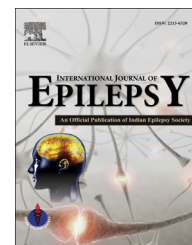


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Original Article

Assessment of quality of life in Indian adults with epilepsy and their caregivers

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ABSTRACT

Background: Epilepsy is the most common neurological disorder which requires chronic treatment. This has prominent impact on the quality of life of the patient and their caregivers. This study was planned to assess and correlate the quality of life in epilepsy (QOLIE) in these two groups, in India.

Material and methods: A total of 160 subjects with definite diagnosis of epilepsy according to ILAE and their caregivers were included in the study. The QOLIE 31 and SF 36 proforma were used as assessing instruments for subjects and caregivers respectively.

Results: Factors such as early age of onset of epilepsy, lesser duration of epilepsy, increased interval between seizures in subjects on monotherapy, socioeconomic and educational status had better quality of life (QOL) in subjects than age, gender, marital and employment status. On the other hand for caregivers following factors-age, gender, relation with the subjects and socioeconomic status had influenced the QOL. The QOL of the caregivers was directly proportional to the QOL of their respective subject.

Conclusion: This study reaffirms the findings of the previous studies that key to improving quality of life of people with epilepsy, are good control of seizure and reducing side effects (by minimizing antiepileptic drugs) along with holistic care. Caregivers QOL is also proportionally affected by subjects QOL and it is seen to have adverse outcomes when the caregiver is female (mother or wife), elderly, of low socioeconomic status and when subject has poor seizure control.

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Epilepsy affects the emotional well being, cognitive and social functioning of the patient. Problems like medication effects and seizure worry impinges on the overall functioning of the subject as well as the caregivers. The quality of life of an

individual or society gives information regarding the general well being of the people. It is important to evaluate the various challenges in daily life of the patient and their caregivers when on treatment. The quality of life assessments and

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seizure severity are parameters which are helpful in documenting as well as monitoring the progress while on treatment.

Epilepsy is common neurological disorder. The incidence of seizure disorder in developed countries is reported to be 40–70 per 100,000 and 100–190 per 100,000 in developing countries.^{1–4} In India the incidence is reported to be approximately 49.3 per 100,000.⁵ The cumulative incidence of epilepsy (the chance of acquiring epilepsy at some time during life) is 2–4%.⁴ This cumulative incidence varies with age, with higher percentage seen in elderly age group. A study done in Rochester, Minnesota, reported the cumulative incidence of 0.9%, 1.7%, and 3.4% for the people with age 20, 50 and 80 years respectively.⁶ Moreover, the cumulative incidences for a particular region depends on the population of that specific age group. Where in Denmark cumulative incidence is just 1.3% at age 80; Iceland study showed 5.4% with same age group.⁷ Epilepsy is a multifaceted chronic disorder which has diverse and complex effects on the overall well being including physical, psychological, social, occupational, and financial aspects, and has a great negative impact on quality of life (QOL) of the subjects.

In various studies, an interaction of various factors including clinical variables (e.g., seizure frequency, severity, illness duration, treatment side effects, psychiatric comorbidity), social disadvantage (e.g. divorce, unemployment, social stigma, illness intrusion into social life), and family circumstances (e.g. family caregiver characteristics, social support) were reported to affect the quality of life of the patient. The high prevalence of anxiety-depression^{8,9} and socio-occupational^{10,11} decline among subjects according to some recent studies is also responsible for overall poor QOL.

The caregiver of an epileptic also faces the grave consequences of the chronic disorder which has a great negative impact on their quality of life. They also experience disturbances in their work and routine activities which has a strong negative psychological and socio-occupational effect on their lives.

It is important for clinicians to understand that how satisfied people living with epilepsy are with their life and thereby help them lead more fulfilling lives. The overall outcome and QOL of subjects with epilepsy can be improved by adopting holistic approach of management. There is also a need to understand psychological and socio-occupational state of caregivers and to give mental support and appropriate pharmacological or non-pharmacological treatment for underlying psychological distress.

