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Economic Burden and Treatment Profile of Epilepsy Patients in Rural India

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Abstract

Introduction and objective: Epilepsy is a long term disease and it requires chronic therapy. Due to less number of neurologist and poor economic status of the patients, they do not take treatment despite the availability of effective and affordable medication which leads to high treatment gap. In developing countries like India the economic burden due to epilepsy in not adequately examined. This economic cost of the disease leads to large impact on the patients and his/her family. Hence, cost estimates are very important in health care planning and delivery of services. This study aimed to explore the profile of pharmacological management in epileptic patients and also to estimate the direct cost associated with epilepsy management.

Methods: The prospective study was done in a Community Health Centre in district Churu, Rajasthan, India under the auspicious of Epilepsy Care and Research foundation. It included 7200 epileptic patients from majority of states from all over India from 1994 to 2018. Seizures were classified according to ILAE Classification (1981). Patients who attended the camps monthly were assessed by a neurologist. The records were maintained by entry of details of each patient on epilepsy card.

Results: There was male preponderance with a male to female ratio of 2:1. 87% of the epileptic patients belonged to rural areas. Of all the total epileptic patients 75% were either illiterate or had primary education upto 10th standard. The most common seizure type seen in our study was generalized seizures which accounted for 64% followed by had partial seizures which accounted for 29%. The most common drug used in our patients was Phenytoin prescribed to 54% of the patients followed by phenobarbitone prescribed to 51% of patients. 90.2% patients were fully controlled or well controlled on drugs. 51.2% of the patients were managed on single drug for seizure control and 32.6% required two drugs. The magnitude of treatment gap was found to be 33% which was very high. In our study the average cost per month for the patients who were on monotherapy was Rupees 96.6 and who were on dual therapy was Rs 149.

Conclusion: This large study highlights the current scenario of patients with epilepsy in India especially focusing on the treatment profile and economic burden of antiepileptic drugs on these patients. Most of the patients can be controlled on monotherapy or dual therapy the monthly cost of which is less than Rupees 150. Despite this low cost of drugs per month there is poor compliance seen in the patients. Also there is a huge treatment gap among epileptic population in our country. This calls for frequent awareness programs to make people more aware of the disease so that they can acknowledge the fact that this disease is treatable.

Keywords: *Economic Burden; Treatment Profile; Epileptic Patients; Treatment Gap*

Introduction

Epilepsy has become the health problem in the entire world with approximately 1% of the population being affected by it. Importantly, majority of the people accounting for approximately 80% suffering from epilepsy are from developing world [1,2]. The given epidemiology ranges from 1.228 to 8.87 per 1000 in various studies from India [3]. It is ranked either as first or the second most common neuro-

logical disease in India [4]. Epileptic patient may sometimes have to suffer with significant disability, social stigmatization, problems in education, employment, personal development, social and personal relationships [5]. This poor health awareness and misbeliefs about the disease are more common in rural areas and it is estimated that seventy percent of Indians are settled in rural areas [6]. As it is a long term disease it requires chronic therapy. Due to various cultural and economic differences epilepsy care in developing countries differs from that in developed countries [7]. Also because of less number of neurologist in the country, many times, the patient may visit a primary care physician, who may have less sufficient knowledge about the type of epilepsies and their management [7]. As majority of the epileptics come in low and middle income group, they do not take treatment despite the availability of effective and affordable medication which leads to high treatment gap [8].

Aim and Objective

It is important to understand the challenges in the diagnosis and treatment of epilepsy, and efforts should be made to reduce the treatment gap in epilepsy. This study was done to look into the treatment profile of the patient, to estimate the financial burden of epilepsy on an individual and their family, to acknowledge the high treatment gap in our country due to various factors, including lack of access to or knowledge of AEDs, poverty, cultural beliefs, stigma, poor health delivery infrastructure, and shortage of trained professionals.

