

## Treatment Gap Issues in Community Sample of People with Epilepsy

Bajaj, M. K. \*

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Assistant Professor Clinical Psychology, Department of Psychiatry, Government Medical College & Hospital, Sector-32, Chandigarh

Acknowledgement: Dr Gagandeep Singh, Professor and Head, Department of Neurology, DMCH, Ludhiana and ICMR, New Delhi.

### Abstract

*Aim of the study was to identification of the factors leading to treatment gap in a community sample of persons with epilepsy in north India. Sample: A population of semi-urban slum area of Ludhiana city N=15750 was surveyed in an ICMR study, out of this 114 cases were found screened positive with active epilepsy. Details were obtained from database of community study. Active epilepsy cases were provided free medicines on monthly basis in the community itself. A total number of 67 patients were not on follow ups and 47 were on follow ups in the community. All 67 patients were contacted door to door by the author. Only 24 patients were traced and interviewed. The first group n=47 named follow up group and second group n=24 formed treatment gap group. Measures: Screening questionnaire for epilepsy validated on epilepsy patients and controls, Socio-economic scale (Modified) by Udai Pareek and Semi structured interview schedule to assess issues related to treatment gap was specifically developed which also includes Socio-demographic and clinical details of the patients. Results: two groups were significantly different in respect to type of seizures frequency of seizures episodes. Occupation of the patient and mother's educational level were also found to be significantly different in both the groups. In the study of factors related to treatment gap, indirect cost- in the form of absence from the work lead to daily income loss in labor class was significant factor in 29% patients; dissatisfaction with the treatment was noted in the 63 % people with epilepsy, 58.33% of the patients do not have adequate knowledge of right treatment of this condition, 29% of the patients did not believe in the anti-epileptic treatment, they were following the faith healers advice, 20 % patients were not seeking the treatment because of stigma, co-morbidity of mental retardation and psychosis was found in 8.5% and 14.28 % patients could not receive treatment because of family conflict. Conclusion: dissatisfaction with the treatment and lack of adequate knowledge were the main factors found in this study which were related to the treatment gap in this study.*

**Key words:** Treatment gap, Epilepsy.

**Introduction:**

Epilepsy is the most common chronic neurological disorder, affecting approximately 50 million people worldwide, of whom 40 million are estimated to live in developing countries. Several studies have reported that a large proportion of patients with epilepsy in developing countries do not receive appropriate treatment for their condition, a phenomenon known as the treatment gap (Mbuba, et al., 2008 & Meinardi, H et al., 2001). The treatment gap is defined as the number of people with active epilepsy not on treatment or on inadequate treatment, expressed as a percentage of the total number with active epilepsy (Kale, R, 2002 & Mbuba, et al., 2008). A recent systematic analysis that investigated the magnitude of the treatment gap in developing countries found an overall rate of 56% (95% CI 31–100%) (Meinardi, H et al., 2001) and the following region-specific and location-specific rates: Latin America, 55% (95% CI 39–79%); Asia, 64% (95% CI 24–100%); Africa, 49% (95% CI 14–100%); rural populations, 73% (95% CI 50–100%); and urban populations, 47% (95% CI 34–64%). The authors ascribed

the wide variations in the estimates to a lack of uniformity in the definition of 'treatment gap' and in methods of its estimation. In the highly literate population of Kerala, southern India it was observed a treatment gap rate of 38% (95% CI 35%–41%) (Radhakrishnan, K. *et al.*, 2000). Treatment gap a percent of measure of population not receiving the treatment, estimated to be upto 73.7% to 78% in India ( Ray et al., 2002). The treatment gap is reported to be influenced by various factors, including lack of access to or knowledge of anti-epileptic drugs, poverty, cultural beliefs, stigma, poor health delivery infrastructure and shortage of trained professionals (Radhakrishnan, 2009). In a recent systematic review, the main causes of the treatment gap were cost of treatment (median 62%, range 11–90%), non-availability of AEDs (median 53%, range 18–44%), belief in traditional treatment (median 44%, range 6–82%), and superstitions and cultural beliefs (median 40%, range 7–65%) (Radhakrishnan, K. *et al.*, 2000). In developing countries, a large proportion of patients with epilepsy, despite being diagnosed and initiated on AED treatment, soon