This study enumerates the factors which affect the quality of life of individuals with epilepsy and the consequences of living with an epileptic on the caregiver. Hence the study highlights the areas which can be amended in the management of epilepsy.

1. Methods

1.1. Subjects

The study (cross-sectional design) was conducted in the Department of Neurology, G.B. Pant Hospital, New Delhi

between April 2010 and November 2011. All the consecutive subjects and their caregivers attending the Out Patient Department (OPD) or admitted in wards was included in the study after written consent and ethical clearance from the Institutional Ethics Committee.

1.2. Inclusion and exclusion criteria

Subjects aged 18–60 years with definitive diagnosis of epilepsy according to definition by ILAE for duration of at least one year were included in the study following a written informed consent. They were escorted by their caregivers willing to participate in the study. Subjects with co-morbid neurological illness including mental retardation, motor disability, visual and hearing impairment, language disability, psychosis or psychiatric disease, history of recent status epilepticus, stroke and pregnant females were excluded from the study.

Caregivers defined as closest family member or friend who lived with the patient or as any person who spent a greater part of life with the patient, witnessed seizures, took active part in treatment, attended physician appointments as a companion and cooperated with the patient to achieve compliance with the treatment were included while those caregivers with any neurological or psychiatric disorder which may affect the assessment were excluded from the study. They were aged between 18 and 60 years and literate enough to answer the questionnaire.

1.3. Instruments

1.3.1. QOLIE 31 (version 1)

This form with 31 item questionnaire was used for the assessment and scoring of QOL in epilepsy subjects after taking permission from its developers. It is a shorter version of QOLIE 89. The QOLIE 31 form was translated into the local (Hindi) language and accuracy was ascertained by back translation. It covered all the aspects of health – related QOL (physical health and psychological domains), contextual issues (social relations and environment domains) and general subjective wellbeing (general facet on health medication side effect and QOL). Some questions have been modified e.g. ‘ability to drive’ has been changed to ‘ability to travel independently’ to meet our socio-cultural milieu. The socio-economic status was scored using the Kuppaswamy Socio-economic grading scales with income range of the year 2007.¹²

1.3.2. SF 36 (version 2)

The back translated (Hindi) form of SF 36 version 2 was used for the scoring of the caregivers which was provided by the Quality metric group. A total of 36 items were divided into two main domains Physical Component Summary (PCS) and Mental Component Summary (MCS). This covers the Physical Functioning (PF), Physical Role (RP), Emotional Role (RE), Social Functioning (SF), Mental Health (MH), Bodily Pain (BP), Vitality (VT) and General Health (GH).

The maximum score was 100, for both of the forms. Higher scores denoted better quality of life whereas lower scores showed poor quality of life of the person studied.

Table 1 – The socio-demographic details of the epilepsy subjects and their caregivers.

Socio-demographic characteristics	Caregivers (n = 160)		Patients (n = 160)	
	N	%	n	%
Mean age in years	41.62 ± 9.29		25.91 ± 8.64	
Age distribution				
<20		–		30.62
20–30		20.62		48.12
30–40		20		12.50
40–50		41.87		6.87
50–60		17.50		1.87
Gender				
Male	104	65	92	57.5
Female	56	35	68	42.5
Marital status				
Married			70	43.75
Unmarried			90	56.25
Religion				
Hindu			140	87.5
Muslim			19	11.87
Christian			01	0.625
Educational status				
10th			70	43.75
12th			30	18.75
Graduate & post graduate			43	27
Professionals			17	10.62
Occupational status				
Student			54	33.75
Unemployed			17	10.62
Housewife			30	18.75
Others			58	36.25
Economic status				
Lower				0
Upper lower				38.12
Lower middle				18.75
Upper middle				40
Upper				3.12
Relation with patient				
Father		35		
Mother		23.12		
Husband		13.75		
Wife		9.37		
Brother		10.62		
Others		8.12		

1.4. Analysis

Chi square test, Analysis of Variance (ANOVA) and multiple regression analysis were employed on SPSS package to ascertain statistical significance. Appropriate tests were used to compare the QOLIE-31 and SF-36 responses with seizure status and duration of epilepsy and other factors. The results of our study were compared with previous studies. In all tests, values of $p < 0.05$ were considered statistically significant.

