

## Effect of a Designed Educational Protocol on Quality of Life among Patients with Epilepsy

Eman Abd-Elrahman Mohamed<sup>1</sup>, Soad Mohammed Abd-Elghany<sup>2</sup>, Dalia Mohamed Abdelkhalik Kishk<sup>3</sup>, Rasha Hassan Abass Shady<sup>4</sup>

<sup>1,2</sup> Lecturer of Medical Surgical Nursing, Faculty of Nursing, Mansoura University

<sup>3</sup> Lecturer of Community Health Nursing, Faculty of Nursing, Mansoura University

<sup>4</sup> Assistance prof of Medical Surgical Nursing, Faculty of Nursing, Mansoura University

\*Corresponding author: Eman Abd-Elrahman Mohamed, email: eal\_eman@mans.edu.eg

### Abstract

**Background:** Epilepsy is a disabling neurological disorder worldwide, affecting quality of life, which imposes a great burden on patients and their caregivers. Improving the quality of life is precisely one of the main objectives of therapeutic education, which are considered the gold standard in the delivery of health care. **Aim:** To evaluate the effect of a designed educational protocol on quality of life among patients with epilepsy. **Design:** A quasi-experimental research design using a one-group (pre-posttest) approach was used. **Setting:** The study was conducted at inpatient neurological department and outpatient clinics affiliated to Mansoura Main University Hospital. **Subjects:** A purposive sample of 100 patients diagnosed with epilepsy were selected. **Tools:** Four tools were used for data collection: Tool I: Structured interview questionnaire, Tool II: Knowledge assessment questionnaire, Tool III: Epilepsy self-management scale, and Tool IV: Quality of life in epilepsy inventory-31(QOLIE-31) scale. **Results:** There was a high statistically significance difference in the total mean score of knowledge, self- management practices, and quality of life pre and post implementing the designed educational protocol among the studied patients ( $p < .001$ ). There was a significant positive correlation between the total score of knowledge, self- management practices among the studied patients and their quality of life at 3 and 6 months post implementing the designed educational protocol ( $p < .001$  &  $p = .006$ ;  $p = 0.022$  &  $p = 0.041$ ) respectively. **Conclusion:** The designed educational protocol proved that, there was an improvement in the knowledge and self- management practices total scores of the studied patients, which consequently had a positive effect on their quality of life. **Recommendation:** The designed educational protocol should be planned in a continuous manner and applied on regular basis to patients with epilepsy.

**Keywords:** Designed educational protocol, Epilepsy, Quality of Life of epilepsy has been detected to have decreased from 1990 to 2016, but it rests an essential cause of mortality and morbidity.<sup>(2)</sup>

### Introduction

Epilepsy is a serious neurological disease characterized by unpredictable, unprovoked frequent seizures, which are sudden and abnormal rushes of electrical activity in the brain that have an impact on both physical and mental abilities.<sup>(1)</sup> Epilepsy affects people of all ages, race, social class, and geographical regions. The worldwide burden

In the recently published report on the global burden of disease study classifies epilepsy as the second most burdensome neurological condition regarding the disability-adjusted life years.<sup>(3)</sup>

According to World Health Organization (WHO), the prevalence of epilepsy is about 50 million people worldwide making it the

most common chronic neurological disorder globally.<sup>(4)</sup>The prevalence of seizures in united states is approximately 7 to 15 cases per 1000 person in overall population, affecting more than 2.5 million people.<sup>(5)</sup> While, in Egypt, the prevalence of epilepsy was estimated to be 9.98/1000;<sup>(6)</sup> with a lower prevalence among adolescents than children below 12 years.<sup>(7)</sup> In Arab countries, the prevalence and incidence of epilepsy varies. Moreover, the researches shows a high prevalence rate of epilepsy in Egypt comparable with that in other Arabic and European countries with a higher rate in the rural than in the urban population.<sup>(8&9)</sup>

