

## Community Awareness and Attitudes towards Epilepsy in Rural Districts of Maharashtra, India: A Questionnaire Survey

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### Abstract

**Introduction:** Epilepsy is a disease associated with myths and taboos, leading to poor understanding and knowledge regarding causes, effects and treatment availability. Public understanding of epilepsy has not been investigated sufficiently so the purpose of this study to understand the opinions of people with epilepsies in 64 rural districts of Maharashtra during Free Epilepsy Detection and Treatment Camps, 2012-13 to 2018-19 to evaluate their knowledge on Epilepsy regarding the impact of diagnosis and their experience of health services.

**Methods:** The survey was conducted in 64 centres at different dates during free epilepsy detection and treatment camps organized by Epilepsy Foundation in association with National Health Mission government of Maharashtra. A total of 12,583 Patients suffering from Epilepsy were interviewed at the camp and a questionnaire survey was conducted. The questionnaires contained 15 questions based on Epilepsy and seizures.

**Results:** For this study, responses from all included patients (N = 12,583) were noted. All the patients were divided into 4 regions of Maharashtra, the overall awareness of epilepsy was 55.14%, and the highest awareness was seen in Vidharbha Region and least in Rest of Maharashtra region 63.04% and 50.05% respectively.

**Conclusion:** People with epilepsy in Maharashtra are not very acquainted with epilepsy and have many erroneous beliefs about the condition. Negative attitudes are pervasive within communities in Maharashtra. The National Health Mission government of Maharashtra should conduct the awareness programs to clarify the purported modes of transmission of epilepsy, available treatment options and care offered during epileptic seizures during community sensitizations in our settings.

**Keywords:** Epilepsy; Awareness; Stigma; Maharashtra; India

### Introduction

Sir Van Gogh, Alfred Nobel, Napoleon Bonaparte, Sir Isaac Newton, Joan of Arc, Julius Caesar, Famous Cricketers Tony Grieg and Jhonty Rhodes suffer from a common disease, known as Epilepsy. Epilepsy was derived from the Ancient Greek word meaning "to seize, possess, or afflict". It is a group of neurological disorders characterized by epileptic seizures.

Epilepsy is characterized by an enduring predisposition to generate seizures and by its neurobiological, cognitive, psychological, and social consequences leads to increase in stigma and social withdrawal. Epilepsy is defined by International League against Epilepsy (ILAE; 1993) as a condition characterized by recurrent (two or more) epileptic seizures, unprovoked by any immediate identified cause [1].

Over 50 million people across the world are suffering from Epilepsy, 80% of the epileptics reside in developing countries, according to the World Health organization (WHO) [2].

One fifth of those suffering from epilepsy are residing in India. Its prevalence is about 1% in our population [3]. The prevalence is greater in the rural (1.9%) compared to urban population (0.6%) [4]. Recent literature states the overall prevalence is 5.50 - 10 per 1000 of People with epilepsy in India [3,5,6]. There's poor evidence on the incidence of epilepsy in India, In the study of Banerjee., *et al.* they suggested an age-standardized incidence rate of 27.3/100,000 per year [7].

Stigma can be defined as the relation "between the differentness of an individual and the devaluation society places on that particular differentness". However, for stigmatization to be consistently effective, the stigmatized person must acquiesce to society's devaluation. Because people with epilepsy have so often internalized society's devaluation of them, they have not felt empowered to change the situation. Indeed, negative stereotypes of persons with epilepsy have been so ingrained in the collective belief system that they have become an accepted part of many people's concept of the disorder [8]. In India and other developing countries it is a known fact that people with epilepsy experience stigma, a mark of infamy, disgrace, or reproach because of the condition [9]. This stigma causes, social and personal expectations of people with epilepsy are often restricted, and this may affect their quality of life even more than the medical condition itself. Epilepsy is associated with mental illness and cognitive disability, hence restrictive rules and regulations are imposed on people with epilepsy [10,11]. This may directly or indirectly result in people suffering from epilepsy to be anxious and to suffer from low self-assurance [12]. Another problem pertaining to the stigma imposed by the society, people suffering from Epilepsy have lower marriage rates and may be unemployed or underemployed due to increase school drop outs rate or increase risk of injury at certain work places. Epilepsy-related stigma not only affects the person but also impacts on family and personal relationships [13,14].

Public understanding of epilepsy has not been investigated sufficiently. Clearly, attitude and knowledge about epilepsy amongst persons suffering from epilepsy and caregivers reflects the real magnitude of social problems against epilepsy. Hence we conducted a survey among patients with epilepsy and caregivers of children suffering from epilepsy.

