ORIGINAL ARTICLE

Between the Person and the Pill: Factors Affecting Medication Adherence in Epilepsy Patients

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Abstract

Background: The majority of people afflicted with epilepsy live in developing countries. Poor adherence to prescribed medication is considered the main cause of unsuccessful drug treatment for epilepsy. Our study aims to evaluate the factors influencing medication adherence in epilepsy patients at a public hospital in Mumbai, India.

Method: This cross-sectional study was carried out on a cohort of 313 epilepsy patients regularly attending an out-patient clinic at a tertiary-care hospital. A semi-structured questionnaire was used to assess demographic information, the level of medication adherence, and various factors that could influence adherence. Brief Illness Perception Questionnaire and WHO QoL-BREF Scale were also administered to the study population.

Results: Patients on anti-epilepsy medication reported an overall good quality of life and a good level of adherence. 90.1% of study participants reported being adherent with their treatment regimen. The main factors found to impact medication adherence were the duration of non-availability of medications in the public sector, and the monthly cost of the medications in the private sector. Other therapy-related, health system-related, socioeconomic, and psychosocial variables were not found to be significant determinants of medication non-adherence in our setting.

Conclusion: Ensuring that anti-epilepsy drugs remain available in the public sector, and/or making them more affordable in the private sector are the main interventions likely to improve medication adherence in clinical settings such as ours.

Introduction

Epilepsy is the second most common neurological disorder, affecting almost 50 million people worldwide.[1] Antiepileptic drug (AED) therapy aims to achieve a balance between the prevention of seizure episodes, and the reduction of side-effects of AEDs to tolerable levels; to improve the patient's quality of life, provide cost-effective care and ensure patient satisfaction.[2-5] Good adherence to treatment and proper health education are fundamental to the successful management of epilepsy.[6,7]

Recent studies have shown that up to 70% newly diagnosed patients with epilepsy can be successfully treated (i.e. be seizure-free for several years) with antiepileptic drugs.[5] After 2 - 5 years of successful treatment, drugs can be withdrawn in about 70% of children and about 60% of adults without relapse.[8] Poor adherence to prescribed medication is considered the main cause of therapeutic failure in epilepsy patients.[9,10]

Approximately 85% of people afflicted with epilepsy live in developing countries.[5] In a resource-limited setting like India and with pre-existing heavy chronic disease burden, successful treatment outcomes are essential to reduce morbidity and mortality, improve the quality of life, enhance earning capacity, reduce hospitalizations due to disease or its complications, and reduce societal and public health costs. Since medication non-adherence is the main cause for therapeutic failure in epilepsy,[9] it is essential to assess the factors that influence adherence in common clinical settings in India. Clinicians and policymakers can then address these factors, while working in concert with patients, for better individual and overall treatment outcomes.

Aims and Objectives

To assess the level of medication adherence amongst epilepsy patients enrolled in the study.

To assess the factors affecting medication adherence in epilepsy patients.

To assess the quality of life of the study participants.

To study the perceptions held by the study participants about the illness.

Methods

This cross-sectional study was carried out over a study period of 6 months in the Department of Neurology at a tertiary-care public hospital in Mumbai, India. The study participants comprised of epilepsy patients on regular AED therapy. The study cohort of 313 epilepsy patients was obtained by consecutively enrolling all patients registered at our out-patient epilepsy clinic who met the criteria for participation.

The inclusion criteria were patients above the age of 18 years and of either sex, who had been taking AEDs for at least 6 months, and gave written valid informed consent to participate. The exclusion criteria were patients newly diagnosed with epilepsy, patients with

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cognitive deficits or psychosis, patients who did not meet the inclusion criteria, and patients unwilling to participate.

The study was approved by the Institution Ethics Committee prior to commencement. Written valid informed consent was obtained from all participants before administering the study instruments.

Study Material

Demographic Questionnaire: Obtained information about the participant's age, sex, education, income, occupation, area of residence, type of family, religion, alcohol consumption, and smoking status.

