Assessment of quality of life of patients with epilepsy in the neurology OPD of a tertiary care University hospital

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ABSTRACT

Epilepsy is a chronic disease which has a major influence on the quality of life of epileptic patients. A cross-sectional study conducted on patients either sex, aged ≥18 years, with epilepsy to identify the factors that influence their quality of life. Data including the patient demographics (age, sex, educational status, employment status), duration of epilepsy, frequency of seizure episodes during the past month, drugs prescribed, were obtained from the patient case records and by direct history interview of the patients. Quality of life of the patients was assessed using a standard validated questionnaire on Quality of Life in Epilepsy (QOLIE-31-P). Univariate linear regression analysis, student t-test and one way ANOVA were performed to analyze the data collected. A P value of less than 0.05 was considered statistically significant. 130 patients (73 males (56.2%) and 57 females (43.8%); mean age 34.89±10.18 years were included and the mean quality of life (QOL) score was 60.3 ±15.72 (range 20.45-97). There was a significant association between age, sex, duration of epilepsy, seizure frequency, employment status, seizure worry, emotional well-being, energy/fatigue, cognitive function, medication effects, social functioning & distress and the QOL (P <0.05) whereas, educational status and type of therapy had no effect on the QOL of the patients (P >0.05).The care of the epileptic patients must be taken into account by considering the various factors influencing the quality of life in these patients.

Keywords: antiepileptics; epilepsy; pharmacotherapy; quality of life

INTRODUCTION

Epilepsy is a neurological condition that knows no geographic, social or racial boundaries, occurring in men and women and affecting people of all ages, though more frequently affecting young people in the first two decades of life and people over the age of 60 (Sander JW., 2003). A person with epilepsy faces uncertainty over the diagnosis of his or her condition, over whether and when seizures will occur, over the nature of the seizures and how best they can be controlled, and over whether they will, ultimately, remit. The unpredictability of the nature and course of epilepsy is a key factor in the psychosocial handicaps it engenders for people in whom it develops. Another centrally defining aspect of epilepsy is its stigmatizing nature (Trimble, MR, 1994).

Quality of Life (QOL) is an important outcome measure in clinical research, taking into account patient's subjective evaluation of his own being and supplementing the traditional medical approach, based on the examination of symptoms, signs and laboratory findings as defined from the doctor's perspective (Devinsky., O, 1993).

World Health Organization (WHO) defined QOL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL Group., 1995). The term incorporates multidimensional aspects of individual's physical health, psychological state and social relationships (Baker., GA, 1998). The unique feature of epilepsy among other chronic conditions is its direct effect on the brain. This might contribute to more disturbed psychosocial functioning in patients diagnosed with epilepsy as compared to other chronic, stigmatizing disorders (Hermann., BP, 1993).

QOL is an important measure in epilepsy, which is often a chronic and debilitating condition and unique among the chronic illnesses due to the multidimensional impact on psychosocial functioning (Baker., GA, 1998).

MATERIALS AND METHODS

A cross-sectional study was carried out for a period of eight months in a 1700 bedded tertiary care teaching

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Table 1: Demographic characteristics of patients

Characteristics		Number of patients (n=130)
Sex	Males	73 (56.2%)
	Females	57 (43.8%)
Educational Status	Illiterate	0
	Preschool	13 (10%)
	High School	86 (66.1%)
	Higher Secondary	17 (13.1%)
	Graduate	14 (10.8%)
Occupational status	Employed	72 (55.4%)
	Unemployed	58 (44.6%)
Place of residence	Rural	53 (40.8%)
	Urban	77 (59.2%)

Table 2: Pattern of use of antiepileptic drugs in patients

Therapy	Number of patients (n=130)
Monotherapy	76 (58.5%)
Two Drug Combinations	44 (33.8%)
Three Drug Combinations	10 (7.7%)
TOTAL	**130 (100%)**

hospital in South India with ethical approval and consent of the patients.

Patients of either sex, aged ≥18 yrs, with the definite diagnosis of active epilepsy (person with epilepsy who has had at least one epileptic seizure in the previous *5* years, regardless of AED treatment) not classified into subgroups were included in the study. Patients with concomitant illnesses (tumours, degenerative diseases and metabolic pathologies) that provoke seizures and patients with serious physical or mental limitations which prevented them from completing the QOLIE-31-P questionnaire were excluded from the study.

The data including age, sex, place of residence, educational status, employment status, duration of epilepsy and frequency of seizure episodes during the past month, were obtained by direct history interview of the patient, number of antiepileptic drugs (monotherapy/polytherapy) prescribed was obtained from the patient medication records and entered in a specially designed proforma. Quality of Life (QOL) was determined by using a validated Quality of Life in Epilepsy-31-P questionnaire (QOLIE-31-P) after obtaining necessary permission from the author of the questionnaire (Cramer., JA, Van Hammee., G, 2003).

