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

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Abstract

- 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 stigma.

- **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.
- To know about doctor's perception about epilepsy treatment pattern in patients.

- **<u>Research Methodology:</u>**
- **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 will be used. Primary data for doctor and patient opinion and secondary data for prevalence data.
- **Primary data will be collected from the respondent through observation or direct communications.**
- **Source of primary data:**
- Field observations
- Survey Questionnaire
- **Source of Secondary data:** From ILAE, AES, WHO and other journals from PubMed and others.

Study participants

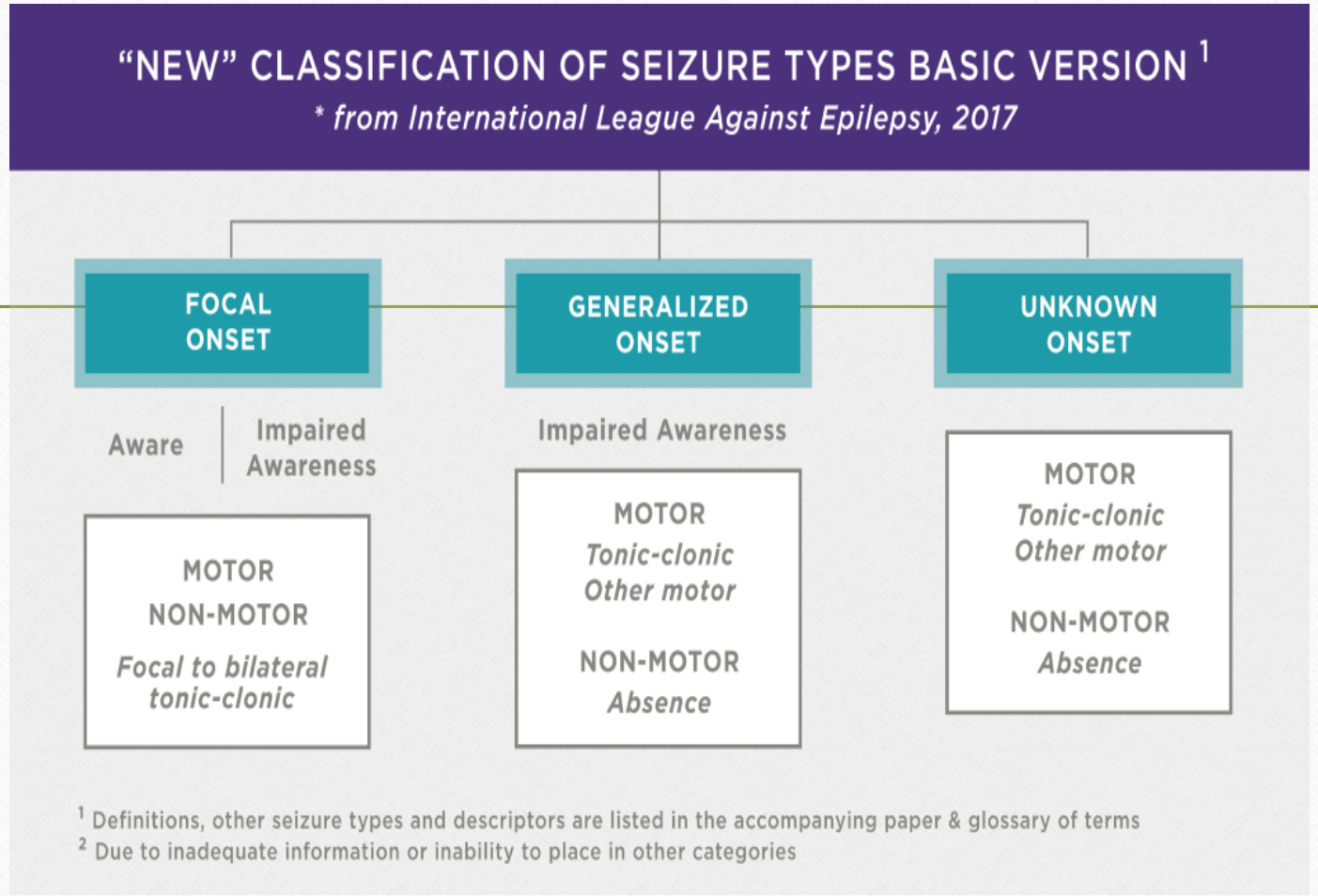
- The study was conducted under the OPD patients in various hospitals such as JJ Hospital, Nair Hospital, Bombay Hospital under 300 patients covering all these areas and some clinics of working area.
- Patients in IPD was excluded because of the patient's serious health.
- Hospital Doctors- 20 doctors

