



## QUALITY OF LIFE IN EPILEPSY PATIENTS

## Medicine

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## ABSTRACT

QOL issues are most relevant in chronic disorders as epilepsy. In epilepsy patients seizures maybe infrequent and brief, while social, psychological sequels and adverse medications effects are persistent. Thus this work was designed to study the impact of epilepsy and anti-epileptic drugs (AEDs) on the overall quality of life aspects of adult Saudi epileptic patients hopping to improve the management of epilepsy. This was cross sectional study done on 200 adult Saudi epileptic patients. It was done in neurology outpatients clinics in King Abdulaziz specialist hospital and King Faisal hospital. The data was gained from (QOLIE-31 version 0.1) questionnaires. Data were analyzed using SPSS by (t) test. Our results showed that 44 % of patients had bad to fair QOL (5% and 39% respectively). And that the males recorded higher score on all itmes of QOLIE-31 scale than females. Also (46%) were non-compliant to treatment and consequently they had significantly higher seizure frequency and shorter seizure free period than the compliant group. therefore compliant group had a better QOL. we also found patients on monotherapy have a better quality of life. Our results revealed that the earlier the onset of seizures, the worse the overall QOL. And the longer the duration of illness, the more the worries towards the impact of seizures on the cognitive function, the less the ability to adopt to social functions, and the worse the general QOL.

## KEYWORDS

## INTRODUCTION

Epilepsy is both a medical diagnosis, a social label (Jacoby et al)<sup>1</sup> and is a significant public health problem (Nagarathnam M. et al)<sup>2</sup>. Epilepsy is a brain disorder characterized by an enduring predisposition to epileptic seizures and leads to neurobiological and social consequences (Fisher RS et al)<sup>3</sup>. Unpredictable nature and course of epilepsy, stigma (Baker)<sup>4</sup>, 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 problems- (Poochikian-Sarkissianet S al, Stavem K et al, and Basu S et al)<sup>5,6,7</sup>, 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 (The WHOQOL Group)<sup>8</sup>.

Quality of life (QOL) issues are most relevant in chronic disorders such as epilepsy, in which mental and social problems extend well outside the usual range of symptoms of disease (Cramer, 1994)<sup>9</sup>.

QOL questionnaire assesses multiple daily functions and these functions are dependent on the cultural, ethnic and economic differences (PhabphalK, et al)<sup>10</sup>. Health Related Quality Of Life (HRQOL) refers to the way in which individuals function, and to their perceived well being in physical, mental, and social domains of life (Devinsky et al)<sup>11</sup>.

Epilepsy is the paradigm of a disorder in which QOL issues assume paramount importance. Seizures may be infrequent and brief, while the social and psychosocial sequelae of seizures and epilepsy and the adverse medication effects are persistent. Several antiepileptic drugs (AEDs) may have similar efficacy in term of seizure control, yet may have differential impact on HRQOL (Baker et al)<sup>12</sup>.

Difficulties in patients with epilepsy may be attributed to a number of causes. Firstly, the disease process itself and any resultant brain damage or dysfunction. Secondly, treatment with AEDs and their side effects as tiredness, double vision, cognitive deficits or the sequelae of surgery may affect the patient's QOL greater than the occurrence of seizures itself. Thirdly, socio-demographic variables, including age, sex and race may also play a role, (McGuire)<sup>13</sup>.

The management of epilepsy encompasses a number of actions that go beyond seizure control without adverse treatment effects. These include psychological and social interventions to help affected individuals to live a normal life and minimize the effects of the disease and its treatment on the various aspects of daily living (Carlo Cianchetti et al)<sup>14</sup>.

In children and adolescents, an impact of epilepsy on the QOL of the entire family is expected. The assessment of the quality of life (QOL) is relevant for a comprehensive treatment of patients with epilepsy (Haneef Z et al)<sup>15</sup>.

Poorer QOL was observed in PWE than those with other chronic illness and without pilepsy (Santhose J et al)<sup>16</sup>. It has been also observed that betterment in clinical parameters not lead to the improvement of social functioning and QOL (MathiakKA et al)<sup>17</sup>. 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 (Ronen GM et al)<sup>18</sup>.

QOL showed to vary across the world depending on the cultural, economic and community milieu (Tran DS et al)<sup>19</sup>. 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 to initiate interventions for the betterment of QOL (Baka et al)<sup>20</sup>.

(Beran, R G)<sup>21</sup>, pointed out that “The purpose of treating epilepsy is not necessarily that of seizure eradication but rather the maximal improvement of QOL for the patient”.

