"A Population-based study of stigma on the quality of life of people with epilepsy, as well as the perceptions of physicians regarding drug therapy for these patient"

Dissertation Submitted to

The IIHMR University, Jaipur

for the partial fulfilment for the award of the degree of Master of Business Administration

(MBA)

In

Pharmaceutical Management

By

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2021-23

DECLARATION BY STUDENT

I hereby declare that this dissertation titled “A Population-based study of stigma on the quality of life of people with epilepsy, as well as the perceptions of physicians regarding drug therapy for these patients” Is the Bonafede record of my original research work. I declare that no other university or institution has requested it for the purpose of awarding a degree or diploma. The text properly acknowledges information derived from other authors' published or unpublished works.

NIRAJ KUMAR

Date – 6th June 2023

ACKNOWLEDGEMENT

I feel favored and thankful in making a move to offer my thanks to many individuals who have added to the culmination of this task.

First and foremost, I want to say thank you. the Almighty God, whose grace has been throughout the dissertation work.

I am very much thankful to Dr. SAURABH BANERJEE (Dean, School of Pharmaceutical management, IIHMR University, Jaipur) for allowing us to carry out the dissertation project. I would like to convey my sincere appreciation to my industry mentor. (Marketing Manager at MSN Laboratories) for providing continuous support, guidance, motivating mentorship and sharing a vision and providing me the opportunity for bringing the initial ideas to accomplish the dissertation project.

I want to express my gratitude to the entire faculty of the School of Pharmaceutical Management and non-teaching staff for their generous help.

I am also thankful to the Doctors and the Pharmacists & patients for their cooperation in filling out the form and collection of responses thereby providing me a friendly environment which made me very comfortable to carry out the project further.

I am immensely thankful and express my gratitude to be the student of (IIHMR) Indian Institute of Health Management and Research, Jaipur for facilitating the conduction of this project work. Last but not least I might want to thank my folks and companions for their steady help.

NIRAJ KUMAR

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INTRODUCTION

Epilepsy is a neurological sickness described by seizures and unexplained seizures. Epilepsy is a transitory weakness of cerebrum capability because of irregularities in the mind. Changes in behavior, cognition, emotion, movement, or a combination of these can be signs of these effects. People of all ages, from infants to adults, are affected by epilepsy. It can be brought on by a variety of things, such as a genetic predisposition, damage to the brain, infection, poor growth, or an unidentified cause.

Seizures can run in seriousness and term from gentle aggravations to delayed seizures or bunches. Side effects that happen during a seizure rely upon the piece of the cerebrum that is impacted and may incorporate seizures, loss of cognizance, muscle fits, vibes of torment, or other strange ways of behaving.

The conclusion of epilepsy typically incorporates an exhaustive assessment of the patient's clinical history, side effects, actual tests, and frequently extra tests like an electroencephalogram (EEG) to record cerebrum work, mind imaging, and blood tests to decide the reason.

Epilepsy is typically treated with antiepileptic medications to control seizures. Occasionally, additional treatments like diet (like the ketogenic diet) or surgery. The objective of treatment is to lessen the recurrence and seriousness of seizures while limiting incidental effects and further developing the individual's general personal satisfaction.

It is vital to recall that epilepsy is an intricate issue, and the administration of epilepsy requires a multidisciplinary approach with specialists, epileptologists, and different specialists to give quality consideration and backing to epilepsy patients.

Analyses of Epilepsy Drug Market: -

Market Epilepsy medication sales are expected to rise. at a CAGR of 3.5 percent from 2022 to 2027.

The Coronavirus episode fundamentally affects the market's development as a few nervous system science exercises, like clinical preparation and examination, were upset because of the pandemic. The eruption impacted the epilepsy patients as well as unfairly impacted the epilepsy treatment centers. Due to the risk of SARS-CoV-2 transmission from one patient to another or from a medical provider to a patient, patients were severely restricted in their access to medical facilities. Concerns about patient-to-patient transmission also reduced standby admissions in areas with widespread COVID-19 infection or in hospitals with COVID-19 inpatients. For instance, according to an article dispersed in Walk 2020 named "Epilepsy and Covid: A survey of 212 pediatric neurologists from 49 nations, "Updated Evidence and Narrative Review," found that in-person outpatient visits decreased while telemedicine usage increased during the pandemic. Consequently, COVID-19 has a significant impact on the initial expansion of the market. Nevertheless, inferable from the resumption of a couple of elective philosophy and operations across the globe, the market is supposed to gather some forward speed all through the following couple of years.

The rise in new medication endorsements over the past few years and the rising incidence of epilepsy worldwide are significant factors contributing to the growth of the epilepsy drugs market. According to the World Health Organization's February 2022 update, epilepsy is one of the most common neurological conditions worldwide and affects approximately 50 million people. An expected 49 individuals with epilepsy are analyzed for each 100,000 individuals in top level salary countries every year. This number can reach as high as 139 for every 100,000 in low-and center pay countries. Treatment is necessary for epilepsy because of its high prevalence, which drives market expansion.

Market participants are also contributing to the market's expansion by increasing the availability of affordable medications for the treatment of epilepsy. For instance, in March 2021, India-based Alkem Laboratories introduced Brivasure, a low-cost medication for treating epilepsy. In February 2021, Sun Pharmaceutical Industries also made the announcement that it would launch an affordable line of Brivaracetam-containing anti-epilepsy medications in India.

Additionally, strategic alliances and rising public awareness of epilepsy are anticipated to drive market expansion. For instance, National Epilepsy Awareness Month (NEAM) will be observed in the United States in November 2021. Such mindfulness crusades are likewise expected to add to the development of the market.

As a result, the aforementioned factors are expected to accelerate market expansion in the coming years. Anyway, optional impacts related with drugs and the new end of licenses on huge meds could impede the improvement of the market.

Epilepsy Medications Market Patterns: -

Second era of epileptic medications should hold the greatest piece of the general business inferable from a couple of enormous advantages, for instance, reduced drug participation, less risky ominous events, and a more beneficial outcome on mental capacities. In a similar vein, the rising prevalence of epilepsy will contribute to the market's interest in pharmaceuticals.

The different market players' presentation of second-line meds for the treatment of epilepsy is additionally driving the section's development. Similarly, Dr. Reddy's Labs introduced Vigabatrin tablets, an antiepileptic medication, to the US market in February 2021 after receiving approval from the US Food and Drug Administration.

In addition, the market leaders are expanding their product offerings by acquiring additional businesses. For instance, in January 2022, UCB purchased Zogenix for USD 1.9 billion in order to expand its epilepsy portfolio by acquiring Fintepla (fenfluramine), which is marketed as a treatment for seizures associated with Dravet disorder, a rare form of epilepsy. This arrangement keeps on extending UCB's broad helpful contribution in the epilepsy market by securing a recently promoted item for patients with uncommon and hard to-treat pediatric vagrant epilepsy conditions.

As a result, new product launches and the acceptance of second-generation epilepsy medications are expected to significantly expand the market over the forecast period.

Epilepsy Indian Market: -

India is estimated to have over 10 million people with epilepsy (PWE). It accounts for roughly one percent of our population. In the Bangalore Metropolitan Provincial Neuro- epidemiological Review (Consumes), a pervasiveness rate of 8.8/1000 population was observed, with the rate in rural networks (11.9) being two times that of metropolitan regions (5.7). The prevalence is higher in the country (1.9%) than it is in the metropolitan population (0.6%). With the exception of social shame and detachedness, which further exacerbate the disease burden, the assessed weight of epilepsy using the DALYs only accounts for 1% of the global total weight. In this section, we discuss the current state of epilepsy in India, recent developments, and their implications for the field. This review also examines the significance and demand for epilepsy surgery in India, as well as epidemiological estimates of epilepsy's cause and risk factors in India. There is a significant need to strengthen epilepsy services in India, where there are fewer than 2000 nervous system specialists and an estimated 5 to 6 million patients with dynamic epilepsy. This is especially true in provincial and underserved regions, where the prevalence of epilepsy is much higher. Various studies have found that the general prevalence of epilepsy in India is 5.59 to 10 per 1,000 people. In Kerala, the age-changed prevalence rate of dynamic epilepsy is 4.7 per 1,000 people. Strategic contrasts in the assessment of the commonness, such as differences in how epilepsy is characterized, the inability to avoid pseudo-seizures, syncope, and other epileptic mimics, and missed cases when covering might affect the specific commonness.

The latest occurrence review from India proposes an age-normalized frequency pace of 27.3/100,000 every year. In India, the number of people with medically intractable epilepsy is unknown. High temp water epilepsy (HWE) is a sort of reflex epilepsy where seizures are set off by quickly pouring heated water over the head The predominance of HWE in South India goes from 1.14 to 2.99 cases per 1,000 individuals. In rural South India, it was reported that HWE was responsible for 3.6-3.9% of all epilepsy cases.

