

## “Assessment Of Epilepsy-Related Stigma And Treatment-Seeking Behavior: A Cross-Sectional Analysis”

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### Abstract

Epilepsy remains one of the most misunderstood and socially stigmatized neurological disorders worldwide, with the burden being especially pronounced in low- and middle-income countries such as India. Beyond recurrent seizures, People With Epilepsy (PWE) frequently experience social discrimination, psychological distress, and restricted opportunities in education, employment, and marriage. These challenges are largely driven by inadequate public awareness, deeply rooted cultural beliefs, and persistent misconceptions that often associate epilepsy with supernatural causes. This cross-sectional study aimed to assess Awareness, Perceptions, and Behaviors (APB) related to epilepsy and to examine the impact of epilepsy-related stigma on treatment-seeking behavior among PWE attending outpatient healthcare facilities. Data were collected using a structured questionnaire capturing socio-demographic characteristics, clinical profiles, level of epilepsy-related knowledge, experiences of perceived and enacted stigma, and healthcare-seeking practices. Treatment-seeking behavior was evaluated based on delay in medical consultation, adherence to antiepileptic medications, and preference for biomedical versus alternative or faith-based treatments. The results indicated that a considerable proportion of PWE experienced moderate to high levels of stigma. Fear of disclosure, social avoidance, and negative effects on personal and professional life were commonly reported. Higher stigma scores were strongly associated with poor APB levels, delayed initiation of medical treatment, irregular medication adherence, and increased reliance on non-medical therapies. Rural residence, lower educational status, and limited access to specialized healthcare services further intensified stigma and inappropriate treatment practices.

**Keywords:** Epilepsy; Epilepsy-related stigma; Treatment-seeking behavior; Awareness, Perceptions, and Behaviors (APB); Cultural beliefs; Healthcare utilization; Medication adherence; Social discrimination; Public awareness; Neurological disorders.

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### I. Introduction

Epilepsy is a chronic neurological disorder characterized by recurrent, unprovoked seizures resulting from abnormal electrical activity in the brain. It affects individuals of all ages, genders, and socioeconomic backgrounds, making it one of the most common neurological conditions worldwide. According to global estimates, over 50 million people live with epilepsy, with nearly 80% residing in low- and middle-income countries. India alone accounts for a substantial proportion of this burden, with millions of People With Epilepsy (PWE), including a significant number who experience drug-resistant forms of the disorder.[1] Despite advancements in diagnostic techniques and the availability of effective antiepileptic drugs, epilepsy continues to be surrounded by widespread misconceptions and social stigma. In many communities, particularly in rural and resource-limited settings, epilepsy is often misunderstood as a supernatural or contagious condition rather than a treatable medical disorder. Such beliefs contribute to fear, discrimination, and social exclusion, which can be as debilitating as the seizures themselves. PWE frequently encounter barriers in education, employment, marriage, and social participation, leading to reduced quality of life and psychological distress.[6] Awareness, Perceptions, and Behaviors (APB) related to epilepsy play a critical role in shaping public perceptions and health-seeking behavior. Inadequate knowledge and negative attitudes can discourage timely medical consultation, promote reliance on traditional or faith-based healing, and result in poor adherence to antiepileptic therapy. These challenges are further compounded by limited access to specialized healthcare services and trained neurological professionals, particularly in rural areas.[8] Understanding epilepsy-related stigma and its influence on treatment-seeking behavior is therefore essential for developing effective public health interventions. By examining Awareness, Perceptions, and Behaviors (APB) and social attitudes toward epilepsy, especially among PWE, healthcare providers and policymakers can design targeted awareness programs and culturally sensitive strategies aimed at reducing stigma, improving healthcare access, and enhancing overall disease management.

