## **ORIGINAL RESEARCH**

# Impact of epileptic patient's knowledge level on their quality of life

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#### ABSTRACT

**Background and objective:** Inadequate epileptic patient's knowledge regarding their disorder may affect the quality of their life. The aim of the study was to determine the impact of epileptic patient's knowledge on the quality of their life.

**Methods:** Research design: a descriptive study was conducted in the period from February to April 2017 to determine the impact of epileptic patient's knowledge on the quality of their life. Setting; this study was carried out in the neurology department and neurology outpatient clinic of Assiut Neurology University Hospital. Patients; a sample of sixty epileptic male and female patients, with an age range between 18 to 65 years was included. Two tools were used: Tool I: Structured patient interview questionnaire sheet and it included two parts: Part one: Sociodemographic data about of the studied patients, Part two: knowledge assessment regarding their disorder using Epilepsy Patient Knowledge Questionnaire (EPKQ). Tool II: Quality of Life in Epilepsy (QOLIE 31).

**Results:** The highest percentage of the studied sample were male, married, their mean age was  $38.97 \pm 11.21$ , and their duration of epilepsy was  $16.82 \pm 9.7$ . 58.3% were having satisfactory level of knowledge regarding their condition.

**Conclusions and recommendation:** The present study concluded that: epileptic patients are lacking knowledge regarding their condition (58.3% vs. 41.7%). There was No significant correlation between total QOL and score of knowledge. Recommendation: A self-management program is needed for patients with epilepsy in order to improve their knowledge regarding their disease.

Key Words: Epileptic, Patient's knowledge, Quality of life

#### **1. INTRODUCTION**

Epilepsy is considered one of the commonest neurological disorders which is caused by an abnormal electrical activity in the brain and is associated with sudden recurrent attacks of loss of consciousness and/or sensory disturbances or seizures. The incidence of epilepsy in developed countries is about 50 per 100,000/year.<sup>[1]</sup> Epilepsy is a disorder of the brain which is characterized by predisposition to generate epileptic seizures, and by the neurobiological, cognitive, psychological, and social consequences of this condition.<sup>[2]</sup>

Major disruptions in functioning and everyday living are caused by epilepsy, which leads to reduction in patient's quality of life (QOL). A negative impact on epileptic patient's QOL is imposed by their need for treatment with antiepileptic drugs. Therefore, understanding what factors have the greatest impact on these is of great importance for improving epileptic patient's overall QOL. Which include five dimensions; demographics, physical health, psychological health, social health,<sup>[3–5]</sup> and epilepsy-specific issues.<sup>[6]</sup>

Epilepsy is not only a medical condition but it is also a

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social problem, epileptic patient's quality of life is influenced by social and cultural negative effects, as well as repeated seizures.<sup>[7,8]</sup> Epileptic patients experience lower quality of life than normal people,<sup>[9,10]</sup> and QOL in patients with epilepsy was lower than that in patients with other chronic diseases, it also hinders the ability of persons to engage with their community.<sup>[11]</sup> **2.5 Tools Tool I: Str Section on** tients (age of anilance

The effects of antiepileptic drugs and patient's psychosocial problems greatly affect patients' quality of life even if seizures are controlled. There was a correlation between epileptic patient's knowledge about epilepsy and their ability to cope with the disease; studies also suggest that epileptic patient's knowledge about epilepsy is generally limited.<sup>[12]</sup>

#### 1.1 Aim of the study

To determine the impact of epileptic patient's knowledge on the quality of their life.

#### 1.2 Research question

Does epileptic patient's knowledge have an impact on their quality of life?

## 2. PATIENTS AND METHOD

#### 2.1 Research design

A descriptive study was conducted in February, March and April 2017 to determine the impact of epileptic patient's knowledge on quality of their life.

#### 2.2 Setting

This study was carried out in the neurology department and neurology outpatient clinic of Assiut Neurology University Hospital.

#### 2.3 Patients

A sample of sixty epileptic male and female patients, with an age range between 18 to 65 years was included in this study. The sample size was calculated using the epi info sample size calculation system. The power was set at 90% and level of significance at  $p \leq .05$ , a sample of 60 patients was specified for this study but this sample size was increased to 75 patients considering any drop out of the included patients in the form of not answering any of the questionnaires and final estimation of the results was done on 60 patients.

#### 2.4 Exclusion criteria

Mentally ill patients, patients with hearing or visual difficulties, newly diagnosed epileptic patients, comatosed patients, patients who have disabilities that could impact on their quality of life other than epilepsy as cancer or amputation and patients with learning disabilities. **Tool I: Structured patient interview questionnaire sheet:** This was developed by the researchers and it included two sections:

*Section one:* Sociodemographic data about of the studied patients (age, sex, marital status, educational level and duration of epilepsy).