2. Results

2.1. Socio-demographic details of epilepsy subjects

A total of 160 subjects with epilepsy were recruited with a mean age of 25.91 ± 8.64 years of whom 92 were males and 68

Table 2 – The clinical details of the epilepsy subjects.

Clinical characteristics	Patients (n = 160)	
	n	%
Mean duration of epilepsy in years	9.46 ± 7.45 years (range 1–45 yrs)	
Duration of epilepsy		
<5 yrs		41.25
>5–10 yrs		23.12
>10–15 yrs		16.25
15–20 yrs		13.12
>20 yrs		6.25
Age of onset		
1–10 yrs		20.62
10–20 yrs		58.75
20–30 yrs		13.12
30–40 yrs		6.25
40–50 yrs		1.25
Seizure frequency		
>1/month		21.25
>1/6 month		23.12
>1/yr		23.12
<1/yr		32.50
Time since last episode		
<1 month		15.62
1 year		53.12
1–3 yrs		21.25
>3 yrs		10
Family history		
Present	13	8.12
Idiopathic generalized epilepsy	5	
Juvenile myoclonic epilepsy	6	
Tuberous sclerosis	2	
Absent	147	91.88
Type of seizure		
GTCS	82	51.25
GTCS + Myoclonus	21	13.12
Partial with secondary generalization	52	32.5
Others	5	3.12
Seizure aetiology		
Idiopathic generalized seizures	75	46.87
Intracranial Granuloma	40	25
Juvenile Myoclonic Epilepsy	24	15
Others	21	13.12
Antiepileptic therapy		
Monotherapy		60
Polytherapy		40

were females (Male to Female ratio = 1:1.35). The socio-demographic details including age, gender, marital status, religion, education, occupation, and economic status of these subjects are shown in Table 1. Majority of the subjects were in 2nd–3rd decades of life out of which 70 subjects were married and belonged to lower middle and upper lower class. The study population consists mostly of students, housewives and unemployed subjects, whereas, 63.75% of subjects were not engaged in any productive work.

2.2. Clinical details of epilepsy subjects

The mean duration of epilepsy was 9.46 ± 7.45 years; 103 (74.37%) subjects had epilepsy of <10 year duration, of which 66 had epilepsy of <5 years duration. The mean age of onset of epilepsy was 16.51 ± 8.62 years. Majority of subjects had onset

of epilepsy in 1st – 2nd decades of life. Most common type of seizure reported was generalized seizures followed by partial seizures. The details of the epilepsy characteristics in subjects are presented in Table 2.

Sodium valproate, 32/96 (33.33%) was the commonest anti-epileptic drugs (AED) taken as monotherapy, followed by phenytoin 27 (28.12%) and carbamazepine 24 (25%). Oxcarbazepine (10), divalproex sodium (2) and lamotrigine (1) were other drugs used for monotherapy. For combinational therapy, 56 subjects were on two AEDs of which valproate and carbamazepine ($n = 13$) was most commonly prescribed combination followed by other combinations.

Electroencephalography (EEG) was done in 105 subjects, of which only 23 (21.9%) subjects had abnormal EEG. Along with EEG, 154 subjects had undergone neuroimaging either computer tomography (CT) or magnetic resonance imaging (MRI) of brain. The common neurological features observed were normal, single or multiple granuloma, gliosis, subependymal nodule or cortical tubers, and basal ganglia calcification. Seventy two (72) subjects underwent CT scan only, 46 subjects underwent MRI brain only and 36 subjects underwent both. Six (6) subjects with clinical diagnosis of Juvenile Myoclonic Epilepsy (JME) did not undergo any neuroimaging. Of these 154 subjects, 95 (61.68%) had normal neuroimaging. The commonest abnormality which was seen on imaging was single or multiple granulomas, seen in 47 (30.51%) epilepsy subjects.