Epilepsy have numerous underlying causes and several risk factors have been reported including, genetic background, brain tumor, trauma, stroke, infection, metabolic disturbances, autoimmune reactions, chemical exposures, and neuro-developmental disorders.<sup>(10)</sup> The individuals with epilepsy experienced symptoms can varied broadly, based on the region of the brain that affected, and may include abnormal movements, unusual sensations, emotions, behaviors, convulsions, or even loss of consciousness.<sup>(11)</sup>

Epilepsy has physical, cognitive, psychological, and social consequences and becomes the most devastating brain disorder when seizures are not effectively controlled well, that severely impacting the quality of life(QOL).<sup>(12)</sup> Quality of life is a broad concept applied to the totalilty of physical and psychosocial functions, it defined as the perception of the individuals of their position in life concerning the value systems and culture in which they live and in relation to their beliefs, goals, expectations, concerns, and standers. It is found that, QOL of patients with epilepsy is lower than that of

patients with other chronic disorders, whereas epilepsy has a massive effect on the essential health aspects of QOL which interfering with routine patients daily living activities.<sup>(13)</sup>In addition, seizures are impulsive and frequently debilitating, likely to influence daily activities and have a negative impact of QOL in patient with epilepsy. After seizure, mainly its recurrence and uncontrolled nature, a variety of physical harms can occur, ranging from wounds to sudden death.<sup>(14)</sup>

Besides having a physical impact, epilepsy is often linked with various psychosocial concerns affecting the individual's QOL.<sup>(15)</sup> Depression, anxiety disorders, psychosis and suicidality are the utmost common mental health conditions in patients with epilepsy which is 2–3 times higher than the general population.<sup>(16)</sup> Furthermore, patients with epilepsy experienced psychological problems has major negative effects on their QOL than seizures themselves.<sup>(17)</sup>For centuries, despite a realistic change in mentalities, the epilepsy still remains has sparked fear, misunderstanding, and social stigmatization.<sup>(18&19)</sup>A socially feared disease with sometimes inexplicable and even creepy outbursts that can be seen as shameful for the patient when they happen in public.<sup>(20)</sup>

Because of all these problems, in addition to anti-seizure medication therapy, education provided to patient and the patient's family become more essential and critical.<sup>(21)</sup>The QOL has been described as pragmatic end point in the care of patients with epilepsy. It is becoming widely understood that evaluating a patient's QOL is crucial to managing their epilepsy. The care of patients with epilepsy remains essential in a more global way to improving their QOL, which is

specifically one of the main goals of therapeutic education, and it is no longer limited to the simple control of seizures.<sup>(22)</sup>

The nurse can play a central role in improving QOL of patients with epilepsy through counseling the patients and their family. These nursing efforts can help patient for therapy adherence and result in superior long-standing management with better seizures control and minimize side effects of medications that upset patient QOL.

A lack of structure and inability to meet the epileptic patients' needs to cope with their disease is one of the insufficiencies in existing primary care for patients with epilepsy that are well-recognized, Therefore a bundle of care should established to assist epilepsy management in the community and improving their QOL through, applying a comprehensive epilepsy education.<sup>(23)</sup>

Protocols, guidelines, checklists, and care bundles are strategies used to encourage the constant delivery of high quality care; but, for these to be effective, they must be suited for the task at hand and applied correctly. Epilepsy specialist nurses can embrace a dynamic role and efficiently convey this protocol. This will increase patient's knowledge, compliance to management plan, promote their self-efficacy to care for themselves, improve their QOL, and it could be reduce patient morbidity and mortality rates.<sup>(24)</sup>

