Quality Of Life For Patients With Epilepsy In Baghdad City.

نوعية الحياة لمرضى الصرع في مدينة بغداد.

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الخلاصة

الهدف : لتعيين نوعية الحياة لمرضى الصرع ولايجاد العلاقة مابين الصفات الديمو غرافية والحالة الاقتصادية الاجتماعية، والمعلومات السريريه ونوعية الحياة.

المنهجية: أجريت دراسة وصفية في العيادات الاستشارية لطب الجملة العصبية في مستشفيات بغداد (مستشفى بغداد التعليمي، مستشفى اليرموك التعليمي، مستشفى جراحة الجملة العصبية ومستشفى العلوم العصبية) للفترة من 15 كانون الاول 2012 ولغاية 30 تموز 2013. اختيرت عينة غير احتمالية "غرضية" من (100) مريض مشخصين بالصرع والذين يرتادون العيادات الاستشارية في المستشفيات المذكورة اعلاه المعلومات من خلال استخدام استبانة مصممة و مكونة من ثلاثة اجزاء، الجزء الاول شمل صفحة البيانات الديمو غرافية و يحتوي (8) فقرات و الجزء الثاني شمل المعلومات السريرية الخاصة بمرضى الصرع و المتكون من (6) فقرات، والجزء الثالث الديمو غرافية و يحتوي (8) فقرات و الحياة للمرضى الصرع-13). حددت ثباتية استمارة الاستبانة من ثلاثة اجزاء، الجزء الاول شمل صفحة البيانات الديمو غرافية و يحتوي (8) فقرات و الجزء الثاني شمل المعلومات السريرية الخاصة بمرضى الصرع و المتكون من (6) فقرات، والجزء الثالث المسح الخاص بنوعية الحياة (نوعية الحياة للمرضى الصرع-13). حددت ثباتية استمارة الاستبانة من خلال اجراء الدراسة المصغرة و حددت مصداقيتها من خلال مجموعة من الخبراء (19) خبير من وصف وتحليل البيانات اجراءات التحليل الاحصائي الوصفي والذي تضمن التكرارات والنسب المئوية والوسط الحسابي والانحراف المعياري والاحصاء الاستدلال الذي معامل التوافق.

المعياري والاحصاء الاستدلالي الذي شمل اختبار معامل التوافق. المعياري والاحصاء الاستدلالي الذي شمل اختبار معامل التوافق. بين (المستوى التعليمي ونوعية الحياة=0.010 والحالة الاقتصادية الاجتماعيةونوعية الحياة=0.000، مدة الاصابةونوعية الحياة=0.020 وكذلك تكرار التعرض للنوبة ونوعية الحياة= 0.000) ونوعية الحياة، وعدم وجود علاقة معنوية ما بين (الجنس، الحالة الزوجية، الحالة المهنية، نوع النوبة وعدد الادوية المستخدمة لعلاج الصرع) ونوعية الحياة بشكل عام.

النوبة وعدد الادوية المستخدمة لعلاج الصرع) ونوعية الحياة بشكل عام. الاستنتاجات: استنتجت الدراسة ان نوعية الحياة لمرضى الصرع قد سجلت مستوى متوسط، كما ان اغلبية المرضى كانوا من الشباب ذوي مستوى تعليمي متدني ومستوى اقتصادي متوسط وكذلك اكثر من نصف العينة هم من غير المتزوجين وربات البيوت وكذلك لديهم زيادة بتكرار عدد النوبات.

التوصيات: أوصت الدراسة بضرورة زيادة الوعي لدى المرضى بأهم التحديات الناتجة من الصرع، عن طريق تحسين نظم الدعم الاجتماعي للفرد من خلال العلاج الجماعي والعلاج الاسري. كذلك استخدام برامج التعليم والتدريب لتحسين خبرات الممرضين والممرضات(عن طريق اعطاء محاضرات بصورة دورية للكادر التمريضي) من اجل لعب دور اكبر في العناية بالمرضى. العمل على دعم الوعي العام باتجاه مرضى الصرع وذلك بانشاء كتيب مخصص لهذا الغرض وكذلك استخدام البرامج التلفزيونية. كما ان الباحث يقترح القيام بدراسة جديدة لغرض تقييم معارف الممرضات حول كيفية التعامل مع مرضى الصرع.

