

Healthcare-Seeking Behavior of Patients with Epileptic Seizure Disorders Attending a Tertiary Care Hospital, Kolkata

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ABSTRACT

Introduction: Neurological diseases are very important causes of prolonged morbidity and disability, leading to profound financial loss. Epilepsy is one of the most important neurological disorders. Healthcare seeking by epilepsy patients is quite diverse and unique. **Aims and Objectives:** The study was conducted among the epilepsy patients, to assess their healthcare-seeking behavior and its determinants. **Materials and Methods:** Three hundred and fifteen epilepsy patients, selected by systematic random sampling, in the neuromedicine outpatient department of a tertiary care hospital were interviewed with a predesigned, pretested, semi-structured proforma. **Results and Conclusion:** More than 90% sought healthcare just after the onset of a seizure. The majority opted for allopathic medicine and the causes for not seeking initial care from allopaths were ignorance, faith in another system, constraint of money, and so on. A significant association existed between rural residence and low social status of the patients with initial care seeking from someone other than allopaths. No association was found among sex, type of seizure, educational status of the patients, and care seeking. The mean treatment gap was 2.98 ± 10.49 months and the chief motivators were mostly the family members. Patients for anti epileptic drugs preferred neurologists in urban areas and general practitioners in rural areas. District care model of epilepsy was proposed in the recommendation.

Keywords: Antiepileptic drug, healthcare seeking, modern medicine, treatment gap

Introduction

In the present world of ours, non-communicable diseases are becoming a lot more important health concerns both in the developing and developed countries. Neurological diseases are a leading cause of disability and their treatment entails prolonged hospitalization with a commensurate financial toll. Epilepsy is an important neurological disorder prevalent in India. Developing countries used to carry 90% of the financial burden

of epilepsy, as 85% of world's 40 million people with epilepsy live in developing countries.⁽¹⁾

Epilepsy as 'recurrent unprovoked seizures' is always shrouded in mystery because of its episodic, unpredictable, and varied manifestations.⁽²⁾ Healthcare seeking of epilepsy is an interesting field of study. Social stigma associated with the disease greatly modifies the healthcare-seeking behavior. Social beliefs play a pivotal role in this regard. In a country like India where the population is so diverse in every regard, starting from education and per capita income to beliefs in healthcare-seeking behavior in epilepsy is quite varied, ranging from modern allopathic treatment to traditional methods like witchcraft.

Shrovan and Farmer⁽³⁾ first introduced the term 'Treatment gap,' in 1988, to indicate that more than 80% of the people with epilepsy in developing countries

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did not receive appropriate treatment. In India, the treatment gap varied between 73.7 and 78% among the rural population against the urban population, where it was shown to be 34.7% in Chandigarh and 6% among Parsis in Bombay.⁽⁴⁾

In this present scenario, where epilepsy has already been declared as a public health problem⁽⁵⁾ by the World Health Organization (WHO) and the International League Against Epilepsy (ILAE), and the situation being considerably grave in India, this study was planned in the Department of Neuromedicine, Medical College, Kolkata, which is a premier institution and hospital in India and caters to a huge number of patients from all over the state and some neighboring states, regularly, with the objective of assessing the healthcare-seeking behavior and its determinants among the epilepsy patients.

Materials and Methods

The present observational, descriptive, cross-sectional, hospital-based study was conducted in the outpatient department (OPD) of the Department of Neuromedicine of the Medical College, Kolkata, situated in Kolkata, during the period from October 2008 to June 2009, among the diagnosed epilepsy patients attending the said OPD.

Analyzing the last five years' hospital records, the average yearly attendance of epilepsy patients in the Neuromedicine OPD of the Medical College was calculated to be 840, with negligible yearly variation. As the study period was nine months, the expected attendance in this period came up to 630. Considering the feasibility, the desired sample size was chosen as 50% of those patients, that is, 315. The study sample was selected using the systematic random sampling technique, following the inclusion criteria of the study, and entry of the study subject was continued until the total desired sample size of 315 was arrived at. The inclusion criteria for the study population were age of the epilepsy patient ≥ 12 years, willingness to participate in the study, and presence of informant/spouse/parent/near relative with the patient.

