

Demographic Study on Social Stigma in Epileptic
Patient, Their Quality of Life and Doctor's Perception
About Medication

By

Jahnvi Sinha

*Dissertation submitted for the partial fulfillment of the
MBA Pharmaceutical Management*

Academic year, 2017-2019



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TO WHOMSOEVER MAY CONCERN

This is to certify that **Jahnvi Sinha** student of MBA Pharmaceutical Management from The IIHMR University, Jaipur has undergone internship training at **Eisai Pharmaceuticals Pvt. Ltd.** from 4th Feb 2019 to 4th May 2019.

The Candidate has successfully carried out the study on **Demographic Study on social stigma in epileptic patients, their quality of life and doctor's perception about medication** assigned to her during internship training and her approach to the study has been sincere, scientific and analytical.

The Internship is in fulfillment of the course requirements.

I wish her all success in all her future endeavors.

Dr. Sandeep Narula
Dean, School of pharmaceutical Management
The IIHMR University, Jaipur

Dr. Abhishek Dadhich
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TO WHOMSOEVER IT MAY CONCERN

This is to certify that **Ms. Jahnavi Sinha** student of the IIHMR University (2017- 2019 batch) has completed her dissertation with us from 11th February 2019 to 10th May 2019. She undertook **“Demographic study on social stigma in epileptic patient, their quality of life and doctor’s perception about medication”** as her dissertation project & successfully completed the requirement of the project.

She comes across as a committed, sincere & diligent person who has a strong drive & zeal for learning.

We wish her the very best for her future endeavors.

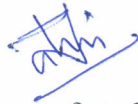
Yours faithfully,
For Eisai Pharmaceuticals India Pvt. Ltd.,

A handwritten signature in black ink, followed by the date '17-5-19' written below it.

Authorized Signatory,
Human Resources

CERTIFICATE BY SCHOLAR

This is to certify that all ethical issues have been considered while collecting data for my dissertation titled **Demographic study on social stigma in epileptic patient, their quality of life and doctor's perception about medication** and submitted by **Ms Jahnavi Sinha Enrolment No 0120** under the supervision of **Dr. Abhishek Dadhich** for award of MBA in Hospital and Health of the University carried out during the period from 04/02/2019 to 08/05/2019 embodies my original work and has not formed the basis for the award of any degree, diploma associate ship, fellowship, titles in this or any other institute or other similar institution of higher learning.



Signature of student

Contents

Definition of Epilepsy	7
Causes	7
Treatment gaps in epilepsy	7
Abstract	9
Background	10
Methodology	10
Survey Instrument	11
Study participants	11
Sampling	11
Sample size	11
Inclusion Criteria of patients	11
Exclusion Criteria of patients	11
Data Analysis and Interpretation-	12
(i) The reasons of discontinuing the epilepsy medication among respondents	13
(ii) Types of social stigma among respondents	14
(iii) Various types of seizure among respondents	15
(iv) The current status of respondents with epilepsy	16
(v) Molecules preferred the most for the epilepsy treatment by doctors	17
Fig. 5 Molecules preferred for epilepsy treatment by doctors	17
(vi) Patients are on multiple medications for epilepsy treatment	18
(vii) Diseased patient's rate in OPD for treatment	19
Interpretation-	19
Appendix	21
Questionnaire (For Patient related)	21
Questionnaire (For Doctor's)	22
Discussions	23
Findings and conclusion	23
References	24

DISSERTATION TOPIC

Demographic study on social stigma in epileptic patient, their quality of life and doctor's perception about medication

Definition of Epilepsy

Epilepsy is a chronic disorder, the hallmark of which is recurrent, unprovoked seizures. A person is diagnosed with epilepsy if they have two unprovoked seizures (or one unprovoked seizure with the likelihood of more) that were not caused by some known and reversible medical condition like alcohol withdrawal or extremely low blood sugar.

The seizures in epilepsy may be related to a brain injury or a family tendency, but often the cause is completely unknown. The word "epilepsy" does not indicate anything about the cause of the person's seizures or their severity.

Many people with epilepsy have more than one type of seizure and may have other symptoms of neurological problems as well. Sometimes EEG (electroencephalogram) testing, clinical history, family history, and outlook are similar among a group of people with epilepsy. In these situations, their condition can be defined as a specific epilepsy syndrome.

Causes

Epilepsy is not contagious. The most common type of epilepsy, which affects 6 out of 10 people with the disease, is called idiopathic epilepsy and has no identifiable cause.

