Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

Tribal ethnicity also identifies particularly vulnerable persons with epilepsy: A cross-sectional study from Central India

Divya Ganjoo
All India Institute of Medical Sciences
Mayank Sharma
All India Institute of Medical Sciences
Hemant Kumar Tiwari
All India Institute of Medical Sciences
Naina Bharadwaj
All India Institute of Medical Sciences
Sanskriti Yadav
All India Institute of Medical Sciences
Sheetal Mishra
All India Institute of Medical Sciences
Ashish Datt Upadhyay
All India Institute of Medical Sciences
Naveen Shukla
All India Institute of Medical Sciences
Shelly Gandhi
All India Institute of Medical Sciences
Sumi Jain
Department of Health & Family Welfare
Rohit Bhatia
All India Institute of Medical Sciences
Mamta Bhushan Singh
mbsneuro@gmail.com

All India Institute of Medical Sciences
Victor Patterson
University of Khartoum

Research Article

Keywords: Treatment Gap, Vulnerable populations, Primary care, India

Posted Date: February 24th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-8648241/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License

Additional Declarations: No competing interests reported.

Abstract

Background

Large epilepsy treatment gaps persist in low- and middle-income countries, including India. Even within underserved communities, some persons with epilepsy (PWE) remain disproportionately more likely to be untreated. Identifying such particularly vulnerable persons with epilepsy (PVPWE) is essential for designing equitable, primary care–oriented interventions.

Methods

We conducted a cross-sectional study nested within an ongoing implementation research programme evaluating epilepsy care strengthening at the primary care level in rural Chhattisgarh, Central India. Six neurologist-led outreach epilepsy clinics were held between September 2023 and January 2025 in two rural blocks. Factors associated with treatment status were analysed using univariate comparisons and multivariate logistic regression.

Results

Of 534 PWE included, 324 (60.7%) were untreated at the time of clinic presentation. Untreated PWE were older, had a later age of epilepsy onset, and had lower household incomes. Tribal ethnicity was strongly associated with untreated epilepsy, with 70% of tribal PWE untreated compared to 53% of non-tribal PWE ($p < 0.001$). In multivariate analysis, tribal ethnicity remained independently associated with lower odds of being on treatment (adjusted OR 0.45; 95% CI 0.28–0.70).

Conclusions

Within high treatment-gap rural settings, tribal ethnicity identifies a subgroup of PWE who are particularly vulnerable to remaining untreated. Primary care–based epilepsy programmes should explicitly recognise and prioritise tribal PWE through targeted outreach, community engagement, and continuity-of-care strategies to reduce inequities in epilepsy treatment access.

Background

Even within communities battling a large treatment gap, there are persons with epilepsy (PWE) who are significantly more vulnerable and more likely to be living with untreated epilepsy compared to others. While epilepsy treatment gap is multifactorial and there have been many studies that have looked into possible reasons for it[1,2], not much is known about these *particularly vulnerable persons with epilepsy* (PVPWE) who are embedded within poor resource, high treatment gap communities.

In low-and-middle-income countries (LMICs) including India, not only is the burden of epilepsy and the levels of treatment gap disproportionately higher compared to the rest of the world, but there is often an arbitrary distribution of available health resources, further worsening a bad situation. Recognizing PVPWE within communities can go a long way towards ensuring a more equitable healthcare resource allocation. It may also be insightful to understand what puts these PVPWE at a higher risk of remaining untreated compared to other members of the same community living with epilepsy.

In response to the setting of the 90-80-70 Intersectoral Global Action Plan (iGAP) targets for epilepsy[3], there has been a renewed urgency in many countries to find ways to improve understanding of the processes and mechanisms that perpetuate epilepsy treatment gaps. The LMICs have a lot of ground to cover in this regard. While one may keep the notional iGAP 90-80-70 targets as a broad guiding light, more pragmatic targets informed by the urgency of need within communities that are most vulnerable, would be an effective strategy to speedily mitigate deficiencies in care.

During an ongoing implementation study in a severely underserved region of Central India, we were also keen to document the patterns of health-seeking behavior in the community where we were working. The question we were looking to answer was, *"What puts PWE at a greater risk of remaining untreated within a high treatment gap community?"* We wanted to identify PVPWE and understand what attributes put PWE at a greater risk of remaining untreated in communities that have large epilepsy treatment gaps.

