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Research Article

Assessment of Health Related Quality of Life in Patients with Epilepsy

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ABSTRACT

Background: Estimation of Quality of life is a useful outcome measure to know about epilepsy care from patient's perspective. Assessing QOL of epileptic patients is important so as to manage the epilepsy and to implement some interventional programs in order to improve the quality of life of these patients. The study aims to find out the impact of epilepsy on quality of life of epileptic patients

Material and method: This was a cross-sectional, questionnaire-based study, conducted from March to August 2019 for a period of 6 months, after approval from Institutional Ethics Committee. Data was analyzed using Statistical Package for Social Sciences (SPSS) version 25. The quality of life in epilepsy (QOLIE-31) was used for collecting data on health-related QOL.

Result: The study group consisted of 65 patients of whom 48 were males (73.84%) and 17 were females (26.15%). Their ages ranged from 19 to 60 years. (mean age: 35.65). Majority of the patients were in the age range of 30-41 (40%). 50.8% participants were from nuclear family and 49.2% were from joint family system. Most of the patients had lower class socioeconomic status (61.5%). As regard to the employment status, 38.4% of patients were full time employed, 13.8% were part time employed. 29.2% were unemployed and 9.23% were retired and 9.23% were students. The medication analysis revealed that 30.6% of the participants were on monotherapy whereas 69.0% were on polytherapy. The mean total QOLIE-31 score was 39.12 (SD-5.00).

Conclusion: Epileptic patients had poor QOL with low total QOLIE-31 score, unemployment, use of combination therapy and people belonging to lower class were associated with lower quality of life in individuals with epilepsy.

Keywords: Health Related Quality of life, Epilepsy, Quality of Life in Epilepsy (QOLIE-31) questionnaire

INTRODUCTION

EPILEPSY

A paroxysmal event which arises due to excessive discharge from hyper synchronous neurons is known as seizure. Epilepsy is a central nervous system disorder in which a person experience recurrent epileptic seizures. There is disruption of electrical activity in the brain which causes synchronized and excessive neuronal discharge.[1] Epilepsy is not a communicable disease. The most common type of epilepsy, affecting 6 out of 10 people with the disorder, is known as idiopathic epilepsy the cause of which is unknown. On the other hand secondary epilepsy or symptomatic epilepsy is the epilepsy with an identifiable cause. Approximately 50 million people worldwide suffer from epilepsy, which makes it one of the most prevalent neurological disease. Globally, each year around 2.4 million people are diagnosed with epilepsy. An estimated 80% of the people suffering from epilepsy are found in low and middle income countries. Approximately 70% of the time, people with epilepsy responds to the treatment being given. About three fourth of people living in low and middle income countries that suffers from epilepsy do not get the treatment they require.[2] Neurodevelopment delay, cognitive impairment, comorbid depression and anxiety are usually seen in epileptic patients.[3] Moreover, epileptic patients face educational and vocational challenges, have problems with independent living, and become victims of stigma and common public misunderstanding.[4] Comorbid and psychosocial issues like this must be taken into account when treating and caring for epileptic patients. The International League Against Epilepsy (ILEA) defines epilepsy not only as "a chronic condition of the brain characterized by an enduring propensity to generate epileptic seizures" but also by "the cognitive, psychological, neurobiological and social consequences of this condition."

(5) These common issues and comorbidities must be addressed by the clinicians treating the epilepsy. Treatment should not only be given to reduce the frequency of seizures, but should also aim at minimizing the side effects, taking into account the coexisting health and social problems faced by the patient and thereby improving the quality of life (QOL).

The prerequisite of this study is to determine the burden of disease, injuries and disabilities and to measure Health Related Quality of Life (HRQOL) which will help to monitor progress so as to attain the Nation's health goal and assessment of HRQOL surveillance data can identify individuals with relatively poor perceived health and help to guide interventions in order to improve their situations and avoid more serious consequences.

Estimation of Quality of life is a useful outcome measure to know about epilepsy care from patient's perspective. Assessing QOL of epileptic patients is important so as to manage the epilepsy and to implement some interventional programs in order to improve the quality of life of these patients.

MATERIAL AND METHODS

The study was conducted in Tertiary Care Hospital, Dehradun. The patients attending the outpatient and inpatient facilities of the department of neurology and general medicine with clinical diagnosis of epilepsy were included in the study. This was a cross-sectional, questionnaire-based study, conducted from March to August 2019 for a period of 6 months, Total 65 epileptic patients were enrolled in the study that satisfies the inclusion and exclusion criteria. Inclusion criteria were male and female patients who were willing to participate of age above 18 years, and with the diagnosis of epilepsy for at least one year. Exclusion criteria were patients with other concomitant chronic illness and psychiatric disorder, patients in unconscious state and patient below 18 years and not willing to participate.

They were explained the nature and purpose of the study and necessary consent were obtained. Questionnaires were developed to collect socio-demographic data (age, gender, employment status, qualification etc.) and clinical characteristics of epilepsy (age at onset, seizure frequency and medication etc.)

