

# Prevalence, Demographic Profile, and Psychological Aspects of Epilepsy in North-Western India: A Community-Based Observational Study

Ashok Panagariya<sup>a</sup> Bhawna Sharma<sup>b</sup> Parul Dubey<sup>c</sup> Vipin Satija<sup>d</sup>  
Monika Rathore<sup>e</sup>

<sup>a</sup>Professor Emeritus Neurology, SMS Medical College, Jaipur, India; <sup>b</sup>Professor Neurology, SMS Medical College, Jaipur, India; <sup>c</sup>Consultant Neurologist, Manipal Hospitals Goa, Panaji, India; <sup>d</sup>Consultant Neurologist, MGS Hospital, New Delhi, India; <sup>e</sup>Professor Preventive and Social Medicine, SMS Medical College, Jaipur, India

## Keywords

Epilepsy · Prevalence · Seizure · India · Knowledge attitude · Jaipur · Rajasthan

## Abstract

**Aims:** This study was undertaken to determine the prevalence of active epilepsy, assess the sociodemographic profile, and psychological aspects of epilepsy in the Jaipur district of Rajasthan, India. **Methods:** We conducted a community-based, cross-sectional observational study covering both rural ( $n = 165,660$ ) and urban ( $n = 179,142$ ) populations of Jaipur district using a house-to-house survey. An adapted, pre-designed World Health Organization screening questionnaire was used to identify the cases. Those confirmed by neurologists as true seizures were included in the study. Cases were classified as per the International League against Epilepsy recommendation. Global Mental Health Assessment Tool electronic questionnaire was used to analyze psychological aspects of cases. The caregivers of the patients participated in the knowledge, attitude, and prac-

tice (KAP) survey. **Results:** A total of 380 patients (258 men, 122 women) were identified with active epilepsy. The estimated prevalence of active epilepsy was 1.1/1,000 population and 71% of cases belonged to low socioeconomic classes. Primary treatment gap was documented in 18.8% of cases in our study, 38% of cases were non-compliant to treatment with poorer compliance in those on polytherapy, 76% had some psychiatric disorder, anxiety and depression being the commonest, and positive family history of epilepsy was found in 4.7%. KAP survey revealed that only 15% of the respondents believed that epilepsy is non-curable, 74% denied its infectious nature, 26% believed that epilepsy occurs due to past sins, and 81% said that they would not marry persons with epilepsy. **Conclusion:** A relatively low prevalence (1.1/1,000) of active epilepsy and a smaller primary treatment gap (18.8%) was found in our study population. Almost three-fourth of cases had an associated psychological problem, Though caregivers were aware of the nature of disease, majority would not prefer to marry a person suffering from epilepsy.

© 2018 S. Karger AG, Basel

## Introduction

Epilepsy is a common chronic neurological disorder seen by neurologists [1]. The World Health Organization (WHO) estimated a prevalence of approximately 50 million people with epilepsy throughout the world, out of which 80% belong to low and middle income countries [2]. With an estimation of 4–10 people per 1,000 harboring epilepsy worldwide, it has posed a major health risk, especially in the developing countries such as India [2]. Epidemiological studies of epilepsy across developing countries are only few. Some studies report significantly higher prevalence rates in the developing countries as compared to developed countries 12.7/1,000 in rural areas and 5.9/1,000 in urban areas [3, 4]. From 1964 onwards, various epidemiology studies in India have reported widely varying prevalence rates ranging between 1.3 and 11.9 per 1,000 population [5–11]. The application of epidemiological data of epilepsy extends beyond prevalence and incidence [7]. Reported treatment gaps from these studies help to understand the gap in medical care better and help in policy making for prevention and management of epilepsy also.

In India, previously conducted epidemiological studies have been in the form of mental health surveys, multicenter hospital studies, and community-based door-to-door studies [12–14]. The present study is undertaken to determine the prevalence rate and sociodemographic profile of patients with epilepsy in the Jaipur district of Rajasthan, situated in North-western India. The study also evaluates the psychological aspects, disease control, associated neurological disorders, and knowledge and attitude of caregivers of patients toward epilepsy.

## Methods

### *Study Area and Sample Population*

We conducted a community-based, cross-sectional observational study in Jaipur district of Rajasthan. The study was approved by the Ethics Committee of Sawai Maan Singh (SMS) Medical College, Jaipur, Rajasthan. Jaipur district has an area of 11,152 km<sup>2</sup> and a total population of 5,252,388 (population density: 471 persons/km<sup>2</sup>).

Sampling: Jaipur district is comprised of 12 blocks in rural area and 70 municipal wards in city area. These were labelled as a Primary Sampling Unit (PSU). A uniform 2-stage sampling was done. To ensure geographical representation, the 12 PSUs were divided into 3 regions in such a way that each region had 4 PSUs. During the first stage of sampling, 2 PSUs from each region (6 PSUs) were selected randomly. During the second stage, 1 com-

munity health center, 1 primary health center, and 1 sub center from all 6 PSUs were selected randomly (Table 1). In addition the largest and the smallest wards of urban city area were also selected as PSUs.