Thus this work was designed to study the impact of epilepsy and anti-epileptic drugs (AEDs) on the overall quality of life aspects of adult Saudi epileptic patients hoping to improve the management of epilepsy.

## PATIENTS and METHODS

### Patients:

This study was implemented in the neurology outpatient clinic in King Abdulaziz specialist hospital and King Faisal hospital.

200 adult Saudi epileptic patients (116 males, 84 females) with age ranged from 18-54 years were included in the study. The patients were informed that their participation in the study is voluntarily and they were randomly selected. In addition the name is not needed and the answers on the questionnaire that used to collect the data are top secret. Consent was obtained for all the participants

### Exclusion criteria:

- Patients under 18 years (to exclude children and adolescents, as they required a special questionnaires for estimation of their QOL).
- Patients who have concurrent active medical or psychiatric illness that cause current symptoms and require treatment.
- Patients on medication that could affect the central nervous system (CNS) (other than the AEDs).
- Patients who have a change in their antiepileptic drug < 4 weeks before the interview.
- Patients with intractable epilepsy (i.e. failure of medical treatment for at least 2 years to ensure that all the major AEDs have been pushed to their therapeutic limits).

### Methodes:

All the studied patients were subjected to full medical ,neurological and conventional EEG study.

Assessment of quality of life using: Quality of Life in Epilepsy Inventory-31 Scale (QOLIE-31 version 0.1).The Quality of Life in Epilepsy Inventory (QOLIE-31) contains seven multi-item scales that tap the following health concepts : emotional well-being ,social functioning ,energy/ fatigue , cognitive functioning , seizure worry , medication effects , and overall quality of life, yielding a composite score from 0 to 100 [1]. A higher score indicates a higher self-reported QOLIE.

Questionnaire was translated into Arabic and underwent a revision in order to ensure compatibility with the original one .The questionnaire was given to the patient and after a short explanation, it was filled out and collected on the spot. The distribution and collection of the questionnaires was done by the research team. Data were analyzed using SPSS by (t) test.

## RESULTS

Most of our studied cases (90%) had primary generalized seizures and 10% had partial seizures (6% had simple partial seizures and 4% had simple partial seizures with secondary generalization).

**Table (1):** represents age and some clinical data of the studied epileptic patients and the sex differences.

Seizure frequency showed wide variation ranging from 1-60 seizures/year. Thirty two patients were seizure free for more than one year but at least had a seizure during the past 12-24 months prior to the study. The mean seizure free period preceding the study onset was 17.7 weeks.

No significant sex difference could be detected in any of the studied items.

Applying the QOLIE-31 questionnaire as a measurement for different aspects of QOL in patients with epilepsy showed that 44% of our studied epileptic patients had bad to fair quality of life (5% & 39% respectively). On the other hand 43% had good QOL and 13% had very good QOL, Fig. (1).

Males recorded generally higher score on all times of QOLIE-31 scale than females, but the difference was statistically significant only as

regard seizure worry, emotional wellbeing, and medication effect subscales, table (2).

Most of our studied cases (81%) were on monotherapy and only (19%) were on polytherapy.

Patients on polytherapy recorded higher seizure frequency (10.9 ± 13.9 seizure/year for monotherapy versus 14.7 ± 13.1 seizure/ year for polytherapy) and shorter seizure free period (18.5 ± 23.9 weeks for monotherapy versus 14.3 ± 23.9 weeks for polytherapy) before the study onset than those on monotherapy group but the difference was statistically insignificant.

Patients on monotherapy recorded generally higher scores on the total scale and various subscales of the QOLIE-31 than patients on polytherapy, but the difference was statistically insignificant.

Nearly half of our studied epileptic patients (46%) were non-compliant to treatment.

Compliant patients had significantly lower seizure frequency (8.7 ± 11.1 seizure/ year for compliant versus 14.8 ± 15.8 for non compliant) and significantly longer seizure free period (23.2 ± 25.9 weeks for compliant versus 11.2 ± 19.2 weeks for non compliant patients) than non-compliant patients.

Epileptic patients who are compliant to antiepileptic medication had generally higher scores on the total and all subitems of the QOLIE-31 scale than non-compliant patients, but the difference was statistically significant only for total score, worries towards the effect of epilepsy on their cognitive functions, and their emotional wellbeing (Table 3).

An obvious linear correlation was detected between seizure severity and the total as well as various subitems of the QOLIE-31 scale, where well controlled epileptic patients (seizure free and mild seizure severity) have highly significant better scores on the total and various items of the QOLIE-31 scale than the uncontrolled epileptic patients (Moderate and severe seizure severity) expect as regard the medication effect sub-scale, (Figure 2).

