

Cross-sectional Observational Retro-prospective Study of Treatment Gap in Epilepsy Patients at Tertiary Care Center

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Abstract

Context: *Epilepsy is one of the most common neurological disorders and highly prevalent in India. Its prevalence is about 1% of our population, this being higher in the rural as compared with the urban population. This study is conducted to evaluate the incidence of treatment gap & demographic characteristics in patients of Epilepsy.*

Methods: *Total 500 patients diagnosed clinically with epilepsy by neurologist were screened. A total of 500 patients having seizures were screened in OPD and IPD of Neurology department during 4 months period.*

Results: *Out of 500 patients, 265 (53%) patients had treatment gap and 235 (47%) patients had no treatment gap. Various factors were responsible for treatment gap which includes; physician related factors (21.57%), treatment related factors (8.65%), patient related factors (41.37%) socio-economical factors (14%) and education related factors (13.95%)*

Conclusion: *Treatment gap is seen to be more common in younger age group & with illiteracy. Treatment gap was found in rural areas more than the urban areas. Most of the factors were related to the healthcare facility in India. Strategies have to be defined to increase the awareness about epilepsy, its prevention and benefit of treatment, myths & misconception.*

Key words: *Epilepsy, Treatment gap, demographic*

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Introduction

Neurological diseases are a leading cause of disability and their treatment entails prolonged hospitalization with a commensurate financial toll. Developing countries used to carry 90% of the financial burden of epilepsy^[1]. Epilepsy is one of the most common neurological disorders and highly prevalent in India. It is estimated that there are more than 10 million persons with epilepsy (PWE) in India. Its prevalence is about 1% of our population,^[2] this being higher in the rural (1.9%) as compared with the urban population (0.6%).^[1,3] In the Bangalore Urban Rural Neuro-Epidemiological Survey (BURNs), a task force project supported by the Indian Council of Medical Research (ICMR) covering a population of 102,557, a prevalence rate of 8.8 per 1,000

population was observed, with the rate in rural communities (11.9%) being twice that of urban areas (5.7%)^[4] The burden of epilepsy as estimated using the disability-adjusted life years (DALYs) accounts for 1% of the total burden of disease in the world due to social stigma and isolation, which PWE in our country face, this in turn leads to escalation of the disease burden.^[5]

The treatment of epilepsy is very long-term However, more than 70% of patients who are treated achieve long-term remission or freedom from seizures, usually within 5 years of diagnosis^[6]. People with epilepsy do not follow prescribed drug regimens, leading to uncontrolled seizures and poorer quality of life^[7]. Health-care seeking behavior and adherence are complex issues affected by many factors. This irregularity in the treatment is called “treatment gap”. A simple definition of the “treatment gap” is the number of people with an illness, disease, or disorder who need treatment but have never taken it for various reasons^[8]. Also after starting the treatment many patients do not continue the treatment for various reasons

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& this was considered as secondary treatment gap. We wanted to analyze various factors like non-availability of experts, antiepileptic drugs, social & economical factors etc. which may be responsible for the treatment gap. The gap is defined in terms of those people with epilepsy who are not being appropriately treated and is the result of an array of medical, political, social, economic & cultural factors^[9]. A study “The epilepsy treatment gap in developing countries: a systematic review of the magnitude causes, and intervention strategies” done in Kenya in 2003 with active convulsive epilepsy that had similar characteristics to people with epilepsy in other parts of Africa. They found that the epilepsy treatment gap was 62% as measured by detection of AEDs in blood samples. This finding represents a reduction from 74% measured during a survey in 2003 and could be attributed to setting up an epilepsy clinic with a continuous supply of AEDs and sensitization of the community^[10].

Objectives

1. To evaluate the incidence of treatment gap & demographic characteristics in patients of Epilepsy.
2. Determine the reasons behind the treatment gap in epilepsy patients from the department of Neurology in a tertiary care center.

Materials and Methods

It is a Cross-sectional, observational, retro-prospective study carried out in total 500 patients diagnosed clinically with epilepsy by neurologist. The study was conducted at a tertiary hospital in Mumbai and the duration of study was 16 weeks. Patients were screened according to the inclusion and exclusion criteria and were enrolled both from inpatient and outpatient departments. Patients with all age groups and of either sex with confirmed diagnosis were enrolled. Patients who fulfilled the inclusion criteria were enrolled in the study after taking their informed consent for participation in the study. As the data to be collected was qualitative, $N = 4pq/L^2$ formula was used to calculate the sample size, which was calculated as 500. After enrollment of patients their history of disease, demographic characteristics, treatment, and information of treatment gap and reasons behind treatment gap were noted on case record form while interviewing the patients.