Section two: Knowledge assessment regarding their disorder using Epilepsy Patient Knowledge Questionnaire (EPKQ): This is for assessment of epileptic patient's knowledge regarding their disorder and includes knowledge about; definition of epilepsy (n = 1), safety measures patients can take to reduce the chance of epileptic seizures (n = 3), compliance of patients to their epilepsy medications (n = 4), social activities (n = 1) and legalities of driving (n = 2) and employment (n = 2).

This section included 13 questions in the form of multiple choice questions, fill in the blank, true or false.

Patients were considered as having satisfactory level of knowledge if their total score was  $\geq 50\%$ , and unsatisfactory level of knowledge if their total score was < 50.

**Tool II: Quality of Life in Epilepsy (QOLIE 31):** It includes seven multi-item scales as follows: emotional wellbeing, social functioning, energy/fatigue, cognitive functioning, seizure worry, medication effects, and overall quality of life. The scoring converts raw numeric values of items to scores of 0-100, where higher scores reflect a better QOL. A QOLIE 31 is obtained by taking the average of the multi item scale scores.

Overall score for the QOLIE 31 was derived by weighting and summing QOLIE 31 scale scores, higher scores ( $\geq 60$ ) represented a better quality of life, while lower scores (< 60) represented a bad or worse quality of life.

#### Validity and reliability of the tools:

A content validity index of 93% was found for the used tools indicating a strong agreement among the experts who revised the tools that the items measure what they are designed to measure.

Internal consistency reliability was reported for the used first tool has ranged from .81-.86 using the Cronbach alpha coefficient.

Internal consistency reliability for the multi-item QOLIE 31 was calculated using the Pearson correlation coefficient and it ranged from 0.77 to 0.85.

#### Field work:

• An approval from the ethics committee in nursing fac-

ulty was obtained.

- Hospital administration permission was obtained from the head of neurology department and neurology outpatient clinic to collect the necessary data.
- The tools for data collection were prepared after extensive literature review using faculty library and internet sources.
- The tools were tested by five experts in the field (3 nursing staff and two neurology medical staff) for testing applicability and validity of the tools.
- In order to test clarity and applicability of the tools; a pilot study was carried out during January 2017 on 6 patients, patients included in the pilot study were included in the main study as there were no changes done in the tools.
- An individualized interview was followed with patients for filling the study tools.

#### 2.6 Ethical considerations

An institutional ethics committee approval was obtained to conduct this study, patients who were willing to participate in the study were required to give an informed written consent after explaining the nature and purpose of the study to them. Confidentiality of the obtained data was assured to patients during their initial interview with the researcher and patients were also informed that their participation is voluntary and they can withdraw from the study any time.

## **3. RESULTS**

Data entry and statistical analysis were done using the SPSS ver. 23. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables, mean and standard deviations for the quantitative variables. The level of significance was set at (p = .05).

Table 1 reveals that among the studied sample, 70% were male, the highest percent (75%) were married, 35% were having basic education, the mean duration of epilepsy was  $16.82 \pm 9.75$ , and regarding age the mean age was  $38.97 \pm 11.21$ .

Table 2 illustrates that the highest percent of the studied sample (58.3%) was having a satisfactory level of knowledge regarding their condition.

Table 3 reveals that the highest quality of life scores were in the medication effects domain with a mean and standard deviation of  $74.49 \pm 25.46$  while the lowest quality of life scores were in the emotional well-being domain with a mean and standard deviation of  $53.40 \pm 17.75$ .

Table 4 shows that there was a statistically significant difference between epileptic patient's knowledge and their age. Table 5 reveals that the highest overall total quality of life scores in epileptic patients was in patients aged less than 40 years, female, single, secondarily educated and their duration of epilepsy less than 10 years.

As shown in Table 6, a positive correlation was found between knowledge level and seizure worry, overall QOL, cognitive domain, medication effects and social function and a statistically significant difference was found between knowledge level and quality of life medication effects domain. No significant correlation between total QOL and score of knowledge.

Table 1.	Distribution	of the so	ciodemog	raphic c	lata o	f the
studied p	patients					

	N. (60)	%
Gender		
Male	42	70.0
Female	18	30.0
Age (years)		
< 40	34	56.7
$\geq$ 40	26	43.3
Mean $\pm$ SD (Range)	38.97 ± 11.21 (18.	.0-65.0)
Marital status		
Single	11	18.3
Married	45	75.0
Divorced	4	6.7
Level of education		
Illiterate	20	33.3
Basic education	21	35.0
Secondary	19	31.7
Duration of epilepsy: (years)		
< 10	13	21.7
10 - < 20	24	40.0
$\geq$ 20	23	38.3
Mean ± SD (Range)	$16.82 \pm 9.75 (1.0 -$	44.0)

