



Comparing long-term outcomes of epilepsy patients from a single-visit outreach clinic with a conventional epilepsy clinic: A cross-sectional observational study from India



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ABSTRACT

Purpose: To compare long-term treatment outcomes in epilepsy patients from a single-visit outreach clinic on the Lifeline Express (LLE) with a conventional hospital (AIIMS) based epilepsy clinic in India.

Methods: Using a cross-sectional observational study design, consecutive epilepsy patients from fifteen LLE clinics conducted from 2009 to 2014 were compared to epilepsy patients registered in the same duration at the AIIMS epilepsy clinic. The primary outcome was to determine if patients were still taking AEDs. To determine current AED status, patients from the LLE clinic were contacted telephonically. For the AIIMS patients, hospital records were reviewed and phone calls made to those patients who had not followed-up for more than a year.

Results: In the 5 years under review, 1923 and 1257 patients had consulted at the LLE and AIIMS clinics respectively. Long-term outcomes were available for analysis in 688 AIIMS and 531 LLE clinic patients. Of the AIIMS patients, 581(87%) were continuing AEDs, 49(7%) had discontinued AEDs after being seizure-free for at least 5 years, 39(6%) had discontinued AEDs without medical advice and 19(2.8%) were dead. Outcomes in 531 LLE patients revealed that 351(72%) continued to be on AEDs, 34(7%) had discontinued AEDs on advice, 106 (22%) had discontinued AEDs without any medical advice and 40 (7.5%) were dead. The treatment gap in the LLE patients was reduced from 49% at first contact to 22% at follow-up 2–8 years later.

Conclusions: Even single-visit epilepsy clinics may be an effective option for reducing treatment gap in limited-resource regions of the world.

1. Introduction

Of the 60 million persons with epilepsy (PWE) worldwide, 80% live in low and middle-income countries (LMICs). Epilepsy care in LMICs including India, is poorly organised, inaccessible to the majority and leaves millions untreated [1]. There are no systems to systematically audit quality or outcomes of epilepsy care that is being provided. Health care facilities and doctors caring for PWE are overwhelmed by patient loads. There is a paucity of resources, including time, that are needed to periodically review quality of care. India has about 12 million PWE but there are no clearly defined, minimum, evidence-based, standard-of-care recommendations for varying levels of care viz-a-viz

primary, secondary and tertiary and there is no mechanism by which individual patient outcomes are even broadly tracked. For example, data regarding how many PWE continue prescribed treatment for as long as needed, how many go into remission, or even how many PWE attending any hospital clinic may have died while being treated, is not known. Clearly, there is scope not just to increase availability and improve access to care but also a need to critically evaluate the care that is being provided.

One of our ongoing projects in the context of improving access to epilepsy care has been an outreach clinic on the Lifeline Express (LLE). This is a train that serves as a mobile hospital and travels countrywide providing multiple health services to the most inaccessible, rural Indian

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communities. The LLE is run by the Impact India Foundation, an Indian non-governmental organisation [2]. One weekend epilepsy clinic is conducted at each of the stops of the LLE since 2009. All services provided on the LLE, other than the epilepsy clinic, do not require patient follow-ups. However, for epilepsy that is not the case. In spite of this serious limitation, we have chosen to continue volunteering for the epilepsy clinic as it is an unparalleled opportunity to meet and provide care, including epilepsy information and awareness, to the most underserved and uniformed patients. Arranging regular follow-up services for PWE who are seen on the LLE remains an unfinished agenda that we continue to work on. In the meanwhile, we have information that some patients prescribed epilepsy treatment on the LLE do follow-up with doctors locally or occasionally even at the tertiary care government hospital in Delhi where some of the investigators work. In the past, an early (7–9 months) follow-up of some LLE patients was attempted and the results were published [3]. However, we remained curious as to what would happen to patients over a longer duration? Many of these patients may not have had an opportunity to consult with a suitable doctor after our encounter with them on the LLE. This model of epilepsy care, with the neurologist making a single contact with the patient, and no systematic follow-ups, is not widely practiced. Therefore, there is no data about patient outcomes from such a clinic. If such outreach clinics make any meaningful impact in the long-term and at least some patients benefit from it, then this may be one model of care that may be worth replicating. In a country like India, where about 70% patients still reside in small towns and villages with hardly any epilepsy care facilities in the vicinity, outreach clinics may provide some respite.

