

Impact of epilepsy on patient's physical and psychosocial functioning: Iraqi study

Intisar A. G. Khudhur¹, Fakhria J. Mehabet²

1. Assistant Professor, Psychiatric Nursing/ Nursing Faculty, Al-Zaytoonah University, Amman/ Jordan

2. Assistant Professor, Adult Nursing/ Nursing Faculty, Al-Zarkaa University, Al-Zarkaa / Jordan

ABSTRACT

Background: Epilepsy is a common neurological disease, which affect people of all ages. It is stigmatizing, unpredictable and disabling illness.

The primary **objective** of this study was to assess the physical and psychosocial problems facing patients with epilepsy. A total of 100 patients with epilepsy were compared with 100 normal subjects to find out the differences between the two groups regarding the physical and psychosocial problems. The questionnaire was generated from previous studies and the short form healthy survey (SF- 36).

It was modified and tested for validity and reliability.

Results: The mean age of our patients was 32.5 years. 69% from them were single and 68% were male. The result showed that there were statistically differences between the two groups regarding all of the four domains $p=0.000$. Most of the patients complained from threat to death (88%) and they were affected by the social stigma (86%), more than half of the number of the sample didn't know why the attack happened (78%), while half of them were unable to control their disease in spite of taking medication.

Conclusions: This is an Iraq study prepared to understand the effect of epilepsy on patient's physical and psychosocial functioning. It was found that epilepsy has a great impact on patient's life especially on patients psychological functioning with significant differences. Understanding patient's problems can lead to a good progress in nursing assessment, intervention, and reaching the ultimate goal in controlling these problems that are more likely improve quality of their life.

Key words: Epilepsy, impact, quality of life.

CORRESPONDING AUTHOR

Dr. Intisar A. G. Khudhur

Al Mejdaf Street/ Section 5

Telaa Alali

Amman- Jordan

Tel: 00962795968063

Email: intesarabbas1959@yahoo.com

INTRODUCTION

Epilepsy is a neurological disease causing seizures that result from an excessive electrical discharge in the brain, they are sudden, involuntary and time limited alteration in behavior, including change in consciousness, motor activity, autonomic functioning or sensation.¹ Epilepsy, affects 0.5 to 1% of people of whom 60% are estimated to have partial epilepsy.²

The World Health Organization (WHO) 2000 studies found that the global physical, social, and economic consequences of epilepsy are high, accounting for 0.5% of the whole burden of diseases in the world.³ Patients with epilepsy face many uncertainties, regarding the diagnoses of their condition, whether and when the seizures will occur, the nature of the seizures and how best they can be controlled.⁴ The most serious hazard of epilepsy is not the seizures itself, but the associated behavioral and psychosocial problems that are prone to develop in patients with this disorder.⁵ The International League against Epilepsy (ILAE) and World Health Organization (WHO) emphasize on the removal of barriers to a better life for those with this disease.^{6,7}

Relative to other chronic illnesses (asthma, cardiac disorders, and diabetes) the number of psychological problems

has been found more prevalent among persons with epilepsy.⁸ Traditionally, control of seizures in patients with epilepsy is viewed as the most important clinical outcome. Yet, current antiepileptic drugs do not always achieve this; around 30%-40% of the cases remained uncontrolled despite of pharmacological intervention.⁹

A large part of social problems contribute to the overall of therapy's side effect, such as unemployment or underemployment, social isolation, and psychological distress.⁶

These problems may affect the quality of life of people with epilepsy. Many researchers found that persons with epilepsy rated themselves as having a lower quality of life and have more psychological difficulties than other disabled people.¹⁰

There are numerous studies that have evaluated the physical, psychosocial functioning, and the qualities of lives in patients with epilepsy carried out in USA, European countries, and Canada, some of them have similar results the other differs. The majority of past researches conclusions were drawn on wider international countries. Even though the case finding in one country are used to support the health care practice in other countries, however it is possible that differences in cultural

regulations, social conditions and in practice make it difficult to generalize the findings of the studies to other eastern populations.

