

# A study to assess medication adherence and quality of life among epilepsy patients seeking treatment at AIIMS Bhopal

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## ABSTRACT

**Background:** Epilepsy is a disorder of the brain with a permanent predisposition to produce epileptic seizures. There are cognitive, psychological, neurological, and social causes of this condition. It is the second most common problematic neurologic disorder, affecting more than 70 million people throughout the world. More than 65% of the global burden of epilepsy occurs in developing countries. **Objective:** To assess medication adherence and quality of life among epilepsy patients and to find any correlation between medication adherence and quality of life. **Material and Methods:** This descriptive study was conducted on epileptic patients who were seeking treatment at AIIMS Bhopal. Two hundred epileptic patients were enrolled in this study via purposive sampling techniques. Data was collected through face-to-face interview method. The data was analysed using descriptive and inferential statistics. **Results:** In this study, a total of 200 patients with epilepsy were found to be eligible to participate; there were 23 patients (11.5%) with low medication adherence, 95 patients (47.5%) with moderate medication adherence, and 82 patients (41%) with high medication adherence. Patients with epilepsy who follow recommended treatment have a good quality of life, particularly in the spiritual sector (169; 85%). The overall quality of life is moderate for 142 patients (71%) and good for 58 patients (29%). Medication adherence and quality of life were shown to be strongly positively correlated, with a Karl Pearson correlation coefficient of 0.67. **Conclusion:** The result of this study concluded that improving medication adherence is important to improving the quality of life among epilepsy patients.

**Keywords:** Epilepsy, medication adherence, quality of life

## Introduction

'Epilepsy is a brain disorder with an enduring propensity to produce epileptic seizures and the cognitive, psychological, neurological, and social causes of this condition', says the definition of this ailment. Around the world, 50 million people are affected, regardless of their nationality, location, age, race, or social status.<sup>[1]</sup>

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The second most problematic neurological disorder is epilepsy throughout the world. It is a global public health issue that affects more than 70 million people throughout the world, and developing countries have more than 65% of the global burden. In Africa, the number of people affected by epilepsy is approximately 10 million. The most affected country is Ethiopia in Africa, with an approximate prevalence of 5.2 per 1000 people. Epilepsy is a debilitating disease, and the consequences of this disease are as follows: psychological and neurological damage, social indictment, spoiled quality of life, frequent physical injury, poor academic performance, and decreased employment as a result of a reduced lifetime.<sup>[2]</sup>

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Millions of people throughout the world suffer from epilepsy, a chronic neurological illness marked by recurring seizures that have a big impact on their everyday lives. Although improvements in medical therapies have provided viable alternatives for controlling seizures, the best outcome frequently depends on rigorous adherence to the recommended prescription regimens. Medication adherence, which is measured by the extent to which patients follow doctors' orders to take their prescriptions, is crucial for epilepsy management and reducing the physical, psychological, and social ramifications of epilepsy.

The estimated number of epileptics in India in 2019 was 10 million (95% UI 8 40–11 9), of which 4 million (284–25) had epilepsy of idiopathic aetiology and 6 million (528–689) had secondary epilepsy.<sup>[3]</sup> This common disease can be controlled and treated at an affordable cost very effectively. Adherence to medication is a major pillar of the effectiveness of antiepileptic drugs.<sup>[4]</sup>

Despite the acknowledged importance of medication adherence, non-adherence remains a pervasive issue among individuals with epilepsy. Reasons for non-adherence are diverse and may include concerns about side effects, forgetfulness, economic constraints, and misconceptions about the necessity of continued treatment. This study seeks to identify and address these barriers, aiming to improve patient education and support systems to enhance medication adherence rates.

The objective of this research study is to comprehensively explore the relationship between medication adherence and the quality of life experienced by patients with epilepsy. Quality of life is a multifaceted construct that encompasses various dimensions, including physical, psychological, social, and environmental well-being. In the context of epilepsy, understanding how adherence influences these dimensions is essential for developing tailored interventions and optimizing therapeutic strategies.