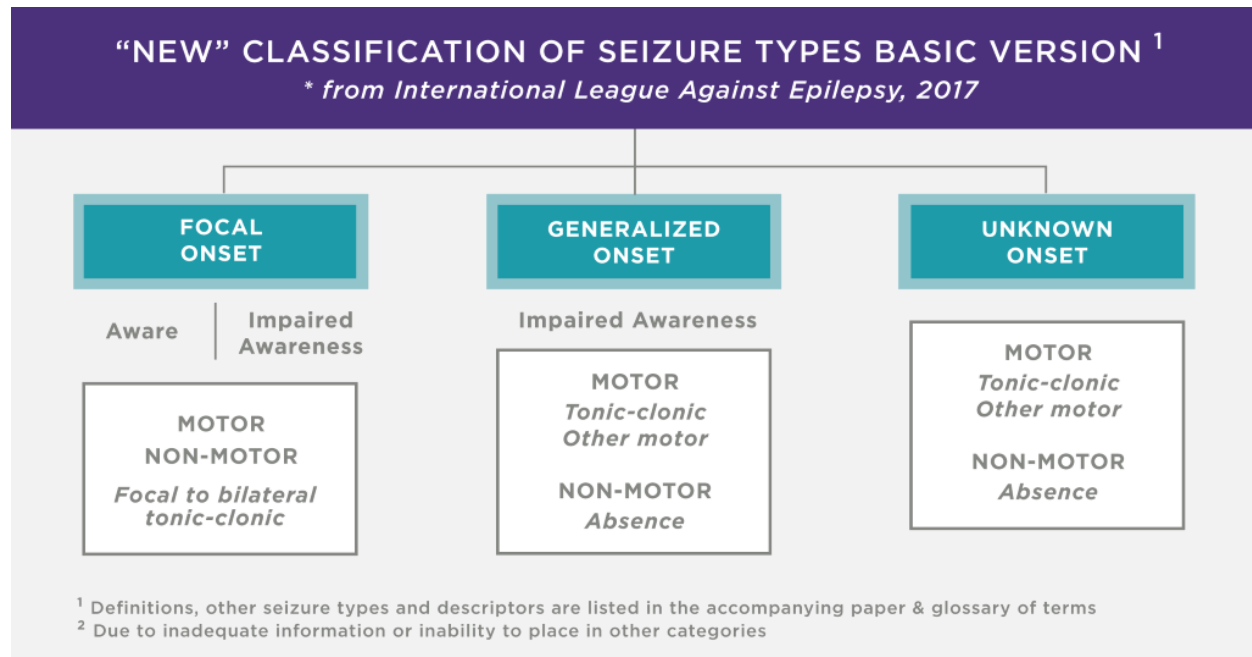
Epilepsy with a known cause is called secondary epilepsy, or symptomatic epilepsy. The causes of secondary (or symptomatic) epilepsy include:

- Brain damage from prenatal or perinatal causes (e.g. a loss of oxygen or trauma during birth, low birth weight);
- Congenital abnormalities or genetic conditions with associated brain malformations;
- A severe head injury;
- A stroke that restricts the amount of oxygen to the brain;
- An infection of the brain such as meningitis, encephalitis, neurocysticercosis,
- Certain genetic syndromes; and
- A brain tumour.

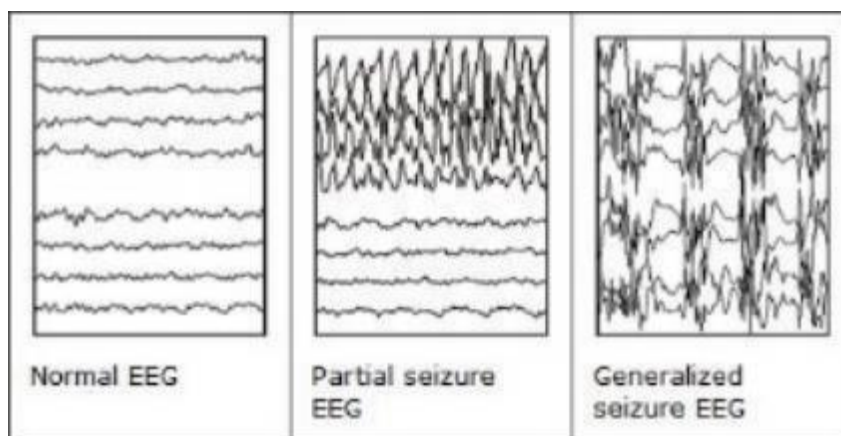
Treatment gaps in epilepsy

The epilepsy treatment gap, defined as the proportion of people with epilepsy who require treatment but do not receive it, has been proposed as a useful parameter to compare access to and quality of care for epilepsy patients across populations.

Prior anecdotal and descriptive estimates suggest a treatment gap of more than 80% in many low-income countries, yet one recent systematic review and meta-analysis suggest that the treatment gap in developing countries is as low as 56%.



The diagram shows, the normal seizure, partial seizure EEG, generalized seizure EEG graphs, which defines the movements of fluctuation of waves.