Materials and Methods

In this prospective non-interventional, study, done in centre situated at Ratannagar, a Community Health Centre in district Churu under the auspicious of Epilepsy Care and Research foundation, an NGO involved with epilepsy work, a total of 7200 patients were included who visited the centre on 1st Tuesday of every month from 1994 to April 2019. These patients were included from different geographical areas and different demographic populations of India and informed consent was taken from them. Seizures were classified according to International League against Epilepsy classification (1981). An epilepsy card containing all details were recorded by a neurologist including the demographic profile, risk factors and treatment profile of the patients. On the basis of the control of seizures, they were classified as fully controlled(patients who were seizure free for 1 year on drugs), well controlled(patients who had 1-2 episodes of seizures on drugs) and uncontrolled(patients who had frequent episodes of seizures despite appropriate drugs given in adequate doses).

Drug resistant epilepsy

ILAE defines drug-resistant as "failure of adequate trials of two tolerated and appropriately chosen AED schedules (whether as monotherapies or in combination) to achieve seizure freedom".

Treatment gap

In many developing countries, people with epilepsy do not receive appropriate treatment for their condition, a phenomenon called treatment gap (TG), which is defined as the number of people with active epilepsy not on treatment (diagnostic and therapeutic) or on inadequate treatment, expressed as a percentage of the total number with active epilepsy [9]. The TG has two components: Those not accessing or unable to access biomedical facilities for diagnosis and treatment and, if accessing biomedical treatment, those not adhering to the prescribed antiepileptic drugs (AEDs) [9,10].

Treatment gap was calculated on the basis of above definition. All patients were given medicines every month free to ensure better compliance. On follow up, all patients were screened for compliance and epilepsy control by a team of doctors. All patients were also provided with an identity card. The data of these patients were statistically evaluated.

Results

Demographic and clinical profile of patients

The study included 7200 patients. There was male preponderance (male - 66.6% and female - 33.7%) with a male to female ratio of 2:1. The median age was 28 years with most of them below 30 years of age (Table 1). Most of these epileptic patients belonged to rural

areas (n = 6264, 87%). There was high rate of illiteracy seen in our study. Of all the total epileptic patients 75% were either illiterate or had primary education upto 10th standard.

The most common seizure type seen in our study was generalized seizures which accounted for 64% (n = 4608) of patients, 29% (n = 2088) had partial seizures (Table 2). Many patients in our study had cognitive and behavioral disorders which included 13% of patients (n = 936) with mental retardation, 25% with behavior disorders (n = 1800) and 49% with impaired memory (n = 3528) (Table 3).

Age Group (Years)	Number of Patients	% of Patients
0 - 10	1097	15.23%
11 - 20	1506	20.9%
21 - 30	2624	36.45%
31 - 40	1110	15.42%
41 - 50	544	7.56%
51 - 60	181	2.52%
Above 60	138	1.92%

Table 1: *Age wise percentage distribution of person with epilepsy.*

Seizure Type	Number of Patients	% of Patients
GTCS	4608	64%
Complex Partial Seizures	1584	22%
Simple Partial Seizures	504	7%
Secondary Generalization	468	6.5%
Unclassifiable	36	0.5%

Table 2: *Percentage distribution of seizure types.*

Clinical features	Number of patients	Percentage of patients
Family history	324	4.5%
Mental Retardation	936	13%
Behavioral Disorder	1800	25%
Loss of Memory	3528	49%
Aura present	1368	19%
Post ictal confusion/ Headache	3456	48%

Table 3: *Features associated with epileptic patients.*

Treatment and treatment gap

The most common drug used in our patients was Phenytoin prescribed to 54% (n = 3888) of the patients followed by phenobarbitone prescribed to 51% (n = 3672) of patients (Table 4). Out of 7200 patients, 706 patients (9.8%) were uncontrolled, that is, they were drug resistant. On the other hand rest 90.2% patients were fully controlled or well controlled on drugs. 51.2% (n = 3686) of the patients were managed on single drug for seizure control and 32.6% (n = 2347) required two drugs. Only 16.2% (n = 1167) of our patients required polytherapy, that is, more than two drugs (Table 5).

