

Determinants of quality of life among people with epilepsy attending a secondary care rural hospital in south India

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ABSTRACT

Context: Epilepsy is associated with profound physical, psychological, and social consequences. **Aims:** To assess the quality of life (QOL) among people with epilepsy attending the outpatient department of a secondary care hospital and to determine the various social and demographic factors affecting it. **Materials and Methods:** The QOL of 100 people with epilepsy attending the outpatient department of a community-based secondary care hospital was assessed using the WHOQOL-BREF (WHOQOL: World Health Organization QOL) questionnaire. Univariate analysis and logistic regression was done to determine the factors associated with poor QOL. **Results:** The QOL scores for all the domains ranged between 15.7 and 74.55 with a mean score of 51.49 [standard deviation (SD) 12.3]. The mean scores in the physical, psychological, social, and environmental domains were 55.7, 37.92, 57.75, and 50.56, respectively. Age more than 30 years [odds ratio (OR): 4.33, 95% confidence interval (CI): 1.73-10.82], female gender (OR: 2.90, 95% CI: 1.16-7.28), and currently married (OR: 3.82, 95% CI: 1.21-12.11) were the factors significantly associated with lower QOL scores. **Conclusions:** The QOL among people with epilepsy was lower in the psychological domain. Age more than 30 years, female gender, and being married were identified as the factors associated with poor QOL scores among people with seizure disorders.

Key words: Quality of life, epilepsy, world health organization quality of life-BREF

Introduction

Epilepsy is a public health-care concern in developing countries accounting for a sizeable morbidity and economic loss.^[1] A systematic review that combined the overall prevalence of epilepsy in India showed it to be 5.59 per 1,000 population.^[2] Epilepsy is associated with profound physical, psychological, and social consequences.^[3] The focus of management of epilepsy nowadays is also toward ensuring optimal quality of life (QOL) along with control of seizure activity and neurological impairment.^[4]

The objectives of the study were to assess the QOL among people with epilepsy attending the outpatient department of a secondary care hospital and to determine the various

social and demographic factors affecting it. The effort to describe the QOL in people with seizure disorders provides a more holistic approach to the measurement of health.

There are various disease-specific instruments like the Quality of Life in Epilepsy Inventory-89 (QOLIE-89), the Quality of Life in Epilepsy Inventory-31 (QOLIE-31), and the Washington Psychosocial Seizure Inventory which are widely used to assess the QOL among people with epilepsy. But for want of a locally validated instrument, this study used the WHOQOL-BREF (WHOQOL: World Health Organization QOL) questionnaire for assessing the QOL.^[5-7] Generic instruments assess a broad range of functioning and allow comparisons across patients with different diseases. The questionnaire has been used in other similar studies for assessing the QOL among epilepsy patients, and a vernacular version has been validated in India.^[8-10]

Materials and Methods

The study was conducted in the outpatient department of a secondary level hospital run by the Community Health

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Department of a medical college. The hospital provides primary and secondary level health care to the residents of a rural developmental block with a population of around 1,20,000 and to many who voluntarily seek services in and around Vellore (Tamilnadu, India).

The study participants were 100 consecutive people above the age of 18 years who were diagnosed to have epilepsy for more than one year and were currently on treatment at the hospital. Those with moderate to severe mental retardation and severe cognitive impairment were excluded.

The study questionnaire had two parts. The first part had questions related to demographic details and details of treatment. The second part was the translated version in Tamil of the WHOQOL-BREF. The WHOQOL-BREF instrument comprises 26 items measuring the following broad domains: Physical health, psychological health, social relationships, and environment.^[11] The domain scores demonstrated good discriminant validity, content validity, internal consistency, and test-retest reliability, and correlated at around 0.9 with the WHOQOL-100 domain scores. The WHOQOL instruments were developed collaboratively in a number of centers worldwide, and have been widely field-tested.^[11]

The four domains of the WHOQOL-BREF: Physical health, psychological health, social relationships, and environment were rated on a five-point Likert-type scale. As per the WHO user manual, raw scores for the domains of WHOQOL-BREF were calculated by adding values of single items and were transformed on the scale ranging from 0 to 100, where 100 is the highest and 0 is the lowest QOL score.^[12] The mean score were calculated and those with a score 50 and above were classified as having a higher QOL and others as having a lower QOL. Variables were categorized and univariate analysis was done to find associations between different variables and the QOL scores. Logistic regression was done using selected variables and adjusted odds ratios (ORs) were calculated.

Results

Among the study participants, 55% were male, 54% were below the age of 30 years, and 62% belonged to low socioeconomic status; 70% were currently married. The demographic characteristics of the study population were as shown in Table 1.