Abstract

Epilepsy is a chronic disease that affects the brain for all ages. More than 70% of population with epilepsy covers low and middle income areas of India. The epilepsy patients and their families live with social stigma and discrimination from the society. The study is about the patients conditions and their problems. A different hospitals survey on neurologic disease epilepsy on more than 250 patients in Bombay. Patients include age group between 05 years to more than 50. Pediatric children, women, students, geriatric groups were the sample population for the study. In the screening questionnaire result shown is, the most common seizure is partial seizure in patients. Epilepsy is a global healthcare issue, which is affecting upto 70 million people worldwide, which impacts their quality of life. The reasons for increasing epilepsy among people is anxiety and depression and physical and psychological disturbance burden, which is impacting negative on our lives. People with epilepsy having high risk of SUDEP (Sudden unexpected death in Epilepsy patients). It also reduces life expectancy, lowers employment rate, and adversely impacts caregivers quality of life. High treatment gap is the common problem in epilepsy patients in treating epilepsy in low and middle income countries. Many AEDs like Levitracetam, Lamotrigine, Lacosamide and Clobazam are the first choices of molecules by the doctors. The study is performed and seen that what are the conditions, where patients suffer to have a medication and treatment and having social stigmatization.

Objectives:

To study the demographic study of epilepsy in patients and social stigma in patients.

Objective 2- To assess the reasons of discontinuation of medication in patients.

Objective 3- To know about the expectation of patients from the current treatment.

Research Methodology:

Study Type: Cross-sectional study

Study Duration: Three Months (5th February to April)

Tool used: Tableau, Ms-Excel

Data Collection method: The primary and secondary data was used. Primary data for doctor and patient opinion and secondary data for prevalence data.

Primary data was collected from the respondent through observation or direct communications.

Source of primary data:

- A. Field observations
- B. Questionnaire

Source of Secondary data: From ILAE, AES, WHO and other journals from PubMed and others.

Background

The aim of the study is to understand the patient knowledge, their necessity, treatment pattern, and how the patients is taking cure and treatment of their health. In a survey of patients, covered some working area hospitals of Bombay, Maharashtra. Including various mixed areas of low-income families and middle-income families and also high-income families. Covered major hospitals for the survey, example Nair Hospital, JJ hospital, Bombay Hospital, some doctor's clinic, where number of patients for CNS problems were more. Many patients found for epilepsy, many were new patients, many of them are for follow-ups, many of them are of too serious conditions.

The overall study is done on patients and doctors, to match the ideology of both patients and doctor's perception about the medication, their seizure freedom, seizure frequency reduction, treating patterns of various doctors, patients curable. All the healthcare departments believe in old treatment pattern, for epilepsy the older golden molecules are still the best molecules of the doctors as a first line choice of doctor's example Valproic acid, Carbamazepine, and some newer medication such as Levetiracetam, Lamotrigine.

Methodology

Methodology used for the survey is random cross-sectional questionnaire survey on epileptic patients. The survey is done randomly on OPD patients in sitting areas of various hospitals. The questionnaire is delivered to patients and their families. Out of 300 patients survey, 252 patients responded completely to fill the data.

The questionnaire was distributed to the patients above age group of 18, and below 18 is filled by the patient's family member. The cross – sectional study was conducted among patients from Feb 21st 2019 to 31st April at various State Government Hospitals in Bombay. The purpose of the study was informed to patients before survey, and assured them for the privacy survey.

Survey Instrument

The study questionnaire was composed of questions in two parts-

- a) Related to the patient's disease profile.
- b) Related to the patient's treatment profile.

Also, the survey is undergone with doctor's, discussed about patient's seizure freedom, treating patterns.

Study participants

The study was conducted under the OPD patients in various hospitals such as JJ Hospital, Nair Hospital, Bombay Hospital under 300 patients covering all these areas and some clinics of working area.

Patients in IPD was excluded because of the patient's serious health.

Sampling

Purposive sampling was used.

Sample size

The sample size was taken randomly in OPD area, where old patients, adults were the part of the study. The study was performed under 300 patients who were there for the diagnosis.

Inclusion Criteria of patients

- a) Patients who came to OPD for the treatment
- b) Age above 18 years
- c) Both sex (males and females)
- d) Those who filled the complete questionnaire

Exclusion Criteria of patients

- a) Having critical treatments, patients of IPD, patients for operations.
- b) Having significant psychiatric problem
- c) Mental patients
- d) Age less than 18 years

Data Analysis and Interpretation-

Demographic details of 252 patients with epilepsy

Parameter	N%
Age in years	
<25	27
25-40	149
40-60	76
Gender	
Male	166
Female	86
Socioeconomic status	
Low <3000	187
Middle >3000	113
Occupation	
Employed	152
Housewife	23
Student	93
Marital Status	
Married	243
Unmarried	57
Religion	
Hindu	221
Muslim	79

