

## Original Article

# A Cross Sectional Study of Socio-cultural and Clinical Determinants of Health-related Quality of Life in Indian Patients with Epilepsy

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**Background** : Health-related Quality of Life (HRQoL) is a vital component of adherence to treatment in patients with epilepsy. The present study was conducted to determine the level of HRQoL in patients with epilepsy attending the Outpatient Department of our hospital.

**Materials and Methods** : This cross-sectional study was done by the Neurology Department of tertiary-level care Municipal Hospital in Mumbai from January, 2021 to December, 2021. Inclusion criteria included patients with a confirmed diagnosis of epilepsy, age 18 and older, receiving anti-epileptic drugs, and the ability to provide written consent. The QOLIE-31 questionnaire and a study proforma were administered to the patients.

**Results** : 248 patients were included in the study. The QOLIE-31 overall score ranged from 17.4 to 78.6, and the average overall score was 66. It was observed that mean QOLIE-31 score was significantly lower (poorer QoL) in patients aged more than 40 years (58.6±8.4 *versus* 72.4±13.5, p-value <0.05), female patients (51.4±8.6 *versus* 69.5±7.5, p-value <0.05), married (51.1±7.8 *versus* 68.4±9.4, p-value <0.05), epilepsy for more than 10 years (59.4±9.4 *versus* 71.6±10.6, p-value <0.05), and those on polytherapy (57.5±10.8 *versus* 72.5±9.6, p-value <0.05).

**Conclusions** : Older age, female gender, being married, higher seizure frequency, longer duration of epilepsy, and polytherapy were the factors associated with significantly lower QoL.

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**Key words** : Epilepsy, Health-related Quality of Life, Socio-cultural and Clinical Determinants.

Epilepsy is a chronic neurological non-communicable condition that is characterized by a predisposition to repeated epileptic seizures. It affects around five million people all over the globe every single year. Epilepsy is expected to be diagnosed in around 49 out of every 1,00,000 people living in nations with high incomes each year. This rate may reach 139 per 1,00,000 people in countries that have a low or moderate income<sup>1</sup>.

Because of the burden of polypharmacy, increased socio-economic expenses, lower employment rates, and lower income, epilepsy patients have much greater rates of health-related Quality of Life (HRQoL) impacts than healthy people<sup>2</sup>.

As a consequence of this, health-related Quality of Life, also known as HRQoL, is an essential component for better epilepsy treatment results. When compared to other chronic conditions, such as cancer, diabetes, and cardiovascular disease, epilepsy lags far behind in terms of the amount of research that has been conducted to evaluate the quality-of-life

### Editor's Comment :

■ This article underscores the profound impact of epilepsy on Quality of Life, highlighting the challenges faced by individuals with this condition. It reveals how seizure frequency, medication side effects of polytherapy and social stigma collectively affect emotional well-being, daily functioning, and overall satisfaction with life. Addressing these issues requires a holistic approach that includes medical treatment, psychological support, and social integration.

improvements associated with successful treatment.<sup>3</sup> There have been very few studies on the QoL in epilepsy assessed using QOLIE-31 questionnaire carried out in India. Research in this field will discover variables impacting QoL and may lead to solutions that improve the care of epilepsy patients. As a result, the current research was carried out to evaluate the QoL of epilepsy patients who presented themselves at our hospital.

### MATERIALS AND METHODS

#### Study Design and Sample Population :

This cross-sectional study was performed on the epileptic patients attending the outpatient clinic of Department of Neurology, Lokmanya Tilak Municipal Medical College, Mumbai, from January, 2021 till December, 2021. Inclusion criteria included having medical records with confirmed diagnosis of epilepsy based on ILAE diagnostic criteria 2017, passing at

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least 1 year from the onset of the disease, age 18 and older, receiving anti-epileptic drugs, and the ability to provide written consent. In order to meet the criteria for exclusion, patients must be at least 80 years old, have non-epileptic seizures, acute symptomatic seizures, inappropriate psychiatric disorders, and provide personal agreement without being solicited. Before any patients were enrolled in the study, it was given the go-ahead by the Institutional Ethics Committee.