We conducted this study to determine long-term epilepsy patient outcomes in India. The primary outcome we were interested in looking at was the number of patients who continued to take AEDs as advised. We were interested in looking at this outcome in two groups of patients: one who had consulted only once with a neurologist on the LLE and were not offered any regular follow-up after the visit and the second who were on treatment at a tertiary care hospital with the option of regular follow-up visits over the long term.

2. Methods

2.1. Standard protocol approvals, registrations and patient consents

This cross-sectional observational study was conducted at the All India Institute of Medical Sciences (AIIMS), a tertiary care teaching hospital in New Delhi, India. All patients or their legal representatives (for minor and disabled patients) gave a verbal informed consent and the institutional ethics review board approved the study. The study was designed in compliance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement [4].

2.2. Study design

This was a cross-sectional observational study.

2.3. Setting

Outcomes had to be evaluated in two groups of epilepsy patients and both were drawn from very different settings. The first group of patients were those who had consulted at one of the LLE epilepsy outreach clinics between the years 2009 to 2014. All services offered at these clinics are free to patient and doctors and epilepsy educators work pro bono. The clinics consist of patients being given group epilepsy education sessions lasting for at least 25–30 minutes. This is followed by individual patients sitting with neurologists for consultation where a clinical syndromic diagnosis of epilepsy is made and treatment prescribed. The patients then once again meet with epilepsy educators for specific need-based counselling and also to be explained how the medicines have to be taken. These clinics were heterogeneous with

respect to the geographical location, socioeconomic status and locally available health care facilities. Each of these locations was at distances varying between 70–1700 kilometers from New Delhi.

The second group of patients were those who had been registered in the OPD Epilepsy clinic of one of the investigators (MBS) at AIIMS in the same period, i.e., between 2009–2014. These patients were identified through patient files maintained in the records department of AIIMS. Patients consulting the AIIMS epilepsy clinic are usually called for follow-up visits every 3–12 months depending on their epilepsy characteristics, need for investigations and also their convenience. A patient's case file is sent to the OPD clinic in anticipation of his visit if he has sought a prior appointment or has to be retrieved on request if the patient follows-up without an appointment. If a patient does not appear after scheduling an appointment, he would be marked absent in his file, which would then be returned to the record section. There is no provision of keeping track of patients who miss an appointment and if they do not come back ever, there is no system to collect this information. For patients who do follow-up, an entry is made in the OPD file, which includes all relevant clinical details and response to treatment. Patients were considered *regular* in follow-up visits if they had come at least once in a year after being registered. If they had attained epilepsy resolution (as described below) and the doctor had stopped their AEDs and they had come regularly while on treatment, they too were considered *regular*. If *regular* patients had come for their last follow-up visit in or after January 2017, their treatment status was recorded by reviewing the entry made in their OPD file on the last visit. Patients who had not followed-up for more than an year, i.e. had not come after December 2016, were considered *irregular* in follow-up visits.

2.4. Definitions

In this study we followed the practical clinical definition of epilepsy accepted by ILAE in 2014 [5]. Epilepsy was diagnosed if a patient had at least two unprovoked seizures occurring more than 24 h apart or even one unprovoked seizure with a high probability of further seizures. Acute symptomatic seizures were diagnosed as per Beghi et al [6]. Non-epileptic seizures were diagnosed if the patient or caregiver's description of seizure semiology made non-epileptic seizures likely. Treatment gap was defined as the number of PWE who had been seizure-free for less than five years but had discontinued AED(s) on their own without consulting a doctor. If a patient had stopped AED(s) as per a doctor's advice after being seizure-free for at least five years at AIIMS and for an unknown number of years for the LLE patients, he was considered to have attained epilepsy resolution. Stopping treatment either while continuing to have seizures or after remaining seizure-free for only up to 12 months was termed premature stopping of AEDs.

2.5. Eligibility criteria

All epilepsy patients seen between 2009–2014 in the LLE epilepsy clinics and all new patients registered in the AIIMS OPD clinic in the same duration were eligible to be enrolled in the study. Patients from both groups who had either presented with acute symptomatic seizures or nonepileptic seizures were excluded. Patients where seizures were a part of a progressive neurological condition were also excluded. Simple febrile seizures were also excluded. If a patient of either group had not been prescribed any AED, he was excluded.

