

Quality of life in patients with epilepsy in India

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ABSTRACT

Background: People with epilepsy have impairment in their quality of life (QOL) due to effect of epilepsy on various aspects of their life and the medication effects. Systematic studies on QOL in epilepsy from developing countries are sparse. **Objectives:** To assess the QOL in people with epilepsy and to evaluate various factors affecting the QOL in them. **Materials and Methods:** People with generalized and partial epilepsy on medication aged more than 18 years were included in the study. The QOL was assessed with QOLIE-89 instrument. Statistical significance was evaluated by the use of Chi-square test and one-way analysis of variance (ANOVA). **Results:** Sixty people with epilepsy were studied among whom the older patients had lower overall QOL scores compared to younger patients. Female patients had lower scores compared to males. Married people had lower quality of health score. Patients with simple partial seizures had lowest overall QOL mean score. There was reduction in the overall QOLIE scores with increasing duration of the epilepsy. Patients who had their last seizure within 10 months prior to evaluation had lower mean overall scores. **Conclusion:** QOL was impaired in people with epilepsy with increased impairment in women, older patients, simple partial seizures, and those with recent seizure.

Key words: Epilepsy, marriage, quality of life

Introduction

Epilepsy carries an enormous social stigma and people with epilepsy tend to have lower quality of life (QOL).^[1] They are prone to have poorer self-esteem, higher levels of anxiety, and depression. They are more likely to be underemployed or unemployed with lower rates of marriage and greater social isolation.^[2,3]

In many parts of the world, epilepsy continues to be viewed as witchcraft, contagious, and possession by devils and ancestral spirits.^[4] An Indian study reported that 15% of respondents believed epilepsy to be insanity, 40% believed that the child with epilepsy should not go to school or their children should not play with them and 66% objected in their children marrying someone who had epilepsy.^[5] Similar observations were found in a study from Taiwan which also reported that 31% of

respondents believed that people with epilepsy should not be employed in jobs.^[6]

Although there are numerous studies assessing the QOL of people with epilepsy from all over the world, similar studies from the developing countries, especially India are sparse. It is necessary to ascertain the magnitude of the problem as a part of the systematic approach to challenges in epilepsy management. Thus, we conducted the present study in order to assess the QOL in epilepsy in our region.

Materials and Methods

The cross-sectional prospective study was carried on patients with epilepsy attending the Neurology outpatient department at the KLEs Dr. Prabhakar Kore Charitable Hospital and Medical Research Centre, Belgaum, India from October 2005 to November 2007. Added to this 1000 bed Hospital are three Primary Health Centres located in the rural section of the district, catering the health needs of people in this region and adjoining sections of southern Maharashtra. Nearly 80% of the patient input is from these regions and beyond. Ethical clearance was obtained from the institutional ethical committee. People with epilepsy on antiepileptic medication aged more than 18 years were included in

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the study following a written informed consent. Patients aged less than 18 years or with learning disabilities, progressive neurodegenerative diseases, psychiatric disease and comorbid systemic or neurological illnesses which could affect QOL were excluded from the study.

A structured questionnaire regarding education, occupation, marital state, details of the epilepsy including the antiepileptic medications was administered to all the study subjects. Information was sought to exclude comorbid symptoms of systemic illness, other neurological, or physical illnesses. All patients underwent detailed clinical examination. The seizures were classified according to the 1981 ILAE criteria. QOL was assessed by patient inventory using QOL in Epilepsy version 1.0 (QOLIE-89) questionnaire. The questionnaire was translated to Kannada and Marathi, the two most common regional languages, independently by regional institution of translation. The same was back translated and validated by testing the questionnaire in a pilot study. The questionnaire was then administered to the study subjects by one of the authors.

Statistical Analysis

Statistical analyses were performed using Statistical Package for Social Sciences (SPSS) for Windows version 16.0. Mean and standard deviation for each of the demographic, epilepsy data, and the QOL scores were calculated. Statistical significance was evaluated by the use of Chi-square test. One-way analysis of variance (ANOVA) was used to test the difference between groups to evaluate whether the means were significantly different from each other. Two-tailed “*P*” values below 0.05 were considered significant. The results were tabulated and graphically represented using Microsoft Office for Windows 2007.

