

Family Centered Intervention on Quality of Life and Associated Factors among Patient with Epilepsy.

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ABSTRACT: Epilepsy is a disorder with a high social significance due to its high frequency and the stigmatisation of its sufferers. Chronic epilepsy has many negative social and psychological effects. This study aims to focus on empowering the patient as well as caregiver through family centered intervention by providing education about epilepsy.

Methods: A prospective interventional study was conducted in 64 patients with caregiver during a study period of 6 months. Detailed literature review was conducted by using tertiary, secondary, primary resources. All the required study materials like informed consent document, patient information sheet and data entry form were designed. The study was conducted only after getting endorsement from the Institutional Ethical Committee (IEC). 64 patients, who met the inclusion criteria, were enrolled in the study based on DASS score. Intervention was given in three stages and assessment was carried at three points (pre-intervention, immediately after intervention and one month after intervention). Data was gathered and analyzed.

Result : The finding showed no significant difference in the mean depression score. However the adherence score was statistically significant at three points (pre-intervention, immediately after intervention, one month after intervention); that is, adherence score exhibited greater improvement. The anxiety score between the first and second assessment differed slightly. However, the second and third assessment revealed no change in anxiety score, indicating that the anxiety score initially reduced and then remains steady.

I. BACKGROUND

Epilepsy entails a significant social stigma and is associated with lower quality of life (QOL) for those who have it. They are more likely to experience lower self-esteem, more anxiety, and sadness. They have lower rates of marriage, higher levels of social isolation, and a higher likelihood of being underemployed or unemployed. Epilepsy continues to be stigmatised as witchcraft, a spreading disease, and the possession of ancestral spirits and devils in many regions of the world.

According to a research conducted in India, 15% of respondents thought epilepsy was a sign of insanity, 40% said children with epilepsy shouldn't attend school or play with their children, and 66% opposed their kids getting married to someone who had epilepsy. Similar findings were made in a Taiwanese survey, which also revealed that 31% of respondents thought that people with epilepsy shouldn't work.

It is being widely understood that a crucial part of clinical management comprehends the distinctive and intricate effects of epilepsy on a person's quality of life. Quality of life (QOL) measures have been suggested to have a variety of potential uses in clinical care, including: developing baseline data to assess the efficacy of follow-up interventions; highlighting to the clinician the patient's difficulties; assisting the clinician in comprehending the patient's perspective; prioritising treatment interventions; and directing patient education and self-management programmes. The integration of QOL into clinical care is gaining support, although there are still a lot of practical issues and questions. One of these queries relates to the proper operationalization and definition of QOL. Epilepsy has a multifaceted effect on a person's life that can affect a variety of functional and psychosocial dimensions. Seizures may cause physical and cognitive issues, but epilepsy has also been linked to psychological and emotional issues, social isolation, and issues with education, career, family life, and leisure time. Given the varied and potentially wide-ranging effects that epilepsy can have on an individual, quality of life (QOL) should be included in any model used to analyse the effects of epilepsy.

AIMS AND OBJECTIVES

The aim of the study is to examine the effects of family centered intervention on quality of life in epilepsy patients.

To assess the level of depression before and after intervention.

To assess the level of anxiety before and after intervention.

To assess the level of drug adherence before and after intervention.

MATERIALS AND METHODS

STUDY DESIGN: The study was conducted as a prospective interventional study.

STUDY SITE: Department of neurology of a tertiary care hospital KMCT, Mukkam, Kozhikode.

STUDY DURATION: The study was conducted for a duration of 6 months.

STUDY POPULATION: A minimum of 64 patients with epilepsy, who consulted the Neurology department during the study period were included in the study.

INCLUSION CRITERIA

All patients aged 18 years and above with a diagnosis of epilepsy and under treatment with antiepileptic drugs from the inpatient and outpatient units

Patients who provided a written informed consent to participate in the study, and patients who expressed willingness to abide by the rules of the study.

Patient who have scored moderate and above moderate using DASS 21 scale for depression and anxiety are included in the study.

EXCLUSION CRITERIA

Patient with cognitive impairment like Alzheimer’s or unstable psychiatric illness

Patients with chronic illness, cancer, brain tumour.