The sample size was 3,42,000. Sample size was calculated by expecting 5.59/1,000 prevalence of epilepsy, and considering 95% confidence level with a sampling error of  $\pm 5$ . It was determined based on finite population correction factor with a designing effect of 1.2.

### *Patient Identification, Data Collection, and Analysis*

Our investigator team comprised of 10 community workers with prior experience in data collection for epidemiological studies, 5 neurologists, and 2 psychologists. A 3 days training was given to community workers by experts from the Departments of Preventive and Social Medicine and Neurology regarding how to obtain data and fill the WHO questionnaire in the community. A house-to-house survey was conducted in the defined area.

Informed consent was obtained from the head of the family. They were enquired about anyone in the family with history of convulsion. Consent was taken from the adult patient and in case of children the head of the family gave the consent. All the suspected cases were interviewed using an adapted pre-designed validated screening questionnaire by the WHO, for the first level screening of active seizure cases (sensitivity 98%, specificity 92%) [15]. Those cases which, on applying the questionnaire, were not found to have epilepsy and those who had had their last seizure episode more than 5 years ago were excluded. The sociodemographic characteristics and details relevant to the disease were obtained. B.G. Prasad socioeconomic classification system was used for assessing socioeconomic status [16].

### *Diagnostic Criteria*

All the cases thus identified with the WHO questionnaire were then motivated to visit the nearest medical facility on a scheduled day and time for neurological assessment. Neurologists of the investigator team assessed them for confirming diagnosis of seizures. Those who had non-epileptic attacks were excluded from the study. Only those who had true seizures were recruited and further evaluated for active epilepsy. A few home visits were also made by the neurologist team for those cases who could not attend the facility even after 2 reminders and it was ensured that all the identified cases were assessed by the neurologists of the team before their final inclusion in the study.

Only cases with active epilepsy were recruited out of all epilepsy identified. They were classified as per the standardized seizure classification by International League against Epilepsy Task Force on Classification and Terminology [17, 18]. Epilepsy was considered to be “active” only if the individual had at least one seizure in the last 5 year period, regardless of antiepileptic treatment. Patients with all types of seizures (generalized, partial, and partial with secondary generalization) were included in the study. Family history of seizures was considered positive when any of the first or second degree relatives were also suffering from epilepsy. Data regarding age, sex, socioeconomic status, educational status, dietary habits, types of seizures, treatment history whether seeking treatment from general physician or neurologists/specialists, drugs received, and associated neurological abnormalities were collected.

**Table 1.** Sample distribution of Jaipur district population used in this study

Regions	Selected tehsils/blocks (PSUs)	Selected health care facilities	Names of selected towns/villages	Population* to be surveyed
North-Eastern Region	Shahpura	CHC	Shahpura (U)	27,902
		PHC	Dhanota (R)	5,078
		Sub-center	Raopura (R)	6,634
	Jamwa-Ramgarh	CHC	Jamwa-Ramgarh (R)	13,286
		PHC	Nayala (R)	7,765
		Sub-center	Papar (R)	2,172
South-Eastern Region	Bassi	CHC	Bassi (R)	21,722
		PHC	Badawa (R)	5,015
		Sub-center	Papadasoli (R)	2,192
	Chaksu	CHC	Chaksu (U)	29,290
		PHC	Padampura (R)	6,167
		Sub-center	Kattawala (R)	3,611
North-Western Region	Govindgadh	CHC	Govindgadh (R)	8,352
		PHC	Khejaroli (R)	16,250
		Sub-center	Nagal Kajoo (R)	8,217
	Dudu	CHC	Dudu (R)	46,601
		PHC	Bobas (R)	4,874
		Sub-center	Asalpura (R)	7,724
Jaipur City Proper	Jaipur City Proper		Ward No. 3 (U)	1,05,287
			Ward No. 40 (U)	16,653

\* Population as estimated by the Office of the Chief Medical Health Officer (2007–2008); rural (R) and urban (U) area as per criterion used in census 2001.

PSUs, primary sampling units; CHC, community health center; PHC, primary health center.

**Table 2.** Prevalence of epilepsy per 1,000 persons (rural and urban)

	Number of cases	Population	Prevalence per 1,000
Overall	380	344,802	1.1
Rural	304	165,660	1.835
Urban	76	179,142	0.424

Psychological aspects of the patients were assessed by using the Global Mental Health Assessment Tool electronic questionnaire [19].

The caregivers of patients were also asked to answer a set of 4 questions designed to cover the knowledge, attitude, and practice (KAP) regarding epilepsy [20]. Caregivers were those family members who were actively involved in patient care, such as parent, child, sibling, or spouse. The questions followed a simple “yes” or “no” answer format and only one response was allowed per patient.

Count data was summarized in the form of proportions. Differences in proportions were analyzed using the chi-square test. Level of significance was kept 95% for all statistical analysis.

## Results

### Prevalence

Trained investigators detected 450 suspected cases of epilepsy, out of which only 395 cases were found to have epilepsy according to the adapted pre-designed validated screening questionnaire by the WHO. In addition, 15 patients were further excluded due to other disorders such as cardiovascular diseases, vertigo, hypoglycemia, tremors, and non-epileptic attack disorders. Finally, only 380 patients were diagnosed with active epilepsy and were included in the study. An overall prevalence of 1.1 patients per 1,000 population was found, 1.8 patients per 1,000 population in rural areas and 0.4 patients per 1,000 population in urban areas (Table 2).