Ethical clearance and informed consent of the patients was taken before the study. Techniques followed were interview of the patients and attending caregiver, with the predesigned, pretested semi-structured proforma and analysis of the records available with the patients. Analysis was done using Epi info 3.4.3 and statistical package for social sciences 16.0 softwares.

Results

Among the 315 epilepsy patients, the majority of the study population belonged to the age group of 16 to 30 years (54.6%); they were males (66.03%) and were

Hindu (69.2%). The mean age of the study population was 29.98 ± 12.70 years; 75.2% were from the urban areas, whereas, 24.8% were from the rural areas. One hundred and forty-three (45.39%) of the study population were from Kolkata proper, and the remaining were from different districts of West Bengal like Haora (19.04%), 24 Parganas North (13.33%), Hooghly (7.66%), 24 Parganas South (5.03%), Medinipur (2.53%), Bardhaman and Nadia each 1.90%, and Murshidabad (0.63%).

Regarding the education status, 102 (32.4%) of the study population had completed primary education, followed by 56 (17.8%) who failed to complete primary education, and 14.3% who were illiterate. A majority of the study population were unskilled labor (30.2%), followed by unemployed (23.2%), students (13.3%), skilled labor (12.7%), self-employed (8.9%), and homemakers (7.6%); 47.6, 25.4, and 15.5% of the study population belonged to class IV, V, and III of the Prasad scale, respectively. The mean per capita income for the total study population, males and females, was seen to be 678.70 ± 915.8 , 737.16 ± 1066.98 , and 565.07 ± 491.45 , respectively.

The study population of 34.9, 30.2, and 26% had complex partial seizure, simple partial seizure, and generalized tonic-clonic seizure, respectively; 55.2% of the patients were on monotherapy, whereas, the remaining were on polytherapy. A majority (45.7%) had their onset of disease between 11 and 20 years and the mean duration of epilepsy was seen to be 8.58 ± 7.04 years.

Regarding the source of the first healthcare-seeking after the onset of seizure, 81.6% of the population opted for allopathic medicine, 8.9% preferred homeopathy, and 7.6% sought care from traditional medicine. Only 1.9% opted for Jharphook, Jalpara, and so on, as the initial mode of treatment. Females had more preference for homeopathy and traditional medicines than allopathic ones compared to males, [Table 1].

In 96.8% of the cases, the actual time gap between the onset of seizure and care seeking was less than 24 hours. All the female patients had sought care within 24 hours of the onset of seizure [Table 2]. The actual time gap between the onset of seizure and starting of Antiepileptic drug (AED) was less than 24 hours in 80.3% of the cases. The

Table 1: Distribution of the study population according to the source of first healthcare seeking (n=315)

Source of first treatment	Male		Female		Total	
	No	%	No	%	No	%
Allopathic medicine	174	83.7	83	77.6	257	81.6
Homeopathy	14	6.7	14	13.1	28	8.9
Traditional medicine	14	6.7	10	9.3	24	7.6
Others	6	2.9	0	0.0	6	1.9
Total	208	100	107	100	315	100

mean time gap between the onset of seizure and the start of AED for the study population was 2.98 ± 10.49 months, which for males was 3.64 ± 12.59 months and for females was 1.68 ± 3.71 months, the difference in the mean time gap (between the onset of seizure and starting of AED) between the male and female study population was not statistically significant ($P=0.522$) [Table 3].

In 94.9% of the cases the motivator was a family member. In 3.2% of the cases, care seeking was self-motivated. In 1.3% of the cases they were motivated by a doctor/health worker, and in 0.6% of the cases, they were motivated by peers/colleagues.

Among the study population ($n=58$) who did not choose allopathic treatment as the initial mode of healthcare seeking, the reasons were ignorance (50%), faith on another system (29.3%), constraint of money (10.3%), and non-availability of allopathic doctors at the time of need (10.3%).

The first AED was taken from the general practitioner by 21.27%, of which 53.73% were from the rural areas and 46.2% from the urban areas; 20.32% took their first AED from a specialist, of which 34.37% were from the rural and 65.63% from the urban population. A study population of 0.63% took their first AED from a psychiatrist, and they were all from the urban area; 57.78% got their first AED from a neurologist of whom 10.94% were from the rural areas and 89.01% from the urban areas.

