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# Illness Perception is a Predictor of Medication Adherence and Health Related Quality of Life in Patients Living with Epilepsy

Unyime Eshiet<sup>1\*</sup>, Bertha Ekeh<sup>2</sup> and Sidney Oparah<sup>3</sup>

<sup>1</sup>Department of Clinical Pharmacy and Biopharmacy, University of Uyo, Nigeria. <sup>2</sup>Department of Internal Medicine, University of Uyo Teaching Hospital, Nigeria. <sup>3</sup>Department of Internal Medicine, University of Calabar Teaching Hospital, Nigeria.

#### Authors' contributions

This work was carried out in collaboration among all authors. Author UE designed the study, performed the statistical analysis, wrote the protocol and wrote the first draft of the manuscript. Authors BE and SO managed the analyses of the study and the literature searches. All authors read and approved the final manuscript.

#### Article Information

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Original Research Article

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#### ABSTRACT

**Objective:** To determine the relationship between illness perception, medication adherence and health related quality of life in patients living with epilepsy.

**Design:** A cross-sectional prospective survey among patients living with epilepsy recruited from two tertiary referral centers in Nigeria.

**Methods:** Patients' illness perception, adherence to antiepileptic drugs, and health related quality of life were determined using the brief illness perception questionnaire (BIPQ), the eight-item Morisky medication adherence scale (MMAS-8), and the patient weighted quality of life in epilepsy instrument (QOLIE-10-P) respectively. Correlation and linear regression analysis were used to test the relationship between the assessment variables. Statistical significance was set at p < 0.05.

<sup>\*</sup>Corresponding author: E-mail: unyimeeshiet@uniuyo.edu.ng;

**Results:** Multivariate linear regression revealed that patients' medication adherence score was predicted by their illness perception score (B = -0.030; p = 0.033). Also, patients' QOLIE score was predicted by their illness perception score (B = -0.318; p = 0.0001). **Conclusion:** In patients living with epilepsy, illness perception is a predictor of their adherence to

antiepileptic drug regimen and their health-related quality of life.

Keywords: Epilepsy; illness perception; predictor; adherence; quality of life.

#### **1. INTRODUCTION**

Rating scales have been used in epilepsy management to define patient status and changes that occur during long term observation of the patient. The scores derived from such scales can be used as guidelines for intervention, treatment, or prediction of outcome. The concept of using rating scales in evaluating clinical parameters including physical examinations and functional performance is termed clinimetrics [1]. In epilepsy management, clinimetric scales have been used in determining important assessment variables including patients' quality of life in epilepsy (QOLIE) [1].

Epilepsy can be associated with great physical, psychological and social consequences and its effect on a person's quality of life can be greater than that of some other chronic conditions [2,3]. A number of factors are believed to contribute to this, including the unpredictability of seizures as well as the stigma usually associated with epilepsy [3].

According to the World Health Organization (WHO) report, an estimated 10% of the global burden of brain and mental disorders is caused by epilepsy, calculated in disability-adjusted life years. This calculation also includes premature deaths and loss of healthy life due to disability. The estimate does not include the stigma and social exclusion or the impact on the family of those with epilepsy. Epilepsy is often misunderstood, resulting in fear. secrecy. stigmatization and the risk of social discrimination [2].

The impact of epilepsy on the quality of life of the patient can be considerably high with farreaching and life-long consequences. There is now growing recognition that when assessing the impact of epilepsy, patients and physicians should look beyond counting seizures [3]. Primary aspects of quality of life influenced by epilepsy include but not limited to education, employment, independence, driving, and social isolation [4,5,6,7]. Medication adherence is an important part of patient care and is indispensable in the attainment of clinical goals [8]. Medication nonadherence does not only impact negatively on the clinical outcome but also affects the financial outcome of the health system. The multi-factorial causes of medication non-adherence need to be understood before appropriate interventions can be implemented to improve medication adherence [9].