## **Materials and Methods**

### **Study area**

Maharashtra is a state on the west coast of India which ranks second in the population and third largest state by India in terms of area. It consists of 36 districts in total. According to recent census, the population of Maharashtra is 11,23,72,972 in number. The per capita income is 2,600 \$ as per 2017-18 report. Maharashtra has a literacy rate of 82.34% and 45.22% live in urban regions as per 2011 census.

### **Overview and specific aims**

The study was a survey based study conducted in rural districts of Maharashtra during the Free Epilepsy Detection and treatment camp organised by Epilepsy Foundation in association with National Health mission (Government of Maharashtra). Participants of the sample were selected based on Purposive sampling method of 12,584 participants.

The primary endpoints of this study were to 1. Describe our sample of people with epilepsy and caregivers of children with epilepsy, in terms of demographics; 2. Collect responses of the participants present during the camp and segregate it based on their answers and region they belonged to; and 3. Understand the knowledge of the population regarding awareness of Epilepsy.

### **Study period**

The study was a onetime study. The study took place at 64 different centres in Maharashtra during the Free Epilepsy Detection and Treatment Camp organised by Epilepsy Foundation in association with National Health Mission (Government of Maharashtra). The sample was collected over 6 years duration from 2012-13 to 2018-19.

**Data collection and assessment**

Data was collected by volunteers of the Foundation who were aware about Epilepsy; Causes, Effects, Treatment and side effects. Volunteers were even fluent with the local language of the region being Marathi and/or Hindi, for the better translation and explanation of each question to the participants.

**Survey questions**

There were 15 questions all together in the survey which was translated to Marathi for the participants, each question had three options, a) Yes; b) No; c) No response the question appropriate to the participant was ticked by them.

**Data management and analysis**

Data were entered into a Graph Pad Instat 3.0 version database. Quality control was performed by the investigator by reviewing hard-copy forms for completeness, running validation checks and verifying a minimum of 10% of electronic entries. Descriptive statistics were computed to assess the specific aims.

**Results**

A total of 12,583 participants from 64 centres had given their responses to the 15 questions based questionnaire. We had divided Maharashtra into 4 parts based on the geographical region *i.e.* Vidharbha region ( $n_1 = 3532$ ), Marathwada region ( $n_2 = 3566$ ), Konkan Region ( $n_3 = 936$ ) and Rest of Maharashtra region ( $n_4 = 4549$ ) and samples were collected based on the population size of the respective area (Table 1).

Region	Samples (n)
All Regions	12,583
Rest of Maharashtra	4549
Konkan region	936
Marathwada region	3566
Vidharbha region	3532

**Table 1:** Area wise breakage of survey data.

The responses of the questions in the total sample have been listed below in figure 1 and table 2, 64.32% knew what epilepsy was, 63.07% had knowledge that epilepsy was a disorder of the brain and not related to any mental conditions. Out of the total participants 60.25% had themselves or their relatives consulted a Neurophysician for their seizure disorder, and 62.25% of them were taking medicines regularly as prescribed by the Neurophysician. Only 57.02% of the patients were aware that the treatment of epilepsy was required for long period of time and 53.56% knew that if the seizures were uncontrolled they would have to revisit a Neurophysician. About 50.48% patients knew about the do’s and don’ts related to their condition whereas 53.81% knew about emergency services available at nearby hospitals for a seizure activity.

A low 52.27% of the people knew about the diagnostic tests for Epilepsy, and 45.34% were about the cognitive involvement in epilepsy. About 51.71% were aware that epilepsy can be controlled with medication, 48.71% knew about the different types of seizures. About 48.19% were aware of the myths surrounding epilepsy and 67.99% felt the need to spread awareness about epilepsy. A total of 55.14% of the total population of patients suffering from Epilepsy and their care givers had the knowledge about the condition in the rural districts of Maharashtra.