Among them, 36% of them were on more than one antiseizure drug. Eighteen percent of the study participants had at least one episode of a seizure in the

past six months and 72% had a history of seizures for more than five years.

The total QOL scores for all the domains ranged between 15.7 and 74.55 with a mean of 51.49 [standard deviation (SD) 12.33]. The mean QOL scores obtained in the physical, psychological, social, and environmental domains were 55.7 (SD: 14.7), 37.92 (SD: 15.83), 57.75 (SD: 14.57), and 50.56 (SD: 12.31), respectively.

Forty-one percent were in the lower QOL group, whereas 59% were in the higher QOL group. The univariate analysis of factors associated with poor QOL scores showed that age more than 30 years [OR: 4.91, 95% confidence interval (CI): 2.08-11.59], educational status less than fifth standard (OR; 4.74, 95% CI: 1.48-15.19), female gender (OR: 2.56, 95% CI: 1.13-5.79), and being currently married (OR: 4.00, 95% CI: 1.47-10.98) were associated with poor QOL. The results of univariate analysis are shown in Table 2.

When adjusted for other factors, age more than 30 years (adjusted OR: 4.33, 95% CI: 1.73-10.82), female gender (adjusted OR: 2.90, 95% CI: 1.16-7.28), and being currently married (adjusted OR: 3.82, 95% CI: 1.21-12.11) were the factors significantly associated with lower QOL scores. The final logistic regression table is as shown in Table 3.

Table 1: Demographic characteristics of the study participants (n=100)

Demographic characteristic	Categories	Percentage
Age	<30	54
	30-45	36
	>45	10
Gender	Male	55
	Female	45
Socioeconomic status	Low	62
	Middle	37
	High	1
Educational status	Nil	14
	Upto 5 th standard	62
	6 th to 10 th standard	15
Employment status	Higher secondary/college	9
	Employed	43
	Unemployed	7
Marital status	Others (housewife, student)	50
	Currently married	70
	Unmarried	24
	Widow	3
Religion	Divorced	2
	Separated	1
	Hindu	88
	Christian	6
	Muslim	6

Table 2: Univariate analysis of factors associated with the quality of life scores (n=100)

Factor	Category	Poor (<50) n=41 (%)	Good (>50) n=59 (%)	P value	OR (95% CI)
Age	>30 years	28 (60.9)	18 (39.1)	<0.001	4.91* (2.08-11.59)
	<30 years	13 (24.1)	41 (75.9)		
Sex	Female	24 (53.3)	21 (46.7)	0.027	2.56* (1.13-5.79)
	Male	17 (30.9)	38 (69.1)		
Education	Primary/none	37 (48.7)	39 (51.3)	0.008	4.74* (1.48-15.19)
	Secondary or more	4 (16.7)	20 (83.3)		
Religious category	Hindu	37 (42)	51 (58)	0.757	1.45 (0.41-5.18)
	Others	4 (33.3)	8 (66.7)		
Employment	Working	18 (41.9)	25 (58.1)	1	1.06 (0.48-2.38)
	Not working	23 (40.4)	34 (59.6)		
Marital status	Currently married	35 (50)	35 (50)	0.007	4.00* (1.47-10.98)
	Single/widow/separated	6 (20)	24 (80)		
SES	Low	29 (46.8)	33 (53.2)	0.148	1.9 (0.82-4.44)
	Middle/high	12 (31.6)	26 (68.4)		
Medication	Polydrug	17 (47.2)	19 (52.8)	0.4	1.49 (0.65-3.41)
	Single drug	24 (37.5)	40 (62.5)		
Seizure in past 6 months	Yes	6 (33.3)	12 (66.7)	0.59	0.67 (0.23-1.96)
	No	35 (42.7)	47 (57.3)		

*Statistically significant odds ratio from univariate analysis, CI: Confidence interval, SES: Socioeconomic status, OR: Odds ratio

Table 3: Multivariate analysis of factors associated with low QOL scores among people with epilepsy

Factor	Adjusted OR	95% Confidence interval
Age (>30 years)	4.33**	1.73-10.82
Sex (female)	2.90**	1.16-7.28
Education (<5 th standard)	2.45	0.68-8.86
Marital status (currently married)	3.82**	1.21-12.11
SES (low)	1.71	0.61-4.78
Medication (polydrug)	1.44	0.51-4.07
Seizure in past 6 months (yes)	0.60	0.16-2.26

**Statistically significant OR from multivariate analysis, OR: Odds ratio, SES: Socioeconomic status, QOL: Quality of life

Discussion

The routine follow-up of patients with epilepsy usually is limited to the control of seizure episodes and monitoring of drug dosage and side effects, and there is no proactive approach to seek out the real impact of epilepsy on the life of the patients. An understanding of the degree of satisfaction of the lives of people with epilepsy will aid health-care providers to propose targeted interventions to improve their QOL and health-care outcomes.