CAUSES: -

Idiopathic: - Most of the time, epilepsy has no known cause. Idiopathic epilepsy is the term for this. It is believed that genetics may also play a significant role in idiopathic epilepsy, despite the fact that genetics is still the subject of research..

Abnormalities: - Seizures can result from some brain abnormalities. These irregularities might incorporate cerebrum deformities, for example, cortical dysplasia upon entering the world or gained anomalies coming about because of mind harm, growths, strokes, or sicknesses like meningitis or encephalitis.

Genetic factors: - A few epilepsies have solid hereditary variables. Transformations or changes in specific qualities increase the gamble of epilepsy. These genetic conditions can come about naturally or through inheritance from parents

Brain Injury: - Epilepsy can result from head trauma, such as a severe blow to the head in an accident or a sports injury. If the injury causes severe damage to the brain, there is a greater chanceof developing epilepsy.

Diseases: - A few sicknesses that influence the mind, like meningitis, encephalitis, or neurocysticercosis, can cause seizures. Seizures and electrical disturbances can be brought on by these diseases' potential to cause inflammation and injury to brain tissue.

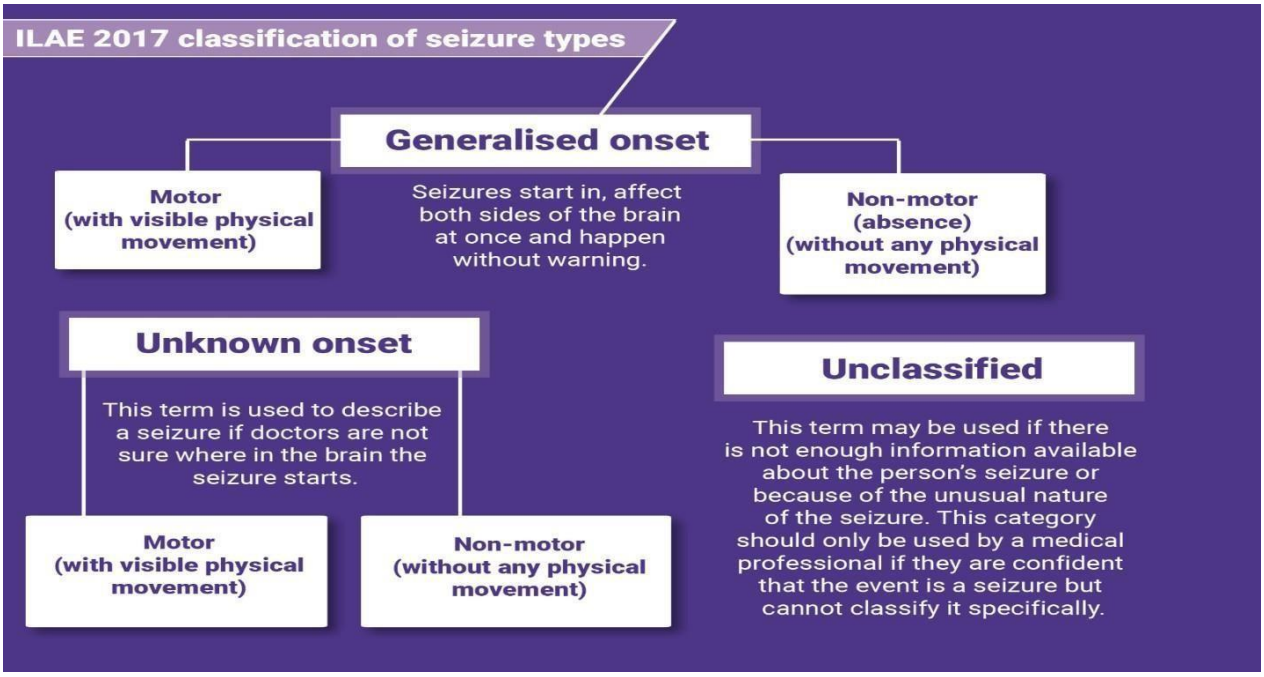
Developmental Disorders: - A few formative problems, for example, mental imbalance range issues and neurodevelopmental messes, are related with an expanded gamble of epilepsy.

Stroke and blood vessel disease: - When blood flow to the brain is disrupted, resulting in brain damage, stroke occurs. Individuals who have suffered a heart attack or have specific vascular illnesses that influence bloodstream to the cerebrum might be at higher risk of seizures.

Brain tumors: - Convulsions and seizures can be brought on by both benign and malignant brain tumors. Seizures might be one of the early side effects prompting a finding of psychological sickness.

Drug and alcohol use: - Long time utilization of specific medications and liquor can build the gamble of epilepsy.

Types of Seizure: -



Treatment gaps in epilepsy: -

The primary gap that exists between epilepsy sufferers and those who seek appropriate diagnosis, treatment, and care is epilepsy treatment. This unfair treatment is a global problem that affects people in both developed and developing nations.

Many factors contribute to differences in epilepsy treatment: -

Lack of knowledge and understanding: - In numerous networks, epilepsy is as yet encircled by deception and disgrace. Because of this lack of mindfulness, patients delay seeking medical assistance and frequently do not receive treatment.

Limited health care: - The vital clinical offices, prepared specialists, symptomatic devices, and drugs to analyze and treat epilepsy are not adequate in certain areas, especially in low-pay countries.

Limited access to medical services: - Due to restrictions, transportation issues, and the absence of nearby emotional wellness offices, people with epilepsy may be denied access to clinical

offices in provincial or remote areas.

Financial constraints: - The price of medications, diagnostics, and follow-up care for epilepsy can be a significant barrier for many people. This is especially true in nations that do not provide universal health insurance or have high out-of-pocket expenses.

Availability and affordability of drugs: - In some areas, certain calming medications are difficultto obtain because they are either not readily available or reasonable. Poor care or the use of the best options could result from this.

Religion and culture: - Epilepsy comprehension and executives can be influenced by religion and culture. Traditional and alternative treatments may be preferable to evidence-based interventions that result in poor control.

Abstract: -

Epilepsy is a constant sickness that influences the cerebrum at whatever stage in life. India's low- and middle-income regions are home to over 70% of epileptics. Patients with epilepsy and their families face social discrimination and stigma. Research is worried about the patient's condition andissues. a study of neurological epilepsy disorders in more than 150 Hyderabad patients.
Patients range from 05 to 60 years old. Examples of this work include women, students, the elderly, and children. The majority of patients' seizures, according to the survey's findings, were partial seizures.

Epilepsy is a global health issue that has a negative impact on the quality of life for approximately 70 million people. Anxiety, depression, and the burden of disability on our lives are to blame for therise in epilepsy. Individuals with epilepsy are at high gamble for SUDEP (Abrupt Surprising Passingin Individuals with Epilepsy).

It also affects caregivers' quality of life and reduces life expectancy. Huge treatment variations are a typical issue in epilepsy treatment among individuals with epilepsy in low-and center pay nations. Physicians favor a variety of AEDs, including Clobazam, Lamotrigine, brivaracetam, Levetiracetam, and Lacosamide. This study was led, and obviously patients experience the ill effects of medication use and disgrace.

LITERATURE REVIEW

Ashok Panagariya *et.al.*, 2018 focuses on the prevalence of epilepsy in Rajasthan, India's Jaipur region, as well as its mental angles and socio-segment profile. He carried out a cross- sectional, community-based, observational study that included both rural and urban populations. The predominance of dynamic epilepsy was viewed as 1.1 per 1,000 populaces, with a higher commonness i n rustic regions. The study found a higher prevalence of epilepsy beginning in childhood and a male preponderance. Generalized seizures characterized most cases. The concentrate likewise featured the low financial status of most cases and a moderately more modestessential treatment hole. Anxiety and depression were common mental health issues among epilepsypatients. A substantial number of respondents were unwilling to marry a person who suffers from epilepsy, as the knowledge, attitude, and practice survey revealed. The review presumed that while the commonness of epilepsy was low, there is a requirement for further developed mindfulness, schooling, and admittance to clinical treatment for epilepsy in the district. **[1]**

Bharucha *et al.*, 2003 He gives a concise outline of the study of disease transmission of epilepsy in India. It features that predominance rates in India are identical to those in different nations, however, there is an absence of occurrence studies. The visualization for people with epilepsy in emerging nations is more regrettable, and the etiology of epilepsy implies different risk factors, forexample, neurocysticercosis and febrile seizures. Cost and a lack of case identification are cited asreasons for the treatment gap highlighted in the article. Patients' lives are impacted by the stigma associated with epilepsy, and they frequently seek both allopathic and conventional treatments. Thearticle concludes by calling for more research and collaboration to address these issues. **[2]**