SAMPLE SIZE

$$n = \frac{[(Z\alpha + Z\beta)\sigma]^2}{ES}$$

n = required sample size

Zα = is the Z value of an α error

Zβ = is the Z value of a β error

σ = standard deviation

$$n = \frac{[(1.96+0.84)\times 7]^2}{ES}$$

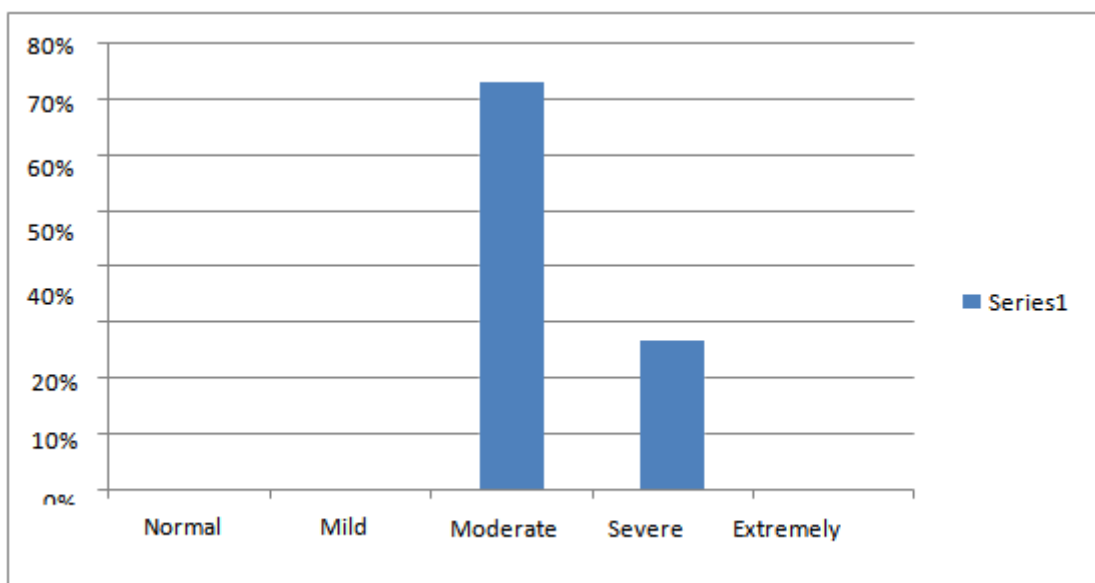
$$= [3.92]^2 \times 4$$

$$n = 64$$

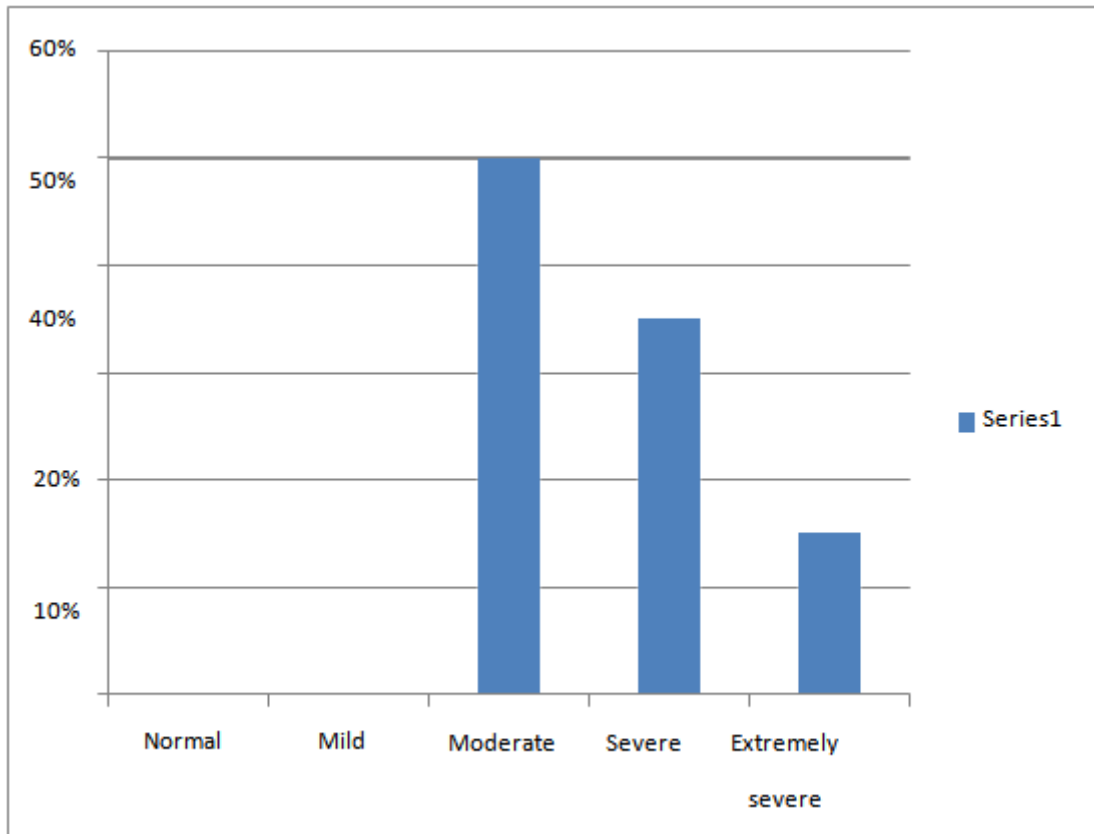
II. RESULTS

This prospective interventional study was conducted in the department of Neurology of KMCT Hospital for a period of 6 months. Although 64 patients were selected for the study, only 60 patients completed the program. All the required study materials like informed consent form, patient information sheet, data entry form was designed. Various scales like Beck Anxiety Scale, Beck Depression scale, MARS- 1 Scale were used. The level of depression, anxiety and adherence before and after the intervention was assessed.