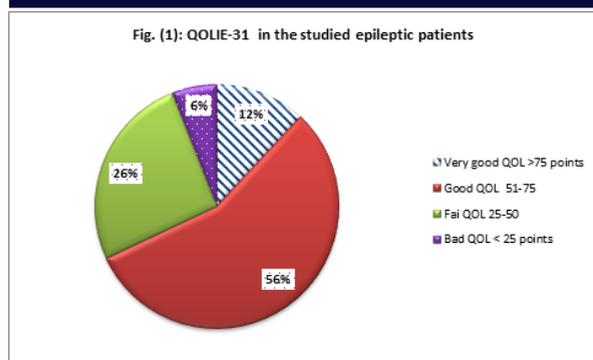
Correlation studies (r) between the age of seizure onset and QOLIE-31 scales shows significant direct correlation (r = 0.217, P = 0.030) between the age of seizure onset and the overall QOL subscale indicating impaired overall QOL in those with early onset of epilepsy.

Correlation between the duration of the disease and QOLIE-31, shows negative significant correlation between the duration of epilepsy and each of the following: cognitive function (r = -0.23, P = 0.024), social functioning (r = -0.25, P = 0.013), and total score of the QOLIE-31 (r = -0.23, P = 0.024). This indicates more worries toward the impact of epilepsy on cognitive function, and social function and bad QOL among those with longer duration of illness.

Regarding the control of seizures, in terms of the period of freedom of seizures in weeks since the last fit, it was positively, significantly (P < 0.001) correlated to the total score of QOLIE-31 and all sub-items (except for the medication effect) of the scale. These findings indicate that the longer the seizure free period, the higher the scores and the better the QOL.

**Table (1): Age and clinical data of studied epileptic patients**

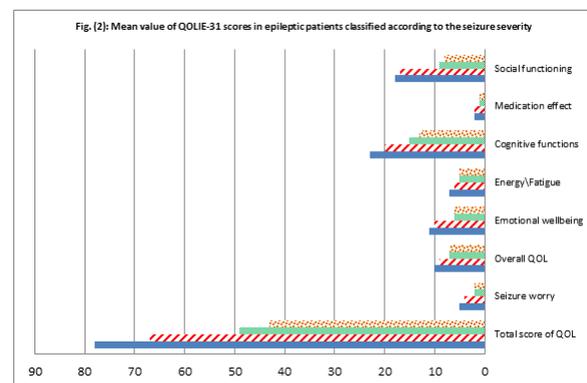
	Total N.=200		Males N. = 116	Females N. = 84	P- value
	Range	Mean ± SD	Mean ± SD	Mean ± SD	
Age (years)	18-54	27 ± 9.1	27.3 ± 9.3	26.5 ± 9	0.683
Age of onset (years)	3-47	18.1 ± 8	18.1 ± 8	18.2 ± 8.1	0.917
Duration of illness (year)	1-37	8.9 ± 6.6	9.2 ± 6.6	8.4 ± 6.7	0.524
Duration of therapy (years)	1-37	7.9 ± 6.2	8.2 ± 6	7.5 ± 6.6	0.620
Seizure frequency (year)	1-60	11.5 ± 13.7	12.4 ± 15.8	10.2 ± 10.3	0.441
Seizure free period (weeks)	1-76	17.7 ± 23.7	17.7 ± 25.6	17.7 ± 21.2	0.993



**Table (2): Mean of QOLE-31a scale for total number of patients and both sex**

QOLIE-31	Total N.=200		Males N. = 116	Females N. = 84	P-value
	Range	Mean ± SD	Mean ± SD	Mean ± SD	
Seizure worry	0-8	2.7 ± 2.44	3.4 ± 2.5	1.8 ± 2.1	0.001**
Overall QOL	1.4-12.6	8.2 ± 2.4	8.5 ± 2.5	7.8 ± 2.2	0.146
Emotional wellbeing	0.6-15	7.8 ± 3.5	8.6 ± 3.2	6.7 ± 3.8	0.007**
Energy/ fatigue	1.2-9.6	6 ± 1.8	6 ± 2.1	5.9 ± 1.5	0.812
Cognitive function	0.9-27	16.4 ± 6.6	16.6 ± 6.6	16.1 ± 6.6	0.703
Medication effect	0-3	1.6 ± 1	1.8 ± 1	1.3 ± 1.1	0.020*
Social functioning	0-21	11.3 ± 5.7	12 ± 5.7	10.3 ± 5.6	0.156
Total score of QOL	11.9-89.8	53.8 ± 17.6	56.8 ± 17.6	50 ± 17.4	0.061

