

RESEARCH ARTICLE

Quality of Life in Patients with Epilepsy: Study from a Northern Indian Teaching Hospital

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ABSTRACT

Objectives: Epilepsy is a significant public health problem in the world today. The social stigma and impact on quality of life (QOL) may pose a bigger challenge than the clinical severity. In India, there are not many studies using quality of life in epilepsy (QOLIE-31) questionnaire to study the QOL in epileptic patients. This study may be useful in planning the management of patients with epilepsy. So, our study was conducted to determine the level of health-related QOL (HRQOL) of patients with epilepsy in a teaching hospital.

Materials and methods: This was a cross-sectional, questionnaire-based study conducted in a teaching hospital from March to October 2015. The subjects included both male and female adults of at least 18 years of age with a diagnosis of epilepsy, which was present for minimum 1 year. The QOLIE-31 was used for collecting data on HRQOL.

Results: Totally, 70 patients with epilepsy were included in the study. The standard deviation (mean) total score of QOLIE-31 in our study was 60.46. There was a significant difference in the total score of QOLIE-31 within the monotherapy and polytherapy group as the total score of QOLIE-31 was better in monotherapy group as compared with polytherapy group.

Conclusion: The study revealed that patients who were on a single drug (monotherapy) had a much better QOL than the patients on more than one drug (polytherapy).

Keywords: Monotherapy, Polytherapy, Quality of life in epilepsy questionnaire, Seizure worry.

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INTRODUCTION

Globally, epilepsy is a significant public health problem today with 50 million people suffering from it, wherein

85% of them are from developing countries.¹ Its prevalence is 5.1% in urban and 5.5% in rural areas of India.²

Epilepsy, a brain disorder, is characterized by an enduring predisposition to epileptic seizures, leading to neurobiological and social consequences.³ Unpredictable nature, its course, stigma attached to it,⁴ poor self-esteem, with higher levels of anxiety, associated depression, educational underachievements, under- or unemployment, less marriages, higher divorce rates, more social isolation, side effects of treatment, and cognitive and psychiatric problems⁵⁻⁷ impair quality of life (QOL) in epilepsy patients. The QOL is an individual's perception of their position in life in respect to the culture and value systems in which they live and in context to their goals, expectations, standards, and concerns.⁸ A questionnaire that assesses multiple daily functions depending on the cultural, ethnic, and economic differences is QOL.⁹

The overall aim of treating epilepsy should be complete control of seizures without causing any untoward reaction due to the medication. The patients' perceptions often include other parameters, such as effects of epilepsy on daily activities and functions.¹⁰ Epilepsy can be associated with great physical, psychological, and social consequences,¹¹ and so its impact on a person's QOL can be more than that of chronic conditions.¹² People with epilepsy have reported a poorer QOL because they have poor self-esteem and a high level of anxiety and depression.¹³ In some cases, the social stigma and impact on QOL may pose a bigger challenge than the clinical severity.¹⁴ The important factor for better outcome in the treatment of epilepsy is health-related quality of life (HRQOL). Research assessing the QOL associated with successful treatment of epilepsy lags that of other chronic diseases like cancer, diabetes, and cardiovascular disease.¹² Very few studies have been carried out on quality of life in epilepsy (QOLIE-31) in India, and research in this area will identify factors affecting QOL and may lead to strategies that improve the management of patients with epilepsy. So, our study was conducted to determine the level of HRQOL of patients with epilepsy in a teaching hospital.

MATERIALS AND METHODS

This was a cross-sectional, questionnaire-based study conducted in a teaching hospital from March to October 2015 after the approval from the Institutional Ethics

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Committee. The subjects included both male and female adults with minimum 18 years of age with a history of epilepsy present for minimum 1 year. They were explained the nature and purpose of the study. A necessary consent was obtained. Patients excluded comprised ones with associated psychotic disorders, severe mental retardation, strokes, head injuries, brain tumors, and any recent brain surgery. The sociodemographic data (including age, sex, employment status, educational level) were collected from subjects and also the clinical aspects of epilepsy (like seizure frequency, duration of epilepsy, and medication) (Table 1). The number of seizures occurring in the last year prior to the interview is defined as seizure frequency. The QOLIE-31 was used for collecting data for HRQOL, consisting of seven subsets and one item of overall health. The responses were used on Likert rating scales, which were later transformed into linear scales that ranged between 0 and 100. A higher score of QOLIE-31 indicates better QOL in patients with epilepsy.¹⁵

Statistical analysis data were analyzed using Statistical Package for Social Sciences software. Descriptive statistics were expressed as the mean \pm standard deviation (SD) and percentage as appropriate.