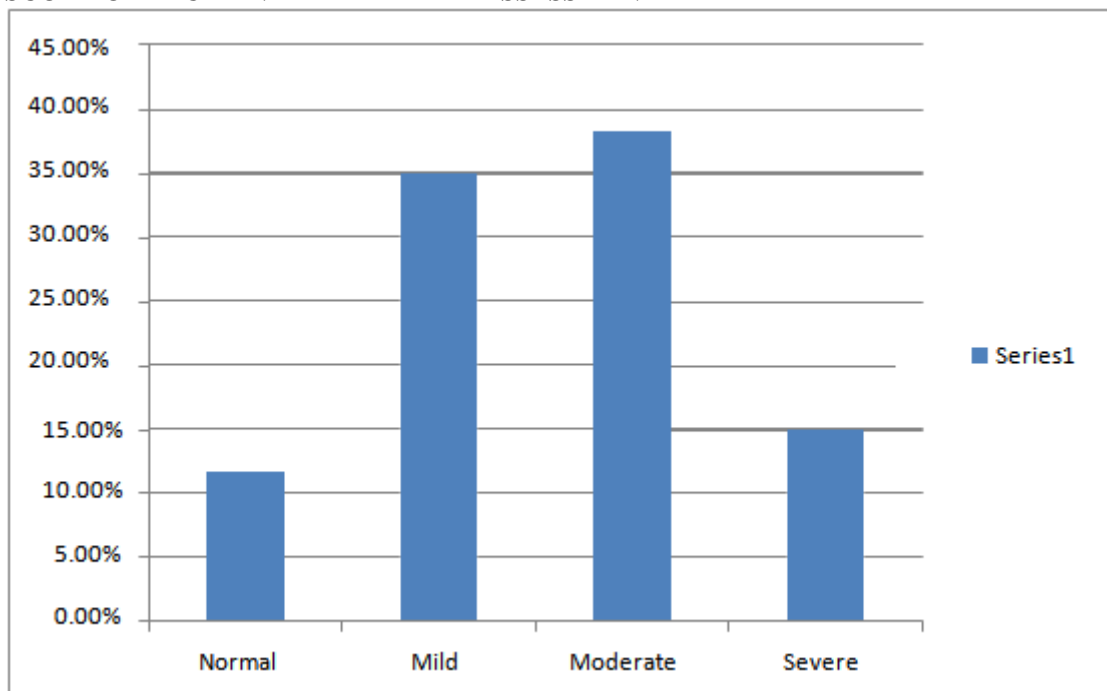
1) SCORE OF DASS-21 DEPRESSION



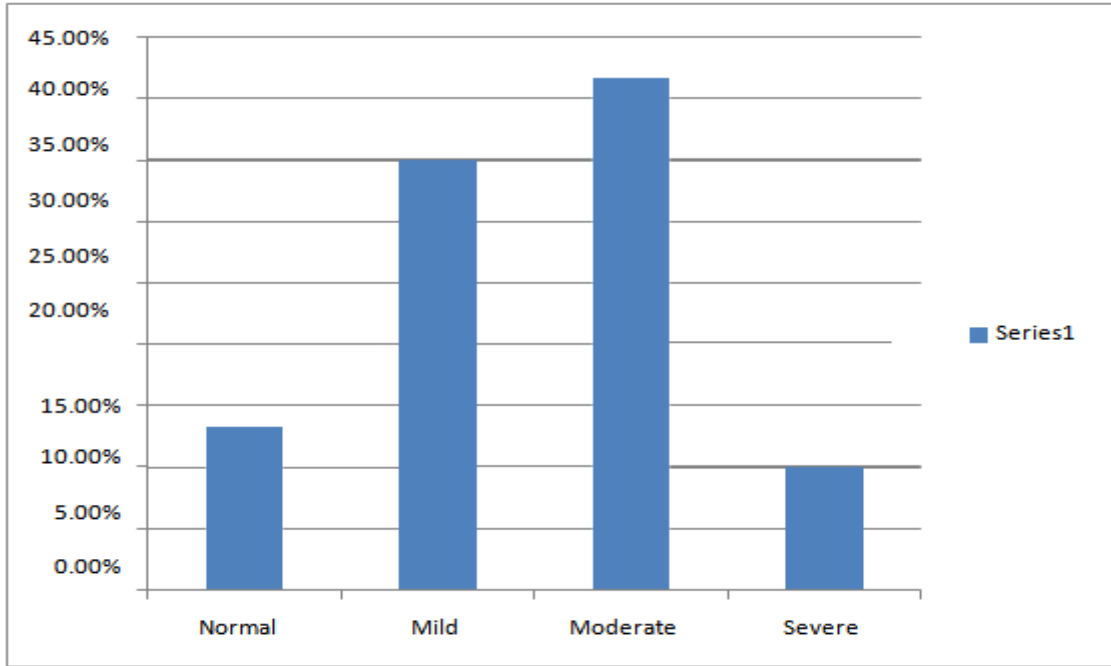
2) SCORE OF DASS-21 ANXIETY