Drug	Number of patients	Percentage	Average cost per month (in Rupees)
Phenytoin Sodium	3888	54%	1,39,968
Phenobarbitone	3672	51%	1,76,256
Levetiracetam	960	13.33%	8,06,400
Sodium valproate	1539	21.37%	3,69,360
Carbamazepine	1370	19.03%	1,64,400
Clobazam	853	11.85%	1,53,540

Table 4: *Drugs used in patients of Epilepsy.*

Number of drugs	Number of patients	Percentage
One	3686	51.2%
Two	2347	32.6%
More than 2	1167	16.2%

Table 5: *Distribution of antiepileptic drugs.*

Drugs used as monotherapy were phenytoin(n=1685), phenobarbitone (n=1105), sodium valproate(n=105), levetiracetam (n= 170), carbamazepine (n= 621) (Table 6). In dual therapy the most commonly used drug combination was phenytoin with phenobarbitone (n = 1526) followed by phenytoin and clobazam (n = 164) and then phenytoin and sodium valproate (n = 141) and sodium valproate and carbamazepine (n = 141). Other patients were fully or well controlled on drugs.

Drug	Number of patients	Cost per month of total patients
Phenytoin	1685	60,660
Phenobarbitone	1105	53,040
Carbamazepine	621	74,520
Sodium Valproate	105	25,200
Levetiracetam	170	1,42,800

Table 6: *Monotherapy Cost.*

8.48% of the patients who had GTCS were poorely controlled on drugs. The percentage was higher in patients who had partial seizures, that is, 13.79% patients were poorely controlled on drugs (Table 7). The magnitude of treatment gap was found to be 33% which was very high. 13% of them visited quacks first, 10% went to faith healers, 6% to tantricks and 4% never consulted anyone (Table 8). 64.3% of these patients belonged to low income status. Also, of them 94% were either illiterate or had education just upto 10^{th} standard.

Type of seizures	Total number of patients	Well controlled and completely controlled patients	Uncontrolled
GTCS	4608	4217	391 (8.48%)
Partial seizures	2088	1800	288 (13.79%)
Secondary generalized	468	444	24 (5.13%)
Unclassified	36	33	3 (8.33%)

Table 7: *Distribution of response of treatment in various types of seizures.*

First Consultation	Percentage
Neurologist/Physician	67%
Quack	13%
Faith Healers	10%
Tantrik	6%
Never consulted anyone	4%

Table 8: *First consultation.*

Economic burden of epilepsy

In our study the average cost per month for the patients who were on monotherapy was Rupees 96.6 and who were on dual therapy was Rs 149. Average cost for the patients who were controlled on poly therapy was Rupees 251.38.

Discussion

Demographic and clinical profile of patients

In this study a total of 7200 patients were included. Their median age of onset of seizure was 28 years with majority of them below 30 years of age which is similar to past study done in 1998 [6]. In some previously done studies [11-13]. Majority of the patients had onset of seizures before the age of 20 years. The rates were low in patients above 40 years of age [14-16]. The onset of seizures continued to rise with increasing age only in Rochester study [17]. There was one study which depicted a bimodal distribution of age in which first peak was seen during early childhood and 2nd during later age of life at their 70s and 80s [18,19].

Increasing incidence of strokes and head injuries in India in later stages of life may be responsible for this second peak [18].

The overall preponderance of male over females was observed in this study which was consistent with other studies done in last several years [20]. Several cultural factors and comparatively higher mortality among female children due to poor care may lead to this high prevalence in male. In contrast almost similar prevalence rate in male and females was seen in Radhakrishnan., *et al.* and Das., *et al.* [11,12]. Also, in a study done in rural Tanzanian district female preponderance was reported [21].

Maximum patients in our study belonged to rural population which is similar to the other several studies, however the percentage was higher in our study [12,18,22]. There are several factors which contribute to this urban and rural difference. They are poor antenatal/postnatal care, malnutrition, birth injury, increased incidence of infections, high rates of head injuries, and also limited health services in rural regions.

Generalized seizure was the most common seizure type (64%) followed by complex partial seizure (29%) which is similar to the other studies done in India [23,24]. While in other studies rate of generalized seizures has been reported as high as 88% [25]. In contrast focal-seizure was the most common type of seizure in two other performed hospital based studies [26,27]. Rochester study was an exception to our study in which 60% patients had partial seizures [25]. This difference in our study can be attributed to the difference in history narrated by their relatives, as many times the initial part of seizure is missed and it is witnessed once it has generalized.