2.3. Socio-demographic details of caregivers

The mean age of care givers was 41.62 ± 9.29 years, 104 (65%) were males and 56 (35%) females (M to F ratio is 1.8:1). Majority of the caregivers were the parents (58.12%); 60.21% of these were fathers and rest (39.79%) mothers. As shown in Table 1, 22 (13.75%) caregivers were husbands, 15 (9.37%) were wives and 17 (10.62%) were brothers of subjects.

2.4. Quality of life assessment of epilepsy subjects

The mean score calculated from QOLIE 31 scale was 60.28 ± 17.3 . The socio-demographic parameters such as gender (male: 60.02, female: 60.63; $p = 0.82$), age (<20: 60.94 ± 19.66 , 20–30: 60.26 ± 16.27 , >30: 59.39 ± 16.41 ; $p = 0.99$), marital status (married: 61.88, unmarried: 58.22; $p = 0.18$) and employment (employed: 60.26, unemployed: 60.30; $p = 0.64$) did not influence QOL of subjects while on the other hand educational status (matriculation: 55.04 ± 15.73 , higher secondary: 63.08 ± 19.22 , graduate and higher: 77.97 ± 8.24 , professionals: 65.4 ± 13.87 ; $p = 0.002$) and socioeconomic status (upper: 70.7 ± 16.63 , upper middle: 65.33 ± 15.37 , lower middle: 58.22 ± 16.18 , upper lower: 55.15 ± 18.31 ; $p = 0.002$) was directly proportional to outcome. Various factors directly related to epilepsy were also associated with the quality of life of the subjects. Early age of onset of epilepsy (1–10 yrs: 59.81 ± 16.41 , 10–20 yrs: 59.34 ± 18.06 , 20–30 yrs: 64.13 ± 15.25 , >30 yrs: 62.19 ± 17.45 ; $p = 0.166$), longer history with disease (<5 yrs: 62.33 ± 17.53 , 5–10 yrs: 60.75 ± 17.73 , 10–15 yrs: 57.65 ± 16.17 , 15–20 yrs: 59.42 ± 17.34 , >20 yrs: 53.7 ± 17.79 ; $p = 0.536$), patient with JME (GTCS: 60.12 ± 16.35 , partial seizures with/out secondary seizures: 60.24 ± 18.53 , JME: 58.14 ± 18.14 ; $p = 0.27$) had worse QOL than their counter parts but the difference was not significant. Frequency of seizures affects the QOLIE 31 scores inversely ($p = 0.0001$); on the other hand seizure free duration ($p = 0.003$) and subjects on monotherapy (0.05) had better quality of life which was statistically significant (as depicted in Fig. 1).

2.5. Quality of life assessment of caregiver of epilepsy subjects

The QOL of the caregivers assessed as per the SF 36 scale showed the mean score of Physical component summary (PCS) and Mental component summary (MCS) as 65.75 ± 18.35