N. = Number; \* P < 0.05; \*\* P < 0.01; a Quality of Life in Epilepsy Inventory-31



**Table (3): Age and clinical data of studied epileptic patients**

QOLIE-31	Compliant N. = 108	Non-Compliant N. = 92	P-value
	Mean ± SD	Mean ± SD	
Seizure worry	2.9 ± 2.6	2.4 ± 2.2	0.263
Overall QOL	8.5 ± 2.4	7.7 ± 2.3	0.088
Emotional wellbeing	8.5 ± 3.5	7 ± 3.4	0.042*
Energy/ fatigue	6.1 ± 1.9	5.8 ± 1.8	0.409
Cognitive function	17.6 ± 6.6	14.9 ± 6.3	0.040*
Medication effect	1.5 ± 1	1.7 ± 1.1	0.589
Social functioning	12.1 ± 5.7	10.4 ± 5.6	0.144
Total score of QOL	57.5 ± 17.6	49.8 ± 17.2	0.031*

a Quality of Life in Epilepsy-31 Scale; \* P < 0.5

**DISCUSSION**

Epilepsy is both a medical diagnosis and a social label. The possibility of recurrent seizure is a silent but ever-present component of daily life for most patients who carry the diagnosis of epilepsy (Jacoby et al)<sup>1</sup>.

Our results showed that 44 % of adult Saudi epileptic patients had bad to fair QOL as measured by the QOLIE-31 inventory (5% and 39% respectively).

Kochen<sup>22</sup>, using the same scale on 200 adult epileptic patients in Argentina, found that 60% scored bad to fair QOL, (2% and 58% respectively). Also, Emanuela-Bota<sup>23</sup> noticed that patients suffering from epilepsy tend to have a lower quality of life.

In this study, males recorded generally higher score on all items of QOLIE-31 scale than females, but the difference was statistically significant only as regard seizure worry, emotional wellbeing, and medication effect subscales. Other authors have reported that female population presenting a significantly lower QOLIE total score than the male population Shetty et al<sup>24</sup>. In a study conducted in Georgia, female patients had significantly lower scores in terms of the fear of developing new seizures (Djibuti M et al)<sup>25</sup>. Similar results were found in a study conducted by Buck, et al<sup>26</sup> showing low scores of energy/ fatigue and overall quality of life scores in women from 15 European countries. This was in agreement with Riberio et al.,<sup>27</sup> and Devinsky et al.,<sup>28</sup> who found that female adolescents had significantly lower HRQOL on the attitudes toward illness and health perceptions subscales, and tend to have poorer overall HRQOL than males, but the authors attributed this to the greater denial of illness by male adolescents.

Consistent with our findings, significant associations were reported between female gender and lower QOLIE-31 global and subdomain scores, including seizure worry (Alanis, et al)<sup>29</sup>. The girls showed more anxiety, less happiness and more negative attitude towards epilepsy (JUDIT LAM et al)<sup>30</sup>. Some authors attributed this gender difference in QOL in epilepsy to psychological factors, such as problems related to family and motherhood and concerns about reproductive difficulties associated with epilepsy and its treatment (Djibuti, M and Buck, D)<sup>25,26</sup>. On the other hand, Nagarathnam M et al<sup>2</sup> recorded no significant association between total QOL score and gender was observed and similar observations were drawn from earlier studies (Sinha A et al and Thomas SV et al Kinyanjui DWC et al)<sup>31,32,33</sup>.

The significantly better quality of life recorded among epileptic males than females may be explained by the fact that females are more shamed from the occurrence of seizure in public place, they are emotionally upset more than males, and they are more worried about the hereditary transmission of the disease of their newborns as well as, the possible side effects of the AEDs on their babies, as the majority of females are in the childbearing period.

Non-compliance with AEDs is a major factor in the recurrence of seizures among epileptic patients. Nearly half of our studied epileptic patients (46%) were non-compliant to treatment and consequently this noncompliant group had significantly higher seizure frequency and shorter seizure free period than the compliant group.

This non-compliance may be due to the misunderstanding of the need for medication and an attempt to deny the “difficulty” of having epilepsy. Also, Stanaway et al.<sup>34</sup> reported that 37% of the epileptic patients were not taking medication as prescribed and that 31% of seizures were estimated to occur was a result of failure to comply.

