

Epilepsy in Rural Settings: Treatment Gap, Seizure Control, and Social Determinants: A Community-Based Cross-Sectional Survey Across Three Hundred and Forty Affected Individuals

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Abstract — Epilepsy affects approximately 12 million individuals in India, with the majority living in rural areas where specialist neurological services are scarce. The treatment gap defined as the proportion of affected individuals not receiving adequate antiepileptic drug (AED) therapy has been estimated at 50-70% in many rural Indian surveys, with substantial heterogeneity by geography, gender, and socioeconomic status. We undertook a community-based cross-sectional survey of 340 individuals with active epilepsy across twelve rural villages served by a tertiary medical centre. The treatment gap in our cohort was 42.4%, with substantial variation by subgroup: 72.6% in those with less than five years of education, 71.4% in tribal community members, 68.4% in those living more than 20 km from a clinic, and 58.4% in women. Seizure-free status over the preceding 12 months was achieved by 44.7% of adherent patients but only 8.3% of poorly adherent or untreated patients. Independent predictors of treatment gap included distance to clinic, low education, female sex, household poverty, family-reported stigma, tribal community membership, and traditional healer use. Community health worker (CHW) visits were strongly protective. The findings reinforce the case for community-based epilepsy programmes with CHW outreach, structured AED supply, and stigma-reduction education.

Keywords — Epilepsy; Treatment Gap; Rural Health; Antiepileptic Drugs; Adherence; Stigma; Community Health Worker; Seizure Control.

1. Introduction

Epilepsy affects approximately 50 million people globally, with nearly 80% living in low- and middle-income countries. India contributes approximately a quarter of this global burden, with an estimated 10-12 million affected individuals. The clinical challenge of epilepsy in resource-limited rural settings is qualitatively distinct from that in tertiary urban centres. Diagnosis is often delayed or absent; AED supply is intermittent; specialist neurological review is rare; and the cultural and social dimensions of epilepsy stigma, traditional explanations, marriage and employment consequences substantially shape patient and family engagement with biomedical care. The 'treatment gap' defined as the proportion of individuals with active epilepsy not receiving adequate AED therapy has emerged as the standard metric of programmatic adequacy. World Health Organization surveys have estimated the gap at 50-70% in rural India, although individual studies report wide ranges depending on case ascertainment methods and definitions. The gap reflects multiple intersecting barriers: financial cost of AED supply, geographic distance to clinics, low awareness of treatable epilepsy as a biomedical condition, stigma constraining help-seeking, and reliance on traditional healers (Jha, Kumar, & Neha, 2026; Bhatnagar, Kumar, & Shivam, 2026; Yatish, Khatoon, & Kumar, 2026). We undertook a community-based cross-sectional survey of individuals with active epilepsy across twelve villages in a

rural catchment served by a tertiary medical centre. The aim was to characterise the contemporary treatment gap, examine its demographic and socioeconomic distribution, document seizure control outcomes across treatment-engagement strata, and identify intervention-amenable predictors that could inform community-based programme design (Kumar, Sharma, & Gupta, 2026; Kumar, Gautam, & Maitiy, 2026).

2. Methods

The study was conducted across twelve villages in a defined rural catchment area served by a tertiary medical centre and its affiliated primary health centres. The catchment population approximated 38,000 individuals, with a mix of agricultural and tribal communities, three primary health centres, and a community health worker network with approximately one CHW per 1,000 population. Community health workers conducted door-to-door screening using a validated epilepsy screening questionnaire over a six-month period, with positive screens referred for structured clinical assessment by a neurologist. Active epilepsy was defined as a history of at least one unprovoked seizure in the preceding 24 months in an individual with a prior diagnosis of epilepsy, or two or more unprovoked seizures separated by at least 24 hours regardless of treatment status. Diagnoses were confirmed by structured neurological assessment, with EEG and brain

imaging performed where feasible. Patients with a single provoked seizure, febrile seizures in childhood, or alcohol-withdrawal seizures without other criteria for epilepsy were excluded. The final cohort comprised 340 individuals with confirmed active epilepsy.