### **Significance of the study**

Epilepsy is a multifaceted neurological condition in developing countries. It was found that, in Egypt, the incidence rate of epilepsy was higher than that reported in New York, United State, and in the Netherlands.<sup>(25)</sup> According to the **(Statistical record of MUH, 2022)**, epilepsy represented

about 58% of all neurological diseases diagnosed during the years 2021-2022.<sup>(26)</sup> Epilepsy characterized by frequent seizure attacks, has its impact on overall QOL. The QOL is considered a significant healthcare outcome measure.<sup>(27)</sup> Through providing relevant information with high professional experienced nurses can help relative's extension a greater sense of control, which is basic for self-management and optimal QOL.<sup>(28)</sup>

However, the research area is home to a huge number of patients with epilepsy, there are limited studies on the QOL of adult patients with epilepsy in developing countries like Egypt. Despite, deficiencies in caring of patient with epilepsy are well determined in Egypt, patients are still discharged from the health care facility with no education, signifying a chief problem with their treatment.<sup>(29)</sup>

Because of located a high treatment gap, a multifactorial method is needed for improvement of this gap and appropriate control of epilepsy. In Egypt, it was found that, adequate patients training contributes to manage annoying epilepsy. Patients with epilepsy have different educational desires and needs to implement many self-control practices to manage their disease.<sup>(30)</sup> As improving the QOL among patients with epilepsy through applying the DEP that can be effective. When reviewing the literature in Egypt, researchers found limited studies regarding QOL of adult patients with epilepsy. Therefore, the current study conducted to evaluate the effect of a designed educational protocol (DEP) on QOL among patients with epilepsy.

### **Aim of the study**

To evaluate the effect of a designed educational protocol on quality of life among patients with epilepsy.

### Research Hypothesis

**H1:** Patients' knowledge score about epilepsy is expected to be improved post implementation of the designed educational protocol.

**H2:** Patients' self- management practices score about epilepsy is expected to be improved post implementation of the designed educational protocol.

**H3:** Patients will exhibit improvement in QOL domains post implementation of the designed educational protocol.

**H4:** Patient' knowledge and self-management practices has a positive effect on epilepsy QOL post implementation of the designed educational protocol.

### Operational Definition

#### Designed educational protocol.

Scientifically written instructions that guide, support and educate patients in the specific steps to be taken and help patients making decisions regarding appropriate health care. The DEP for patient with epilepsy includes: improving patients' knowledge about the epileptic disease, promoting self-management practices and enhancing their QOL.<sup>(31)</sup>

### Subjects and Method

#### Study design

A quasi-experimental research design using one group (pre-posttest) method was used to accomplish this study.

#### Setting of the study

The current study was conducted at inpatient neurological department along with outpatient clinics affiliated to Mansoura Main University Hospital. The neurological department consisted of two units (A&B) composed of 42 beds. Neurology (A) unit

caring for males patients and consisted of two rooms with 19 beds. While neurology (B) unit for females patients, and consisted of three room with 23 beds.

### Subjects

A purposive sampling technique of 100 patients was selected from the mentioned setting according the following:

#### -Sample size calculation:

Steve Thompson formula was utilized to calculate the sample size, at 5%  $\alpha$  error (95.0% significance) and 20.0  $\beta$  error (80.0% power of the study).<sup>(32)</sup>

$$N = \frac{N \times P (1-P)}{(N-1 \times (d^2 / Z^2)) + P (1-P)}$$

n= Sample size

N= Total society size (360 patients)

Z= the corresponding standard class of significance 95 d=error percentage = (0.05) =1.96.

P=percentage of availability of the character and objectivity= (0.5)

d =error percentage = 0.05. The sample size was calculated to be 100 patients.

- **Patients' inclusion criteria:** Conscious patient, aged from 20-60 years, diagnosed with epilepsy at less than six months duration, from both genders, with different level of education and occupation, and who agreed to participate in this study.

-**Patients' exclusion criteria:** Patient with epilepsy suffering from other conditions which could affect QOL such as: neurological diseases such as brain tumor and stroke; co-morbid neurodevelopmental disorders; patients with seizures secondary to neurological infections or substance abuse as alcohol withdrawal seizure; functional neurological symptom disorders, pregnant women, and in addition to cognitive and communication impairment.