Sr. No.	Question	Yes (%)	No (%)	NR (%)
1	Do you know what Epilepsy is?	64.32	35.24	0.43
2	Is Epilepsy a disorder of the brain or related to any mental conditions?	63.07	34.86	2.06
3	Have you Consulted any Neurophysician for your seizures?	60.25	38.05	1.69
4	Are you taking medications regularly as prescribed by a Neurophysician?	62.25	35.19	2.55
5	Are you aware that treatment for seizure disorder is for life time?	57.02	40.5	2.46
6	Are you aware that if you continue getting seizures with the current medication you have to change the medication	53.56	42.96	3.46
7	Do you know what to do and what not to do during a seizure disorder?	50.48	46.61	2.9
8	Are you aware regarding the emergency treatment given in your nearby hospital when you get a seizure?	53.81	43.37	2.8
9	Are you aware that EEG and MRI testing have to be done to diagnose a seizure disorder?	52.27	45.65	2.06
10	Are individuals with a seizure disorder cognitively deficit?	45.34	50.02	4.62
11	Are you aware that seizure disorder can be controlled with medication?	51.71	42.34	5.94
12	Are you aware there are different types of seizures?	48.71	47.55	3.72
13	Are you aware that during an occurrence of a seizure, the individual should not be treated with onions and slippers/shoes?	45.23	50.94	3.84
14	It is a myth that seizure disorder is because of some kind of black magic is this true?	51.12	45.52	3.34
15	Do you feel the need to spread awareness about epilepsy?	67.99	27.28	4.71

Table 2: The percentage of response to the survey from all the camps in Maharashtra.

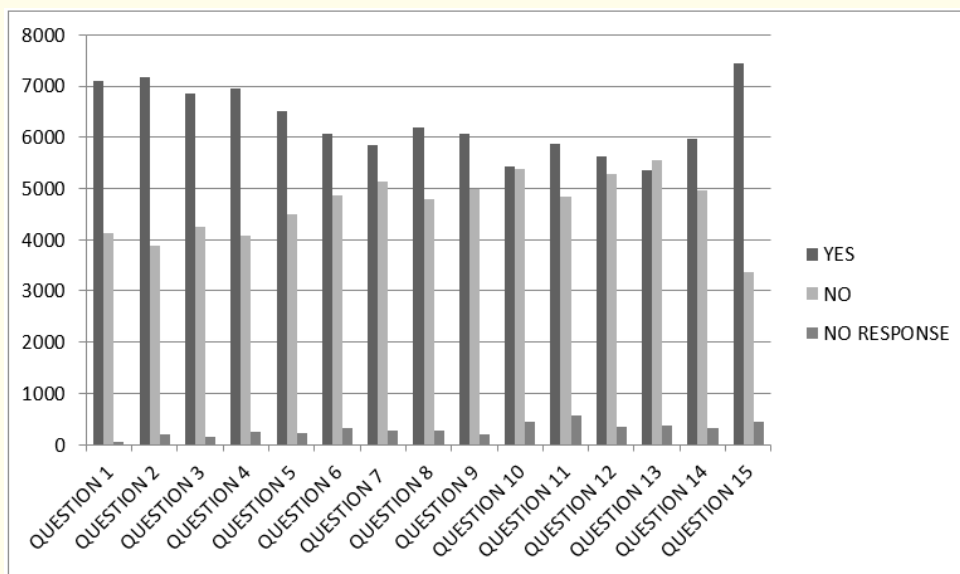


Figure 1: Responses of survey from all districts of Maharashtra (N = 12583).

The responses of the participants from different parts of Maharashtra have been shown in the respective tables and figures below.

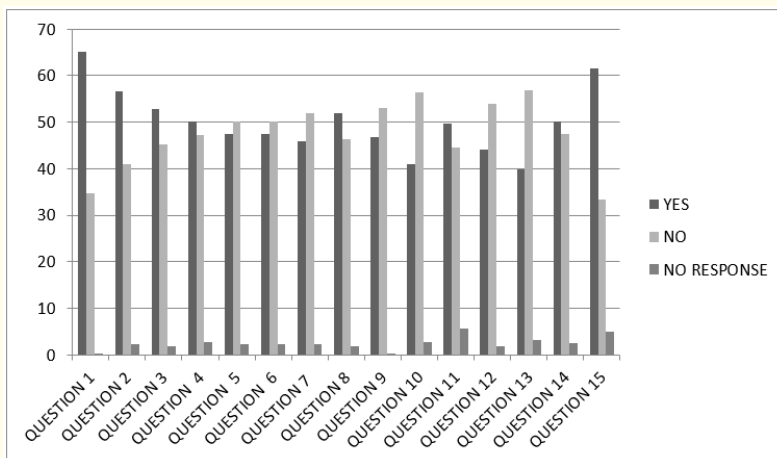


Figure 2: Response of survey from rest of Maharashtra camps (n = 4549).