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discontinue the treatment. In epidemiological surveys, such patients would be categorized as not being on treatment. Das *et al.* 2007, coined the term 'secondary treatment gap' to designate this phenomenon. In a prospective observational study of 1450 patients followed in an urban clinic in north-eastern India, 620 (43%) discontinued their treatment within 1 year. Among these individuals, 89% experienced more than two breakthrough seizures following AED discontinuation. The principal reasons that were cited for AED discontinuation were the inability to afford the treatment and a lack of information about the consequences of medication non-adherence. An economic analysis that set out to establish the expected costs and cost-effectiveness of first-line AEDs (that is, phenobarbital, phenytoin, carbamazepine and valproic acid) concluded that the current large treatment gap in developing countries could be reduced considerably by scaling up the routine availability of low-cost AEDs such as phenobarbital and Phenytoin (Radhakrishnan, K. *et al.*, 2009) Unfortunately, most patients with epilepsy in developing countries are treated with multiple—and often

expensive—AEDs simultaneously. The simultaneous use of multiple AEDs caused the cost to escalate enormously. A sizeable proportion of these patients could be weaned off unnecessary AEDs, resulting in better seizure control, fewer adverse effects, and financial savings. The irrational polytherapy for epilepsy that is common in resource-poor countries can probably be attributed to the increasingly widespread availability of AEDs (including new AEDs) in recent years, combined with inadequate knowledge of about current trends in the pharmacotherapy of epilepsy among primary and secondary care physicians, who provide the initial treatment for the majority of patients with epilepsy in these countries. One of the most important roles for epilepsy specialists at the tertiary referral centres in resource-poor countries should be the continuing medical education of other medical practitioners down the line.

**Aim:** The aim of the study was to identification of the factors leading to treatment gap in a community sample of persons with epilepsy in north India.

**Objectives:** Primary Objectives: a. Survey of incidence and prevalence of

epilepsy in selected area of population b. Assessment of factors leading to Treatment gap. Secondary objective: To develop appropriate strategies or plan to reduce the treatment gap in this population

### **Methodology**

**Sample:** A population of semi-urban slum area of Ludhiana city N=15750 was surveyed and out of this 114 cases were found screened positive with active epilepsy. Monthly OPDs were conducted to treat them and anti-epileptic drugs were supplied free of cost to them. Out of 114 patients 67 patients were not on follow up in monthly OPDs. Patients who were regularly visiting the monthly OPDs were n=47. After visiting the homes of the patients who were not on follow ups 24 patients were found to be in the treatment gap. Those patients who were migrated (n=20), off treatment (n=7), taking treatment from outside (n=15) and died (n=1) were excluded from the study. The first group n=47 named follow up group and second group n=24 formed treatment gap group.

### **Measures:**

1. Screening questionnaire for epilepsy validated on

epilepsy patients and controls.

2. Socio-economic scale (Modified) by Udai Pareek
3. Semi structured interview schedule to assess issues related to treatment gap was specifically developed after literature review which also includes Socio-demographic and clinical details of the patients.

### **Procedure:**

A door to door survey was conducted by the two trained field workers (special training in identification of epilepsy cases) in an urban slum area of Ludhiana city to determine the prevalence of epilepsy. This area is under the Urban Health Centre of DMC & H, Ludhiana. Seven colonies were selected for survey on a registered population of 15,750 people under the guidance of the Auxiliary Nurse Midwives working in the area under the Department of Social and Preventive Medicine. After door to door survey, screen positive patients were evaluated by the neurologist and confirmed the diagnosis of seizure disorder. EEG monitoring was done in

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positive cases to make diagnosis. Neurological evaluation of screened positive patient was done by the Principal Investigator. During each assessment a comprehensive interview of the subject and an accompanying person who has witnessed the seizures was conducted to take detailed medical history, detailed description of seizures, antecedent events, review of past and current treatment records and investigations. After all investigations and clinical interview 114 people with active epilepsy were identified. The once in a month on a fix day free OPDs are conducted at the community health center of DMCH by the neurologist with special interest in epilepsy. These patients are provided free medication on monthly basis. All the patients are telephonically contacted two to three days advance and their response were noted to ensure the regular treatment of all the patients (details are presented in the bar diagrams).

In present study patients who were attending the monthly OPDs regularly formed the **follow up group**, rest of the patients who were not coming to the monthly OPDs, were contacted at their homes with the help of trained field

workers. They were assessed through semi structured interview (Annexure-2) for the reasons for not coming to OPDs. They were interviewed to know the current status of the treatment. The informed consent was obtained from all the patients.

To carry out the present study a semi structure interview schedule was developed on the basis of literature review for the assessment of treatment gap issues. Along with the clinical and socio-demographic data sheet which include (age, gender, education, religion, SES, Occupation, Handedness, type of seizures, duration of seizure disorder, current frequency of seizures and last seizure attack details were recorded. There were some open ended questions asked about the illness causes and treatment. In addition to above all the patients who have taken any kind of treatment the details of the current treatment were also recorded. This interview schedule was conducted with the patients and their relatives. It took average half an hour to complete with one patient. Total six visits were planned to the community and all the patients were interviewed. If the patient was found unavailable, their care givers were

interviewed. At the end of the interview they were psycho-educated and encouraged for the regular and appropriate treatment of this condition.