### Profile of cases

A total of 258 were men and 122 were women with a male:female ratio of 2.1:1. Most of the cases were within the age group of 10–20 years. Half of the study population

**Table 3.** Age groups of onset of seizures according to seizure types

Onset year							
Type of seizure	<10 years	10–20 years	20–30 years	30–40 years	50–60 years	>60 years	Total, n (%)
Absence	3 (100.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	3 (0.78)
CPS	3 (33.33)	3 (33.33)	3 (33.33)	0 (0.00)	0 (0.00)	0 (0.00)	9 (2.36)
Generalized	141 (49.47)	78 (27.37)	41 (14.39)	25 (8.77)	0 (0.00)	0 (0.00)	285 (75)
Myoclonic	3 (50.0)	0 (0.00)	3 (50.00)	0 (0.00)	0 (0.00)	0 (0.00)	6 (1.57)
SPS	26 (63.41)	6 (14.63)	3 (7.32)	0 (0.00)	3 (7.32)	3 (7.32)	41 (10.78)
SPSG	24 (66.67)	9 (25.00)	3 (8.33)	0 (0.00)	0 (0.00)	0 (0.00)	36 (9.4)
Total	200 (52.63)	96 (25.26)	53 (13.95)	25 (6.58)	3 (0.79)	3 (0.79)	380 (100.00)

Chi-square value = 140.659; df = 20; *p* value 0.00.

CPS, complex partial seizures; SPS, simple partial seizures; SPSG, simple partial with secondary generalization.

**Table 4.** Age and sex distribution of cases according to type of seizures

Sociodemographic characters	Type of seizure						
	Absence, n (%)	CPS, n (%)	Generalized, n (%)	Myoclonic, n (%)	SPS, n (%)	SPSG, n (%)	Total, n (%)
Gender							
Male	3 (1.16)	9 (3.48)	204 (79.06)	3 (1.16)	22 (8.53)	17 (6.59)	258 (67.89)
Female	0 (0.00)	0 (0.00)	81 (66.36)	3 (2.48)	19 (15.57)	19 (15.57)	122 (32.10)

Chi-square value = 19.201; df = 5; *p* value 0.002.

Age, years							
<10	3 (5.45)	0 (0.00)	33 (60.00)	0 (0.00)	4 (7.27)	15 (27.27)	55 (14.47)
10–20	0 (0.00)	6 (4.41)	96 (70.58)	3 (2.20)	25 (18.38)	6 (4.41)	136 (35.78)
20–30	0 (0.00)	0 (0.00)	65 (81.25)	0 (0.00)	3 (3.75)	12 (15.00)	80 (21.05)
30–40	0 (0.00)	3 (5.36)	50 (89.28)	0 (0.00)	0 (0.00)	3 (5.36)	56 (14.73)
40–50	0 (0.00)	0 (0.00)	28 (82.35)	3 (8.82)	3 (8.82)	0 (0.00)	34 (8.94)
50–60	0 (0.00)	0 (0.00)	13 (100.00)	0 (0.00)	0 (0.00)	0 (0.00)	13 (3.42)
>60	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	6 (100.00)	0 (0.00)	6 (1.57)
Total	3 (0.78)	9 (2.34)	285 (75.00)	6 (1.58)	41 (10.79)	36 (9.47)	380 (100.00) <sup>a</sup>

Chi-square value = 101.962; df = 25; *p* value 0.000.

CPS, complex partial seizures; SPS, simple partial seizures; SPSG, simple partial with secondary generalization.