13% were diagnosed with mental retardation in our study. This was in consistency with other studies by RK Sureka., *et al.* [7] and Razdan S., *et al*. [28] and was lower than Rantanen's study on children with epilepsy that reported that cognitive function was mildly retarded in 22%, and moderately to severely retarded in 28% [29].

Treatment and treatment gap

The most frequently used antiepileptic drug was phenytoin sodium followed by phenobarbitone. In previously done study the most frequently used antiepileptic drug was sodium valproate either alone or in combination, followed by carbamazepine, phenytoin sodium, clobazam, vigabatrin, diazepam and phenobarbitone [30].

In our study 9.8% of patients had drug resistant epilepsy which was less when compares to study done in Singapore where the prevalence rate of drug resistant epilepsy was 21.5% [31].

Most of the patients who were drug resistant had partial seizures with or without secondary generalization which was consistent with study done in Georgia in 2017 [32].

51.2% patients in our study were controlled on monotherapy. This was also similar to the results of other study where patients were mostly chronic and 50% were controlled on monotherapy [6]. In contrast, in the study of Reynold and Shorvon, it was stated that 80 to 90% of the newly diagnosed patients could be controlled on one drug [33]. In our study 32.6% patients required 2 drugs to control seizures. This percentage of patients who required more than 2 drugs was more when compared with one study done in Rajasthan [6] and lower than in a study from New Zealand where incidence was 38% [34].

In our study the treatment gap was 33%. Of them majority were from low income group and were illiterate or had education upto 10^{th} standard. In one systematic review there was a wide range of difference of the treatment gap between various countries estimated from active epilepsy [35]. In China (Province of Taiwan), Norway, Singapore, the United Kingdom of Great Britain and Northern Ireland, the United States of America, and select populations in Argentina, Brazil and France gap was 10% or less. On the contrary, treatment gaps were greater than 95% in China, Ethiopia, the Gambia, the Lao People's Democratic Republic, Nigeria, Pakistan, Panama, Togo, Uganda, the United Republic of Tanzania and Zambia. There was a wide range of treatment gaps being observed within countries as well. For example, in urban middle income population treatment gaps in India ranged from 22% to 90% in a sample of rural villages [36,37]. This treatment gap in our study could also be attributed to the fact that 13% of them visited quacks first, 10% went to faith healers, 6% to tantricks and 4% never consulted anyone. So, majority of the initial consultations are with traditional healers. It was seen in a study from an urban centre that 40% of the epileptic patients opted for treatment other than consulting allopathic doctor, with a preference to sorcery or voodoo by 28.8% of people [38]. In Nigeria, when enquired almost 90% of the patients had a belief that doctors can effectively treat epilepsy, large number of population, that is, 33% still preferred to combine medical treatment with sorcery or native treatment [38].

Economic burden

The most important cost category in a patient with epilepsy is cost of AEDs. In our study it was seen that majority patients were controlled on monotherapy or dual therapy. The average cost per month for patients who were on monotherapy was Rupees 92 and who were controlled on dual therapy was Rupees 149. Also who required polytherapy the average cost was Rupees 251.38. This showed that with cost less than Rupees 120 majority of the epileptic patients can be cured. This is similar to previous studies reported from Nigeria [37] and in most countries worldwide. In our study the average annual cost of the AEDs required per patient was Rupees 3,016. In a study done in South India the total annual cost per patient amounted to Rupees 13,755 which was more in comparison to our study [39]. This could possibly be explained by the lower cost of older and cheaper antiepileptic drugs (AEDs) used in our study. Probably due to the use of cheaper generic antiepileptic drugs costs from developing countries like Burundi, Columbia, and India were same as of our study [40,41].

Conclusion

This large study highlights the current scenario of patients with epilepsy in India especially focusing on the treatment profile and economic burden of antiepileptic drugs on these patients. Maximum patients can be managed at rural centres without sophisticated investigations and with minimal cost of drugs per month. The mean monthly cost of antiepileptic drugs in India is very less. Most of the patients

can be controlled on monotherapy or dual therapy the monthly cost of which is less than Rupees 150. Despite this low cost of drugs per month there is poor compliance seen in the patients. Also, there is a huge treatment gap among epileptic population in our country. This calls for frequent awareness programs to make people more aware of the disease so that they can acknowledge the fact that this disease is treatable.

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