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QUALITY OF LIFE (QOL) AND ITS SOCIO-CLINICAL DETERMINANTS AMONG PATIENTS WITH EPILEPSY ATTENDING A TERTIARY CARE HOSPITAL IN NORTHERN INDIA: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Aim: Epilepsy is a chronic neurological illness with significant physical, psychological, and social burden that negatively impacts the Quality of Life (QOL) of the sufferers. This research aimed to assess QOL and to examine its socio-clinical correlates among the patients with epilepsy attending a tertiary care institute of Saharanpur, Uttar Pradesh, India.

Materials and Methods: Cross-sectional hospital-based research was carried out among 110 adult patients with epilepsy aged 18–60 years. Data collection was done by a sociodemographic structured questionnaire, a clinical profile evaluation form, and the QOLIE-89 survey. Descriptive statistics and regression analysis were used to examine characteristics linked with QOL.

Results: The mean overall QOLIE-89 score was 57.8 ± 3.5, indicating a moderate QOL. The highest domain scores were observed for role limitation due to physical health (66.5 ± 18.3) and emotional health (64.7 ± 18.5), whereas health perceptions (49.9 ± 7.3), social support (51.1 ± 9.4), and work/driving/social function (52.3 ± 6.5) showed the lowest scores. None of the sociodemographic or clinical variables demonstrated a statistically significant independent association with overall QOL ($p > 0.05$).

Conclusion: Patients with epilepsy had moderate QOL, with greater impairment in psychosocial and functional domains. Although no significant socio-clinical predictors of overall QOL were identified, the findings highlight the need for comprehensive epilepsy care that addresses both medical and psychosocial aspects.

Keywords: Epilepsy; Health-related QOL; QOLIE-89; Psychosocial determinants; Seizure disorders; Treatment adherence.

INTRODUCTION

Epilepsy is a prevalent chronic neurological disorder that affects almost fifty million individuals around the world and contributes immensely to disability and poor well-being.[1] Even though there have been many advancements in diagnosis and therapy for seizure management, epilepsy still carries considerable physical, psychological, cognitive, and social burdens.[2] Consequently, the emphasis on epilepsy care is no longer limited to reducing the frequency of seizures but extends to the concept of health-related QOL that becomes progressively more significant to patients' outcomes.[3]

QOL in epileptic individuals is a multifaceted concept that includes physical well-being, cognitive performance, psychological well-being, social life, and functional status.[4] Apart from seizure control, several socio-demographic and clinical characteristics play a major role in the differences in QoL among epilepsy patients.[5] These factors include age, gender, educational level, occupation, socioeconomic status, frequency of seizures, length of illness, therapy type, side effects of antiepileptic drugs, and presence of comorbid disorders.[3,6-10]

In addition, certain psychosocial factors such as anxiety, depression, stigmatization due to epilepsy, and lack of adequate social support have also been found to adversely affect QOL, with their effects surpassing those of clinical variables.[11,12]

These findings have been consistently replicated in studies carried out among various communities and health care facilities. Sharma et al. (2022) indicated that education, occupation, seizure burden, and treatment-associated factors were strongly correlated with QOL among patients with epilepsy in Western Rajasthan.[3] Choudhury et al. (2024) also showed that socio-demographic variables along with the presence of comorbidities in the form of mental illness were important determinants of poor QOL among patients of juvenile myoclonic epilepsy in Northern India.[6] Furthermore, Nagarathnam et al. (2017) showed that stigma and polytherapy are important determinants of poor QOL among people who have epilepsy in Southern India.[13] Similar studies also pointed out the effect of socio-demographic and treatment-associated factors on patient-related outcomes and the requirement for a holistic approach to the management of epilepsy.[14,15]

Although QOL is becoming increasingly recognised as an essential outcome in the management of epilepsy, the information on its socio-clinical factors is still inadequate in the tertiary care settings of Northern India. Prior research has mostly examined individual aspects such as seizure control, stigma, or mental comorbidities. Still, it has not evaluated the cumulative impact of demographic and clinical parameters on patient-reported QOL. Thus, the current research was carried out to assess the health-related QOL and to find the association of socio-demographic and clinical variables with QOL in epilepsy patients attending a tertiary care center at Saharanpur, Uttar Pradesh, India.

MATERIALS AND METHODS

2.1 Study Design and Setting

A cross-sectional observational research was performed to evaluate QOL and the socio-clinical variables among people with epilepsy. The research was done at the Psychiatry Department of a tertiary care institution in Saharanpur, Uttar Pradesh, India, during the period from June 2024 to December 2025.