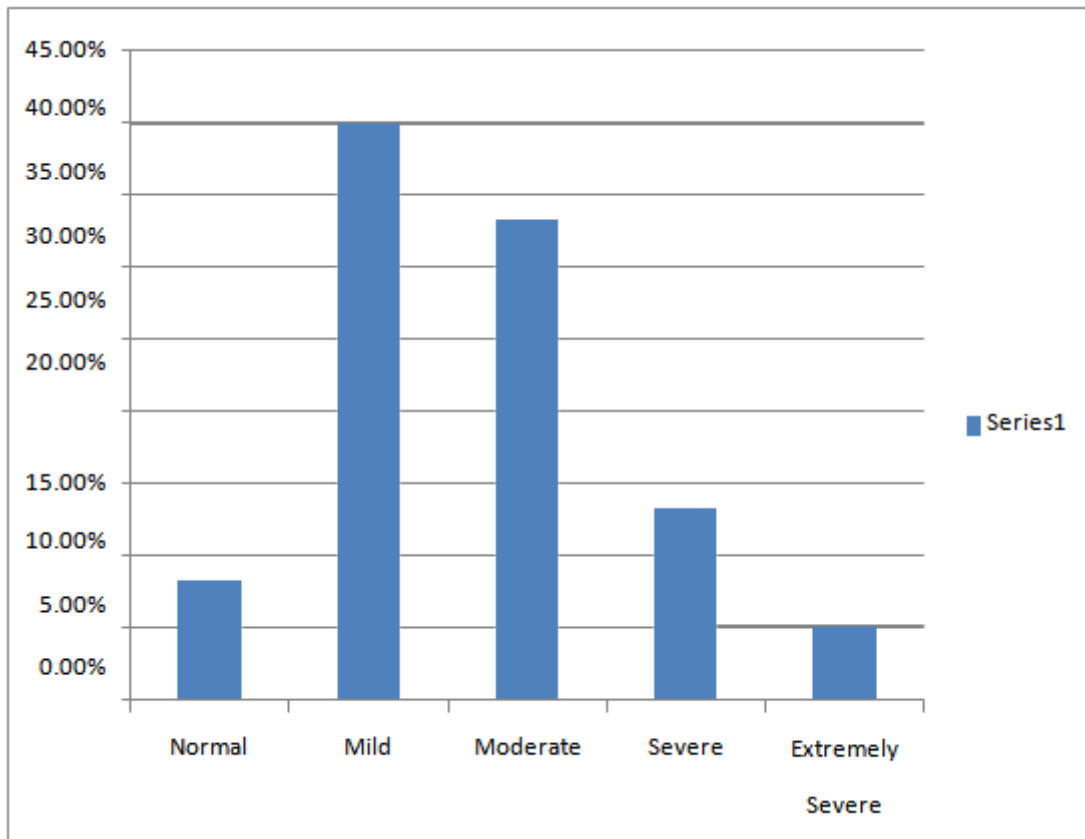
3) SCORE OF BECK ANXIETY AFTER 1st ASSESSMENT



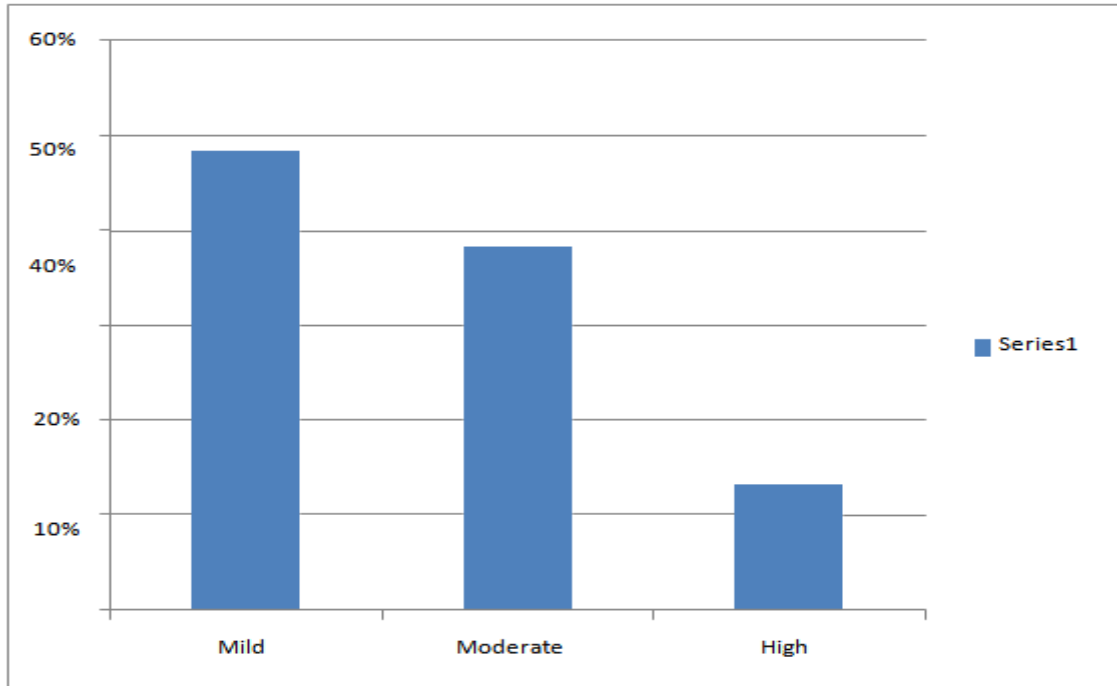
4) SCORE OF BECK ANXIETY AFTER 2nd ASSESSMENT