### **Tools for Data Collection**

The researchers used four tools for data collection as the following:

**Tool I: Structured interview questionnaire.** This tool was developed by the researchers to collect the required baseline data based on extensive reviewed literature.<sup>(10, 11, 15&33)</sup> It involves two parts as the following:

**Part (1): Socio- demographic characteristics.** This part was utilized to assess patients' socio- demographic data regarding age, gender, level of education, occupation, marital status, monthly income, and area of residence.

**Part (2): Clinical- relevant data.** It contained items related to the age of onset of the first attack of epilepsy, duration of disease, type of seizure, family history, prescribed medication, presence of aura, seizure triggers, seizure frequency during the last month, duration of seizure per minut, and seizure frequency per month.

**Tool II: Knowledge Assessment questionnaire:**

The researchers developed this tool after studying literatures.<sup>(34,35,36 &37)</sup> It Included 8 items to assess the patients' knowledge level regarding different aspect of epileptic disease such as: definition, causes, seizure triggers, symptoms that precede the occurrence of seizure, manifestations of epilepsy, epilepsy problems and complications, risks that should be avoided to prevent hazards during seizure attacks, and side effects of anti-epileptic drugs.

**Scoring system.** The patients' answers regarding each knowledge question were scored from a 3-point Likert scale; a score 2 was given to correct and complete answer, while score 1 for the correct and incomplete answer, and score 0 was given to wrong

answer or don't know. Based on **Assar et al. (2022),<sup>(38)</sup>** the total possible score ranged from 0-16 with higher scores indicating high level of knowledge.

**Tool III: Epilepsy Self- Management Scale:**

This tool was adopted from **Begley et al., (2018)<sup>(39)</sup>** to assess self- management practices frequency among patients with epilepsy. This scale contained 5 subscale into which 38 questions are divided as the following:

- **Lifestyle management:** this subscale contained questions regarding stress management, sleep, exercise, diet, and personal hygiene especially mouth care.
- **Medication management:** included questions used to assess antiepileptic drug compliance, skipping doses, follow up, handling medication running out, and antiepileptic drug refill.
- **Safety management:** contained questions regarding staying out late at night, swimming precautions, using power tools, bathing safety, medication safety, climbing objects, drinking a lot of coffee and cigarettes smoking.
- **Seizure management:** this subscale included questions used to assess seizure control practices such as avoiding seizure triggers, notifying the doctor about having frequent seizures than usual, keeping seizure medication when going away from home, performing blood tests as the doctor orders, having ways of reminding to take seizure medication.
- **Informative management practices:** included questions to assess information about keeping seizure frequency diary, keeping record of experienced types of seizures, reporting physician in case of antiepileptic drug side effects, carrying

information pointing having epilepsy, community support and socialization.

### Scoring System

Each question on the scale is rated on a 5-point Likert scale from never do (1) to always do (5). The total possible score ranged from 38-190 with higher overall scores indicating more frequent use of self-management practices.

### Tool IV: Quality of Life in Epilepsy Inventory- 31 (QOLIE-31) Scale

The researchers adopted this tool from **Cramer (2019)**<sup>(40)</sup> to assess the QOL, in addition to evaluate the effect of a DEP on QOL among patients with epilepsy. This tool included 31 items. It comprised seven multi item scales that include the following health domains as the following:

- **Energy/ fatigue effect:** this domain included 4 sub items used to assess patient's energy and tiredness.
- **Emotional well-being:** included 5 sub items to assess patient's feelings.
- **Cognitive functioning:** contained 6 sub items used to assess problem solving abilities, memory problems, concentration on reading and concentration on doing a thing at a time.
- **Social functioning:** included 5 sub items used to assess social limitations, leisure time activities, driving and transportations, and work limitations.
- **Medication effects:** contained 4 sub items used to assess physical and mental effects of antiepileptic drug, and worry about taking antiepileptic medications for a long time.
- **Seizure worry:** it included 5 sub items to assess seizure worry.
- **Overall quality of life:** this domain comprised 2 sub items which cover questions regarding how epileptic patient

will feel and how things have been for the patient during the previous 4 weeks.