	Yes	No	No response
Question 1	65.22	34.62	0.16
Question 2	56.72	41.03	2.25
Question 3	52.89	45.3	1.8
Question 4	50.04	47.15	2.81
Question 5	47.42	50.24	2.34
Question 6	47.42	50.24	2.34
Question 7	45.92	51.92	2.16
Question 8	51.87	46.24	1.71
Question 9	46.77	52.96	0.27
Question 10	40.89	56.36	2.75
Question 11	49.81	44.55	5.64
Question 12	44.19	53.92	1.89
Question 13	39.87	56.86	3.27
Question 14	50.12	47.49	2.39
Question 15	61.63	33.39	4.98

Table 3: The percentage to response to the survey in the camps held in rest of Maharashtra region.

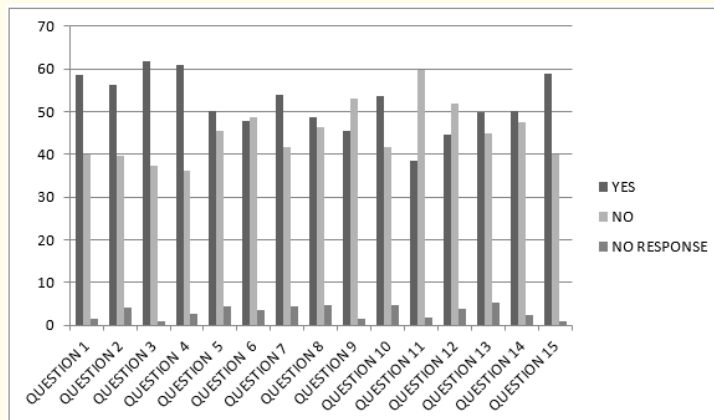


Figure 3: Response of survey from Konkan camps (n = 936).

	Yes (%)	No (%)	No response (%)
Question 1	58.59	39.92	1.49
Question 2	56.24	39.55	4.21
Question 3	61.92	37.21	0.87
Question 4	61.03	36.21	2.76
Question 5	50.08	45.48	4.44
Question 6	47.71	48.8	3.49
Question 7	53.89	41.65	4.46
Question 8	48.71	46.47	4.82
Question 9	45.48	53.13	1.39
Question 10	53.63	41.77	4.6
Question 11	38.44	59.71	1.85
Question 12	44.48	51.86	3.66
Question 13	49.95	44.77	5.28
Question 14	50.16	47.43	2.41
Question 15	59.01	40.04	0.95

Table 4: Percentage response of survey from Konkan (n = 936).

	Yes	No	No response
Question 1	57.01	42.02	0.97
Question 2	69.29	28.59	2.21
Question 3	64.09	34.27	1.64
Question 4	71.05	26.25	2.7
Question 5	64.97	32.68	2.35
Question 6	55.06	40.44	4.5
Question 7	52.29	43.92	3.79
Question 8	52.55	43.74	3.71
Question 9	54.09	42.95	2.96
Question 10	46.69	48.50	4.81
Question 11	52.68	44.09	3.23
Question 12	53.43	42.11	4.46
Question 13	42.73	53.74	3.53
Question 14	52.15	44.31	3.54
Question 15	73.56	22.46	3.98

Table 5: Percentage response of survey from Marathwada camps (n = 3566).

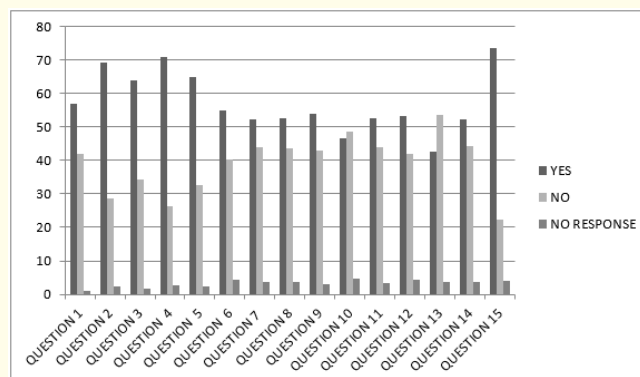


Figure 4: Response of survey from Marathwada region (n = 3566).