2.2 Study Population

The research cohort included adult patients with epilepsy attending the Psychiatry outpatient department (OPD) and inpatient department (IPD) of the institute. Eligible participants were consecutively recruited throughout the study period.

2.3 Selection Criteria

Patients between 18 and 60 years of age who were diagnosed with epilepsy using the ICD-10 classification system and provided signed consent were enrolled in the study. Patients with major psychiatric comorbidities, cognitive impairment, severe physical illness, or inability to participate in interviews were excluded.

2.4 Sample Size and Sampling Technique

The prevalence-based technique was used to determine the sample size:

$$n = \frac{z^2 \times p \times q}{e^2}$$

Where:

Z = 1.96 (95% confidence level)

p = 0.01 (prevalence of epilepsy)

q = 0.99

e = 0.02 (margin of error)

After adding the 15% non-response rate, the sample size was determined to be 110 participants. The non-probability sequential sampling technique was employed to recruit the eligible epileptic patients from the Psychiatry OPD and IPD [16].

2.5 Data Collection Tools

Data were obtained using structured questionnaires on socio-demographic and clinical characteristics and the QOL in Epilepsy Inventory-89 (QOLIE-89). QOLIE-89 is a self-administered 89-item, 17-domain measure of health-related QOL in epileptic patients. Scores were determined by a 0-100 scale, with higher scores representing better QOL. The total composite QOL score was generated by summing weighted domain scores. All tests were administered by trained interviewers following defined procedures to ensure consistency.

2.6 Study Variables

The sociodemographic variables employed include age, sex, marital status, occupation, household income, education, and place of residence. The other variables include age at onset of disease, duration of epilepsy, type of seizure, frequency of seizures, compliance with medications, treatment history, and history of family members with epilepsy. The health-related QOL was the dependent variable measured using QOLIE-89.[17]

2.7 Ethical Considerations

The approval from the Institutional Ethics Committee had been obtained prior to the conduct of the research (Approval no: IEC/SMMH/June 2024/05). Informed consent from all the subjects had been obtained, in addition to complete confidentiality and anonymity of the collected data.

2.8 Statistical Analysis

The data were recorded in MS Excel and were examined using SPSS v26.0 software. The descriptive analysis was employed to describe the features of the participants. Continuous data were presented in the form of Mean ± SD, while categorical data were presented as frequencies and percentages. Simple and multiple regression analyses were performed to determine features related to QOL and independent predictors. A p-value <0.05 was regarded as statistically significant.

RESULTS

3.1. Socio-demographic and Clinical Characteristics of Patients

The study population was predominantly young adults (18–30 years, 56.4%) and male (54.5%). The majority of the participants were from the OBC community (50.9%), educated up to elementary or high school (70.9%), unemployed (65.5%), belonged to socioeconomic class III (55.5%), lived in a nuclear family (74.5%) and dwelt in rural areas (69.1%). The commonest features seen in the clinic were generalized epilepsy (61.8%), monotherapy (66.4%), good medication adherence (58.2%), seizure onset between 11 and 20 years of age (44.5%), length of illness 6–10 years (41.8%), and monthly seizure frequency (41.8%) (Table 1)

Table 1: Distribution of Sociodemographic and Clinical Attributes among Study Subjects (N = 110)

Variables		Frequency (%)
Age Group (years)	18-30	62 (56.4)
	31-40	31 (28.2)
	41-50	14 (12.7)
	51-60	3 (2.7)
Sex	Male	60 (54.5)
	Female	50 (45.5)
Marital Status	Single	59 (53.6)
	Married	46 (41.8)
	Divorced	3 (2.7)
	Widowed	2 (1.8)
Religion	Hindu	68 (61.8)
	Muslim	42 (38.2)
Caste/Community	General	31 (28.2)
	OBC	56 (50.9)
	SC	23 (20.9)
Education Status	Illiterate	11 (10.0)
	Primary to High School	78 (70.9)
	Intermediate and above	21 (19.1)
Occupation level	Unemployed	72 (65.5)
	Unskilled worker	15 (13.6)
	Semiskilled worker	4 (3.6)
	Skilled worker	19 (17.3)
Socioeconomic Class	Class I	9 (8.2)
	Class II	28 (25.4)
	Class III	61 (55.5)
	Class IV	10 (9.1)
	Class V	2 (1.8)
Type of Family	Nuclear	82 (74.5)
	Joint	28 (25.5)
Overcrowding Status	Yes	48 (43.6)
	No	62 (56.4)
Place of Residence	Rural	76 (69.1)
	Urban	34 (30.9)
Distance from Tertiary Healthcare Facility	5–10 km	29 (26.4)
	10–20 km	27 (24.5)
	20–30 km	17 (15.5)
	>30 km	37 (33.6)
Health Insurance Coverage	Yes	38 (34.5)
	No	72 (65.5)
Mobile Phone Access	Yes	105 (95.5)
	No	5 (4.5)
Age at onset (years)	≤10 years	18 (16.4)
	11–20 years	49 (44.5)
	21–30 years	28 (25.5)
	>30 years	15 (13.6)
Duration of Illness (years)	≤5 years	42 (38.2)
	6–10 years	46 (41.8
	11–15 years	15 (13.6)
	>15 years	7 (6.4)
Seizure Frequency	Daily	14 (12.7)
	Weekly	28 (25.5)
	Monthly	46 (41.8)
	Less than monthly	22 (20.0)
Drug Regimen	Monotherapy	73 (66.4)
	Polytherapy	37 (33.6)
Family History	Present	24 (21.8)
	Absent	86 (78.2)
Type of Epilepsy	Generalized epilepsy	68 (61.8)
	Focal epilepsy	42 (38.2)