Treatment gap was defined per WHO criteria as the absence of adequate antiepileptic drug therapy in an individual with active epilepsy. Adequate therapy required (a) current daily AED prescription, (b) self-reported adherence to at least 80% of prescribed doses in the preceding 30 days, and (c) AED supply availability without significant interruption during the preceding 6 months. Individuals not meeting any of these criteria were classified as having a treatment gap. AED adherence was subdivided into adherent ($\geq 90\%$ doses), partially adherent (50-89%), and poorly adherent ($<50\%$ or no AED prescription). Primary outcomes were the proportion of participants in treatment gap and the proportion seizure-free during the preceding 12 months. Secondary outcomes included quality of life on the QOLIE-31 instrument, employment and educational engagement, marital status and family relationships, and use of traditional healers. Multivariable logistic regression identified independent predictors of treatment gap with clinically prespecified covariates. Sensitivity analyses examined the subset of newly diagnosed patients (symptom onset within past 2 years) separately.

3. Results

3.1 Cohort Characteristics

Table 1. Demographic and clinical characteristics of the rural epilepsy cohort (n=340)

Characteristic	Value
Age, mean (SD), years	32.4 (16.8)
Children and adolescents (<18 years), n (%)	68 (20.0)
Working-age adults (18-59), n (%)	218 (64.1)
Older adults (≥ 60), n (%)	54 (15.9)
Female sex, n (%)	158 (46.5)
Years of formal education, mean (SD)	4.8 (4.6)
Less than 5 years education, n (%)	158 (46.5)
Never attended school, n (%)	68 (20.0)
Tribal community membership, n (%)	78 (22.9)
Annual household income $<₹50,000$, n (%)	148 (43.5)
Living in joint family arrangement, n (%)	248 (72.9)
Distance to nearest clinic, median (IQR), km	12 (6-22)
Distance >20 km, n (%)	102 (30.0)
Age at first seizure, mean (SD), years	18.4 (14.6)
Duration of epilepsy, median (IQR), years	8 (3-16)
Newly diagnosed (within past 2 years), n (%)	74 (21.8)
Family history of epilepsy, n (%)	58 (17.1)
History of febrile seizures in childhood, n (%)	78 (22.9)
History of CNS infection (suspected or	42 (12.4)

documented), n (%)	
History of head injury preceding onset, n (%)	32 (9.4)
Perinatal complication history, n (%)	38 (11.2)
Use of traditional healers (current or past), n (%)	124 (36.5)

3.2 Seizure Types and Aetiologies

Seizure type distribution is shown in Figure 1. Focal seizures (with or without awareness) accounted for the largest fraction (40.6%), followed by focal-to-bilateral tonic-clonic seizures (22.9%) and generalised tonic-clonic seizures (22.9%). Other generalised seizure types absence, myoclonic, atonic together accounted for 8.2%, predominantly in children and adolescents. A small fraction (5.3%) remained unclassified given limited available imaging and EEG. Aetiological characterisation, where feasible, identified a structural cause in approximately 30% (post-traumatic, post-infectious, perinatal hypoxic-ischaemic, or vascular), an unidentified aetiology in approximately 60% (consistent with the limited imaging access typical of this setting), and presumed genetic generalised epilepsy in approximately 10%.

