

Quality of life in epilepsy at Jordan University Hospital

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ABSTRACT

الأهداف: دراسة تأثير الصرع على نوعية الحياة و تقييم الآثار النفسية لهذا المرض على الأشخاص الذين يعانون منه في مستشفى الجامعة الأردنية، بالإضافة إلى مقارنة نتائج هذه الدراسة بنتائج الأبحاث المنشورة في الشرق الأوسط والدول الغربية.

الطريقة: أجريت هذه الدراسة في مستشفى الجامعة الأردنية، عمان، الأردن وذلك خلال 6 أشهر من مارس إلى سبتمبر 2009م، وشملت الدراسة 50 مصاباً بالصرع وتبلغ أعمارهم 18 عاماً أو أكثر ممن قاموا بمراجعة عيادة الأعصاب. لقد قام المرضى بتعبئة استبيان تقييم تأثير الصرع على نوعية الحياة وكذلك استبيان تقييم الحالة النفسية والعصبية وذلك بعد ترجمتهما إلى اللغة العربية.

النتائج: لقد كان متوسط عمر المرضى 37.6 عاماً (26 ذكراً، و24 أنثى). وكان عدد المطلقين اثنان، أما عدد المرضى الذين خسروا أعمالهم فقد كان ثلاثة، وخلال السنة التي سبقت الدراسة أصيب 40% من المرضى بأقل من نوبة صرع واحدة في الشهر فيما لم يُصاب 32% من المرضى بأي نوبة خلال هذه السنة، وأصيب ثلثي المرضى بنوبات الصرع التوتيرية الرمعية (نوبات الصرع الكبير). لم يُصَبْ غالبية المرضى (84%) بأية جروح ناتجة عن الصرع، فيما أشار ثلاثة أرباع المرضى (73.4%) إلى فعالية الأدوية المضادة للصرع والتي لم تؤدي إلى آثار جانبية خطيرة. ولم يَقم الصرع بالتحكم بالنشاطات اليومية لحوالي 42 مريضاً (84%)، كما أن نسبة كبيرة من المرضى (55-88%) لم يحسُّوا بأن الصرع قد أثر على كافة نواحي حياتهم اليومية. وحدث الشعور بالاختلاف والتمييز في 7 مرضى فقط، فيما عانى 42% من المرضى من الاكتئاب الطفيف.

خاتمة: أشارت النتائج إلى جودة نوعية الحياة لدى مرضى الصرع في هذه الدراسة بالمقارنة مع الدراسات الأخرى، بالإضافة إلى قلة شعورهم بالتمييز، وقلة تأثير الصرع على حياتهم اليومية، غير أن هذه الدراسة تتفق مع التقارير الأخرى في وجود نسبة ملحوظة من الاكتئاب لدى مرضى الصرع والتي يمكن تخفيفها بزيادة الدعم المعنوي من الأسرة والمجتمع.

Objectives: To study the quality of life (QOL) and psychiatric symptoms in epilepsy patients at the Jordan University Hospital (JUH), and to compare these findings with those from Middle Eastern and Western literature.

Methods: Fifty epilepsy patients, aged 18 years, or older, attending the Neurology Clinic at Jordan University Hospital, Amman, Jordan over a 6-month-period from March to September 2009, were requested to complete a questionnaire on QOL in epilepsy, as well as a neuropsychiatric inventory, both translated into Arabic.

Results: The patients' mean age was 37.6 years, with 26 males, and 24 females. Only 2 patients were divorced and 3 lost their job due to epilepsy. During the year prior to the study, 40% of patients had less than one attack/month and 32% were seizure-free. Two-thirds of patients had tonic-clonic seizures. Most (84%) did not sustain injuries due to the seizures. Approximately 3/4 of patients (73.4%) stated that their seizures were very well controlled with antiepileptic drugs, which did not lead to major side effects. Forty-two patients (84%) did not have any restriction of daily activities due to epilepsy and substantial proportions (range 52-88%) did not perceive any impact of epilepsy on aspects of daily living. Feelings of stigma were noticed in only 7 patients. Mild depression was noted in 42% of patients.

Conclusion: Compared with others, this study shows a good QOL in patients with epilepsy, less stigma, and little impact of epilepsy on daily living with, however, similar to other reports, a significant rate of depression, which could have been alleviated by better family and social support.