3. Data collection

3.1. Data at enrollment

The baseline characteristics of patients, duration of epilepsy, types and frequency of seizures and AEDs that had been prescribed originally were collected from the LLE database or from patient records at AIIMS.

3.2. Follow-up data

A structured proforma was used to collect follow-up clinical data. The main item on this proforma sought to determine if the patient was still continuing to take AEDs, had attained epilepsy resolution and stopped AEDs as per any doctor's advice, had discontinued AEDs without consulting a doctor or had died. Response to AEDs in patients who were continuing to take treatment as advised and reasons for discontinuation of AEDs were also enquired using both open and closed-ended questions. For determining the current treatment status of LLE patients, telephonic follow-up was attempted and responses were recorded after speaking either to the patient or to the patient's primary caregiver. For AIIMS patients who had been following-up regularly, current data was extracted from patient files available in the records department. For patients who were irregular and had not followed-up at AIIMS in or after December 2016, a telephonic follow-up was attempted as was done in the LLE patients. All telephonic follow-ups were done by one of the investigators (CP). For all telephonic follow-ups, a patient was called a minimum of three times on different occasions before abandoning the attempt and declaring the patient 'not reachable'.

3.3. Method of following-up to know current status

This was done in two ways: either by patient file review or by contacting patients telephonically. For all patients enrolled from the LLE clinic, the current status was determined telephonically. For patients who were enrolled from the AIIMS clinic, the status for *regular* patients was noted from the patient files. For *irregular* patients, a telephonic follow-up was attempted.

3.4. Outcomes

The primary outcome we were interested in was to see the number of patients who were continuing to take AED as advised. We also looked at deaths, discontinuation of AEDs and resolution of epilepsy in either group. Reasons for discontinuation of AEDs were also noted.

3.5. Statistical analysis

Statistical analysis was performed using Stata version 14.2 For categorical variables χ^2 test was used and for continuous variables, *t*-test and Wilcoxon rank-sum test were used. Values in absolute numbers as well as in percentages were compared between the two groups.

4. Results

Over a 1-year period extending from June 2017 to 2018, an attempt was made to follow-up all eligible PWE seen on the LLE and AIIMS epilepsy clinics (Table 1). In the 5-years from 2009 to 2014, 1257 new patients had been registered at the AIIMS clinic and 1923 patients had been seen across 15 locations on the LLE clinic. There were 78 exclusions from the LLE clinic (Fig. 1) and 25 patients, who had first been seen on the LLE clinic before presenting at AIIMS, were analyzed along with the LLE patients as they were considered to be following advice given on the LLE. For the AIIMS patients, file reviews were done in 443 who had been regular in follow-up. Of patients who needed to be followed up telephonically, phone numbers were not available for 219 patients seen at AIIMS and 357 patients seen on the LLE. A telephonic follow-up was attempted in 570 AIIMS patients and 1488 LLE patients. Due to a variety of reasons (Fig. 1), telephonic follow-up was not possible in 325 patients registered at AIIMS and 957 patients seen on the LLE. Follow-up of 245 and 531 patients could be conducted telephonically in either group respectively. So, finally long-term outcome was available for analysis in 688 AIIMS patients and 531 LLE clinic patients. Of the AIIMS clinic patients, 581 (87%) were continuing AEDs, 49 (7%) had discontinued AEDs after being seizure-free for at least 5

Table 1
Baseline characteristics of epilepsy patients seen at AIIMS and Lifeline Express clinics.

Variable	AIIMS group N = 1232	LLE group N = 1845	p-Value
Age (Years)	N = 1229	N = 1842	
Mean \pm SD	25.34 \pm 11.76	23.3 \pm 12.74	< 0.001
Sex			
Male	826 (67%)	1203 (65.2%)	0.29
Age at onset (Years)	N = 1141	N = 1465	
Mean \pm SD	16.37 \pm 11.5	13.09 \pm 10.58	< 0.001
Epilepsy risk factors ^a		N = 1121	
Present	396 (32.1%)	471 (42%)	< 0.001
Seizure frequency	N = 639	N = 1264	
\geq 1 seizure/ month	439(68.7%)	872(69%)	0.57
< 1 seizure/ month	200(31.3%)	392(31%)	
Seizure type	N = 1166	N = 1374	
Focal/ focal onset	782 (67.1%)	911 (66.3%)	< 0.001
Generalised	195 (16.7%)	312 (22.7%)	
Unclassified	189 (16.2%)	151 (11.1%)	
Neuroimaging	N = 905	N = 302	
Abnormal	544 (60.1%)	151 (50%)	0.002
EEG	N = 777	N = 207	
Abnormal	240 (30.9%)	87 (42%)	< 0.01
AED usage at enrolment	N = 1050	N = 1217	
Present	999 (95.1%)	622 (51.1%)	< 0.001
Maximum number of AEDs	N = 1110	N = 1097	
Monotherapy	560 (50.5%)	780 (71.1%)	< 0.001
2 or more AEDs	550(49.5%)	317(28.9%)	