### Data Collection and Data Analysis :

In this study we used the Hindi version of QOLIE-31 questionnaire and a checklist proforma which contained demographic variables (age, sex, employment status, marital status) and information about the disease (the nature of the episodes, duration of disease, number of episodes per month, familial history of epilepsy). The seizures were classified according to the 2017 ILAE criteria<sup>4</sup>. The QOLIE-31 questionnaire is a self-administered, widely used measure of HRQoL in Epilepsy. It contains 31 questions and seven multi-item scales<sup>5</sup>. The QOLIE-31 questionnaire includes questions designed to assess overall HRQoL perception and additional seizure-related areas: seizure worry, emotional well-being, energy/fatigue, cognitive functioning, medication effects, social functioning, as well as an overall score. The QOLIE-31 scale responses are assigned numeric values ranging from 1 to 100, with higher scores indicating a higher HRQoL<sup>6</sup>. The QOLIE-31 questionnaire was translated into Hindi, then back-translated and tested in a pilot study to ensure its accuracy. Patients' responses to each query are mapped to multiple-choice response options. Scores range from 0 to 100, with higher scores indicating a higher QoL<sup>7</sup>. Calculated scores are 'T' scores. After fulfilling the inclusion and exclusion criteria, patients with Epilepsy entered the study with informed consent.

The data were compiled and entered in SPSS version 23 for statistical analysis. Categorical data were described as frequency distribution and quantitative data as means. To assess the association of mean QOLIE-31 overall score and patient variables, independent t test was used, considering p value < 0.05 as statistically significant.

### RESULTS

This study the total number of participants were 248. The age range of patients was 18-77 with a mean age of 34.6±8.9 years. There were 102(41%) female and 146(59%) male participants. Demographic features of patients are shown in Table 1 and clinical features

Variables	Frequency	Percent	
Age groups (years)	18 to 20	57	23%
	21 to 40	76	31%
	41 to 60	68	27%
	61 to 80	47	19%
Gender	Female	102	41%
	Male	146	59%
Married	Married	167	67%
	Illiterate	80	32%
	Till primary	46	19%
Education	Till secondary	57	23%
	Till graduation	65	26%
Family history of epilepsy	42	17%	
Employment	Unemployed	78	31%
	Employed	170	69%

are listed in Table 2. Statistical data about clinical features show that 42 (17%) had focal onset seizures and 206(83%) had generalized onset seizures. A positive familial history of epilepsy was seen in 42(17%) of patients. 55 (22%) patients the duration of epilepsy was more than 10 years. 61(25%) patients had less than 1 episode, 154(62%) had more than 1 episode per month whereas 33(13%) patients were seizure free for more than 1 year. In the present study, 154(62%) of all patients were on polytherapy and 94 (38%) on monotherapy. In this study, the QOLIE-31 overall score ranged from 17.4 to 78.6 and the average overall score was 66 (SD = 11).

Table 3 shows descriptive statistics about the QOLIE-31 score with its subscales separately, highest mean score being for emotional wellbeing subscale. In Table 4, the association of various patient related parameters and mean QOLIE-31 score was assessed.

Variables	Frequency	Percent
<b>Types of Seizures</b>		
<b>Focal Onset</b>	42	17%
With preserved awareness	20	8%
With Impaired awareness	22	9%
<b>Generalized Onset</b>	206	83%
Tonic-clonic	156	63%
Tonic	26	10%
Atonic	15	6%
Myoclonic	9	4%
<b>Duration of Epilepsy</b>		
≤ 5 years	74	30%
5 to 10 years	119	48%
>10 years	55	22%
<b>Number of seizure episodes per month</b>		
<1	61	25%
>1	154	62%
Seizure free for 1 year	33	13%
<b>Medication</b>		
Monotherapy	94	38%
Polytherapy	154	62%

Table 3 — Mean subscale scores of QOLIE-31

Subscales of QOLIE-31	Mean ± SD
Seizure worry	55.6 ± 13.05
Quality of Life	66.7 ± 14.1
Emotional well being	71.4 ± 14.2
Energy / Fatigue	65.4 ± 10.6
Cognitive	66.8 ± 11.2
Medication effect	69.3 ± 14.2
Social function	64.6 ± 14.3
Overall Score	65.7 ± 10.5

Table 4 — Association of different patient variables and mean overall QOLIE-31 score

Patient variables	N	Mean ± SD	p-value*	
Age	<40 years	133	72.4 ± 13.5	<0.05
	>40 years	115	58.6 ± 8.4	
Gender	Male	146	69.5 ± 7.5	<0.05
	Female	102	61.4 ± 8.6	
Education	Illiterate	80	66.5 ± 12.5	0.45
	Literate	168	61.8 ± 14.1	
Marital status	Married	167	51.1 ± 7.8	<0.05
	Unmarried	81	68.4 ± 9.4	
Employment	Unemployed	78	69.5 ± 10.5	0.15
	Employed	170	66.8 ± 8.1	
Family history of Epilepsy	Yes	42	65.5 ± 7.5	0.09
	No	206	68.8 ± 12.1	
Duration of Epilepsy	<10 years	193	71.6 ± 10.6	<0.05
	>10 years	55	59.4 ± 9.4	
Seizure per month	>1 per month	154	64.7 ± 8.9	<0.05
	<1 per month	94	69.3 ± 10.4	
Medication	Monotherapy	94	72.5 ± 9.6	<0.05
	Polytherapy	154	57.5 ± 10.8	

