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Quality of Life in Patients with Epilepsy in the Middle Euphrates Neuroscience Center in Al-Najaf City

Hawra'a Ghannam Abdel-Hussein Al-Nassar, Nursing, University Of Kufa, Faculty Of Nursing, Iraq.

Mobile / 07805434319, e-mail /hawrag.alnassar@uokufa.edu.iq

ABSTRACT:

Epilepsy is defined as a hypersynchronous discharge of a group of neurons at the level of the cerebral cortex, and is expressed through sudden changes in behavior, whose clinical manifestations depend on the site of origin and the cerebral topographic path performed by the brain discharge during its propagation. A Descriptive Cross-Sectional Design is used through the present study in order to : assess the quality of life in patients with epilepsy, and to find out the relationship between patients; quality of life and their demographic and clinical data. The period of the study is from 8th January 2019 to 28th May 2019. A Non-Probability (Purposive Sample) of (31) of epileptic patients, are included in the study. The data were collected through the utilization of the developed questionnaire using an interview technique after the estimation of the validity and reliability of the study instrument. Reliability of the questionnaire is determined by using the Alpha Cronbach's technique, and the validity through (15) experts from different specialties (Face Validity) for reviewing the study instrument. The data was analyzed through using of the descriptive and inferential statistical analysis approaches. The findings of the present study indicate that the overall assessment of patients' responses to the quality of life for patients with epilepsy scale items is (fail), that there is a highly significant correlation between the quality of life for patients with epilepsy and their (age). The study concludes that the level of quality of life of patients with epilepsy is poor. The study recommends that further studies should be carried out to improve and explore effective methods to improve the quality of life of patients of people with epilepsy, and health education programs should be applied to increase the patients' knowledge regarding how to improve their sense of control and the factors affecting their abilities.

KEY WORDS: Assessment, Quality of Life, Epilepsy.

INTRODUCTION:

Globally, epilepsy is a significant public health problem today with 50 million people suffering from it, where in 85% of them are from developing countries (Sureka ., et al, 2017). A World Health Organization (WHO) report estimated that 10% of the global burden of brain and mental disorders is caused by epilepsy, calculated in disability-adjusted life years(Fact sheet, 2008).

Epilepsy is defined as a hypersynchronous discharge of a group of neurons at the level of the cerebral cortex, and is expressed through sudden changes in behavior, whose clinical manifestations depend on the site of origin and the cerebral topographic path performed by the brain discharge during its propagation (Pamela ., et al, 2018).

In 2005, the International League Against Epilepsy (ILAE) defined epilepsy as: "a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure" (International League Against Epilepsy, 2003).
As a condition, epilepsy is misunderstood, leading to fear, secrecy, stigmatization and the risk of social discrimination.1 In some patients, the social stigma and impact on quality of life can pose a greater challenge than the clinical severity(Jacoby A & Austin, 2007). Research assessing the quality of life associated with successful treatment of epilepsy is far behind that of other chronic conditions, such as cancer, diabetes and cardiovascular disease (International League Against, 2003). The International League Against Epilepsy believes however, that with the appropriate treatment, more than three quarters of people living with epilepsy could lead normal lives free of seizures(IBID).

The impact of epilepsy on quality of life can be substantial with far-reaching and life-long consequences because of unpredictable nature, its course, stigma attached to it, poor self-esteem, with higher levels of anxiety, associated depression, educational underachievements, under- or unemployment, less marriages, higher divorce rates, more social isolation, side effects of treatment, and cognitive and psychiatric problems impair quality of life (QOL) in epilepsy patients. The QOL is an individual's perception of their position in life in respect to the culture and value systems in which they live and in context to their goals, expectations, standards, and concerns. A questionnaire that assesses multiple daily functions depending on the cultural, ethnic, and economic differences is QOL(Sureka ., et al, 2016).

Epilepsy can be associated with great physical, psychological, and social consequences, and so its impact on a person's QOL can be more than that of chronic conditions (International League Against Epilepsy, 2003). People with epilepsy have reported a poorer QOL because they have poor self-esteem and a high level of anxiety and depression. In some cases, the social stigma and impact on QOL may pose a bigger challenge than the clinical severity. The important factor for better outcome in the treatment of epilepsy is health-related quality of life (HRQOL). Research assessing the QOL associated with successful treatment of epilepsy lags that of other chronic diseases like cancer, diabetes, and cardiovascular disease. Very few studies have been carried out on quality of life in epilepsy (QOLIE-31) (Sureka ., et al, 2016).