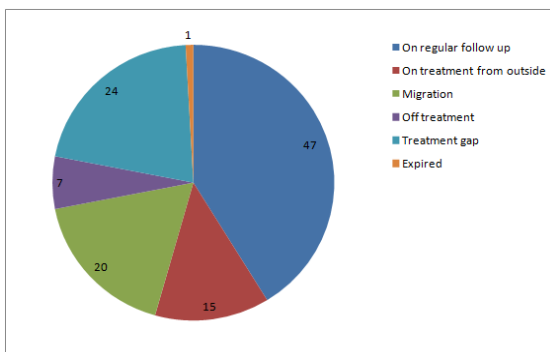
**Statistical analysis:**

Descriptive statistical method chi square was used to know the differences between both the groups on categorical variables. Measures of central tendency and dispersion e.g. mean and standard deviation was used to analyze the data. Treatment Gap issues were assessed qualitatively with the descriptive statistical methods.

**Results and discussion:**

Present study was carried out with the aim of identification of factors leading to the treatment gap in people with epilepsy. A good number of patients were compliant to the treatment in our study (figure 1).

**Figure 1** Active epilepsy patients in frequency with respective details of sample.



On review of the records of the monthly OPD data 47 patients were in the follow up group and 15 patients were on treatment from local physician out of 67 patients. So total 62 patients were on regular treatment in addition to above 7 patients were also off-treatment, suggests a good compliance rate.

In comparison to initial assessment at the time of beginning of the study the no. of patients with primary treatment gap and secondary treatment gap out of 114, were 25.44% and 14.91% respectively. But after more than one year of free treatment from monthly OPDs this number is significantly reduced to 7.52 % in primary treatment gap, and slightly increased to 18.27% this may be because of the high number of patients were migrated and they were excluded from the analysis. On the other hand in the beginning of the study 51.75 % patients were taking anti-epileptic treatment but after more than one year we reviewed that 66.66 % patient are on regular anti-epileptic treatment. This gain shows that free medicines and regular monthly OPDs has significantly increased the patients for effective and right treatment of this condition.

It is also noted that treatment gap was equal to the study which was done in the highly literate population of Kerala, Southern India in which a treatment gap rate of 38% (95% CI 35%–41%)[3]. But in the review of the studies from India by Ray et al. 2002 estimated treatment gap to be upto 73.7% to 78%. In our study it is approximately 40 %, but because of high migration rate this

finding should be interpreted with caution.

On further analysis of the socio-demographical and clinical variables significant between group differences were noted in the type of seizure disorder, frequency of seizures, occupation of the patients and mother’s education (**Table-1**).

**Table 1** showing the clinical and socio-demographic variables with significance in treatment gap group and in the follow up group.

Socio-demographic and Clinical variables	Follow up group N=47 Frequency (%)	Treatment gap group N=24 Frequency (%)	Significance
<b>Age in Years</b> Mean (SD)	33.2 (15.99)	29.0 (17.24)	0.156 (Not significant)
<b>Duration of seizures Disorder in months</b> Mean (SD)	134.83 (126.90)	143.75 (88.53)	0.359 (Not significant)
<b>Type of seizure disorder</b> Complex partial+ others Generalized tonic clonic	26 (55.32) 21 (44.68)	4(16.66) 20(83.34)	0.0042 (Very significant)
<b>Frequency</b> Daily weekly Monthly annually	5(10.63) 42(89.37)	8(33.33) 16(66.67)	0.04 (significant)
<b>Gender</b> Male Female	28(59.57) 19( 40.43)	14(58.33) 10(41.67)	0.92 (Not significant)
<b>Education</b> Educated Illiterate	42(89.37) 5(10.63)	17(70.83) 7(29.17)	0.61(Not significant)
<b>Marital status</b> Married Unmarried	21(44.67) 26(55.32)	14(58.33) 10(41.67)	.276(Not significant)
<b>Occupation</b> Business Labourer None	13(27.65) 5(10.63) 29 (61.70)	3(12.50) 9(37.50) 12 (50)	0.02 significant
<b>Social economic status</b> Rich Poor	46(97.87) 1(2.13)	22(91.67) 2(8.33)	0.545 (Not significant)
<b>Religion</b> Hindu Sikh + others	36(76.59) 11(23.41)	18(75) 6(25)	0.96(Not significant)
<b>Class</b> Non SC SC+BC	14 (29.78) 33(70.22)	2(8.33) 22(91.67)	0.08(Not significant)
<b>Cast</b> Upper Lower + artisan	14(29.78) 33(70.22)	8(25) 16(75)	0.97(Not significant)
<b>Mothers’ education</b> Educated Illiterate	19(40.43) 28(59.57)	3(12.50) 21(87.50)	0.032 ( significant)
<b>Family type</b> Joint Nuclear	6 (14.63) 41(85.33)	3(12.50) 21(87.50)	0.975(Not significant)