K. Radhakrishna *et al.*, He looked into the prevalence and pattern of epilepsy in Kerala, South India, as well as the population's knowledge, attitude, and practice (KAP) toward the condition.. Through a surveyof 238,102 people in a semi-urban area, 1,175 were found. The age scope of 10 to 19 years of age had the most noteworthy commonness, with a predominance proportion of 4.9 cases per 1,000 individuals. The study found that generalized epilepsy accounted for 58.8% of cases, while localization-related epilepsy accounted for 30.6%. Negative attitudes toward epilepsy were observed, including misconceptions regarding heredity and employability, despite a high awarenessrate (99 percent). To improve Keralan's understanding and attitudes toward epilepsy, the study emphasizes the need for education and the inclusion of epilepsy-related knowledge in school curricula. **[3]**

Mandaville *et al.*, 2017 He focused on the information, perspectives, and practices (KAP) among patients with epilepsy going to a tertiary center in Delhi, India. He wanted to compare the KAP of epilepsy patients in Delhi to data from India that was already available. Patients had an elevated level of awareness of epilepsy and its treatment, according to the findings, but they continued to hold the belief that epilepsy was caused by sin and had supernatural causes. The study also pointedto regional variations in KAP throughout India, which could be a result of literacy, awareness of epilepsy, and the application of various medical systems. The review emphasized the need for nationwide awareness programs to dispel misconceptions about epilepsy and improve patients' overall quality of life.**[4]**

Pream Prakesh *et al.*, 2018 He wanted to compare the stigma and dysfunction experienced by epileptics and a control group. Thirty people with epilepsy diagnoses made up the sample, with thirty healthy people serving as the control group. The review used a cross-sectional plan and surveyed brokenness and saw shame utilizing the Brokenness Investigation Poll (DAQ) and the Disgrace Size of Epilepsy (SSE), individually. The epileptic group displayed a severe level of dysfunction in a variety of domains, including social, vocational, personal, family, and cognitive, when compared to the control group. Stigma, on the other hand, did not significantly differ betweenthe two groups. A common neurological condition, epilepsy can have a significant impact on a person's psychosocial well-being. People who have epilepsy frequently experience negative perceptions, a lack of social acceptance, and a lack of social connectivity as a result of the stigma that surrounds the condition. His research emphasizes the significance of comprehending and addressing epilepsy sufferers' stigma in order to enhance their quality of life.**[5]**

R Sridharan *et al.*, (2023) He wanted to find out how common epilepsy is and how it is spread in India. Twenty studies were included in the analysis, with a large sample size of 598,910 people, 3,207 of whom had been diagnosed with epilepsy. It was estimated that the crude prevalence of epilepsy in the nation was 5.35 per 1,000 people, indicating a significant burden. Further examination of the information uncovered varieties in commonness rates across various populaces.There may bea disparity between urban and rural populations, as the prevalence rates in urban areas(5.11) were slightly lower than those in rural areas (5.47). Age-explicit rates exhibited a higher predominance of epilepsy in more youthful age gatherings, with the beginning of epilepsy happening inside the initial thirty years of life. The survey likewise shed light on the treatment hole,a basic issue in epilepsy for the executives. More than 70% of epileptics in rural areas did not receive the proper treatment, highlighting the significant gaps in healthcare access and delivery, accordingto the findings.

According to the estimated prevalence rates, approximately 5.5 million people in India were affected by epilepsy, with most cases occurring in rural areas. Alarmingly, a significant number ofthese people did not receive specific treatment in accordance with current standards. The review highlights the critical requirement for further developed medical care foundations, especially in rustic regions, to guarantee opportune findings, therapy, and the executives of epilepsy. Epilepsy patients' quality of life can be significantly improved and the disease's impact on those affected andsociety reduced by closing the treatment gap and providing comprehensive care and support.**[6]**

Sanjeev V. Thomas *et al.*, 2011 He draws attention to the widespread misconceptions and forms of discrimination that epilepsy sufferers face, highlighting the negative effects these stigmas have on their day-to-day lives. The author effectively demonstrates the pressing need for society to address and eradicate these stigmas by presenting a wealth of research findings The social, cultural,and economic factors that contribute to the perpetuation of stigma are better understood by the

reader. In addition, the emphasis placed on gender disparities in epilepsy adds a significant layer to the discussion and encourages readers to consider the obstacles women in various regions of the world face. He primarily addressed the issue of stigma, but he also discusses potential solutions and ongoing efforts to combat this problem. It effectively raises awareness about the significant challenges faced by individuals with epilepsy and emphasizes the importance of addressing and dismantling societal stigmas by highlighting the positive steps being taken by advocacy groups, healthcare professionals, and policymakers. He instills a sense of hope and encourages readers to become more actively involved in challenging the stigma surrounding epilepsy. Defying the disgrace of epilepsy" is an honorable peruse that prompts peruses to ponder their own mentalities and ways of behaving towards epilepsy, at last cultivating a more comprehensive and sympatheticculture **[7]**

Sanket Newale *et al.*, (2016) The demographics, comorbidities, and use of antiepileptic drugs (AEDs) in adult epileptic patients are examined in his study, "Results of a cross-sectional survey." broke down the utilization of AEDs in light of the kind of epilepsy, age gathering, and orientation of 973 grown-ups with epilepsy. Guys made up 61.3 percent of the review populace, with a mean period of 35.6 years. Only 3.6% of patients were uneducated, and 45.3% of them were employed. Patients had high educational attainment. A history of brain injury was found in only 1.2% of patients, making it uncommon. The fact that the mean frequency of seizures over the preceding six months was 24.0

indicates that there was a significant amount of variation in how frequently seizures occurred. The average duration of epilepsy in the patient cohort was 5.8 5.8 years.. The most regularly carried out examination was electroencephalogram (EEG), which was led in 59.7% of the patients. Hypertension was the most common comorbidity that was observed, affecting 3.3% of patients. Levetiracetam was the most frequently prescribed AED, being used by 59.9 percent of patients. Valproate (16.3%), clobazam (14.8%), and phenytoin (13.6%) were also commonly used AEDs. The essential elements affecting AED choice were viability and security/decency profile.

His findings indicate that adult epilepsy is common and that hypertension is the most common comorbidity. Levetiracetam is the AED that is recommended the most frequently at all age and gender-specific social events. Importantly, the ongoing treatment strategy is secure and effective at controlling seizures. However, it is essential to note that the cross-sectional design of this study, which provides a snapshot of the population at a specific time, limits its scope. To more readily grasp grown-up patients' epilepsy the executives and treatment results, extra exploration, including longitudinal examinations, would be useful.**[8]**

Patrick W Corrigan *et al.*, (2002) He focuses on the effects of stigma on people with mental illnesses and emphasizes the significance of gaining a deeper comprehension of the depth and breadth of prejudice against them. It features two types of shame: public shame, which alludes to the response of everybody towards individuals with dysfunctional behavior, and self-disgrace, which is the bias people with psychological instability incorporate and coordinate towards themselves. He explains that stereotypes, prejudice, and discrimination can be used to understand both public and self-stigma. Stereotypes are social knowledge structures that represent concepts onwhich the majority of a social group agrees. Bias includes embracing pessimistic generalizations and creating pessimistic profound responses, while segregation is the conduct reaction to bias. Self-stigma can lead to people refusing assistance or pursuing life opportunities out of fear of being

rejected, and prejudice can cause hostility or avoidance. **[9]**

P W Corrigan *et al.*, (2000) He finds the procedures used to battle shame towards people with extreme dysfunctional behavior and accentuates the significance of consolidating social mental examination on generalizations. There are three significant findings mentioned: the resiliency of stereotypes to change in spite of education programs, the potential rebound effect of attempting to suppress stereotypes through protest, and the factors that enhance the effectiveness of contact between people with mental illness and the general public. The abstract suggests possible directions for future research as well as practical strategies for reducing stigma**. [10]Patricia Braga *et al.*, (2020)** He features the predominance of epilepsy as a serious neurological sickness and reveals insight into the critical difficulties looked by people with epilepsy. It emphasizesthe negative effects of stigma, prejudice, and discriminatory practices, which make it hard to integrateinto society and affect important things like marriage, employment, and education.The adverse results of disgrace and segregation are highlighted, remembering the negative impactsfor the personal satisfaction of people with epilepsy. The section additionally references significantglobal goals and reports that require the assurance of the freedoms of individuals with epilepsy andthe improvement of admittance to mind. Instructive projects and mindfulness drives are underlinedas compelling devices for diminishing shame and separation. These efforts have the potential to contribute to the creation of a setting that is more welcoming and supportive for epileptics by fostering comprehension and dispelling misconceptions. By and large, this survey gives a succinctyet exhaustive outline of the issues encompassing epilepsy, the effect of shame and segregation, thesignificance of bringing issuesto light, and the requirement for cooperative endeavors to work on the existences of people with epilepsy. **[11]**