Due to missing data N varies for each variable. Percentages apply to columns.

^a Family history, perinatal insult, febrile seizures, prior CNS infections and head injury.

years, 39(6%) had discontinued AEDs without medical advice and 19(2.8%) were dead. Outcomes in 531 LLE patients revealed that 351(72%) continued to be on AEDs, 34(7%) had discontinued AEDs on advice, 106 (22%) had discontinued AEDs without any medical advice and 40 (7.5%) were dead.

Comparing baseline characteristics, PWE enrolled in the LLE clinic were both younger in age and also had a younger age of onset of epilepsy (Table 2). They were also more likely to have an identifiable epilepsy risk factor compared to PWE enrolled at the AIIMS clinic. Patients from LLE also reported generalized seizures more frequently and tended more often to be on monotherapy compared with the AIIMS patients.

In the follow-up, patients who had prematurely stopped AEDs cited one or more reason for it (Table 3). Cost of treatment was cited as the reason for discontinuing treatment in 21.7% of the LLE patients compared to only 2.6% of AIIMS patients. Most (56%) AIIMS patients, who prematurely discontinued treatment, did so as they thought that their epilepsy was 'cured' if they had remained seizure-free for at least an year. While the LLE clinic patients had a significantly higher treatment gap as compared to the AIIMS patients both at the time of enrolment and at follow-up, it fell significantly from 50% when they had first been seen to 22% at follow-up. Patients reporting a benefit in terms of reduction in seizure frequency of at least one lesser seizure per month, were 43% in the AIIMS group compared to 29% in the LLE clinic group. Finally, there were 19 deaths in the AIIMS group compared with 40 in the LLE clinic group (Table 4).

5. Discussion

Trying to bridge the gap in epilepsy care by some form of periodic outreach clinics is a popular practice not only in India but many other low-resource countries of the world [7–10]. This is probably the first study documenting long-term outcomes in PWE who consulted with a neurologist just once in an outreach clinic and were then left without any systematic long-term follow-up plan. Our results demonstrate that even a one-time consultation provided to patients in this manner can