Methods

8.1. Standard protocol approvals, registrations and patient consent

In the Central Indian state of Chhattisgarh, ongoing implementation research is evaluating impact of capacity building at primary care level, on access to epilepsy care in the community (ICMR grant I-1321[4]). This work is funded by the Indian Council of Medical Research and the Non-Communicable Diseases and Mental Health division of the Government of Chhattisgarh, India is partnering and providing logistical support for it. All patients or their legally authorized representatives (for minor and disabled patients) gave a written informed consent and the institutional ethics review board approved the study. With assistance from the Chhattisgarh government health machinery, several outreach epilepsy clinics were organized in an attempt to speed up the process of identification, diagnosis and initiation of antiseizure medication (ASM) treatment in PWE in the area.

8.2 Study design and location of Outreach Clinics

This was a cross-sectional study design nested within the larger implementation research cohort. The blocks of Nagri and Ambagarh Chowki (AC) were selected out of 146 blocks in the state of Chhattisgarh. A block is an administrative subdivision of the district specifically created for rural development and Panchayati Raj institutions. The block selection was based upon the recommendation of the Health

Department and took into consideration several factors including low levels of government health clinic utilization in the midst of high levels of poverty and illiteracy in the community.

8.3 Mechanism of the Outreach Clinics

Dates for the Epilepsy Outreach Clinics were decided at least 4–6 weeks in advance. The community was informed about the clinics using multiple approaches such as display of banners at government clinics and prominent places, engagement with local opinion makers and influencers, messaging through social media and word of mouth by primary care doctors. Community health workers (CHWs) known as 'Mitanins' (meaning female friends) in the state of Chhattisgarh were engaged. By 'line listing' or the process of creating a detailed, comprehensive list of all households or individuals within a specific geographic area, CHWs were able to inform and mobilize PWE within their allotted work areas to attend the outreach epilepsy clinic on the designated date. Wherever necessary, transport assistance was provided to PWE for attending the clinic. If no family member was available, CHWs also volunteered to assist and accompany PWE to the clinic. Patients were encouraged to pre-register for the clinic through Helpline numbers that were displayed on all publicity material.

8.4 At the Epilepsy Outreach Clinic

All PWE who turned up at any outreach epilepsy clinic were led in an orderly way through the 1. Registration desk 2. Consent to participate in the study 3. Group counselling for epilepsy 4. Neurologist consultation for diagnosis and prescription 5. Data entry station 6. Pharmacy, where 1-month free of charge ASMs were dispensed as per prescription and 7. Individual counselling to explain prescription and attend to any other individual queries. A helpline number was shared with all patients for any later questions or concerns. Consecutive PWE who consented were enrolled in the cross-sectional study. A neurologist, neurology research scholars and fellows and data entry staff formed the 10-member core research team at the outreach clinic. Additional man power provided by the health department was employed in the pharmacy, to provide interpreter services wherever needed and in other support positions.

8.5 Inclusion and Exclusion criteria and Definitions

All patients who were diagnosed with active epilepsy by the neurologist and prescribed ASMs, were included in the study if they consented to share information. Patients with epilepsy in remission were excluded. We followed the practical clinical definition of epilepsy accepted by ILAE in 2010[5]. Epilepsy was diagnosed if a patient had at least two unprovoked seizures occurring more than 24 hours apart. Focal and generalized seizure type and epilepsy type were as per ILAE 2017 operational definitions[6]. Acute symptomatic seizures were diagnosed as per Beghi et al.[7] Functional dissociative seizures (FDS) were diagnosed if the patient's description of seizure semiology made FDS more likely. Patients who reported at least one seizure in the last 1 year were classified as active epilepsy and no seizures in the last 5 years were classified as epilepsy in remission. On the basis of treatment status, patients were classified into 'On Treatment', if they were on any ASM(s) by prescription on the day of the epilepsy clinic and 'Untreated' if they were not on any ASM(s) by prescription. For assigning economic categories, the

Prasad socioeconomic status classification was used[8,9]. Patients from blocks other than Nagri and AC who heard about the clinic and came seeking treatment, were provided care but excluded from this study.