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Epilepsy is characterized by enduring unprovoked seizures, and it can affect many aspects of quality of life (QOL) such as educational achievement, employment, social relationships, and marriage.¹

It is also associated with cognitive and psychiatric comorbidities as well as physical injury. People who suffer from epilepsy are at risk of losing consciousness in precarious situations such as while driving, swimming, or crossing the street. Depending on the nature of the seizures and the circumstances in which they occur, people may fracture bones, suffer brain damage, or sustain other traumatic injuries. Approximately 4-40% of epilepsy patients are at risk of sudden death related to their seizures.² Quality of life is worse in patients with epilepsy than in the general population.³ Over 80% of seizures are well controlled with antiepileptic drugs (AEDs) and/or epilepsy surgery. However, many people do not adhere to treatment recommendations because of stigma as well as sociocultural and psychiatric reasons. Stigma has been historically associated with epilepsy, and is one of the reasons of the impact of epilepsy on patients.⁴ Psychiatric comorbidity, especially depression and anxiety, associated with epilepsy, is well described.⁵ Better mood has been shown to be the strongest predictor of improved QOL in people with epilepsy, even more so than cognitive ability, response to medication, and seizure control.⁶ People with epilepsy in the USA and Europe are more prone to poorer self-esteem and higher scores of anxiety and depression than are people without epilepsy.⁷ International epilepsy associations as well as the WHO have recognized the high priority of research in both the developed and developing world on the psychosocial and functional outcomes of epilepsy management.^{8,9} Few studies on epilepsy and its risk factors have been carried out in Jordan.¹⁰⁻¹² Only one study from Sudan dealt with the QOL of patients with epilepsy and its social aspects.¹³ However, none of these studies have addressed concomitantly the issue of QOL in epilepsy as well as the interaction of psychiatric comorbidities and QOL. Only one Jordanian study addressed the public's attitude towards epilepsy in Jordan.¹⁴ Due to the paucity of Jordanian studies, this study was carried out in the neurology clinic of Jordan University Hospital (JUH) over a 6-month-period with the purpose of: 1) assessing QOL in epilepsy patients, especially the perceived impact of epilepsy on daily living as well as the feeling of stigma, and 2) to provide data on the comorbidity of psychiatric symptoms in epilepsy. The results will be compared with data from Middle Eastern and Western literature.

Methods. All consecutive adult epilepsy patients, aged 18 years, or older, attending the neurology clinic of Jordan University Hospital (JUH), Amman, Jordan between March and September 2009 were included. Patients with mental retardation or cognitive deficits, such as aphasia, were excluded. The diagnosis and classification of epilepsy were according to the

International League Against Epilepsy. The JUH is a 600-bed tertiary care referral center serving a considerable proportion of the middle-class medically insured Jordanians. The consent and approval of the ethics committee of JUH were obtained, and patients, following the signature of a consent form and the explanation of the aim of the study, were requested with the help of 2 fellows in neurology to complete a questionnaire translated in Arabic. This had been previously validated and demonstrated to be useful in studying Arabs, including Jordanians, with epilepsy.⁷ The questionnaire covered the following subjects: seizure type and frequency, injuries associated with seizures as well as an adverse events profile according to a scale that has been validated and shown to be a reliable measure for antiepileptic drug (AED) side effects in other studies.¹⁵ It also addressed the extent of worry over epilepsy, as well as the perceived impact of epilepsy and its treatment on social relationships and activities, employment, overall health and feelings of self.⁷ A 3-item scale, developed originally for use in stroke patients, and subsequently adapted for use in epilepsy, was used to appreciate feelings of stigma.⁷ Health status was assessed using a well-established generic health-status measure, the 36-item Short Form Health survey (SF-36), for which UK population norms are available.¹⁶ The SF-36 addresses 8 health concepts: physical functioning, social functioning, physical role limitations, emotional role limitations, mental health, energy/vitality, pain, and general health. The patients were also requested to report on their perceived health status as well as any limitations in their daily activities imposed by the epilepsy. On a 1-5 scale (grade 1 = excellent, and grade 5 = bad), patients were requested to mention their expectations of their future health status in the actual year compared to the one prior to the study. Finally, the questionnaire included demographic details regarding patients' age, gender, marital, and employment status. In addition to the above questionnaire, a Neuropsychiatric Inventory (NPI), translated into Arabic, was utilized and it had been previously validated and shown to be useful for evaluating psychiatric symptoms in patients with epilepsy.¹⁷ No specific statistical analysis was used.