(i) The reasons of discontinuing the epilepsy medication among respondents

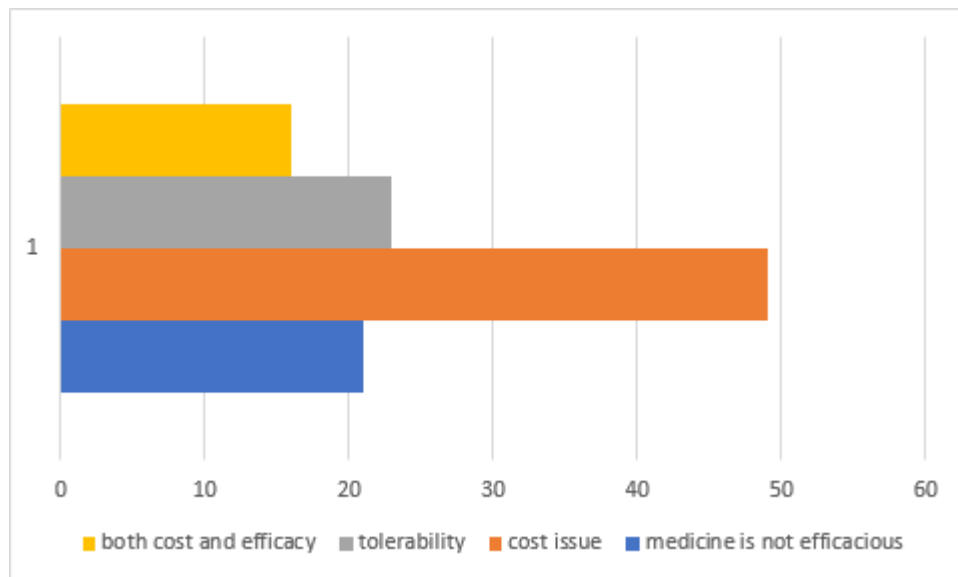


Fig.1. The reasons of discontinuing the epilepsy medication

Interpretation-

The survey was done under 252 patients, in the State and Government hospitals. India is middle-class income country. The reasons of discontinuing the epilepsy medication are cost, efficacy and tolerability, and the majority of discontinuation issues in patients is the pricing issue. In India, majority of patients require low cost treatment, patients in government hospitals, who go for further treatment, having very low financial income.

From fig.1, The study shows the patients conditions, in which patient is discontinuing the medication. Out of 109 patients, 49 patients were having costs issue of epileptic medication, means 44.9%, approx. 50% patients having the treatment cost issue. Income wise patients of low income populations are affected more for the better treatment than the normal family groups.

(ii) Types of social stigma among respondents

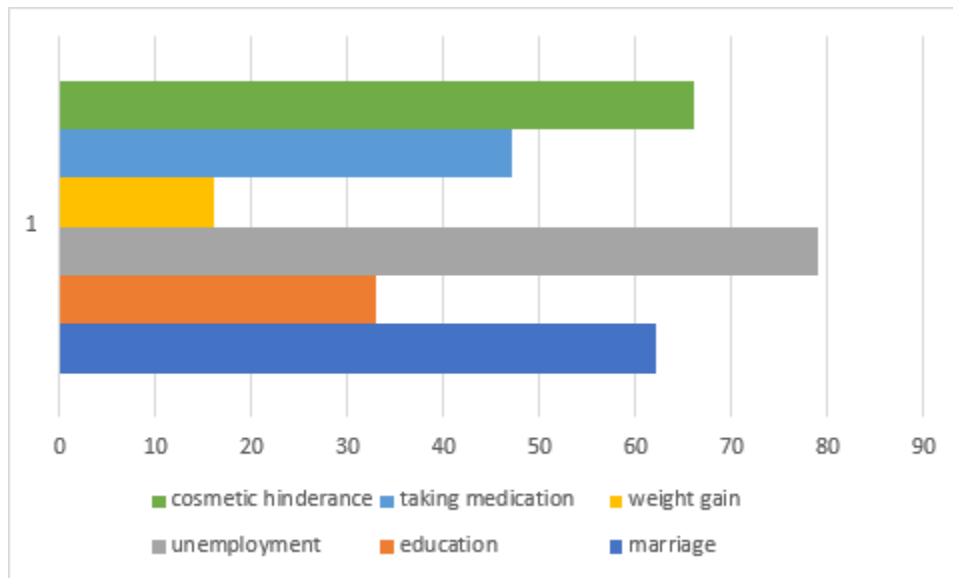


Fig. 2 Various type of social stigma in patients.