8.6 Data Collection and Instruments

Data was collected using a questionnaire that included basic demographic characteristics, personal information pertaining to family configuration, education, vocation, financial status, Government of India health insurance - Ayushman Bharat (AB) - beneficiary status[10] etc., and epilepsy-related information including epilepsy treatment status. Any records of previous treatments that were available with the PWE were also checked. Data was collected using a questionnaire developed for this study, which recorded basic demographic characteristics, socioeconomic status, and clinical history. The English version of the questionnaire, containing the specific items relevant to the analysis presented in this study, is provided as Supplementary File 1.

8.7 Statistical analysis

Statistical analysis compared demographic and clinical variables between treated and untreated groups. For univariate analysis, continuous variables were compared using the t-test, while categorical variables were analyzed using the Chi-square test. Multivariate logistic regression was employed to determine factors independently associated with treatment status, calculating adjusted odds ratios (AOR) and 95% confidence intervals (CI). A p-value of < 0.05 was considered statistically significant.

Results

Between September 2023 and January 2025, six outreach clinics were conducted – three each at Nagri and AC blocks. A total of 742 persons registered for the clinics, 683 were diagnosed with epilepsy and started on treatment with ASM(s) and 534 fulfilled inclusion criteria and were included in this study and considered in the final analysis. Of 534 PWE, 324 (61%) were categorized as ‘Untreated’ and 210 (39%) as ‘On treatment’. Significant differences were observed in several baseline characteristics between the groups (Table 1).

Table 1
Baseline characteristics of the study participants

Variable/ Treatment Status	Untreated Group (n = 324)	On Treatment Group (n = 210)	p-value
N = 534	324 (60.7)	210 (39.3)	
Age (years)	27.5 (18.0-37.5)	23 (15.0–36.0)	< 0.001
Age at onset of epilepsy (years)	14.0 (6.0–25.0)	9.0 (3.0–18.0)	< 0.001
Monthly family income (INR)	3000 (1500–9000)	5000 (2000–10000)	< 0.001
Camp location			
Ambagarh Chowki (253)	172 (53.1)	81 (38.6)	0.001
Nagri (281)	152 (46.9)	129 (61.4)	
Sex			
Female	127 (39.2)	74 (35.2)	0.3
Male	197 (60.8)	136 (64.8)	
Cultural identity			
Non-tribal	155 (47.8)	138 (65.7)	< 0.001
Tribal	169 (52.2)	72 (34.3)	
Educational status			
Illiterate	62 (19.3)	37 (17.7)	0.1
Below high school	202 (62.9)	119 (56.9)	
High school & above	57 (17.8)	53 (25.4)	
School dropout			
Yes	223 (69.9)	139 (66.8)	0.7
No	72 (22.6)	52 (25.0)	
Never attended school	24 (7.5)	17 (8.2)	
Employment status			
Employed	109 (42.9)	62 (42.8)	0.9
Unemployed	145 (57.1)	83 (57.2)	
Marital status			

Data is presented as median (IQR) or frequency (percent). INR: Indian rupee, IQR: Interquartile range.

Variable/ Treatment Status	Untreated Group (n = 324)	On Treatment Group (n = 210)	p-value
Married	140 (52.4)	68 (45.0)	0.1
Unmarried	127 (47.6)	83 (55.0)	
Ayushman Bharat beneficiary			
Yes	238 (73.7)	166 (79.0)	0.1
No	85 (26.3)	44 (21.0)	
Current seizure frequency			
Daily	45 (13.9)	34 (16.2)	0.002
Weekly	28 (8.6)	21 (10.0)	
Monthly	128 (39.5)	70 (33.3)	
Yearly	92 (28.4)	55 (26.2)	
< 1/year	24 (7.4)	9 (4.3)	
Not well defined	7 (2.2)	21 (10.0)	

Data is presented as median (IQR) or frequency (percent). INR: Indian rupee, IQR: Interquartile range.

The untreated group was older (median 27.5 vs 23 years, $p < 0.001$), had a later epilepsy onset (median 14 vs 9 years, $p < 0.001$) and also a lower monthly family income (median 3000 INR vs 5000 INR, $p < 0.001$). Patients at AC were significantly more likely to be untreated as compared to patients from Nagri (53% vs 47%, $p = 0.001$). Among tribal patients, 70% were untreated, compared to 53% of non-tribal patients ($p < 0.001$). More treated participants had completed high school or above (25%) compared to untreated patients (18%) though this difference did not reach statistical significance. School dropouts and never attending school showed no significant difference. Sex, employment status, marital status, and AB beneficiary status did not differ significantly between the two groups. While daily and weekly seizure frequencies were relatively comparable, a notably larger proportion of treated participants (10%) reported seizure frequencies that were 'not well defined,' compared to 2% in the untreated group.