## II. Materials And Methods

### Study Design And Setting:

This study adopted a prospective, observational, cross-sectional design to evaluate the Awareness, Perceptions, and Behaviors (APB) related to epilepsy.[7] The research was carried out at Yeshodha Multispecialty Hospital, a tertiary care healthcare facility located in Latur, Maharashtra, India. The hospital serves a diverse population from both urban and surrounding rural regions, making it an appropriate setting to assess variations in awareness and perceptions of epilepsy.[4]

### Participant Selection:

The study population comprised two distinct groups: People With Epilepsy (PWE) receiving clinical care at the hospital and a non-epileptic comparison group consisting of hospital visitors and patient attendants. A total of 197 participants were enrolled in the study, including 101 PWE and 96 individuals without a history of epilepsy.[16] Participants were eligible for inclusion if they were aged 18 years or older and able to read, write, or communicate effectively in English or Marathi. Individuals with non-epileptic seizures, suspected but undiagnosed seizure disorders, or cognitive impairment that could interfere with questionnaire responses were excluded from the study. Participation was voluntary, and informed consent was obtained from all participants prior to enrollment.

### Data Collection Tool:

Data were collected using a standardized, structured questionnaire comprising 25 validated items. The questionnaire was designed to assess three core domains of epilepsy-related Awareness, Perceptions, and Behaviors (APB):

#### Awareness

Awareness in epilepsy refers to the understanding of the medical nature, causes, symptoms, and treatment options for the disorder. It includes recognizing epilepsy as a neurological condition rather than a mental or supernatural phenomenon.[12] In our study, awareness among People With Epilepsy (PWE) was higher than in the general population, yet misconceptions persisted regarding heredity, contagion, and alternative treatments. Enhancing awareness is crucial for early diagnosis, proper management, and prevention of stigma.[23] Public health initiatives, educational campaigns, and community programs can strengthen knowledge about epilepsy, correct myths, and encourage evidence-based care, ultimately improving patient outcomes and quality of life.

#### Perceptions

Perceptions encompass the beliefs, attitudes, and social viewpoints regarding epilepsy held by individuals and communities. These shape how people interpret seizures, respond to patients, and integrate them into social, educational, and occupational settings.[22] In the study, stigma, fear of disclosure, and social avoidance were common among non-epileptic participants, reflecting negative societal perceptions. Misconceptions associating epilepsy with supernatural causes or moral failings contribute to discrimination.[23] Addressing perceptions requires culturally sensitive interventions that challenge myths, promote empathy, and foster acceptance. Positive perceptions are essential to reducing social barriers, encouraging medical treatment, and supporting the psychological well-being of People With Epilepsy.

#### Behaviors

Behaviors refer to the actions and practices of individuals in response to epilepsy, including treatment-seeking, medication adherence, and responses during seizures.[24] The study revealed that PWE were more likely to seek medical care and follow prescribed antiepileptic therapy, whereas non-epileptic participants often relied on traditional or faith-based remedies. Harmful practices, such as placing objects in a patient's hand or making them smell a shoe during seizures, were still observed.[21] Promoting safe and evidence-based behaviors involves educating communities, training caregivers, and encouraging timely hospital visits. Improved behavioral practices can prevent complications, enhance treatment outcomes, and reduce stigma associated with epilepsy.

Responses were recorded using a three-point response format: *Yes*, *No*, and *Don't Know*. To ensure clarity and accurate understanding, the questionnaire was administered in the local language where necessary, under the supervision of trained personnel.

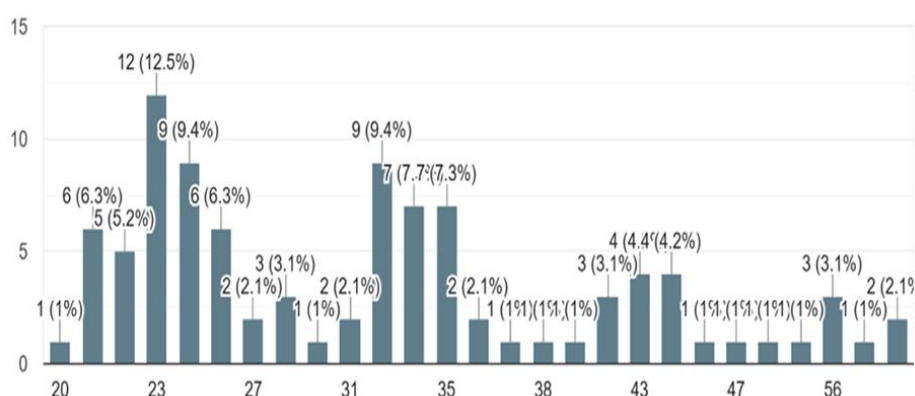
**Table 1: Standardized Questionnaire Comprising 25 Validated Questions Used For Assessing The Awareness, Perceptions, And Behaviors (APB) Among Patients With Epilepsy (PWE):**

