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Factors associated with quality of life of patients with epilepsy attending a tertiary care hospital in Kolkata, India

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Abstract

Epilepsy is one of the most important neurological diseases with prolonged morbidity and disability leading to profound financial loss. There have not been many studies investigating factors influencing the quality of life in an epilepsy patient in India. This study was conducted among the epilepsy patients attending a tertiary care hospital in West Bengal, India. Two hundred and four epilepsy patients attending the Outpatient Clinic of the Department of Neuromedicine, Medical College, Kolkata were interviewed with the Bengali version of QOLIE 9 (i.e. Quality of life in Epilepsy 9 questionnaire). The mean of total QOLIE score was 18.02 ± 4.87, the range being 10 to 30. Multiple linear regression analysis revealed that workdays lost due to epilepsy in last three months, use of two or more antiepileptic drugs, higher frequency of seizure, and longer time gap between onset of seizure and consultation with neurologist were significant predictors for poorer quality of life score in the epilepsy patient.

INTRODUCTION

Epilepsy is one of the most important neurological diseases with prolonged morbidity and disability leading to profound financial loss. World Health organization has considered it as a grave public health problem. Quality of life (QOL) has been defined as 'a composite measure of physical, mental and social wellbeing as perceived by each individual or by group of individuals that is to say, happiness, satisfaction and gratification as it is experienced in such life concerns as health, marriage, family work, financial situation, educational opportunities, self-esteem, creativity, belongingness and trust in others'.[1]

QOL is influenced by biological factors as well as cultural, social and religious beliefs and values. Many factors influence the QOL of people with epilepsy like seizure severity, stigma, fear and the presence of cognitive and psychiatric problems[2,3].

There has been considerable interest regarding the effects of epilepsy on QOL in the developed countries. However, such studies are lacking in the developing country. Thus, this study was proposed to investigate the factors associated with QOL among the epilepsy patients attending a tertiary care clinic in West Bengal, India.

METHODS

The present observational, descriptive, cross sectional, hospital based study was conducted in the Outpatient Clinic of Department of Neuromedicine of Medical College, Kolkata, which is an important metropolis of East India. Study period was from October 2008 to June 2009. The study was conducted among the diagnosed epilepsy patients attending the said Clinic.

From the last 5 years' hospital records, the average number of epilepsy patient attending the Neuromedicine Outpatient Clinic of the Medical College was 840, with negligible yearly variation. As the study period was 9 months, the expected number of patient attending the Clinic was 630. Considering feasibility, 50% of the study population were included in the study and were selected by systematic random sampling technique. Out of them, 204 patients fulfilled the inclusion criteria and were selected for the study.

The *inclusion criteria* were patients aged

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between 15 years to 65 years, duration of antiepileptic drug (AED) intake of at least one year, regular intake of AED, ability to understand Bengali, willing to participate in the study and presence of informants (spouse / parent / near relative) with the epilepsy patients. *Exclusion criteria* were patients with presence of serious medical or surgical problem not related to epilepsy, but may affect the results or evaluation of QOLIE; mental retardation or overt cognitive impairment, absence of informant, and refusal to participate in the study.

For those who fulfilled the inclusion criteria, the QOL was assessed using the Bengali version of the QOLIE-9 (Quality Of Life in Epilepsy) questionnaire. The health related QOL instruments for epilepsy population had been developed from the questionnaires used for evaluating the general population. The instruments developed for assessment in epilepsy include the QOLIE-89, QOLIE-31 and QOLIE-10. Studies have suggested that shorter version such as QOLIE-10 is as effective as its longer versions.[3] The QOLIE-10 was translated and validated in Bengali by Basu S *et al*[3] and converted to QOLIE-9. The Bengali translated version of QOLIE-9 was found to be valid and reliable.[3]

Apart from the QOLIE-9 questionnaire, the study subjects were also required to fill up a pre-designed, pre-tested semi-structured proforma for assessing the socio-demographic variables of the study population. The socio-demographic variables included age, sex, residence, educational status, and marital status. Clinical variables were also assessed which included family history of epilepsy, frequency of seizure, age of onset of seizure, duration of epilepsy, time since last seizure, status of response; workdays lost due to epilepsy, and total out of pocket expenditure. The operational definition of response was ≥50% reduction in seizure frequency after 12 weeks of treatment with AED as suggested by Engel *et al*.[4] Patients fulfilling the above criteria were categorized as "responders" and the others were regarded as "non-responders". Patients who had no seizure for the previous 6 months (from the date of interview) were regarded as "seizure free".

