

Assessment of quality of life in epilepsy in Andhra Pradesh

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Abstract

Lower quality of life (QOL) was observed among people with epilepsy than those free from it. Identification of factors influencing QOL may be helpful in improving epilepsy care. Psychiatric morbidities have been shown to influence QOL adversely. This study aimed to determine the variables associated with QOL in patients with epilepsy free from psychiatric morbidities. Four hundreds patients attending a tertiary care hospital in Andhra Pradesh were recruited. QOL was measured using Telugu version of QOLIE89 (Quality of life 89) instrument. Mean of total QOL score was 42.30 ± 7.66 (range 24-67). Those who were married, stayed in rural areas, not lettered, involved in agriculture and had low income levels ($p < 0.01$) were found to have lower mean total QOL score. Multivariate regression analysis showed that previous exposure of knowledge on QOL, reaction to the diagnosis of epilepsy, stress in being alone and feeling of health getting worse were significant predictors of poor QOL in patients with epilepsy ($p < 0.01$). Previous exposure of knowledge on QOL, response to the diagnosis of epilepsy, stress in being alone and feeling of health getting worse were significant predictors of lower quality of life among people with epilepsy.

INTRODUCTION

Epilepsy is a significant public health problem in the world. It has been estimated that at least 50 million people suffer from epilepsy and 85% of them belong to developing countries.¹ In India, the prevalence of epilepsy is 5.1% in urban and 5.5% in rural areas.² Epilepsy is a brain disorder characterized by an enduring predisposition to epileptic seizures and leads to neurobiological and social consequences.³ Unpredictable nature and course of epilepsy, stigma,⁴ poor self-esteem, higher levels of anxiety, depression, educational under achievements, under or unemployment, lower rate of marriage, higher divorce rate, greater social isolation, treatment side effects, cognitive and psychiatric problems⁵⁻⁷ have been reported to impair quality of life (QOL) in epilepsy patients. QOL is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.⁸ QOL questionnaire assesses multiple daily functions and these functions are dependent on the cultural, ethnic and economic differences.⁹ In India, factors influencing QOL in patients with epilepsy were studied in Vellore¹⁰, Manglore¹¹, rural areas of Vellore¹², Delhi¹³,

Kolkata¹⁴ Trivandrum¹⁵ and Hyderabad.^{16,17} Identification of factors determining quality of life may aid to develop strategies to manage and improve epilepsy care.¹⁸ Psychiatric morbidities have been demonstrated to determine the QOL adversely than epilepsy related factors.¹⁹ In this study, an effort was made to find out predictors of the QOL in epilepsy patients free of psychiatric co-morbidities in a tertiary care hospital situated in the southern portion of Andhra Pradesh.

METHODS

An Institutional Ethics Committee of SVIMS, Tirupati, approval, before embarking on the study, was obtained and individual participant consent was taken, prior to recruitment, in the study. A cross sectional descriptive design with purposive sampling technique was employed in the study. Data on 400 patients with epilepsy attending Neurology Out Patient Department and Epilepsy Clinic, Sri Venkateswara Institute of Medical Sciences, Tirupati and who fulfilled the inclusion criteria of the study were collected. The criteria for inclusion were: definite diagnosis of epilepsy; under regular treatment for a minimum period of

one year, on prescribed antiepileptic drugs (AEDs) at the time of recruitment, willing to participate in the study, and was able to speak the local language. Hospitalized persons with epilepsy, psychiatric and personality disorders, mentally challenged; those who could not complete the instrument due to visual and hearing impairment; undergone any form of epilepsy surgery; were under the drug regimen other than AED such as anxiolytics, sedatives, hypnotics, antidepressants, antipsychotics, narcotics and tranquilizers; patients with chronic illness (Hypertension, asthma, diabetes mellitus, stroke); and persons those who were eligible but not willing to take part in the study due to lack of time or disinclination were also excluded. Subjects were interviewed with a standardized questionnaire.

Patients, who fulfilled the inclusion criteria, were administered an adapted version of QOLIE89 (Quality of Life in Epilepsy-89), which had two parts. The Part I had details of demography and medical history, while part II, contained items on quality of life (QOL).