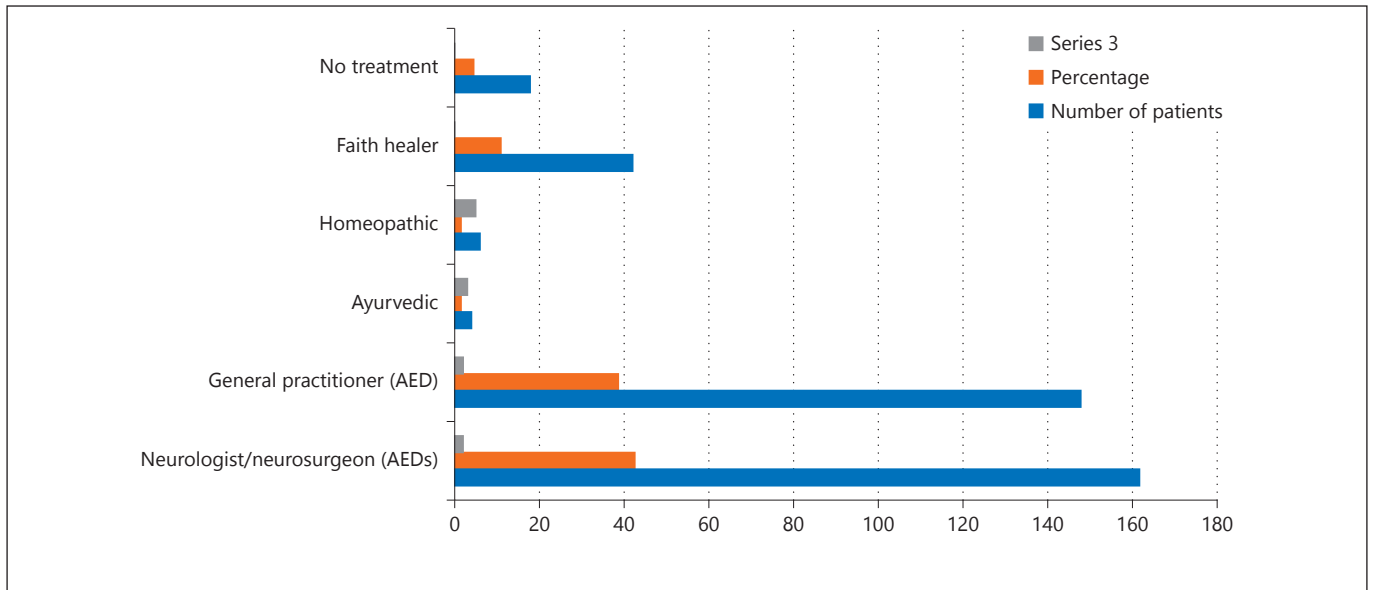
(52%) had seizure onset before 10 years of age, and only a small proportion of patients (1.5%) had seizure onset beyond 50 years of age (Table 3).

Majority of cases (285 of 380, 75%) suffered from generalized seizures followed by 41 patients (11%) suffering from simple partial seizures (SPS) and 36 patients (9.4%) from SPS with secondary generalization. Absence seizures were found in <1% cases only (Table 4).

Majority (336, 88%) cases were vegetarian. Generalized seizures were present in 74.41% of the vegetarian

subjects (250 of 336). Majority of the cases (71%) were from low socioeconomic class (270 of 380; Table 5). A total of 167 (44%) patients were illiterate, 55 (14%) had primary education, 34 (8.9%) had secondary education, and 25 (6.5%) completed graduation. Socioeconomic status significantly associated with different types of seizures ( $\chi^2=28.15$ , df = 6, *p* ≤ 0.001; Table 5).

More than 40% (162) were taking treatment from neurologists, 148 (39%) from general practitioners, 4 (1.0%) from ayurvedic physicians, 6 (1.6%) from homeopathy



**Fig. 1.** Mode of various treatments in patients with epilepsy. AEDs, anti-epileptic drugs.

**Table 5.** Demographic profile of patients with epilepsy

Dietary habits	Absence, n (%)	CPS, n (%)	Generalized, n (%)	Myoclonic, n (%)	SPS, n (%)	SPSG, n (%)	Total, n (%)
Non-vegetarian	0 (0.00)	0 (0.00)	35 (79.54)	0 (0.00)	6 (13.63)	3 (6.82)	44 (11.57)
Vegetarian	3 (0.89)	9 (2.68)	250 (74.40)	6 (1.78)	35 (10.42)	33 (9.82)	336 (88.42)

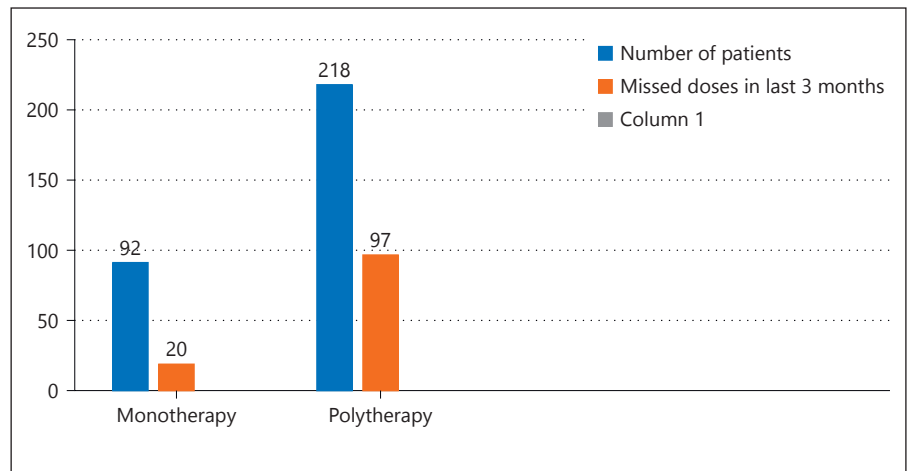
Chi-square value = 3.238; df = 5; p value 0. 789.

Socioeconomic status <sup>a</sup>							
Poor	0 (0.00)	3 (3.19)	77 (81.91)	0 (0.00)	3 (3.19)	11 (11.70)	94 (24.73)
Low	0 (0.00)	3 (1.70)	135 (76.70)	0 (0.00)	32 (18.18)	6 (3.40)	176 (46.31)
Middle	3 (2.88)	3 (2.88)	70 (67.30)	3 (2.88)	6 (5.77)	19 (18.26)	104 (27.36)
Upper middle	0 (0.00)	0 (0.00)	3 (50.00)	3 (50.00)	0 (0.00)	0 (0.00)	6 (1.57)

Chi-square value = 138.693; df = 15; p value 0.000.