Analysis was done using Epi info 3.4.3 and SPSS 16.0 softwares. Descriptive measures like mean, standard deviation were used to summarize numerical variables. While categorical variables were summarized by using frequencies and percentages, the mean values between various groups were compared using t test, Man Whitney test and Kruskal Wallis test whichever applicable. Correlation between QOLIE 9 total score and various clinicosocial variables was computed using Pearson's correlation coefficient. Multiple linear regression analysis was done with the independent variables found significant in the univariate analysis and correlation.

RESULTS

Of the 204 patients studied, 141 (69.1%) were males. Majority (148, 72.6%) were residing in rural areas. Sixty seven patients (32.8%) were married, 135 (66.2%) were never married and 2 were separated. One hundred and twenty eight patients (62.8%) had primary or below primary education, 76 (37.3%) had education above primary level. Family history of epilepsy was present in 26 patients (12.8%). Most of the patients were started AED treatment by Neurologist (113, 55.4%), followed by General Practitioners (45, 22.3%) and Specialists in Internal Medicine / Pediatrics (44, 21.6%). Only two patients were started AED by Psychiatrists. One hundred and fourteen patients (55.9%) were on monotherapy, whereas 90 (44.12%) were taking two or more AEDs. One hundred and ninety two patients (94.1%) were responders, while 12 (5.9%) patients were non-responders.

Mean total score of QOLIE was 18.02 ± 4.87, range 10 to 30. Low score implied better quality of life. As for the relationship between the socio-demographic and clinical variables with total score of QOLIE, significant association of higher total QOLIE score was found with rural residence ($t=4.29$, $p=0.001$), family history of epilepsy ($U=1591.0$, $p < 0.01$), AED treatment started by General Practitioners, Internists and Pediatricians ($\chi^2=13.44$, $p=0.004$), use of two or more AEDs ($U=1646.00$, $p < 0.001$), absence of seizure freedom ($t=5.977$, $p=0.001$) and non-responder ($U=169.00$, $p=0.001$). But no significant association was found with education ($t=0.51$, $p=0.64$), gender ($t=1.87$, $p=0.064$) and marital status ($\chi^2=3.972$, $p=0.135$) (Table 1).

Significantly higher total QOLIE score was also associated with higher seizure frequency ($p=0.001$), more workdays lost due to epilepsy in last 3 months ($p=0.001$), longer time gap between onset of seizure and consultation with neurologist ($p=0.001$), longer duration of epilepsy ($p=0.004$), higher total out of pocket expenditure for epilepsy ($p=0.001$), and lower age of onset of seizure ($p=0.016$). No significant correlation was observed between other variables and the total QOLIE scores (Table 2).

Table 1: Univariate analysis showing relationship of some clinicosocial variables with the total QOLIE score (n=204)

Variables	QOLIE Score (Mean ± SD)				p value
Gender Mean ± SD	Male 18.45 ± 4.99 (n=141)	Female 17.08 ± 4.49 (n=63)			t =1.87 p=0.064
Residence Mean ± SD	Urban 17.16 ± 4.4 (n=148)	Rural 20.3 ± 5.3 (n=56)			t =4.29 p=0.001
Education of patients Mean ±SD	Primary & below primary 18.16 ± 4.95 (n=128)	Above primary 17.80 ± 4.75 (n=76)			t=0.51 p=0.64
Marital status Mean ±SD	Never married 18.45 ± 4.79 (n=135)	Currently married 17.19 ± 5.02 (n=67)	Separated 17 ± 0.001 (n=2)		χ^2=3.972 p=0.135 using Kruskal wallis test
Family history of epilepsy	Present 15.77 ± 3.45 (n=26)	Absent 18.35 ± 4.96 (n=178)			U=1591.0 p < 0.01 Using Man whitney U Test
Started AED by Mean Rank	General Practitioner 19.60 ± 5.241 (n=45)	Internist / Pediatrician 19.66 ± 5.32 (n=44)	Psychiatrist 15.00 ± 0.001 (n=2)	Neurologist 16.81 ± 4.193 (n=113)	χ^2=13.44 p=0.004 Using Kruskal walis test
No. of AED used	Monotherapy 15.51 ± 3.620 (n=114)	Polytherapy 21.21 ± 4.36 (n=90)			U=1646.00 p < 0.001 Using Man whitney U Test
Response to treatment	Responder 17.54 ± 4.546 (n=192)	Non-responder 25.83 ± 2.758 (n=12)			U=169.00 p=0.001 Using Man Whitney U test
Seizure freedom	Present 16.66 ± 4.353 (n = 134)	Absent 20.63 ± 4.765 (n = 70)			t = 5.977, p = 0.001