Interpretation-

The survey is done on 252 patients by questionnaire, patients having social stigma like good education, unemployment, cosmetic hindrance, weight gain, taking epileptic medication, and marriage. Out of 252 patients, 79 patients informed that they are unemployed, including which 33 were females and 46 were males. Unemployment is the biggest social stigma in patient, they are afraid of that they will not get a job. Out of 252 patients, 66 patients are having fear of cosmetic hindrance, including rashes, dryness, or any skin infection.

MARRIAGE	24.60%
GOOD JOB	31.34%
EDUCATION	13.09%
TAKING MEDICATION	18.65%
PHYSIOLOGICAL CHANGES	26.19%

Patients are depressive, lost, and having fear. They are worried about the risk factors of epilepsy such as sudden death, paralysis, also the patients who are having AIDS.

(iii) Various types of seizure among respondents

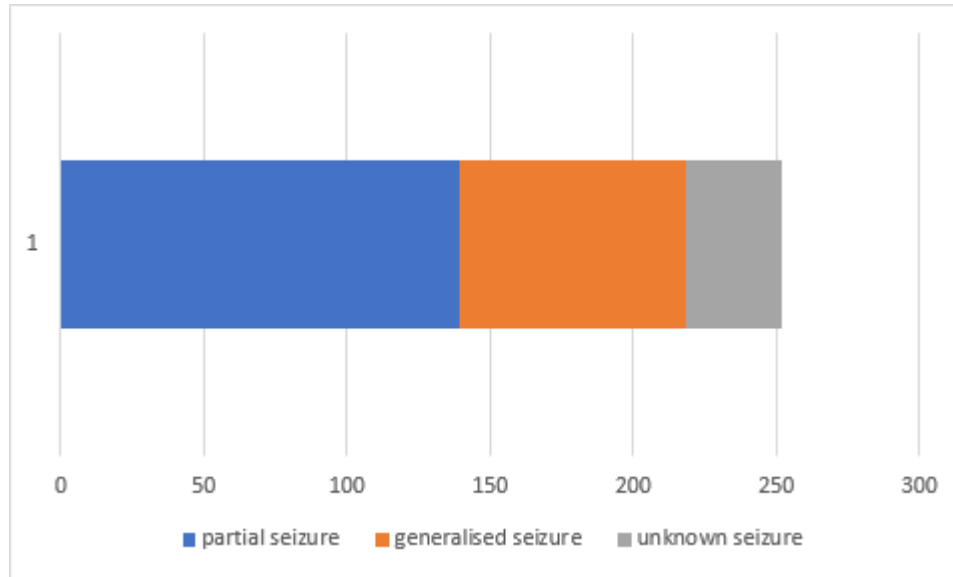


Fig. 3 Various types of seizures in patients

Interpretation-

The study is observed under the patients who are newly registered for the epilepsy treatment in the OPD hospital. Fig. 3 study shows the data of 252 patients, having Partial seizures of both simple partial and complex partial seizures. There are many reasons which causes seizures in the brain, like genetic, head injury, trauma, neuro surgery, alcohol consumptions, AIDS. In this study, patient of 252 data is collected and 55.1 % shown partial epilepsy, generalized seizure of 31.3%, unknown seizure of 13% found. Partial seizure is the most common seizure among patients.

(iv) The current status of respondents with epilepsy

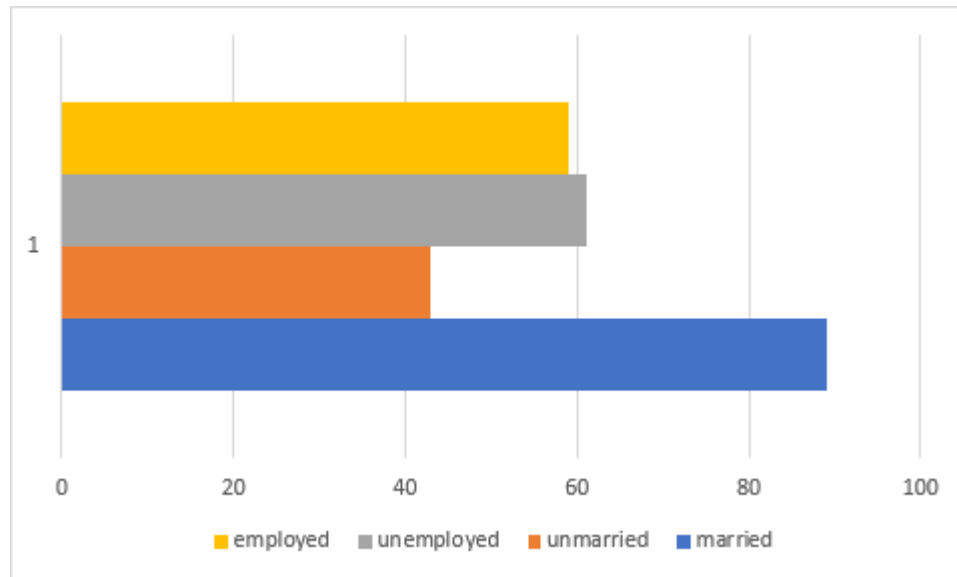


Fig. 4 The current status of patients with epilepsy

Interpretation-

The study completed under 252 patients, the data is collected based on the patient current status, like unemployment, employment, married, unmarried.