Results. There were 50 patients (26 male, 24 female; M/F ratio=1.083), and the mean age was 37.6 years (range 16-66 years). The age and gender distribution are shown in **Table 1**, which demonstrates that 36 patients (72%) were below the age of 45 years. Twenty patients (40%) were married, 24 (48%) single, and 6 (12%) were divorced or widowed (2 divorces due to the epilepsy). Twenty-one patients (42%) were employed, 19 (38%) not employed (3 of them lost their job due to the epilepsy, 4 retired, 4 housewives, and 8 looking

for a job) and 10 (20%) were students. The mean age of the patients at the onset of the attacks was 23 years, and the mean duration of the seizures prior to the study was 11 years (range 1-36 years). During the year prior to the study, 14 patients (28%) had one or more seizures/month, 20 (40%) less than one attack/month, and 16 (32%) were seizure-free. Comorbidities, namely, long-term health problems associated with the epilepsy, were present in 22 patients. Thirty-two patients (64%) had tonic-clonic seizures, 5 (10%) had petit mal absence, 4 (8%) had complex partial seizures, one had (2%) myoclonic seizures, and 8 (16%) unclassifiable seizures. Thirty-five patients (70%) had the attacks at any time of the day or night, 8 (16%) within 2 hours of waking up, and 7 (14%) during sleep. Most (42 patients, 84%) did not have injuries due to the seizures, while only 8 patients (16%) sustained injuries, some having had more than one injury (3 head and scalp injuries necessitating suturing, 3 closed head injuries needing a 24-hour-observation in the hospital, 3 dental injuries, 3 body wounds, 3 limb fractures, and one had a fractured nose). All of the injuries occurred in patients with chronic epilepsy having an onset more than 15 years prior to the study. All the patients recovered fully from those injuries, thus, they were still capable of self-completing the questionnaires.

Regarding AEDs, 23 patients (46%) were taking one AED, 20 (40%) were taking 2, and 7 (14%) more than 2 AEDs. Thus, 54% of patients were on polytherapy. Around three-quarters of the patients (73.4%) mentioned that their seizures were very well controlled by AEDs, 22.2% reported that the control was acceptable, and 4.4% that it was bad. Around 35.6% of patients had concerns regarding the side effects from AEDs. Table 2 shows the side effects from AEDs: substantial proportions of patients did not have any side effects. However, among those who had frequent adverse effects ('often' and 'always' categories combined), the most common was behavioral problems (anger/emotional lability), followed by memory disturbances and drowsiness. Thirty-two patients (64%) had mild adverse events, 14 (28%) had moderate, and 4 (8%) had severe side effects leading to a change of the AED. Side effects were noted in 26 patients on polytherapy (mainly nervousness in 15 patients, headache and memory problems each in 11, and sleepiness in 10). Twenty-four patients (48%) did not have a change of the AED, however, a change of the AED occurred once in 14 patients (28%), twice in 4 patients (8%), and more than twice in 8 patients (16%). Thus, a change of AED was carried out in 52% of patients, either due to side effects or poor control of the seizures. Concerning AED compliance, 33 patients (66%) mentioned that they never missed a dose of the AED, 7 patients (14%)

Table 1 - Age and gender distribution.

Age (Years)	Gender		Total
	Male	Female	
16-24	7	3	10
25-34	9	6	15
35-44	4	7	11
45-54	3	4	7
55-64	2	3	5
>64	1	1	2
Total	26	24	50

Table 2 - Side effects of antiepileptic drugs.