The complex interrelationships among the psychological, sociological, and physical variables related to living with epilepsy have not been well examined in Arabic countries

These relationships are important also for nurses in planning effective nursing care and interventions. Therefore, the purpose of this research was to identify the physical and psychosocial problems commonly associated with epilepsy which allows for better identification of interventions that are more likely to improve the quality of life of such people.

The aim of this study were to:

- a) Asses the types and the extent of physical, psychological, social and general health perception problems among epileptic patients.
- b) Evaluate the problems facing epileptic patients after comparing them with control group.

Methodology

One hundred patients diagnosed with epilepsy were chosen from neurological outpatient department from two hospitals in Baghdad/ Iraq. A formal

consent was obtained, and all of the patients agreed to participate in this study.

The participants were recruited according to the following criteria:

- 1-Participants should be diagnosed with epilepsy
- 2-Their age should be between 18-60 years old
- 3-Free from any acute disease, and chronic diseases such as diabetes, renal failure, hypertension, cardiac diseases and physical deformities.
- 4-Free from brain tumor, and not treated from psychiatric conditions.
- 5-All the participants receiving a treatment for epilepsy.

The finalized sample size was compared with (100) normal subjects to find out the most common problems facing patients with epilepsy after adjustment for their demographic characteristics.

Instrument: A questionnaire format was designed based on previous studies (10-12), review of literatures related to this study, the short form healthy survey (SF-36) (13,14) and the researchers experience. The questionnaires were modified because we believe that the modification accommodate best to the social culture status of Iraqi epileptic patients The Questionnaires format were used to measure four domains; physical

problems; psychological problems; social and role limitation problems; mental health and general health perception problems.

The Questionnaires consist of 3 points Likert type scale never, sometimes, always.

The final questionnaires format was included two parts:

- 1- The Socio-demographic data, information about the patients and the normal subjects.
- 2- The four domains, the physical problems; the psychological problems; the social and role limitation problems; and the mental health and general health perception.

In order to determine the validity of the questionnaires, they were reviewed by 20 experts most of them agreed about the items and test retest was done.

Answers to the questioners to each item were given on 3 point scale never, sometime, always; for each scale the score was calculated as the mean of response to the items.

Statistical analysis was performed using the Statistical Package for Social Sciences (SPSS) version 11.5 .A descriptive statistics was used to the socio-demographic characteristics of the sample. The frequency and the percentages, in addition T test and F test were used to find out the differences

between the two groups and for data analysis.

Results

Results indicated that most of the patient's age were less than 30 years old (62%) with mean and standard deviation is (31.54±2.05) for the patients and (31.9±2.03) for the normal subjectes, they were single (69%) and (68%) of the studied sample were male. The majority of the patients can only read and write (45%) and (25%) had secondary school level. (38%) of the sample were suffering from epilepsy before 2 years, while (26%) had the disease before 8 years.

To find the real impact of epilepsy on patients, a comparison between responses of the two groups (epileptic and normal subject) was done, result of physical dimension showed that 74% of epileptic patients feared from injury after the attack, while (60%) complain from losing their memory. Almost half of our epileptic sample (48%) was non-compliance with their medication (table 2).

A significant differences were found between the two groups regarding the Psychological problems domain (P= 0.000). Most of them had threatened to death (88%). They had fears from the attack and its sequences (76%), and more than the half of the selected sample

had hopelessness after the attack as shown in table 3.

Table 4 illustrated that most of the patients were severely affected by the social stigma (86%) and felt burden on their family (64%). In the other hand this study result revealed that epilepsy didn't change patient's role in their family.

In regard to mental health and patients perception domain, it was found that there were significant differences between the two groups ($P=0.000$) table 5.

The table shows that two third from patients didn't know why the attack happened (78%) and they were unable to have children (68%), the table also showed that patients always afraid if their children have epilepsy (68%) while half of them think that they were unable to control their epilepsy.