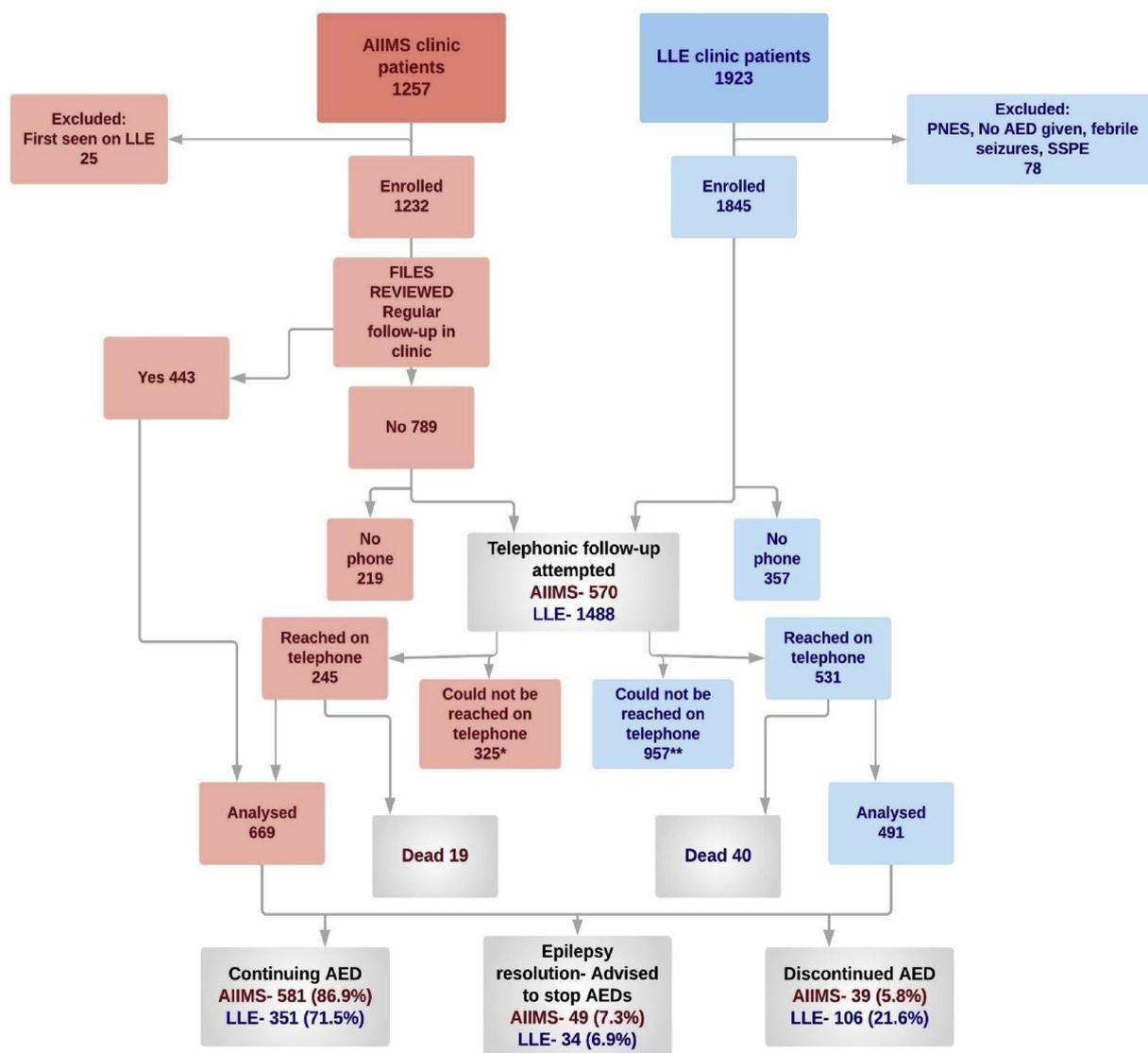


Fig. 1. Flowchart of eligible epilepsy patients and long-term outcomes.

*Wrong number- 43, Phone number not in service- 122, Switched off- 41, Out of coverage- 25, Not answering- 62, Responsible person not available- 32.

**Wrong number- 317, Phone number not in service- 249, Switched off- 195, Out of coverage- 48, Not answering- 70, Responsible person not available- 69, Language barrier- 9.

Table 2

Comparison of reasons for stopping AEDs prematurely by AIIMS and Lifeline Express clinic patients.

Reason for stopping AED prematurely	AIIMS group ^a	LLE group ^a	p-value
1. Access to healthcare/ availability of AEDs	3(7.6%)	8(7.5%)	0.99
2. Financial constraints	1(2.6%)	23(21.7%)	0.005
3. Recourse to alternative therapies	6(15.4%)	19(17.9%)	0.72
4. Perceived lack of benefit from AEDs	5(12.8%)	23(21.7%)	0.34
5. Side effects of AEDs	2(5.1%)	6(5.6%)	0.99
6. Presumed epilepsy was cured ^b	22(56.4%)	36(33.9%)	0.01
7. Believed treatment was of fixed duration and was over ^c	3(7.7%)	9(8.5%)	0.99
8. Not known	2(5.1%)	5(4.7%)	0.99
Total	39	106	

^a Absolute numbers do not add up to total as patients might have more than one reason for discontinuation.

^b Were seizure free for at least 12 months.

^c Were still continuing to have seizures.

Table 3

Summary of long-term epilepsy treatment outcomes in AIIMS and Lifeline Express clinic patients.

Variable	AIIMS group	LLE group	p Value
Treatment gap at enrolment	N = 1232 51(4.9%)	N=1845 595(48.9%)	< 0.001
Treatment gap at follow up ^a	N = 669 39 (5.8%)	N = 491 106(21.6%)	< 0.001
Seizure frequency ^b	N = 293	N = 308	
No change	162(55.3%)	207(67.2%)	0.001
Benefited	125(42.7%)	88(28.6%)	
Deteriorated	6(2%)	13(4.2%)	
Deaths at follow up ^c	N = 688 19(2.8%)	N=531 40(7.5%)	< 0.001

^a Total number of patients who could be followed up and were alive.