Table 2: Distribution of the study population according to the time gap between the onset of seizure and healthcare seeking ($n=315$)

Time gap	Male		Female		Total	
	No	%	No	%	No	%
Within 24 hours	198	95.2	107	100.0	305	96.8
>24 hours to <1 year	4	1.9	0	0.0	4	1.3
1–2 years	2	1.0	0	0.0	2	0.6
>2 years	4	1.9	0	0.0	4	1.3
Total	208	100	107	100	315	100

Table 3: Distribution of the study population according to the time gap between onset of seizure and starting of antiepileptic drug ($n=315$)

Time gap	Male		Female		Total	
	No	%	No	%	No	%
Within 24 hours	170	81.7	83	77.6	253	80.3
>24 hours but <3 months	4	1.9	6	5.6	10	3.2
4–6 months	12	5.8	4	3.7	16	5.1
7–9 months	2	1.0	4	3.7	6	1.9
10–12 months	6	2.9	10	9.3	16	5.1
>12 months	14	6.7	0	0.0	14	4.4
Total	208	100	107	100	315	100
Mean \pm SD (months)	3.64 ± 12.59		1.68 ± 3.71		2.98 ± 10.49	
						U=10793.0, P=0.522

A majority (47.0%) of the study population came to the tertiary care within 24 hours of onset of seizure. However, 27.0% of them sought care at the tertiary level after 12 months. The mean gap was 25.08 ± 51.03 months, which in case of males was 25.47 ± 52.65 months and for females was 24.33 ± 47.95 months, and the difference was not statistically significant ($P=0.418$).

Among the 315 study population, 257 sought allopathy treatment initially, whereas, 58 opted for treatment other than allopathy. On exploring the relation of some sociodemographic variables with the initial healthcare-seeking behavior of the study population, a significant association was seen between rural residence ($P=0.0001$) and low socioeconomic status of the patients ($P=0.005$). The other variables did not show a statistically significant relationship [Table 4].

Discussion

The present study observed that a majority of the study population had sought care almost simultaneously with the onset of seizures, with very little delay. Different studies⁽⁶⁻⁸⁾ had shown that the people with epilepsy were not taking AED due to non-availability and non-accessibility of AEDs in the vicinity. However, the other important reasons were the preference of the people for treatment from traditional practitioners, although AED was accessible, as highlighted by these studies.⁽⁶⁻⁸⁾ In the present study it was observed that only 8.9% of the study population sought care from homeopathy, 7.6% from traditional practitioners, and 1.9% opted for Jharphook, Jalpara, and so on. These findings were similar to the findings of Bhattacharya *et al.*⁽⁷⁾ and Pal *et al.*⁽⁶⁾ in their studies on epilepsy, conducted among the school going children at a suburban area of Kolkata and the rural area of West Bengal, respectively. However, Singh *et al.*⁽⁹⁾ had a dissimilar finding in their study conducted in rural Haryana, where he had seen more people who consulted quacks and faith healers as a first choice. It should be mentioned here that the quacks were much less popular in rural West Bengal compared to the licensed medical practitioners, as observed by Pal *et al.*^(8,10) in their two studies, conducted in West Bengal.

Although considering the time gap between the onset of epilepsy and first search for healthcare, the present study observed that 96.8% of the study population sought care within 24 hours, 81.6% chose allopaths for their initial healthcare, and the family members were the chief motivators for care-seeking in 94.9% of the cases. The reasons for not seeking allopathic treatment as the initial mode of treatment were found to be ignorance (50%), faith in another system (29.3%), constraint of money (10.3%), and non-availability of allopathic doctors (10.3%). No studies were available to corroborate the present study findings.

Table 4: Relationship of some sociodemographic variables with the initial healthcare-seeking behavior of the epilepsy patients (n=315)