Results

As shown in Table 1 that total of 500 patients had seizures were screened & enrolled in Epilepsy OPD & IPD at Neurology department during 16 weeks period. Out of which 311 patients were males and 189 patients were females.

Table 1: Gender wise distribution of epilepsy patients

Number of epilepsy patients	Female	Male
500	189	311

Incidence of treatment gap

As shown in Table 2 that within the 500 epilepsy patients enrolled, 235 (47%) patients with no treatment gap and 265 (53%) patients with treatment gap.

Table 2: Distribution of patients with treatment gap

Total number of patient	Total number of patient had treatment gap	Total number of patient had no treatment gap
500	265	235
Percentage	53%	47%

Incidence rate of treatment gap is calculated by using following formula:

$$\text{Incidence} = \frac{\text{No. of person had treatment gap}}{\text{Total no. of person diagnosed with epilepsy}} \times 100$$

$$= \frac{265}{500} \times 100$$

$$\text{Incidence} = 53\%$$

Hence the incidence of treatment gap in epilepsy patient at neurology OPD of K.E.M. Hospital Mumbai was found to be 53%

As shown in Table 3, 265 patients had treatment gap, 118 patients had primary treatment gap (23.6%) and 123 secondary treatment gap (24.6%) and 24 patients had both primary and secondary treatment gap (4.8%).

Table 3: Distribution of patients had treatment gap with primary & secondary gap

patients had primary treatment gap	patients had secondary treatment gap	patients had both primary and secondary treatment gap
118	123	24
23.6%	24.6%	4.8%

Table 4: Gender wise distribution of patients had treatment gap

Total number of male patient	Treatment gap in Male	Total number of Female patients	Treatment gap in Female
311	168	189	97
Percentage	54.01%	Percentage	51.32%

As shown in above **Table 4** out of 265 patients who had treatment gap, 168 patients were males (63.40%) and 97 patients were females (36.60%).

As shown in **Table 5**, out of total 265 patients, 58 patients were between 5-18 years age (21.87%) and 207 were above 18 years of age (78.13%). Out of 235 patients who had no treatment gap 39 patients were between 5-18 years age (16.60%) and 196 patients were above 18 years of age (83.40%).

Table 5: Distribution of patients of treatment gap by age

Total number of patients between 5-18 years of age group	Treatment gap between 5-18 years of age group	Total number of patients above 18 years of age group	Treatment gap above 18 years of age group
97	58	403	207
Percentage	59.79%	Percentage	51.36%

Table 7: Distribution of reasons with the common factors

Sr. no.	Reasons behind treatment gap	Total number of patients had reasons behind treatment gap	Percentage
1	Physician Related Factors	85	21.57%
	i) Physician are not available	20	5.07%
	ii) Not diagnosed/misdiagnosed	46	11.67%
	iii) Negligence to patient	19	4.82%
2	Treatment Related Factors	34	8.63%
	i) Adverse Effect of treatment	10	2.52%
	ii) No improvement with treatment	10	2.52%
	iii) Medicine are not available	14	3.54%

As shown in **Table 6**, within 500 patients, 441 patients visiting OPD were from Mumbai territory (urban), from them 227 (51%) patients had a treatment gap which was less than the patients coming from outside the Mumbai territory, 59 patients were coming from outside the Mumbai territory (rural) & 38 (64.41%) patients of them had a treatment gap.

Table 6: Distribution of patients by their location

Total no. of patients	Patient from urban territory	Patient from rural territory
500	441	59

Total no. of patients had treatment gap	Patients with treatment gap	Patient with treatment gap
265	227	38
Percentage	51%	64.41%

As shown in **Table 7**, the underlying reasons behind the treatment gap were, physician related factors with 85 patients (21.57%), treatment related factors with 34 patients (8.63%), patient related factors with 163 patients (41.37%), socio-economic factors with 57 patients (14.47%) and educational factors with 55 patients (13.96%). Within 265 patients with treatment gap 120 patients shows only one factor within the all factors while 145 patients' shows multiple factors.

