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HEALTH-RELATED QUALITY OF LIFE AND KNOWLEDGE ABOUT EPILEPSY AMONG PATIENTS WITH EPILEPSY

Medical Science

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ABSTRACT

Introduction: People with epilepsy have impairment in their quality of life (QOL) due to effect of epilepsy on various aspects of their life and the medication effects. Epilepsy carries an enormous social stigma and people with epilepsy tend to have lower quality of life (QOL).

Aim: The aim of this study to check the quality of health in epilepsy patients and to assess the extent of knowledge in patients regarding epilepsy

Methods: A structured questionnaire was used to collect information on demographic profile, seizure characteristics, knowledge regarding cause of epilepsy, details of alternative forms of treatment taken and attitude towards medical treatment.

Results: 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 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).

Conclusion: Our findings suggest that optimizing seizure control might reduce the need for health care, particularly at the secondary level, thus reducing the costs of epilepsy both to society and to the person with epilepsy.

KEYWORDS

epilepsy, quality of life, knowledge

INTRODUCTION

Epilepsy is one of the most prevalent neurological conditions across the globe. It has been estimated that around 50 million people worldwide suffer from epilepsy and nearly 80% of the cases of epilepsy occur in the developing countries due to inefficient healthcare facilities, poor sanitation and high rate of brain infections (De bore *et al*., 2008). Epilepsy can be associated with profound physical, psychological and social consequences and overall the QOL (Quality of life) was worse in patients with epilepsy than in the general population. The World Health Organization (WHO) defined QOL as an 'individual's perceptions of his position in life, in the context of the culture and value system in which he lives and in relation to his goals, standards and concerns. The disability and psychosocial impact caused by epilepsy in socio-culturally determined traditional societies like India is phenomenal and impose huge economic burden to the individual and the society. Understanding the social and economic impact becomes critically important for effective control and prevention of epilepsy in resource-poor settings like India.

AIM

The aim of this study to check the quality of health in epilepsy patients and to assess the extent of knowledge in patients regarding epilepsy.

MATERIAL AND METHODS:

The study was carried on patients with epilepsy attending the Neurology outpatient department at Ivy Multi-specialty Hospital Hoshiarpur, Punjab India. The duration for the project was up to six months. Data were collected through interviews by using previously adopted standard questionnaire that was translated into local languages. In addition to providing a translation, the data quality was assured by daily checking to control the quality of data collected from the study subject by supervisors. A structured questionnaire was used to collect information on demographic profile, seizure characteristics, knowledge regarding cause of epilepsy, details of alternative forms of treatment taken and attitude towards medical treatment. Data analysis was performed using SPSS statistical software.

RESULTS:

A total of 80 patients who fulfilled the inclusion criteria were recruited in to the study. Data shows the demographic details of the respondents. The age of the respondents ranged between 18–60 years with majority seen in the 23–36years (33.9%). Most of the respondents were males (61.2%) and 53.1% were married and living with spouse. The occupation of majority of the respondents was unskilled labour (37.6%). Factors affecting QOL included age, place of residence, socioeconomic condition, maternal education, seizure type and frequency and number of antiepileptic drugs

Table 1. QOL of patients with generalized and partial epilepsy based on gender

QOL	Generalized		P value	Partial		P value
	Male	Female		Male	Female	
BP	64.23 ± 31.77	50.37 ± 25.04	0.010	51.53 ± 29.11	43.07 ± 27.80	0.601
GH	38.07 ± 29.80	55.58 ± 19.29	0.001	34.61 ± 19.73	59.23 ± 31.77	0.201
Vitality	53.65 ± 25.91	47.18 ± 15.48	0.015	69.23 ± 24.28	38.46 ± 21.73	0.334
PF	03.07 ± 30.98	63.64 ± 47.02	0.425	78.92 ± 23.94	63.84 ± 39.16	0.319
RF	47.03 ± 40.71	54.68 ± 48.41	0.465	43.84 ± 46.59	58.46 ± 49.01	0.215
SF	60.09 ± 23.16	65.36 ± 17.91	0.421	66.73 ± 25.31	69.50 ± 23.38	0.273
RE	34.46 ± 11.83	58.55 ± 39.09	0.571	41.28 ± 31.67	46.15 ± 24.17	0.576
MH	54.07 ± 21.82	73.08 ± 21.47	0.624	68.30 ± 21.09	62.30 ± 13.00	0.572

QOL: Quality of life BP: Bodily pain; GH: General health; PF: Physical functioning; RF: Role functioning; SF: Social functioning; RE: Role emotional;

Regarding family history, 35% of study patients are having one or more person in family with epilepsy. Which is less, compared with other group 65% of patients have no person in family with epileps.10% of study patients are having one or more person in family with epilepsy. 62% patients are attended school and college, 28% patients are uneducated who didn't completed the school. 28% of male patients were smoking cigarettes, 16% are drinking alcohol. 34% of patients are adherent to the treatment, 46% are not adherent to the treatment.