Table 1: Sociodemographic Profile

Variables	N (70)
<i>Age (years)</i>	
18–28	38
29–38	18
39–48	8
49–58	4
>58	2
<i>Gender</i>	
Male	42
Female	28
<i>Marital status</i>	
Married	51
Unmarried	19
<i>Religion</i>	
Hindu	54
Muslim	12
Christian	4
<i>Education</i>	
Professional	0
Graduate/post graduate	9
Intermediate	7
High school	17
Middle school	19
Primary school	5
Illiterate	11
<i>Occupation</i>	
Government employee	6
Private employee	14
Business	8
Agriculture	22
Unemployed	20

Table 2: Comparison with QOLIE-31 Scores

Subscales of QOLIE-31	Mean	SD	T-Score
Seizure worry	64.04	22.33	52
Overall QOL	56.64	16.59	44
Emotional well-being	59.6	15.92	46
Energy/fatigue	51.42	18.25	48
Cognitive functioning	63.98	21.54	52
Medication effect	88.064	17.93	61
Social function	59.14	26.30	47
Overall score	60.46	17.80	48

Table 3: QOL with different Medicines

Subscale	Mean (SD) N=70			
	Phenytoin	Valproate	Carbamazepine	Polytherapy
Seizure worry	65.82 (20.94)	69.14 (24.25)	75 (35.35)	57.89 (19.14)
Overall QOL	55.73 (13.96)	67.5 (25.64)	46.25 (5.3)	48.75 (6.29)
Emotional well-being	58.82 (16.23)	66 (16.92)	56 (16.9)	48 (5.65)
Energy/fatigue	48.03 (16.16)	57.77 (21.97)	47.5 (31.81)	52.5 (8.66)
Cognitive functioning	61.72 (20.51)	67.29 (29.15)	72.83 (28.98)	59.07 (12.46)
Medication effects	90.62 (19.18)	74.54 (14.31)	81.95 (25.52)	84.72 (20.96)
Social functioning	56.67 (23.93)	65.41 (32.29)	75 (35.35)	43.18 (19.11)
Overall score	58.32 (14.64)	65.95 (22.93)	64.44 (25.94)	51.06 (7.43)

RESULTS

Totally, 70 patients with epilepsy (irrespective of the type of epilepsy) were included in our study consisting of 42 men and 28 women aged between 18 and 58 years. The mean total score of QOLIE-31 was 60.46. The highest mean score was the medication effect (88) and the lowest was energy/fatigue subscale (51) (Table 2). There was a significant difference in the total score of QOLIE-31 within the monotherapy and polytherapy groups as the total score of QOLIE-31 was better in monotherapy group as compared with polytherapy group. The QOL was better in valproate group as compared with carbamazepine group. Similar seizure worry score was seen more in carbamazepine and phenytoin groups (Table 3).

DISCUSSION

Epilepsy has been having a considerable impact on QOL with lifelong consequences. To improve the QOL in patients is an essential component to further improve the management of patients with epilepsy.¹⁶ The mean total score of QOLIE-31 had similar findings to a study conducted in India,¹⁷ but higher than studies conducted in Australia (52.9)¹⁸ and Africa (52.1).¹⁹ A study conducted in Malaysia²⁰ reported a higher mean total score of

QOLIE-31 (68.9). The majority of the studies had used QOLIE-31 questionnaire (different translations), different study methodologies with different inclusion and exclusion criteria, which would have accounted for the different scores. The higher the score, the better the standard of medical care is, as also reported in our study and thus better prophylaxis for this disease. Our study was partially similar to the studies conducted in Africa¹⁹ and Malaysia for scores of QOLIE-31.²⁰ In our study, the emotional well-being subscale was near to lowest, and seizure worry was the highest. The difference in pattern may be due to the reason that different countries have a difference in beliefs, culture, and socioeconomic factors which affect QOL measures, and so, findings from other countries may not be relevant to the local situation we have here in India. No significant difference was found in the QOL scores when compared with education and employment status in sociodemographic scales. Some studies have reported that unemployment is mostly related to the state of seizure control, the age of onset and duration of illness, the type of medication, severity and frequency of seizures.²¹ The subjects had a similar frequency in all the studies. People with frequent seizures had significantly poorer HRQOL than those with infrequent or no seizures.²² A study reported that seizure frequency was the single most important clinical predictor of psychosocial dysfunction and emotional maladjustment in epilepsy patients.²³ Longer duration of epilepsy has been reported as a predictor for poor QOL²³ due to greater complications and disabilities. Our study found no significant association between duration of epilepsy and QOL. This may be due to small sample size in our present study. Patients on a single drug (monotherapy) had a better QOL as compared with patients on more than one drug (polytherapy). A similar finding was shown in a study by Thomas et al.²⁴ This may be due to the fact that patients on polytherapy have more severe and complicated disease. However, other studies have proved that there was no association between QOLIE-31 and type of drug therapy.²⁵ Among patients receiving monotherapy, cognitive function was least impaired in carbamazepine group. Few studies have shown that cognitive effect profile of carbamazepine is better than phenytoin in epilepsy patients.^{26,27} Furthermore, scores for medication effect were better in carbamazepine group as compared with valproate group, indicating that the patients in the valproate group were more worried about the side effects of the drug. This may be due to better adverse effects of carbamazepine as compared with other drugs used in the treatment of epilepsy.²⁸

CONCLUSION

It is evident that there are many factors that influence QOL of people with epilepsy from our present study and

also other studies. The type of drug therapy followed by a patient with epilepsy plays a very important role. Patients who were on monotherapy had a better QOL mainly because of the lesser side effects as compared with those on polytherapy. Also, adding clinical counseling and other interventions to address the physical, mental, psychological, social, and emotional aspects of health well-being is likely to achieve better health outcomes for epilepsy patients, as seen by us in our present study with the involvement of psychiatric doctors. To remove the stigma with epilepsy and improve QOL of patients with epilepsy, raising the awareness in society regarding present effective therapy by public awareness and educational campaigns may be helpful.²⁹

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