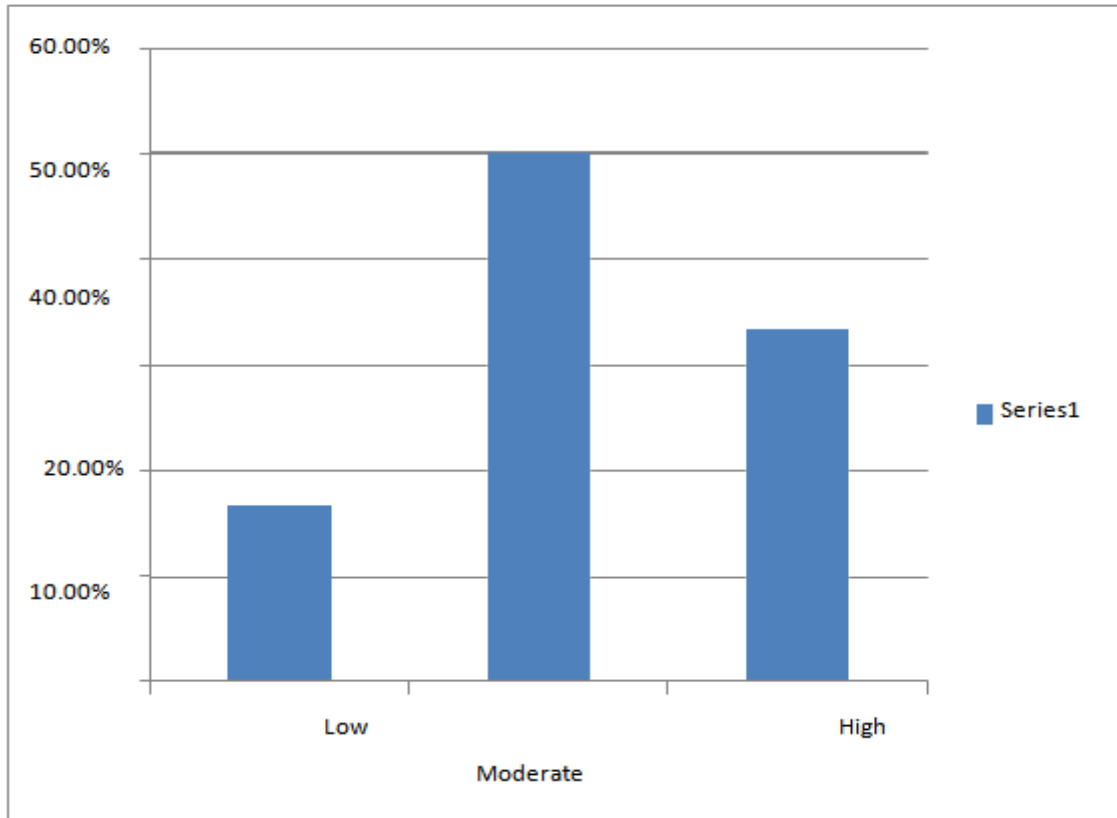
5) SCORE OF BECK ANXIETY AFTER 3rd ASSESSMENT