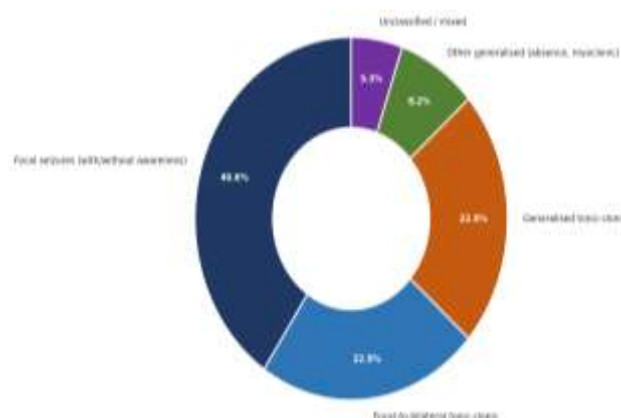


Fig.1: Seizure type distribution in the rural epilepsy cohort

3.3 Treatment Gap and Its Distribution

The overall treatment gap in this cohort was 42.4%. 144 of 340 individuals were not receiving adequate AED therapy at the time of survey. The gap distribution by demographic and socioeconomic subgroup is shown in Figure 2. The highest treatment gap was observed in individuals with less than five years of education (72.6%) and tribal community members (71.4%), reflecting the overlap between low literacy, geographic isolation, and stigma in this subgroup. Distance to clinic showed a near-linear relationship with treatment gap: 22% in those within 5 km, 38% at 5-20 km, and 68% beyond 20 km. Women had a substantially higher gap than men (58.4% vs 28.6%), reflecting culturally mediated help-seeking asymmetries and family priorities around women's healthcare seeking.

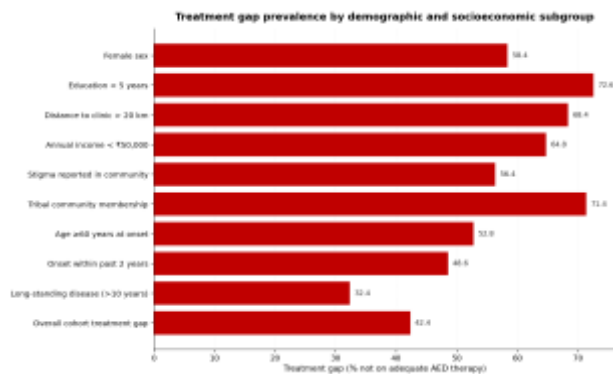


Fig.2: Treatment gap prevalence by demographic and socioeconomic subgroup

Table 2. AED treatment patterns in the cohort

Treatment characteristic	n (%) or value
Ever received any AED, n (%)	262 (77.1)
Currently on AED therapy, n (%)	196 (57.6)
Discontinued AED in past 12 months, n (%)	66 (19.4)
Never received AED despite known diagnosis, n (%)	78 (22.9)
Number of AEDs currently used, median	1
Phenobarbitone (current), n (%)	68 (34.7)
Phenytoin (current), n (%)	52 (26.5)
Sodium valproate (current), n (%)	38 (19.4)
Carbamazepine (current), n (%)	32 (16.3)
Levetiracetam (current), n (%)	18 (9.2)
Other / newer AEDs (current), n (%)	8 (4.1)
AED adherence $\geq 90\%$ (last 30 d), n (%)	132 (38.8)
AED adherence 50-89%, n (%)	64 (18.8)
AED adherence <50% / not prescribed, n (%)	144 (42.4)
AED supply interruption (>1 week) in past 6 mo, n (%)	78 (22.9)
Out-of-pocket AED cost reported as burden, n (%)	138 (40.6)
Free AED access through government programme, n (%)	82 (24.1)
AED-related side effects reported, n (%)	118 (60.2 of those on AEDs)
Side effect leading to discontinuation, n (%)	32 (16.3 of those on AEDs)

3.4 Seizure Control by Adherence

Seizure-free survival over 24 months differed substantially by AED adherence (Figure 3). Adherent patients ($>90\%$ doses) showed a 24-month seizure-free probability of approximately 46%, with most relapses occurring within the first 6 months and the curve flattening thereafter. Partially adherent patients showed an intermediate trajectory with 26% seizure-free at 24 months. Poorly adherent or untreated patients showed the steepest event curve, with only 9% remaining seizure-free at 24

months a frequency approaching the natural history of untreated epilepsy.