METHODS AND MATERIALS

Design of the Study:

A Descriptive Cross-Sectional Design is used through the present questionnaire study in order to achieve the study objectives. The period of the study is from 8th January 2019 to 28th May 2019.

Setting of the Study:

The study is conducted in Al-Najaf Al-Ashraf City/Al-Najaf Al-Ashraf Health Directorate / Al-Sadder Medical City/ Middle Euphrates Neuroscience Center.

Sample of the Study:

A Non-Probability (Purposive Sample) of (31) who visit Al-Sadder Medical City/ Middle Euphrates Neuroscience Center for treatment or follow up or both, are included in the study sample.

Including Criteria:

The researcher used the following criteria for specifying the study subjects those who are included in the study, patients out of these criteria are basically excluded:

1- All participants are diagnosed with epilepsy for at least six months.
2- The age of the all participants is 20 years old and older
3- All participants are from Iraqi Nationality .
4- Alert patients, free from any change in the level of consciousness.

Study Instrument:

An assessment tool is adopted and developed by the researcher to assess the quality of life for patients with epilepsy. The final study instrument consists of three parts**:**

Part I: Patients' Demographic Data.
Part II: Patients' Clinical Data.
Part III: Quality of Life in Epilepsy Scale – QOLIE- 31.

Data Collection:

The data has been collected through the utilization of the developed questionnaire, and by means of a structured interview technique with the subjects who were individually interviewed, by using the Arabic version of the questionnaire and they were interviewed in a similar way, by the same questionnaire for all those subjects who are included in the study sample. The data collection process has been performed from February 10 , to 4 March 2019. Each subject spends approximately (20-25) minutes to complete the interview.

Validity of the Instrument:

A content validity of the study instrument conducted through a group of experts who have more than 10 years of experience in nursing field.

Statistical analysis:

The data were analyze through application of the descriptive and inferential data analysis methods, included:

- Frequency, percentage, and mean of scores.
- Chi-square.
- Alpha Cronbach for the reliability of questionnaire (Internal consistency).

STUDY RESULTS AND FINDINGS

Table (1) **Distribution of the Study Subjects by their Demographic Data and Clinical Data**

Items	**Sub-groups**	**Patients group** **Total = 31**	
		Frequency	**Percentage**
Age / Years	18-28	20	64.5
	29-39	6	19.4
	40-50	3	9.7
	51-62	2	6.5
Gender	Male	14	45.2
	Female	17	54.8
Marital Status	Single	17	54.8
	Married	14	45.2
	Widowed	0	0.0
	Divorced	0	0.0
	Separated	0	0.0
Residency	Urban	5	16.1
	Rural	26	83.9
Levels of Education	Illiterate	9	29.0
	read and write	5	16.1
	Primary school	3	9.7
	Intermediate school	6	19.4
	Preparatory school	4	12.9
	Institute	0	0.0

	College or Postgraduate	4	12.9
Occupation Status	Governmental Employee	7	22.6
	House wife	15	48.4
	Self-employed	0	0.0
	unemployed	9	29.0
	Retired	0	0.0
Economic Status	adequate	9	29.0
	Adequate to Some Extent	17	54.8
	Inadequate	5	16.1

Table (**1**) shows that the highest percentage of the study sample (64.5%) are within (18-28) years old. Regarding gender, the study results reveals that the majority (54.8%) are females. In addition, the study results present that (54.8%) of the participants are single. Moreover, (83.9%) of the study sample are from rural areas. Regarding the level of education, (29%) of the participants are unable to read or write, while (19,4 %) of them are intermediate school graduates, and (16.1 %) are able to read and write. With regards to the occupational status, (48.4%) of the study subjects are housewives. Concerning the socioeconomic status, (63.3%) of the participants have an income that is adequate to some extent.

Table (3.2) Statistical Distribution of Patients Group by their Clinical Data

Items	**Sub-groups**	**Patients group** **Total = 31**	
		Frequency	**Percentage**
Types of Epilepsy	General	27	87.1
	Partial	4	12.9
Duration / years	1-6	16	51.6
	7-12	13	41.9
	13-18	1	3.2
	19-24	1	3.2
Frequency of fits per month	1-5	29	93.5
	6-10	1	3.2
	11-15	1	3.2

Other diseases	Yes	1	3.2
	No	30	96.8

Table **(2)** reveals that the highest percentage of the study subjects (87.1%) have a general epilepsy, while (12.9 %) of them have partial epilepsy. Concerning the duration of the disease, the study results show that (51.6 %) of the participants have the disease for a duration of (1-6) years.