Side effects	Frequency n (%)			
	Always	Often	Rarely	Never
Dizziness	0 (0)	1 (2)	9 (18)	40 (80)
Tiredness	3 (6)	4 (8)	9 (18)	34 (68)
Discomfort	0 (0)	3 (6)	8 (16)	39 (78)
Increased activity	1 (2)	1 (2)	5 (10)	43 (86)
Nervousness	6 (12)	8 (16)	7 (14)	29 (58)
Headache	2 (4)	8 (16)	11 (22)	29 (58)
Itching	2 (4)	1 (2)	4 (8)	43 (86)
Blurred vision	0 (0)	5 (10)	2 (4)	43 (86)
Nausea	2 (4)	5 (10)	8 (16)	35 (70)
Difficulty in concentration	3 (6)	6 (12)	5 (10)	35 (70)
Gum problems	3 (6)	2 (4)	6 (12)	38 (76)
Tremors	4 (8)	3 (6)	10 (20)	33 (66)
Increase in weight	1 (2)	8 (16)	1 (2)	40 (80)
Decrease in weight	0 (0)	4 (8)	1 (2)	45 (90)
Drowsiness	6 (12)	11 (22)	3 (6)	30 (60)
Memory problems	8 (16)	9 (18)	3 (6)	30 (60)
Sleep disturbances	8 (16)	5 (10)	2 (4)	35 (70)
Anorexia	4 (8)	5 (10)	1 (2)	40 (80)
Anger, emotional lability	6 (12)	14 (28)	5 (10)	25 (50)

Table 3 - Perceived impact of epilepsy on aspects of daily living.

Aspect of daily living	A lot	Some-what	A little	Not at all	Not applicable
Relationship with spouse/partner	1 (2)	2 (4)	1 (2)	17 (34)	29 (58)*
Relationship with other family members	3 (6)	1 (2)	2 (4)	44 (88)	-
Social life	5 (10)	3 (6)	2 (4)	40 (80)	-
Ability to work	6 (12)	1 (2)	1 (2)	17 (34)	25 (50)#
Overall health	7 (14)	9 (18)	8 (16)	26 (52)	-
Relationship with friends	4 (8)	4 (8)	0 (0)	42 (84)	-
Feelings about self	8 (16)	11 (22)	3 (6)	28 (56)	-
Future plans	10 (20)	7 (14)	4 (8)	29 (58)	-
Standard of living	9 (18)	5 (10)	6 (12)	30 (60)	-

*single, #student/unemployed

Table 4 - Neuropsychological changes* (n=50).

Type	Frequency		Intensity			
	<Once/ week	>Once/ week	Always	Mild	Moderate	Severe
Agitation, n=11 (22%)	9	2	-	6	5	-
Depression, n=21 (42%)	13	4	4	16	5	-
Anxiety, n=9 (18%)	6	-	3	5	3	1
Irritability/lability, n=12 (24%)	6	4	2	7	3	2
Sleep disturbances, n=8 (16%)	4	-	4	6	2	-
Change in appetite, n=6 (12%)	1	1	4	1	2	3
Apathy, n=4 (8%)	4	-	-	1	3	-
Euphoria, n=1 (2%)	1	-	-	1	-	-

*Some patients had more than one neuropsychological change

said that they missed some doses of the AED less than once a month, 3 (6%) more than once a month, and 7 (14%) once or more per week.

Most patients (84%) mentioned that the epilepsy did not lead to a restriction of their daily activities, while only 8 (16%) said that their activities were restricted, among them 2 due to uncontrolled epilepsy and 6 due to comorbidities. Table 3 shows the perceived impact of epilepsy on aspects of daily living. It demonstrates that all aspects of daily living were not at all affected in substantial proportions of patients (ranging from 52% for overall health, to 88% for the relationship with other family members). However, among the minority in whom those aspects were greatly affected, future plans were mostly affected (20%).

Only a few patients felt stigmatized by their disease: among the 50 patients with epilepsy, only 3 mentioned that they had a feeling of inferiority compared to the people around them, 2 felt that others were uncomfortable in dealing with them, and 2 felt that people tried to avoid them. Regarding perceived health status, 4 patients (8%) mentioned that it was excellent, 20 (40%) very good, 21 (42%) good, 2 (6%) more or less good, and 3 (6%) that it was bad. Their expectations of their future health status were excellent to acceptable (grade one to 4) in 78% of patients and bad (grade 5) in 22%. The neuropsychological changes, according to the NPI, are shown in Table 4, which demonstrates that the most common was depression, followed by irritability/lability, and agitation. Only a few patients had a change in appetite, apathy, or euphoria. None of the patients had delusions, hallucinations, disinhibition,

or abnormal motor behavior. Most patients had mild neuropsychological changes with a frequency of less than once/week.

