Original Article

Evaluation of self-reported medication adherence and its associated factors among epilepsy patients in Hospital Kuala Lumpur

Abstract

Introduction: Reports on medication adherence and its associated factors in patients with epilepsy in South East Asian countries are lacking. The primary purpose of this study was to assess the degree of medication adherence and its relationship with patient's satisfaction, psychosocial factors, quality of life and mental health in a sample of Malaysian epilepsy patients.

Methodology: It is a cross-sectional study and was carried out in the outpatient Neurology Department of Hospital Kuala Lumpur, Malaysia (n=272). Data was collected by administering the structured questionnaire.

Results and Discussion: Results showed that 49.3% of the epilepsy patients were non-adherent to their prescribed regimen. Univariate analysis showed significant associations between medication adherence and the following factors: race, seizure frequency, overall patient satisfaction, medication taste and smell, medication cost and physical appearance, medication effectiveness, complexity of medication regimen, patient barrier, patient understanding, patient role functioning, patient positivity, vitality and general interest. Multiple regression analysis indicated that factors that are influencing medication adherence are seizure frequency (P = 0.048), overall patient satisfaction (P = 0.043) and patient understanding about their illness (P = 0.001). The model chosen for testing the relationship between medication adherence and its associated factors give an R^2 value of 25.2% with an adjusted R^2 of 21.4%. The F value was also significant (P = 0.000). Based on the research findings, the researchers recommends that clinicians need to play a vital role in educating the patients on their disease conditions. By educating the patients on nature of epilepsy, different modalities of treatment and benefits of adherence to treatment will help in the better adherence and management.

Key words:
Associated factors, epilepsy, medication adherence, medication compliance

Introduction

Epilepsy is ranked among the top three causes of neurological disability in developed countries according to the World Health Organization, particularly among the young which can be quite burdening.[1] Epilepsy affects 40 million people worldwide and three-quarters remain untreated, especially in developing countries. In spite of the huge magnitude of the problem, epilepsy can be controlled in three-quarters of the patients if early diagnosis and treatment is done. In Malaysia, 30% of the country's estimated 230,000 epilepsy sufferers do not respond to the currently available antiepileptic medication.[2] Though there are many forms of treatment, the

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antiepileptic drug (AED) therapy remains as the treatment of choice for controlling epileptic seizures. As in majority of the patients, seizure type and frequency are better controlled with medication.[3] Epilepsy has tremendous effects on physical, psychological, and social aspects of a patient.

Factors such as age at disease onset, seizure etiology, seizure type, epilepsy syndrome, comorbid conditions, and nonadherence to AEDs could lead to poor seizure control among epilepsy patients. Noncompliance to medication is considered one of the most important factors for failure in the control of epileptic seizures and can have adverse effects on clinical, social, and economic outcomes of the patients.[4-7] Nonadherent to medication can have many unwanted consequences such as poor control of the disease leading to increase in clinic visits, hospitalizations, and also decrease in productivity such as missing school and work. Finally leading to increase in healthcare costs incurred. However, nonadherence could be a modifiable factor in seizure control. It is reported that as many as 30–50% of persons with epilepsy are noncompliant to their prescribed regimen, thus interfering with their optimal treatment. Again, it is crucial to understand that noncompliance significantly increases the risk of seizure, A and E visits, hospitalization, road traffic accidents, fractures, and death. Therefore, compliance is a key contributor to suboptimal management.[8] The terms compliance and adherence will be used synonymously in this study.

Successful collaborations with healthcare professionals can influence adherence. Patient point of view of the doctor – patient relationship was examined, and it was discovered that amount of visits and adequate communication between the two individuals improved adherence.[9] The main factor associated with healthcare system includes availability and accessibility. Absence of accessibility to healthcare, long waiting time for hospital visits, and difficulty in getting prescription filled, and unsatisfactory clinic visits may contribute to poor compliance.[10-12] Attitude and perception about the treatment can impact how probable it is for a patient to be compliant.[13] Patients with epilepsy usually score lower on quality of life scales than healthy people. Health-related quality of life is an important psychosocial characteristic which may impact an individual's ability to manage their chronic disease.[14] Driving, independence, and employment were the concerns recorded most frequently and appraised as the most important.[15] AED therapy by reducing the seizure frequency, enhances the quality of life.[16,17] Mental components such as anxiety and depression might need to be explored when adherence is poor. There is a noteworthy relationship between depression and the level of adherence.[18]

