Quality of Life among Patients with Epilepsy: Institutional-based Survey, Western Rajasthan, India

Dear Sir,

Epilepsy is the most common neurological disease with 50 million patients with epilepsy worldwide, of which 20% of patients are residing in India.\(^1\) The incidence and prevalence of epilepsy in India are 0.2–0.6/1,000 population and 3.0–11.9/1,000 population per year, respectively. Multiple factors affect the quality of life (QOL) among patients with epilepsy, which leads to profound physical, psychological, social, and cognitive effects. Although many studies are assessing the QOL among patients with epilepsy in India, there is a paucity of such data from Rajasthan.\(^2\) Therefore, the present study was proposed to assess the QOL among patients with epilepsy attending an institute of Western Rajasthan.

An institutional-based cross-sectional study was carried out in Western Rajasthan from January 2020 to January 2021 after getting ethical clearance from the Institutional Ethics Committee with reference number AIIMS/IEC/2020-21/2098. The sample size was calculated using Cochran’s formula and the sample was taken by using a purposive sampling technique. A total of 250 patients with epilepsy were interviewed after taking informed consent. Inclusion criteria included patients available during the time of data collection, gave consent to participate in the study, 18–60 years of age, diagnosed with epilepsy at least 1 year or before, understood Hindi or English, and had partial or generalized seizures. Exclusion criteria included patients with head injuries, stroke, brain tumors, learning disorders, and who developed seizures after brain surgery.

A telephonic and face-to-face interview was conducted using the Hindi version of the QOL in Epilepsy-31 (QOLIE-31) questionnaire. The permission for using standardized QOLIE-31 questionnaire was obtained through mail from the developer. This questionnaire was derived from QOLIE-89 developed by the RAND (Research and Development) organization in 1993. It contains 31 items and consists of seven subscales: seizure worry, overall QOL, emotional well-being, energy/fatigue, cognitive functioning, medication effects, and social functioning. The precoded numeric values of subscale items are converted to a 0-100-point scale. T-scores are determined for each of the 0–100-point scales. Higher T-score reflects a more favorable QOL. The value of the T-score lies between 11 and 73.\(^3\) The data were analyzed using IBM SPSS v. 20. Descriptive and inferential statistics were used to describe the sociodemographic and clinical variables using frequency, percentage, mean, and standard deviation. The Chi-square test was used for determining the association between the overall QOL score and selected sociodemographic and clinical variables.

In the present study, the age of the respondents ranged between 18 and 60 years with a mean age of 30.76 years, which was similar to the study by Addis et al.\(^4\) (29.64). Out of 250 patients, 63.6% of patients were male and 36.4% were female. About 39.6% of patients were having higher secondary education and 28% were unemployed. Partial seizures were found in 9.2% of patients, whereas 90.8% of patients had generalized seizures. About 17.2% of patients were on monotherapy, 78.8% on polytherapy, and 4% were not taking any treatment presently [Table 1].
### Table 1: Frequency and percentage distribution of patients with epilepsy as per sociodemographic and clinical variables

| Variables                          | f  | n=250 % |
|-----------------------------------|----|---------|
| **Sociodemographic variables:**   |    |         |
| Age (in years)                    |    |         |
| 18-25                             | 103| 41.2    |
| 26-35                             | 79 | 31.6    |
| 36-60                             | 68 | 27.2    |
| Gender                            |    |         |
| Male                              | 159| 63.6    |
| Female                            | 91 | 36.4    |
| Marital status                    |    |         |
| Unmarried                         | 75 | 30.0    |
| Married                           | 175| 70.0    |
| Education                         |    |         |
| Illiterate                        | 10 | 4.0     |
| Primary                           | 16 | 6.4     |
| Secondary                         | 47 | 18.8    |
| Higher secondary                  | 99 | 39.6    |
| Graduation                        | 67 | 26.8    |
| Above graduation                  | 11 | 4.4     |
| Occupation                        |    |         |
| Government employment             | 13 | 5.2     |
| Private employment                | 68 | 27.2    |
| Unemployment                      | 70 | 28.0    |
| Self-employment                   | 44 | 17.6    |
| Homemaker                         | 55 | 22.0    |
| Social background                 |    |         |
| Rural                             | 93 | 37.2    |
| Urban                             | 157| 62.8    |
| Income per month (in rupees)      |    |         |
| <15,000                           | 135| 54.0    |
| 16,000-25,000                     | 47 | 18.8    |
| 26,000-35,000                     | 56 | 22.4    |
| 36,000-45,000                     | 12 | 4.8     |
| **Clinical variables:**           |    |         |
| Patient’s age at onset (in years) |    |         |
| 0-20                              | 128| 51.2    |
| 21-40                             | 113| 45.2    |
| 41-60                             | 9  | 3.6     |
| Type of seizure                   |    |         |
| Partial seizure                   | 23 | 9.2     |
| Generalized seizure               | 227| 90.8    |
| Duration of epilepsy (in years)   |    |         |
| 1-10                              | 183| 73.2    |
| 11-20                             | 52 | 20.8    |
| 21-30                             | 10 | 4.0     |
| 31-40                             | 5  | 2.0     |
| Treatment                         |    |         |
| Monotherapy                       | 43 | 17.2    |
| Polytherapy                       | 197| 78.8    |
| No treatment                      | 10 | 4.0     |