Results

The study group consisted of 60 patients of whom 37 were males and 23 were females with age ranging from 18 to 56 (mean: 26.73 ± 10.81) years. Majority of the patients were younger than 30 years (<20 years = 26.7%, and 20–30 years = 38.3%). Eighteen study subjects were skilled workers, 16 did house-hold work, 14 were students, seven did business, three were professionals, and two were unskilled labourers. Fifty-three respondents had formal education while seven were not educated. 45.65% of the study subjects were married.

The mean duration of epilepsy was 7.44 ± 7.71 years. Thirty-eight patients had generalized tonic clonic

seizures (GTCS), nine had simple partial seizures, eight had complex partial seizures, and five had juvenile myoclonic epilepsy (JME). Twenty four patients (40%) had had up to five seizures till the time of interview; 19 had six to 25 seizures (31.7%) and 17 had more than 25 seizures (18.3%). Patients with complex partial seizures and JME had higher number of seizures. Majority had seizures during 10 months preceding the interview ($n = 46$; 76.7%) and 10 patients had seizures more than 20 months before the interview. Thirty seven (61.67%) were on monotherapy, 18 were on two drugs and five patients received more than two drugs. Antiepileptic medication included phenobarbitone in 33 (55%), phenytoin in 20 (33.3%), valproate in 15 (25%), carbamazepine in 10 (16.7%), oxcarbazepine and clobazam in 4 each (6.7%), topiramate and lamotrigine in 2 each (3.3%).

The overall QOLIE scores in various patient subgroups in relation to age, gender, marital status, number of seizures, antiepileptic drugs, and interval from last seizure are given in Table 1. There was negative correlation with increasing age and the QOL scores with significant correlations in bodily pain, emotional well being, memory and language ($P < 0.05$). The student subgroup in the study had higher scores with significantly higher scores in overall, bodily pain, seizure worry, and social support QOL scores ($P < 0.05$). Overall mean QOL score revealed lower scores in female patients who had lower scores in health perception, physical, and emotional role limitation of daily living, bodily pain work/social function, attention/concentration, health discouragement, seizure worry, medication affects, social support, and social isolation. Among them, the difference in perception of adverse affect of medication was statistically significant.

Married patients had lower quality of health score in all the subgroups of evaluation when compared with the unmarried patients of marriageable age. Among them, energy/fatigue, emotional wellbeing, health discouragement, and social isolation parameters showed statistically significant low QOL score in married patients [Table 2].

Patients with simple partial seizures had lowest overall QOL mean score followed by generalized tonic clonic seizures patients. Patients with complex partial seizures and JME had better overall scores. Patients with secondarily generalized seizures showed lower QOL scores in health perception, overall QOL, work/social function, energy/fatigue, health discouragement, emotional wellbeing, seizure worry, and social isolation. The patients with GTCS had lower scores due to bodily pains and social support. Patients with JME had lower

scores in emotional role limitation of daily activity, memory, and medication effects. However, these differences of scores were not statistically significant between the groups.

There was reduction in the overall QOLIE scores with increasing duration of the epilepsy [Table 1]. The QOLIE scores were lower when the duration was more than 15 years with statistically significant reductions in physical and emotional role limitation of daily activity, attention/concentration and patients' perception of language dysfunction showed statistical significantly lower QOL scores in patients with duration more than 15 years [Table 3].

There was tendency towards lower QOL scores in patients with increasing number of seizures with people who had more than 45 seizures having the lowest overall scores. Patients on monotherapy had higher overall QOL scores compared to those received two or more antiseizure drugs. However, these differences were not statistically significant.

Patients who had their last seizure within 10 months prior to evaluation had lower mean overall QOL scores. These patients had lower scores in health perception, overall QOL, emotional role limitation of daily activity, work/social function, feeling of emotional wellbeing, energy/fatigue, health discouragement, seizure worry