^b Total number of patients whose data on seizure frequency was available both at enrolment and follow-up. Results shows the proportion of patients with change in seizure frequency from time of enrolment to follow up. Cut-off frequency of 1 seizure/month has been taken.

^c Total number of patients who could be followed up.

Table 4
Comparison of patients of AIIMS and Lifeline Express clinic: Association of variables with patients following and not following advice.

Variables	AIIMS group (N = 669)		p-Value	LLE group (N = 491)		p-Value
	Following medical advice 630 (94.2%)	Not following medical advice 39 (5.8%)		Following medical advice 385 (78.4%)	Not following medical advice 106 (21.6%)	
Age						
< 20 years	242 (93.4%)	17(6.6%)	0.53	173(78.6%)	47(21.4%)	0.89
≥ 20 years	386(94.8%)	22(5.2%)		211(78.1%)	59(21.9%)	
Age at onset						
< 20 years	447(94.5%)	26(5.5%)	0.34	232(75.6%)	75(24.4%)	0.81
≥ 20 years	146(92.4%)	12(7.6%)		40(74.1%)	14(25.9%)	
Gender						
Male	423(94.8%)	23(5.2%)	0.29	244(76.3%)	76(23.7%)	0.11
Epilepsy risk factors ^a						
Present	225(93%)	17(7%)	0.32	128(81.5%)	29(18.5%)	0.04
Frequency of seizures at enrolment						
≥ 1 seizure/ month	224(93.7%)	15(6.3%)	0.46	142(72.8%)	53(27.2%)	0.12
< 1 seizure/ month	110(95.7%)	5(4.3%)		109(80.1%)	27(19.9%)	
Type of seizures						
Focal/ Focal onset	420(94.2%)	26(5.8%)	0.93	189(78.8%)	51(21.2%)	0.33
Generalised	96(93.2%)	7(6.8%)		62(72.9%)	23(27.1%)	
Unclassified	91(93.8%)	6(6.2%)		28(70%)	12(30%)	
Neuroimaging						
Abnormal	299(94.3%)	18(5.7%)	0.76	55(91.7%)	5(8.3%)	0.03
EEG						
Abnormal	138(94.5%)	8(5.5%)	0.71	28(84.8%)	5(15.2%)	0.51
AED usage at enrolment						
Yes	540(94.7%)	30(5.3%)	0.36	206(85.8%)	34(14.2%)	< 0.001
Consulted any other doctor?						
Yes	94(94%)	6(6%)	0.41	297(85.8%)	49(14.2%)	0.001
No	507(95.8%)	22(4.2%)		88(71%)	36(29%)	
Frequency of seizures at follow up						
≥ 1 seizure/ month	74(89.2%)	9(10.8%)	< 0.05	98(67.1%)	48(32.9%)	0.001
< 1 seizure/ month	440(94.8%)	24(5.2%)		255(82.3%)	55(17.7%)	
Max. number of AEDs						
Monotherapy	250(91.2%)	24(8.8%)	< 0.01	136(67%)	67(33%)	< 0.001
2 or more AEDs	329(96.5%)	12(3.5%)		106(89.8%)	12(10.2%)	

^a Family history, perinatal insult, febrile seizures, prior CNS infections and head injury.

reduce treatment gap by almost 55%. Secondly, seizures reported at baseline by patients from the LLE clinic were more likely to be generalized while patients from the AIIMS clinic more often reported focal seizures. The third important finding from our study is that irrespective of the model of care, a tertiary care clinic or a one-time outreach clinic, most PWE who prematurely stopped AEDs did so because they believed that their epilepsy was ‘cured’ if they had been seizure-free on treatment for at least an year. Fourthly, financial constraints were far more likely to come in the way of treatment of PWE who presented to the LLE clinic than at AIIMS. A significantly higher death rate of 7.8% was documented in the LLE patients compared to 2.8% in the AIIMS patients. Finally, we were unable to determine long-term outcomes in up to 44% PWE from the AIIMS clinic and 71% from the LLE clinic.