The aim of this study is to examine the influence of factors such as sociodemographic, treatment satisfaction, psychosocial factors, quality of life, and mental health on the degree of adherence among epilepsy patients attending Hospital Kuala Lumpur. The impact of social and clinical variables (age, sex, marital status, income level, educational level, seizure type and frequency, duration of epilepsy), patient healthcare satisfaction (overall patent satisfaction, doctor service satisfaction, pharmacy service satisfaction), psychosocial factors (medication taste and smell barrier, medication cost and physical barrier, medication effectiveness, medication side effect, medication complexity, patient barrier, communication barrier, logistic barrier, patient perception of severity, perception of susceptibility, patient attitude and motivation, patient understanding), quality of life (depression, patient role functioning, epilepsy effects), and mental health (patient positivity, patient vitality, patient general interest) on medication adherence was analyzed.

Materials and Methods

This study was carried out in Hospital Kuala Lumpur, Malaysia. Approval to perform the study was obtained from the National Medical Research Register, Clinical Research Centre and Medical Review and Ethics Committee of the Ministry of Health via online application (reference: NMRR-12-1178-14444/KKM/NIHSEC/800-2/2/2P13-45). Prior to that, discussion with hospital authorities was made to obtain full cooperation and permission to carry out the study. Sample size was calculated using single proportion formula according to reported adherence of approximately 50%. Patients that are registered at the neurology clinic were screened and identified epilepsy patients were approached and determined for fitness. They were briefed on the purpose of this study and sign the consent form if they agree to participate. The questionnaire was administered while waiting for their doctor. The inclusion criteria was participants must be diagnosed with epilepsy, undergoing therapy with at least one AED, more than 18 years of age, able to administer their own medications, and agreed to the consent form. Patients were excluded from the study if they are pregnant, under 18, mentally and physically challenged, illicit drug abusers or refused to agree to the consent form. A sample of 272 patients met the inclusion criteria. Questionnaire took about 15–30 min to complete. Questionnaire consists of five sections; patient compliance, patient treatment satisfaction, psychosocial factors, quality of life, and mental health assessment, respectively. They were also given a sociodemographic and clinical data sheet. This instrument was adopted and modified from a previous study in Kelantan, Malaysia. Outcome measures chosen were the patient satisfaction with health care scale, QOLIE-10, and WHO-5 to test patient satisfaction, quality of life, and mental health, respectively, while compliance, and psychosocial factors scale was developed based on clinical importance and results found in literature review. Content and construct validity and reliability of the scale were measured. Demographic and clinical characteristics of the patients were illustrated by descriptive statistics. Associations between medication adherence (missing at least 50% of the doses) and associated factors were first examined using Chi-square, ANOVA, and *t*-test. Then, multiple regression analysis was used to determine the independent associations between medication adherence and independent variables. All statistical analysis was conducted using the Statistical Package for Social Sciences Version 20.0 for Windows. The conventional 5% statistically significant level was used throughout the study.

Results

Of the 272 respondents, 57% were males and 43% were females. The highest percentage of patients receiving treatment was in the 31–40 years old group, dominating the chart by 34.6%. In contrast, the elderly (above 50 years) and the young adults (below 20) only made up a total of 14.7%. More than half of the respondents were not married (55.5%). In terms of education, only a meager of 3.3% did not have formal education, 9.9% studied up to primary school, whereas 86.8% completed high school or higher. Malaysia is well known for its multi-racial and multi-cultural population. Of these respondents, 119 (43.8%) were Malays who contributed almost half of the total sample size, Chinese and Indians respondents summed up to a total of 52.9%, whereas a small 3.3% were of other races. Majority of the respondents have suffered from epilepsy for more than 5 years (64.3%) but did not know the type of epilepsy they are having (77.2%). Most were still having seizure attack during last 6 months (62.9%). Besides epilepsy, 22.8% of the respondents have other chronic diseases. The commonly prescribed AEDs were carbamazepine, levetiracetam, lamotrigine, phenytoin, and topiramate.