Table 1: Overall scores of quality of life in various subgroups

Subgroups (n)	Score (mean ± SD)	Subgroups (n)	Score (mean ± SD)
Age of the patient		Gender	
<20 years (16)	79.26 ± 14.35	Males (27)	76.39 ± 16.64
20-29 years (23)	76.86 ± 18.02	Females (23)	72.16 ± 18.58
30-39 years (12)	69.43 ± 17.92	Marital status	
40-49 years (6)	71.44 ± 18.90	Married (21)	69.57 ± 24.01
>50 years (3)	62.79 ± 22.27	Unmarried (25)	77.22 ± 22.67
Seizure type		Duration of epilepsy	
GTCS (38)	74.53 ± 17.40	<1 years (6)	77.52 ± 11.52
JME (5)	77.91 ± 14.68	1-5 years (26)	74.32 ± 16.36
CPS (8)	79.81 ± 13.41	6-10 years (13)	73.41 ± 19.98
SPS (9)	69.53 ± 22.33	11-15 years (8)	87.67 ± 7.52
Total seizures		>15 years (7)	61.84 ± 21.19
1-5 (24)	76.35 ± 16.53	Number of antiepileptic drug	
6-25 (19)	71.50 ± 16.76	1 (37)	76.23 ± 15.96
26-45 (6)	86.62 ± 5.45	2 (18)	73.55 ± 18.03
>45 (11)	70.49 ± 22.39	>2 (5)	68.32 ± 26.48

Table 2: Quality of life in relation with marital status and interval from last seizure

	Married (N = 21)	Unmarried (N = 25)	≤ 10 months (n = 46)	11-20 months (n = 4)	>20 months (n = 10)
Health perceptions	69.57 ± 24.01	72.16 ± 18.58	63.72 ± 19.46	70.83 ± 20.7	67.08 ± 26.53
Overall quality of life	59.12 ± 21.99	66.42 ± 18.97	60.88 ± 17.55	77.5 ± 14.86	67.5 ± 18.86
Physical functions	57.25 ± 15.42	63.24 ± 19.40	97.83±4.67	98.75 ± 2.5	96 ± 11.01
Role limitation ¼ physical	96.67 ± 7.80	98.00 ± 4.56	78.7 ± 36.37	100.0 ± 0.0	78 ± 34.58
Role limitation ¼ emotional	76.19 ± 37.21	84.80 ± 31.24	59.13 ± 41.94*	100.0 ± 0.0	84 ± 35.02
Pain	56.19 ± 38.79	69.60 ± 43.63	84.07 ± 17.65	89.38 ± 15.33	82.75 ± 27.19
Work/driving/social function	75.94 ± 23.38	85.30 ± 15.09	76.31 ± 27.41	93.31 ± 10.58	85.47 ± 25.79
Energy/fatigue	68.39 ± 28.44	82.08 ± 26.46	51.85 ± 20.91	65.0 ± 22.73	64 ± 23.78
Emotional well being	45.95 ± 18.21	60.20 ± 20.69*	55.7 ± 19.79*	72.0 ± 19.04	71.6 ± 19.73
Attention/concentration	49.33 ± 18.95	64.24 ± 17.76†	79.55 ± 19.55	86.67 ± 14.37	86.11 ± 15.77
Health discouragement	77.61 ± 19.84	83.57 ± 19.09	59.57 ± 27.73*	82.5 ± 23.63	84 ± 26.75
Seizure worry	52.38 ± 26.25	71.20 ± 27.89*	55.1 ± 31.16	85.84 ± 14.81	66.93 ± 33.14
Memory	49.24 ± 33.43	59.38 ± 30.15	77.42 ± 23.8	83.96 ± 15.03	72.63 ± 22.77
Language	75.00 ± 21.33	78.00 ± 26.71	94.84 ± 1 1.73	95.0 ± 10	91 ± 21.85
Medication effects	90.38 ± 17.20	94.83 ± 13.34	77.89 ± 32.05	59.71 ± 34.73	83.89 ± 26.77
Social support	77.51 ± 31.59	75.99 ± 31.59	77.17 ± 17.34	57.81 ± 26.7	81.88 ± 17.29
Social isolation	67.86 ± 21.59	78.75 ± 15.10	82.61 ± 23.71	80.0 ± 23.09	92 ± 14.76
Overall score	72.86 ± 25.33	90.80 ± 19.77*	72.87 ± 17.23	84.17 ± 11.45	79.75 ± 19.13

*P < 0.05, †P < 0.01.