Assessing patients' illness perception, adherence to antiepileptic drugs, and quality of life in epilepsy is important as these assessment variables should be taken into consideration during therapeutic management of the condition. Unfortunately, not many studies have reported these outcome variables in defined populations. Moreover, studies evaluating the quality of life associated with successful treatment of epilepsy are quite a few compared to that of other chronic conditions, such as cancer, diabetes and cardiovascular disease [2]. This study was aimed at determining the relationship between patients' illness perception, adherence to antiepileptic drugs, and their quality of life in epilepsy.

#### 2. METHODS

#### 2.1 Study Design

A cross-sectional prospective survey using validated instruments to interview patients with epilepsy.

#### 2.2 Study Setting

The study was conducted in Nigeria at the University of Uyo Teaching Hospital in Uyo-Akwa Ibom State and the University of Calabar Teaching Hospital in Calabar-Cross River State. Patients were recruited from the Neurology and Medical out-patient clinics of the hospitals.

#### 2.3 Study Population/Sample Size

To ensure sufficient statistical power, all patients diagnosed with epilepsy and receiving treatment

for epilepsy at the hospitals that fulfilled eligibility criteria were identified and recruited into the study.

The eligibility criteria were:

- i. Patients diagnosed with epilepsy.
- ii. Patients receiving treatment for epilepsy in the study sites, and
- iii. Patients who provided a written informed consent to participate in the study.

The diagnosis of epilepsy was done by a neurologist after a detailed history, neurologic examination, and general physical examination. Laboratory evaluations served as adjunctive assays.

## 2.4 Determination of Patients' Illness Perception, Medication Adherence and Quality of Life in Epilepsy

Standardized instruments were used for the evaluation of patients' illness perception, medication adherence, and quality of life in epilepsy.

Instruments used were:

- i. The Brief Illness Perception Questionnaire (BIPQ),
- ii. The Eight-item Morisky Medication Adherence Scale (MMAS-8) and
- iii. Patient Weighted Quality of Life in Epilepsy Questionnaire (QOLIE-10-P).

#### 2.4.1 The brief illness perception questionnaire

The Brief illness perception questionnaire was used to assess the patients' perception of the condition. It has eight items plus one causal scale. All of the items except the causal question are rated using a 0-to-10 response scale. A high overall score reflects а poor perception/threatening view of the illness. Five of the items assess cognitive illness representations: consequences (Item 1), timeline (Item 2), personal control (Item 3), treatment control (Item 4), and identity (Item 5). Two of the items assess emotional representations: concern (Item 6) and emotions (Item 8). One item assesses illness comprehensibility (Item 7). Assessment of the causal representation is an open-ended response item that asks patients to list the three most important causal factors in their illness (Item 9) [10]. A systematic evaluation

of the validity and reliability of the brief illness perception questionnaire has been conducted. The brief illness perception questionnaire scores correlate moderately with most of the measured health outcomes. Pearson's correlations for testretest reliability were generally acceptable (range 0.5–0.7) [10,11].

# 2.4.2 The eight-item Morisky medication adherence scale

The Eight-Item Morisky Medication Adherence Scale (MMAS-8) was used to determine the patients' level of adherence to antiepileptic drug therapy. It is based on the medication adherence questionnaire developed by Morisky et al. in 1986 [12]. The MMAS-8 was developed by Morisky et al. in 2008. The first seven items are Yes/No responses while the last item is a 5-point Likert response. It focuses on medication taking behaviours, especially related to underuse, such as forgetfulness, so barriers to adherence can be identified more clearly. A sensitivity of 93% and 53% specificity were reported while validating in "very low-income minority patients treated for hypertension seeking routine care in a clinic setting" [13]. MMAS is also validated with acceptable validity and reliability in patients with other chronic diseases. As a result, it is probably the most accepted self-report measure for adherence to medication [13,14,15]. Hence, it is recommended to serve as a screening tool for validated conditions in the clinic setting.