As mentioned in there is a statistically significant relationship between medication compliance and overall patient satisfaction ($P < 0.001$), medication taste and smell ($P < 0.001$), medication cost and physical appearance ($P < 0.001$), medication effectiveness ($P < 0.001$), complexity of drug regimen ($P < 0.001$), patient barrier ($P < 0.005$), patient understanding ($P < 0.001$), depression ($P < 0.001$), patient role functioning ($P < 0.001$), patient positivity ($P < 0.001$), patient vitality ($P < 0.001$), and patient general interest ($P < 0.001$).

According to Chi-square and *t*-test results, the variables such as race, seizure frequency, overall patient satisfaction, medication taste and smell barrier, medication cost and physical barrier, medication effectiveness, complexity of medication regimen, patient barrier, patient understanding, patient role functioning, patient positivity, vitality, and general interest were significantly associated with medication nonadherence. Multiple regression analysis was used to test if these individual factors significantly predicted the respondent's medication compliance. The results of the regression indicated the three predictors explained 25.2% of the variance ($R^2 = 0.252$, F (13,258) = 6.678, $P = 0.000$). Frequency of seizure ($\beta = -0.128$, $P = 0.0048$), overall patient satisfaction ($\beta = -0.136$, $P = 0.0043$), and patient understanding ($\beta = -0.179$, $P = 0.001$) significantly predicts medication compliance.

Discussion

The aim of our study was to assess the influence of different factors on medication adherence on patients with epilepsy receiving treatment in Hospital Kuala Lumpur. The impact of social and clinical variables (age, gender, marital status, income level, educational level, seizure type and frequency, duration of epilepsy), patient healthcare satisfaction (overall patent satisfaction, doctor service satisfaction, pharmacy service satisfaction), psychosocial factors (medication taste and smell barrier, medication cost and physical barrier, medication effectiveness, medication side effect, medication complexity, patient barrier, communication barrier, logistic barrier, patient perception of severity, perception of susceptibility, patient attitude and motivation, patient understanding), quality of life (depression, patient role functioning, epilepsy effects), and mental health (patient positivity, patient vitality, patient general interest) on medication adherence was analyzed.

Our cross-sectional survey data indicate that seizure frequency, overall patient satisfaction, and patient understanding influences medication adherence. It is also suggested that better compliance to medication will improve the prognosis of outpatients with epilepsy.

This study found that 49.3% of the epilepsy patients in urban Kuala Lumpur were not adhering to their medication therapy. The finding was similar when compared with a study done in Kelantan, Malaysia, who reported that 52.2% of epilepsy patients did not comply with their drug regime in using the self-reported method.[19] However, other studies reported a lower percentage of noncompliance of 40, 42, and 31.8%.[20-22] All these studies used self-reported assessment of compliance and were also conducted at neurology clinic. There are studies reported higher rates of noncompliance using Morrisky scale.[23-25] Some factors such as cognitive bias and poor memory can interfere in the response provided. This probably gave rise to the difference in noncompliance rate. When more objective studies such as measuring AED drug levels and count pills directly were done, 37, 44, and 42.7% were found to be noncompliant.[26-28] Their results were different possibly because of the limitations of self-reported method and sample size used.

The results on the relationship between medication adherence, demographic data, and clinical characteristics were not very conclusive. The nature of the illness makes it difficult to predict such a relationship. Adherence was highly associated with race in univariate analysis but not associated with duration of illness, age, marital status, income level or even gender which was similar in a study done in Palestine.[23] Multiple regression analysis showed that frequency of seizure is a statistically significant predictor ($P = 0.048$) in influencing medication adherence. This is consistent with findings that poor compliance was related to an increased frequency of seizures.[24] A study in Germany measured postictal serum levels of antiepileptic medications and confirmed that in at least 44% of cases the seizure was related to poor compliance.[29]

The Malay patients were the highest among the ethnic groups in terms of seizure frequency. Statistical analysis identified a significant difference in the seizure frequency among the three racial groups. Unfortunately, there were no studies that discussed the relationship between seizure frequency and race. Thus, it might be commendable to explore the relationship not only between seizure frequency and race but also between seizure frequency and gender.