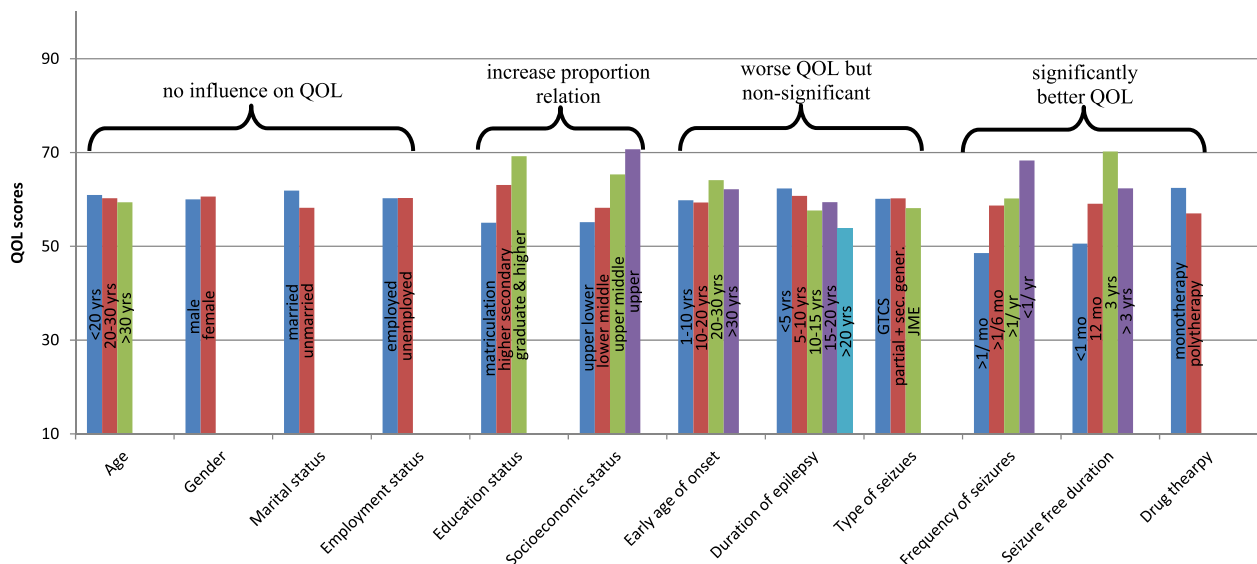


Fig. 1 – Comparison of the QOLIE-31 scores of the epilepsy subjects. The influence of the individual parameter studied for assessing QOL are shown against their respective QOL score. Factors like age, gender, marital and employment status did not affect the QOL whereas, early age of onset, duration of epilepsy, type of seizures depicted poor QOL though non-significantly. There was a significant relationship in case of frequency of seizures, seizure free duration and drug therapy; which directly influence the QOL in epilepsy subjects.

Table 3 – Relationship between QOL of caregivers of epilepsy subjects and SF 36 scores.

Parameters	Mean PCS score \pm SD	Mean MCS score \pm SD
Mean score	65.75 \pm 18.35	65.79 \pm 18.9
Age distribution	(p = 0.53)	(p = 0.73)
20–30	68.52 \pm 18.39	67.54 \pm 20.57
30–40	68.79 \pm 19.78	69.06 \pm 18.94
40–50	63.95 \pm 18.54	64.25 \pm 17.85
50–60	63.32 \pm 16.09	63.7 \pm 19.58
Gender	(p = 0.001)	(p = 0.5)
Male	69.4 \pm 17.37	67.89 \pm 17.54
Female	58.98 \pm 18.35	61.91 \pm 20.54
Age of onset	(p = 0.201)	(p = 0.385)
1–10 yrs	65.65 \pm 18.44	64.97 \pm 22.38
10–20 yrs	64.6 \pm 18.24	64.36 \pm 18.29
20–30 yrs	73.3 \pm 18.8	71.9 \pm 18.89
>30yrs	61.35 \pm 16.75	68.6 \pm 11.25
Seizure frequency	(p = 0.01)	(p = 0.313)
>1/month	54.31 \pm 15.59	56.49 \pm 19.86
>1/6 month	65.6 \pm 16.95	65.62 \pm 18.76
>1/yr	65.4 \pm 18.2	65.7 \pm 18.7
<1/yr	73.11 \pm 16.48	70.64 \pm 17.79
Time since last episode	(p = 0.255)	(p = 0.880)
<1 month	54.31 \pm 15.59	56.49 \pm 19.86
1 year	65.6 \pm 16.95	65.62 \pm 18.76
1–3 yrs	65.4 \pm 18.2	65.7 \pm 18.7
>3 yrs	73.11 \pm 16.48	70.64 \pm 17.79
Duration of epilepsy	(p = 0.24)	(p = 0.046)
<5 yrs	68.45 \pm 18.56	66.82 \pm 17.65
>5–10 yrs	64.68 \pm 16.09	66.82 \pm 15.5
>10–15 yrs	60.87 \pm 19.13	60.67 \pm 19.07
15–20 yrs	69.06 \pm 20.27	71.18 \pm 21.86
>20 yrs	57.62 \pm 16.52	58.39 \pm 22.21
Economic status	(p = 0.001)	(p = 0.025)
Upper lower	60.36 \pm 18.29	63.64 \pm 18.98
Lower middle	61.72 \pm 17.65	63.64 \pm 17.02
Upper middle	71.57 \pm 16.31	69.76 \pm 18.93
Upper	81.3 \pm 14.75	80.1 \pm 14.75
Relation with patient	(p = 0.011)	(p = 0.080)
Father	67.2 \pm 17.56	65.8 \pm 17.1
Mother	58.44 \pm 19.73	59.2 \pm 21.8
Husband	74.37 \pm 15.14	73.2 \pm 15.09
Wife	58.58 \pm 19.3	62.56 \pm 17.2
Brother	68.8 \pm 18.09	68.6 \pm 22.83
Others	70.02 \pm 17.15	71.14 \pm 20.03
Antiepileptic therapy	(p = 0.328)	(p = 0.843)
Monotherapy	68.45 \pm 18.15	67.01 \pm 18.82
Polytherapy	61.71 \pm 17.77	63.99 \pm 19.02