Literacy							
Illiterate	0 (0.00)	3 (1.79)	118 (70.65)	3 (1.79)	29 (17.36)	14 (8.38)	167 (43.94)
Just literate	0 (0.00)	0 (0.00)	18 (100.00)	0 (0.00)	0 (0.00)	0 (0.00)	18 (4.73)
Primary	0 (0.00)	6 (10.91)	43 (78.18)	0 (0.00)	0 (0.00)	6 (10.91)	55 (14.47)
Middle	3 (0.78)	0 (0.00)	30 (62.50)	3 (6.25)	9 (18.75)	3 (6.25)	48 (12.63)
Secondary	0 (0.00)	0 (0.00)	34 (100.00)	0 (0.00)	0 (0.00)	0 (0.00)	34 (8.94)
Senior secondary	0 (0.00)	0 (0.00)	3 (33.33)	0 (0.00)	3 (33.33)	3 (33.33)	9 (2.36)
Graduation	0 (0.00)	0 (0.00)	25 (100.00)	0 (0.00)	0 (0.00)	0 (0.00)	25 (6.57)
Post-graduation	0 (0.00)	0 (0.00)	6 (66.66)	0 (0.00)	0 (0.00)	3 (33.33)	9 (2.36)
Total	3 (0.78)	9 (2.34)	285 (75.00)	6 (1.58)	41 (10.79)	36 (9.47)	380 (100.00)

CPS, complex partial seizures; SPS, simple partial seizures; SPSG, simple partial with secondary generalization.



**Fig. 2.** Mode of treatment and patient compliance to therapy.

**Table 6.** Seizure control and delay in treatment

Type of seizure	Number of patients	Good control	Frequency >5/month	Delay in treatment of >1 year
Generalized	285	89	83	70
Absence	3	0	0	0
SPS	41	22	16	3
CPS	9	3	6	3
SPSG	36	11	13	3
Myoclonic	6	3	0	0
<b>Total</b>	<b>380</b>	<b>128<sup>a</sup></b>	<b>118</b>	<b>79<sup>b</sup></b>

<sup>a</sup> Already on treatment with chi-square = 18.538 with 3 degrees of freedom,  $p = 0.000$ .

<sup>b</sup> Delay in treatment of >1 year with chi-square = 31.238 with 6 degrees of freedom,  $p = 0.000$ .

CPS, complex partial seizures; SPS, simple partial seizures; SPSG, simple partial with secondary generalization.

**Table 7.** Neurological abnormalities

Gender	Yes, <i>n</i> (%)	No, <i>n</i> (%)	Total, <i>n</i> (%)
Male	26 (10.08)	232 (89.92)	258 (100.00)
Female	14 (11.48)	108 (88.52)	122 (100.00)
<b>Total</b>	<b>40 (10.53)</b>	<b>340 (89.47)</b>	<b>380 (100.00)</b>

**Table 8.** Psychological assessment of patients

Psychiatrist's clinical diagnosis	Patient, <i>n</i> (%)
Anxiety	132 (34.7)
Depression	122 (32.1)
Other disorders (phobia, mania, OCD, etc.)	36 (9.5)

OCD, obsessive compulsive disorder.

practitioners, 42 (11%) from faith healers/quacks, and 18 (4.8%) were under no treatment (Fig. 1). A total of 310 patients were on antiepileptic medications; out of them, 92 (30%) were on mono-therapy and 218 (70%) were on polytherapy (Fig. 2).

A total of 128 patients had good control, defined as no seizure in the last 2 years, out of which 89 had generalized seizures, 22 had SPS and 11 had partial seizures with secondary generalization. Of these, 118 patients had a his-

tory of more than 5 episodes of seizures per month. A total of 79 patients showed delay in treatment for over 1 year (Table 6).

We identified neurological abnormalities in 40 patients (11%; Table 7). The most common signs observed were hemiparesis, monoparesis, speech and language problems, and mental retardation.

Family history of epilepsy was positive in 18 patients; among them, 5 were first degree relatives.

**Table 9.** Patient responses to selected KAP questions

Questions	Yes response, <i>n</i> (%)	No response, <i>n</i> (%)	Not known, <i>n</i> (%)
Is it curable?	270 (82.06) <sup>a</sup>	59 (17.93)	51 (13.42)
Is it infectious?	25 (8.16)	281 (91.83)	74 (19.47)
Is it the result of past sins?	101 (28.37) <sup>b</sup>	255 (71.62)	24 (6.31)
Would you marry a person with epilepsy?	47 (12.36) <sup>c</sup>	306 (80.52)	27 (7.10)

KAP, knowledge, attitude, and practices.

Anxiety and depression were the most frequent comorbid psychiatric disorders, occurring in approximately 254 patients (67%) whereas other disorders such as phobia, mania, and obsessive compulsive disorder were seen in 36 patients (9.4%; Table 8).