Hanneke M de Boer *et al.*, (2010) He demonstrates the worldwide prevalence of epilepsy-related stigma and social exclusion. In order to improve the quality of life for those who are affected, it emphasizes the significance of reducing stigma. The paper audits the verifiable and social understandings of epilepsy and how they have molded the experience of disgrace. It discusses current initiatives aimed at reducing epilepsy stigma and acknowledges the ongoing difficulties thatpeople with epilepsy face in a variety of life areas. In general, the passage calls for an end to discrimination and social exclusion against epileptics. **[12]**

Aparna Nair *et al.*, (2011) He significant impact that stigma has on the lives of epileptics, particularly in economically disadvantaged nations, is brought to light in this passage. The paper examines the ways in which epilepsy-related stigma contributes to stereotyping, prejudice, and discrimination through a systematic review of sociological and social psychological research. Additionally, a brief discussion of the typical approaches taken to address and lessen stigma is included. It is emphasized that healthcare providers, social workers, support groups, and policymakers all need to work together and have a comprehensive understanding of how epilepsy is perceived in society and culture. The passage emphasizes the significance of societies determining the specific factors that contribute to stigma and putting in place appropriate strategiesto promote inclusion and eradicate discrimination against epileptic individuals. **[13]**

Deepa Anand Bapat *at el.*, (2021) He explained that the India, a nation with a significant numberof epilepsy patients and limited infrastructure support, the neglected state of epilepsy caregivers is highlighted in this review. The survey sums up accessible exploration on trouble among these guardians, uncovering a huge weight in this populace. Their financial situation, family functioning, and physical and mental health are all negatively impacted by caregiving. While patient characteristics and psychosocial factors remain relatively unexplored, the influence of seizure-related variables on perceived burden is evident. In the identified studies, the specific requirementsof each group were overlooked due to methodological limitations like small sample sizes and failureto distinguish between adult and pediatric caregivers. In the Indian context of epilepsy caregiving,the review emphasizes the need for larger, well-designed studies focusing on culture-specific psychological and social factors. **[14]**

Siew Tim Li *at al.*, (2019) His cross-sectional review centers around guardian trouble among those really focusing on grown-ups with epilepsy, filling a hole in the writing. Perceived burden, qualityof life, psychological distress, family functioning, and social support are all examined in the study. Discoveries demonstrate that family working is the primary indicator of guardian trouble, close by different factors, for example, providing care hours, number of parental figures, disposition towards epilepsy, and segment and clinical qualities. The study shows that caregiver burden has a big effect on caregivers' mental health and quality of life. It emphasizes the significance of taking into account the family unit and implementing interventions that cater to the particular requirements of this subset of caregivers. Overall, this study highlights the significance of providing caregivers with comprehensive support within the family context and contributes to our understanding of the complexities of adult epilepsy caregiving. **[15]**

Objective of the study: -

1. To investigate patient social stigma and the demographics of epilepsy patients.
2. To determine the reasons for medication discontinuation
3. To be familiar with the assumptions for the patients from the ongoing treatment
4. To determine the patient's quality of life

Research Methodology: -

Study Type: Cross-sectional study

Research Design: - Depending on the research objectives and available resources, studies was designed as cross-sectional or longitudinal.

Sampling: - The need to select a representative sample of epilepsy patients from the target population. This has been done through interaction with various epileptic patients of different hospital of Hyderabad.

In addition, physicians specializing in epilepsy management was identified and included as participants in this study.

Data collection: - Data was collected through self-assessment, observation, questionnaire or face to face interaction with the patients in hospitals.

The essential and optional information was utilized.

Essential information for specialist and patient assessment and auxiliary information for predominance information

Essential information was gathered from the respondent through perception or direct interchanges. Primary data source:

1. Field Perceptions
2. Questionnaire

Source of Secondary data: - from PubMed and other journals, including ILAE, AES, WHO, and others. Stigma, quality of life, and physician opinion can all be measured using validated questionnaires and standardized tools. These measures include stigma (e.g., seen, stigmatized) and quality of life (e.g., physical, emotional, social).

These actions give data on the degree and effect of disgrace on the personal satisfaction of patients with epilepsy.

Evaluation of quality of life: - The Poll on Personal satisfaction with Diabetes and different instruments was utilized to assess personal satisfaction. These actions give a superior comprehension of what epilepsy and shame mean for human existence and catch numerous parts of personal satisfaction, including physical, mental, social, and in general wellbeing.

Physician's Evaluation: - Through questionnaires or interviews, it was identified that how physicians perceive drug treatment for epilepsy patients.

These questions were asked about their knowledge of medications that are available, prescriptions, beliefs about how effective they are, worries about side effects, and opinions about treatment options.

Data Analysis: - Statistics like descriptive statistics, correlation analysis, and regression analysis was examined and identified the relationship between variables in quantitative data gathered fromresearch and questions. Subjective information from meetings or unassuming inquiries were investigated utilizing topical examination.

Study Duration: - Three Months (6^{th} march to 31^{st} may)

Tool used: - Tableau, Ms.-Excel, Power BI

Methodology: -

Procedure utilized for the overview is an irregular cross-sectional poll study on epileptic patients. The survey is administered at random to OPD patients in various hospitals' sitting areas. Patients and their loved ones receive the questionnaire. 150 patients from a total of 200 completed the survey to complete the data.

Patients over the age of 18 received the questionnaire, and family members of patients under the age of 18 completed it. From the 1st of April 2023 to the 31st of May, patients at various Hyderabad Clinics participated in the cross-sectional review. The study's goal was to inform patients before the privacy survey and prepare them for it.

Survey Instrument: -

There were two sections of questions in the study questionnaire:

1. Related to the disease profile of the patient.
2. Learn about and evaluate the patient's treatment plan.

The patient's seizure freedom and treatment patterns are also discussed during the survey with doctors.

Study Area

The review was led under the OPD patients in different emergency clinics, for

example,

Rainbow hospital

Niloffer hospital

NIMS hospital

Care hospital

Star hospital In Hyderabad with less than 200 patients. Patients in IPD were avoided due to the patient's serious wellbeing.

Sampling: -

It was done with purposeful sampling.

Sample size: -

In the OPD area, where elderly patients and adults participated in the study, the sample size was selected at random. Under the supervision of 150 patients present for diagnosis, the study was carried out.

Inclusion Criteria of patients: -

1. Patients who came to the OPD for treatment
2. Patients over the age of 18
3. Patients of both sexes (males and females)
4. Patients who completed the entire questionnaire.

Exclusion Criteria of patients: -

1. Having basic medicines, patients of IPD, patients for activities.
2. Having a significant mental health issue;
3. Mental patients;
4. Being younger than 18 years old

Data Analysis and Interpretation: -

Age in years	
<20	25
21-40	79
41-60	41
Gender	
Male	91
Female	59
Occupation	
Employed	52
Housewife	67
Student	31
Marital status	
Married	67
Unmarried	83

Gender: -

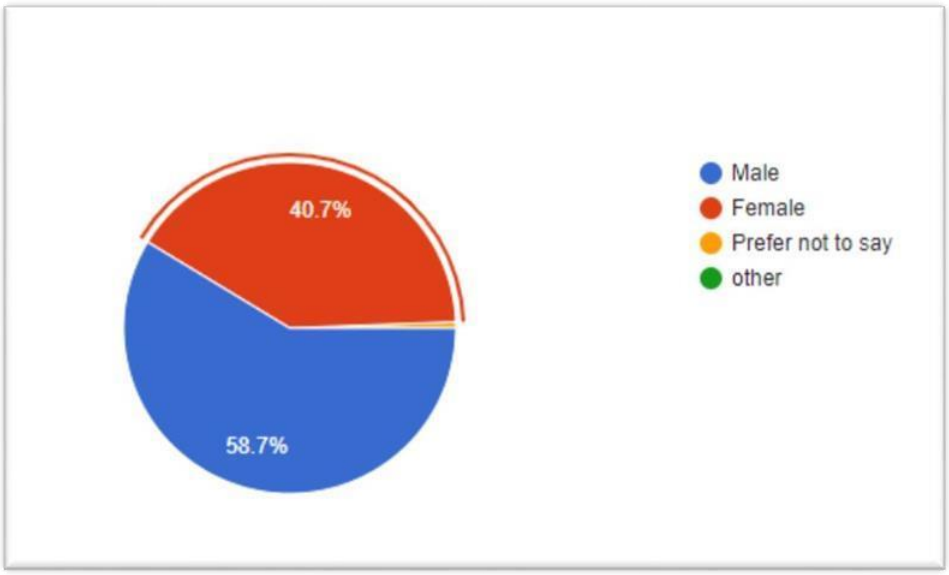


Fig.1 Gender of the patients

Interpretation: -

This study was conducted on 150 patients with epilepsy in Hyderabad. Most of the patients are from government hospitals; private hospital patients are also included in this study. This study shows that out of 150 patients suffering from epilepsy, 41.2% are female, and 58.2% are male. This data shows that patients suffering from epilepsy in Hyderabad are more likely to be female than male.