Q. No.	Question	Yes	No	Don't Know
<b>SECTION A: AWARENESS</b>				
1	Have you heard about epilepsy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2	Is epilepsy a brain disorder?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Is epilepsy a mental disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Is epilepsy a hereditary disorder?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Do supernatural powers cause epilepsy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Is epilepsy contagious?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Is epilepsy caused by the sins of the patient or their ancestors?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Is epilepsy treatable with modern medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Is epilepsy treatable with Ayurvedic medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Can faith healers treat epilepsy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>SECTION B: PERCEPTIONS</b>				
11	Can a child with epilepsy study?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Will you allow your child to play with a child who has epilepsy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Is the child discriminated against by schoolmates?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Is the child discriminated against by teachers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Can a child with epilepsy play games?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Can a person with epilepsy take up a job?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	Can a person with epilepsy marry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Will you reveal your daughter's epilepsy status before marriage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Will you reveal your son's epilepsy status before marriage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Can a person with epilepsy have children?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Are you discriminated against by your spouse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>SECTION C: BEHAVIORS</b>				
22	During an epileptic attack, will you put keys in the patient's hands?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	During an epileptic attack, will you make the patient smell a shoe?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	During an epileptic attack, will you take the patient to a hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	Is branding useful in epilepsy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### III. Statistical Analysis

The collected data were systematically compiled and expressed as frequencies and percentages to enable a clear comparison of knowledge, attitudes, and practices related to epilepsy between patients and non-patient participants. Comparative analysis was performed to evaluate differences in awareness levels and social perceptions across the two study groups.[12] Pearson's Chi-square test was applied to each questionnaire item to assess the statistical significance of differences in Awareness, Perceptions, and Behaviors (APB) responses between People With Epilepsy (PWE) and the control group. All statistical tests were conducted using a two-tailed approach, and a p-value of less than 0.05 was considered indicative of statistical significance.



**Figure 1: Age Distribution Of Study Participants, Illustrating The Demographic Profile Of People With Epilepsy (PWE) And Non-Epileptic Individuals.**

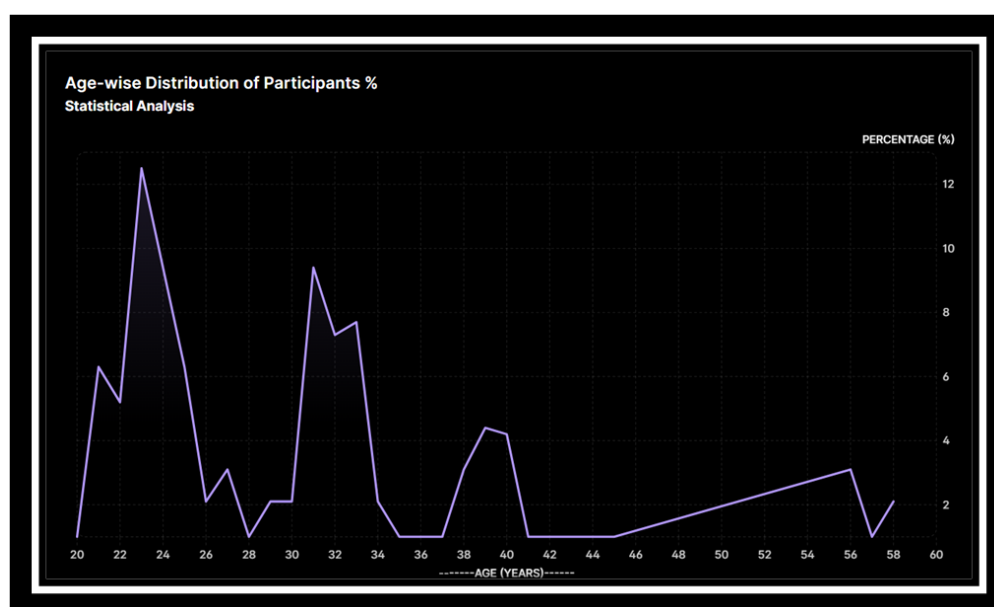
### IV. Age Distribution Of Study Participants