#### 2.4.3 Patient Weighted Quality of Life in Epilepsy (QOLIE-10-P) questionnaire

Patient-weighted quality of life in epilepsy was assessed by the QOLIE-10-P, an adapted and extended version of the brief questionnaire QOLIE-10 [16]. The QOLIE-10 is a selfadministered questionnaire that covers general and epilepsy-specific areas. It is designed to be completed by patients alone and not their caregiver. QOLIE-10 was derived from the QOLIE-31 and comprises of seven components namely: seizure worry (1 item), overall quality of life (1 item), emotional well-being (1 item), energy-fatigue (1 item), cognitive functioning (1 item), medication effects (2 items - physical effects and mental effects) and social function (3 items - work, driving, and social function). For each of the domains, the degree of impairment within the last four weeks is rated. The overall score in QOLIE-10-P ranges from 0 to 100, with higher scores representing better quality of life [16].

#### 2.5 Data Analysis

Data were analyzed using the IBM Statistical Products and Services Solutions (SPSS) for Windows, version 25.0 (IBM Corp, version 25.0 Armonk, NY and USA). Frequencies and means were used to summarize descriptive statistics. Correlation and linear regression analysis were used to test the relationship between both assessment variables. Statistical significance was set at p < 0.05.

#### 3. RESULTS

#### **3.1 Clinical Parameters of Respondents**

A total of 193 patients with epilepsy participated in the study. The clinical parameters of the respondents is as shown in Table 1.

#### 3.2 Mean Scores of Patients' Illness Perception, Medication Adherence and Quality of Life in Epilepsy

The mean scores of the patients' illness perception, medication adherence, and quality of life in epilepsy is as presented in Table 2.

#### 3.3 Relationship between Patients Illness Perception, Medication Adherence and Quality of Life in Epilepsy

Correlation analysis was conducted among the assessment variables to observe the relationship which exists between the variables. In this bivariate analysis, results showed that patients' medication adherence score was significantly negatively correlated with their illness perception score (r = -0.328; p = 0.001), suggesting that as patients' illness perception score decreased, their medication adherence score increased. Also, patients' quality of life in epilepsy score was significantly negatively correlated with their illness perception scores (r = -0.415; p = 0.001), suggesting that a decrease in patients' illness perception scores would result in an improvement in the patients' quality of life score.

Multivariate linear regression revealed that patients' medication adherence score was predicted by their illness perception score (B = -0.030; p = 0.033), showing that every unit decrease in illness perception score increases medication adherence by 0.030 units. Furthermore, patients' weighted quality of life in epilepsy score was predicted by the illness

perception score (B = -0.318; p = 0.0001). This shows that every unit decrease in illness perception score improves quality of life by 0.318 units.

#### 4. DISCUSSION

Correlation and linear regression analysis are commonly used techniques for assessing the relationship between quantitative variables. Both techniques can be used to investigate the presence of a linear relationship between variables [17].

The authors' found the patients' medication adherence to be significantly negatively correlated with their illness perception, and that illness perception was a predictor of medication adherence. Thus, revealing that an improvement in patients' perception of epilepsy would enhance adherence to prescribed antiepileptic drugs. Patients' beliefs determine patients' behaviour towards the management of their illness. It affects self-care measures, including adherence to treatment regimen [18].

The quality of life of people living with epilepsy is impaired when compared with the general population. The impaired quality of life of people living with epilepsy is significantly associated with symptoms of depression, anxiety, perceived stigmatization and poor seizure control [19]. There is an increased risk of depression, poor self -esteem, and suicide among persons living with epilepsy. Many of them live in perpetual fear of having another seizure [20]. Depression is a powerful predictor of quality of life in epilepsy. Boylan et al. in their study concluded that depression but not seizure frequency predicts the quality of life in treatment-resistant epilepsy [21]. We found that the health-related quality of life of the patients was negatively correlated with their illness perception. Furthermore, regression analysis revealed that the health-related quality of life of the patients was influenced by their illness perception. The better the perception of the patients towards their condition, the better their quality of life in epilepsy. Our finding suggests that the health-related quality of life of patients with epilepsy can be improved by improving their perception of the condition. It is believed that patients' perception of their condition affects treatment outcomes as perception of their patients' condition directly influences their coping behavior as well as their emotional response to the illness [18].