Age of the patients: -

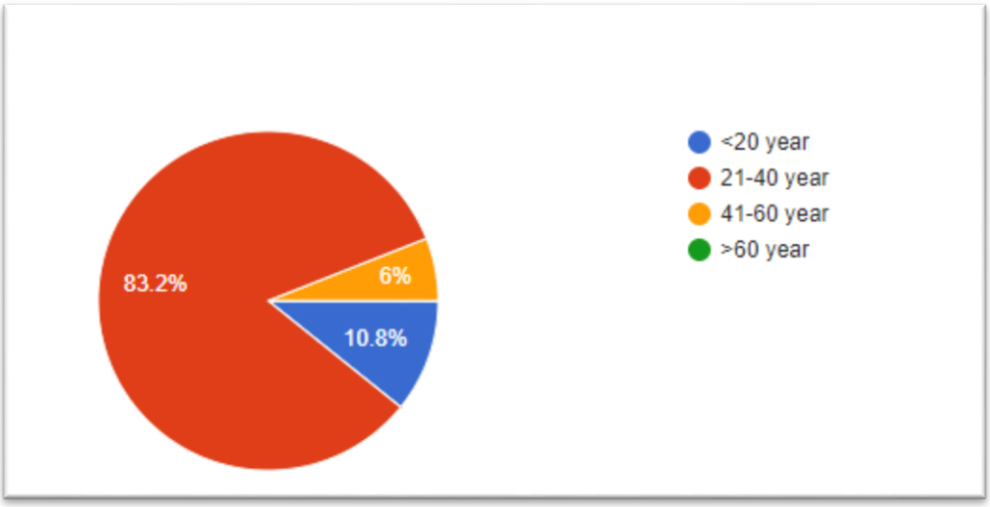


Fig. 2 Age of Epileptic Patients

Interpretation: -

The study was completed with 150 patients, and the data was collected based on the current status of patients diagnosed with epilepsy for so many years.

Marital Status

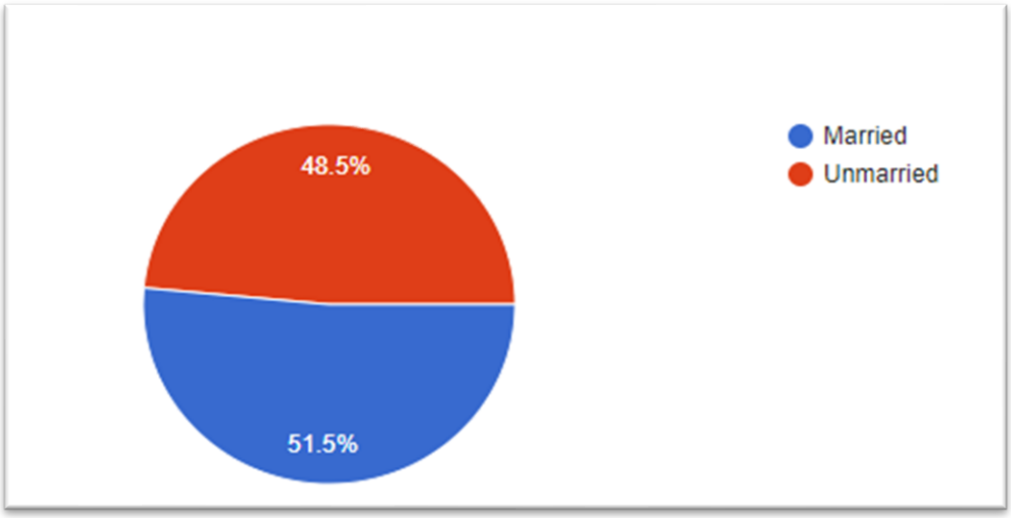


Fig.3 marital status of the patient

OCCUPATION

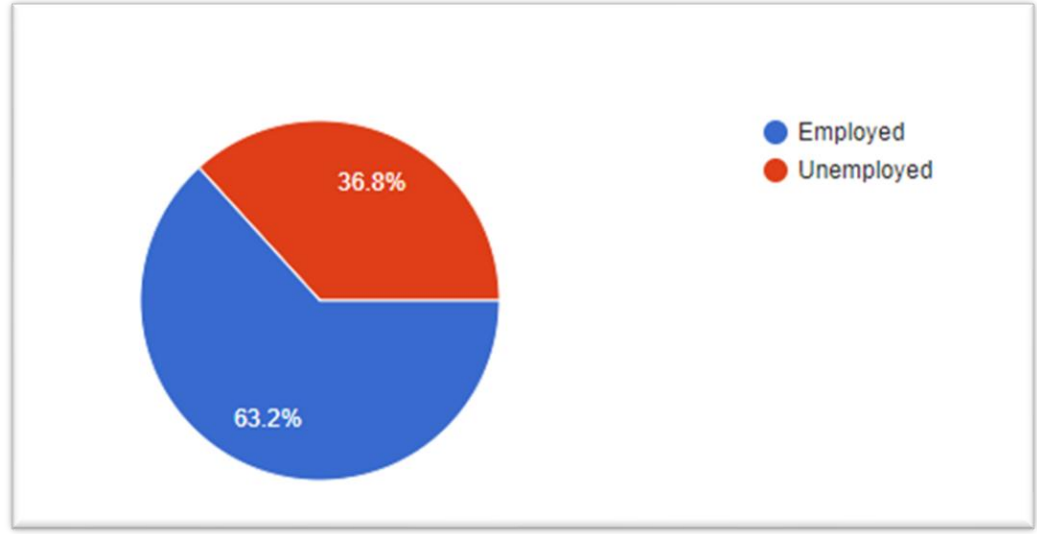


Fig. 4 Occupation of the patients

Are you aware of Epilepsy?

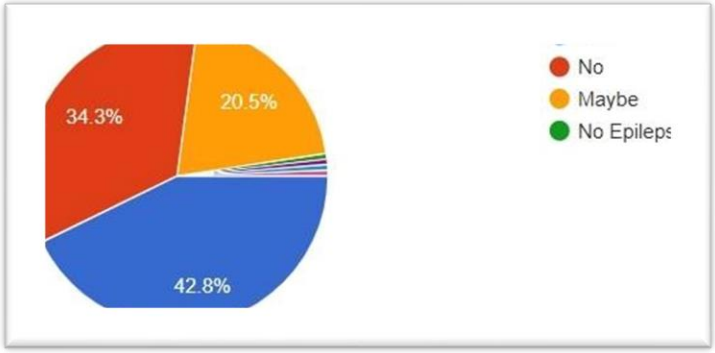


Fig 5 Awareness of Epilepsy

Interpretation: -

The study was completed in 150 patients, and the data was collected based on the patients' understanding of epilepsy. And as per the study, 42.8% are aware of epilepsy treatment and disease; apart from this, the rest of the people are not properly aware of the cause of the disease aswell as treatment.

How much is the control over your attacks?

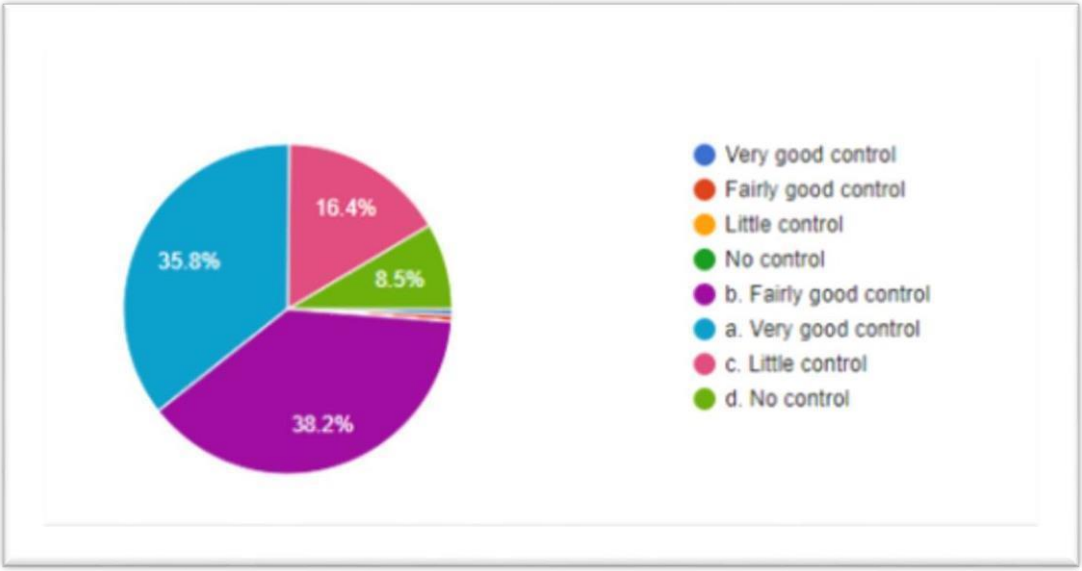


Fig.6 control over epilepsy attack

Interpretation: -

The study was completed with 150 patients, and the data was collected based on the patient's control over epilepsy after seeking epilepsy treatment. So as per the study, 38.2% of the patients have fairly good control, 35.8% have very good control, and the rest (16.4%) have little control and 8.5% have no control. This data shows that the majority of people have good control over epilepsy.