The QOLIE-31-P is a brief survey of health-related quality of life for adults (18 years or older) with epilepsy. This version differs from the original QOLIE-31 (version 1) in the addition of questions about how much distress the patient feels about problems and worries related to epilepsy. This questionnaire is available in English and various regional languages; all being validated by the author. The questionnaire should be completed only by patients with epilepsy (not the patient care taker) because no one else knows how they feel. There are 38 questions about health and daily

activities which are divided into eight subscales (Seizure worry, Overall QOL, Emotional wellbeing, Energy/fatigue, Cognitive functioning, Medication effects, Social functioning and Distress). The scoring procedure first converts the answers of items to 0-100 point scores, with higher scores reflecting better quality of life.

Both English and Tamil versions of the QOLIE-31-P questionnaire were used for the study. The patients were explained about the questionnaire and were asked to fill the questionnaire on their own either in English or in Tamil. The responses were scored as stated in the questionnaire. Univariate linear regression analysis, student t-test and one way ANOVA were performed on R-2.12.1 statistical package to analyze the data collected. A P value of less than 0.05 was considered statistically significant.

RESULTS

Demographic data

The study was conducted in 130 patients who attended the neurology OPD, with a definite diagnosis of active epilepsy. There were 73 males (56.2%) and 57 females (43.8%) with the mean age of 34.89±10.18 years (range 19-60 years). The educational status of 66.1% patients was up to high school level, 10.8% patients were graduates, 13.1% had an educational status of up to higher secondary level and 10% patients had up to preschool level. There were no illiterates. The occupational status showed that 55.4% of the patients were employed and 44.6% were unemployed. Majority were from urban background (59.2%) than from rural areas (40.8%) (Table 1). The mean duration of epilepsy was 13.35±10.54 years. A family history of epilepsy was observed in 12 patients (12%).

Table 3: Scores of Qolie-31-P Subscales

Subscales	Mean score	Minimum score	Maximum score
Seizure Worry	56.68 ± 23.63	0	100
Overall QOL	63.75 ± 19.96	0	100
Emotional Wellbeing	57.45 ± 17.92	16	100
Energy/Fatigue	55.88 ± 19.3	5	100
Cognitive Functioning	61.81 ± 21.88	0	100
Medication Effects	68.35 ± 21.52	16.66	100
Social Functioning	63.17 ± 22.47	4	100
Distress	51.24 ± 10.16	24	71

Table 4: P- values of various factors on the QOL

Parameter		Mean score	P-value
Sex	Female	51.72 ± 14.43	<0.000*
	Male	67 ± 13.31	
Employment status	Employed	63.51 ± 16.0	0.0083*
	Unemployed	56.32 ± 14.54	
Therapy	Monotherapy	62.57 ± 15.56	0.051
	Polytherapy	57.1 ± 15.54	
Educational status	High School	59.9 ± 16.22	0.703
	Graduate	64.44 ± 10.49	
	Preschool	57.62 ± 20.37	
	Higher secondary	60.95 ± 13.13	
Seizure frequency	0	74.04±8.54	<0.000*
	≥ 1	50.84±12.14	

*Statistically significant

Table 5: Univariate linear regression analysis of various parameters on QOL

Parameter		P- value	Karl Pearson correlation (r)
Age		0.0113*	- 0.222
Duration of epilepsy		0.002*	- 0.27
Cost of illness		0.201	- 0.113
QOLIE-31-P SUBSCALES	Seizure worry	<0.001*	0.761
	Overall QOL	<0.001*	0.701
	Emotional wellbeing	<0.001*	0.753
	Energy / Fatigue	<0.001*	0.541
	Cognitive Function	<0.001*	0.845
	Medication Effects	<0.001*	0.52
	Social functioning	<0.001*	0.72
	Distress	<0.001*	0.409

*Statistically significant

Antiepileptic drug (AED) therapy

Out of 130 patients, 76 patients (58.5%) received monotherapy (a single AED) and 54 patients (41.5%) received polytherapy (combination of AEDs) with 44 patients (33.8%) on two drug combination and 10 patients (7.7%) on three drug combinations [Table 2]. Out of 76 patients (58.5%) on monotherapy, majority were on phenytoin (53.1%).