Table 2. Frequency distribution of epileptic patterns	tients
regarding their knowledge level	

Knowledge level	N. (60)	%			
Unsatisfied	25	41.7			
Satisfied	35	58.3			
Mean $\pm$ SD (Range)	$7.02 \pm 1.92 \ (3.0-11.0)$				

**Table 3.** Distribution of the studied sample regarding their quality of life level

	Mean ± SD	Median (Range)
Seizure worry	$54.62 \pm 27.55$	57.0 (9.0-100.0)
Overall quality of life	$62.33 \pm 18.02$	62.5 (32.5-100.0)
Emotional well-being	$53.40 \pm 17.75$	56.0 (20.0-92.0)
Energy/fatigue	$58.33 \pm 18.45$	60.0 (15.0-100.0)
Cognitive	$55.37 \pm 28.50$	55.7 (0.0-100.0)
Medication effects	$74.49 \pm 25.46$	80.6 (11.1-100.0)
Social function	$60.24\pm20.73$	62.5 (16.3-100.0)

#### Table 4. Relation between level of knowledge and patient's personal and clinical data

Knowledge level					
Unsatisfied		Satisfied		<i>p</i> -value	
N.	%	N.	%		
18	42.9	24	57.1	.775	
7	38.9	11	61.1		
19	55.9	15	44.1	.011*	
6	23.1	20	76.9		
7	63.6	4	36.4	.174	
18	36.7	31	63.3		
7	35.0	13	65.0	714	
10	47.6	11	52.4	./14	
8	42.1	11	57.9		
6	46.2	7	53.8	270	
12	50.0	12	50.0	.570	
7	30.4	16	69.6		
	Knowledge level         Unsatisfied         N.         18         7         19         6         7         18         7         18         7         18         7         18         7         10         8         6         12         7	Knowledge level         Unsatisfied         N.       %         18       42.9         7       38.9         19       55.9         6       23.1         7       63.6         18       36.7         7       35.0         10       47.6         8       42.1         6       46.2         12       50.0         7       30.4	Knowledge level         Satisfied           Unsatisfied         %         N.           18         42.9         24           7         38.9         11           19         55.9         15           6         23.1         20           7         63.6         4           18         36.7         31           7         35.0         13           10         47.6         11           8         42.1         11           6         46.2         7           12         50.0         12           7         30.4         16	Knowledge levelUnsatisfiedSatisfiedN.%N.18 $42.9$ $24$ $57.1$ 7 $38.9$ 11 $61.1$ 19 $55.9$ $15$ $44.1$ 6 $23.1$ $20$ $76.9$ 7 $63.6$ $4$ $36.4$ 18 $36.7$ $31$ $63.3$ 7 $35.0$ $13$ $65.0$ 10 $47.6$ $11$ $52.4$ 8 $42.1$ $11$ $57.9$ 6 $46.2$ $7$ $53.8$ 12 $50.0$ $12$ $50.0$ 7 $30.4$ $16$ $69.6$	

\**p* < .05

Table 5. Relation between sociodemographic variables and overall QOLIE-31

	QOL					
	Mean ± SD	Median (Range)	<i>p</i> -value			
Gender						
Male	$59.11 \pm 14.21$	58.78 (31.13-91.74)	.778			
Female	$61.49 \pm 16.43$	57.18 (34.74-95.57)				
Age (years)						
< 40	$60.65 \pm 15.84$	60.78 (31.13-95.57)	.512			
$\geq$ 40	$58.75 \pm 13.57$	56.71 (39.39-89.95)				
Marital status						
Single	$60.35 \pm 14.03$	58.72 (34.74-95.57)	.826			
Ever-married	$59.71 \pm 15.11$	58.35 (31.13-91.74)				
Level of education						
Illiterate	$59.84\pm10.86$	59.25 (39.39-76.15)	777			
Basic education	$58.80\pm20.15$	54.92 (31.13-95.57)	.///			
Secondary	$60.94 \pm 11.85$	58.35 (39.70-89.75)				
Duration of epilepsy (years)						
< 10	$65.99 \pm 10.47$	60.68 (56.09-91.74)	149			
10 - < 20	$59.44 \pm 14.44$	58.70 (35.98-89.95)	.140			
$\geq 20$	$56.75 \pm 16.66$	52.78 (31.13-95.57)				

## 4. **DISCUSSION**

From the results of the present study we can see that the majority of the studied patients were males, married, and the highest percent of them were having basic education, with mean age of  $38.97 \pm 11.21$  and their mean duration of epilepsy was  $16.82 \pm 9.75$ .