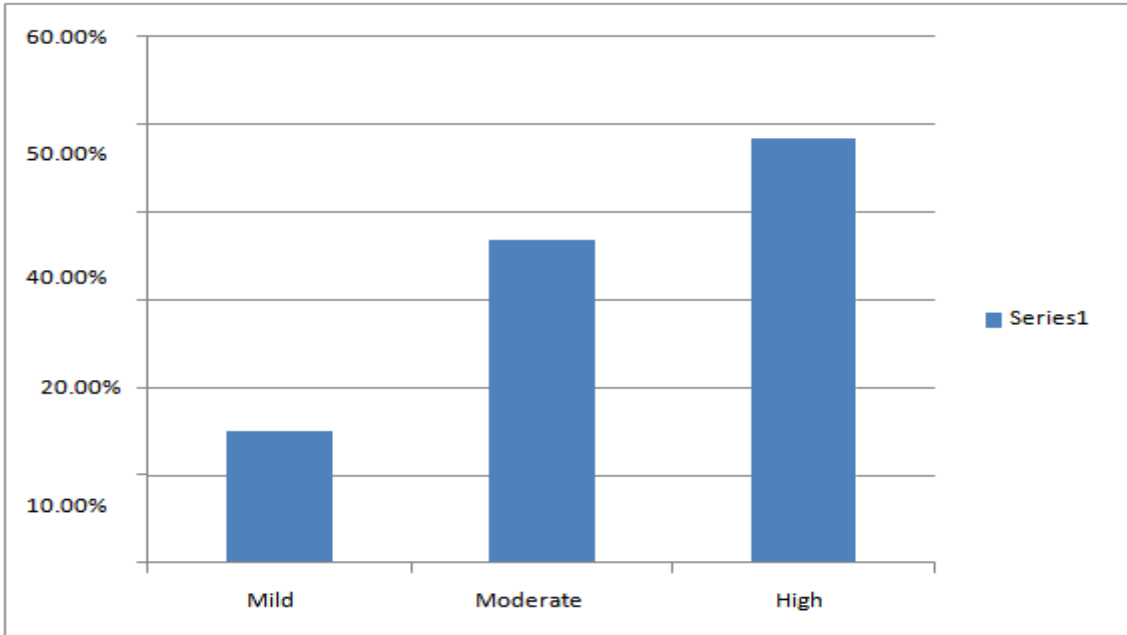
6) SCORE OF MARS-1 AFTER 1ST ASSESSMENT



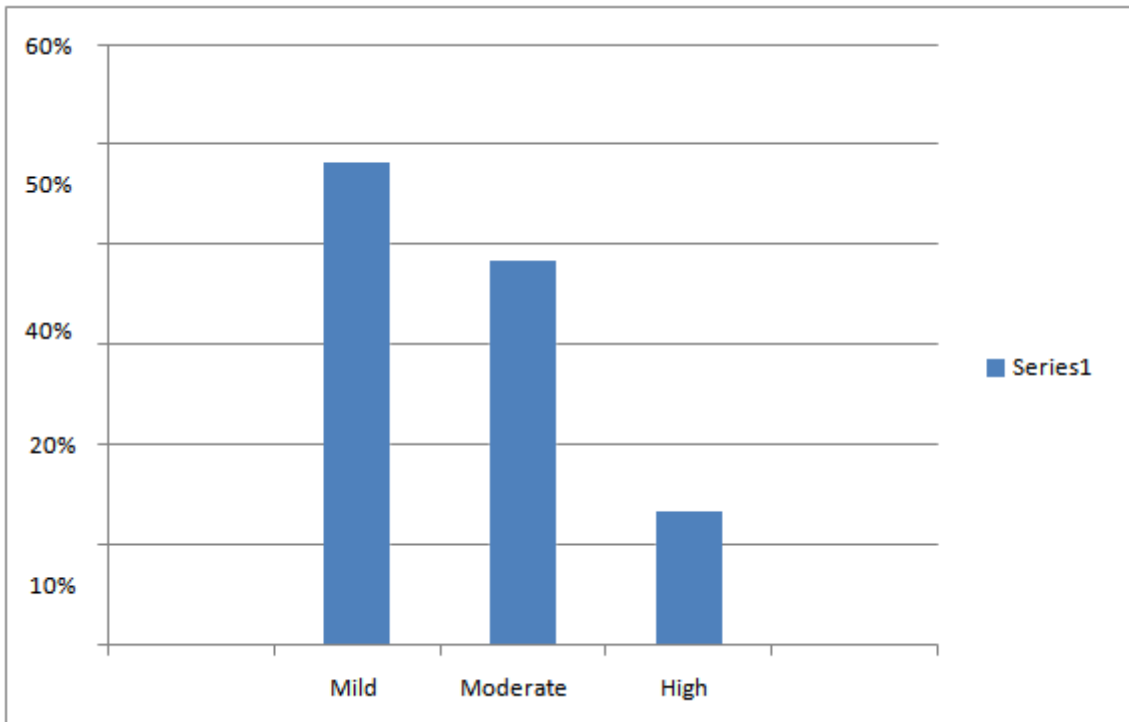
7) SCORE OF MARS-1 AFTER 2ND ASSESSMENT