Analysis of Qolie-31-p data

The mean quality of life score was 60.3±15.72 (range 20.45- 97)**.**The mean score of various QOLIE-31-P subscales were Seizure worry (56.68±23.63), Overall QOL (63.75±19.96), Emotional wellbeing (57.45±17.92), Energy/fatigue (55.88±19.3), Cognitive functioning

(61.81±21.88), Medication effects (68.35±21.52), Social functioning (63.17±22.47) and Distress (51.24±10.16) (Table 3).

Females and unemployed patients had lower QOL score than males and employed patients. Student t – test showed a significant difference in QOL with respect to sex (P<0.000) and employment status (P=0.008). Patients on monotherapy had higher QOL score than patients on polytherapy but this difference was not statistically significant (P=0.05). The QOL score was found to be increasing as the educational status increased. But one way ANOVA showed no significant association between educational status and QOL (P= 0.703). Analysis of seizure frequency by student t-test

showed a significant association between seizure frequency and the overall QOL score (P <0.000) [Table 4].

QOL was found to be decreased as age, duration of epilepsy and the total cost of epilepsy treatment per month increases i.e., they had a negative correlation with the QOL. Univariate linear regression analysis showed a significant effect of age (P=0.011), duration of epilepsy (P=0.002) and all the QOLIE-31-P subscales on the QOL of the patient (P<0.001) whereas the effect of total cost of treatment per month was not statistically significant (Table 5).

DISCUSSION

A study was carried out in 130 patients with active epilepsy, aged ≥18yrs, who attended the neurology outpatient department of a tertiary care teaching hospital. To assess the quality of life and to identify the factors associated with quality of life in each active epileptic patients, the present study used QOLIE-31-P questionnaire. Quality of life is an important measure in epilepsy which is a chronic and debilitating condition and unique among the chronic illnesses due to the multidimensional impact on psychosocial functioning. It incorporates multidimensional aspects of individuals' physical health, psychological state and social relationship (Baker, GA et al, 1998).

In this study, the mean QOL score was 60.3±15.72 (range 20.45- 97). The patients were found have more distress followed by seizure worry and lower energy (fatigue).The study demonstrated that all the QOLIE-31-P domains such as seizure worry, overall QOL, emotional well-being, energy/fatigue, cognitive functioning, medication effects, social functioning & distress had a significant association with the quality of life (P <0.001).

The mean age of the study population was 34.89±10.18 years (range 19-60 years) and the mean duration of epilepsy was 13.35±10.54 years. In the present study, QOL was found to be decreased as age and duration of epilepsy increased. Lower QOL score was also exhibited by females and unemployed persons. QOL was found to be decreased as the education level decreased but this was not statistically significant.

A study carried out in Georgia to identify the clinical, demographic, and socioeconomic variables that influences the QOL reported that clinical factors such as high seizure frequency and long duration of epilepsy had a significant influence on QOL. There was a strong correlation of advanced age, female sex and a low education level with low quality of life scores (Djibuti., M, Shakarishvili., R, 2003).

In this study, monotherapy (52%) was slightly higher than polytherapy and it was found that there was no significant association between type of therapy (monotherapy/polytherapy) and QOL. But a study carried out in another tertiary care hospital in India reported that polytherapy is associated with lower QOL in patients with epilepsy (Sanjeev V. Thomas et al, 2005).

Seizure frequency is used as a clinical assessment tool, and reduction in seizure frequency is considered a key outcome measure in clinical practice and in trials of antiepileptic therapy (Benny M Silaen, Rusli Dhanu., Hasan Sjahri, 2008). Frequency of seizures was described as one of the most relevant determinants of poor QOL scores.[14] In the present study, QOL was found to be decreased as the number of seizure increased. This finding is similar to the reports given by other studies (Djibuti., M, Shakarishvili., R, 2003; Sanjeev V. Thomas et al, 2005). A study reported that as seizure frequency increased, patients had more impaired health-related quality of life, regardless of time since last seizure, gender and comorbid status. Another study reported that higher seizure frequencies were associated with higher costs care and with reduced QOL for patients with epilepsy (Gus A Baker, et al, 1997).

A study carried out in Europe suggested that reducing side effects and achieving better control of seizures were key to improving the quality of life of people with epilepsy, as was reducing the stigma and handicap associated with it (Leidy NK, et al, 1999).

A major limitation is that this study did not compare the QoLIE scores between patients with well controlled seizures and patients with poorly controlled seizures. This may be the reason for wide range in the mean scores ranging from 20.45 to 97.

Evaluation of Quality of life in epilepsy relatively measures the outcome of treatment for epilepsy. The care of the epileptic patients must be taken into account by considering the various factors influencing the quality of life in these patients and the management of epilepsy should be focused on better control of seizure with appropriate use of AEDs preferably monotherapy which decreases the side effects of therapy and improves the quality of life.

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