**Table 1: Contd...**

| Variables                          | f  | n=250 % |
|-----------------------------------|----|---------|
| Comorbidity                       |    |         |
| No                                | 215| 86.0    |
| Yes                               | 35 | 14.0    |
| Hypertension                      | 23 | 65.71   |
| Diabetes mellitus                 | 4  | 11.42   |
| Both hypertension and diabetes mellitus | 2  | 5.71    |
| Heart surgery                     | 2  | 5.71    |
| Cancer                            | 1  | 2.85    |
| Tuberculosis                      | 1  | 2.85    |
| Rectal prolapse                   | 1  | 2.85    |
| Skin problem                      | 1  | 2.85    |
| Family history                    |    |         |
| No                                | 241| 96.4    |
| Yes                               | 9  | 3.6     |
| Mother                            | 3  | 33.33   |
| Father                            | 1  | 11.11   |
| Grandmother                       | 1  | 11.11   |
| Grandfather                       | 1  | 11.11   |
| Paternal uncle                    | 1  | 11.11   |
| Maternal uncle                    | 1  | 11.11   |
| Sister                            | 1  | 11.11   |
| Any triggering factor known       |    |         |
| No                                | 208| 83.2    |
| Yes                               | 42 | 16.8    |
| Stress                            | 19 | 45.23   |
| Lack of sleep                     | 10 | 23.80   |
| Missed dose                       | 6  | 14.28   |
| High temperature                  | 3  | 7.14    |
| Hunger                            | 2  | 4.76    |
| Headache                          | 2  | 4.76    |
| Presence of seizure in past 4 weeks |    |         |
| Yes                               | 45 | 18.0    |
| No                                | 205| 82.0    |

### Table 2: Subscale-wise mean and standard deviation of quality of life among patients with epilepsy

| Subscale                          | (n=250) Means±SD |
|-----------------------------------|-------------------|
| Seizure worry                     | 58.82±25.75       |
| Overall QOL                       | 67.29±16.91       |
| Emotional well being              | 75.07±20.66       |
| Energy/fatigue                    | 65.78±23.11       |
| Cognitive functioning             | 78.93±23.48       |
| Medication effects                | 72.09±25.07       |
| Social functioning                | 82.4±22.04        |

The present study showed that 4.4% of patients had poor QOL (T-score: 11–31), 24.8% had fair QOL (T-score: 32–52),
| Variables                             | Quality of life | X2   | df | P    |
|--------------------------------------|-----------------|------|----|------|
|                                      | Poor/Fair       | Good |    |      |
| Age                                  |                 |      |    |      |
| 18-25                                | 34              | 69   | 1.84 | 2 | 0.39 |
| 26-35                                | 22              | 57   |     |    |      |
| 36-60                                | 16              | 52   |     |    |      |
| Gender                               |                 |      |    |      |
| Male                                 | 43              | 116  | 0.65 | 1 | 0.41 |
| Female                               | 29              | 62   |     |    |      |
| Marital status                       |                 |      |    |      |
| Unmarried                            | 27              | 48   | 2.70 | 1 | 0.10 |
| Married                              | 45              | 130  |     |    |      |
| Education                            |                 |      |    |      |
| Illiterate                           | 4               | 6    | 14.87* | 5 | 0.01 |
| Primary                              | 10              | 6    |     |    |      |
| Secondary                            | 13              | 34   |     |    |      |
| Higher secondary                     | 28              | 71   |     |    |      |
| Graduation                           | 12              | 55   |     |    |      |
| Above graduation                     | 5               | 6    |     |    |      |
| Occupation                            |                 |      |    |      |
| Government Employment                | 5               | 8    | 8.86 | 4 | 0.06 |
| Private Employment                   | 13              | 55   |     |    |      |
| Unemployment                         | 27              | 43   |     |    |      |
| Self-employment                      | 9               | 35   |     |    |      |
| Homemaker                            | 18              | 37   |     |    |      |
| Social background                    |                 |      |    |      |
| Rural                                | 28              | 65   | 0.12 | 1 | 0.72 |
| Urban                                | 44              | 113  |     |    |      |
| Income per month                     |                 |      |    |      |
| <15,000                              | 51              | 84   | 13.31* | 3 | 0.00 |
| 16,000-25,000                        | 9               | 38   |     |    |      |
| 26,000-35,000                        | 8               | 48   |     |    |      |
| 36,000-45,000                        | 4               | 8    |     |    |      |
| Patient’s age at onset (in years)    |                 |      |    |      |
| 0-20                                 | 41              | 87   | 3.05 | 2 | 0.21 |
| 21-40                                | 27              | 86   |     |    |      |
| 41-60                                | 4               | 5    |     |    |      |
| Type of seizure                      |                 |      |    |      |
| Partial seizure                      | 8               | 15   | 0.44 | 1 | 0.50 |
| Generalized seizure                  | 64              | 16   |     |    |      |
| Duration of epilepsy (in years)      |                 |      |    |      |
| 1-10                                 | 53              | 130  | 2.74 | 3 | 0.43 |
| 11-20                                | 13              | 39   |     |    |      |
| 21-30                                | 3               | 7    |     |    |      |
| 31-40                                | 3               | 2    |     |    |      |
| Treatment                            |                 |      |    |      |
| Monotherapy                          | 8               | 35   | 2.63 | 2 | 0.26 |
| Polytherapy                          | 61              | 136  |     |    |      |
| No treatment                         | 3               | 7    |     |    |      |
| Comorbidity                          |                 |      |    |      |
| Yes                                  | 11              | 24   | 0.13 | 1 | 0.71 |
| No                                   | 61              | 154  |     |    |      |
| Family history                       |                 |      |    |      |
| Yes                                  | 4               | 5    | 1.11 | 1 | 0.29 |
| No                                   | 68              | 173  |     |    |      |