### Scoring System

The scores of subscales are calculated depend on the mean from each subscale items, while the product of the mean subscale scores and specified weights used to obtain the overall score. The weights were determined by regressing an external measurement of QOL on the subscale scores. The first question within the QOLIE-31 (“Overall, how would you rate your QOL”) is scored as 0 for (“Worst possible QOL”) to 10 (“Best possible QOL”), then multiplied by 10 to create scores that ranged from 0 to 100, with higher scores reflected a better QOL.

### Validity and Reliability

**Validity:** A panel of ten professional expertise from neurology, medical-surgical nursing, community health nursing, and medical biostatistics reviewed the study tools to evaluate its content validity for relevancy, clarity, simplicity, comprehensiveness, and applicability. According to **Güven and İsler (2015)**, ten experts were enough to offer a feedback for content validity.<sup>(41)</sup> All suggested modifications were done by the researchers, then the final tools format was prepared. **Reliability:** The internal consistency of the study tools was assessed by using Cronbach's Coefficient alpha. This technique indicated high reliability of the final version of the tools. The correlation coefficient were: Tool II (r) =0.903 , Tool III (r) = ranged from 0.81 to 0.84 and tool IV (r)= 0.898.

### Pilot Study

A pilot study was carried out by the researchers on ten percent of patients (n=10)

who were excluded from the study sample to evaluate the tools' clarity, feasibility, and applicability and to estimate the required time to fill out the study tools. The pilot trial confirmed the viability, efficacy of the study tools. Accordingly, the necessary modifications were done in the form of adding questions about the effect of antiepileptic drugs in tool (II).

### **Ethical considerations**

- An ethical approval was obtained from Research Ethical Committee, Faculty of Nursing, Mansoura University on the study proposal with **(IRP: Ref. No.p.0432)**.
- After clear explanation was given about the importance, nature, and expected outcomes of the study, the researchers obtained an official approval from the managers of the study setting to carry out the current study.
- Informed consent was taken from each study patient after explanation the purpose and nature of the study.
- Anonymity, privacy, confidentiality, and security were absolutely warranted during the research phases as well as the right to withdraw from the study at any time without penalty.
- Respect for values, culture, ethics, and beliefs was shown.

### **Fieldwork and Data collection:**

Data collection covered 7 months started from the beginning of March, 2023 to the end of September, 2023, data were collected during morning and afternoon shifts. The field work was carried out throughout four phases in order to achieve the aim of the current study as the following:

#### **Phase(1): Preliminary / assessment phase:**

In this phase, the researchers started with stating the study problems, and formulating

hypothesis. The study tools were designed after the researchers acquainted with the extent of the study hypothesis. Tools (I&II) were developed by the researchers after an extensive reviewed literature, while the standardized tools (III&IV) used without any content modifications.

The final English version of the tools was translated into Arabic to be simple and clear to the patients and were reviewed by experts to test the content validity and evaluate the Arabic version of the tools in terms of relativity. Then the final Arabic version of the tools were piloted for possible modifications and then settled for data collection. Written approval to conduct the study was assembled from the relevant authorities before the beginning of data collection.

Afterward, the researchers coordinated the study procedure with the health care givers after a clear and full explanation of the study aims and nature. As a part of the standard pre-test assessment, each patient was interviewed individually to collect baseline data using all the study tools after the researchers introduced themselves; explaining the study nature, purpose, and plan; confirming disclosure of the collected data, that will be used only for scientific study, and after reiterating the approval from each patient.