The study is performed on age more than 20, students are not included in this study. The patients which were under the study found that, married are found 35.3%, Unmarried are 17.06%, Unemployed is found 24.2%, and Employed is found 24.2%.

(v)Molecules prefer the most for the epilepsy treatment by doctors

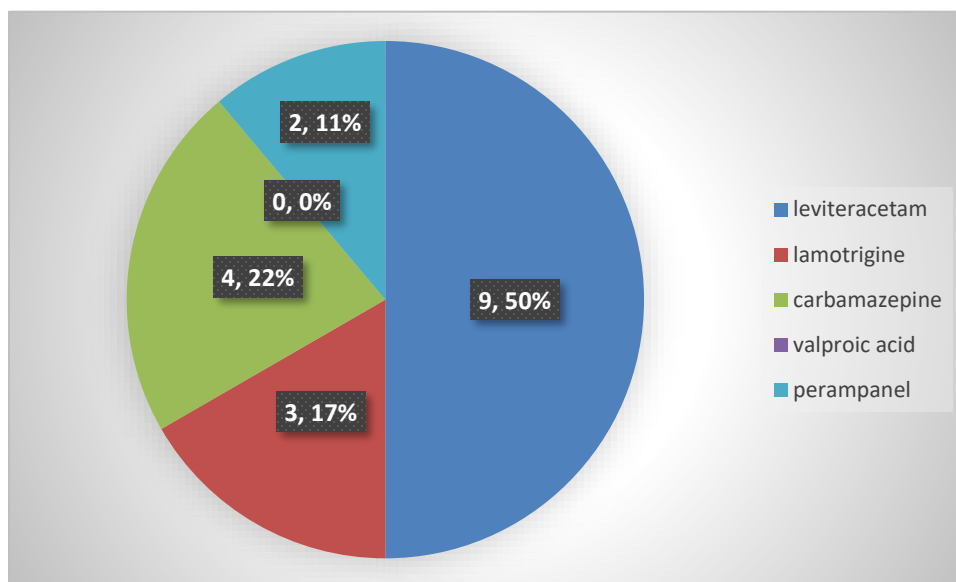


Fig. 5 Molecules prefer for epilepsy treatment by doctors

Interpretation-

In most of the hospitals, discussed doctors about the various molecules, used for epilepsy treatment, most of the doctors prefer Levetiracetam because of the first line of choice of molecule. Fig. 5 shows in study that more than 50% doctors prescribe Levetiracetam to their patients. They believe that literature reviews shown the better efficacy and it's a molecule which can be given to any patient in all type of seizure. Many other golden medicines like Valproic acid, Carbamazepine are also currently prescribed by the doctors. Second preferable molecule is Carbamazepine among doctors.

(vi) Patients are on multiple medications for epilepsy treatment

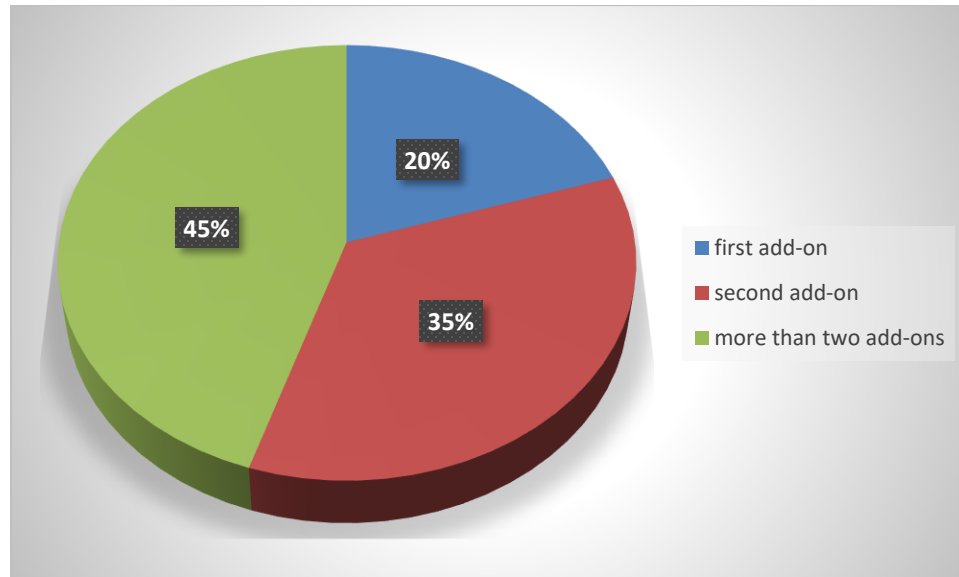


Fig. 6 Patients are on multiple medications for epilepsy treatment

Interpretation-

Fig. 6 study was on the multiple medication for the epilepsy control shows that patients who are already on the treatment from a longer time, are on more than two add-ons, because patients are still not get controlled on first add-on only. Patients are on Levetiracetam+ carbamazepine, Levetiracetam+Perampanel+Carbamazepine.

