

Quality of life among epileptic patients in Qassim Region, KSA

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ABSTRACT

الأهداف: دراسة جودة الحياة لدى مرضى الصرع السعوديين والعوامل المؤثرة عليها في منطقة القصيم.

المنهجية: تم إجراء دراسة مسحية باستخدام معيار جودة الحياة لمرضى الصرع يحتوي على 31 سؤالاً في عيادة الأعصاب في مستشفى الملك فهد التخصصي ومستشفى بريدة المركزي ومستشفى الملك سعود في عنيزة في الفترة يونيو 2018م - مايو 2019م. تم استخدام اختبار ت للعينات المستقلة وتحليل التباين الأحادي لقياس المقارنة بين العوامل المؤثرة والمقياس الكلي لجودة الحياة واختبار معامل الارتباط سبيرمان للمقارنة بينها وبين المقاييس الفرعية. ثم تم استخدام نموذج الانحدار الخطي المتعدد لضبط العوامل المحيرة.

النتائج: متوسط درجات جودة الحياة 64.23 ± 17.8 وجدنا ارتباطاً بين الوظيفة ومقياس جودة الحياة الكلي ($p < 0.001$) وجميع المقاييس الفرعية (امتدت من -136 لمقياس الطاقة الى مقياس الأنشطة الاجتماعية -193) وبين عدد مضادات الصرع والمقياس الكلي والفرعية باستثناء مقياس قلق النوبة ومقياس الراحة النفسية ونوع الصرع ومقياس الراحة النفسية ($\rho = -0.159$) وقلق النوبة ($\rho = -0.226$) والوظيفة المعرفية ($\rho = -0.166$)، والمقياس الكلي ($p < 0.001$). لم يكن هناك أي ارتباط بين جودة الحياة والعوامل الأخرى.

الخاتمة: الوظيفة ونوع الصرع وعدد مضادات الصرع لها تأثير على جودة الحياة لدى مرضى الصرع السعوديين.

Objectives: To explore the influence of epilepsy on quality of life (QoL) among people with epilepsy in Saudi Arabia, and its association with sociodemographic and clinical characteristic aspects in the Qassim region.

Methods: A cross-sectional multi-centered study done in the Qassim region from June 2018 to May 2019. A self-administered questionnaire was provided to 216 participants who attended the neurology clinic. We used a validated Arabic version of the QoL in Epilepsy (QOLIE-31) to measure the QoL.

Results: The mean of the overall QOLIE-31 score was 64.23 ± 17.8 . we found that employment status had a significant influence on the overall score ($p < 0.001$) and all other QOL domains (ρ ranged from -0.136 for energy fatigue to -0.193 for social function) Patients with focal seizures were significantly higher in emotional wellbeing ($\rho = -0.159$), seizure worry ($\rho = -0.226$), cognitive function ($\rho = -0.166$) and overall score ($p = 0.010$) than patients with the generalized type. Monotherapy patients have higher scores in total ($p < 0.001$) and all subscales except seizure worry and emotional wellbeing than those on polytherapy.

Conclusion: Employment status, type of seizure, and AED number are the most important factors affecting Saudi patient's QoL.

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Many studies in multiple countries have tested quality of life (QoL) in epilepsy, and have highlighted areas of common concern. It has been shown that among Arabian people, epileptic patients are generally more susceptible to having higher levels of anxiety and depression.¹ In Kenya, researchers have compared QoL between persons with epilepsy (PWE) and healthy people who have the same environment, social relationship, and living circumstances. These authors found that low education level, unemployment rate, unskilled employment, and low income were higher in PWE compared to their non-epileptic

accompanying people.² Despite the high prevalence rate in Saudi Arabia (6.54 per 1000),³ there has been limited research about the impact of QoL in epileptic patients. To better identify the factors that influence Saudi epilepsy patients, here we explore the influence of epilepsy on QoL among Saudi epileptic patients.