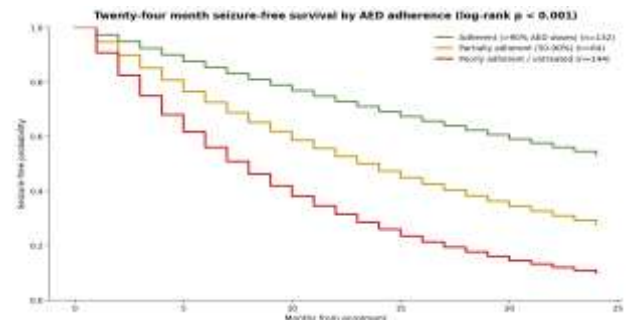


Fig.3: Twenty four month seizure-free survival by AED adherence

Table 3. Seizure control and social outcomes by treatment status

Outcome	Adherent (n=132)	Partially adherent (n=64)	Treatment gap (n=144)
Seizure-free in past 12 months, n (%)	59(44.7)	12 (18.8)	12 (8.3)
Seizure frequency <1/month, n (%)	98(74.2)	32 (50.0)	32 (22.2)
Seizure frequency ≥ 1 /month, n (%)	34(25.8)	32 (50.0)	112 (77.8)
Status epilepticus in past 12 mo, n (%)	2 (1.5)	4 (6.3)	18 (12.5)
Seizure-related injury in past 12 mo, n (%)	12 (9.1)	12 (18.8)	42 (29.2)
ED visit for seizure in past 12 mo, n (%)	8 (6.1)	18 (28.1)	52 (36.1)
Hospital admission for seizure, past 12 mo, n (%)	6 (4.5)	12 (18.8)	32 (22.2)
Currently employed (working-age adults), n (%)	68/82 (82.9)	28/42 (66.7)	42/94 (44.7)
Children/adolescents attending school, n (%)	16/22 (72.7)	8/14 (57.1)	12/32 (37.5)
Married (working-age adults), n (%)	52/82 (63.4)	24/42 (57.1)	42/94 (44.7)
Family-reported stigma documented, n (%)	32(24.2)	28 (43.8)	82 (56.9)
Used traditional healer in past year, n (%)	18(13.6)	22 (34.4)	82 (56.9)
QOLIE-31 score, mean	68	54	42
Mortality during 24-mo follow-up, n (%)	4 (3.0)	2 (3.1)	12 (8.3)

3.5 Predictors of Treatment Gap

Multivariable logistic regression identified ten independent predictors of treatment gap (Figure 4). Distance to nearest clinic greater than 20 km carried the strongest single association (adjusted OR 4.62), followed by low education (<5 years), tribal community membership, household poverty, stigma reported by family, traditional

healer use, and female sex. The strongly protective association with CHW visit in the past 6 months (OR 0.34) identifies community outreach as the single most effective intervention point. The findings suggest that the treatment gap is jointly driven by structural barriers (distance, cost) and sociocultural barriers (stigma, traditional explanations, gender disparities), with CHW engagement bridging both.

3.6 Programmatic Recommendations

Table 4. Operational recommendations from the survey

Element	Current state	Programmatic target
Free AED access for active epilepsy	24% of cohort	100% via supply chain reliability
CHW visits for known epilepsy cases (q3mo)	32% of cohort	100% with structured visit template
AED supply continuity (no interruption >1 wk)	77% past 6 mo	≥95% with buffer stock at PHC
Structured patient education completed	36% of cohort	≥80% with CHW-led education
Family-engaged stigma reduction sessions	18% of cohort	≥60% within 12 months of dx
School engagement for affected children	37.5% of children	≥80% with teacher orientation
Tele-neurology consultation available	Limited	Monthly via PHC infrastructure
Female-specific outreach programmes	Minimal	Quarterly women-only sessions
Tribal community partnership programmes	Limited	Dedicated tribal CHW liaisons
Pre-eclampsia / pregnancy-AED management	Ad hoc	Structured pre-conception counselling
Driving and occupational counselling	Rare	Routine at diagnosis
Status epilepticus emergency education	Limited	Family-facing buccal midazolam where appropriate