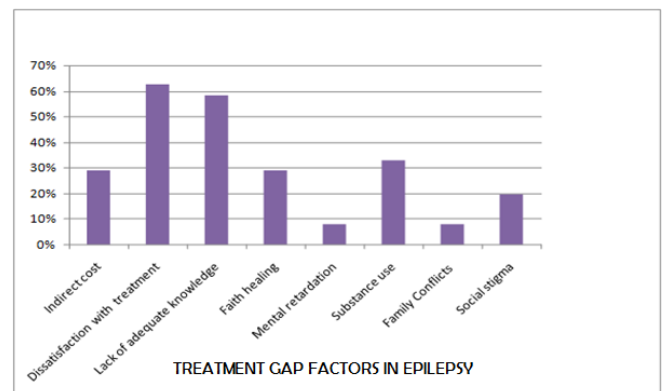
<b>Family size</b>			
Large+medium	23(48.93)	15(62.5)	.405(Not significant)
Small	24(51.07)	9(37.5)	
<b>House ownership</b>			
Own	44(93.62)	22(91.67)	0.76 (Not significant)
Rented + others	3 (6.38)	2(8.33)	
<b>Household assets</b>			
7-15	33(70.22)	16(66.67)	.97(Not significant)
0-6	14(29.78)	8(33.33)	
<b>Type of house</b>			
Pucca+mixed	42(89.37)	20(83.34)	.73(Not significant)
Kaccha	5(10.63)	4(16.66)	
<b>No. of rooms</b>			
Three/two	35(74.46)	19(79.16)	.88(Not significant)
One	12(25.54)	5(20.84)	
<b>Drinking water</b>			
Piped/ own hand pump	44(93.62)	21(87.50)	.67(Not significant)
Common hand pump	39(6.38)	3(12.50)	

It was noted that those people who are having GTC type of seizures and frequent seizures episodes and doing labor work are from the treatment gap group as compare to follow up group. It suggests that they have a poor seizure control may be because of irregular or not taking the appropriate such as anti-epileptic drugs. It further emphasized the importance of regular use of anti-epileptic drugs to control the future episodes. Mothers education was also found to important factor in this condition, most of the mothers were illiterate in treatment gap group as compare to follow up group, emphasize the importance of parental education in the treatment of epilepsy. The follow up group and treatment gap group were not significantly different in respect of mean age, duration of seizures, gender, education of the patient, marital status,

social economic status, religion, class, cast, family type, family size, house ownership, house hold assets, type of house, no of rooms and drinking water facility.

In present study it was found that direct cost could not be related as we are providing the free medicines in the monthly OPDs but it was observed that indirect cost- in the form of absence from the work leads to daily income loss in labor class was significant factor in 29% patients (**figure 2**).

**Figure 2** bar diagram showing the factors studied in the study for treatment gap with their percentages.





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Radhakrishnan (2009) in a recent systematic reviewed that the main causes of the treatment gap were cost of treatment (median 62%, range 11–90%) but in our study it was the indirect cost of the treatment as we have provided the free treatment to the patients. In one of the study it was found that indirect costs increase if the patient does not undergo effective treatment, and a small effort in alleviating the direct cost would bring down the cost of treatment, including the indirect one[11].

Dissatisfaction with the treatment was noted in the 63 % people with epilepsy in this study (figure 2). They were not satisfied with the treatment because of recurrent seizures despite anti-epileptic drugs and fear of side effects of the drugs and soon discontinued the treatment these findings are consistent with findings of Das *et al.*, 2007. He coined the term 'secondary treatment gap' to designate this phenomenon [6]. In a prospective observational study of 1450 patients followed in an urban clinic in north-eastern India, 620 (43%) discontinued their treatment within 1 year [6]. Among these individuals, 89% experienced more than two breakthrough seizures following AED discontinuation.

The principal reasons that were cited for AED discontinuation were the inability to afford the treatment and a lack of information about the consequences of medication non-adherence. In our study almost around 58.33% of the patients do not have adequate knowledge of right treatment of this condition. Some of the patients having seizures after long time, therefore they attributed that there is no need for continued treatment. Mani *et al.*, (1998) done a study in South India and found that frustration because of dissatisfaction with the treatment was the significant factor in 20% of patients for discontinuation of the treatment leading on to treatment gap (Mani *et al.*, 1998).