WHO QOL-BREF Scale[11]: Validated and reliable 26-item scale measuring the following broad domains of quality of life: physical health, psychological health, social relationships, and environment; with each question rated on a 5-point Likert-type scale.[11] The four domain scores are scaled out of 100 each, in a positive direction; implying that higher scores reflect a higher quality of life.

Brief Illness Perception Questionnaire (B-IPQ):[12] A 9-item validated and reliable instrument based on the original Illness Perception Questionnaire-Revised (IPQ-R), rated using a 0-to-10 Likert-type response scale.[12]

A semi-structured self-report questionnaire obtaining information on factors perceived by study participants as contributing to their medication non-adherence behavior. This included treatment, hospital, health system, psychosocial, socioeconomic and provider-related factors.

Statistical Analysis

Statistical analysis was carried out using SPSS software after importing the data into MS Excel. The population was divided into two groups for analysis- adherent, and non-adherent. Categorical data was analyzed using Chi-square test, quantitative data was compared using Students' 't' test, and ordinal data was analyzed using Mann-Whitney Test. Bivariate and multivariate analyses using logistic regression were conducted to further evaluate the relationship between medication adherence status and the other variables under study.

Results

Demographics

The mean age of the study sample was 37.4 years (SD 14.05). The youngest participant was 18 years old, and the oldest was 84 years old. In our cohort, 21% of the participants had studied up to college or further, 39% studied up to secondary school, 26% studied up to primary school, and 14% had not completed primary schooling. Of note, 40% of the participants were presently unemployed, and only 2% lived by themselves. In our study sample, 53% participants were married, 2% divorced/widowed and 45% were single. Further, 9% participants gave a positive history for routine consumption of tobacco in any form, and 5% reported routine alcohol consumption.

Medication Adherence

The patients were asked to self-report whether or not they were adherent with their AED therapy. In our cohort, 90.1% of participants reported being adherent with their treatment regimen ('excellent' or 'good' level of adherence), while 9.9% were non-adherent ('somewhat' or 'poor' adherence).

Factors Affecting Medication Adherence

Amongst health system-related and provider-related factors, the duration of non-availability of AEDs in the public sector (p-value: 0.027) and the monthly cost of medication in the private sector (p-value: 0.00036) were found to be significantly associated with medication non-adherence. Amongst socioeconomic factors, only the patient's monthly income was significantly associated with medication adherence (p-value: 0047).

From the therapy-related factors under study, the number of times patient forgot to take medications (p-value: 0.0009) and the number of times the patient stopped taking medication on their own (p-value: 912E-0.9) were associated with non-adherence. The symptom control achieved, experience of adverse effects, mastery of complex techniques (inhalation/injection etc.), impairment of normal lifestyle by treatment, duration of treatment and complexity of regimen, number of missed appointment- and physical impairments such as visual/hearing impediments, problems with swallowing, and impaired mobility-were all found to be insignificant.

The patients were also asked about their attitudes towards treatment (i.e. belief that taking medication is important, regimen in easy to follow, fear of adverse effects, fear of dependence on medications, feeling stigmatized by disease), and these were found to have no significant influence on medication adherence.

Quality of Life

Patients on anti-epilepsy medication reported an overall good quality of life, with 'environment' being highest (83.56) and 'psychological health' the lowest (76.41) out of the four domains. On average, they rated their own quality of life as 3.1 out of a maximum of 5 points, and their health status as 3.21 out of a maximum of 5 points. Quality of life was not significantly associated with medication adherence.

Psychosocial Findings

Amongst psychosocial factors, perception of health status (p-value: 0.025) was found to influence medication adherence. However, other factors like stressful daily schedules, sleep quality, appetite quality, satisfaction in relationships and with work productivity, and perception of quality of life, were all insignificant.

Of the patients who self-reported experiencing depression symptoms, 44.2% were non-adherent to their medication regimen. Both male and female patients reported experiencing psychological ill-health (anxiety, depression, irritability) however these were not associated with non-adherence.