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and 70.8% had good QOL (T-score: 53–73) [Figure 1]. The mean QOL score in the present study was 56.88 ± 11.46, which was comparable with the study done by Addis et al.\(^4\) that showed a similar result with 55.81 as the mean QOL score. Similarly, Sureka et al.\(^5\) also showed a mean QOL score of 60.46, whereas a study conducted by Jauhari et al.\(^6\) showed 39.12 as the mean QOL score.

In the present study, the subscale scores of the QOLIE-31 questionnaire ranged from 58.82 ± 25.75 to 82.4 ± 22.04 with the highest and lowest subscale scores for social functioning and seizure worry, respectively [Table 2], which was similar to the study by Pimpalkhute et al.\(^7\) This infers that social functioning least affects the QOL among patients with epilepsy as compared with seizure worry. However, in the study by Addis et al.,\(^4\) subscale scores ranged from 46.50 ± 15.55 to 64.98 ± 19.43 with the lowest score of energy subscale, which was different from the results of the present study. Moreover, a study by Nagarathnam et al.\(^8\) concluded highest and lowest scores for medication effects and social functioning subscales, respectively. The difference in the findings may be due to the diverse culture and socioeconomic factors, which affect the QOL. The present study revealed that education, income per month, presence of triggering factor, and presence of seizure in the past 4 weeks were statistically significant with the overall QOL score at \(P < 0.05\) [Table 3], which was similar to the study findings by Jauhari et al.\(^9\) that showed unemployment and lower socioeconomic class to be associated with lower QOL among patients with epilepsy. Furthermore, Anu et al.\(^{10}\) revealed comparable findings of low educational qualification leading to poor QOL, whereas in the study by Honari et al.\(^{11}\) there was no significant statistical relationship between QOLIE-31 overall score and clinical and demographic variables.

The study was limited to a single institution so the results could not be generalized and the seizure-free period was taken as 1 month that should be at least 6 months. Based on previous studies, it is recommended that QOL in patients with epilepsy can be compared for more than one institution and on a larger population.

The study revealed that social functioning least affects the QOL for patients with epilepsy as compared with seizure worry and low energy. Therefore, QOL among patients with epilepsy should be improved by reducing seizure worry and improving energy levels. Patients should be counseled and informed about the importance of taking antiepileptic drugs on time to prevent seizure episodes. Patients and family members should be educated regarding the care before, during, and after seizure episodes to improve the QOL.

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**Conflicts of interest**

There are no conflicts of interest.

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**Table 3: Contd...**

| Variables | Quality of life | X² | df | \(n=250\) | \(P\) |
|-----------|----------------|----|----|---------|------|
| Poor/Fair | Good           |    |    |         |      |
| Any triggering factor known |  |    |    |         |      |
| Yes       | 28             | 14 |    | 35.29*  | 1    | 0.00 |
| No        | 44             | 164|    |         |      |      |
| Presence of seizure in past 4 weeks |  |    |    |         |      |
| Yes       | 31             | 14 |    | 43.01*  | 1    | 0.00 |
| No        | 41             | 164|    |         |      |      |

*Significant (<0.05). Note: Due to a smaller number of patients in the poor category, it was merged with the fair category.
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Letters to the Editor

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