In the same line with the mean age of the studied sample, Hsiu-Fang et al.<sup>[13]</sup> reported that the mean age included in

their study was  $39.43 \pm 11.3$ , while they found that regarding gender; 50.3% of their sample were male and the rest of the sample were female.

Tab	le 6.	Correlati	on of Q	OLIE-31	and	knowledge score
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OOLIE 31 domains	Knowledge score			
QULIE-51 domains	<i>r</i> -value	<i>p</i> -value		
Seizure worry	0.080	.545		
Overall quality of life	0.020	.880		
Emotional well-being	-0.106	.418		
Energy/fatigue	-0.161	.218		
Cognitive	0.150	.253		
Medication effects	$0.312^{*}$	.015		
Social function	0.152	.245		
Total QOL	0.139	.240		
* <i>p</i> < .05				

Also in the same line with our previous study results to a large degree, Kováts et al.<sup>[14]</sup> reported that regarding mean age of their study sample it was  $36.92 \pm 12.33$ , 55.3% of them were living with a spouse, the highest percent in their study (40.4%) were having high school education and 58.2% were female.

Kadir et al.<sup>[15]</sup> disagreed with our study result regarding marital status when they reported that 56.45% were single and 40.7% were married, and regarding mean age they also reported different result as the mean age was  $28.8 \pm 10.6$ .

More than half of the studied sample was having a satisfactory level of knowledge regarding their condition. Lucretia et al.<sup>[16]</sup> disagreed with the present study results when they reported that patients lack knowledge regarding their condition, my interpretation for this result that because of the advances in informational technology and patients nowadays are more oriented regarding their disease than the year in which they had conducted their study.

Regarding quality of life level in the studied sample it was noted that the highest quality of life scores were in the medication effects domain with a mean and standard deviation of  $74.49 \pm 25.46$  while the lowest quality of life scores were in the emotional well-being domain with a mean and standard deviation of  $53.40 \pm 17.75$ . This study result disagree with the results documented by Saadi et al.<sup>[17]</sup> who found the highest scores in the overall QOL with a mean and SD of ( $56.8 \pm 18.6$ ) and the lowest QOL in the seizure worry with a mean and SD of ( $32.1 \pm 24.0$ ).

Regarding association between patient's sociodemographic characteristics and their overall quality of life it was noted that the highest overall quality of life scores in epileptic patients was in patients aged less than 40 years, in my opinion it might be related that younger patients are dealing more with internet sources and TV programs which acquaint them with more knowledge regarding their medical condition, and this doubtlessly reflects positively on their quality of life. Female patients gained a higher overall score than male and in our community females accept their medical conditions than males and are also more involved in household duties that make their acceptance of disease better, single; from my point of view those patients are having more spare time to adjust their lives according to medical condition and are able to live a better life than those who are married, and secondary educated patients are also higher in the scores this reflects the fact that educated patients are more knowledgeable regarding their condition, while there was no difference between quality of life scores of patients according to their marital status.

The previous study result comes in the same line with the study conducted by Tedrus et al.<sup>[18]</sup> and Wada et al.<sup>[19]</sup> who found that there was no significant association between total quality of life scores and marital status and they translated that as the perception of better marital adjustment among patients with epilepsy does not reflects to a better quality of life. But this result comes in disagreement with Elliott et al.<sup>[20]</sup> and Chen et al.<sup>[21]</sup> when they declared that better marital adjustment is positively associated with better perception of quality of life in married patients with epilepsy. Also this previous study result contradicts the results by Zhao et al.<sup>[22]</sup> who reported that married patients with epilepsy have better quality of life than those who are not married.

Current study results comes in disagreement with Hsiu-Fang et al.<sup>[13]</sup> who found that male patients have gained higher overall quality of life scores than females (56.32  $\pm$  26.6 vs. 48.95  $\pm$  29.4) also they disagree with our study result in the association between age and overall quality of life when they found that patients aged 20-40 years their overall QOL score was 60.06  $\pm$  15.3 while patients aged 41-65 years their overall QOL score was 66.11  $\pm$  18.1.

A positive correlation was found between knowledge level and seizure worry, overall QOL, cognitive functioning, medication effects and social function and a statistically significant difference was found between knowledge level and quality of life medication effects domain.

This study result comes in agreement with the study conducted by Hsiu-Fang et al.<sup>[13]</sup> who reported that patient's knowledge of epilepsy can indirectly impact on epileptic patient's quality of life.

## 5. CONCLUSION

The present study concluded that; epileptic patients are lacking knowledge regarding their condition (58.3% vs 41.7%). There was No significant correlation between total QOL and dis score of knowledge.

#### Recommendation

A self-management program is needed for patients with epilepsy in order to improve their knowledge regarding their

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disease.

## **CONFLICTS OF INTEREST DISCLOSURE**

The authors declare that there is no conflict of interest.

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