and 65.79 \pm 18.9 respectively. As observed from Table 3, in comparison to the subjects, caregiver's QOL was significantly affected by gender (male has better scores than female) and socioeconomic status (higher class were better than lower class). On the other hand, age, duration of epilepsy, frequency of seizures and seizure free duration have statistically significant negative correlation with the QOL and SF-36 scores. Caregivers of the subjects having onset of epilepsy in 3rd decade and 4th decade had higher PCS and MCS score than 1st and 2nd decades with similar QOL scores. Polytherapy was found to be associated with poor QOL of caregivers though differences were not statistically significant. When the PCS and MCS scores of the subjects and the caregivers were compared, it was found that the subjects who had poor overall

QOL (QOL-31 score) significantly had poor scores for their caregivers too (PCS $p = 0.009$ and MCS $p = 0.001$). Moreover, factors such as being a female, age >30 yrs, seizure frequency <1/yr, seizure free duration >3 years, being wife of patients and polytherapy has shown different PCS and MCS scores.

3. Discussion

Epilepsy is a multifaceted chronic disorder which has diverse and complex effects on the overall well being including physical, psychological, social, occupational and financial aspects, and has a great negative impact on quality of life (QOL) of the subjects and their caregivers. There are limited studies aiming to find various possible factors affecting QOL of subjects suffering from epilepsy and their caregivers. In India, there are very few studies covering study population from different regions addressing QOL in people with epilepsy but these studies did not consider the QOL of their caregivers.^{13–18} However, couple of recent studies have reported the correlation of QOL of epilepsy subjects and their caregivers.^{19,20} Living with epilepsy would not only affect the patient but the caregivers too.

The study was aimed to evaluate various factors affecting the quality of life of 160 epilepsy subjects (age >18 years) and their caregivers of one year duration. Majority of subjects with epilepsy were male (57.5%), and 78.75% were in 2nd–3rd decades of their life. The mean age of subjects with epilepsy was 25.9 years which was slightly younger than that reported in older studies.^{11,21–27} This is possibly because of differences in study population with higher proportion of students and young house wives included in the study. Differences in the demographic profile such as being unmarried (56.25%), students, housewives or unemployed (63.75%), belong from upper middle (40%) or upper lower (38.12%) socioeconomic class, were reported due to the different socio-cultural values in India.

In 1998, Cramer²⁷ for the first time validated QOLIE-31 scale to evaluate QOL of epilepsy subjects. According to him, the total score of QOLIE-31 in epilepsy varies from 40 to 60 points. In the present study, the total QOLIE-31 score was 60.28 \pm 17.3, which differ from the scores reported by Guekht²⁸ (42.13 \pm 4.14), and Thomas⁷ (68.0 \pm 15.8). The results showed that the factors such as age ($p = 0.994$), gender ($p = 0.827$) and employment status ($p = 0.641$) had no influence on QOL of subjects, however QOL scores were better ($p = 0.186$) among unmarried subjects and significantly ($p = 0.002$) better in those who had achieved higher educational status. These results vary amongst different studies, for example Thomas,¹¹ Kumari,¹³ Sinha¹⁴ had reported that age, gender, marital status, educational status and occupational status had no bearing on QOL. However, Rajabi²³ observed better QOL in females, those with higher educational level, and employed subjects. The possible explanation for the scores obtained in our study would be due to better social and economical support among the subjects who were well educated, employed and secured.