Background of the study

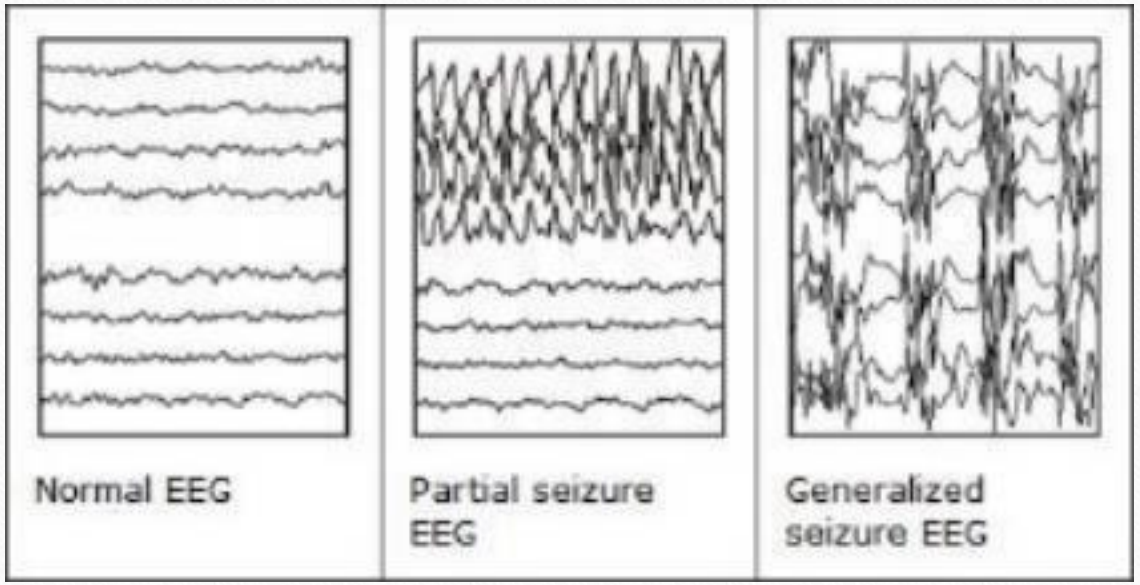
- The aim of the study is to understand the patient knowledge, their necessity, treatment pattern, and how the patients is taking cure and treatment of their health. In a survey of patients, covered some working area hospitals of Bombay, Maharashtra. Including various mixed areas of low-income families 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.


"NEW" CLASSIFICATION OF SEIZURE TYPES BASIC VERSION [1]
* from International League Against Epilepsy, 2017
FOCAL ONSET
GENERALIZED ONSET
UNKNOWN ONSET
Aware
Impaired Awareness
MOTOR
NON-MOTOR
Focal to bilateral tonic-clonic
Impaired Awareness
MOTOR
Tonic-clonic
Other motor
NON-MOTOR
Absence
MOTOR
Tonic-clonic
Other motor
NON-MOTOR
Absence
[1] Definitions, other seizure types and descriptors are listed in the accompanying paper & glossary of terms
[2] Due to inadequate information or inability to place in other categories

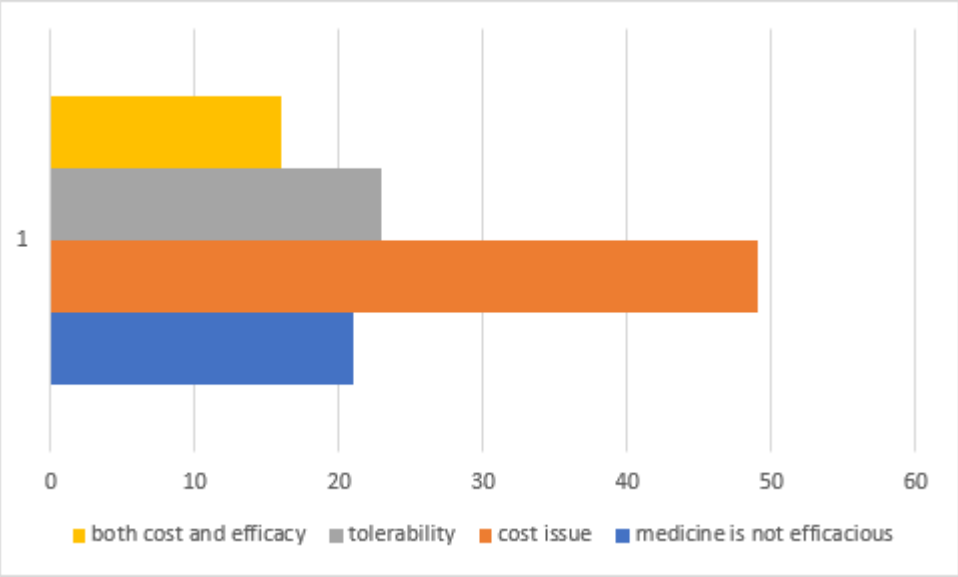
The diagram shows, the normal seizure, partial seizure EEG, generalized seizure EEG graphs, which defines the movements of fluctuation of waves.