The quality of life in epilepsy (QOLIE-31) was used for collecting data on health-related QOL with the permission of QOLIE development group.

 It is a epilepsy specific questionnaire which includes 31 questions containing seven domains to be measured: 1) Seizure worry; 2) Overall Quality of life; 3) Emotional well-being; 4) Energy/fatigue; 5) Cognitive functioning; 6) Medication effects; 7) Social functioning.

Statistical analysis

Data was analyzed using Statistical Package for Social Sciences (SPSS) version 25. Paired sample t- test was used to compare the means between groups. Paired sample correlation which shows bivariate Pearson correlation coefficient was used to calculate the correlation. The results were tabulated and graphically represented using Microsoft Office for Windows 2010.

RESULTS

The study group consisted of 65 patients of whom 48 were males (73.84%) and 17 were females (26.15%). Their ages ranged from 19 to 60 years. (mean age: 35.65). Majority of the patients were in the age range of 30-41 (40%). 50.8% participants were from nuclear family and 49.2% were from joint family system. Most of the patients had lower class socioeconomic status (61.5%). 33.9% population was living in urban areas and 66.1% in urban areas. As regard to the employment status, 38.4% of patients were full time employed, 13.8% were part time employed. 29.2% were unemployed and 9.23% were retired and 9.23% were students. The medication analysis revealed that 30.6% of the participants were on monotherapy whereas 69.0% were on polytherapy. 44.7% people were single, 47.6 % were married and 7.7% were widow.

Age group of 21-30 had the highest percentage of onset age of epilepsy with 35.50%. And lowest percentage of 1.50% between the age range of 41-50. Generalized seizures were most common with the percentage of 72.30% and partial seizure had 18.50% prevalence. Other seizure types contributed 9.20%. 30.8% individuals never missed medication, 49.3% missed medicine less often than once a month, 16.9% missed medicine less often than once a week and 3% were drug defaulter. 7.69% people had seizure once or more in a week, 46.10% had seizure once or more in a month, 43% had seizure once or more in a year and 3.07% had seizure not at all in the past year.

With p-value of <0.05 the type of therapy data, socioeconomic status and employment status showed a statistically significant difference between the means of the population.

The mean total score of QOLIE-31 was 39.12. The highest mean score was the medication effects-32.24 and the lowest was overall quality of life-15.72.

Total score of QOLIE-31 subscales

The mean total score of QOLIE-31 was 39.12. The highest mean score was the medication effects-32.24 and the lowest was overall quality of life-15.72.

Table 1-

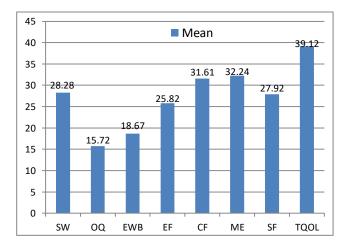| SUBSCALES OF QOLIE-31	MEAN (SD)
Seizure worry (SW)	28.28 (0.68)
Overall quality of life (OQ)	15.72 (0.83)
Emotional well-being (EWB)	18.67 (1.53)
Energy/fatigue (EF)	25.82 (0.92)
Cognitive function (CF)	31.61 (2.01)
Medication effect (ME)	32.24 (0.31)
Social function (SF)	27.92 (0.96)
Total Quality of life score (TQOL)	39.12 (5.00)

Figure 1- Total score of QOLIE-31 subscales

Comparison of total QOLIE-31 score with respect to type of therapy

Paired sample correlation showed statistical significance between type of therapy (p value < 0.05) and there exist positive correlation between the groups.

Table 4.2- Total QOLIE-31 score according to type of therapy

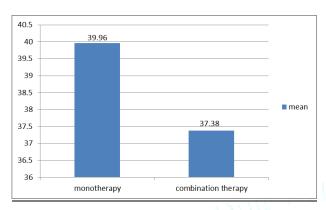| TYPE OF THERAPY	MEAN (SD)
Monotherapy	39.96 (3.19)
Combination therapy	37.38 (5.30)

Figure 4.2- Total QOLIE-31 score according to type of therapy

Comparison of total QOLIE-31 score with respect to socioeconomic status

Paired sample correlation show statistical significance between socioeconomic status (p value < 0.05). And a positive correlation exists between the groups.

Table 3.1.6-Total QOLIE-31 score according to socioeconomic status

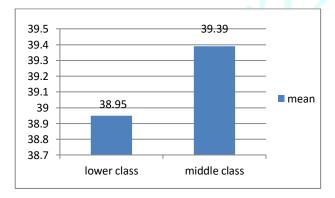| SOCIOECONOMIC STATUS	MEAN (SD)
Lower class	38.95 (5.27)
Middle class	39.39 (4.63)

Figure 3.1.6-Total QOLIE-31 score according to socioeconomic status

Comparison of total QOLIE-31 score with respect to employment status

Paired sample correlation showed a negative correlation between students and unemployed group and there was statistical difference in means students and unemployed group (p value <0.05). And in other groups there was no statistical significance.