#### *KAPs of care givers*

A total of 59 (18%) said that the disease is incurable, 281 (92%) denied the infectious nature of disease, and 255 (72%) said that the disease was not related to past sins. Majority of people (81%) were reluctant to marry patients affected with epilepsy (Table 9).

## Discussion

The prevalence of active epilepsy in the present study is 1.1 persons per 1,000 population, which is lower than other similar studies [18, 21–23]. Some Indian studies describe a prevalence rate per 1,000 population ranging from 2.5 in Kashmir to 4.9 in Kerala [9, 24]. The criteria for inclusion of cases in our study were very stringent. We included only those patients who were identified with true epilepsy as diagnosed by a team of neurologists, which led to the exclusion of all the cases with non-epileptic disorders, which are very often confused with epilepsy in population-based studies. This could be a reason of lower estimation of prevalence in our study as compared to earlier ones. Also, an overall improvement in health care in Rajasthan and a consequent increased treatment rate as supported by our results further could be a contributing factor.

Socioeconomic status may influence epidemiological trends in epilepsy. A higher prevalence in rural areas (1.8 patients per 1,000 population) compared to urban areas (0.4 patients per 1,000 population) was observed in our study. This indicates the relative impact of low socioeconomic and educational status and relatively lesser approachability to specialist care.

Our study revealed a male preponderance of epilepsy. A male versus female ratio of 2.1:1 was found which is comparable to other similar studies [5, 10, 25]. Lower disease prevalence among women in the sample may be attributed to under diagnosis as a direct consequence of social and cultural issues, which results in decreased social support and increased social isolation, preventing them from visiting healthcare facilities. The social stigma associated with the disease can be a great social barrier for marital prospects, particularly amongst young women, in these parts of the country. Several reports have suggested lower marriage rates among people with epilepsy than in the general population and found that female gender is a major determinant of the Quality of Life (QoL) in patients with epilepsy [26–28]. The higher male ratio may also be attributed to higher incidence of head trauma and alcohol abuse in men thereby increasing the risk of epilepsy.

Age analysis in our study shows a higher prevalence of onset in childhood (52% <10 years of age at seizure onset). Similar trends in epilepsy onset in younger age groups have been cited in the literature [5, 14]. In the developing world, epilepsy onset in childhood is commonly associated with inadequate antenatal and perinatal care. Poor socioeconomic conditions in rural areas, maternal malnutrition, and inadequate care during pregnancy are greatly responsible for antenatal complications such as fetal infections. Despite government efforts to promote maternal and child healthcare, many rural populations continue to conduct childbirth deliveries by untrained dais at home, which often leads to perinatal complications such as hypoxic insult to the brain. Various studies from the developing countries, in contrast to developed nations, have reported higher rates of central nervous system infections such as neurocysticercosis and tuberculosis, which may result from poor sanitation and lack of hygiene, contributing further to the higher burden of epilepsy in younger subjects [29, 30].

Indian studies have reported generalized seizures as the common seizure type [32, 33], our study too revealed similar finding (75%).

In our study, over 50% (167) of the patients were illiterate and only 8% (25) of the patients had completed graduation. Despite the high rate of illiteracy (34% as per 2011 population census) in Rajasthan, data from the KAP survey yielded positive results, with an estimated 82% respondents believing epilepsy to be curable. This finding reflects a major shift in understanding of the disease among the sample population. Yet, the enormous social stigma and compromised QoL faced by patients cannot be marginalized as evidenced by the majority of KAP survey respondents, particularly from upper and middle socioeconomic groups, objecting to marrying a patient with epilepsy (80%). This is similar to other studies where most participants refused to marry patients with epilepsy [9, 31, 34, 35]. Unfortunately, Indian society is pervaded with many fears and misconceptions regarding epilepsy, which are difficult to tackle and need to be directly addressed by persistent educational efforts.

Interestingly, while other Indian studies report an estimated treatment gap of up to 74–78% (Mani and Rangan, 1997), our results indicated a significantly lower treatment gap of 19% with a large number of patients (81%) receiving anti-epileptic drugs. A mere 11% of the patients acceded to quacks/faith healers, while 4.7% were under no treatment. A reduced treatment gap despite the low socioeconomic and high illiteracy status of the patients implies improved acceptability and availability of medical treatment in this area. There are epilepsy clinics in Jaipur district, which are run by NGOs for many years; this probably explains that about 50% of the overall cases and 90% of the urban patients in our study were under the care of neurophysicians/neurosurgeons. There is also increased accessibility to neurology specialists due to improved super-specialty training facilities in Rajasthan over the last decade. However, the seizure frequency records obtained in this study showed that epilepsy was less than optimally controlled in 31% of patients who had more than 5 seizures per month. Taking into account the predominance of polytherapy (70%) in the study population on antiepileptic medications, we postulate that these patients are, in fact, difficult cases that have developed drug resistant epilepsy due to failure in seeking early medical treatment, non-compliance to medications, and/or inability of the treating doctors to follow principles of rational polytherapy. Indeed, a large number of patients (37%) in our study

reported non-compliance to medications, which may be attributable to long treatment duration, multiple dosing schedules within a day, high cost of treatment, unavailability of drugs in remote areas, and irregular follow-up visits to the physicians [29]. Furthermore, a significant proportion of associated neurological abnormalities in cases (31%) could indicate underlying structural lesions in the brain, which might also contribute to the high theorized incidence of difficult-to-treat epilepsy in our study population.

