). Provision of treatment at a primary care level is, therefore, only likely to be successful if it is combined with education of patients and their communities.

The majority of the patients attending the health centers were experiencing frequent tonic-clonic seizures, often resulting in injury. Both our study and that of Tekle-Haimanot et. al. (5) found that 10% of patients had sustained burns during seizures. Problems with education, employment and marriage were also reported frequently and 24% of patients felt stigmatized by their epilepsy. A study in Kenya showed that patients with a long history of untreated epilepsy were just as likely to respond to treatment as patients with recent onset of epilepsy (20) and there is, therefore, potential for significant gains in health, productivity and social integration with appropriate treatment. We have anecdotal reports of patients whose seizures have been controlled remarrying or returning to work and data on treatment outcome are currently being collected.

Conclusion: The project has increased awareness of epilepsy and its potential for treatment amongst the rural population and illustrates how existing healthcare infrastructure, initially developed for treatment of infectious diseases, can with few additional resources be adapted for the growing burden of NCDs such as epilepsy. Awareness of the extent of this burden has been increased amongst healthcare professionals and administrators, which will help chronic NCDs gain the greater priority that they justify.

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