Table 3.1.5-Total QOLIE-31 score according to employment status

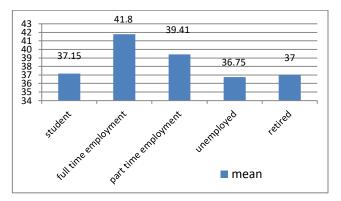| EMPLOYMENT STATUS	MEAN (SD)
Student	37.15 (2.36)
Full time employment	41.80 (4.94)
Part time employment	39.41 (4.14)
Unemployed	36.75 (4.76)
Retired	37.00 (4.56)

Figure 3.1.5-Total QOLIE-31 score according to employment status

DISCUSSION

Epilepsy is not a communicable disease, but it has an enormous social stigma and people with epilepsy usually have lower quality of life as compare to other individuals. [6] The disorder is usually considered to be witchcraft or people think that the patients of this disorder are possessed by some spirits and believe that those with epilepsy are cursed and the society usually treats them as insane or psychiatric patient. [7] It can affect people economically, socially and culturally. In India and China, epilepsy may be used as justification to deny marriage.[8] The stigma may result in some people with epilepsy denying that they have ever had seizures.[9] The present study assesses the various aspects like socio-demographic and clinical characteristics that affects the health related quality of life in patients with epilepsy.

The mean total score of QOLIE-31 of this study was 39.12 (SD-5.00) , which is low as compare to study conducted by **Gebre AH et al** [10] mean total score of 77.97 (SD-20.78)

In this study, medication effect had the highest mean score, 32.24 (SD- 0.31). This indicates that patients have experienced low physical and mental effects related to anti-epileptic drugs. In contrast, overall QOL functioning was with the lowest mean score, 15.7 (SD- 0.83), which indicates things in the past time were worse and difficult. The findings were similar with the study conducted by **Norsa'adah B et al** [11] who noticed that worrying about seizure had the major contribution on QOL, while medication effect had the least.

The study conducted by **Mishal Alosaimi A et al** [12] shows that being female was associated with low seizure worry score which indicates that being female was a risk for worry and fear for seizure. Similar findings were recorded in this study also. Although **Brusturen Bota E et al** [13] concluded that gender did not affect quality of life. **Ali Gholami et al** [14] noted that female patients have better QOL.

There is mixed opinion regarding the impact of marital status on the QOL. **Prem Singh et al** [15] concluded from his study that QOL falls with single status and married people have better QOL. This study shows that widowers have low

QOL as compared to single and married people and married people had better QOL when compared with single people. However, study conducted by **Ashwin M et al** [16] showed that being married was associated with poor QOL scores among people with seizure disorder. And according to **Brusturen Bota E et al** [13] marital status did not influence QOL of patients.

There are many studies suggesting that patients on monotherapy have better QOL than the patients who are on polytherapy. [17,18, 19, 20, 21, 22, 23] Similar finding was found in our study also. Patients on polytherapy had more seizure worry and the energy/fatigue and cognitive function as well as social function score was low. The overall quality of life of patients on polytherapy was low.

In this study, unemployment had a negative impact on QOL of patients; they had more seizure worried and were not social. Next were the retired patients who were having low QOL scores. The people from lower class and living in rural areas had low QOLIE scores as compare to middle class families and people living in urban areas. Similar findings were recorded by **Mohamed Shakir et al** [24], **Paramadam Srujana M et al** [19] and **Brusturen-Bota E et al** [13]

In this study, the patients who were complaint with the medications had good QOL; except the patients who were drug defaulters, although they were less in number but they had good total QOL score. This might happen because they were not ready to accept that they suffer from this disorder due to social stigma. Similar results were noted in the studies conducted by **Mishal Alosaimi A et al** [12] who noted that the patients who were not compliant to treatment had low QOL.

Increased seizure frequency had major effect on the patients QOL as concluded from many studies. **Gebre AH et al** [10] reported seizure frequency to be significant predictor of QOL. A study conducted by **Prem Singh et al** [15] concluded that the QOL falls with increased seizure frequency; similar results were reported from this study. The patients who experienced seizures weekly had low QOL as compare to the patients who had not experienced seizure from past one year. **Brusturen-Bota E et al** [13], **Thomas SV et al** [17] and **Mrabet H et al** [25] also reported same findings.

CONCLUSION

It is evident from the study that the patients with epilepsy have low quality of life. Quality of life of patients with epilepsy falls with unemployment, with the use of combination therapy. Socio-demographic characters like lower class people had low QOL score. Although, there was no significant differences in the mean of total QOL between groups for socio-demographic and clinical characteristics. The total QOILE-31 score was low 39.12.

Counseling and addressing other aspects of health well-being is likely to achieve better health outcomes and enhancing awareness in the society regarding the effective treatment options available through public educational campaigns may help in removing the stigma associated with epilepsy and improve the QOL of the patients.

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