Methods. A cross-sectional study was carried out in the Neurology Clinic at King Fahad Specialist Hospital, King Saud Hospital and Buraidah Central Hospital in Qassim from June 2018 to May 2019. Our inclusion criteria included: patients diagnosed with epilepsy by a specialist, and able to complete the questionnaire. Patients with progressive central nervous system (CNS) disease, acute or severe chronic CNS diseases, disturbance of consciousness, language dysfunction, history of psychiatric illness, history of drug abuse, and patients whose type of seizure was not specified were excluded. Our study consisted of 228 epileptic patients, and we excluded 12 patients who were diagnosed as structural epilepsy, but seizure type was not specified. We used the PubMed database to search for prior related studies using the keywords “quality of life” “epilepsy”, and “QOLIE-31”, filtering for studies published in the last 5 years.

A self-administered questionnaire included three main compartments: demographics (gender, age, marital status, educational level, employment status); clinical characteristics of the seizure [age of onset, duration of epilepsy, number of AEDs, and medical history of chronic diseases (e.g., diabetes, hypertension, asthma, and others)]; and the type of seizure.

We used a validated Arabic version of the QOLIE-31 (developed by 1993, Rand, translated by Alaa Eldin Elsharkawy, 2015). It measures QoL in epileptic patients through 7 subscales: 5 items for seizure worry testing, 5 items for emotional role functioning, 4 items for energy/fatigue, 6 items for cognitive functioning, 3 items for medication effects, 5 items for social role functioning, 2 items for overall QoL, and one item for overall health. Each scale was converted into a 0–100 scale in which the value is distributed evenly for each question (the lower the score, the greater the disability).

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Official approval from the Regional Ethical Committee (20180601, June 3, 2018) and responsible authorities was obtained. The objectives of our study were clarified to the participants by stressing the importance of the data and its confidentiality. There was no obligation to participate. Informed consent was provided to each participant before starting the questionnaire. Data were coded in the Excel sheet database using a unique identification number. The data information was saved in a password-protected laptop belonging to the Principal Investigator and CI, and all data were kept confidential. Only the research team had access to the database for analysis purposes. All aspects of the study were in accordance with the Helsinki declaration.

The Statistical Package of Social Science (SPSS 23 for mac, IBM, Chicago, United States evaluation version)

Table 1 - Participant demographics.

Description	n=216 (%)
Age mean (SD)	30 (± 12)
Gender n (%)	
Female	115(53.2)
Male	101(46.8)
Marital status n (%)	
Married	79(36.6)
Single	129(59.7)
Divorced	5(2.3)
Widowed	3(1.4)
Employment status n (%)	
Employed	66(30.6)
Unemployed	150(69.4)
Educational level n (%)	
Primary school	35(16.2)
Secondary school	25(11.6)
High school	75(34.7)
University	81(37.5)
seizure type n (%)	
Generalized	176(81.5)
Focal	30(13.9)
Focal to bilateral	2(0.9)
AED type n (%)	
Polytherapy	94(43.5)
Monotherapy	115(53.2)
Not on medication	6(2.8)
Years since diagnosis n (%)	
<5 years	66 (30.6)
5–10 years	62(28.7)
>10 years	85(39.4)

SD - standard deviation, n - sample size

software was used for the analysis. Categorical variables were presented as frequencies (n) and proportions (%). T-tests and one-way analysis of variance (ANOVA) were used to compare the overall QOLIE-31 scores between the groups, and the Spearman correlation coefficient was used to measure its relation with the different subscales. We used a multiple linear regression model to control for confounders. Internal consistency reliability assessment of the Arabic version of the QOLIE-31 scale was assessed by Cronbach's alpha. The final overall QOLIE-31 score was 0.885

Results. The mean (\pm standard deviation) age of the participants was 30 \pm 12 years. Table 1 shows the demographic and clinical characteristics of the participants. The overall mean QOLIE-31 score was 64.23 \pm 17.8 (maximum possible score=100). The highest domain score was for social function, while the seizure worry was the lowest (Table 2).

Table 3 shows the association between overall QOLIE-31 score and demographics and clinical characteristics. Employment status, the number of AED, and seizure type had a significant influence on QoL. While gender, marital status, age, and years since diagnosis did not differ significantly.