Discussion

Most individuals with epilepsy live outwardly normal lives, but fear from injury, losing memory and anxiety about impending seizures, social stigma, adverse effects of medication, the presence of cognitive or psychiatric complications, and often sleep disturbance can have a negative impact on their life.^{2,5,15}

In comparing the current study results with other studies it revealed that there were some differences in Iraqi patients demographic data, such as age and education status, it was found that the age of the patients in this study were (less than 30) while the patients ages were higher in other studies.^{7,10,11,16}

Most of our respondent patients were single, male, and half of them were (Illiterate/primary level), similar as Mrabet¹⁶ who found that (47.3%) of Tunisian patients were illiterate and had primary level of education. The current study results indicated that the duration of epilepsy was lower than the other studies (based on the comparison with Tunisian patients). Respondents in our study were most likely to say that their epilepsy affected all of the four dimensions negatively but in different percentages. The highest percentage was feeling that epilepsy threatened their life (88%), and social stigma (86%) with significant differences between the two groups ($p=0.000$). physical dimension of our patients not affected by epilepsy so much. patients were afraid from injury which limited their movement. Also most of them loosed their memory and this is may be because drugs side effects. The present study results regarding losing memory were higher than Baker¹¹

who found that less than the half of people living in Iran and in the Gulf were also complaining from loss of memory due to antiepileptic drugs side effect . Moreover, he found that there were a great differences in relation to patients compliance rates with medications in his studied population, however, in this study noncompliance rate were also high (48 % for always and 28% for sometimes) and this is also because of antiepileptic drugs side effect.

The present findings revealed that psychological and mental health and patient's perception domains affected by epilepsy more than physical domain most of the patients had a fear from death, sequences of the attack, hopelessness, which may affected their mental health and had a great impact on their lives.

Earlier studies showed that epilepsy was the cause of a significant level of anxiety to the half of the respondents and perceived by them as affecting many different aspects of their lives, Baker¹⁰ and Colling⁵ in their study's results showed also incident of depression and anxiety among epileptic patients. This should be taking in consideration when trying to help patients with epilepsy. Our result showed that epileptic patients had no fear from marriage and sex but they were afraid if their children have the

same disease. This finding is different from other studies⁵ results who found that people with epilepsy experience difficulty in situations requiring not only intimate contacts with others but also in more superficial situations. Patients also felt stigmatized by their epilepsy and felt burden on their families that makes them feel of low self-stem, with a statistical differences between the two groups this comes in agreement with Baker¹¹, Mrabet¹⁶ and Rajab⁷.

The present study found important differences in patients' perception of their health status more than normal subjects because they were always thinking why the attack happened, Doughty et al.,¹⁷ found in his European study that there were some gaps in knowledge, particularly in issues relating to medication and cause of epilepsy. Our result showed that patients were unable to control the disease which has a great effect on all of their life aspects, such as social relationship, activities, and employment. The findings confirm clearly the impact of epilepsy on patients psychological functioning.

Conclusion

The present study had highlighted the physical and the psychosocial problems affecting epileptic patients. This study revealed that most of the patients

complained from psychological and mental health problems, and there were significant differences found between the two groups related to all of items of psychological problems. The psychological problems had the greatest impact on patients' life.

A large percentage of the sample in the present study reported being stigmatized because of epilepsy and they felt that epilepsy threatened their lives. Nurses play an importance role in the assessment and management of patients with epilepsy. Understanding the most common problems facing them may lead to a good progress in assessment, intervention, and reaching the ultimate goal in controlling these problems that are more likely improve quality of their life.

The researchers recommend further studies to find out the relationship between the socio-demographics variables and the physical and psychosocial problems facing epileptic patients.

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ANNEX

Table 1. Characteristic of 100 patients with epilepsy and the control group

	Characteristic of the sample	Patients		Normal subjects	
		No	%	No	%
1	Age less than 30	62	62	60	60
	31 – 40	21	21	22	22
	More than 41	17	17	18	18
M ± SD		31.54±2.05		31.9±2.03	
Total		100	100	100	100
2	Sex				
	Male	68	68	62	62
	Female	32	32	38	38
Total		100	100	100	100
3	Marital status				
	Single	69	69	60	60
	Married	31	31	35	35
	Divorced	0	0	5	5
Total		100	100	100	100
4	Level of education				
	Cannot read and write	5	5	2	2
	Read & Write	45	45	40	40
	Primary school	25	25	23	23
	Secondary school & above	25	25	35	35
Total		100	100	100	100
5	Duration of disease				
	6 months-2 years	38	38		
	3 years - 4 years	11	11		
	5 years - 6 years	7	7		
	7 years - 8 years	26	26		
9 years -10 years	18	18			
Total		100	100		