In our study, the compliant group of patients had a better QOL than the non-compliant group especially as regard the cognitive function, emotional well-being and the total score of the QOLIE-31 scale. This may be attributed to the lower seizure frequency and longer seizure-free period, and thus feeling a better control of the condition, in the compliant group than the non-compliant one.

Seizure frequency is a key factor that influences various domains of life. In this context we found a significant negative relationship between seizure severity (in terms of seizure frequency) and QOL. These findings are in agreement with earlier studies done by Arnston et al.,<sup>35</sup> and more other studies found a negative correlation of average statistical significance between the number of seizures and overall quality of life score, cognitive function and QOLIE-31 total score. Emanuela B et al<sup>36</sup> found a negative correlation of low statistical

significance between the number of seizures and the fear of new seizures, emotional state, energy/fatigue scores and the effects of medication. Other studies have reported that the high frequency of epileptic seizures has negatively influenced (high statistical significance) all QOLIE scales scores (Djibouti et al; Loring et al)<sup>25,37</sup>.

The frequency of epileptic seizures also influenced the total score, the fear of new seizures, emotional state, energy/fatigue scores in the study conducted by Piperidou et al<sup>38</sup>. Frequency of seizures per month was positively correlated with QOLE total scores and was highly statistically significant (Prem Singh)<sup>39</sup>.

Although most workers in the field of epilepsy recommended monotherapy over polytherapy in management of epilepsy, and although the mono-therapy group were better controlled (lower seizure frequency) than the polytherapy group. Also other studies in India concluded that various factors have been associated with low QOL with epilepsy, as use of two or more antiepileptic drugs, higher frequency of seizure and the long-time gap between onset of seizure and consultation (Nagarathnam M)<sup>2</sup>.

Epileptic patients on monotherapy have a better quality of life than those treated with more than one medication. The results of the study carried by JUDIT LAM<sup>30</sup> confirmed a significant differences between the patients on mono- and on bitherapy in three question-groups. A deviation was found in cognitive functions and indicated the adverse effects of the drugs, which appear to increase the more drugs are used. The more positive perception of the quality of life by the patients on monotherapy, the patients well controlled by monotherapy, with less adverse effects, have better cognitive functions and are socially more active and this explains their more positive perception of their 'social and role functioning' (Baker, et al and. Nagarathnam M)<sup>42</sup>.

Our results revealed that patients with early onset of seizures scored less, on the overall QOL scale which means that, the earlier the onset of seizures, the worst the overall QOL.

Also we found that patients with longer duration of illness scored less, on the total QOLIE-31 scale, cognitive function and social functioning sub-scales, ( $P < 0.05$ ), which means that, the longer the duration of illness, the more the worries towards the impact of seizures on the cognitive function, the less the ability to adopt to social functions, and the worse the general QOL. In parallel with the results of the current study, Szaflarski et al<sup>40</sup> and Prem Singh<sup>39</sup> found poor quality of life with increase duration of illness. Emanuela et al<sup>23</sup> found no significant correlations between age of onset of epilepsy and QOLIE scores. There was a negative correlation of low statistical significance between disease age and overall quality of life, energy/fatigue, cognitive function scores and QOLIE-31 total score. These data are similar to those from other studies showing that QOLIE total score decreases with the increasing duration of epilepsy. In some studies, duration of epilepsy was an independent predictor of the score related to the fear of new seizures (Shetty et al)<sup>34</sup>. However, Herodes et al<sup>41</sup> reported lower QOLIE total scores correlated with reduced length of disease and significant effects on energy and emotional state scores.

A highly significant correlation between the duration of seizure-free period and total score of the QOLIE-31 and most sub-items was observed among our epileptic patients. This is in agreement with Amer, et al<sup>42</sup> who found a positive correlation between the duration of seizure free period and both the total score of the QOLIE-31 scale and the seizure worry sub-scale. Contrarily Jacoby,<sup>1</sup> in a study of people with well controlled epilepsy (seizure free for at least 2 years) using a number of psychometric scales, found that the longer this period was, the more the patients were worried about their epilepsy. The differences between these studies could be related to differences in scales used to measure QOL, differences in the nature of the populations studied regarding their acceptance of their disease status, and their anticipation for the recurrence of seizures.

### Conclusion:

Epilepsy can affect multiple variables that impact patients' quality of life. The impact of epilepsy on quality of life can be substantial with far-reaching and life-long consequences. When assess the impact of epilepsy, patients and physicians should look beyond counting seizures. In addition, QOL measures should also be a part of the periodic follow-up of patients with epilepsy. Our study emphasize that complaint epileptics, monotherapy, low frequency of seizure and

short duration of illness are associated with higher quality of life in persons with epilepsy.

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