Variable	Allopathy treatment (n=257) (%)	Other than allopathy treatment (n=58) (%)	Total (n=315) (%)	Odds ratio and CI (95%)	Chi-square	P value
Sex						
Male	174 (67.7)	34 (58.6)	208 (66.0)	1.48 (0.79–2.76)	1.74	0.187
Female	83 (32.3)	24 (41.4)	107 (34.0)			
Residence						
Urban	213 (82.9)	24 (41.4)	237 (75.2)	6.86 (3.55–13.31)	43.74	0.0001
Rural	44 (17.1)	34 (58.6)	78 (24.8)			
Types of seizure						
Generalized	96 (37.4)	14 (24.1)	110 (34.9)	1.87 (0.94–3.80)	3.64	0.057
Partial	161 (62.6)	44 (75.9)	205 (65.1)			
Socioeconomic status of the family						
High	80 (31.1)	5 (8.6)	85 (27.0)	4.79 (1.75–14.18.)	12.17	0.005
Low	177 (68.9)	53 (91.4)	230 (73.0)			
Educational status of the patient						
Primary or below	164 (63.8)	39 (67.2)	203 (64.4)	0.86 (0.45–1.64)	0.24	0.622
Above primary	93 (36.2)	19 (32.8)	112 (35.6)			
Educational status of head of the family						
Primary or below	215 (83.7)	53 (91.4)	268 (85.1)	0.48 (0.16–1.36)	2.22	0.14
Above primary	42 (16.3)	5 (8.6)	47 (14.9)			

The mean time gap between the onset of seizure and the start of AED was 2.98 ± 10.49 months as observed in the present study. In their study Thomas *et al.*⁽¹¹⁾ found that the treatment delay for those who were on AEDs was 3.0 ± 3.0 years (range 0.08 – 12 years). The delay in treatment was attributed to the use of traditional medicines, non-disabling nature of the seizures, and different diagnosis. Less time gap in the present study might be due to the fact that the study population did not prefer traditional medicines as the initial mode of treatment.

Source of the first AED for the study population widely varied according to their residence in the present study. The people with rural residence received AED mainly from the general practitioners (53.73%), followed by specialists (MD Medicine/MD Pediatrics) in 34.37% of the cases. However, the urban people consulted neurologists (89.01%) for their first AED intake followed by specialists (65.63%), and general practitioners (46.27%). This wide variation was probably due to the availability of neurologists, and the awareness and affordability of the urban people. Similar findings of the rural-urban difference was also observed by Malmgren *et al.*⁽¹²⁾ in her observation across Europe. Bhattacharya *et al.*⁽⁷⁾ had also seen direct consultation of neurologists by 58.2% of his study populations in an urban area of West Bengal.

On analyzing the relationship of some sociodemographic variables with the initial healthcare-seeking behavior, no significant association was observed in the case of sex, types of seizure, and educational status of the epilepsy patients, and their head of the family, with the initial healthcare-seeking behavior. However, a significant

association was observed in the case of the residence and socioeconomic status of the family. Pal *et al.*^(6,8,10) also did not observe any association with sex, income, maternal literacy, and medical variables in their study in rural West Bengal.

The present study revealed that the majority of the study population was in the age group of 16 – 30 years; they were Hindu males, and came from urban areas. A majority of the study population had completed primary education, were unskilled laborers, and unemployed.

More than 90% sought health care just after the onset of a seizure. The majority opted for allopathic medicine and causes for not seeking initial care from allopaths were ignorance, faith in another system, constraint of money, and non-availability of allopath doctors at the time of need. A significant association existed between rural residence and the low social status of the patients with care-seeking from sources other than allopaths. Most of the patients started AED almost after the onset of seizure, for AEDs preferred neurologists in urban areas, whereas, general practitioners in rural areas.

Therefore, the major chunk of cases at these levels, are presently not diagnosed. These patients, if they get their treatment in the Primary Health Centre (PHC) or Community Health Center according to the vicinity, a substantial financial burden on epilepsy patients can be reduced. Neurologists in present India are available mainly in the Metros and tertiary care hospitals. If a neurologist can be kept as a Nodal neurologist for a district, as suggested by the district model for the epilepsy control program by Gourie Devi *et al.*,⁽⁵⁾ training

of specialists of medicine and pediatrics, of the district, regarding epilepsy, can be organized. They in turn can give training to the medical officers of the Bureau of Primary Health Care (BPHC) and the Primary Health Center (PHC). Thus, a referral chain can be established from the PHC Medical Officer (MO) to the nodal neurologist.

This referral chain, if established, can allow the follow-up of the epilepsy patients in the local healthcare facility only, and simultaneously allow the referral of difficult-to-treat epilepsy cases to the care of a neurologist.

PHC medical officers in turn can train the peripheral health workers regarding case detection of epilepsy, thus reducing the treatment delay. The peripheral health workers can also play a pivotal role in increasing community awareness regarding epilepsy.

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