The patients who are already on medication and taking medicines from more than six months to one year, are under more than three add-ons. The reason behind of having more add-ons are as follows-

- Patients skip the medication.
- Patients is not controlled on the medication, still occurring seizures.
- Patients with epilepsy transforming from partial to generalized seizure.

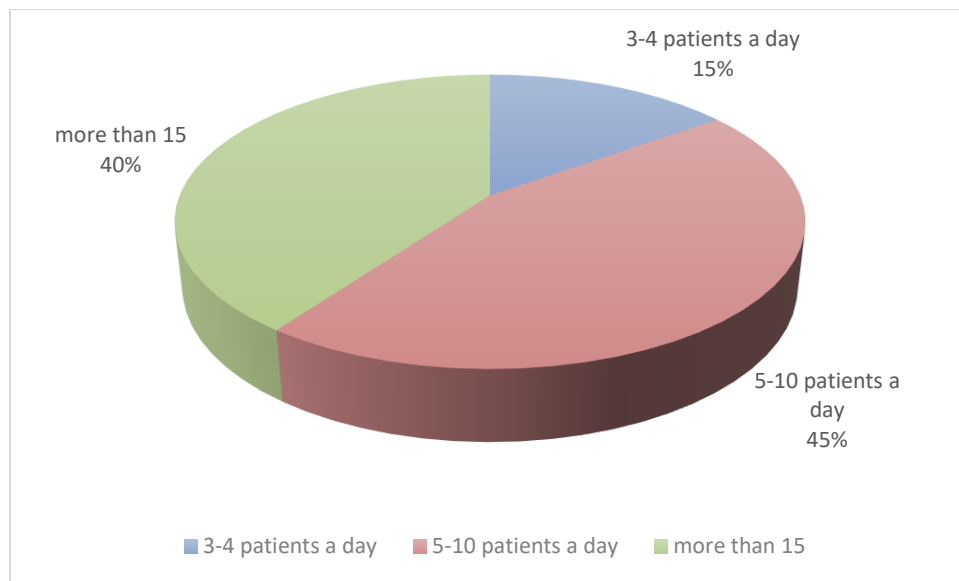
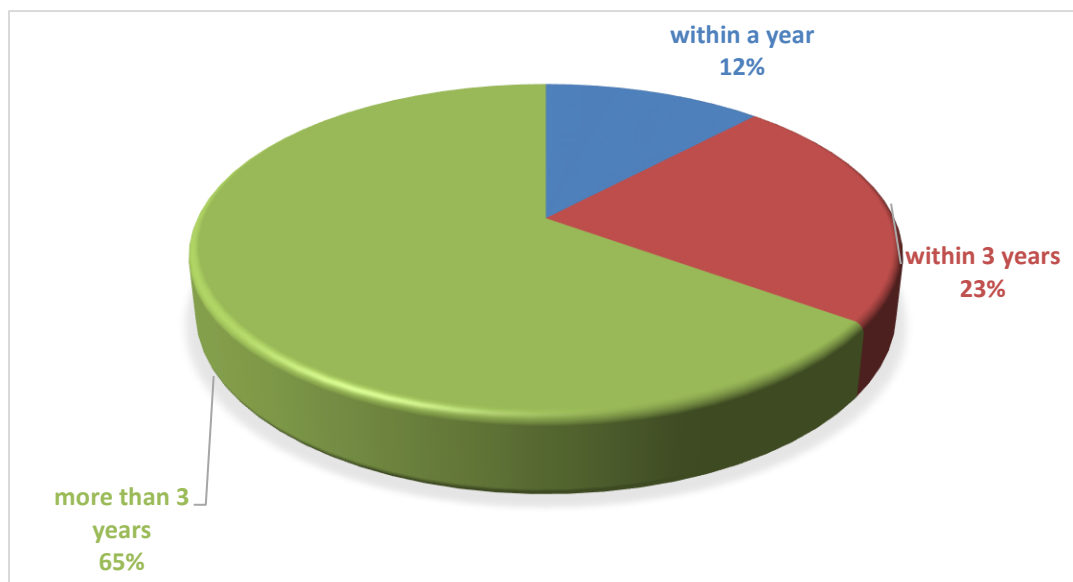
(vii) Diseased patient's rate in OPD for treatment**Interpretation-**

Fig. 7 shows the data of chances of seizures occurring in newly patients, who were coming for the treatment of epilepsy for the first time in their life history. Doctors undergone through survey Per Epilepsy specialist, Neuro Physician treats more than 10 patients per day. In a OPD are of hospital, more than 40 patients undergone for the treatments, which includes new patients, follow-up patients.