Discussion. In our study from the Middle East, we address both the QOL in epilepsy as well as the psychiatric comorbidities. We found that 73.4% of patients reported that their seizures were very well controlled with AEDs. Nineteen out of 50 patients (38%) were unemployed, only 3 due to the epilepsy. Despite the small number of our patients, this finding disagrees with that from another study that noted among 3847 patients with epilepsy, 10% of respondents said that epilepsy was the reason they were not working.⁷ Berto³ also noted that the frequency of seizures is the most relevant determinant of the quality of life in epilepsy. A few of our patients felt stigmatized because of support from their family, and some of them were hiding the disease from their surroundings. This is in accordance with a study carried out by Baker et al⁷ on the QOL of people with epilepsy in Iran, the Gulf, and Near East, and who found, interestingly, that fewer respondents in their study reported feeling stigmatized by their epilepsy compared to their earlier study in Europe. This latter study also noted some important between-country differences, whereby respondents in Oman were most likely, and those in Jordan least likely to report feeling stigmatized. This is in clear contradiction with another report from Jordan,¹⁴ which concluded that attitudes of Jordanians towards epilepsy are comparable with results from Asian countries, but more negative when compared with reports from the Western countries. According to Jacoby,⁴ stigma is due to under-resourced medical services, poor seizure control, and inadequate knowledge of epilepsy.

Depression was the most common neuropsychiatric disturbance in our study (Table 4). This agrees with other reports.^{5,18} The good control of seizures in 73.4% of our patients explains the presence of mild depression: 13 out of our 21 patients with depression had symptoms less than once/week and only 2 out of 21 ever talked of suicide, thus, there was no mortality in our patients, in contradiction to Jallon² who mentioned that suicide rates in epilepsy ranged from 0-25%, and that they were related to psychiatric comorbidity.² The high comorbidity of depression and epilepsy can be explained by the existence of common pathogenic mechanisms whereby one condition facilitates the occurrence of the other.¹⁹ Depression and anxiety can accompany all types of epilepsy, but may be especially noteworthy in partial epilepsy syndromes with foci in the frontal or temporal lobes.²⁰ Sandstrom²¹ concluded that not only major depressive disorders have an impact on the QOL in epilepsy patients, but also interictal mood disorders

that constitute a large proportion of mood symptoms in the population with epilepsy.

Due to the good seizure control in our patients (73.4%), epilepsy had little impact on aspects of daily living (Table 3), with a very good perceived health status in 48% of our patients. This is in full agreement with other series.²²⁻²⁷ Baker et al⁷ reported that substantial proportions of individuals with epilepsy in Iran, The Gulf, and Near East felt that many aspects of their daily lives were largely unaffected by their condition, particularly those from Jordan and Bahrain in contrast to respondents from Oman.

Substantial proportions of our patients did not report any side effects from the AEDs, despite 54% being on polytherapy, and this led to mild adverse effects in a minority of patients. This explains the good compliance with treatment in 66% of our patients as well as the absence of impact of epilepsy in a large proportion (range 52-88% of patients). This is in accordance with other reports.^{1,28,29} Another study from Sudan concluded that poor QOL in epilepsy reflects the impact of side effects of treatment, illness chronicity, and social underachievement.¹³ According to St Louis, adverse effects of AEDs result in detrimental QOL in epilepsy patients, and these may be obviated in most patients by dose reduction of monotherapy, reduction, or elimination of polytherapy, or substituting a better tolerated AED.³⁰ Sleep disturbances were found in 16% of our patients. According to Xu et al,³¹ sleep disturbances are negatively associated with everyday functioning and well being, and therefore contribute significantly to the burden of epilepsy.³¹

In conclusion, despite the limitations of this study (the small number of patients, absence of statistical analysis, and being a hospital-based series), it clearly demonstrates that, in contrast to patients with epilepsy from other Arab countries, those from Jordan appear to fare best overall in terms of life quality, which is in accordance with Baker et al,⁷ mainly due to good seizure control. Nevertheless, a significant proportion of our patients had depression, albeit mild, and this could have been alleviated by increasing public awareness of epilepsy in Jordan as well as by better family support. As noted by Charyton et al,³² persons with epilepsy need encouragement to actively seek and sustain supportive personal relationships that may help improve their QOL.

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Related topics

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