Table 4 demonstrates the Correlation between patients' personal and clinical data with different QOL subscales. To adjusted for the confounder effects on the relation between QOL and patients' personal and clinical data, a multiple linear regression model was conducted. It revealed that among all included factors, only 3 factors had an adjusted effect on patients' QOL keeping all other factors constant. First was generalized seizures, as patients with generalized seizures showed a lower QOL score (by 7 points) than others after adjusting for all other factors (B=-7.0). Polytherapy was the second, as patients who receive multiple drugs recorded a lower adjusted QOL score (by about 10 points), keeping all other factors constant (B=9.4). Employment status was the third, as unemployed patients had a lower QOL (by about 6 points), keeping all other factors constant (B=6) (Table 5).

Discussion. In this study, we mainly assessed the QoL among PWE and its association with seizure type. The overall mean QOLIE-31 score of our sample (64.23 \pm 17.8) is consistent with the global mean QOLIE-31 score: 59.8 \pm 8.0.⁴ The highest domain score was for social function, and seizure worry was the lowest domain scores, which implies that seizure type is an important factor affecting QoL (Table 2). Also, Gaus et

al. concluded that medication effects and seizure worry subscales were the most predictive elements for anxiety and depression.⁵

Consistent with the previous literature, employment status in our sample was significantly associated with the overall score and all the 7 subscale scores.^{6,7,8}

Table 2 - Mean QOLIE-31 subscale scores.

Subscales	Mean	SD
Energy/ fatigue	59.93	20.91
Emotional wellbeing	62.18	21.71
Seizure worry	53.53	26.22
Overall health	72.29	21.37
Cognitive	65.56	25.61
Medication effect	63.02	30.69
Social function	73.08	25.20

SD - standard deviation, QOLIE-31 - quality of life in epilepsy

Table 3 - Relationships between overall QOLIE-31 score and demographics and clinical characteristics.

Characteristic	Mean	F, t (df)	P-value
*Gender			
Male	64.73	.385 (214)	.700
Female	63.79		
*Employment status			
Employed	71.10	3.874(214)	< 0.001***
Unemployed	61.20		
**Age:			
\leq 20	64.17	.221(212)	.882
21-44	63.87		
45-59	64.96		
\geq 60	69.02		
**Marital status			
Single	63.79	1.699(212)	0.168
Married	65.73		
Divorced	64.60		
Widow	42.60		
**Educational level			
Primary school	57.43	2.98(212)	0.032***
Secondary school	60.54		
High school	65.44		
University	67.17		
**Number of AED			
Polytherapy	58.62	9.289(212)	< 0.001***
Monotherapy	68.80		
Not on medication	68.48		
**seizure type			
Generalized	63.14	4.389(205)	0.014***
Focal	72.11		
Focal to bilateral	46.29		
Years since diagnosis			
<5 years	67.63	1.812(212)	.166
5-10 years	63.89		
>10 years	62.15		

*independent t test - t(df), **one-way ANOVA test F(df), *** significant association at $p=0.05$, df - degree of freedom, QOLIE-31 - quality of life in epilepsy, AED - antiepileptic drugs

Table 4 - Correlation analysis for relation between patients personal and clinical data with different QOL subscales.

characteristic	Emotional wellbeing subscale	Seizure worry subscale	Overall health subscale	energyfatigue subscale	Cognitive subscale	Medication effect subscale	Social function subscale
<i>Age in years</i>							
rho	-.031	.103	-.014	-.074	.064	-.038	.057
P-value	.648	.131	.834	.280	.346	.582	.402
<i>Years since diagnosis</i>							
rho	-.036	-.016	-.142	-.040	-.039	-.064	-.196
P-value	.602	.821	.039*	.565	.568	.354	.004**
<i>Gender</i>							
rho	-.050	-.082	.063	-.048	-.086	.053	.077
P-value	.466	.228	.357	.483	.208	.438	.261
<i>Marital Status</i>							
rho	-.059	.025	.045	-.072	.036	.019	.060
P-value	.392	.720	.506	.295	.595	.778	.380
<i>Education level</i>							
rho	.144	.072	.279	.127	.130	-.077	.256
P-value	.035*	.294	<.001**	.063	.057	.260	<.001**
<i>Seizure type</i>							
rho	.159	.226	-.056	.068	.166	.096	.072
P-value	.022*	.001**	.418	.326	.016*	.167	.302
<i>Employment Status</i>							
rho	-.186	-.182	-.185	-.136	-.175	-.141	-.193
P-value	.006**	.007**	.006**	.046*	.010*	.039*	.004**
<i>AED number</i>							
rho	-.132	-.129	-.216	-.185	-.257	-.274	-.228
P-value	.053	.059	.001**	.006**	<.001**	<.001**	.001**

rho - Spearman correlation coefficient, ** $p < 0.001$, * $p < 0.05$, QOL - quality of life