Despite a majority of 86% of the respondent having high literacy (attended secondary school or higher), the percentage of drug noncompliance was still very high. In fact, this group of respondents contributed 43% of the total percentage of noncompliance group. However, there was no statistically significant association found between education level and medication noncompliance.

Relationship between health treatment satisfaction and adherence

This study demonstrated that adherence was a predictor to patient healthcare satisfaction particularly in the overall patient satisfaction domain (P = 0.043), but not in the doctor service satisfaction and pharmacy service satisfaction domain. This suggests that satisfaction with the treatment given or environment in the clinic could influence adherence. Moreover, patients who are adherent will be more likely to have higher satisfaction in terms of physical, emotional, and present health.

Although the doctor service satisfaction and pharmacy service satisfaction domain were found to be statistically insignificant, the relationship between patients, physician, and pharmacist should be an important factor in influencing adherence; more research data are needed support this hypothesis.

Relationship between psychosocial factors and adherence

In our study, the psychosocial factors that were significantly correlated with medication compliance were medication taste and smell, medication cost, and physical appearance, medication effectiveness, medication complexity, and patient barrier such as forgetfulness, movement difficulty, and patient understanding. Previous researchers found that patient barrier such as forgetting medication were also associated with compliance.[26,30-32] Forgetfulness may be the one of the prime reasons for nonadherence. On contrary, patients who are adherent to medication report that they follow their medication schedule as advised.[26,33] Therefore, clinicians should emphasize the use of reminder method to address forgetfulness.

In multiple regression analysis, patient understanding was found to be the strongest predictor to adherence ($\beta = -0.179$, P = 0.001). Therefore, it is found that understanding the importance of taking the AED as prescribed was less among nonadherent patients. Compliance was found to be positively correlated with understanding of drug instructions.[34] Better disease and medication understanding was associated with better drug compliance.[4,26] Some patients do not even understand what epilepsy is all about. In previous studies in Taiwan, Hong Kong, and Malaysia, epilepsy was largely confused with dementia by 90% of the interviewees.[35-37] Earlier, 77.2% of the respondents were reportedly unaware of their epilepsy type. This is consistent with the study's findings that patients are lack of understanding about epilepsy, the medications, and thereafter influenced medication adherence. By educating the patients on nature of disease, different modalities of treatment, and benefits of adherence to treatment will help in the better adherence and management.

Relationship between quality of life and adherence

Frequent seizure and longer course of disease mean the poorer quality of life and poor therapeutic compliance are a major cause of uncontrolled epilepsy.[41] In the self-reported questionnaire, the subjects were asked to reflect on their experiences such as depression, employment and social limitations, effect of AED on driving, psychological, and physiological aspects of life. They are also asked to reflect on their fear on expecting their next episode of seizures and their perception on quality of life. The study revealed that there was a statistically significant correlation between patient role functioning domain (P = 0.015), which meant that driving, work, and social limitations could be perceived to affect the quality of life. Driving, independence, and employment are the most important factors that affect the quality of life among epilepsy patients.[15] Nonetheless, unemployment is also a statistically significant factor among people with epilepsy in developed countries.[38]

Relationship between mental health and adherence

It was hypothesized that consistent with findings in studies of adherence in other diseases, mental health such as positivity, vitality, and patient general interest would be significantly associated with adherence. Despite the use of validated measures of self-reported adherence, there was no trend toward such a relationship between patient positivity, vitality, and general interest of mental health and adherence. This was quite unexpected, since this finding has been widely reported and replicated in other disease populations.[39,40]

Conclusion

The aim of this study was to assess the degree of medication adherence and to examine its relationship with patient's satisfaction, psychosocial factors, quality of life, and mental health in a sample of epilepsy patients receiving treatment in Hospital Kuala Lumpur. Our cross-sectional survey data indicated that seizure frequency (P = 0.043), overall patient satisfaction (P = 0.048), and patient understanding (P = 0.001) influences medication adherence among epilepsy patients. On the basis of these findings, the researcher recommends that clinicians need to play a vital role in educating the patients on their disease conditions. By educating the patients on nature of epilepsy, different modalities of treatment, and benefits of adherence to treatment will help in the better adherence and management.

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Conflicts of interest

There are no conflicts of interest.

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