	Yes (%)	No (%)	No response (%)
Question 1	71.06	28.89	0.05
Question 2	71.87	27.26	0.97
Question 3	69.30	28.93	1.77
Question 4	73.55	24.64	1.81
Question 5	68.35	30.22	1.43
Question 6	59.59	38.34	2.07
Question 7	57.40	39.88	2.12
Question 8	60.24	37.01	2.75
Question 9	61.61	36.19	2.2
Question 10	53.92	42.80	3.28
Question 11	57.49	36.02	6.49
Question 12	54.05	42.67	3.28
Question 13	56.07	41.90	2.03
Question 14	52.16	46.28	1.56
Question 15	78.96	18.50	2.54

Table 6: Percentage response of survey from Vidharbha camps (n = 3566).

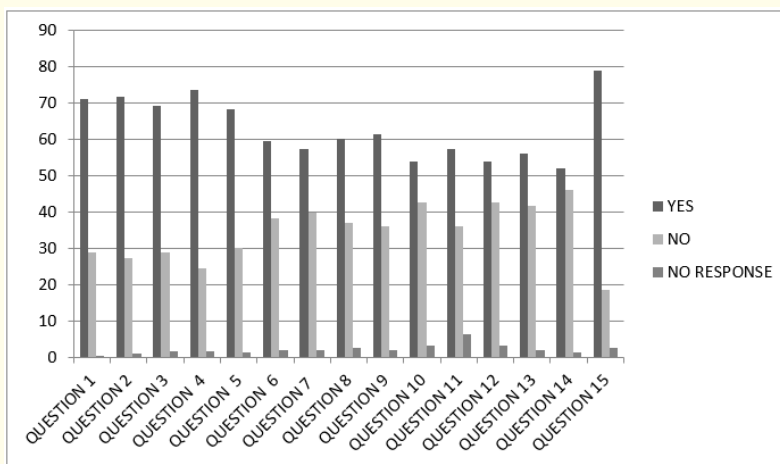


Figure 5: Response of survey from Vidarbha region (n = 3532).

The overall awareness of epilepsy was seen better in Vidharbha Region (63.04%), followed by Marathwada (57.44%) and Konkan Region (51.95%) and the least were seen in the rest of Maharashtra region (50.05%). The region with the highest awareness was Gondia district (68.24%) in Vidharbha region and least in the Beed district (41.83%) of Marathwada region.

**Discussion**

Knowledge and attitude of patients towards a certain disease are important as they determine the outcome especially for those diseases requiring lifelong therapy. The present survey-based study had been specially planned and designed to examine the knowledge and attitudes toward epilepsy, in a Rural Districts of Maharashtra, India. Among the rural area participants, only 64.32% knew about

disease and only 57.02% of participants were aware that the treatment of epilepsy was required for a long period of time. Only 53.56% of participants knew that if the seizures were uncontrolled they would have to revisit a Neurophysician. This proves that the rural participants lack actual knowledge about epilepsy.

This study also demonstrated that only 52.27% of the people knew about the diagnostic tests available for epilepsy, and only 45.34% of participants were aware about the cognitive involvement in epilepsy. Only 55.14% of the total population suffering from Epilepsy and their care givers had the knowledge about the condition in the rural districts of Maharashtra.

Previous studies showed that knowledge about epilepsy was found to be significantly associated with the duration of with epilepsy and months on follow-up. This might indicate that lack of adequate education by the health professionals concerning the disease before the commencement of therapy. Studies carried out in developed and developing countries investigated public awareness and attitudes toward epilepsy reported that people living within different parts of the world and even those sufferers have poor knowledge regarding the cause, nature, and treatment of epilepsy. Further, Saengsuwan., *et al.* reported a weak and negative correlation between knowledge and attitude toward epilepsy.

Regarding the attitudes towards epilepsy, stigma and social ostracism were evident. Various non-scientific conceptualizations of epilepsy are responsible for the sociocultural stigma and resultant discrimination against persons with epilepsy. Increasing knowledge in the general population regarding the nature of epilepsy, possible treatments available, and nearby health center facilities offering needed medical care might also help. Finally improving the treatment and care of people suffering from epilepsy by providing readily available medical treatments could improve seizure control, reduce epilepsy burden and improve quality of life among those with epilepsy [15-18].

## Conclusion

The knowledge and attitude towards epilepsy is relatively low even if with increased literacy, technology, and communication devices. There is a need for awareness and informational campaigns to help change the perception of epilepsy and maximize the chance that people with epilepsy will present for treatment. The National Health Mission government of Maharashtra should conduct the awareness programs to clarify the purported modes of transmission of epilepsy, available treatment options and care offered during epileptic seizures during community sensitizations in our settings.

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## Conflict of Interest

No conflict of interest.

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