ABSTRACT

Objectives: To determine quality of life for patients with epilepsy in Baghdad city and to find out relationship between demographic characteristics (age, gender, educational level, marital status and socioeconomic status) and quality of life, and to find out relationship between clinical data and quality of life.

Methodology: A descriptive study is carried out in neurological outpatient clinics in Baghdad Hospitals (Baghdad Teaching Hospital, AL Yarmouk Teaching Hospital, Neurosurgical Hospital and Neuroscience Hospital) for period from Dec. 15th 2012, to 30 July 2013. To achieve the objectives of the study, a non probability "purposive" sample of 100 patients that diagnosed as epileptic by neurologists, who were visit the neurological outpatient clinics of the above listed hospitals were selected according to the criteria of the study sample. Data were collected by using questionnaire which has three parts, first part consists of socio-demographic data (8) items, second part consists of special clinical data for patients with epilepsy (6) items, and the third part special survey for quality of life (quality of life in epilepsy-31).

Reliability of the questionnaire was determined by the use of pilot study, and its validity determined by panel of experts (19) expert. Data was gathered by interview technique using the questionnaire format and data was analyzed by application of descriptive statistics includes frequencies, percentage, mean of scores and standard deviation and inferential statistical methods.

Results: The findings of the study indicated the quality of life for patients with epilepsy in Baghdad city were in moderate level, also the results showed significant relationship between (educational level and quality of life= 0.010, socioeconomic status and quality of life= 0.000, duration of disease and quality of life=0.020 frequency of seizure) and quality of life, and non significant relationship between (gender=0.559, marital status=0.180, occupational status=0.099, residence0.329, type of seizure=0.783 and number of antiepileptic drugs=0.148) and quality of life.

Conclusions: The study concluded the quality of life for patients with epilepsy were in moderate level=55.9. The majority of patients with epilepsy was young with low educational level and had moderate socio-economic status. More than half of the study sample is single and housewives. More than half of the patients with epilepsy had poor seizure control.

Recommendations: The study recommends increase the patient's awareness to challenges that result from epilepsy, by improving individual's social support systems through group therapy and family therapy. Use

education and training programs (regular lectures for nursing staff) to improving the expertise of nurses this is play an essential role in fostering patients care. Raising public knowledge and attitudes towards people with epilepsy booklets should be designated special for this purpose and education by Television programs. The researcher suggested that further study can be done to assess nurse's knowledge about how to deals with epileptics patients.

Key Word: Quality of life, Patients, Epilepsy. **INTRODUCTION:**

Epilepsy is a common medical and social disorder or group of disorders with unique characteristics. It is consider the second most common disorder of the central nervous system, affecting 1% of the human population. Epilepsy, affects nearly 50 million people in the world Three-quarters live in resource-poor countries with little or no access to medical services and treatment has always been poorly understood by society and has frequently been associated with numerous myths and beliefs ^(1, 2, 3, 4, and 5). Every year 200,000 people in the United States of America will be diagnosed with epilepsy. Thirty to 40 percent of people with epilepsy are severely affected and continue to have seizures even if given treatment ⁽⁶⁾. The International league against epilepsy, international bureau of epilepsy and world health organization in Global campaign against epilepsy 2001 consider epilepsy is a part of many disorder such as neurological and psychiatric disorder is disability adjusted life years has revealed the large global burden and they bring epilepsy "Out of the Shadows" by improving the diagnosis, treatment, prevention and social acceptability of the disorder world-wide ⁽¹⁾. Epilepsy might impact on learning in several ways. One major area of cognitive malfunctioning in people with epilepsy is memory impairment. According to Iraqi Ministry of Health Statistics in Baghdad, epilepsy increasingly as a health problem and the numbers of patient is raised in the last years up to high average in 2011, and in the same year number of patients who admitted to Iraqi Hospitals in 1991 were 898 and this number increased to 4409 in 2011⁽⁷⁾. In Iraq the prevalence of epilepsy in Baghdad city was 8.2/1000 this result is near to the results of prevalence studies carried out in World Health Organization reports in 2001^(8 and9). The improvement of the quality of life in patient with epilepsy is a very important goal of the therapy $^{(10)}$.

OBJECTIVES OF THE STUDY: To determine quality of life for patients with epilepsy in Baghdad city and to find out relationship between demographic characteristics (age, gender, educational level, marital status and socioeconomic status) and quality of life, and to find out relationship between clinical data and quality of life.