The modified QOLIE-89 contains 17 multi-item measures of overall quality of life, emotional wellbeing, role limitations due to emotional problems, social support, social isolation, energy/fatigue, worry about the seizure, medication effects, health discouragement, work/driving/social function, attention/concentration, language, memory, physical function, pain, role limitations due to physical problems, and health perceptions.²⁰ Scores of the 17 QOLIE-89 scales were obtained by mean score within the scales and transformed mean scores linearly to a 0–100 possible score. A five point rating scale containing the dichotomy of yes/no questions were used for all items on “Quality of Life” of individuals suffering from epilepsy. The item scores showed the good discriminant validity, content validity, internal consistency, and test-retest reliability, and correlated at around 0.9 with the QOLIE 89-100 scores. The QOLIE-89 instrument was developed by RAND organization, and was used in studies conducted in India.²¹

Data such as age, sex, religion, marital status, education, occupation and income, residence, housing, habits, family type, family history of epilepsy and consanguinity were recorded.

Statistical Analysis

The data were analysed using SPSS Chicago Inc 16.0 version. Frequencies, mean, standard deviation, ‘t’ test, correlation, stepwise regression, multiple regression, one way analysis of variation,

and Post –Hoc analysis were used for the present study. Means were compared using independent ‘t’ test and one way analysis of variance. The association between total QOL score and variables was examined by Pearson’s correlation coefficient. Stepwise multiple regression was used to ascertain the suitable variables to be assessed in multiple regression analysis. Multiple regression analysis was employed to find out the predictors of QOL in epilepsy patients.

RESULTS

The majority of subjects were aged 18–28 years 193 (48%). Females (n=229, 57%) outnumbered male. Two hundred fifty patients (63%) were married, 138 (34%) unmarried, 7 (2%) lost a spouse and 5 separated. In patients, Hindu was the predominant religion 375(94%), followed by Islam 20 (5%) and Christianity 5 (1%). One hundred ninety six patients (49%) were living with parents, or single parent 8 (2%) or children 183(46%) or others 6(1%) or as single 7 (2%). Preponderance of patients was living in rural areas 236 (59%). When categorized based on behavioural traits, the majority of them were non-smokers 371 (93%), teetotallers 386 (97%) and not abused the drugs 396(99%). Ninety patients (22%) had a family history of epilepsy. The higher number of patients had a high school education 101 (25%). One hundred sixty five (41%) patients were unemployed, 104 (26%) were farmers, 76 (19%) were employed in the private sector, 29 (7%) were in business and 26 (6%) were government employees. A higher proportion of patients 125 (31%) had an income of Rs.675–2024 per month.

One way analysis of variance and post-hoc analysis indicated that those who were staying in rural when compared to urban areas had a lower mean total QOL($p<0.01$). Married people had a lower mean total QOL score than those who were unmarried ($p<0.01$). Lower mean total QOL was observed in illiterates when compared to professional course educated ($p<0.01$). Those who were involved agriculture had lower mean total QOL than those who had government jobs ($p<0.01$). The mean total QOL score was significantly lower in those who had low income than those who had high income ($p<0.01$). No significant association was observed with age ($p=0.14$), gender ($p=0.82$), religion ($p=0.65$), living with parents, single parent, children or others ($p=0.25$) and family history of epilepsy ($p=0.37$) (Table 1).

Table 1: Association between variables and quality of life (n=400)

	Variables	Mean	Standard Deviation	F value	P value
1.	Age (years)				
	a. 18-28	75.69	19.32		
	b. 29-38	71.76	21.26		
	c. 39-48	70.89	18.88	1.65	0.14
	d. 49-58	70.76	14.40		
	e. > 58	100	--		
2.	Gender				
	a. Male	73.27	20.22	0.048	0.82
	b. Female	73.71	19.21		
3.	Marital status				
	a. Married	70.92	19.60		
	b. Not married	78.26	19.10	3.80	0.01
	c. Widow/widower	72.85	14.96		
	d. Divorced/separated	74.0	21.9		
4.	Religion				
	a. Hindu	73.44	19.82		
	b. Muslim	73.15	17.01	0.423	0.65
	c. Christian	82.50	12.58		
	d. Others	---	---		
5.	Living with				
	a. Parents	75.40	19.75		
	b. Single Parent	78.75	20.31		
	c. Children	71.69	19.29	1.33	0.25
	d. Single	70	19.14		
	e. Others	65	23.45		
6.	Residence				
	a. Urban	77.55	18.14		
	b. Rural	71.05	19.93	4.83	0.01
	c. Semi urban	75.15	20.78		
7.	Family history of epilepsy				
	a. Yes	71.91	20.33	1.65	0.37
	b. No family history	74.06	19.41		
8.	Education				
	a. Professional	89.47	12.68		
	b. Graduate/post graduate	78.78	19.96		
	c. Intermediate	75.34	20.04		
	d. High school	73.66	20.28	5.57	0.01
	e. Middle school	70	17.5		
	f. Primary school	70.19	16.14		
	g. Illiterate	64.72	19.32		
9.	Occupation				
	a. Government employee	84.61	15.8		
	b. Private employee	72.89	19.98		
	c. Business	73.44	18.37	3.12	0.01
	d. Agriculture	69.9	18.66		
	e. Unemployed	74.53	19.85		
10.	Income in rupees per month				
	a. \geq 13,500	82.3	18.51		
	b. 6,750-13,499	81.06	19.36		
	c. 5,050-6,749	78.48	17.34		
	d. 3,375-5,049	73.87	23.52	4.13	0.01
	e. 2,025-3,374	72.2	19.22		
	f. 675-2,024	69.44	18.54		
	g. \leq 675	69.37	17.3		