Our data reveal a positive family history of epilepsy in 18 patients, of which one-third were first degree relatives. Our observations are consistent with the findings of Pal et al. [36]. The familial aggregation of disease may be explained by shared genetics and exposure to similar environmental factors [33]. Molecular genetic research into epilepsy requires the identification of familial epilepsy cases. Future studies could include testing for genetic epilepsies cases with familial epilepsies.

Epilepsy is often associated with psychological and behavioral disorders. While there is no consensus surrounding this, it is important to appreciate the chronic and serious nature of the illness and the multifaceted insecurities that notably impair QoL in these patients [26]. Around one-third of the patients in our study suffered from anxiety and 32% from depression, which may stem from obvious concerns regarding the fear of accidents, fear of losing control, and social embarrassment. That is consistent with other studies conducted in varying settings and cultures [37, 38]. Even outside the bounds of the current scenario, the importance of familial counseling and support, adequate multidisciplinary care, and education must be amply stressed. Nonetheless, despite low literacy rates, social inhibitions, and underlying social fragmentation in the country, the attitude of the population as a whole is improving steadily in India.

## Conclusion

We found a strikingly lower prevalence of epilepsy and smaller primary treatment gap in our study population compared to earlier Indian studies. We postulate that this is partly attributable to improved healthcare facilities and improved availability of neurology specialists in the state as rural epilepsy clinics are being run in the district by NGOs for many years. There is overall increased public awareness and a positive shift in attitude toward epilepsy



with a high proportion of patients consulting specialists for epilepsy care. This is due to improved reach of appropriate treatment options as a result of government health policies, rural epilepsy clinics, and advancement in neurology super-specialty training.

Despite this, several issues remain unattended such as comparatively higher epilepsy prevalence in rural areas and lower socioeconomic classes among women and younger subjects.

Recommendations: A hugely populated country like India requires much more widespread reach of health infrastructure and facilities than is currently available within the rural regions. Psychological well-being of patients and family members still continues to be one of the ignored aspects of epilepsy management and should be made an essential part of the comprehensive epilepsy care. It is obvious that there are a host of modifiable factors regarding epilepsy which need to be dealt with effectively. Epilepsy management demands a multidisciplinary approach; and medical, socioeconomic, cultural, and psychological aspects addressed together are essential in providing improved care to these patients.

## References

- 1 Mbuba CK, Ngugi AK, Newton CR, Carter JA: The epilepsy treatment gap in developing countries: a systematic review of the magnitude, causes, and intervention strategies. *Epilepsia* 2008;49:1491–1503.
- 2 WHO: World Health Organization (WHO) Factsheet: Epilepsy 2015 (cited May 1, 2015). <http://www.who.int/mediacentre/factsheets/fs999/en/>.
- 3 Ngugi AK, Kariuki SM, Bottomley C, Kleinschmidt I, Sander JW, Newton CR: Incidence of epilepsy: a systematic review and meta-analysis. *Neurology* 2011;77:1005–1012.
- 4 Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR: Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. *Epilepsia* 2010;51:883–890.
- 5 Sridharan R, Murthy BN: Prevalence and pattern of epilepsy in India. *Epilepsia* 1999;40:631–636.
- 6 Gourie-Devi M, Gururaj G, Satishchandra P, Subbakrishna DK: Prevalence of neurological disorders in Bangalore, India: a community-based study with a comparison between urban and rural areas. *Neuroepidemiology* 2004;23:261–268.
- 7 Sridharan R: Epidemiology of epilepsy. *Curr Sci* 2002;82:664–670.
- 8 Goel D, Agarwal A, Dhanai JS, Semval VD, Mehrotra V, Saxena V, et al: Comprehensive rural epilepsy surveillance programme in Uttarakhand state of India. *Neurol India* 2009;57:355–356.
- 9 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;41:1027–1035.
- 10 Bharucha NE, Bharucha EP, Bharucha AE, Bhise AV, Schoenberg BS: Prevalence of epilepsy in the Parsi community of Bombay. *Epilepsia* 1988;29:111–115.
- 11 Banerjee TK, Ray BK, Das SK, Hazra A, Ghosal MK, Chaudhuri A, et al: A longitudinal study of epilepsy in Kolkata, India. *Epilepsia* 2010;51:2384–2391.
- 12 MK I: Collaborative Study of Severe Mental Morbidity, 1987.
- 13 Tandon P: Epilepsy in India: Report Based on a Multicentric Study on Epidemiology of Epilepsy Carried Out as a PL 480 Funded Project of the ICMR, 1989.
- 14 Bharucha NE: Epidemiology of Epilepsy in India. *Epilepsia* 2003;44(suppl 1):9–11.
- 15 Placencia M, Sander JW, Shorvon SD, Ellison RH, Cascante SM: Validation of a screening questionnaire for the detection of epileptic seizures in epidemiological studies. *Brain* 1992;115(pt 3):783–794.
- 16 Prosad BG: Changes proposed in the social classification of Indian families. *J Indian Med Assoc* 1970;55:198–199.
- 17 Blume WT, Luders HO, Mizrahi E, Tassinari C, van Emde Boas W, Engel J Jr: Glossary of descriptive terminology for ictal semiology: report of the ILAE task force on classification and terminology. *Epilepsia* 2001;42:1212–1218.
- 18 ILAE Commission Report. The epidemiology of the epilepsies: future directions. *International league against epilepsy. Epilepsia* 1997;38:614–618.
- 19 Sharma VK, Lepping P, Cummins AG, Copeland JR, Parhee R, Mottram P: The global mental health assessment tool—primary care version (GMHAT/PC). Development, reliability and validity. *World psychiatry* 2004;3:115–119.
- 20 Krentel A, Fischer P, Manoempil P, Supali T, Servais G, Ruckert P: Using knowledge, attitudes and practice (KAP) surveys on lymphatic filariasis to prepare a health promotion campaign for mass drug administration in Alor District, Indonesia. *Trop Med Int Health* 2006;11:1731–1740.
- 21 Ebrahimi H, Shafa M, Hakimzadeh Asl S: Prevalence of active epilepsy in Kerman, Iran: a house based survey. *Acta Neurol Taiwan* 2012;21:115–124.
- 22 Benamer HT, Grosset DG: A systematic review of the epidemiology of epilepsy in Arab countries. *Epilepsia* 2009;50:2301–2304.