Table 5 - Multiple linear regression model to assess adjusted effect of epilepsy patients' factors on their QOL

Factors	Unstandardized Coefficients		Standardized Coefficients	t	P-value
	B	SE	Beta		
(Constant)	86.8	8.5		10.2	.001
Seizure type	-7.0	3.0	-0.15	-2.4	.019*
AED	-9.4	2.4	-0.26	-4.0	.001**
Employment	-6.0	2.9	-0.15	-2.1	.041*
Age in years	0.1	0.1	0.06	0.8	.421
Gender	0.7	2.4	0.02	0.3	.754
Marital Status	0.8	1.2	0.04	0.7	.505
Education level	1.7	1.2	0.10	1.4	.153
Model R ² ; significance			0.31; F=5.5; P <0.01		

B - regression coefficient, SE - Standard error, AED - antiepileptic medication, ** $p < 0.001$, * $p < 0.05$

Educated PWE are more likely to have a better understanding of their disease, seizure-triggering factors, and seizure management, which contribute to adherence to medications. Hence, this group will have better QoL. Unexpectedly, we found that the educational level was no longer significant after adjustment for confounders,

which is also in line with the literature.⁹ On the other hand, other studies have found an association.^{10,11}

Gender, age, and marital status were not associated with the overall score or any of the seven subscale scores. Although this is consistent with a study carried out in Japan,⁸ such an association was detected among

an Australian sample,⁶ where they found that PWE older than 65 years have higher overall scores. While in China, Wang et al. used the same measuring scale and found that married PWE had a better QoL than unmarried PWE in young and middle-aged patients.¹² Pimpalkhute et al. reported that the overall score means did not differ significantly within groups for sociodemographic factors among Indian patients.¹³

Also, a systematic review found that age, gender, and marital status were not associated with health-related QoL (HRQoL), and the relationship between educational level and employment status remains controversial.¹⁴ Different beliefs and socioeconomic factors among countries might account for these differing results.

In our sample, PWE on monotherapy has higher scores in total and all subscales, except seizure worry and emotional wellbeing, than those on polytherapy. This is in line with the findings of other studies,¹⁵ which might be because those receiving monotherapy are more adherent than those receiving multiple AED. Another possible justification is that people who are receiving polytherapy have difficulty controlling their seizures.

Considering the type of seizures, participants with generalized type were found to have significantly lower scores in emotional wellbeing, seizure worry, cognitive function, and overall QoL than participants with focal type, which is similar to findings in other studies.¹⁶ However, an Iranian study did not find such an association.¹⁷

In comparison to other Arabic studies, marital status and gender do not have an impact on QoL among Tunisian and Iraqi patients, which is in line with our findings. Employment status was not significantly affected by Iraqi and Tunisian samples. Seizure type has no significant impact on Tunisian PWE. In Iraq, age and educational level significantly affect QOL.¹⁸⁻²⁰ All of these cited studies used the Short Form (SF-36) health survey. Another study conducted in the United Arab Emirates used the World Health Organization Quality of Life abbreviated scale (WHOQOL-BREF), and found no significant differences between QoL and sociodemographic and clinical characteristics.²¹ None of these studies have used the same scale as we have, making it difficult to compare findings.

Although our sample was collected from more than one center in the Qassim region, the size is not sufficient to generalize our results. Other limitations were that we did not measure the seizure frequency; many studies have found that higher seizure frequencies have a negative influence on QoL. Further research is also needed to measure AED level and seizure frequency

to assess whether medication adherence or the difficulty in controlling the seizure can also cause a negative impact among Saudi patients.

In conclusion, as in many countries, epilepsy negatively impacts the QoL of Saudi patients. Moreover, employment status, type of seizure, and AED number were the most important factors considered. Current study results have encouraged the application of behavioral intervention in practice. Therapists should consider other factors, as well as QOLIE31 and its domains, thereby adapting therapy to the patient's specific needs.

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