(Source- ILAE Guidelines)

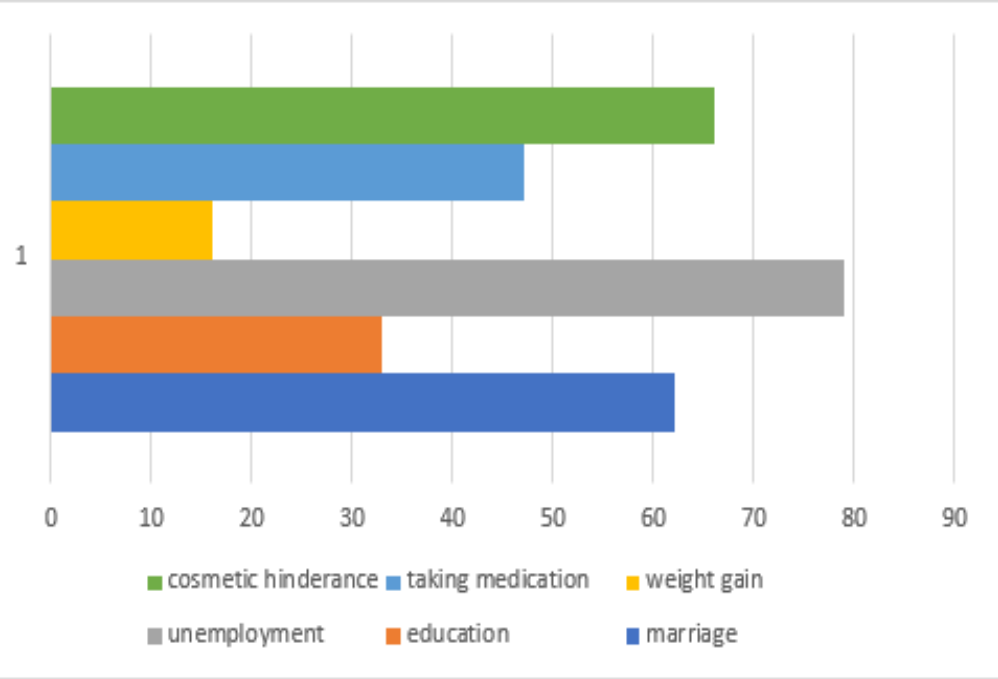
Conclusions and Interpretations-

Question 1 What are the reasons of discontinuing the epilepsy medication?



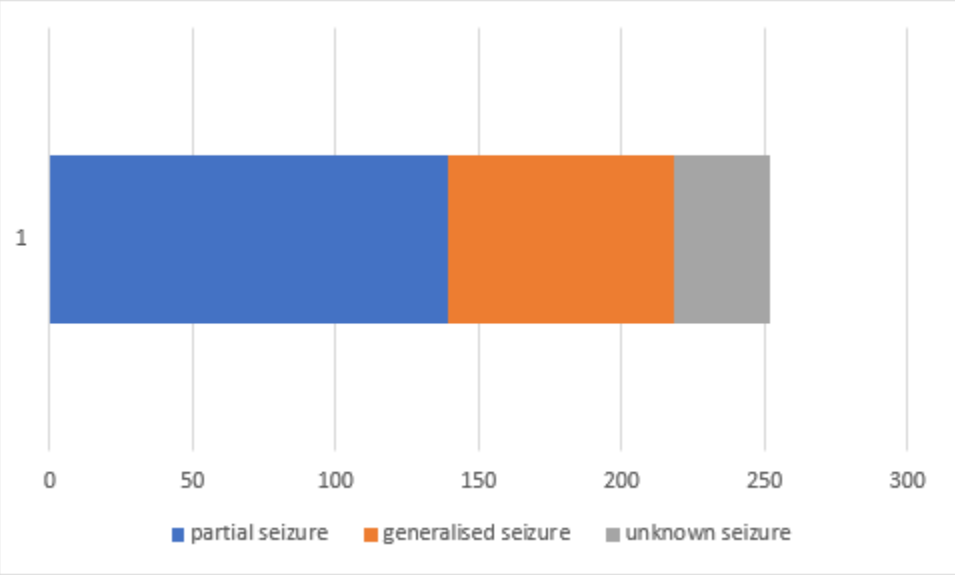
- 44.9% patients shown a result of the reason of discontinuing of medicine.
- In government and State Hospitals, patients are of very less income <3000 Rs.