How long have you been diagnosed with epilepsy?

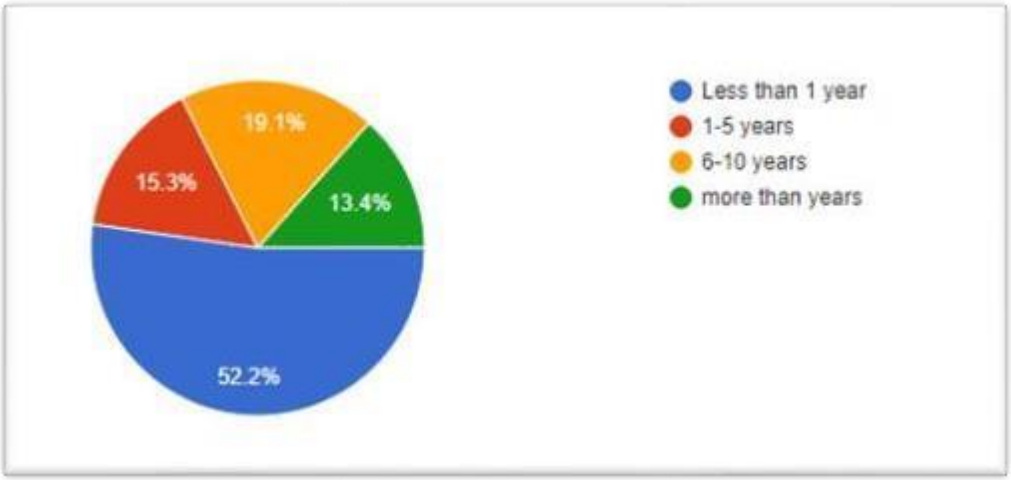


Fig.7 How long they are suffering from epilepsy

Interpretation: -

150 patients participated in the study, and data were gathered based on their current condition. Since so many years ago, epilepsy has been diagnosed in patients. A sample of epileptic patients is the subject of the study. The study included 52.3 percent of patients who had been diagnosed with epilepsy in less than one year, 15.3 percent in the first five years, 19.1 percent in the first six to ten years, and 13.4 percent in the ten years and older. Likewise, that's what specialists informed assuming the patients are on the prescription, they go through nonstop check-ups and subsequent meet-ups; They did not stop taking the medication or miss any doses. The patients who had the fewest seizures were the only ones for whom the aforementioned data were collected.)

Type of seizure experienced by respondents?

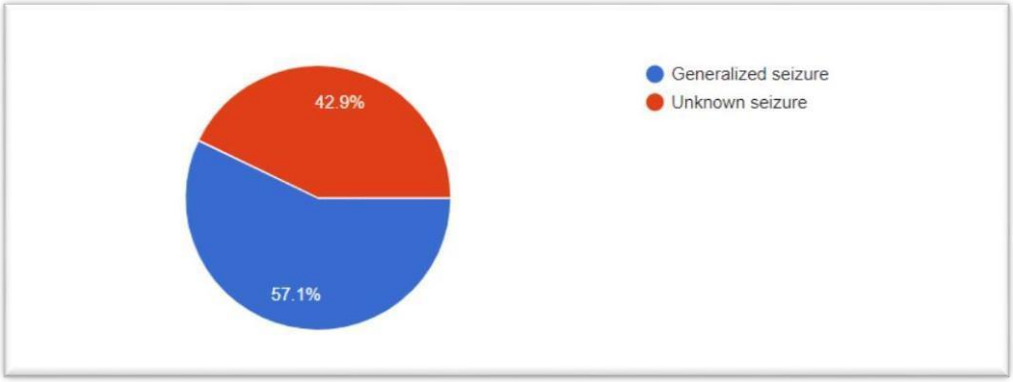


Fig.8 Type of seizure experienced by respondents

Interpretation: -

Patients who have just been registered for epilepsy treatment in the OPD hospital are the subjectsof the study. The review shows the information of 252 patients who had fractional seizures, both straightforward incomplete and complex halfway seizures. Seizures in the brain can be brought onby a variety of factors, including AIDS, alcohol consumption, head trauma, neurosurgery, genetics,and head injuries. The findings of this study, which looked at data from 252 patients, revealed that 13% of patients had unknown seizures and 57.1% had generalized seizures. A generalized seizure is the most common type of seizure in patients.

How would you rate the overall quality of your life?

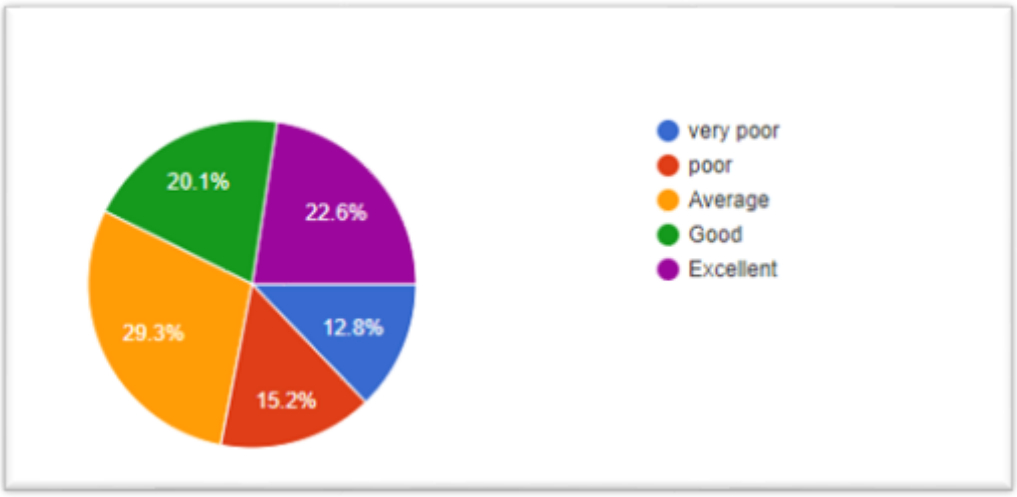


Fig.9 Quality of life of patient

Interpretation: -

Very poor	12.8%
Poor	15.2%
Average	29.3%
Good	20.1%
Excellent	22.6%

The survey is done on 150 patients by questionnaire on the quality of life of the patient afterdiagnosis or treatment of epilepsy. Out of 150 patients, 22.6% informed us that they have excellent

Have you experienced any stigma or discrimination due to your epilepsy?

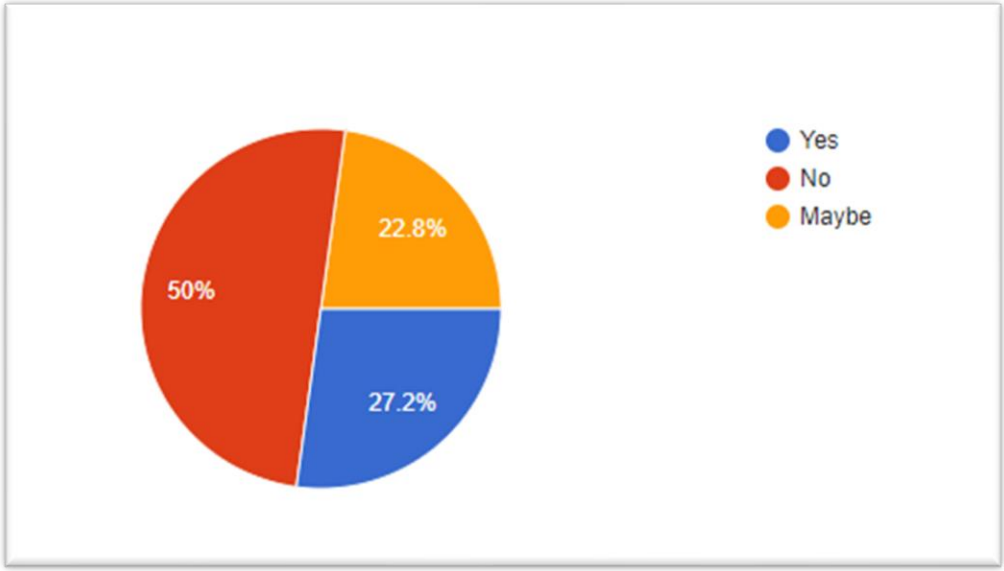


Fig. 10 stigma and discrimination experienced due to epilepsy

If yes, please provide examples of the stigma or discrimination you have faced .How has the stigma or discrimination affected your quality of life?