After adjusting for covariates in the multivariate model (Table 2), younger age of epilepsy onset was associated with higher likelihood of treatment; each one-year increase in age at onset reduced the odds of being treated by 4%. Income showed a positive gradient: compared to the lowest income group, the middle-income group had nearly twice the odds of being on treatment, while the upper-income group had a higher but non-significant odds. Patients attending the Nagri camp had greater odds of being on treatment compared to patients from AC. Tribal individuals had significantly lower odds of being on treatment compared to non-tribal individuals. Those with education of high school or above were more likely to be on treatment, while those with education below high school did not differ significantly.

Ayushman Bharat health insurance beneficiary status was positively associated with treatment uptake. Individuals without insurance had significantly lower odds of being treated. Other variables such as age, sex, marital status, and current seizure frequency were not statistically significant in the adjusted model.

Table 2
Multivariate Logistic Regression Analysis Factors Associated with Treatment Status

Variable/ Treatment Status	Untreated	On Treatment	Unadjusted OR	p value	Adjusted OR	95% CI	p value
N = 534	324 (60.7)	210 (39.3)					
Age (years)	27.5 (18.0-37.5)	23.0 (15.0–36.0)	0.98	0.02	1.01	0.99–1.04	0.1
Age of onset (years)	14.0 (6.0–25.0)	9.0 (3.0–18.0)	0.97	< 0.001	0.96	0.94–0.98	0.003*
Monthly family income (INR)							
Lower	140 (43.2)	54 (25.7)	1.0		1.0		
Middle	104 (32.1)	84 (40.0)	2.09	< 0.001	1.98	1.16–3.37	0.01*
Upper	80 (24.7)	72 (34.3)	2.33	< 0.001	1.71	0.95–3.09	0.07
Camp location							
Ambagarh Chowki (253)	172 (53.1)	81 (38.6)	1.0	0.001	1.0	1.02–2.57	0.04*
Nagri (281)	152 (46.9)	129 (61.4)	1.80		1.6		
Sex, n (%)							
Female	127 (39.2)	74 (35.2)	1.0	0.3	1.0	0.70–1.7	0.6
Male	197 (60.8)	136 (64.8)	1.18		1.1		
Cultural identity							
Non-tribal	155 (47.8)	138 (65.7)	1.0	< 0.001	1.0	0.28–0.70	< 0.001*
Tribal	169 (52.2)	72 (34.3)	0.47		0.45		
Educational status							
Illiterate	62 (19.3)	37 (17.7)	1.0	-	1.0	-	-
Below high school	202 (62.9)	119 (56.9)	0.98	0.9	1.16	0.64–2.12	0.6
High school & above	57 (17.8)	53 (25.4)	1.55	0.1	2.04	1.02–4.07	0.04*
Marital status							

Data is presented as median (IQR) or frequency (percent). INR: Indian rupee, IQR: Interquartile range. *Significant values

Variable/ Treatment Status	Untreated	On Treatment	Unadjusted OR	p value	Adjusted OR	95% CI	p value
Married	140 (52.4)	68 (45.0)	1.0	0.1	1.0	0.63–2.29	0.5
Unmarried	127 (47.6)	83 (55.0)	1.34		1.20		
Ayushman beneficiary							
Yes	238 (73.7)	166 (79.0)	1.0	0.1	1.0	0.26–0.86	0.01*
No	85 (26.3)	44 (21.0)	0.74		0.47		
Current seizure frequency							
Daily	45 (13.9)	34 (16.2)	1	-	1	-	-
Weekly	28 (8.6)	21 (10.0)	0.99	0.9	0.8	0.3-2.0	0.6
Monthly	128 (39.5)	70 (33.3)	0.72	0.2	0.6	0.3–1.1	0.1
Yearly	92 (28.4)	55 (26.2)	0.79	0.4	0.7	0.3–1.4	0.3
< 1/year	24 (7.4)	9 (4.3)	0.49	0.1	0.5	0.1–1.4	0.1
Not well defined	7 (2.2)	21 (10.0)	3.97	0.005	1.9	0.5–6.6	0.2