In this study it was found that QOL was better in subjects where epilepsy occurred in the 3rd decade of their life. The scores were slightly lower in 4th decade but were better than

in 1st and 2nd decades. In affirmation with some studies,²⁹⁻³² most likely explanation to this is when epilepsy started at a young age, the frequent seizures, sleep disturbance and long antiepileptic medication significantly affect the social and cognitive development of child. In our study the duration of epilepsy was negatively correlated with QOL of epilepsy subjects; longer the duration-worse the QOLIE scores; however difference was not statistically significant. Most of the studies did not find any correlation of duration of epilepsy and QOL,^{11,12,22} however few others^{14,22,28} found a negative correlation. In contrast, Szaflarski³³ observed better QOL among subjects with longer duration of epilepsy, and attributed this to better adjustment of patient to social & psychological consequences of the disease and better refinement of coping skills. In the present study, a highly significant negative correlation was found between frequency of seizures and QOL of subjects with epilepsy, similar to observations made by other studies.^{11,13,14,21,23,26,28,33-37} The poor QOL among the subjects and their caregivers lead to more frequent hospital visits, frequent absence from school or work place, and increased expenses of medications.

Among the study population, 60% of the subjects were on monotherapy. The mean total QOLIE 31 score was significantly better among subjects on monotherapy than on polytherapy ($p < 0.05$). The probable explanation of this finding is that subjects on monotherapy had experienced lesser side effect than the cumulative side effect of two or more antiepileptic drug therapy and subjects on polytherapy were likely to have uncontrolled epilepsy. Some previous studies^{11,14,33} reported in favour whereas few studies did not find any correlation between QOL and number of AEDs used.^{26,27} The common AEDs prescribed in our study were sodium valproate followed by phenytoin and carbamazepine, though we found no correlation with QOL of subjects with epilepsy with type of AEDs used, similar to observation made by Thomas et al¹¹

A notable result of this study was that the most common seizure type was GTCS in 64.37% cases (82 GTCS only and 21 GTCS with myoclonus). This finding was similar to some of the previous studies (Ohaeri²²: 100%; Rajabi²⁸: 67%, Mrabet³³: 52.7%, Baker^{21,25}: 68%), while partial seizures was common in few other studies (Thomas¹¹: 58%; Guekht²⁸: 88.4%). The predominance of GTCS in our data is probably due to the unnoticed partial onset of seizures among both family members and treating physicians. There were no differences in the QOL of subjects with GTCS and partial seizures, (mean QOLIE 31 score 60.12 and 60.24 respectively). However subjects with JME had lower QOLIE 31 scores (58.15). Higher frequency of seizures (50% had >1 episode/month) in subjects with JME is possibly the reason for lower QOL in our study. Time interval between the last seizure is an important variable affecting QOL of subjects with epilepsy. We observed that longer interval since the last seizure was associated with significantly better QOL of subjects with epilepsy similar to previous studies.^{14,23,26,33}

When the caregivers were assessed for the QOL by the SF 36 scale, it was interestingly found that there was a highly significant correlation between QOL of subjects and their caregivers ($p < 0.01$). Caregivers of subjects with poor QOL scores on QOLIE 31 had poor scores on SF 36 scale (PCS $p = 0.009$ and MCS $p = 0.001$). Most of caregivers were parents (58.12%) and were in 5th-6th decades (59.37%) with a mean age of 41.62 years, corresponding to fact that majority of our epilepsy subjects were unmarried (56.25%), and students (33.7%). For the unmarried subjects, parents particularly fathers more than mothers were playing the role of caregivers in contrast to older studies^{22,38,39} where mothers were more common. For female married subjects either spouse, in-laws or children were the caregivers. The possible reason is that in India, males are the breadwinner in the family and thus more frequently accompany the subjects. The finding that female caregivers whether mothers or wives had poor QOL (PCS and MCS scores) matched