METHODOLOGY:

Descriptive study was carried out at neuroscience outpatient clinics in Baghdad Teaching Hospitals (Baghdad teaching Hospital, Al Yarmouk teaching Hospital, Neurosurgical Hospital and Neuroscience Hospital) Starting from 15 of December 2012 to 30 of July 2013 to achieve the objectives of the study, a non-probability (purposive) sample of 100 patients that diagnosed with epilepsy at least one year, doesn't have chronic diseases or physical disability mental retardation, does not have antidepressant or antipsychotic medications and who were visiting the neuroscience outpatient clinics of the above listed hospital were selected according to the criteria of the study sample. Data were collected by use questionnaire have three parts, first part consist of socio-demographic and socio-economic data (8) items, second part consist of special clinical data for patient with epilepsy (6) items, and last part consist (32) items quality of life in epilepsy- 31. Reliability of the questionnaire was determined by use of pilot study, and it is validity determined by panel of 19 experts. Data was gathered by interview technique using the questionnaire format and data was analyzed by application of descriptive and inferential statistical methods.

RESULTS:

Socio- Demographics	Groups	Freq	Perc ent	Cum Perc ent	C.S. ^(*) P-value
	20 - 29	69	69	69	
	30 - 39 40 - 49	18 8	18 8	87 95	$\chi^2 = 158.3$
Age Groups	50 - 59	4	4	99	P=0.000 HS
	60 ≥	1	1	100	
	Mean \pm SD	29	$0.45 \pm 8.$	61	
Condon	Male	54	54	54	Binomial
Gender	Female	46	46	100	P=0.484 (NS)
	Single	56	56	56	
	Married	36	36	92	$\chi^2 = 123.5$
Marital Status	Separated	1	1	93	P=0.000
	Divorced	6	6	99	HS
	Widowed	1	1	100	
	Employee	19	19	19	
	Jobless	20	20	39	$\chi^2 = 51.2$
Occupation	Self-employed	17	17	56	ж Р=0.000
	Retired	1	1	57	HS
_	Housewife	38	38	95	
	Student	5	5	100	
Level of Education	Illiterate	10	10	10	$\chi^2 = 84.8$
	Reads and writes	5	5	15	P=0.000

	Primary school graduate		46	61	HS
	Intermediate school graduate	10	10	71	
	Secondary school graduate	13	13	84	
	Institute graduate	9	9	93	
	College graduated	7	7	100	
Residency	Rural	6	6	6	Binomial
Residency	Urban	94	94	100	P=0.000 (HS)
	Up to 2	39	39	39	$\chi^2 = 45.000$
Crowding index	Up to 4	60	60	99	P=0.000
	≥5	1	1	100	HS
	Low : 59 - & less	43	43	43	
Socio-economic Status	Mod. : 60 - 80	44	44	87	$\chi^2 = 18.62$ P=0.000
	High :81 – 100	13	13	100	HS
	Total	100	100	-	

^(*) HS: Highly Sig. at P<0.01; NS: Non Sig. at P>0.05

Result of table 1 indicates of age group (20-29) years were the larger group (69%) of the study sample. approximately half of the subjects are males (54%). Most of study samples (56%) were single. Larger group (46%) of study was primary school. Low and moderate socioeconomic status was large group in study sample (43% and 44%).

Table (2): Association between Demographical Characteristics of the Sample and their Disease History:

Clinical characteristi cs	Groups	Freq.	Percen t	Cum. Percen t	C.S. ^(*) P-value
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		_	-		
	< 5 yrs.	23	23	23	
	5 - 9 yrs.	21	21	44	
	10 - 14 yrs.	21	21	65	$\chi^2 = 11.84$
Date of Diagnosis	15 - 19 yrs.	17	17	82	P=0.037
	20 - 29 yrs.	10	10	92	S
	30 >	8	8	100	
	Mean \pm SD		12.41 ± 9.0	6	
	< 5 yrs.	21	21	21	
	5 - 9 yrs.	21	21	42	
	10 - 14 yrs.	22	22	64	$\chi^2 = 10.40$
Age at onset Approximately?	15 - 19 yrs.	17	17	81	P=0.065
	20 - 29 yrs.	11	11	92	NS
	30 >	8	8	100	
	Mean \pm SD		12.74 ± 9.1	1	
How many	Not occurred at all during last year	22	22	22	$\chi^2 = 21.14$
Seizures occur during last year approximately?	Less than one time in month during last year	23	23	45	P=0.000
approximatery :	Once or more per month during last year?	55	55	100	HS
Type of Seizure	Generalized seizure	94	94	94	Binomial
Type of Seizure	Focal (partial) seizure	6	6	100	P=0.000 (HS)
No. of	One (AED)	67	67	67	Binomial
Medications	Two or more (AED)	33	33	100	P=0.001 (HS)
L		1			