Multiple linear regression analysis of the significant variables in the univariate analysis (Table 3) showed the adjusted R^2 as 0.508 for the proposed model of the present study. More workdays lost due to epilepsy in last 3 months (standardized beta 0.282, p=0.001), use of two or more AEDs (standardized beta 0.402, p=0.001), higher frequency of seizure (standardized

Table 2: Correlation between of some clinicosocial variables and total QOLIE Score (n=204)

Variable	Pearson's Correlation co-efficient (r)	p value
1. Age of patient	0.028	0.7
2. Per capita income of the family of the patients	0.040	0.568
3. Age of onset of seizure	– 0.168	0.016
4. Frequency of seizure	0.424	0.001
5. Time gap between onset of seizure & starting of AEDs	0.084	0.232
6. Time since last seizure episode	– 0.107	0.128
7. Time gap between onset of seizure and consultation with neurologist	0.293	0.001
8. Duration of epilepsy	0.200	0.004
9. Workdays lost in last 3 months due to epilepsy	0.427	0.001
10. Total out of pocket expenditure for epilepsy	0.398	0.001

Table 3: Multiple linear regression analysis of the significant clinicosocial variables found in univariate analysis with total QOLIE score (n=204)

Variables	Standardize Coefficients (Beta)	t value	Significance	95% confidence interval
Place of residence	0.039	0.509	0.611	-1.203 – 2.036
Work day lost in last 3 months due to epilepsy	0.282	4.327	0.001	0.024 – 0.065
Family history of epilepsy	0.079	1.214	0.227	-0.762 – 3.180
Duration of epilepsy	-0.039	-0.615	0.539	-0.114 – 0.060
Total out of pocket expenditure for epilepsy	0.041	0.653	0.515	-0.001 – 0.003
No. of AEDs used	0.402	5.710	0.001	2.570 – 5.298
Frequency of seizure	0.138	1.990	0.049	0.002 – 0.599
Time gap between onset of seizure and consultation with a neurologist	0.218	2.986	0.003	0.006 – 0.032
Types of medical practitioners who started the AED treatment	-0.047	-0.624	0.533	-0.734 – 0.382

beta = 0.138, p=0.049) and longer time gap between onset of seizure and consultation with neurologist (standardized beta 0.218, p=0.003) were significant predictors for poorer QOL score in an epilepsy patient. Other variables were not significant.

DISCUSSION

Epilepsy has profound impact on the QOL of the epilepsy patients. The outcome of epilepsy treatment has been traditionally measured by the seizure frequency, severity, effect of AED and its adverse effects. But recently a number of studies[3,5-8] had highlighted the effects of epilepsy on QOL, which has been increasingly adopted to evaluate the outcome of epilepsy. Most of the studies[5,7,8] on QOL have been conducted in developed countries and very few[3,6] had been reported from India.

In multivariate analysis in the present study, the factors associated with poorer QOL were more workdays lost due to epilepsy in last 3 months, use of two or more AEDs, higher frequency of seizure, all reflecting greater difficulties in control of seizures; and longer time gap between onset of seizure and consultation with Neurologist. A stepwise multiple regression analysis (R^2=0.147) carried out by Thomas SV *et al*[6] from Kerala, India similarly revealed a significant association between poorer total quality of life score (TQOL) and polytherapy (standardized beta -0.196, p=0.041), and Engel score of seizure frequency >6 (standardized beta -0.281, p=0.003). Djibuti M *et al*[5] from Georgia and Basu S *et al*[3] from Bengal also found poorer quality of life to be associated higher seizure frequency. Kabui R *et al*[7] in California also found a shorter time gap since last seizure to be significant. As for our finding of delay in seeking expert treatment from neurologists as a predictor of poorer quality of life, we could not find any previous study with similar finding.

In the univariate analysis of this study, it was also shown that there was significant association in poorer QOL with rural residence, family history of epilepsy, AED treatment started by General Practitioners, Internists and Pediatricians rather than Neurologists. We could not find similar findings in the previous studies elsewhere. The beneficial role of Neurologist suggests the need for more epilepsy education among other physicians in West Bengal, as well as early referral to the Neurologists.

No significant association of QOL was found with gender, religion and education of the epilepsy patients in the present study, which is similar to the findings by Thomas SV *et al*[6] from Kerala. However, Djibuti M *et al*[5] could show an association with female gender in Georgia. Herodes M *et al*[8] in Estonia also showed the importance of unemployment due to epilepsy in affecting QOL, which was not specifically looked for in this study.

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