Medication Adherence	Good adherence	64 (58.2)
	Irregular adherence	31 (28.2)
	Poor adherence	15 (13.6)

3.2. QOL of Patients with Epilepsy

The mean overall QOLIE-89 score of the study participants was 57.8. Among the QOL domains, role limitation due to physical health had the highest mean score (66.5), followed by role limitation due to emotional health (64.7) and overall QOL (63.6). The lowest mean scores were observed for health perceptions (49.9), social support (51.1), and work/driving/social function (52.3), whereas the remaining domains showed intermediate mean scores (Table 2).

Table 2: QOLIE-89 scores Among Study Participants (N = 110)

Domains	Item included	Mean ± SD
Health perceptions	1, 44-48	49.9 ± 7.3
Overall QOL	2, 49	63.6 ± 14.0
Physical functioning	4-13	53.8 ± 12.0
Role limitation – physical	14-18	66.5 ± 18.3
Role limitation – emotional	19-23	64.7 ± 18.5
Pain	24-25	60.0 ± 17.6
Work/driving/social function	26, 36, 43, 65-68, 76-78, 85	52.3 ± 6.5
Energy/fatigue	27, 31, 33, 35	57.4 ± 13.2
Emotional well-being	28-30, 32, 34	57.4 ± 14.3
Attention/concentration	37, 41, 60-64	58.1 ± 10.1
Health discouragement	39, 42	58.0 ± 19.8
Seizure worry	40, 69-73	57.8 ± 14.4
Memory	50-54	58.0 ± 10.9
Language	55-59	58.4 ± 11.8
Medication effects	75, 79, 80	53.3 ± 14.5
Social support	81-83, 86	51.1 ± 9.4
Social isolation	87-88	57.2 ± 21.2
Overall QOLIE-89 score	1-88	57.8 ± 3.5

3.3. Association Between Sociodemographic Characteristics and Overall QOL

The regression analysis indicated that no sociodemographic variables were substantially correlated with overall quality of life ($p > 0.05$). The regression coefficients indicated small differences in QOL scores across gender (B = −0.32, p = 0.626), religion (B = 0.81, p = 0.234), caste (B = 0.86 for General and 0.61 for OBC, p = 0.368 and 0.480, respectively), educational status (B = 0.75 for Intermediate and above and −0.42 for Illiterate, p = 0.620 and 0.624, respectively), occupation (B = 1.25 to −0.27, p = 0.149–0.753), marital status (B = −0.42, p = 0.420), family type (B = −0.08, p = 0.917), and place of residence (B = −0.34, p = 0.639). The health insurance status exhibited a negative coefficient for uninsured patients (B = −1.32), while the correlation lacked statistical significance (p = 0.056). The R^2 values varied between 0.00 and 0.04 throughout the models.

Table 3: Association of Sociodemographic Characteristics with Overall QOL Scores among Epilepsy Patients (N = 110)