In the current study, the QOL scores among people with epilepsy were poor in the psychological domain as compared to other domains and this is a clear indication that epilepsy exerts a detrimental effect on the lives of people that is hidden and not easily recognizable. In a hospital-based study done among people with epilepsy from the tertiary care psychiatric hospital in this area, the mean QOL scores obtained in the physical, psychological,

social, and environmental domains were 58.68 (SD: 15.3), 54.46 (SD: 13.86), 62.83 (SD: 16.62), and 56.05 (SD: 9.53), respectively.^[13] The scores are similar to what we got in the current study except for the psychological domain. We got a lower score in the psychological domain (37.92). In the former study, among the people with epilepsy and psychiatric comorbidity, the psychological domain score was 37.1 (SD: 11.3). Various studies shows that psychiatric comorbidity, especially depression and anxiety, are significantly more common in people with epilepsy and it may go under-recognized, resulting in poorer overall QOL among them.^[13-15]

Age more than 30 years and female gender were the factors significantly associated with lower QOL scores. The age stratification is rather broad to ascertain definitive reasons for this observation; however, due to the small size of the sample, it was not feasible to have more age group classifications. The age group of less than 30 years probably includes students or youth, who may get better care as they are under the guardianship of parents. With increasing age, the stigma in society regarding job opportunities and social life may manifest, and hence the poor QOL. The association between age and QOL among people with epilepsy was noticed in various other studies also.^[16,17]

Studies from India have shown that females with epilepsy felt decreased social support and more social isolation compared to their male counterparts.^[18,19] A study from Europe also reported that female respondents with epilepsy had poorer energy, physical functioning, and mental and general health.^[16] The social system of

patriarchy, with males as the primary authority figures, is central to the organization of much of the Indian society. The system upholds the institutions of male rule and privilege and mandates female subordination. Women with epilepsy might have low social support and more social isolation leading to lower QOL.

Being currently married was found to be associated with obtaining a lower QOL in the current study. A recent study from India showed that energy, fatigue and emotional well-being, were significantly low in married people with epilepsy.^[18] A lower marriage rate has been reported among people with epilepsy as compared to the general population.^[20,21] A high rate of divorce has also been noticed among people with epilepsy in Asian countries.^[22] This could be due to the cultural beliefs and stigma which are still prevalent in the society. The finding could be also because of misclassification by clubbing those who are unmarried with those who are separated/widowed/divorced, as many of those who are single would be young and hence having a good QOL.

Previous research revealed that higher QOL was associated with higher educational attainments.^[16,17] However in this study, when adjusted for other factors, educational status became statistically insignificant. It is reasonable to suggest that educational status increases the potential for awareness of disease, compliance to treatment, and the use of positive coping methods which will also be influenced by other sociodemographic variables.

Indian studies done in tertiary care centers of Kerala and Kolkata revealed that frequency of seizures had an impact on the QOL scores.^[23,24] Increasing frequencies of seizures in patients may limit their physical activity and social functioning and may cause various psychological problems leading to a lower QOL. However, we could not find any significant association between seizure freedom and QOL. This could be due to the fact that we defined seizure freedom as being free from seizures for the past six months. Freedom from seizures for six months may not be enough to have a significant improvement in QOL.

The study was done on patients attending the outpatient department of a secondary care hospital and there is a higher probability of selection bias in the study population. The WHOQOL-BREF is an easy-to-use instrument to assess the perceptions of people about QOL. The scores are therefore highly dependent on the perceptions of people which in turn can be affected by sociodemographic factors. However, perception may not

be very reflective of the physical health and QOL. This maybe the reason that in this study, QOL was found to be significantly correlated with sociodemographic factors but not with treatment experience and clinical outcome such as frequency of seizures. The QOL scores were classified into higher and lower categories using 50 as the cutoff point, and there is a chance that the patients in the two categories may not be very different. Despite these limitations, the study provides some direction toward targeting, for example, females and older people with epilepsy for support in the clinics. Although it might not be easy to modify clinical outcomes with good services and support, it might be much more effective in bringing about a change in QOL. Thus measurement of QOL should become a routine part of clinical management of people with epilepsy.

To conclude, QOL scores among people with epilepsy were poor in the psychological domain. Female gender and increasing age have a higher risk of poor QOL. A better understanding of the degree of satisfaction of the lives of people with epilepsy is necessary for clinicians to better help them to lead more fulfilling lives.

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