Data is presented as median (IQR) or frequency (percent). INR: Indian rupee, IQR: Interquartile range. *Significant values

Discussion

If up to 60% patients with active epilepsy who turn up in response to a public announcement of an epilepsy outreach clinic are untreated or on no prescription ASM(s), the situation would definitely be considered grim. India is a vast and varied country and it may be incorrect to assume that the situation for epilepsy in the rest of the country is also equally bad. There is limited epilepsy data available from all parts of the country but treatment gap figures ranging from 50–90% have been reported[11,12].

Within this community with a high treatment gap, a PWE who was of tribal ethnicity was more likely to remain untreated as compared to non-tribal PWE. We would like to propose that such PWE, who experience treatment gap levels that are significantly higher than other members of the same community be recognized as *Particularly Vulnerable Persons with Epilepsy or PVPWE*. This categorization is not just a matter of semantics but can be an important mechanism to ensure that the dire situation of these patients gets the attention that it deserves, especially at the time of health resource allocation and policy development. These PVPWE also constitute low-hanging fruit where there is likely to be a good

outcome on starting treatment. This optimism stems from the fact that these patients are treatment naïve and a correct diagnosis and institution of one or two appropriate ASMs is likely to stop ongoing seizures in most[13].

It would be interesting to further explore mechanisms by which a tribal ethnicity puts PWE at a higher risk of remaining untreated. Sex, marital and employment status did not differ significantly between untreated and treated PWE. So, what is it that puts a tribal PWE at a greater disadvantage? The answer to this question is beyond the scope of this study but definitely throws up an important research area for future investigators. One third of the world's tribal and indigenous population, amounting to over 104 million, lives in India. Spread across 705 communities, they represent a unique cultural diversity but unfortunately also experience the greatest gaps in health care[14]. While untreated epilepsy patients, wherever they may be, deserve attention and resources; tribal people should be recognised as PVPWE and when limited resources are being triaged, they have to be kept in mind and prioritised.

Other factors that also put patients at a higher risk of remaining untreated were being older at onset of epilepsy and having a lower monthly income. When patients have to rely on out-of-pocket expenses for most medical needs, there is a systematic exclusion of poorer patients from accessing care[15]. We do not fully understand how age of epilepsy onset influenced treatment status in this cohort. When resources are limited, as was the case in these patients, it may be that parents or families prioritize healthcare needs of younger children as compared to older children or adults.[16]

Patients at Nagri were more often on treatment compared to patients from AC. While the same time, effort and resources were invested in making public announcements to inform communities and in conducting the outreach clinics at both locations, significantly more PWE turned at the clinics at Nagri compared to AC 281(53%) vs 253(47%). There may be many reasons for more untreated patients at AC, but fewer PWE turning up at AC for the outreach clinic may also be a reflection of some difference in the health seeking behaviour of the two communities.

The Ayushman Bharat (AB) is a flagship health insurance scheme of the Government of India aimed at achieving Universal Health Coverage amongst the financially disadvantaged and most vulnerable families. Beneficiaries of the AB scheme were more likely to be on treatment than non-beneficiaries. Financial protection through the AB is only provided for secondary and tertiary care hospitalization. As epilepsy diagnosis and treatment initiation and also the continued chronic care is largely provided on an OPD basis, the AB provides no financial assistance to PWE. So, it is difficult to attribute improved treatment rates amongst AB beneficiaries to this scheme. However, AB beneficiaries are more likely to seek treatments for other conditions that are covered under the scheme and that may be responsible for making them familiar with the process of seeking healthcare and also instilling confidence in them about opting for modern medicine based treatments.

With a population of 1.3 billion and an epilepsy patient population of about 12–13 million, India's untreated epilepsy patients in absolute numbers is in several millions. If India and other LMICs with

similar challenges aspire to get anywhere close to the iGAP targets on time, unconventional and innovative solutions would also have to be tested and implemented. One quick and relatively low-cost intervention that is used in India but remains uncoordinated and relies mostly on the volunteering efforts of a few individuals, is the conduct of outreach clinics. The Indian Academy of Neurology, has added an Outreach Services subsection in recent years further underlining the importance and relevance of this method of healthcare dispensation in the country. There is published testimony that validates epilepsy outreach clinics and also provides guidance as to how these can be run in an effective manner[17,18]. An annual calendar of outreach epilepsy clinics can be made, teams of doctors and other support staff to run those clinics familiarized with standard outreach clinic protocols, and some mechanism of telemedicine established for continuity of long-term follow-up care of PWE started on treatments in these outreach clinics[19]. This can benefit PWE in distant, rural corners of the country including the PVPWE, and reduce treatment gaps.