^(*) HS: Highly Sig. at P<0.01; S: Sig. at P<0.05; NS: Non Sig. at P>0.05

Table 2 shows the larger group of patients who have poor control of seizure (55%) for complete study sample. 23% of the study sample is 5 years or less. Generalized seizure is most common seizure type recorded (94%) of study sample and Mono therapy was the most therapy that uses in this study represents (67%) of sample size.

Table (3): Mean of score, Standard Deviation and Relative Sufficiency of Patients Quality of Life:

Main Domains	No.	M.S.	S.D.	R.S.	Ass.
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Energy\Fatigue	100	2.122	0.427	70.7	М
Emotional Well-Being	100	1.820	0.582	60.7	М
Social Function	100	1.724	0.649	57.5	М
Cognitive Function	100	1.463	0.565	48.8	L
Medication Effects	100	1.630	0.542	54.3	L
Seizure Worry	100	1.295	0.504	43.2	L
Overall Assessment	100	1.676	0.288	55.9	М

No. Number: M.S. Mean of Score S.D: Standard deviation. R.S.: Relative Sufficiency Ass: Assessment. M: Moderate. L: Low.

Table (3) deal with assessment quality of life main domains towards patients according to cutoff points, were energy and fatigue indicate moderate the relative sufficiency was (70.7), overall assessment was moderate of relative sufficiency (55.9).

Table (4): Association between Basic Socio-Demographical Characteristics Variables with Overall Assessments due to Compact of all Main domains According to "Under/Upper" Cutoff point:

Main Domain	Basis Information and Demographical Characteristics X Ass. Status	Contingency Coefficients	Approx. Sig.	C.S. ^(*)
	Gender	0.058	0.559	NS
	Age Groups	0.158	0.634	NS
	Marital Status	0.887	0.180	NS
Overall	Occupation	0.291	0.099	NS
Assessment	Level of Education	0.379	0.010	S
	Residency	0.097	0.329	NS
	Crowding index	0.066	0.803	NS
	Socioeconomic Status	0.365	0.000	HS

^(*) HS: Highly Sig. at P<0.01; S: Sig. at P<0.05; NS: Non Sig. at P>0.05

This table shows association between socio-demographic characteristics variables and overall assessment quality of life the level of education was significant relationship with overall assessment quality of life P= 0.010, socio-economic status have highly significant association with overall quality of life assessment P = 0.000.

 Table (5): Association between Basic Information of Disease History Variables with

 an Overall Assessment:

Main Domain	Basis Information and Demographical Characteristics X Ass. Status	Contingency Coefficients	Approx. Sig.	C.S. ^(*)
	Date of diagnosis	0.343	0.020	S
	Age at onset approximately?	0.350	0.016	S
	How many seizures occur during last year approximately?	0.510	0.000	HS
	Type of seizure	0.028	0.783	NS
	No. of medications	0.143	0.148	NS

^(*)HS: Highly Sig. at P<0.01; S: Sig. at P<0.05; NS: Non Sig. at P>0.05

The table represents the correlation between the different clinical characteristics and quality of life domains. The results show that there is highly significant between seizure frequency and main domains quality of life p=0.000, date of diagnosis and age at onset was significant with main domains quality of life.

Discussion:

Throughout the course of data analysis table number (1) indicates that the majority of the study samples were (20-29) years old who were a counted (69%) of study complete study sample. This finding comes along with result obtained from study done by (Jadoou and Mehabes, 1990) were most of his study sample was young and male (68%) which indicated that ⁽¹¹⁾. In regard to marital status, the majority (56%) of the sample were single. Concerning the level of education, most of them (46%) were patients are primary school graduated. This result comes closely with that of (Shakir & Al Asadi, 2011) and (Baker G. et al, 2001)were the single was (56%) and the majority of their study sample have low level of education^(12 and 13). Relative to occupation the approximately one third of the sample was house wife and one- fifth was jobless. Regarding to socio-economic status, the majority of study subjects (44%) are within the moderate level. but the low report that the nearly number is critical significant .this is nearly to (Shakir & Al Asadi, 2011) the most of their study sample had low socio-economic status ⁽¹²⁾. According to respondents most of the patients was have disease duration 5 years and less, this result is nearly to Thomas et, al., 2005 were the most of respondents are 10 years or less duration of epilepsy ⁽¹⁴⁾. Regarding to seizures frequency more than half of study sample suffer from poor control of seizure this