After that, each educated patient was asked to fill out the questionnaire using tools **(I, II, III, IV)** to assess patients' socio-demographic and clinical relevant data, knowledge, practices, and QOL. While the researchers filled out the questionnaire for non-educated patients. The pre-test questionnaire took about 25-30 minutes. Afterward, the data from 100 completed questionnaires were obtained and analyzed to assess patients'

knowledge, practices, and QOL before implementing DEP.

### **Phase (II): Planning phase/ Development of the Designed Educational Protocol**

This phase based on the preliminary/ assessment data, patients' expectations, and recent literature.<sup>(42&43)</sup> The researchers developed the DEP to enhance QOL for studied patients through improving their knowledge and practices.

The researchers used "a step-by-step guide" that developed by **Modernisation Agency and the National Institute for Clinical Excellence (2002)**,<sup>(44)</sup> as a reference to design the current educational protocol which comprises the following steps: select and prioritize a topic, agree objectives, establish a team involve experts, construct awareness and commitment, collect information, baseline assessment, and create the protocol. The educational protocol was designed in a printed Arabic booklet with simple pictures included theoretical content and procedures for fits management, and then revised by specialized professors.

### **Phase (III): Implementation of the Designed Educational Protocol**

This phase was conducted through three sessions, the duration of each session ranged from 40-45 minutes according to the patients' needs and condition. Teaching sessions were conducted three days per week through face to face using different teaching methods (lectures and group discussion). Each patient received a copy of the printed Arabic booklet to ease and assist remembering the knowledge and practices during the DEP implementation.

Patients were informed about the time of the next session at the end of the current session.

Each session was started by a summary about what has been discussed in the previous one and awarding the objectives of the new session, also, the researchers ended each session by a summary of its content and taken feedback from the patients to ensure that they got the extreme benefit. The DEP content was covered into three sessions as follows:

- **First session:** This session involved information about the medical aspect of epilepsy including: definition, causes, and types of epilepsy, predisposing factors of seizures, manifestations and complications of epilepsy, anti-epileptic drugs side effects, and risks that should be avoided to prevent hazards during seizure attacks.
- **Second session:** Included education regarding self- management procedures covered the following areas: medication management; important of adherence and consequence of non-adherence, dietary management to reduce anti-epileptic drug side effects, first aid management of seizures, and safety management activities to minimize the occurrence rate of epileptic seizures.
- **Third session:** This session contained activities regarding life-style modification, daily living activities, exercises, stress management, and informative- management. In addition, the half time of this session was assigned for reinforcement and answering of the patients' questions.

### **Phase IV: Evaluation Phase**

After implementing the DEP, patients' knowledge, self- management practices, and QOL were reassessed using tools (**II, III, and IV**). This phase was carried out two time; the first time was at 3 months post



implementing the DEP, and then, reassessment for retention was carried out at 6 months post implementing the DEP using the same tools.

### Statistical analysis:

All statistical analyses were performed using SPSS for windows version 20.0 (SPSS, Chicago,IL). Continuous data were normally distributed and were expressed in mean  $\pm$  standard deviation (SD). Categorical data were expressed in number and percentage. Correlation co-efficient test was used to test for correlations between two variables with continuous data. The reliability (internal consistency) test for the questionnaires used in the study was calculated. Statistical significance was set at  $p < 0.05$ .

### Results

Table(1): Socio-demographic characteristics among the studied patients: This table shows that, the mean age of the studies patients was 36.8 (10.3) ranged between the age 20 to less than 40 years old. Regarding gender and marital status, more than half of the studied patients (56%) males, and (57%) unmarried. While about one third of them (43%) had secondary education, and (35%) were employed. Concerning monthly income and area of residence, it was found that, approximately two third of the studied patients do not have enough monthly income, and they were living in rural area (65% & 66%) respectively.

Table (2): Clinical relevant data among the studied patients: This table reveals that, the studied patient's median age at the first attack with epilepsy was 28.9 (10.9), 82% of studied patients had generalized seizure, while more half of them 58% followed a prescribed poly-therapy medication.