In view of no existing data of long-term outcomes from such single-visit clinics, we compared outcomes with the conventional hospital-based epilepsy clinic of AIIMS. Clearly patients seen in the two clinics were quite different at baseline on several counts. Patients seen in the LLE clinic were younger, had epilepsy onset at an earlier age, more often recalled epilepsy risk factors, were more likely to have generalized seizures and if on treatment, it was more often monotherapy than polytherapy. The AIIMS clinic from where patients were enrolled is an adult epilepsy clinic, which explains patients being older, while on the LLE patients of any age can seek a consultation and the younger age of patients may just be a reflection of the age-distribution of epilepsy in the community. Also, as AIIMS is a tertiary care hospital with a comprehensive epilepsy program, including pre-surgical evaluation and epilepsy surgery, many patients here have poorly controlled epilepsy and are on polytherapy. However, being on AEDs the ongoing seizures in these patients are more likely to be focal. By contrast, about half the patients seen on the LLE were on no AEDs and reported generalized

seizures more often.

We also compared current long-term LLE patient outcomes with short-term outcomes that we had earlier reported where we had concluded by saying that “most of the contacted patients seen on the Lifeline Express were still taking medications 7 to 9 months after a one-time visit with a neurologist, including half of the treatment-naïve patients [3]. This suggests that this one-time clinic is an effective model of treating epilepsy in the short term.” Surprisingly, after conducting this research and looking at longer-term outcomes of patients, we did not find any significant difference in results. The only departure in the current study from the previous one that is worth mentioning is that while we were able to follow-up about 46% of the patients at the 9 months follow-up, this had dropped to 29% in the current 2–8 year follow-up.

While on the one hand we had not expected such a significant reduction in treatment gap after a single contact clinic on the LLE, results from the AIIMS clinic also surprised us. We discovered that over about 2–8 years, which would be considered a relatively short time in the course of most PWE; we had lost to follow-up almost half (44%) of the epilepsy patients who presented to AIIMS. Many of these patients come from places, which are up to 1500–2000 kilometers away, and they belong to low middle to low socioeconomic status. In the past we have described how many of our epilepsy patients prefer and would be better served by the setting up of a telephonic follow-up system at least for some of them [11]. This may be another reminder to us that we could improve our epilepsy service significantly by setting up an option of telephonic review. This study also brings to light the need to have some kind of ongoing audit of care being provided to epilepsy patients. In a busy hospital like AIIMS, patients dropping out of care prematurely may not be noticed and this may be easy to correct in some instances by

just sending a telephonic message to defaulting patients. In fact many patients who had stopped following-up at AIIMS did so after they were contacted on phone for this study.

The conventional paradigms of providing epilepsy care have proven to be effective in many ways. Yet in many low-resource countries like India, there continues to be an unacceptably high epilepsy treatment gap. There is a need to search for newer systems of providing care taking into account regional challenges that limit access for millions of patients residing in smaller towns and villages. A skewed distribution of specialist doctors with hardly any specialist care available outside of few large metropolitan cities is a serious bottleneck that is difficult to address. We have earlier documented this gap in epilepsy primary and secondary care [12]. A viable option may be to conduct more outreach clinics in the least served communities. Such clinics not only get patients into the ambit of some semblance of care, they also serve to increase awareness about epilepsy and its effective treatment options in these far flung regions. Epilepsy educators who are a regular feature of the LLE clinics have a crucial role in improving patient outcomes by increasing epilepsy literacy amongst PWE and their caregivers. Results from this study reveal that while outreach clinics are not a panacea to all that ails epilepsy care, but they do have a role and are quite effective in reducing treatment gap.

A serious limitation of this study was our inability to follow up a large number of the patients. Long-term follow-up data could be obtained only for 56% (688/1232) patients from the AIIMS clinic and for 29% (531/1845) patients of the LLE clinic. Most of the missing data resulted either due to there being no valid phone number for a patient or due to an inability to establish telephonic contact due to various reasons (Fig. 1). However, in spite of this limitation, we believe that the follow-up data that is available and is presented here has sufficient power in terms of patient numbers to give a sense of the utility of a one-time epilepsy outreach clinic. We are in no way suggesting that a one-time epilepsy clinic is all we should aspire for. All we are hypothesizing is that instead of just leaving tens of thousands of patients untreated, as is the current situation, we can start making an immediate improvement in care by way of epilepsy outreach clinics. The need for patient review or follow-up is crucial and cannot be dismissed. In today's times with the abundance of low-cost telemedicine options including use of the ubiquitous mobile phone, setting up patient follow-up even when patients are far from the treating doctor may not be very difficult. What we seem to lack is enough interest, and commitment to put in place such systems that have a potential of transforming epilepsy care.