The age distribution of the study population demonstrates a predominance of young and middle-aged adults. The highest concentration of participants was observed in the age range of **23–31 years**, with a peak around the early twenties, indicating greater representation of younger adults in the study sample. This age group accounted for the largest proportion of respondents, reflecting increased exposure, awareness, and healthcare interaction during early adulthood.[16] A secondary clustering was noted between **32 and 35 years**, suggesting continued participation among individuals in their early middle age. Beyond the mid-thirties, the frequency of participants showed a gradual decline, with comparatively fewer individuals represented in the higher age groups

above 45 years. Participants aged above 50 years constituted the smallest proportion of the sample.[11] The observed age distribution highlights that epilepsy-related Awareness, Perceptions, and Behaviors were primarily assessed among economically and socially active age groups. This is particularly relevant, as individuals within these age ranges are more likely to experience the social and occupational consequences of epilepsy, including stigma related to employment, marriage, and social participation. The lower representation of older adults may be attributed to reduced healthcare engagement, underreporting, or survival bias.

**Table 2: Age-Wise Distribution Of Participants %:**

S. No.	Age (Years)	Percentage (%)	S. No.	Age (Years)	Percentage (%)
1	20	1.0	16	35	1.0
2	21	6.3	17	36	1.0
3	22	5.2	18	37	1.0
4	23	12.5	19	38	3.1
5	24	9.4	20	39	4.4
6	25	6.3	21	40	4.2
7	26	2.1	22	41	1.0
8	27	3.1	23	42	1.0
9	28	1.0	24	43	1.0
10	29	2.1	25	44	1.0
11	30	2.1	26	45	1.0
12	31	9.4	27	56	3.1
13	32	7.3	28	57	1.0
14	33	7.7	29	58	2.1
15	34	2.1			



**Figure 2: Age-Wise Distribution Of Participants.**

## V. Knowledge Assessment

A clear difference was observed between patients with epilepsy and the general public regarding understanding of the medical nature of epilepsy. While a majority of patients (73.3%) correctly identified epilepsy as a brain disorder, less than half of the non-patient group (45.8%) shared this knowledge. Misconceptions regarding the causes of epilepsy were more prevalent among the general public, with 29.2% attributing seizures to supernatural forces and 39.6% believing epilepsy to be a consequence of ancestral sins. Additionally, 22.9% of non-patients incorrectly perceived epilepsy as a contagious condition, highlighting persistent gaps in basic medical awareness.[3]

## VI. Attitudes And Social Stigma

Negative social attitudes toward epilepsy were evident, particularly among non-patients. Although 83.2% of patients believed they were capable of marriage, only 50% of the general public expressed acceptance of marriage with a person with epilepsy. Social interaction during childhood also reflected stigma, as only 41.7% of non-patients were willing to allow their child to play with a child affected by epilepsy.[1] Workplace participation revealed a similar pattern; while 87.1% of patients felt capable of holding a job, only 56.3% of the

general public agreed. Regarding disclosure, 64.4% of patients indicated they would reveal their daughter's epilepsy status prior to marriage, and 65.3% reported the same for their son, reflecting continued concern over social acceptance.

## **VII. Treatment And Management Practices**

Treatment-related practices revealed a mixed reliance on evidence-based medicine and traditional beliefs. Although 52.1% of the general public supported modern drug therapy, a considerable proportion continued to believe in alternative approaches, with 33.3% endorsing Ayurvedic medicine and 29.2% expressing faith in spiritual or faith-based healers. Encouragingly, appropriate emergency responses were reported by most participants, as 93.1% of patients and 70.8% of non-patients stated they would take a person experiencing a seizure to the hospital. However, harmful traditional practices persisted; 18.8% of patients and 14.6% of non-patients supported making the patient smell a shoe during a seizure, while 26.7% of patients reported placing keys in the patient's hand during an attack.[25]