result is similar to Shakir & Al Asadi, (2011); Guekht et,al., (2007) and Thomas et al., (2005) were most of study sample have poor control of seizure ^(12, 15 and 14). Regarding to seizure type the generalized (grand mal) seizure was the major type of seizure according to the type of seizure the generalized (grand male) epilepsy are the largest recorded. Generalized seizures were the most common seizure type agree with (door-to-door study) was made by AL Ataa, 2001, reported generalized epilepsy the most common type of epilepsy in our country ⁽⁸⁾.Regarding to medications number and type the majority of study sample have mono therapy AEDs and the tegretol is the top one medication, this result agrees with (Kubota & Awaya 2010; Phabphal et, al., 2009) they report the mono therapy and tegretol is top one medication that used by patients in their study ^(16 and 17).

Relative to gender the results show that there is no significant relationship between the subjects' gender and their quality of life domains. This result is supported by Tlusta et, al.,(2009) and Hawari,et, al., (2007) and their findings indicate that there is no significant relationship between the gender and quality of life domains scores^(18 and 19).

Regarding age groups the results show there is no significant relationship between the age and the quality of life domains, these results are different from study by, Shakir and Al Asadi., (2011), their report findings indicates that there a significant relationship between age groups and the quality of life of patients with epilepsy they find the low quality of life associated with elderly patients ⁽¹²⁾.

Also the result shows there is no significant relationship between the occupational status and the quality of life domains. This result is supported by, Joseph et. al., (2011), they found in their across sectional study that there is no significant relationship between occupational status and quality of life scores and Herodes et, al., 2001 they concluded in their study The level of employment among persons with epilepsy was not lower than that in the general population ^(20 and 21).

Concerning with educational levels, nearly half of study sample have been graduated from primary school and in current study statistical analysis shows significant relationship with overall QOL assessment. This result is agrees with Djibuti &Shakarishvili, (2003), their findings indicate that the majority of the study subjects are low level of education and strongly correlated with low level of quality of life scores ⁽²²⁾.

And in regarding to the socio-economic status the results show there is a highly significant relationship between the socio-economic status and the quality of life domains, this result are compatible with Previous study in Northern America and Europe have shown differing results country-by-country (Lam, 2001), The quality of life is represented in all activities of daily living but is dependent three factors one of them socioeconomic factor ⁽²³⁾.

Current study analyzed relationship between quality of life (overall assessment) and clinical characteristics such as frequency of seizures and duration of disease in all patients were duration of disease is significant with overall assessment quality of life scores and frequency of seizures was highly significant with overall assessment quality of life domains scores . This result agrees with Rakesh et al., 2012; Shakir & Al Asadi, 2011; Hawari et, al., 2007 and Guekht et,al., 2007 they find in their studies were concluded frequency of seizures was the most important factor influencing on QOL in adults with epilepsy ^(24, 12, 19 and 15).

Also, seizure type and number of medication has no significant relationship with overall assessment quality of life domains, because the majority of the patients (94%) were generalized (grand mal) seizure and on mono therapy regimen. This result agreed with Al Ataa, 2001 he found in his study the generalized (grand mal) seizure and mono therapy is the most common⁽⁸⁾.

Conclusion:

According to the present study findings, the researcher can conclude the following:

1. The majority of the patients with epilepsy are male, with age group (20-29) years old.

2. Most of the study sample is single and low educational level.

3. The majority of patients with epilepsy is housewives and has moderate socioeconomic status.

4. There is a highly significant relationship between socio-economic status and seizure frequency and quality of life scores.

Recommendations:

According to the results of the study, the researcher recommends that:

1. Increase the patient's awareness to challenges that result from epilepsy, improving individual's social support systems through group therapy and family therapy.

2. Use education and training programs (regular lectures for nursing staff) to improving the expertise of nurses to play an essential role in fostering patients care.

3. Raising public knowledge and attitudes towards people with epilepsy, booklets should be designated special for this purpose.

4. Further study that can assess nurse's knowledge about how to deals with epileptics patients.

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