Therapeutic adherence can be assessed using a variety of techniques, such as self-reporting, pill counting, appointment attendance, history of medicine refills, blood or urine drug levels, and drug diaries.<sup>[5]</sup> Using a variety of collecting techniques, numerous studies have attempted to document medication adherence disparities among the epileptic group. Patient-reported assessments, such as the Morisky Medication Adherence Scale-4 and Morisky Medication Adherence Scale-8, have been among the most commonly used methods.<sup>[6]</sup>

Primary care physicians (PCPs) play a crucial role in monitoring and ensuring that epilepsy patients follow their prescribed treatment regimen. At first, doctors may identify epilepsy and prescribe antiepileptic drugs, then inform patients about the long-term nature of the disorder and the importance of regularly taking medicine to properly control seizures. PCPs provide routine follow-up visits to track patients' progress and ensure they comply with the approved treatment plan. In

addition, they identify and tackle obstacles to adherence, such as adverse effects of medicine, financial limitations, lapses in memory, and misunderstandings regarding treatment. PCPs work together with neurologists and other specialists to organize and manage all aspects of patient care, making necessary changes to drug doses or formulations based on the patient's reaction. In addition, they assess and handle concurrent medical conditions linked to epilepsy, acknowledging their possible influence on the patient's ability to follow their pharmaceutical regimen. PCPs have a crucial role in increasing the adherence to medication among epilepsy patients by promoting healthy lifestyle changes and offering continuous support. This ultimately leads to better treatment results and a higher quality of life.

## Materials and Methods

This was a non-experimental descriptive study conducted on patients with epilepsy seeking treatment at AIIMS Bhopal. 200 epilepsy patients were enrolled in this study via the non-probability purposive sampling technique. Data was collected through face-to-face as well as telephonic interview methods for a duration of approximately 2 months. (10/09/2021 to 03/11/2021)

### Sample size calculation

$$N = Z^2 * p * q / d^2$$

$$Z = 1.96, P = 53, q = 47\%, d = 7.9$$

d is the relative of p (15–20%), and the absolute of p is 1–5%.

$$\text{So } 15\% \text{ of } 53 = 7.9$$

Sample size was calculated using the prevalence of adherence to medication and an allowable relative (53%) error of 15% with a 30% (Covid) non-response rate, so the sample came out to be 198, and the final study was done on 200 patients.<sup>[1]</sup>

### Sampling criteria

#### Inclusion criteria:

- Adolescents and adults who were diagnosed with epilepsy.
- Patients have been on antiepileptic drug treatment for at least three months.
- Patients who know Hindi, English, or both.

#### Exclusion criteria:

- Patients who do not give consent for the study
- Patients with co-morbidities and other psychiatric disorders.

### Data collection tools and instruments

The investigator selected a self-structured questionnaire as the research instrument to assess medication adherence and quality of life among epilepsy patients.

The tool for the study was constructed in four phases:

1. Extensive review of literature, books, and published and unpublished theses.
2. Preparation of the blueprint: the blueprint was prepared under three headings: socio-demographic variables, medication adherence, and quality of life.
3. Guidance and consultation from the guide, co-guide, and subject experts from different relevant fields
4. Modification of the tool as per experts' suggestions and final drafting

## Description of the tools

The tool was organized into three parts, which consisted of the following aspects:

**Section A: Demographic Performa:** The demographic performa and clinical profile consist of 16 items for obtaining information regarding age, gender, marital status, educational status, etc.

**Section B: Binomial Scale (Yes/No):** A binomial scale to assess medication adherence among epileptic patients consists of ten questions. The scoring was done by counting the responses according to the total score obtained. The highest possible score was 10. It was arbitrarily classified into three levels on the basis of percentage: 0–33% (low adherence), 34%–67% (moderate adherence), and 68%–100% (high adherence). The parts of the binomial scale were to assess the level of medication adherence in epileptic patients.

**Section C: Rating scale on quality of life among epilepsy patients:** The rating scale on quality of life among epilepsy patients had 27 items. The scoring was done by just counting the correct responses according to the total score obtained. The highest possible score was 135. It was arbitrarily classified into three levels: [1–45 (low quality of life), 46–91 (moderate quality of life), and 92–135 (high quality of life). The domains of the rating scale on quality of life among epileptic patients are as follows:

- Physical health.
- Psychological health.
- Social domain.
- Spiritual domain.

## Content validity and reliability of the tool

The prepared tool, along with the objectives and blueprint, was submitted to ten experts. Experts were requested to give their opinions and suggestions regarding each item in the tool. The items of the tool were modified according to the recommendations and suggestions of the experts. The inter-rater reliability of the tool (medication adherence) was 0.7481, and for another tool (quality of life), it was 0.968. This indicates the tool is reliable and valid.

## Ethical considerations

The study was approved by the ethical committee of the institute. (Reference number: 2020/MSc (Nursing)/July/06)

## Try out and pilot study

Before the main study, a pilot study was conducted in 20 epileptic patients attending the outpatient department of neurology. Pilot study samples were excluded from the main study. The study was found to be feasible, practical, and acceptable.