Table 3: Duration of epilepsy

	<1 years (n = 6)	1-5 years (n = 26)	6-10 years (n = 13)	11-15 years (n = 8)	>15 years (n = 7)
Health perceptions	67.72 ± 11.47	58.97 ± 21.56	70.19 ± 22.56	78.12 ± 12.75	58.33 ± 19.84
Overall QOL	64.58 ± 5.79	63.59 ± 19.76	59.62 ± 17.88	70.94 ± 14.14	57.5 ± 22.03
Physical functions	95.83 ± 8.01	98.46 ± 3.09	96.92 ± 9.69	99.38 ± 1.77	95.00 ± 7.07
Role limitation ¼ physical	70.00 ± 41.47	89.23 ± 25.44	76.92 ± 39.03	97.50 ± 7.07	40.00 ± 44.72 [†]
Role limitation ¼ emotional	56.67 ± 40.82	71.54 ± 38.02	56.92 ± 45.35	97.50 ± 7.07	34.29 ± 47.21*
Pain	82.92 ± 14.53	87.68 ± 18.46	77.88 ± 22.22	95.00 ± 7.56	71.79 ± 21.44
Work/driving/social function	83.76 ± 24.92	76.81 ± 26.63	79.46 ± 29.00	95.88 ± 6.09	62.68 ± 31.94
Energy/fatigue	58.33 ± 12.11	55.00 ± 24.33	53.46 ± 23.75	61.88 ± 17.51	45.00 ± 19.79
Emotional well being	60.67 ± 12.75	58.69 ± 22.13	59.69 ± 21.01	70.50 ± 15.41	48.00 ± 22.51
Attention/concentration	91.66 ± 11.90	79.32 ± 19.62	78.04 ± 18.52	94.79 ± 8.09	68.85 ± 19.17*
Health discouragement	65.00 ± 24.29	60.00 ± 30.59	67.69 ± 25.22	82.50 ± 24.35	60.00 ± 35.12
Seizure worry	80.28 ± 13.96	50.26 ± 32.48	60.64 ± 32.99	75.17 ± 29.42	52.71 ± 28.48
Memory	82.32 ± 24.72	78.83 ± 18.72	72.76 ± 23.67	85.21 ± 27.22	64.63 ± 30.01
Language	100.00 ± 0.00	97.23 ± 8.37	88.15 ± 19.97	99.50 ± 1.41	83.24 ± 19.93*
Medication effects	74.07 ± 37.63	76.28 ± 32.39	80.55 ± 30.81	92.36 ± 13.59	63.87 ± 38.06
Social support	87.50 ± 11.18	71.15 ± 16.59	81.73 ± 17.94	85.16 ± 12.91	68.75 ± 27.95
Social isolation	93.33 ± 12.11	78.08 ± 25.14	86.15 ± 22.56	100.00 ± .00	75.71 ± 22.25
Overall score	77.52 ± 11.52	74.32 ± 16.36	73.41 ± 19.98	87.67 ± 7.52	61.84 ± 21.19

* $P < 0.05$, [†] $P < 0.01$.

and attention/concentration. Among these parameters emotional role limitation of daily living, feeling of emotional well being and health discouragement parameters showed statistically significant low QOL scores ($P < 0.05$) in patients who had last seizure within 10 months preceding the interview [Table 2].

Discussion

Epilepsy is a chronic and serious neurological disorder with multifaceted uncertainties and stigmatization which have significant negative role in the QOL of those afflicted by the disorder. Nearly 5.5 million people suffered from epilepsy as per an estimate in 2001. Of these, 4.1 million people belonged to the rural sections.^[7] Although epilepsy is a controllable disorder, treatment can be delayed for most families in rural areas because of the inaccessibility of specialist neurological assessment facilities. The present study evaluated in detail the various aspects of social and disease related QOL in patients with epilepsy in this section of the society.

Laccheo *et al.*, found lower physical reserve and energy retention in older adults compared to the younger generation.^[8] Choi-Kwon and group reported that age is a major determinant of the QOL in epileptics from their observations in South Korea.^[9] However, recent data suggest that aging does not exert a negative effect on overall QOL in epileptics.^[10,11] The present study also did not find any association between increasing age and QOL.

Shakarishvilli *et al.*, found that female gender was found to be a major determinant of the QOL in epileptics.^[12] Two Indian studies also reported similar findings.^[13,14] In a European study on the QOL with epilepsy, female respondents had poorer energy/vitality, physical functioning, mental and general health.^[15] When the QOL was evaluated in relation to gender, the overall mean QOL score was found to be lower in females. We found that female patients had emotional and physical difficulties, had bodily pains, had difficulty in attention/concentration and were worried about seizures and medication effects. They also felt decreased social support and more social isolation compared to male counterparts. Of these parameters, worries about physical and mental effect of antiepileptic drug showed significant statistical correlation.