57% of oral treatment patients are not taking the medicine in correct time or missing the dose. 17% of patients therapy are non-adherent.

Table 2 Distribution of Demographic characters

Characterstics		Number of Patients (n=80)	P-value
Sex	Males	43 (53.75%)	<0.000*
	Females	37 (46.25%)	
Education Status	Illiterate	7 (8.75%)	0.0083*
	High School	14 (17.5%)	
	Higher Secondary	36 (45%)	
	Graduate	13 (16.25%)	
	Post Graduate	17 (21.25%)	
Occupational Status	Employed	44 (55%)	0.051
	Unemployed	36 (45%)	
Therapy	Monotherapy	26 (32.5%)	0.703
	Polytherapy	54 (67.5%)	

Table 3 Drug administration with number of patients

Subscales	Mean score	Minimum score	Maximum score
Seizure Worry	56.68 ± 2	3.63	100
Overall QOL	61.75 ± 19.96	0	100
Energy/Fatigue	53.88 ± 19.3	5	100
Cognitive Functioning	65.84 ± 27.88	0	100
Medication Effects	78.35 ± 21.52	16.56	100
Social Functioning	62.27 ± 22.47	4	100
Distress	41.24 ± 10.16	51.24	100
Emotional Wellbeing	57.45 ± 13.92	16	66

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 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

DISCUSSION

Epilepsy, one of the most important non-communicable neurological illnesses, is particularly under resourced and undertreated in the developing world. Epidemiological studies have made it clear that the magnitude of the problem makes it a public health priority. Large numbers of people are at risk of morbidity and mortality, mainly because of difficulties with treatment infrastructure and the availability of suitable drugs. However, people with epilepsy need more than drug treatment because their local cultural context adds a social and economic burden to the physical burden of their seizures. The education of health workers, patients, and the wider community is therefore essential. The treatment gap can only be properly closed if poverty and inequalities of income are dealt with at the local, national, and global levels. A study was carried out in 80 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-questionnaire .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 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). In the present study, QOL was found to be decreased as age and duration of epilepsy increased. At the local level this may mean ensuring that primary health care operates within a community development framework where, for example, there are literacy and income-generating programmes. The burden of epilepsy may be due to the physical hazards of epilepsy resulting from the unpredictability of seizures; the social exclusion as a result of negative attitudes of others toward people with epilepsy; and the stigma, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe. There was a strong correlation of advanced age, female sex and a low education level with low quality of life scores. In this study, monotherapy (52%) was slightly higher than poly therapy and it was found that there was no significant association between type of therapy (mono-therapy/poly therapy) and QOL. Cost of healthcare depends upon a host of modalities including the disease condition, insurance coverage, age of the individual, etc. In addition, cost of healthcare is influenced by other institutional factors namely the service mix, the treatment modalities, brand image of the institution, etc. Reports indicate that hospitals with centralized air conditioning units are associated with higher cost of hospitalization Nurse to patient ratios and staff to bed ratios also influence quality of care. Though it may appear that higher staff would increase the cost of medical care borne by the common man, the findings of the study indicate otherwise. The rational for higher staff to bed ratio, results in provision of better quality of care, which in turn reduces the average length of stay and hence average hospitalization cost. This clearly indicates that accreditations and quality assurance systems help hospitals to streamline their functions and processes, minimize wastage and thereby aid in enhancing quality and reducing cost of care

CONCLUSION

Even though epilepsy is an eminently preventable and treatable condition, it still remains a major public health problem due to high stigma, wide socioeconomic inequity, huge treatment gap, and the poor epilepsy healthcare delivery system in India. Our findings suggest that optimizing seizure control might reduce the need for health care, particularly at the secondary level, thus reducing the costs of epilepsy both to society and to the person with epilepsy. Thus, besides considering the epidemiological aspects, the psychosocial and economic impact of epilepsy becomes more crucial while addressing the problem of epilepsy. Time has been lost and rather than focusing on pilot projects, a sustainable, cost effective, and comprehensive public health response is required to address the challenge of epilepsy in India.

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