3 Patient Related Factors	i)Unable to travel because of epilepsy	163	41.37%
	ii)Lack of care taker to accompany patient	11	2.79%
	iii)Traditional medicine preferred	21	5.32%
	iv) Unsatisfied with clinic service	19	4.82%
	v) Stopped AED himself/herself	11	2.79%
	vi)Stopped AED himself/herself	50	12.69%
	vi)Did not understand the need of follow-up	51	12.94%
4 Socio -economical Factors	i) Cost of treatment	57	14.47%
	ii) Cost of travel	33	8.11%
		24	5.89%
5 Educational Factors	i) Lack of educational services	55	13.96%
	ii)Lack of knowledge about epilepsy and treatment gap	21	5.32%
		34	8.62%

Table 8: distribution of patients with number of factors

	Physician related factors	Treatment related factors	Patient related factors	Socio-eco nomical factors	Edu cational factors
Patients with single factor	32	6	43	12	22
Patients with two factors	40	11	98	22	30
Patients with three factors	17	16	47	20	11
Patients with four factors	3	1	6	2	0

Discussion

We studied treatment gap in epilepsy patients at tertiary care center by cross sectional, observational, retro-prospective study and also found reason behind treatment gap by asking group of questions to patients. This study shows that out of total 500 patients 265 (53%) patients had treatment gap, whereas the previous studies conducted on treatment gap in epilepsy shows that in India, about 78% of the patients with epilepsy are affected by this gap [11] The treatment gap varies from 50 to 70% among persons with epilepsy. [12] Prior anecdotal and descriptive estimates suggest a treatment gap of more than 80% in many low-income countries, [8] [13] yet one

recent systematic review and meta-analysis suggests that the treatment gap in developing countries is as low as 56%. [10]

On analyzing the data we found by demographic characteristics, epilepsy mostly occurs in male than female. [2] Out of 311 males 168(54.01%) had treatment gap and out of 189 females 97 (51.32%) had treatment gap. According to this result there was no significant association with the sex in the treatment gap. Similar result was found in Kolkata where no relative association was observed with the sex in the treatment gap. [14] The treatment gap varied between different age groups, out of 500 patients, 97 patients were between 5-18years of age, among them 58(59.79%) patients had treatment gap and 403 patients were above 18years of age, among them 207(51.36%) patients had treatment gap. Treatment gap in younger age group was predominant than the above 18 years age group because they are more dependent on their parents & the society. Sometimes patient did not inform to parents that he/ she had seizure attacks because even he/ she did not understand what happened to him/ her.

We conducted our study in K.E.M. hospital Parel, Mumbai where the number of patients coming from different parts of Maharashtra, Gujarat and nearest states. According to our study patients coming from outside the Mumbai region had the high incidence of treatment gap. The treatment gap was found in patients coming from the rural areas was [64.41%] which is more than the patients from urban areas [51%]. 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. [15] The reason behind this is the improper healthcare services and unavailability of physicians in rural areas.

Literacy is the major factor as higher literacy rate decreases the treatment gap incidence. In a highly literate population of Kerala, a treatment gap of 38% has been found. [16]

Out of 500 patients, 265 patients had treatment gap; among them 118(44.69%) patients had primary treatment gap and 123 (46.59%) patients had secondary treatment gap and 24 (9.09%) patients had both primary and secondary treatment gap. Therefore, the study suggests that the secondary treatment gap was more than primary treatment gap. This may be attributed to chronicity of disease.

According to study; mean treatment gap is found 3 ± 2 (range 0.1- 10 yrs). Average of primary treatment gap found 3.13 years where secondary treatment gap is 2.57 yrs, whereas the previous studies showed that the mean time gap between the onset of seizure and the start of antiepileptic drug was 2.98 ± 10.49 months [8]. In the study of Thomas *et al.* [17] found that the treatment delay for those who were on anti epileptic drugs 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.

Conclusion

The treatment gap found at the tertiary care center of Mumbai was still 53%, which means that more than half of epilepsy patients didn't get proper treatment. Treatment gap in epilepsy patients still remains big challenge for the health care providers of India. Comparatively this study results indicates that in the recent year the treatment gap in epilepsy patient was decreased compared to previous studies. Treatment gap is seen to be more common in younger age group & with illiteracy. Treatment gap was found in rural areas more than the urban areas. According to the study we found most of the factors were related to the healthcare facility which suggested that India lacks basic healthcare facilities. As we found in the study 8.62% patients had treatment gap due to lack of knowledge about the epilepsy & treatment gap. From this result we

concluded that lack of educational awareness in India is the also an important factor behind the treatment gap. To decrease the treatment gap in epilepsy we need to make some strategies. Educating the healthcare workers on various aspects of epilepsy management may certainly help in overcoming treatment gap to certain extent. To decrease the treatment gap we need to arrange awareness campaigns & seminars for the patients & also the healthcare professional. Such campaigns will help to increase the awareness about epilepsy, its prevention and benefit of treatment, myths & misconception etc. We can also use the media & social networking site for the awareness of epilepsy

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