## Procedure of data collection

The investigator obtained permissions from the concerned authorities prior to the data collection process. The purpose of the study was explained to the respondents, and informed consent was obtained from the study participants. Confidentiality and anonymity were assured to all the participants to gain their confidence and cooperation.

Data was collected from the study participants in the Neurology OPD of AIIMS Bhopal. Neurology OPD was on Monday, Wednesday, and Friday. On every OPD day, a maximum of 8–9 patients used to come either for follow-up or as new outpatients. On every Tuesday, Thursday, and Saturday, 2–3 epilepsy patients who need EEGs are used to attain neurology OPD. Data for the main study was collected from September 10, 2021, to November 3, 2021.

## Data analysis and interpretation

The data obtained was planned to be analysed using descriptive statistics on the basis of the objectives of the study. To compute the data, a master data sheet was prepared by investigators. The data was analysed as follows:

- Socio-demographic data was analysed using frequency and percentage.
- The medication adherence questionnaire and quality of life tool were analysed as per the scoring criteria using frequency and percentage.
- The correlation between medication adherence and quality of life was analysed using the Karl Pearson correlation coefficient.

## Results

The result of the study was divided into four sections:

*Section 1: Distribution of samples based on their demographic and clinical profile:* Among demographic variables, 52% (104) of patients are above 40 years of age, and 48% (96) are below 40 years of age. Among the genders, the majority were male patients (111), 55.5% were female, 44.5% (89) were female, and none of the participants were transgender. The majority are unmarried. 38% (76), 21% (42) participants were married, 26% (13%) were widowed, and 56% (28%) were divorced. The majority of the patients (85) 42% had a medium school diploma, 63% had a high school diploma, and 48% had a bachelor's degree or higher. The majority are in the farming category (86), or 43%. The majority have family income in the 5001–10000 category (143), or 71.5%. The majority live in the urban area (128) (64%). (126) 61% of participants have no family history of epilepsy. The majority of the patients

are on multiple-drug therapy (168) (84%). Most patients forget to take medications 5–8 times weekly (95.5%). (115) 57.5% of participants had 4–6 times the seizure frequency (weekly) before starting treatment. The majority of the patients have generalized seizures (146), or 73%. (115) 57.5% of the participants have adverse effects of epilepsy, which include excessive sleep and headaches. (104) 52% of the population has another disease like hypertension, DM, thyroid disorder, etc., [Table 1]

*Section 2: Distribution of epileptic patients based on their medication adherence:* The researcher found that 95 (47.5%) participants had moderate adherence to medication, 82 (41%) participants had high adherence to medication, and 23 (11.5%) participants had low adherence to medication. [Table 2]

*Section 3: Distribution of epileptic patients based on their quality of life:* The researcher found that 142 (71%) participants had a moderate quality of life and 58 (29%) participants had a high quality of life [Table 3].

*Section 4: To find a correlation between medication adherence and quality of life among epilepsy patients seeking treatment in AIIMS Bhopal:* The researcher used the Karl Pearson correlation formula, and the value obtained was 0.67, which means a strong positive correlation between quality of life and medication adherence at the 0.05 level of significance. The result revealed that medication adherence and quality of life had a strong positive correlation, i.e. as medication adherence increased, quality of life also improved among epileptic patients.

## Discussion

We conducted the present study to investigate medication adherence and quality of life among epilepsy patients. The total sample was 200. More than half (52%) of the study participants were over 40 years of age, and approximately 55.5% of the population was male. Less than half, 37% of the population had a positive family history of epilepsy, and 61% of the population did not have a family history of epilepsy. Nearly 16% of the population was on a single medication, and 84% of the population was on more than one medication. Nearly one-fourth, 27% of the population had focal seizures, and 73% of the population had generalized seizures. Ayu *et al.*<sup>[7]</sup> conducted another study, which revealed that 49% of participants are under 40 years of age, while 34% are above 40 years of age. 45% of the population are males, and three-fourths (75%) of the population did not have a family history of epilepsy. Around 37% of the population was on a single medication, and 46% were on more than one medication. 13% of the population had focal seizures, and 70% of the population had generalized seizures. Nearly three-fourths (75%) of the respondents have side effects from AEDs.