Variables		B	R^2	t	p-value
Gender	Constant	58.02	0	118.7	<0.001
	Male	−0.32		−0.49	0.626
Religion	Constant	57.34	0.01	107.72	<0.001
	Religion (Hindu)	0.81		1.2	0.234
Caste	Constant	57.29	0.01	79.06	<0.001
	Caste (General)	0.86		0.9	0.368
	Caste (OBC)	0.61		0.71	0.48
Educational status	Constant	58.64	0.01	30.61	<0.001
	Education (Intermediate and above)	0.75		0.5	0.62
	Education (Illiterate)	−0.42		−0.49	0.624
Occupation	Constant	57.63	0.04	96.31	<0.001
	Skilled Worker	1.25		1.45	0.149
	Semiskilled Worker	−0.48		−0.46	0.645
	Unskilled Worker	−0.27		−0.32	0.753
Marital status	Constant	58.48	0.01	68.7	<0.001
	Marital status (unmarried/single)	−0.42		−0.81	0.42
Family type	Constant	57.9	0	88.23	<0.001
	Type of family (Nuclear)	−0.08		−0.10	0.917
Place of residence	Constant	58.07	0	97.62	<0.001
	Place of residence (Rural)	−0.34		−0.47	0.639
Health insurance status	Constant	58.71	0.03	105.99	<0.001
	Health insurance (No)	−1.32		−1.93	0.056

Reference categories: Gender: Female; Religion: Muslim; Caste: Scheduled Caste (SC); Educational status: Primary to High school;

Occupation: Unemployed; Marital status: Married; Family type: Joint family; Place of residence: Urban; Health insurance status: Yes.
Model information: B = unstandardized regression coefficient; R^2 = coefficient of determination; t = t-statistics. R^2 is reported once for each regression model rather than repeated for individual predictor rows.

3.4. Association Between Clinical Variables and Overall QOL

The regression analysis demonstrated that age, age at the onset of epilepsy, and the length of the illness did not have a significant relationship with overall quality of life. The age of patients showed a negative association with quality of life that was not statistically significant (B = −0.040, β = −0.094, SE = 0.036, t = −0.983, p = 0.328; R^2 = 0.009, F = 0.967). Correspondingly, the age of epilepsy beginning revealed a negative correlation (B = −0.060, β = −0.115, SE = 0.050, t = −1.208, p = 0.230; R^2 = 0.013, F = 1.459), while the length of the disease presented a minimum negative coefficient (B = −0.009, β = −0.016, SE = 0.055, t = 0.161, p = 0.872; R^2 = 0.000, F = 0.026). Therefore, all three clinical variables demonstrated non-significant p-values in the model (p > 0.05).

Table 4: Association of Clinical Variables with Overall QOL Scores among Epilepsy Patients (N = 110)

Variables	B	Beta (β)	SE	t	p-value	R^2	F (1,108)	Model p-value
Age of patients								
Constant	58.93	-	1.158	50.89	<0.001	0.009	0.967	0.328
Age of patients	−0.040	−0.094	0.036	−0.983	0.328	0.009	0.967	0.328
Age at onset of epilepsy								
Constant	58.98	-	0.996	-	<0.001	0.013	1.459	0.23
Age at onset of epilepsy	−0.060	−0.115	0.05	−1.208	0.23	0.013	1.459	0.23
Duration of illness								
Constant	57.94	-	0.722	-	<0.001	0	0.026	0.872
Duration of illness	−0.009	−0.016	0.055	0.161	0.872	0	0.026	0.872
Dependent variable: Overall QOL score.								
Model information: B = unstandardized regression coefficient; β = standardized regression coefficient; SE = standard error; t = t-statistic; R^2 = coefficient of determination; F = F-statistic.								

3.5. Multiple Linear Regression Analysis of Clinical Predictors of Overall QOL

Multiple linear regression analysis showed that medication adherence, epilepsy type, family history, drug regimen, and seizure frequency were not significant predictors of overall QOL among the study participants (all p > 0.05). Although polytherapy (β = −0.114) and monthly seizure frequency (β = −0.208) showed negative associations with QOL, these associations were non-significant. [Table 5]

Table 5: Multiple Linear Regression Analysis of Clinical Factors Predicting QOL among study participants (N=110)

Variables	Beta	t	p-value	95% CI for B
Constant		55.21	<0.001	[57.096,61.352]
Adherence (Irregular)	0.004	0.040	0.968	[-1.493, 1.555]
Adherence (Poor)	0.013	0.124	0.902	[-1.979, 2.243]
Epilepsy type (Focal)	-0.032	-0.306	0.760	[-1.691, 1.239]
Family history (Present)	-0.070	-0.680	0.498	[-2.166, 1.060]
Drug regimen (Polytherapy)	-0.114	-1.103	0.272	[-2.271, 0.648]
Seizure frequency (Less than monthly)	-0.053	-0.407	0.685	[-3.244, 2.140]
Seizure frequency (Monthly)	-0.208	-1.335	0.185	[-3.574, 0.699]
Seizure frequency (Weekly)	-0.007	-0.45	0.964	[2.523, 2.410]
Dependent variable: QOL Overall scores **Reference categories:** good medication adherence, generalized epilepsy, no family history of epilepsy, monotherapy, and daily seizure frequency. **CI** = Confidence Interval.				