1USD = 60 rupees

The average total QOL score of subscales was as follows: Quality of life (42.30 ± 7.66), pain (16.30 ± 3.45), language (12.93 ± 2.67), memory (33.96 ± 7.38), concentration (24.05 ± 5.77), mental health (27.20 ± 5.97), social isolation (24.14 ± 4.79), fatigue (14.17 ± 4.25), psychosocial life (41.57 ± 10.94), seizure worry (24.05 ± 6.85), social function (20.26 ± 5.21) and total quality of life (7.32 ± 1.95).

In correlation analysis, statistically significant association of total QOL with age, marital status, gender, residence, education, age of onset, feeling of the medication limiting the day to day activities, societal stress, stress in being alone, stress management by viewing television for long time, sharing feelings with spouse, son and others, problem in attending college, change in academic performance, not doing jobs requiring more concentration, previous exposure of knowledge on QOL, reaction to the diagnosis, perception of health, satisfaction with health, rating of health compared to last year, feelings like to get sick a little easier than others, health is becoming worse, epilepsy made physically unwell, physical health interfering with normality activity, limitation in physical activity, happiness with overall social and home life, fear of having a seizure, limitation in working condition, social limitation and QOL during the past four weeks, was observed ($p < 0.01$). No significant association was observed between total QOL score and other variables (Table 2).

In multiple regression analysis, variables like previous exposure of knowledge on QOL, reaction to the diagnosis of epilepsy, stress in being alone and feeling of health getting worse were significant predictors of QOL in patients with epilepsy ($p < 0.01$). The proposed model was able to explain 21% of variation as shown by the adjusted R² (0.209) (Table 3).

DISCUSSION

The emphasis in the management of epilepsy is seizure control and a reduction in the frequency of seizure.²² Clinical symptoms like seizure frequency and severity or other biomedical markers were reported to correlate moderately.²³ Poorer QOL was observed in PWE than those with other chronic illness and without epilepsy.²⁴ It has been also observed that betterment in clinical parameters not lead to the improvement of social functioning and QOL.²⁵ Social, psychological, behavioural, educational and cultural factors have been shown to affect, in addition to episodic seizures, on the quality of life in epilepsy patients.²⁶ QOL showed to vary across the world depending

on the cultural, economic and community milieu.²⁷ Identification of determinants of QOL may lead to the development of strategies towards improving the QOL of epilepsy patients. Sensitivity of QOL to different domains of living can help in finding domains in to initiate interventions for the betterment of QOL.²⁸

In the present study, previous exposure to the knowledge on QOL, reaction to the diagnosis of epilepsy, stress in being alone and feeling of health getting worse were significantly associated with QOL. These variables belong to the domains, physical health and physical function and stress management and emphasize their role in enhancing the QOL in patients of the present study. In our study, patients had previous exposure to the knowledge on QOL from Radio/TV (10%), awareness programmes in out-patient clinic (35%), books/magazines (12%), elders (8%) and parents and relatives (35%). This highlights the importance of outpatient clinics and epilepsy education to parents and relatives of patients in enhancing the epilepsy care.