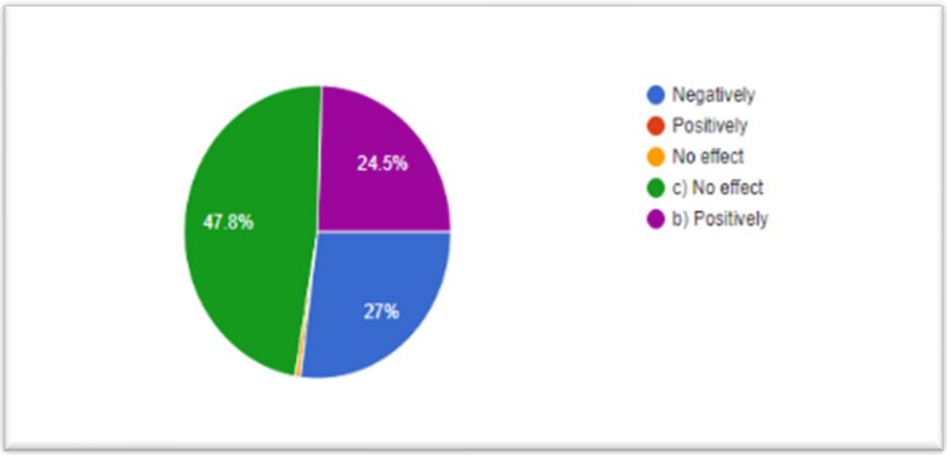


Fig. 11 **How stigma and discrimination due to epilepsy affect the life of the patients.**

Have you discussed your experiences with stigma or discrimination with your healthcare provider?

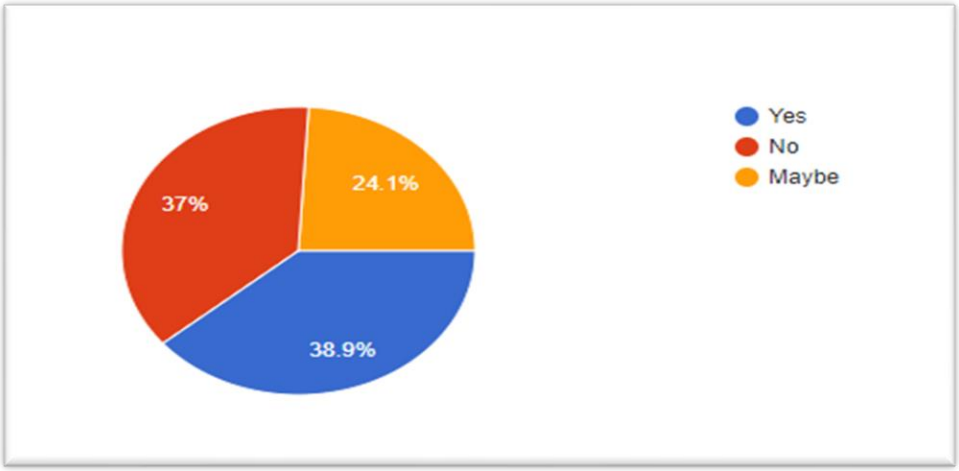


Fig. 12 Discuss the problems of discrimination due to epilepsy with healthcare provider

What kinds of social stigma or discrimination do you face because of your epilepsy?

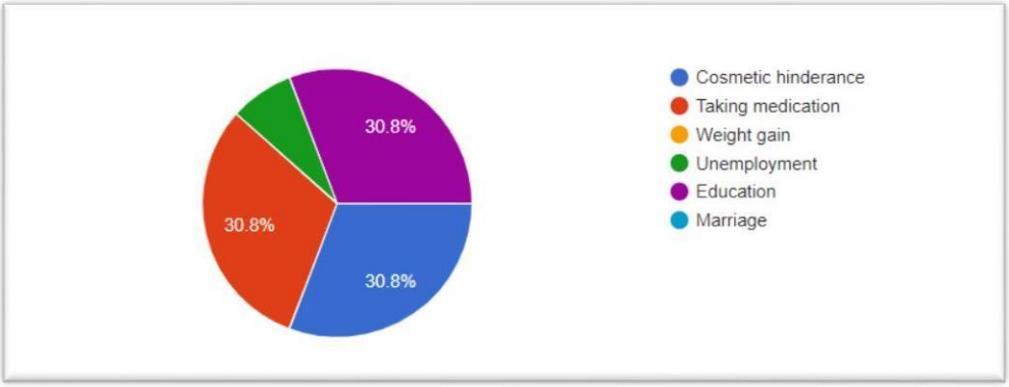


Fig.13 What kinds of social stigma or discrimination do you face because of yourepilepsy?

Interpretation: -

By poll, the study was completed on 150 patients who had social signs of shame, such as well- rounded education, unemployment, restorative obstruction, weight gain, taking epileptic medication, and marriage. I received information from 79 of 150 patients, 33 of whom were female and 46 of whom were male, that they were unemployed. Patients' greatest social stigma is unemployment; Theyare worried that they won't be hired. Out of 150 patients, 66 have a feeling of dread toward correctiveblock, including rashes, dryness, or any skin disease.

Have you looked for help or advising to manage the shame related with epilepsy?

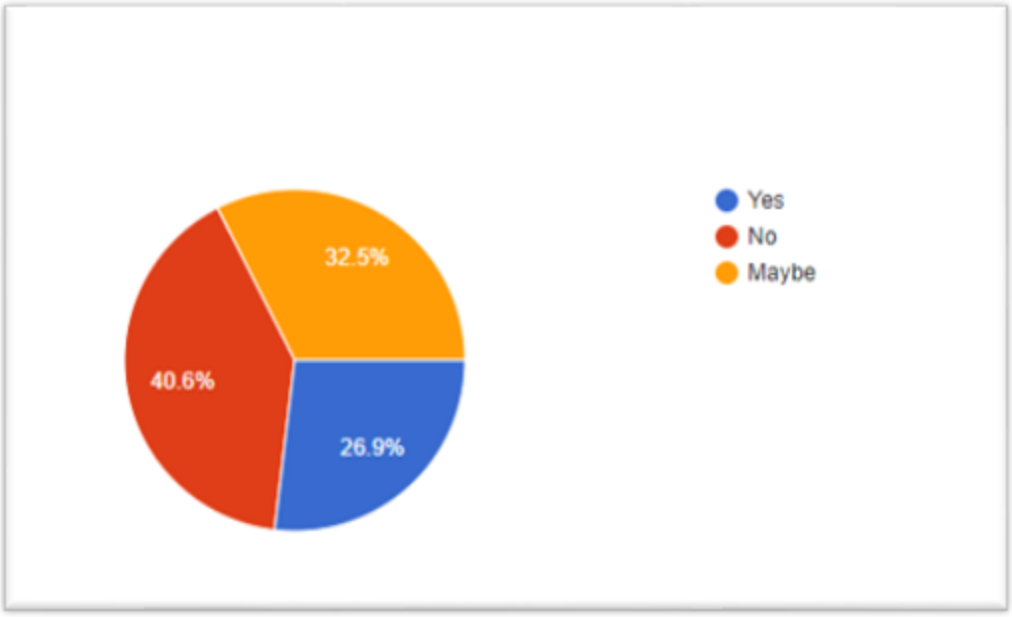


Fig.14 counselling have been taken or not by epileptic patient on social stigma

Interpretation: -

This study was led on 150 epilepsy patients and examined the sorts of separation they face in the public arena and what it means for their psychological wellness. And how many of them seek therapy or counseling to deal with such circumstances? According to this study, only 26.9% of 150 patients sought support or counseling and shared their circumstances with others. The remaining people are handling the situation on their own.

How is the epileptic patient doing right now?