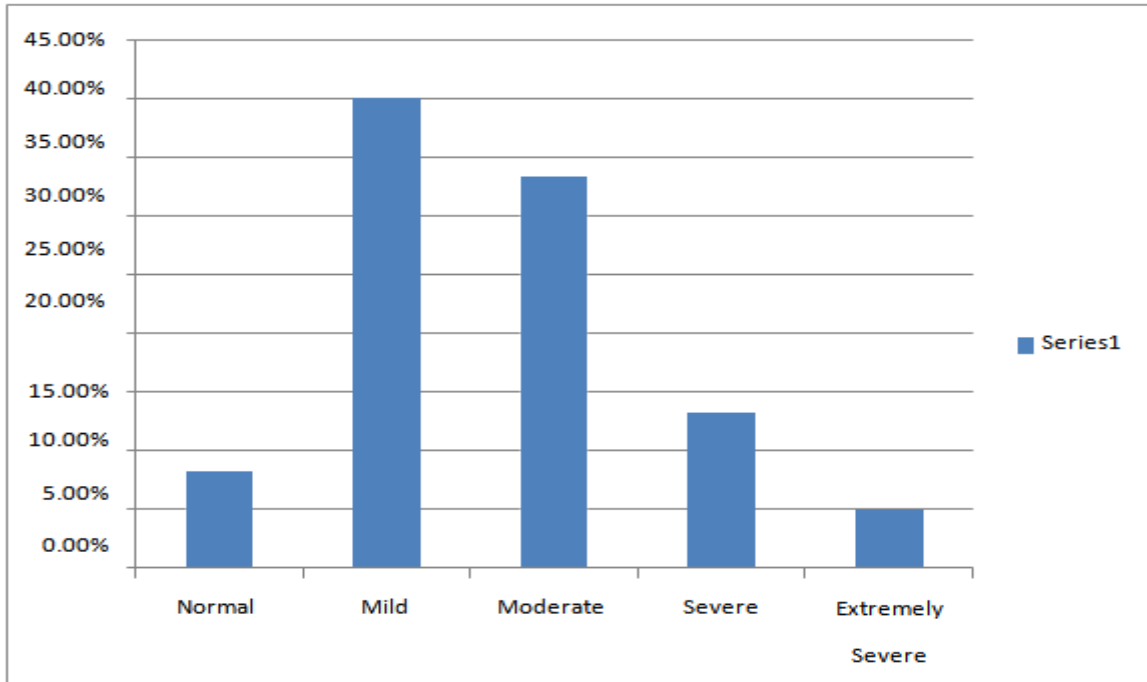
8) SCORE OF MARS-1 AFTER 3rd ASSESSMENT



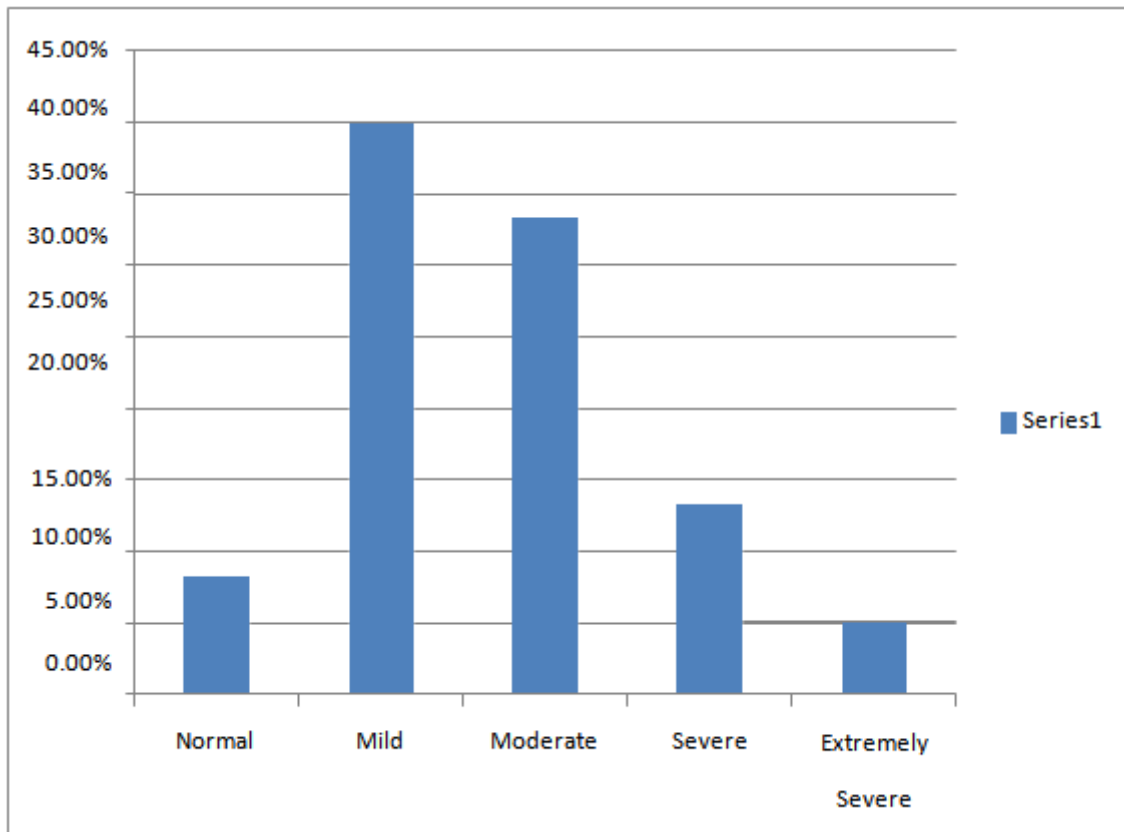
9) SCORE OF BECK DEPRESSION AFTER 1st ASSESSMENT