Concerning seizure triggers, it was estimated that, 42% of studied patients had physical and psychological stressors. It was found that, approximately two third of studied patients (65%) experienced more than two seizures attack in the last month, and more than half of them (55%) experienced more than two frequent seizures monthly. While the mean duration of seizure was lasted 3.3 (1.6) per minute.

Figure(1): Comparison of knowledge total mean score pre-test, 3 months, and 6 months post implementing the DEP: This figure portrays that, there was a high statistically significance difference in the knowledge total mean score between pre and 3 months post DEP implementation among the studied patients  $P < .001$  with total mean 6.4 (2.2), 14.2 (1.4) respectively. Also this figure presents that, there was a high statistically significance difference in the knowledge total mean score between pre and 6 months post DEP implementation among the studied patients  $P < .001$  with total mean 6.4 (2.2), 12.8 (1.5) respectively. On the other hand, the table result interprets that, there was a slight decline in the knowledge total mean score at 6 months post implementing DEP compared to 3 months post implementation.

Figure (2): Comparison of self- management practices total mean score pre-test, 3 months, and 6 months post implementing the DEP: This figure presents a high statistically significance difference in self- management practices total mean score between pre and 3 months post DEP implementation among the studied patients  $P < .001$  with total mean 112.1(6.5), 175.7(3.9) respectively.

Also, there was a high statistically significance difference in self-management

practices total mean score between pre and 6 months post DEP implementation among the studied patients  $P < .001$  with total mean 112.1(6.5), 167.3(4.7) respectively. The table result interprets that, there was a slight decline in the total mean score of self-management practices at 6 months post implementing DEP compared to 3 months post implementation of the DEP.

Table (3): Comparison of QOL domains scores and total mean score pre-test, 3 months, and 6 months post implementing the DEP: This table shows that, there was a high statistically significance difference in the mean scores of all QOL domains pre-test, 3 months, and 6 months post DEP implementation among the studied patients ( $P < .001$ ).

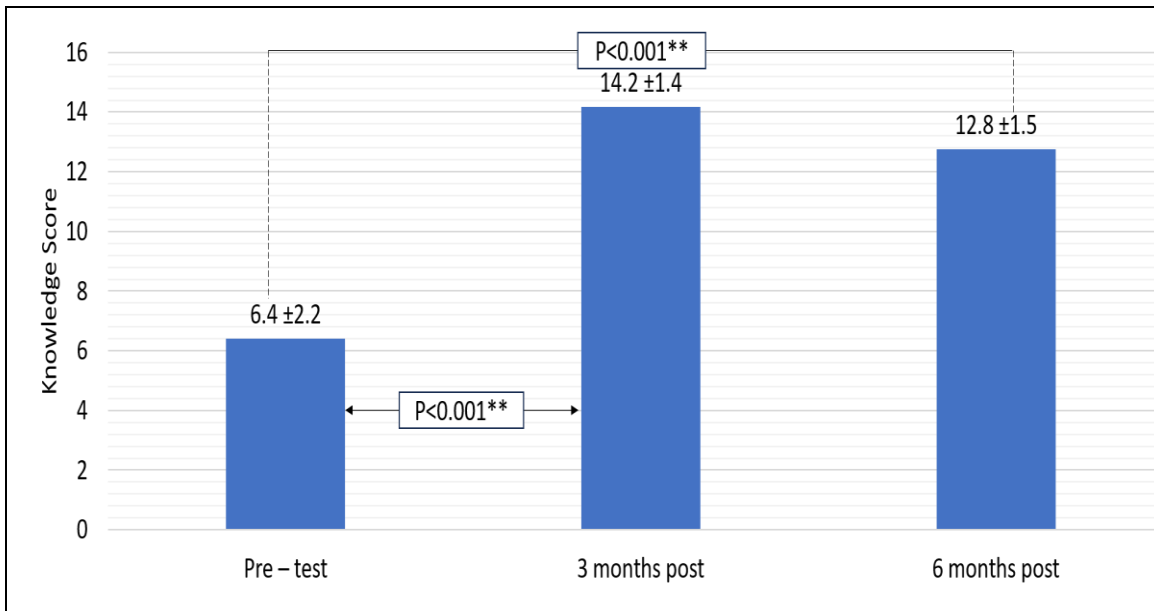
Also it was reveals that, there was a high statistically significance difference in the QOL total mean score between pre and 3 months post implementing the DEP, and between pre and 6 months post DEP implementation ( $P < .001$ ), with the total mean 28.8(7.2) & 60.5 (15.9), 28.8(7.2) & 52.9 (10.3) respectively. The table results interprets that, there was a slight decline in