The response to the diagnosis of epilepsy in patients of our study was denial (6%), anger (9%), acceptance (30%), shock (17%) and depression (38%). The reactions responses of the patients suggest the need of instituting of pre-counselling to maintain the quality of life in these patients. Four to 14% patients in the study reported always, very often, often and sometimes being alone. 'Being alone' is a concern observed in epilepsy patients during a seizure. It is hypothesized that the fear of seizure, and of seizure-related death can cause an impaired psycho-social adaptation to epilepsy, the higher the degree of these fears, the greater the psychopathological risk.²⁹ Another concern expressed by present study patients was health is getting worse. In a response to the question whether your health is getting worse, the answers of the patients were: definitely true (8%), mostly true (18%), not sure (39%), mostly false (17%) and definitely false (18%). There is a need to address these concerns with adequate consideration to reduce the impact of such limitations on the lives of epilepsy patients.²⁹

Various factors have been associated with QOL with epilepsy, in Indian studies, like workdays lost due to epilepsy in last three months, use of two or more antiepileptic drugs, higher frequency of seizure and the long-time gap between onset of seizure and consultation with a neurologist,¹⁴ polytherapy and Engel score of seizure frequency >6 ¹⁵, high seizure frequency³⁰, anxiety and depression^{16,17}, age >30 years, female and currently

Table 2: Correlation analysis between total QOL and variables

Variable	Correlation coefficient(r)	Significance
Age	-0.126	0.01
Marital status	0.138	<0.001
Gender	0.145	<0.001
Residence	-0.217	<0.001
Education	-0.163	0.001
Age of onset of seizures	-0.138	0.01
Medication limits day to day activities	-0.124	0.01
Societal stress	0.134	0.01
Stress in being alone	0.161	,0.001
Stress managed by watching TV for long time	0.130	0.01
Share feelings with spouse	-0.192	<0.001
Share feelings with son	-0.128	0.01
Share with others	0.130	0.01
Problem in attending college	0.104	0.03
Change in academic performance	0.125	0.01
Not doing job that requires more concentration	0.139	0.01
Previous exposure of knowledge on QOL	0.319	<0.001
Reaction to diagnosis of epilepsy	0.147	0.01
Perception on health	0.221	<0.001
Satisfaction on health	0.262	<0.001
Rating of health compared to last year	0.177	<0.001
Get sick a little easier than others	0.222	<0.001
Health is getting worse	0.262	<0.001
Epilepsy made physically unwell	0.218	<0.001
Physical health interferes with normal activity	0.154	0.01
Limitation in physical activity	-0.699	<0.001
Happiness with over all social and home life	0.136	0.01
Fear of having a seizure	0.119	0.01
Limitation in work condition	-0.132	0.01
Social limitation	-0.103	0.01
QOL during past 4 weeks	0.124	0.01

Table 3: Multiple regression analysis showing relationship between quality of life and variables

Variable	Standardized beta	95% CI	Significance
Previous exposure to the knowledge on QOL	0.312	1.121-2.002	0.001
Reaction to diagnosis of epilepsy	0.148	0.369-1.448	0.001
Stress in being alone	0.144	0.304-1.254	0.001
Health is getting worse	0.277	1.244-2.404	0.001

married¹⁰, increasing age, education less than grade V, being single/unmarried, widowed or separated, lower per capita income, a high anxiety score and having a seizure episode in the past one year¹² and educational status.¹¹

Univariate analysis, in the present study, showed that married status, rural residence, illiteracy, agriculture profession and low income were significantly associated with poor quality of life. Poor QOL in married people may be due to seizure exacerbation, non-adherence to AED regimens, low self-esteem, mental illness and inhibited marital role.³¹⁻³⁵ Lower QOL score in rural than urban patients may be due to social deprivation, less access to medical facilities, irregular drug intake, infrequent check-up and lack of resources to go to the treatment giving facilities^{36,37} Education has been reported to influence QOL through its association with employment, higher social class and economic status. Lack of awareness of management practices and education about the disease and non-adherence to regular treatment³⁸ in illiterates might have contributed to the lower QOL in these patients. Inability to afford and access medical facilities in farmers than government employees might be responsible for poor QOL. No significant association between total QOL score and gender and religion was observed. Similar observations were drawn from earlier studies.^{14,15,39} The major contribution of this study is finding of predictors of QOL not reported in literature for comparison and in patients free from psychiatric co-morbidities. This highlights the importance of social-cultural milieu in determining the QOL of epilepsy patients. There is a need to conduct studies in different geographical areas to find out local specific factors influencing the QOL of epilepsy.

The results of the study suggest that besides advocating adherence to the treatment, giving education about epilepsy to patients and patient's attendants, instituting pre-counselling before diagnosis, addressing of their concerns, improving educational levels and accessibility to medical facilities may contribute to the improved quality of life in the epilepsy patients.

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