Question 2- What type of social stigma a patient is having? (if any)



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

Question 3 What type seizure does patients have?

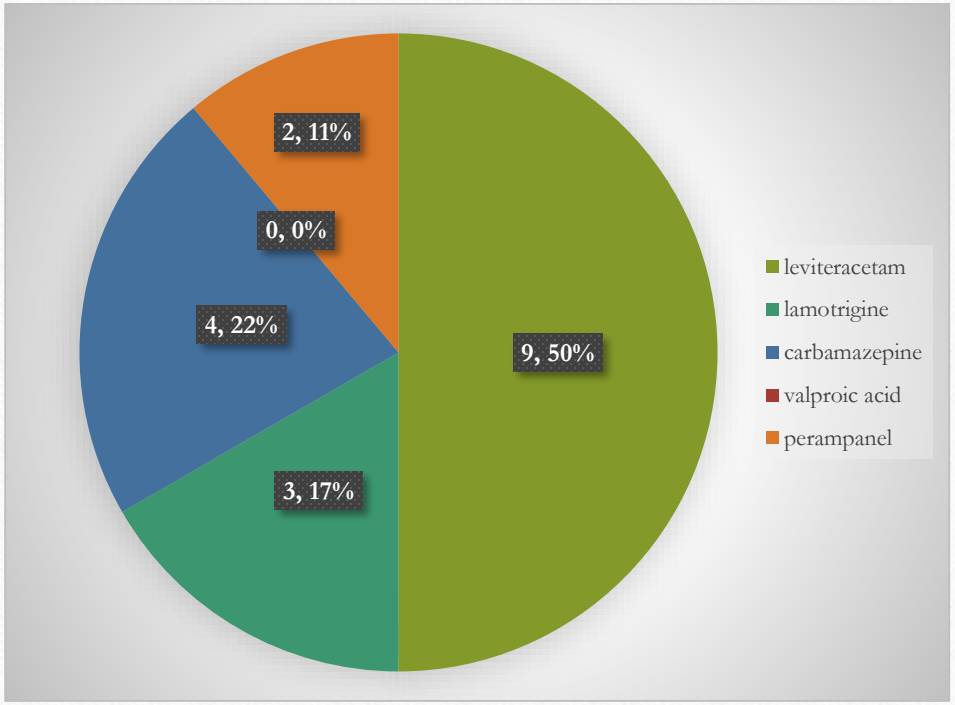


- 55% patients shown partial type of seizure.
- Reasons of having partial epilepsy are-
- Confused memory.
- Head Injury.
- Unknown reasons.
- Surgeries
- Taking alcohol

Demographic details of 252 patients with epilepsy in Mumbai

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

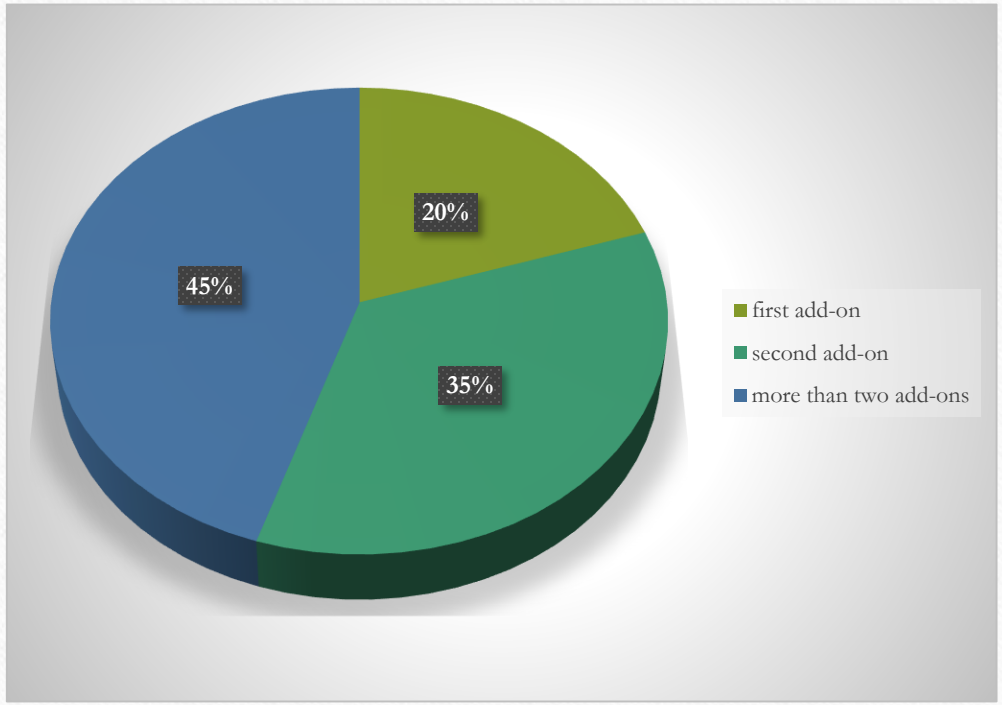
Question- Which molecule you prefer the most for the epilepsy treatment?