(viii) Patient's get seizure free after the treatment

Interpretation-

As per the questionnaire survey, Fig.8 shows the study about only 12% patients get free within a year, which is having very less seizure in a year. And 23% patients may get seizure free within three years, and 65% patients get free in more than three years. Also doctors informed, if the patients are on the medication, they undergo on the continuous check-ups and follow-ups, they didn't discontinue the treatment, not missed the doses. **(The above data is collected only of those patients who was having very less seizure).**



Appendix

Questionnaire (For Patient related)

- 1) What are the reasons of discontinuing the epilepsy medication?
 - a. Medicine is not efficacious
 - b. Can't afford
 - c. Tolerability issue
- 2) What type of social stigma a patient is having? (if any)
 - a. Unemployment
 - b. Marriage
 - c. Education
 - d. Weight gain
 - e. Cosmetic hindrance
 - f. Taking medication for epilepsy
- 3) What is the current status of patient?
 - a. Employed
 - b. Unemployed
 - c. Married
 - d. Unmarried
- 4) What is the age of patient?
 - a. Less than 12
 - b. Between 12-20
 - c. Between 20- 30
 - d. More than 30
- 5) Faced any side effects?
 - a. Rashes
 - b. Behavioral changes
 - c. Dizziness
 - d. Blurred vision
 - e. Headache
 - f. Nausea and Vomiting
- 6) What is your expectation from the treatment?
 - a. Cheap rate medication
 - b. Efficacy and faster resultant
 - c. Tolerable
 - d. Easy dose titration

7) How much is the control over your attacks?

- a. Very good control
- b. Fairly good control
- c. Little control
- d. No control

8) Are you aware of Epilepsy?

- a) Yes
- b) No
- c) May be

Questionnaire (For Doctor's)

1) Which molecule you prefer the most for the epilepsy treatment?

- A. Levetiracetam
- B. Lamotrigine
- C. Valproic acid
- D. Carbamazepine
- E. Perampanel

2) Most of the patients are on?

- A. Add-on
- B. Second add-on treatment
- C. More than 3 add-ons

3) How many patient's do you treat in a day?

- a. 3-4
- b. 5-15
- c. more than that

4) How many patient's get seizure free after the treatment in how many years (seizure freedom)?

- a. Within a year
- b. Within 3 years
- c. More than 3 years

Discussions

Demographic study was performed among patients having non-communicable disease epilepsy. Cross-sectional concluded on patients and majority of patients with epilepsy were males, study performed among 166 males and 86 were females. Study shown various reasons of having epilepsy, patients are having history of brain injury, alcohol consumptions, genetic complications, depression, confused memory. In female patients, the reason of epilepsy found the loss of memory, electrolyte imbalance and poor sleep, dehydration, loss of hearing, hormonal imbalance. Age group of more than 18 shown the discrimination, education, marriage and new job as their stigma. From the patient's data, patients themselves desires of a new job. 31.33% respondents notified for unemployment.

Findings and conclusion

It can be concluded that majority of patients was belonging to low-income family, having income <3000. There were significant results found in the study. The study was performed on middle and low income groups.

- The aim of the objective is to know about the patients Quality of life, having social stigma in patients, and their treating options.
- Patients having social stigma like marriage, jobs, taking medication, good education, prejudice, in which getting job is the most frequently answered as 31.33%
- Patients are on control, taking medications for a longer time, patients are not discontinuing the medication, and shows seizure freedom in a longer duration of 3-4 years medication which is only 23%.
- Doctor's believe in old medication drugs like Levetiracetam, Carbamazepine, not prescribing Perampanel. More than 50% Levetiracetam is used by doctors.

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Confronting the stigma of epilepsy

Sanjeev V. Thomas and Aparna Nair¹

Stigma and Level of Dysfunction among Individual with Epilepsy

Prem Prakash, Vinod Kumar Shinha , Pradeep Kumar

Epilepsy in India I: Epidemiology and public health

Senthil Amudhan, Gopalkrishna Gururaj, and Parthasarathy Satishchandra¹

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

Panagariya A.^a · Sharma B.^b · Dubey P.^c · Satija V.^d · Rathore M.^e

Overcoming the stigma of epilepsy in Asia from ILAE

A scoping review of health-related stigma outcomes for high-burden diseases in low- and middle-income countries

Jeremy C. Kane Sarah M. Murray, Ellen M. H. Mitchell, Jura L. Augustinavicius, Sara Causevic and Stefan D. Baral