Parameter	Frequency (n)	Proportion (%)
Sex		
Male	111	57.51
Female	82	42.49
Duration of epilepsy		
≤ 2 years	55	28.50
3-5 years	43	22.30
≥ 6 years	95	49.22
Presence of Co-morbidity		
None	128	66.32
Yes	65	33.68
Type of Co-morbidity*		
Hypertension	30	46.15
Hypertension + BPH	7	10.77
Hypertension + Diabetes Mellitus	5	7.69
HIV	5	7.69
Peptic Ulcer Disease	4	6.15
Hypertension + Asthma	4	6.15
Osteoarthritis	3	4.62
Tuberculosis	3	4.62
Hepatitis	3	4.62
Leukemia	1	1.54

#### Table 1. Clinical parameters of respondents

\*Among patients with co-morbidities; BPH = Benign Prostatic Hyperplasia

#### Table 2. Mean scores of assessment variables

Outcome	Mean	Minimum	Maximum	Standard
	score	score	score	deviation
Illness Perception Score	55.33	9.00	71.00	9.48
QOLIE Score	8.31	1.25	57.36	8.27
Medication Adherence	3.77	0.50	8.00	1.633
Score				

Illness perceptions have been shown to be related to important outcomes in a number of medical conditions. Reports indicate that patients attending for medical investigations who have already developed negative illness perceptions of their condition are less reassured by results showing no pathological findings [19]. Generally, patients have negative perceptions about their illness, and these perceptions are usually associated with increased future disability and a slower rate of recovery, irrespective of the initial medical severity of the condition [20,22]. Patients diagnosed with an illness generally develop an organized pattern of beliefs about their condition. These patients' beliefs determine patients' behavior towards the management of their illness. Illness perception has been reported to be associated with vital health outcomes of the patient, including quality of life. Negative illness perceptions have been associated with a slower rate of recovery and increased patient disability

irrespective of the initial clinical severity of the condition.

Cognitive-behavioral interventions developed to change patients' illness perceptions have been reported to significantly change patients' illness beliefs during their treatment leading to a faster rate of recovery. Reports show that changing patients' illness perceptions improve recovery following myocardial infarction, and other selfregulatory interventions in illnesses as diverse as diabetes and AIDS have also improved patient outcomes [10,18,23]. Hence, cognitive-based interventions can be used to change negative illness perceptions of patients with epilepsy. A recent study by Eshiet et al. demonstrated that the illness perception of patients with epilepsy improved can be greatly through the implementation of suitable educational interventions [24]. Generally, patients do not express their illness beliefs or perception during

clinical interactions with their healthcare providers. Unfortunately, the patients' illness beliefs and perception are not often sought by healthcare providers during medical interviews [18]. This is an important aspect of clinical clerkship that should not be ignored. Information regarding the patient's illness beliefs will help identify gaps in knowledge that can be filled by healthcare providers via education and counseling interventions.

## 5. CONCLUSION

In patients living with epilepsy, illness perception is a predictor of their adherence to antiepileptic drug regimen as well as their health-related quality of life. Implementing suitable interventions to improve patients' perception of epilepsy may enhance clinical and humanistic treatment outcomes.

#### **CONSENT AND ETHICAL APPROVAL**

The research protocol was approved by the Health Research Ethics Committees of the University of Uyo Teaching Hospital and the University of Calabar Teaching Hospital (Reference numbers: UUTH/AD/S/96/VOL.XIV/ 571& UCTH/HREC/33/454). Also, informed consent was obtained from the participants before recruitment into the study.

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#### **COMPETING INTERESTS**

Authors have declared that no competing interests exist.

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