There are many reports suggesting lower marriage rates among people with epilepsy than in general population.^[2,16,17] Myeong-Kyu Kim studied marital prospects of people with epilepsy in Asians and reported high rate of divorce in epileptic patient in Asian countries.^[18] In the present study, it was found that the married patients had low energy level, easy fatigability, emotional instability, health discouragement and felt more social isolation which reached statistical significance. Overall, female gender and marital status had an impact on QOL in patients with epilepsy. This may be related to cultural belief and male dominance of the Indian society which can be addressed with improvement in basic education and enlightening people about epilepsy in detail.

There is a mixed opinion regarding the impact of the type of epilepsy on the QOL. In a large scale European study, Baker and colleagues reported that patients with GTCS had poor QOL in family relationships, social life and ability to work. These patients also had poor perception of overall health, and had no clear ambitions or plans for the future. They also felt that their standard of living is low with poor relationship with friends and had poor self esteem.^[2] Herodes *et al*, reported lower scores in case of patients with GTCS.^[19] Some studies have reported that patients who experienced a combination of seizures, one being GTCS did poorly compared to others.^[2,20,21] Using QOLIE-31 on Indian subjects with epilepsy, Thomas *et al*, found that localization related epilepsy patients had lower QOL scores in contrast to generalized epilepsy.^[22] Although the present study also revealed similar trend of lower QOL scores in patients with partial seizure with generalization, reason for this was difficult to explain on the basis of seizure type alone, and when analyzed for the severity of the seizures it was found these patients with localization-related epilepsy had more number of seizures than other types of seizure.

Duration of epilepsy, which might play an important role in QOL, was analyzed and it was found that patients with duration of more than 15 years had poor QOL. These patients had significant physical and emotional trauma which had limited their daily activities with poor attention/concentration with feeling of language dysfunction which was statistically significant. These patients also had seizure-worry, fatigability, memory disturbance and health discouragement. They were also worried about long-term side effects of antiepileptic drugs and had poor social support. Herodes *et al*, reported lower scores with shorter duration of epilepsy with significant effects on energy, emotional well being and bodily pain.

Increased seizure frequency had major effect on the QOL in a study done by Herodes *et al*.^[19] Guekht *et al*, reported that patients with frequent seizures had low social contact and feelings of stigmatization.^[22] In the present study, although not statistically significant, there was a trend towards poor QOL with increased number of seizures. It was found that patients with more than 45 seizures had low QOL scores. These patients had emotional and physical factors which had limited their daily activities. They also complained of poor social interaction, decreased energy level and feeling of social isolation.

In recent years, numerous studies have proved improved QOL with monotherapy.^[23,24] This may

be partly due to reduced adverse effects commonly associated with polytherapy. The QOL was evaluated in relation to number of drugs in the present study and was found that patients on polytherapy had lower QOL scores compared to patients on single drug. This difference between mono and polytherapy scores did not show any statistical significance, but it showed definite trend towards good QOL in patients on monotherapy. Patients with polytherapy had poor health perception, limitation of social interaction and work, had low energy level with seizure worry, and health discouragement. This finding is in agreement with previous study which showed polytherapy is associated with poor QOL.^[13]

Strauss argued that longer duration of seizure-free life is the key to better QOL in epileptics.^[25] A high proportion of people who had recent seizures felt more stigmatized by epilepsy in a study done by Jacoby *et al*,^[26] similar findings was reported by Baker and colleagues.^[2] When QOL in relation to the last attack of seizure was analyzed in our study, patients with last seizure within 10 months had statistically significant emotional instability which had limited their daily activity and they also had significant health discouragement.

In summary, the present study demonstrated increasing age, female gender, marital status, type and number of seizure, and duration of epilepsy; polytherapy can independently affect QOL in patients with epilepsy. Seizure number and number of drugs are modifiable parameters which if done may help to improve QOL in these patients.

Conclusion

Females and married patients had lower QOL scores. Patients with localization-related epilepsy had higher number of seizures with poor overall QOL. Longer duration of the disease, increased number of seizures, and most recent seizure attack showed trend toward poor QOL in these patients. Patients on monotherapy had better QOL than patients on polytherapy. Control of seizure, monotherapy, and educating people regarding epilepsy will help to improve QOL in patients with epilepsy.

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