## Acknowledgments

Dr. Rajiv Yadav, Assistant Professor, Department of Preventive and Social Medicine, SMS Medical College for training the social workers and helping with the statistical analysis.

Pfizer Pharmaceuticals for help in editing the article.

## Disclosure Statement

Authors report no conflict of interest.

## Funding

The study was funded by the Neurology Care and Research Society.

## Author Contributions:

A.P.: Conception of the study and editing of manuscript. B.S.: Manuscript preparation and editing. P.D. and V.S.: Manuscript preparation, data collection and analysis, editing. M.R.: Manuscript preparation and data analysis.

- 23 Shakirullah S, Ali N, Khan A, Nabi M: The Prevalence, Incidence and Etiology of Epilepsy. *Int J Clin and Exp Neurol* 2014;2:29–39.
- 24 Koul R, Razdan S, Motta A: Prevalence and pattern of epilepsy (Lath/Mirgi/Laran) in rural Kashmir, India. *Epilepsia* 1988;29:116–122.
- 25 Mani KS: Epidemiology of epilepsy in Karnataka, India. *Neurosci Today* 1997;1:167–174.
- 26 Shetty PH, Naik RK, Saroja A, Punith K: Quality of life in patients with epilepsy in India. *J Neurosci Rural Pract* 2011;2:33–38.
- 27 Ashwin M, Rakesh P, Pricilla RA, Manjunath K, Jacob K, Prasad J. Determinants of quality of life among people with epilepsy attending a secondary care rural hospital in south India. *J Neurosci Rural Pract* 2013;4(suppl 1):S62–S66.
- 28 Myeong-Kyu K: Marital prospects of people with epilepsy among Asians. *Neurol Asia* 2007;12:13–14.
- 29 Carpio A, Hauser WA: Epilepsy in the developing world. *Curr Neurol Neurosci Rep* 2009; 9:319–326.
- 30 Singhi P: Infectious causes of seizures and epilepsy in the developing world. *Dev Med Child Neurol* 2011;53:600–609.
- 31 Danesi MA, Odusote KA, Roberts OO, Adu EO: Social problems of adolescent and adult epileptics in a developing country, as seen in Lagos, Nigeria. *Epilepsia* 1981;22:689–696.
- 32 Gursahani R, Gupta N: The adolescent or adult with generalized tonic-clonic seizures. *Ann Indian Acad Neurol* 2012;15:81–88.
- 33 Pal SK, Sharma K, Prabhakar S, Pathak A: Neuroepidemiology of Epilepsy in Northwest India. *Ann Neurosci* 2010;17:160–166.
- 34 Goel D, Dhanai JS, Agarwal A, Mehlotra V, Saxena V: Knowledge, attitude and practice of epilepsy in Uttarakhand, India. *Ann Indian Acad Neurol* 2011;14:116–119.
- 35 Gourie-Devi M, Singh V, Bala K: Knowledge, attitude and practices among patients of epilepsy attending tertiary hospital in Delhi, India and a review of Indian studies. *Neurol Asia* 2010;15:255–232.
- 36 Pal DK, Pong AW, Chung WK: Genetic evaluation and counseling for epilepsy. *Nat Rev Neurol* 2010;6:445–453.
- 37 Lacey CJ, Salzberg MR, D'Souza WJ: Risk factors for depression in community-treated epilepsy: systematic review. *Epilepsy Behav* 2015;43:1–7.
- 38 Clancy MJ, Clarke MC, Connor DJ, Cannon M, Cotter DR. The prevalence of psychosis in epilepsy; a systematic review and meta-analysis. *BMC Psychiatry* 2014;14:75.