Doctors always prefer Levetiracetam, instead of other molecules like Lamotrigine, carbamazepine, etc.

Levetiracetam is used in combination with other medications to treat certain types of seizures in adults and children with epilepsy.

Question- Most of the patients are on?

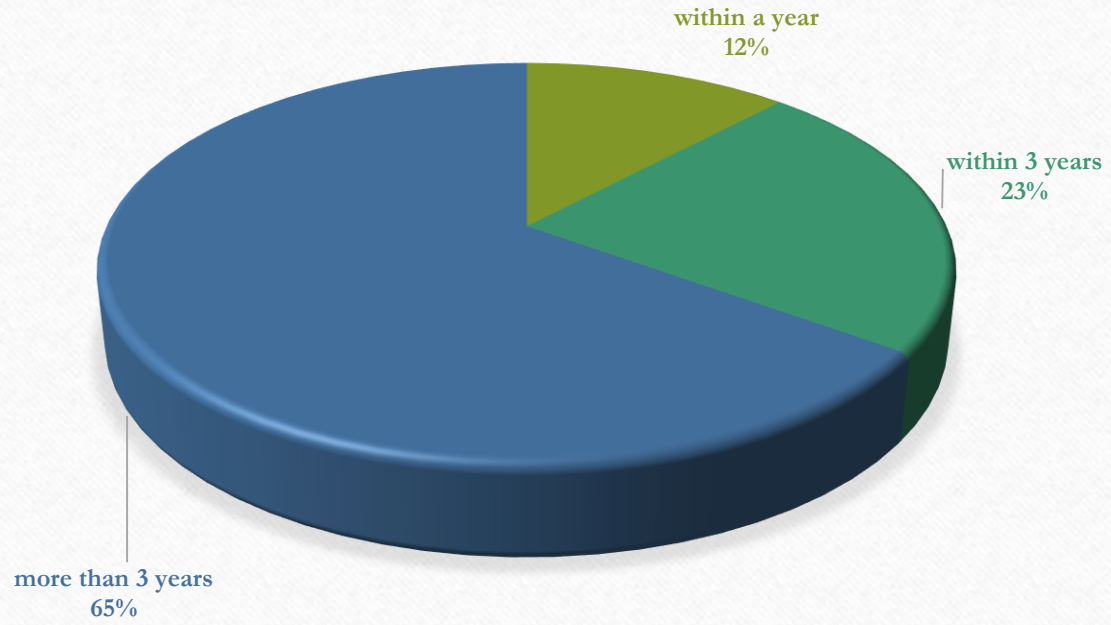


Patients are on more than five medicines, and patients having control on seizures.

45% patients are on more than two medications.

But, patients are not completely seizure free.

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



Conclusion

- 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.

References

- Epidemiology of Epilepsy in India N.E. Bharucha First published: 06 February 2003 **https://doi.org/10.1046/j.1528-1157.44.s.1.5.x**
- Prevalence and Pattern of Epilepsy in India R. Sridharan B. N. Murthy First published: 05 November 2007 **https://doi.org/10.1111/j.1528-1157.1999.tb05566.x**
- Prevalence, Knowledge, Attitude, and Practice of Epilepsy in Kerala, South India K. Radhakrishnan J. D. Pandian T. Santhoshkumar S. V. Thomas T. D. Deetha P. S. Sarma D. Jayachandran E. Mohamed First published: 02 August 2005 **https://doi.org/10.1111/j.1528-1157.2000.tb00289.x**
- **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 Satishchandra[1]

  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. KaneSarah M. Murray,Ellen M. H. Mitchell, Jura L. Augustinavicius, Sara Causevic and Stefan D. Baral