The potential role of CHWs in expanding epilepsy care to underserved communities is also worth emphasizing here. India has about 1 million CHWs serving a population of approximately 500 million people in underserved communities[20]. These CHWs serve as the first point of contact for health-related needs and are a crucial link between the healthcare system and the community, especially in rural areas where access to healthcare facilities may be limited. The process of line-listing that was undertaken to ensure that a large number of PWE could be systematically informed and collected for the outreach clinics is a cost effective and efficient mechanism that is available because of the widely distributed cadres of CHWs. When CHWs participate in the conduct of such outreach epilepsy clinics, it also provides a useful opportunity to them to learn about epilepsy and participate in the continuation of chronic care of PWE in underserved regions.

As we did not conduct a door-to-door survey to identify PWE in the community, it is likely that patients who were unwilling to initiate treatment with ASMs may have been missed. This is a limitation of the study. However, for a country with limited resources, assembling patients through line listing by CHWs at this stage when untreated epilepsy patient numbers in the community are so high, seems a sensible, pragmatic and cost-effective choice. Door-to-door surveys are time-consuming and also require far more resources in terms of money and personnel. CHWs who are embedded within communities are not only aware of which households have PWE(s), they generally also know whether the patient is on treatment or not. Additionally, there is trust and ease of communication between patients and CHWs as they have a shared socio-cultural milieu and are well acquainted with each other.

Conclusion

This study describes demographic and clinical characteristics of epilepsy patients encountered in six outreach clinics at two locations in rural Chhattisgarh. The overall picture of about 60% patients with active epilepsy not being on any treatment is worrisome. We would reiterate the existence of a group of PVPWE in the form of PWE who have a tribal ethnicity. Our findings reveal a greater vulnerability of tribal

patients to remaining untreated. Studies to further understand the health seeking behaviors of tribal PWE and looking at mechanisms in which access to epilepsy care could be facilitated, are needed.

Abbreviations

AB: Ayushman Bharat

AC: Ambagarh Chowki

ASM: Antiseizure Medication

AOR: Adjusted Odds Ratio

CHW: Community Health Worker

CI: Confidence Interval

FDS: Functional Dissociative Seizures

iGAP: Intersectoral Global Action Plan

ILAE: International League Against Epilepsy

INR: Indian Rupee

IQR: Interquartile Range

LMICs: Low- and Middle-Income Countries

PVPWE: Particularly Vulnerable Persons with Epilepsy

PWE: Persons with Epilepsy

Declarations

Ethics approval and consent to participate

The study was approved by the Institutional Ethics Committee of All India Institute of Medical Sciences, New Delhi (approval number: IEC/AIIMS/A1630), and was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants or from legally authorized representatives in the case of minors or participants unable to provide consent.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

This study was supported by the Indian Council of Medical Research (ICMR) (Grant No. I-1321). The Non-Communicable Diseases and Mental Health Division, Government of Chhattisgarh, provided logistical and programmatic support for the conduct of outreach epilepsy clinics. The funding bodies had no role in the study design; data collection, analysis, or interpretation; or in writing the manuscript.

Authors' contributions

MBS conceived and designed the study. DG and the research team coordinated data collection at outreach clinics and follow up. MS performed the data analysis. MBS and DG drafted the manuscript. All authors critically reviewed the manuscript and approved the final version.

Acknowledgements

We acknowledge the support of the Department of Health and Family Welfare, Government of Chhattisgarh. We thank the community health workers (Mitanins), primary care staff, and outreach clinic personnel for their assistance in patient mobilization and clinic operations. We are grateful to all participants and their families for their cooperation.

Authors' information

Not applicable.