## **VIII. Current-Data Overview Of Epilepsy:**

Globally, around 70 million people live with epilepsy (PWE), with approximately 12 million in India, accounting for nearly one-sixth of the worldwide burden. This study (part one of a two-part series) focuses on the epidemiology of epilepsy in India, aiming to inform effective public health strategies for prevention and management. Recent research indicates that the overall prevalence in India ranges from 3.0 to 11.9 per 1,000 people, while the annual incidence is estimated between 0.2 and 0.6 per 1,000 population, figures that are comparable to those in high-income countries despite differences in population characteristics and study methods.[26]

## **IX. Results**

A total of 197 participants were included in the analysis, comprising 101 People With Epilepsy (PWE) and 96 non-epileptic individuals (Non-PWE). The age distribution of the Non-PWE group was predominantly concentrated between 23 and 31 years, representing a younger adult population. Comparative analysis of Awareness, Perceptions, and Behaviors (APB) revealed notable differences between the two groups. Pearson's Chi-square test demonstrated a high cumulative Chi-square value ( $\chi^2 = 317.67$ ), indicating statistically significant variations in awareness, social attitudes, and treatment-related practices across the study population. Participants in the PWE group generally exhibited greater awareness regarding the medical nature of epilepsy and its treatment options; however, stigma-related attitudes and misconceptions were still evident. In contrast, the Non-PWE group displayed lower overall knowledge levels and a higher prevalence of socially restrictive beliefs, particularly concerning education, employment, and marriage of individuals with epilepsy. Practice-related responses further highlighted disparities between the groups, especially in the management of seizure episodes and treatment-seeking behavior. Several traditional and non-scientific practices were more commonly reported among Non-PWE participants. These findings underscore the persistence of epilepsy-related stigma and the influence of inadequate Awareness on Perceptions and Behaviors within the community.

## **X. Conclusion**

The findings of this study highlight a critical paradox in epilepsy care: improvements in medical awareness coexist with persistent social stigma and unsafe traditional practices. While many participants recognized epilepsy as a neurological disorder, their attitudes and behaviors remained strongly influenced by cultural beliefs, fear, and misinformation. These results indicate that knowledge alone is insufficient to bring meaningful change in social acceptance and treatment-seeking behavior. Addressing epilepsy-related stigma requires a comprehensive, multi-layered approach that extends beyond conventional health education. Community engagement, culturally sensitive awareness programs, and supportive policy initiatives are essential to challenge entrenched myths and discriminatory attitudes. Healthcare institutions and public health authorities should prioritize targeted outreach initiatives, strengthen patient support systems, and promote trust in evidence-based medical care. Training healthcare professionals to recognize and counter stigmatizing behaviors, along with large-scale public education campaigns, can play a pivotal role in improving acceptance and quality of care. By addressing both the clinical and sociocultural dimensions of epilepsy, it is possible to move toward a more inclusive, supportive, and stigma-free healthcare environment for people with epilepsy.

## **XI. Abbreviation**

S. NO	ABBREVIATION	FULL FORM	EXPLANATION
1	PWE	People With Epilepsy	Individuals diagnosed with epilepsy who experience recurrent seizures
2	APB	Awareness, Perceptions, and Behaviors	Survey tool to assess awareness, beliefs, and behaviors related to epilepsy
3	HICs	High-Income Countries	Countries with higher economic status and healthcare access



4	<b>NCC</b>	Neurocysticercosis	Parasitic infection of the central nervous system contributing to secondary epilepsy
5	<b>EEG</b>	Electroencephalography	A diagnostic test to measure electrical activity in the brain
6	<b>AED</b>	Antiepileptic Drugs	Medications used to control or reduce seizures in epilepsy
7	<b>LMICs</b>	Low- and Middle-Income Countries	Countries with lower economic status and limited healthcare resources
8	<b>P</b>	P-value	Statistical measure indicating the significance of study results
9	<b><math>\chi^2</math></b>	Chi-square	Statistical test used to assess differences between groups in categorical data
10	<b>MRI</b>	Magnetic Resonance Imaging	Imaging technique for diagnosing structural causes of epilepsy

## XII. Acknowledgment

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