Females reported feeling significantly less social support than males (p-value: 1.61E-11). Amongst females, 62% reported not telling friends about their disease, while only 22% males withheld the fact. Female patients with epilepsy were also significantly less likely to use public transport independently (p-value: 2.53E-06).

Perception of Illness

The total BIP-Q Score, implying an overall poor perception of the disease, was significantly associated with adherence (p-value: 0.0143), as was the extent to which the illness affected the patient emotionally (p-value: 0.00032).

Discussion

This study is a step towards bridging the vast knowledge gap regarding medication non-adherence in chronic diseases, and to our knowledge, is the first study of its kind in the current setting.

The monthly cost of medications in the private sector was found to significantly influence medication non-adherence in our setting (p-value: 0.00036). This is consistent with a Chinese study which found that an inability to buy drugs significantly influenced non-adherence.[13] The duration for which a patient was unable to obtain drugs in the government sector was also a significant factor (p-value: 0.027). Patients having a higher income reported better adherence (p-value: 0.047), which could be because purchasing AEDs in the private sector is more affordable for them. Patients with lower income may feel compelled to stop the medication when it is not available free of cost in the public sector. These results imply that making drugs available in the public sector, ensuring they don't remain unavailable for long durations in the public sector, and/or making them affordable in the private sector are the main interventions likely to improve a patient's adherence.

Patients with good medication adherence reported holding the perception of an overall poorer health status (p-value: 0.025), more negative emotional effects due to the illness (p-value: 0.00032), and an overall threatening perception of the illness (p-value: 0.01438), suggesting that patients with a more negative outlook towards the disease were actually more likely to comply with their medication.

Studies in international settings found that male gender,[14,15] and younger age group[14,15] were associated with non-adherence; however, we found no significant relationship with any sociodemographic variables under study (age, gender, family size, marital status, education level, occupation status). Symptom control (seizure-free period) was shown to significantly influence adherence in other study populations,[14] but not in ours.

Having health insurance, access to healthcare facilities, access to pharmacy, distance of home from hospital, travel time from home to hospital, waiting period in hospital, quality of relationship with the doctor and education by the doctor; were all found not to be significant factors in our study.

Duration of illness has shown variable associations with adherence; with one study finding that a shorter duration results in poor adherence,[15] and another finding the reverse to be true.[13] Despite our study sample encompassing patient across a wide spectrum in terms of treatment duration- including those who have been on therapy for almost their entire lives, as well as patients who started therapy just 6 months before the study period- duration of illness was not found to be a significant factor.

Previous studies have found patients' general attitudes towards drugs[16] and the belief that drugs may be harmful[17] correlated significantly with low adherence, as did regimen-related factors like older AEDs, monotherapy and more frequent dosing[18] increasing regimen complexity[19] and pill burden.[20] Other reported factors include comorbid conditions,[20] adverse effects or fear of them[13,15] and a poor patient-doctor relationship.[13] None of these factors were found to be significant in our study.

Knowing which factors are not relevant in our clinical setting will prevent wastage of resources in futile interventions, and allow focused evidence-based interventions towards appropriately mitigating the relevant factors identified. Public health policymakers should consider the economic aspects (availability and pricing) of AED therapy in public hospital settings like ours, and accordingly devise interventions to retain patients in care, thus improving their clinical outcomes and reducing the cost of the disease burden to the patient and to society.

Conclusion

As medication non-adherence is the most common reason for failing AED therapy, addressing the factors affecting adherence will lead to positive treatment outcomes. Our study finds that ensuring that the antiepileptic drugs remain available in the public sector, and/or making them more affordable in the private sector, are the main interventions likely to improve patients' adherence to therapy in clinical settings like ours.

Study Limitations

The study participants were from a single urban tertiary-care public hospital. This limits the ability to generalize our findings to all Indian epilepsy patients. Questionnaires are efficient data collection tools, but may have limitations due to inaccurate responses, problems with recall, and biases.

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