References

1. Meinardi H, Scott RA, Reis R, Sander JW, ILAE Commission on the Developing World. The treatment gap in epilepsy: the current situation and ways forward. Epilepsia. 2001 Jan;42(1):136–49.
2. Pellinen J. Treatment gaps in epilepsy. Front Epidemiol [Internet]. 2022 Aug 1 [cited 2025 Sept 1];2. Available from: https://www.frontiersin.org/journals/epidemiology/articles/10.3389/fepid.2022.976039/full
3. (PDF) "Epilepsy 90–80–70": The Intersectoral Global Action Plan on epilepsy and other neurological disorders (2022–2031). ResearchGate [Internet]. [cited 2025 Sept 1]; Available from:

https://www.researchgate.net/publication/375358572_Epilepsy_90-80-70_The_Intersectoral_Global_Action_Plan_on_epilepsy_and_other_neurological_disorders_2022-2031

4. Can Capacity Building at Primary Care Level Improve Access to Epilepsy Care in Chhattisgarh? An Implementation Research [Internet]. WNFO. [cited 2025 Sept 1]. Available from: https://www.worldneurologyfoundation.com/global-neurology-research-hub/can-capacity-building-at-primary-care-level-improve-access-to-epilepsy-care-in-chhattisgarh%3F-an-implementation-research
5. Berg AT, Berkovic SF, Brodie MJ, Buchhalter J, Cross JH, Van Emde Boas W, et al. Revised terminology and concepts for organization of seizures and epilepsies: Report of the ILAE Commission on Classification and Terminology, 2005–2009. Epilepsia. 2010;51(4):676–85.
6. Fisher RS, Cross JH, French JA, Higurashi N, Hirsch E, Jansen FE, et al. Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology. Epilepsia. 2017;58(4):522–30.
7. Beghi E, Carpio A, Forsgren L, Hesdorffer DC, Malmgren K, Sander JW, et al. Recommendation for a definition of acute symptomatic seizure. Epilepsia. 2010 Apr;51(4):671–5.
8. Sharma R. Revision of Prasad's social classification and provision of an online tool for real-time updating. South Asian J Cancer. 2013;2(3):157.
9. Ghodke M. Updated BG Prasad's Socioeconomic Status Classification for the Year 2023. Indian J Community Med Off Publ Indian Assoc Prev Soc Med. 2023;48(6):934–6.
10. About PM-JAY - National Health Authority | GOI [Internet]. [cited 2025 Sept 4]. Available from: https://nha.gov.in/PM-JAY
11. Radhakrishnan K, Pandian JD, Santhoshkumar T, Thomas SV, Deetha TD, Sarma PS, et al. Prevalence, knowledge, attitude, and practice of epilepsy in Kerala, South India. Epilepsia. 2000 Aug;41(8):1027–35.
12. Sridharan R. Epidemiology of epilepsy. Curr Sci. 2002;82(6):664–70.
13. Sander JW. The use of antiepileptic drugs--principles and practice. Epilepsia. 2004;45 Suppl 6:28–34.
14. Tribal Health Report, India – First Comprehensive Report on Tribal Health in India [Internet]. [cited 2025 Sept 4]. Available from: https://tribalhealthreport.in/
15. Kamath S, Maliyekkal J, Elstin Anbu Raj S, Varshini RJ, Brand H, Sirur A, et al. Understanding out-of-pocket expenditure in India: a systematic review. Front Public Health. 2025 June 9;13:1594542.
16. Lignou S, Sheehan M, Parker M, Wolfe I. Healthcare resource allocation decisions and non-emergency treatments in the aftermath of Covid-19 pandemic. How should children with chronic illness feature in prioritisation processes? Wellcome Open Res. 2024 Jan 16;8:385.
17. Prajapati C, Singh MB, Padma Srivastava MV, Sreenivas V, Bhatia R, Goyal V, et al. 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. Seizure. 2019 Apr;67:5–10.

18. Bigelow J, Singh V, Singh M. Medication adherence in patients with epilepsy after a single neurologist visit in rural India. Epilepsy Behav EB. 2013 Nov;29(2):412–5.
19. 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. 2017 Dec;53:55–61.
20. Feminist labour organising: Community Health Workers in India Achieve Historic Victories [Internet]. 2025 [cited 2025 Sept 4]. Available from: https://publicservices.international/resources/news/feminist-labour-organising-community-health-workers-in-india-achieve-historic-victories?id=15656&lang=en

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryFile1.docx