In conclusion, this study provides evidence that in all countries that are battling high epilepsy treatment gaps, even one-time epilepsy outreach clinics may have a role. Such outreach clinics may effectively reduce treatment gap and if follow-up mechanisms can also be innovated then such clinics may be able to accomplish what we have not been able to achieve so far.

Author Contributions

Study design: CP, MBS, MVPS, VS, GS.
Principal trial investigator: MBS.
Acquisition of data: CP.
Statistical analysis: VS.
Interpretation of data: CP, VS, MBS.
Drafting of the manuscript: CP, MBS, VP.
Critical revision of the manuscript for intellectual content- All authors.
CP, MBS and VS had access to all the data in the study and take

responsibility for the integrity of the data and accuracy of data analysis.

All authors approved the final version of the manuscript for publication.

Conflict of interest

None of the authors has any conflict of interest to disclose.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.seizure.2019.02.008>.

References

- [1] Espinosa-Jovel C, Toledano R, Aledo-Serrano Á, García-Morales I, Gil-Nagel A. Epidemiological profile of epilepsy in low income populations. *Seizure* 2018;56(March):67–72. <https://doi.org/10.1016/j.seizure.2018.02.002>.
- [2] Impact India Foundation - NGO in India: An International Initiative Against Avoidable Disablement. 2019 Available from: <https://www.impactindia.org/lifeline-express.php#content-start>.
- [3] Bigelow J, Singh V, Singh M. Medication adherence in patients with epilepsy after a single neurologist visit in rural India. *Epilepsy Behav* 2013;29(November (2)):412–5. <https://doi.org/10.1016/j.yebeh.2013.08.034>.
- [4] STROBE Statement: Home. 2019 Available from: <https://www.strobe-statement.org/index.php?id=strobe-home>.
- [5] Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. ILAE Official Report: a practical clinical definition of epilepsy. *Epilepsia* 2014;55(April (4)):475–82. <https://doi.org/10.1111/epi.12550>.
- [6] Beghi E, Carpio A, Forsgren L, Hesdorffer DC, Malmgren K, Sander JW, et al. Recommendation for a definition of acute symptomatic seizure. *Epilepsia* 2010;51(April (4)):671–5. <https://doi.org/10.1111/j.1528-1167.2009.02285.x>.
- [7] A-CL Meyer, Dua T, Boscardin J, Escarce JJ, Saxena S, Birbeck GL. Critical determinants of the epilepsy treatment gap: a cross-national analysis in resource-limited settings. *Epilepsia* 2012;53(December (12)). <https://doi.org/10.1111/epi.12002>.
- [8] Nizamie SH, Akthar S, Banerjee I, Goyal N. Health care delivery model in epilepsy to reduce treatment gap: world Health Organization study from a rural tribal population of India. *Epilepsy Res* 2009;84(April (2)):146–52. <https://doi.org/10.1016/j.epilepsyres.2009.01.008>.
- [9] Wang WZ, Wu JZ, Ma GY, Dai XY, Yang B, Wang TP, et al. Efficacy assessment of phenobarbital in epilepsy: a large community-based intervention trial in rural China. *Lancet Neurol* 2006;5(January (1)):46–52. [https://doi.org/10.1016/S1474-4422\(05\)70254-4](https://doi.org/10.1016/S1474-4422(05)70254-4).
- [10] Watts AE. A model for managing epilepsy in a rural community in Africa. *BMJ* 1989;298(March (6676)):805–7. PMID: 2496864.
- [11] Bahrani K, Singh MB, Bhatia R, Prasad K, Vibha D, Shukla G, et al. Telephonic review for outpatients with epilepsy—a prospective randomized, parallel group study. *Seizure - Eur J Epilepsy*. 2017;1(December (53)):55–61. <https://doi.org/10.1016/j.seizure.2017.11.003>.
- [12] Kumar S, Singh MB, Kumar A, Shukla G, Srivastava MVP, Goyal V, et al. Are epilepsy patients bypassing primary care? A cross-sectional study from India. *Seizure - Eur J Epilepsy*. 2018;1(August (60)):149–54. <https://doi.org/10.1016/j.seizure.2018.07.001>.