DISCUSSION

The current investigation demonstrated that the overall average QOLIE-89 score was 57.8 ± 3.5, indicating a moderate QOL among patients with epilepsy. Among the QOL domains, role limitation due to physical health, role limitation due to emotional health, and overall QOL showed the highest scores. In contrast, health perception, social support, and work/driving/social function recorded the lowest scores, suggesting that epilepsy predominantly affects psychosocial and functional aspects of daily living rather than physical functioning alone. Similarly, Sharma et al. (2022) identified moderate QOL among Indian patients with epilepsy, where worse scores were seen for social and emotional aspects, showing the lasting psychosocial impact of the disorder.[3] Similarly, Shilpasree et al. (2025) found that while physical functions were mostly intact, the social and emotional dimensions were still highly compromised, indicating the requirement for a holistic approach to care in epilepsy management.[14]

The current research revealed that none of the sociodemographic variables, such as age, sex, religion, caste, marital status, education, occupation, family type, place of residence, and health insurance coverage, were significantly correlated with QOL. However, uninsured and rural participants had low QOL scores. Such findings implied that demographic factors alone might not play any independent role in influencing the QOL of patients receiving similar medical care. Similarly, Thomas et al. (2005) revealed that there was no significant correlation between age, gender, and marital status and QOL of epilepsy patients when clinical factors were controlled.[18] Likewise, Newale et al. (2016) also found that sociodemographic factors played a limited role in determining QOL. Such findings suggested that psychological factors and seizure-related factors made a greater contribution to QOL.[19]

The current study further revealed that age at onset, duration of illness, adherence to medications, type of epilepsy, family history, medication regimen, and frequency of seizures did not independently predict overall QOL in the multiple regression analysis. Even though focal epilepsy, polytherapy, family history, and monthly frequency of seizures had negative regression coefficients, these relationships were statistically insignificant, indicating that QOL depends on many other factors besides clinical parameters. Similarly, Baker et al. (1997) found that the effect of clinical variables on QOL was reduced when the impact of psychosocial factors, such as depression, stigma, and social functioning, was controlled.[20] Similarly, Taylor et al. (2011) reported that psychological well-being, emotional health, and social support were better predictors of health-related QOL than the seizure-related clinical variables.[21]

Similarly, the present study showed that epilepsy was most common in younger adults, where all the patients in the study group were unemployed and living in rural areas with middle socioeconomic status. The patients mostly had generalized epilepsy, age at the time of onset of the disease from 11 to 20 years, seizures monthly, and monotherapy. These findings reflect the chronic nature of epilepsy and its considerable social and economic burden. Similarly, Amudhan et al. (2015) concluded that the major burden of epilepsy in India was in the form of the productive period of their life and faced educational, employment, and socioeconomic problems.[16] Likewise, Thomas et al. (2005) found comparable results amongst the patients visiting tertiary care centers for the treatment of the disease, where they recommended managing the seizures along with psychosocial rehabilitation.[18]

Overall, the present study showed that patients with epilepsy had a moderate QOL, with larger impairment in psychosocial and functional areas than in physical health. None of the sociodemographic or clinical variables were found to be significant independent predictors of overall QOL. However, the results suggest that epilepsy continues to have a negative impact on several domains of the patients' daily life, highlighting the need for holistic care that caters to both medical and psychosocial needs. The results should, however, be evaluated considering some restrictions. No causal inferences can be made due to the cross-sectional research design. The single-center setting and the relatively small sample size (N = 110) may restrict the generalizability of the results. Moreover, the use of self-reported QOLIE-89 responses may have introduced recollection and response bias.

CONCLUSION

In conclusion, the current research assessed QOL and associated socio-clinical factors in epilepsy patients coming to a tertiary care center in Northern India using the QOLIE-89 tool. The findings showed a moderate overall QOL with greater deficiencies in psychosocial and functional domains compared with physical health. No sociodemographic or clinical characteristic was shown to be a significant independent predictor of overall QOL, but the results demonstrate the multiple dimensions of epilepsy's effect on patients' general well-being. The findings underscore the importance of incorporating routine QOL assessments into the comprehensive management of epilepsy, which includes seizure control, psychological support, patient education and rehabilitation. Further multicentric longitudinal studies with larger and more diverse cohorts are needed to validate these findings and to better define factors affecting quality of life in people with epilepsy. This evidence may inform the development of targeted therapies to improve long-term patient-focused outcomes.

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