Substance use disorder was common problem in 33 % patients (figure 2). They attributed that these episodes are due to withdrawal of the substance which leads to treatment gap.

29% of the patients( figure 2) did not believe in the anti-epileptic treatment, they were following the faith healers advice these findings supports the findings of the Radhakrishnan *et al.* (2009), they studied that belief in traditional treatment (median 44%, range 6–82%), and superstitions and cultural

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beliefs (median 40%, range 7–65%) are prevalent in Indian population.

In our study 20 % patients (figure 2) were not seeking the treatment because of stigma, these were all young girls. Their family members think that if people will come to know about her diagnosis there will be a problem in getting married in the future as no one will marry with their daughter. In one of the studies it was found that 55% of the women concealed their epilepsy during marriage negotiations. Out of those who concealed, 18% were legally divorced and 20% were separated from their spouses because of the disease (Santosh et al., 2007).

Co-morbidity of mental retardation and psychosis was found in 8.5% respectively (figure 2) this was mainly because of recurrent uncontrolled seizures.

Family dynamics: 14.28 % patients (figure 2) could not receive treatment because of family conflict as the females are dependent on them and the head of the family does not bother about the person with epilepsy especially the females. This is also related to the social perception of the community people, lack of knowledge and lack of education

is the main factor contributing directly or indirectly.

It was observed that most of the patients have poor socio-economic status, therefore illiteracy results in inadequate knowledge of this condition. Popular beliefs of evil spirit are common in these communities because of poverty and illiteracy. Therefore, improving the socio-economic status can improve the level of education and therefore there will be adequate knowledge about this condition.

There is a strong need to train the local physician because they are the first person in which the local patients contact initially. If the local physician has adequate knowledge about this condition then only the adequate treatment of the condition is possible.

From this study it can be concluded that the intervention is required at all levels.

1. Improving the SES of the communities will improve the literacy level of the population.
2. Increasing the awareness of this condition by road show, public meeting, street play and electronic and print media.

3. Primary treating physician training about the epilepsy and its proper treatment.
4. Making sure access of the treatment.
5. Free supply of medicines.
6. Bridging the gap between the treating physician and the community.

**References:**

- Kale, R.(2002) Global campaign against epilepsy: the treatment gap. *Epilepsia* 43 (Suppl. 6), 31–33.
- Sridharan, R. & Murthy, B. N. (1999). Prevalence and pattern of epilepsy in India. *Epilepsia*40, 631–636.
- Radhakrishnan, K. *et al.* (2000).Prevalence, knowledge, attitude, and practice of epilepsy in Kerala, South India. *Epilepsia* 41, 1027–1035.
- Meinardi, H., Scott, R. A., Reis, R. & Sander, J. W. (2001).The treatment gap in epilepsy: the current situation and ways forward. *Epilepsia* 42, 136–149.
- Mbuba, C. K., Ngugi, A. K., Newton, C. R. & Carter, J. A.

- (2008). The epilepsy treatment gap in developing countries: a systematic review of the magnitude, causes, and intervention strategies. *Epilepsia* 49, 1491–1503.
- Das, K. *et al.* Evaluation of socio-economic factors causing discontinuation of epilepsy treatment resulting in seizure recurrence: a study in an urban epilepsy clinic in India. *Seizure* 16, 601–607.
- Radhakrishnan, K. (2009).Epilepsy surgery in India. *Neurol. India* 57, 4–6).
- Gourie-Devi, M., Satishchandra, P. & Gururaj, G. (2003).Epilepsy control program in India: a district model. *Epilepsia* 44 (Suppl. 1), 58–62.
- Indian Epilepsy Society. Indian Guidelines for the Management of Epilepsy: GEMIND.<http://www.epilepsyindia.org/gemind-main.asp> (2008).
- Santosh D, Kumar TS, Sarma PS, Radhakrishnan K. (2007). Women with onset of epilepsy

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- prior to marriage: disclose or conceal? *Epilepsia*. 48(5):1007-10.
- Krishnan A, Sahariah SU, Kapoor SK. (2004) Cost of epilepsy in patients attending a secondary level hospital in India. *Epilepsia* 45(3): 289-91.
  - Mani KS, Rangan G, Srinivas HV, Reddy AK, Kalyanasundaram S, Narendran S. (1998). The Yelander study- a community- based approach to epilepsy in rural South- India epidemiological aspects. *Seizure* (7):281-8.