About half of the participants (47.5%) had moderate adherence to medication, 41% had high adherence to medication, and 11.5% had low adherence to medication. Verma *et al.*<sup>[8]</sup> conducted

**Table 1: Frequency and percentage-wise distribution of samples based on their sociodemographic data**

Demographic variables	Frequency (n)	Percentage (100%)
Age in year		
<40 years	96	48%
>40 years	104	52%
Gender		
Male	111	55.5%
Female	89	44.5%
Transgender	00	00%
Marital status		
Married	76	38%
Unmarried	42	21%
Widow	26	13%
Divorced	56	28%
Educational status		
Primary school	04	2.0%
Medium school	85	42%
Higher secondary school	63	31.5%
Graduation or above	48	24%
Illiterate	00	00%
Employment status		
Housewife	06	3%
Farmer	86	43%
Self-employed	68	34%
Government Service	13	6.5%
Labourer	27	13.5%
Other	00	00%
Monthly family income (Rupees)		
<5000	06	3%
5001-10000	143	71.5%
10001-15000	30	15%
>15000	21	10.5%
Residence		
Rural	39	19.5%
Urban	128	64%
Semi-urban	33	16.5%
Does any family member have epilepsy?		
Yes	74	37%
No	126	61%

Demographic variables (n=200)

**Table 2: Frequency and percentage of medication adherence (n=200)**

Medication adherence	Frequency (n)	Percentage
Low adherence	23	11.5
Moderate adherence	95	47.5
High adherence	82	41

**Table 3: Categorization of participants based on quality of life (n=200)**

Quality of life	Frequency (n)	Percentage
Low quality	00	0%
Moderate quality	142	71%
High quality	58	29%



a previous study that matched the present study's findings, reporting 57% of patients as non-adherent to treatment, 49.6% with moderate adherence, and 7.4% with low adherence levels. The categories of adherence in the present study differ from the previous study in terms of low, moderate, and high medication adherence.

In the present study, we found that a maximum of 71% of the population had a moderate quality of life, whereas 29% of the population had a high quality of life, and no participant had a low quality of life. The quality of life of epilepsy patients in this study aligned with findings from another study by T. Ogundare *et al.*<sup>[9]</sup>

In the current study, the researcher discovered that Karl Pearson's correlation coefficient between medication adherence and quality of life was 0.67, indicating a very high positive association between the two. The findings showed a strong positive link between medication adherence and quality of life, i.e. that as medication adherence increased, epileptic patients' quality of life also increased. In 2016, Lin C-Y *et al.*<sup>[10]</sup> conducted a study using the Medication Adherence Reporting Scale-5, QOLIE, and Liverpool Seizure Severity Scale and investigated the relationship between medication adherence and quality of life. Some of the present study's findings were consistent with the previous study. The findings of the previous study were: The overall QOLIE-31 scores and all the subcategory scores were significantly correlated with the MARS-5 score. The previous study had the following differences: more than one scale was used to assess the quality of life, the sample size was larger (807), the patient's quality of life was measured at follow-up (18 months), and only single drug patients were taken.

In addition, the study highlighted the need for comprehensive patient education and support programs. Providing patients with a thorough understanding of their condition, the importance of adherence, and strategies for overcoming adherence challenges proved to be a pivotal factor in promoting consistent medication use. Equipping patients with the knowledge and tools to manage their epilepsy effectively fosters a sense of self-efficacy and empowers them to take an active role in their own health care.

Epilepsy patients' medication adherence is closely monitored by PCPs. PCPs assess patients' progress and ensure they continue the regimen with regular visits. They also handle drug adverse effects, budgetary restraints, forgetfulness, and therapy misunderstandings. PCPs help epilepsy patients adhere to their medications by promoting healthy lifestyle changes and giving continuing support. This improves treatment results and quality of life.

## Limitations

Although the study's quantitative component gave insightful information about adherence level and its effect on the quality of life of epileptic patients, the study's focus might not have included all of the difficulties and barriers that people with epilepsy

encounter in maintaining medication adherence. Additional elements that may affect medicine adherence in future research include socioeconomic position, cultural attitudes, financial burdens, etc.

## Conclusion

A final investigation on 200 patients suggests that medication adherence enhances quality of life. Drug adherence is positively correlated with quality of life (0.67), and therefore epilepsy patients must adhere to their medications. This study concludes that medication adherence improves epilepsy patients' quality of life. According to the findings, patient education, personalized support systems, and barriers-specific treatments are needed to promote adherence. A holistic approach to epilepsy care improves clinical results and patient well-being and resilience. This study urges healthcare professionals, governments, and stakeholders to work together to promote patient-centred initiatives that help epilepsy patients live fulfilled lives.

## Disclosures human study participants

Consent was obtained by all study participants in this study. Ethical approval prior to the conduct of the study was obtained by the institute ethical committee with reference number 2020/MSc (Nursing)/July/06.

## Animal study participants

All authors have confirmed that this study did not involve animal study participants or tissue.

## Other relationships

All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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Nil.

## Conflicts of interest

There are no conflicts of interest.

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