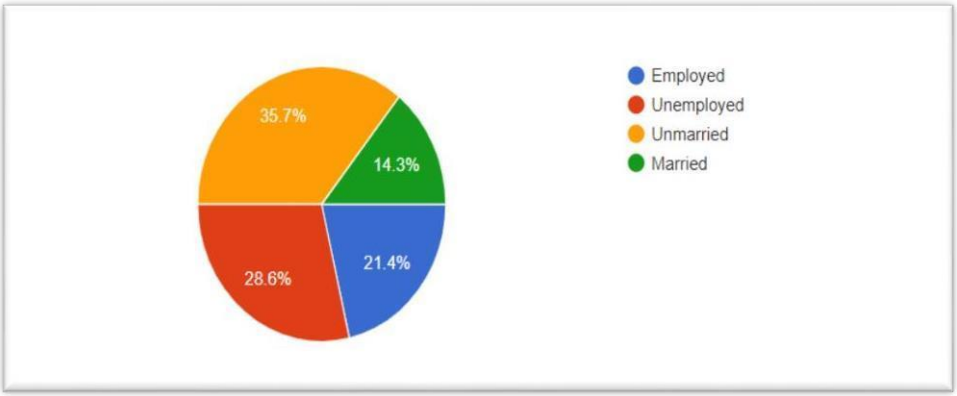


Fig.15 How is the epileptic patient doing right now?

Interpretation: -

The review was finished with 150 patients, and the information was gathered in view of the patient's ongoing status, similar to joblessness, business, marriage, or being unmarried. The review is performed on grown-ups more seasoned than 20; This study does not include students. Married people made up 35.3%, unmarried people made up 17.06%, unemployed people made up 24.2%, and employed people made up 24.2% of the patients in the study.

Molecule prefer for treatment of epilepsy by doctors?

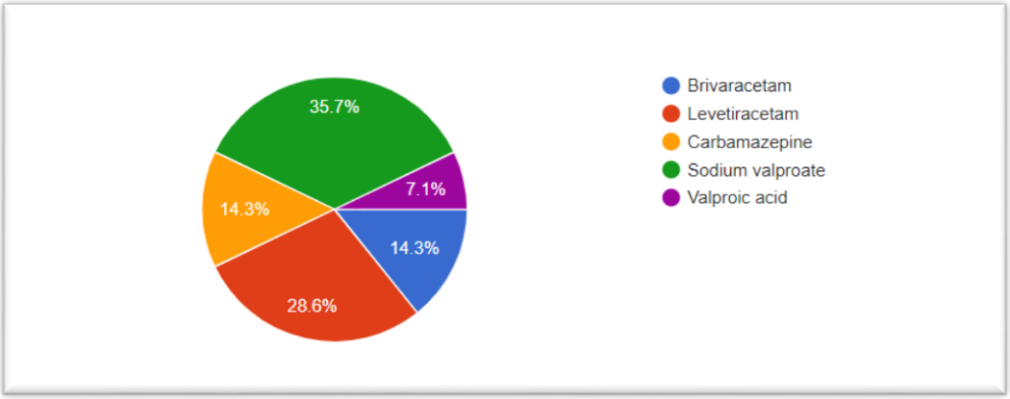


Fig. 16 Molecule used for Epilepsy

Interpretation: -

When discussing the various molecules used to treat epilepsy, doctors in the majority of hospitals favored levetiracetam because it was their first choice. Fig. demonstrates in the study that Brivaracetam is prescribed to patients by more than 28% of doctors. It is a molecule that can be given to any patient who has any kind of seizure, and they believe that literature reviews have demonstrated better efficacy. Carbamazepine and valproic acid are two of many golden medicines that doctors currently prescribe. Doctors prefer carbamazepine as their second choice of the molecule.

Preferred brand for epilepsy

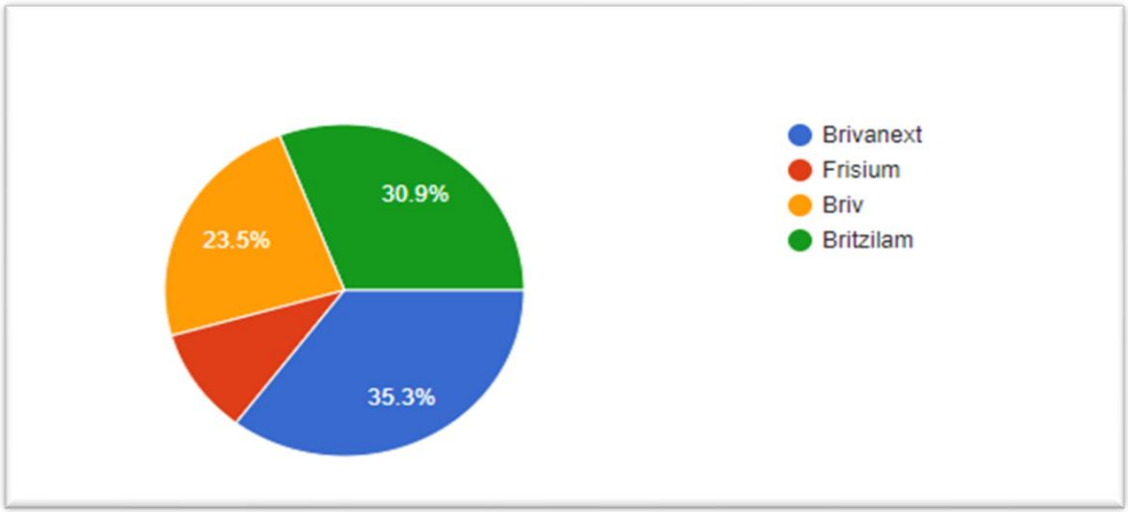


Fig. 17 preferred brand for epilepsy

Appendix: -

Questionnaire (patient Related)

Gender:

a) Male

b) Female

c) Would rather not say

Age:

a) 18-24,

b) 25-34,

c) 35-44,

d) 45-54,

e) 55 +

How long have you been diagnosed with epilepsy?

a) Less than 1 year

b) 1-5 years

c) 6-10 years

d) More than 10 years

How would you rate the overall quality of your life?

a) Very poor

b) Poor

c) Average

d) Good

e) Excellent

Have you experienced any stigma or discrimination due to your epilepsy?

a) Yes

b) No

If yes, please provide examples of the stigma or discrimination you have faced.

How has the stigma or discrimination affected your quality of life?

a) Negatively

b) Positively

c) No effect

Have you sought support or counseling to deal with the stigma associated with epilepsy?

a) Yes.

b) No.

On a scale of 1-5, how knowledgeable do you feel healthcare professionals are regarding epilepsy?

a) None at all;

b) Moderately Knowledgeable;

c) Very Knowledgeable;

d) Very Knowledgeable;

e) Extremely Knowledgeable

Have you discussed your experiences with stigma or discrimination with your healthcare provider?

a) Yes

b) No

Questionnaire for Physicians:

Gender:

a) Male

b) Female

c) Prefer not to say

Age:

a) 18-24

b) 25-34

c) 35-44

d) 45-54

e) 55 and above

How long have you been practicing as a physician?

a) Less than 1 year

b) 1-5 years

c) 6-10 years

d) More than 10 years

How confident do you feel in treating patients with epilepsy?

a) Complete lack of confidence

b) Moderate confidence

c) Very confident

d) Extreme confidence

Do you believe stigma affects the quality of life for people with epilepsy?

a) Yes

b) No

Have you encountered patients who have experienced stigma or discrimination due to their epilepsy?

a) Yes

b) No

If yes, how do you address the stigma-related concerns of your patients?

Do you feel that there is a need for more education and awareness regarding epilepsy among healthcare professionals?

a) Yes

b) No

What are your perceptions of drug therapy for patients with epilepsy? Please provide any commentsor concerns.

What, in your opinion, could be done to lessen the stigma associated with epilepsy and improve the quality of life for people with the condition?

Finding and Conclusions: -

It is possible to draw the conclusion that most patients came from families with incomes below $3000. The study yielded significant conclusions. The review was performed on center and low-pay gatherings and a substantial portion of the patients are from government medical clinics in Hyderabad, Telangana. A greater number of ladies are hitched and experiencing this illness for the last numerous years.

1. The objective seeks information regarding the patient's quality of life, the social stigma they face, and their treatment options.
2. Patients having social shame like marriage, occupations, taking drugs, well-rounded schooling, bias, in which landing position is the most often replied as 31.33%
3. Patients' lives are also impacted as a result of the medication's prolonged duration, which increases their risk of experiencing a variety of side effects like hair loss and weight gain.
4. Patients are in charge, take their medications for longer periods of time, do not stop taking them, and only 23% experience seizure freedom after taking their medications for three to four years.
5. Minor seizures have occurred in all of the patients in this study. Patients with severe seizures are not included in this study.
6. In terms of comprehending the challenges faced by epileptic patients, community research on stigma, its impact on quality of life, and physicians' perspectives on drugs are crucial.
7. Perampanel is not prescribed by doctors because they believe in older medications like Levetiracetam and Carbamazepine. Doctors use more than 40% of Levetiracetam.

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