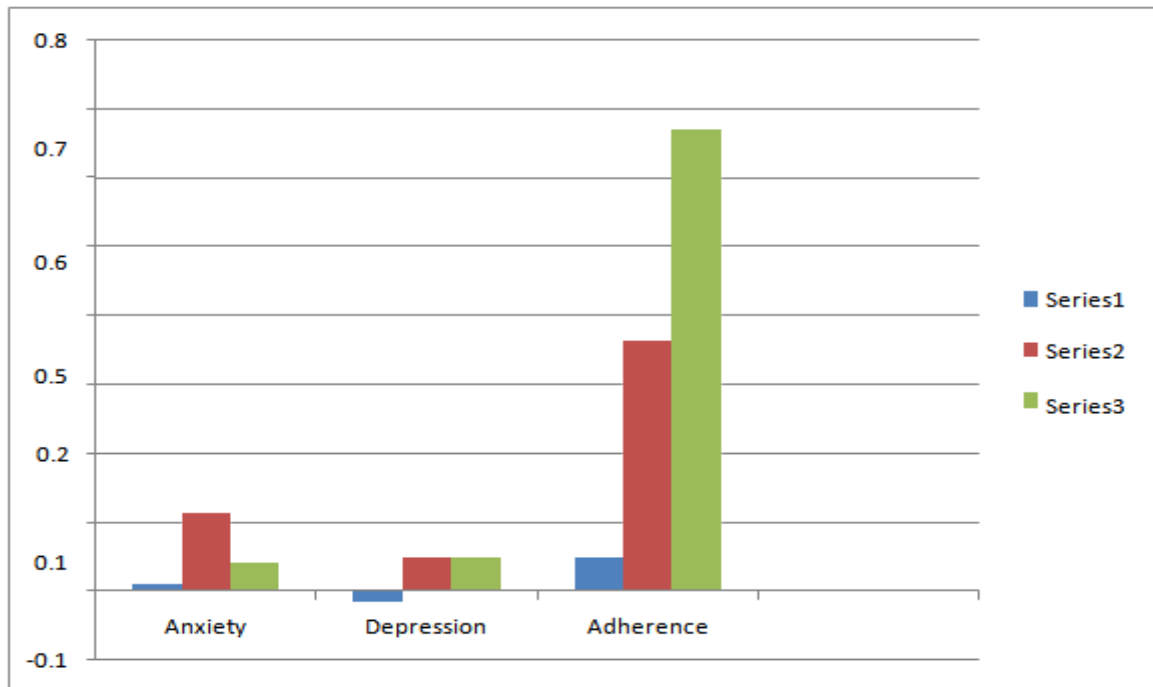
10) SCORE OF BECK DEPRESSION AFTER 2nd ASSESSMENT



11) SCORE OF BECK DEPRESSION AFTER 3rd ASSESSMENT



12) COMPARISON OF ANXIETY, DEPRESSION AND ADHERENCE BEFORE AND AFTER INTERVENTION



III. DISCUSSION

Epilepsy affects both the patient and their family members, requiring family-centered care. However, caregivers often lack knowledge to support the patient. This study aims to empower caregivers by providing necessary skills and knowledge.

In this context, the results of a study by Rau et al., who evaluated the effects of the modular education program on children with epilepsy and their parents, underlined that the education programs resulted in a significant improvement in the children's perceptions, school absenteeism, and frequency of seizures. The education programs helped the parents make significant improvements in their knowledge of epilepsy, their attitude to epilepsy, and their ability to manage epilepsy, and they reduced the parents' fear of epilepsy[18] Family caregivers often feel they lack sufficient knowledge and receive minimal guidance from health professionals to effectively provide care.[17] Caregivers must be supported and empowered in any culture and situation, particularly in the face of chronic disease.

Hasanvand et al. found that the most important educational priority for patients and families with epilepsy is related to drug use and illness, with families showing greater willingness

to receive information.[21] Cabral et al. suggested that psychoeducational interventions, psychosocial support, and resource identification for caregivers can enhance their understanding and confidence in patient care.[16] The findings of most of the studies mentioned above are in line with the current study, indicating an urgent need for the implementation of interventions for caregivers, especially programs with educational priorities.

IV. CONCLUSION

The findings revealed that a patient's adherence to pharmacological therapy was improved by a family-centered intervention programme. While depression remained same, there was a slight decrease in the amount anxiety. In light of this, the study found that some epileptic patients had a low quality of life..

LIMITATIONS OF THE STUDY

Limitations of this study were the psychological issues, individual issues and personality differences of caregivers, which might have affected the results.

To minimize these differences, we attempted to choose the samples randomly.

On the other hand receiving education and information from other sources might have influenced the results .

A significant difference in anxiety and depression cannot be noticed within the duration of 6 months.

ACKNOWLEDGEMENT

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