\*Analyzed using independent 't' test

It was observed that mean QOLIE-31 score was significantly lower (poorer QoL) in patients aged more than 40 years ( $58.6 \pm 8.4$  versus  $72.4 \pm 13.5$ , p-value <0.05), female patients ( $61.4 \pm 8.6$  versus  $69.5 \pm 7.5$ , p-value <0.05), married ( $51.1 \pm 7.8$  versus  $68.4 \pm 9.4$ , p-value <0.05), epilepsy for more than 10 years ( $59.4 \pm 9.4$  versus  $71.6 \pm 10.6$ , p value < 0.05) and those on polytherapy ( $57.5 \pm 10.8$  versus  $72.5 \pm 9.6$ , p-value <0.05). Education level, employment status, family history of Epilepsy and seizure frequency were not significantly associated with poorer QoL.

### DISCUSSION

The current research found that participants had a mean overall score of 65.7, with the emotional wellbeing subscale yielding the highest score. A higher mean total score on the QOLIE-31 (68.9) was obtained in research that was conducted in Malaysia<sup>8</sup>. A higher score, according to the findings of our research, indicates a higher quality of medical treatment. The distribution of scores on the various QOLIE-31 subscales in our research followed a pattern that was somewhat comparable to the studies carried out in Africa<sup>9</sup> and Malaysia<sup>8</sup>. In the course of our research,

we discovered that the emotional well-being subscale scored the highest, while the seizure concern subscale scored the lowest. results from other nations may not be applicable to the circumstances in one's own country because of differences in beliefs, cultures and other socio-economic variables.

We found that younger patients had a higher QoL overall. The age group of less than 30 years often contains students or young people, who, since they are still under their parents' care, are likely to get better medical attention. As people become older, the stigma that society places on them in respect to work chances and social life may become more apparent, which is one reason for the decline in QoL. Multiple more research came to the same conclusion about the connection between Epilepsy patients' ages and their QoL<sup>10</sup>.

We observed that female epilepsy patients had a worse quality of life. Studies conducted in India found that females with epilepsy reported lower levels of social support and higher levels of social isolation compared to their male counterparts who also suffered from the condition<sup>11</sup>. A research that was conducted in Europe found that female responders with epilepsy had lower levels of energy, as well as worse levels of physical functioning, mental health, and overall health.<sup>12</sup> The social structure of patriarchy, in which men are seen as the dominant figures of authority, lies at the heart of the organization of a significant portion of Indian society.

In the present research, it was discovered that having a quality of life that was currently married was connected with having a lower QoL. A recent research that was conducted in India found that those who were married and had Epilepsy had considerably lower levels of energy, weariness, and emotional well-being<sup>13</sup>. People diagnosed with Epilepsy have a much reduced likelihood of getting married compared to the general population as a whole<sup>14</sup>. People diagnosed with epilepsy in Asian nations have also been shown to have a higher than average risk of divorce<sup>15</sup>. This may be the case since many people who are single are young and, as a result, have a high QoL.

It has also been shown that having Epilepsy for a longer period of time is a predictor for a worse QoL as a result of more difficulties and limitations<sup>16</sup>. In addition, the length of time that a patient has had epilepsy was shown to have a substantial connection with QoL. According to Herodes, *et al*, patients with epilepsy who had shorter durations of the condition had lower ratings, with shorter durations also having substantial implications on energy, mental well-being, and

physiological discomfort<sup>17</sup>.

According to the findings of our research, patients who received monotherapy had a higher QoL compared to individuals who received polytherapy. In a study that Thomas and his colleagues conducted found similar results<sup>18</sup>. This might be attributable to the fact that patients receiving polytherapy have more severe and complex diseases than individuals not receiving polytherapy.

According to the findings of a research carried out by Herodes and colleagues, higher seizure frequency had a significant impact on QoL. Additionally, Strauss believed that a longer period of life free of seizures is the key to improving QoL in epileptics<sup>19</sup>. In the current research, there was a tendency toward a lower QoL with an increasing frequency of seizures; however, this association did not reach statistical significance.

The current research has a few limitations. To begin, this was a study conducted in a single location, which means that the findings of our research may not be applicable to other regions of the world. Second, since it was cross-sectional research, it was not possible to determine whether or not there was a temporal trend in the patient characteristics or the QoL ratings.

### CONCLUSION

Our research makes it clear that the QoL of persons who have Epilepsy is affected by a wide variety of different parameters. The following characteristics were shown to be substantially linked with a worse Quality of Life (QoL): greater age, female gender, being married, higher seizure frequency, longer duration of epilepsy and polytherapy.

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