4. Discussion

Across 340 individuals with active epilepsy surveyed in a defined rural catchment, three observations have direct implications for community-based epilepsy programme design. First, the overall treatment gap of 42.4% sits within the expected range for rural Indian populations but masks substantial heterogeneity: gap rates exceed 70% in tribal communities and in those with limited education, while falling closer to 25% in better-educated patients living near clinics. Programmatic design should explicitly address these inequities rather than treating the population as uniform. Second, the consequences of the treatment gap are substantial and extend beyond seizure recurrence. Untreated patients in our cohort showed a 9% 12-month seizure-free

rate (approaching the natural history of untreated epilepsy), but also dramatically lower employment, school engagement, marriage rates, and quality of life, alongside higher rates of seizure-related injury, status epilepticus, ED visits, hospitalisations, and mortality. The cumulative social and economic toll across the affected population is substantial. Each additional patient brought into adequate treatment represents not only personal benefit but a substantial gain in population health and productivity (Jha, Kumar, & Neha, 2026; Bhatnagar, Kumar, & Shivam, 2026; Kumar, Sharma, & Gupta, 2026; Yatish, Khatoon, & Kumar, 2026).

Third, the predictors identified point clearly to intervention design. The strong protective association with CHW visits adjusted OR 0.34 supports the deployment of structured CHW outreach as the central operational lever. The intervention package suggested by the predictors includes: door-to-door CHW visits at least quarterly for known cases, structured patient and family education addressing stigma and traditional explanations, AED supply chain reliability through PHC buffer stock, free AED access for active epilepsy, tele-neurology consultation via PHC infrastructure, and dedicated outreach to women and tribal communities (Catherine, Gupta, Gopi., & Swadhi, 2025; Swadhi, Gayathri, Suresh, Catherine., & Velmurugan, 2025; Vettriselvan, Ramya, et al., 2026; Rasi, & Ashifa, 2019; Vinodh, Subramani., & Vettriselvan, 2026; Subramani, Chillagattu, et al., 2026; Selvi et al., 2026). Implementation considerations include the cost structure of community-based programmes (substantially lower than hospital-based specialist care for this population), the training requirements for CHWs delivering structured epilepsy care (approximately 40 hours of initial training plus ongoing supervision), and the supply-chain reliability for older AEDs like phenobarbitone and phenytoin which remain the workhorses of rural epilepsy care. Newer AEDs (levetiracetam, lacosamide) offer better side-effect profiles but cost and supply constraints limit deployment. Tele-neurology models combining CHW-led primary contact with periodic specialist review through the PHC have shown feasibility (Deepa et al., 2026; Vijayalakshmi et al., 2025; Jha, Kumar, & Neha, 2026; Yatish, Khatoon, & Kumar, 2026).

Limitations include the cross-sectional design which constrains causal inference; the single-catchment setting which may not generalise to other geographies with different cultural contexts; the reliance on structured interview for seizure characterisation given limited EEG and imaging access; the self-reported adherence measures with their inherent biases; and the modest representation of children, which limits subgroup analysis for paediatric-specific issues. Stigma and traditional healer use are measured by self-report and likely under-reported in some contexts.

5. Conclusion

Active epilepsy in this rural Indian cohort showed a treatment gap of 42.4%, with substantial concentration in tribal communities, low-education subgroups, geographically isolated households, and women. Treatment adherence was strongly associated with seizure freedom, employment, school engagement, marriage, and quality of life. Distance to clinic, low education, household poverty, family-reported stigma, and traditional healer use were the strongest independent predictors of treatment gap; community health worker engagement was strongly protective. Community-based epilepsy programmes combining structured CHW outreach, AED supply chain reliability, stigma-reduction education, tele-neurology consultation, and dedicated outreach to disadvantaged subgroups offer the most tractable operational pathway to closing the gap.

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