Table 2. Comparison between the Physical problems of the two groups

Problems	Patients with epilepsy			F value & P value	Healthy subjects			T value & P value
	Never %	Sometimes %	always %		Never %	Sometimes %	Always %	
Depend on others	40	26	34	F=1264.222 P=0.00	62	20	18	T=3.263 P=0.001
Limitation in daily activities because of feeling of fatigue	78	12	10	F=85.497 P=0.000	100	0	0	T=4.927 P=0.000
Effect of disease on his study or work	58	10	32	F=512.087 P=0.000	100	0	0	T=8.070 P=0.000
Non-compliance with medication	24	28	48	F=482.160 P=0.000	100	0	0	T=15.159 p=0.000
Fear from injury after the attack	10	16	74	F=102.422 P=0.000	100	0	0	T=24.873 P=0.000
Loss of memory	16	24	60	F=235.956 P=0.000	60	14	26	T=6.779 P=0.000
Inability to get driving license	65	0	35	F=354.682 P=0.000	44	0	56	T=3.035 P=0.003*

P=0.000 significant

*Not significant

Table 3. Comparison of the Psychological problems between the two groups

Problems	Patient with epilepsy			F value P value	Healthy subjects			T value &P value
	Never	someti mes	Alwa ys		Ne ver	som eti mes	alway s	
	%	%	%		%	%	%	
Threat to death	0	12	88	67.258	10 0	0	0	T=57.56 3 P=0.000
Perception believe nothing can done to help him	36	24	40	650.400	10 0	0	0	T=11.88 2 P=0.000
Hopelessness after the attack	18	26	56	620.225	10 0	0	0	T=17.79 2 P=0.000
Fear from marriage & sex	66	20	14	116.781	66	22	12	T=0.197 P=0.844
Worry about the cost of drug	24	46	30	715.414	10 0	0	0	T=14.40 1 P=0.000
Fear from side effects of drug	30	20	50	716.362	10 0	0	0	T=13.69 6 P=0.000
Fear from the episodes & its sequences	8	16	76	188.107	10 0	0	0	T=27.20 3 P=0.000

P=0.000 significant

Table 4. Comparison between the social problems of the two groups

Problems	Patient with epilepsy			F value p value	Healthy subjects			T value & p value
	Never	some times	Alwa ys		Neve r	some times	alwa ys	
	%	%	%		%	%	%	
Fear that this disease is a social stigma	6	8	86	44.315 p=0.000	100	0	0	T=33.846 P=0,000
Burdon on family	14	22	64	175.287 p=0.000	70	10	20	T=9.160 P=0.000
Limitation in social activity	36	30	34	899.206 p=0.000	84	6	10	T=6.981 P=0.000
Changed in his family role	62	18	20	389.940 p=0.000	100	0	0	T=7.193 P=0.000
feeling of isolation	56	8	26	672.913 p=0.000	70	6	24	T=1.318 P=0.189 *
Feeling of negligence	54	20	26	716.768 p=0.000	56	12	32	T=0.321 P=0.749 *

P =0.000 significant

Table 5. Comparison between Mental health & general health perception of the two groups

Problems	Patient with epilepsy			F value & p value	Healthy subjects			T value & p value
	Never	someti mes	alway s		Neve r	someti mes	alway s	
	%	%	%		%	%	%	
1-Inability to control the disease	8	42	50	240.982 p=0.000	100	0	0	T=22.240 p=0.000
2-preoccupied if their children have same disease	26	6	68	1637.357 p=0.000	100	0	0	T=16.169 p=0.000

3-Did not know why the attack happen	10	12	78	383.935 p=0.000	100	0	0	T=25.867 p=0.000
4-Inability to have children	26	6	68	1637.357 p=0.000	100	0	0	T=16.169 p=0.000

P=0.000 significant