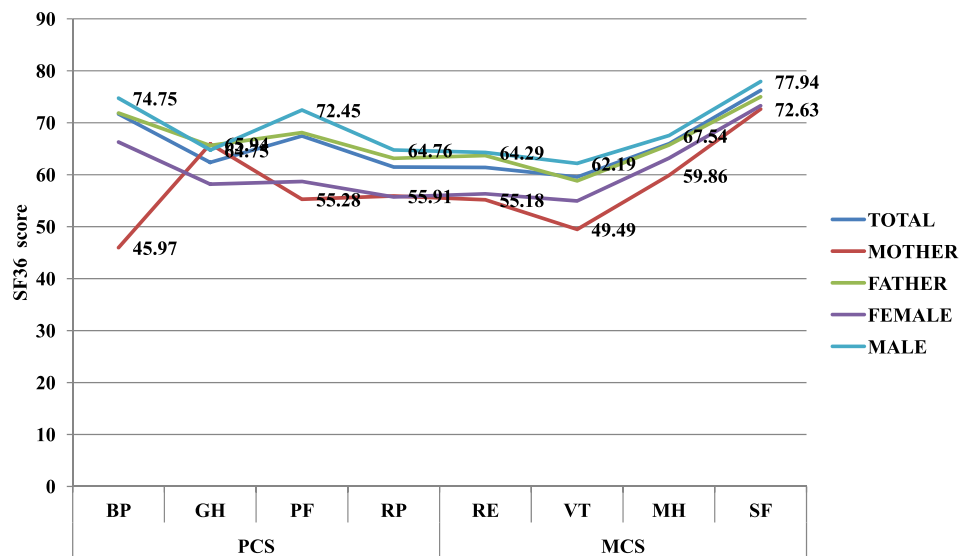


Fig. 2 – Quality of life of caregivers as measured by different components of SF 36 score. It was observed that mother's scores were significantly lesser than total care givers scores followed by females. BP: bodily pain, GH: general health, PF: physical functioning, RP: role physical, RE: Role Emotional, VT: Vitality, MH: Mental Health, SF: Social Functioning, PCS: Physical Component Summary, and MCS: Mental Component.

with the findings previously reported studies.^{22,38,39} The low scores in female and elderly caregivers hints to the fact that females especially mothers and wives were more emotionally connected to the subjects, thus were more affected (Fig. 2).

As similar with the QOL scores of the subjects, their caregivers also got affected by the factors such as socioeconomic factor with significantly positive correlation and longer duration of the disease and high seizure frequency with negative correlation. Several studies in children found that the longer duration of epilepsy and higher seizure frequency were associated with poor QOL in parents,^{40–44} however studies in adults^{22,38} did not found any correlation. AC Westphal-Guitti³⁸ did not find any significant differences in QOL among subjects with temporal lobe epilepsy (TLE) and juvenile myoclonic epilepsy (JME) but they were burdened to a similar degree. Factors such as age of onset of epilepsy in subjects, polytherapy and decreased interval since last episode of seizure had non-significant negative correlation with the QOL of caregivers. Therefore, better seizure control in subjects leads to less hospital visits, more time for socialization and other productive activity directly leading to better quality of life of caregivers.

As this was a cross sectional study, subjects and caregivers were examined and interviewed only once, thereby information given by them may have been inadequate. There was no further follow-up after QOL assessment, and this could be considered as a limitation of this study. Another important limiting factor in this study was strict definition and inclusion criteria for caregivers, that may have led to underestimation of proportion of females as caregivers. Longitudinal study with follow-up is advisable for future studies. Epilepsy has a serious negative impact on the QOL in both subjects and their caregiver which is revealed by the poor QOL scores. Optimising the drug therapy with psychological counselling for the vulnerable subjects and caregivers could be a move towards the personalized medication concept and improving the QOL.

4. Conclusions

This study corroborates the findings of the previous studies that the key to improving quality of life of people with epilepsy are good control of seizure and reducing side effects (by minimising antiepileptic drugs) along with holistic care of epilepsy. The care givers QOL is also proportional to the subject's QOL and it has an adverse outcome when the care giver is female (mother or wife), elderly, of low socioeconomic status, and related with subject of poor seizure control.

Conflicts of interest

All authors have none to declare.

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