Table (3): Overall Assessment of Quality of Life for Patient with Epilepsy:

Overall assessment of patients' satisfaction	**MS**	**RS**	**Assessment**
	1.66	**55.44**	**Fail**

Table (3) shows that the overall assessment of patients' responses to the quality of life for patients with epilepsy scale items is (fail).

Table (4): Correlation between Quality of Life for Patients with Epilepsy and their Demographic Data:

Demographic Data	**Correlation Coefficient**	**Significance P value**
Age	0.66	**0.02**
Gender	0.15	**0.14**
Level of Education	0.22	**0.32**
Marital status	0.31	**0.51**
Residence	0.19	**0.72**
Occupational Status	0.36	**0.24**
Economic status	0.35	**0.09**

Table **(4)** shows that there is a highly significant correlation between the quality of life for patients with epilepsy and their (age) at p-value **< 0.02**.

Table (5): Correlation of Quality of Life for Patients with Epilepsy and their Clinical Data

Demographic Data	**Correlation Coefficient**	**Significance P value**
Types of Epilepsy	0.36	**0.22**

Duration / years	0.77	**0.01**
Frequency of fits per month	0.55	**0.04**
Other diseases	0.45	**0.19**

Table (5) reveals that there is a highly significant correlation between the quality of life for patients with epilepsy and the (duration of the disease) at p-value < **0.01**, and significance in relation with (frequency of fits per month) at p-value < **0.04**.

Discussion:

The Quality of Life is a concept, which is understood as the degree of general well-being that a person reaches in his physical, mental and social aspect. In patients with epilepsy, this is compromised because it is a chronic disease that influences the patient's daily life, both personally and socially.

The present study reveals that (18-28) years old is the dominant age group among the study subjects. This result is supported by (Sureka *et al*; 2017) who studied " Quality of Life in Patients with Epilepsy : Study from a Northern Indian Teaching Hospital". They found that more than of the study sample are within the age of (18-28) .

The study results also show that more than half of the study subjects are females and housewives. This result is agreed with (Norsa'adah *et al*; 2013), they conducted a study to assess The quality of life of people with epilepsy at a tertiary referral center in Malaysia. They found that more than of the study sample are females and housewives. Also Unemployment levels are disproportionately high for people with epilepsy; approximately two to three times greater than the general population and higher than is seen in people living with other disabilities.

The study results also reveal that most of the participants are unable to read or write. This result is similar to (Saadi *et al*; 2016) in their study regarding quality of life in epilepsy in Bhutan. They found that most of the study subjects are unable to read or write.

Concerning the socio-economic status, most of the participants have an income that is enough to what limit. This is may be because of the expensive price of medications, transportation, and the most patients have part time work hours due to their illness. In addition, due to the current situations in our country, more than two thirds of the population live in poverty level or below it.

Concerning the type of epilepsy, the study results show that more than two thirds of the participants have general epilepsy with a duration of (1-6) years. This agrees with (A Staniszewska *et al*; 2015) who studied the quality of life in patients with epilepsy and found that most of the study subjects have a general epilepsy with a duration of six years.

The study result show that the overall assessment of quality of life of patients with epilepsy is poor. This result is similar to (Saadi et al; 2016) in their study about quality of life in epilepsy in Bhutan, where they found that the quality of life in Bhutanese PWE was low.

The study results show that there is a highly significant correlation between the quality of life for patients with epilepsy and their (age). In a study in European countries, they found that education was one of the strongest predictors of low health-related QOL in patients with seizure disorders. Previous research has also revealed that higher QOL was associated with younger age, being married, higher educational attainments and higher levels of employment.

The study results reveal that there is a highly significant correlation between the quality of life for patients with epilepsy and the duration of disease and frequency of fits per month. These results come because epilepsy is a chronic disease, and the longer duration of the disease and recurrent fits are associated with increasing awareness of the disease and adaptation to it.

Conclusion :

Based on the study results, the study concludes the following :

1-The level of quality of life of patients with epilepsy is poor.

2- Patients' age, affect their quality of life.

3- The duration of the disease and frequency of fits per month affect the quality of life of patients with epilepsy.

Recommendations :

Based on the study results and conclusion, the study recommends that:

1-Further research should be carried out to improve and explore effective methods to improve the quality of life of patients of people with epilepsy.
2-Health education programs should be applied to increase the patients' knowledge regarding how to improve their sense of control and the factors affecting their abilities.
3-A multidisciplinary management of these patients is required, with the objective not only of achieving .1 total control of the crises, but also of the patient having the tools to overcome the daily impact that this disease generates on their quality of life with the aim of achieving psychosocial adaptation of the patient and overcome the stigmas that these patients may have and thus contribute to improving the quality of life.

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