the QOL total mean score at 6 months post implementing the DEP compared to 3 months post implementation.

Table (4): Correlation between knowledge, practices and QOL total mean scores pre, 3 months, and 6 months post implementing the DEP. The table illustrates that, there was no significant correlation between the total mean score of knowledge and self-management practices among the studied patients and their QOL total mean score pre implementing the DEP ( $p = 0.366$  &  $p = 0.976$ ) respectively. While, there was a significant positive correlation between total mean score of knowledge and self-management practices among studied patients and their QOL total mean score at 3 months and 6 months post implementing the DEP among the studied patients ( $p < .001$  &  $p = .006$ ,  $p = .022$  &  $p = 0.041$ ) respectively.

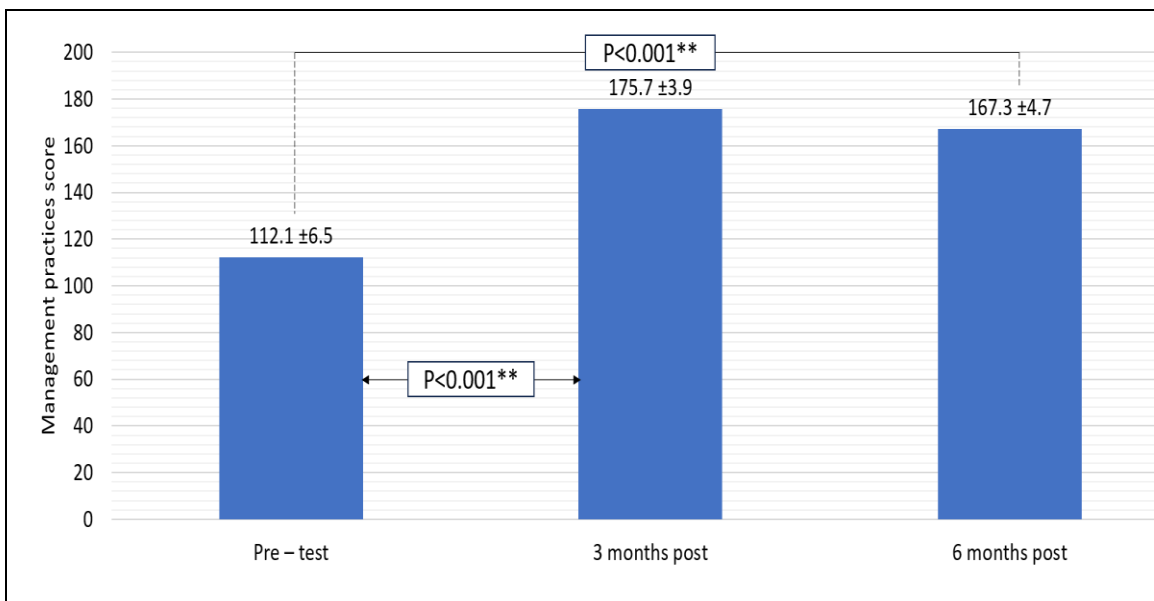
<b>Table 1. Socio-demographic characteristics among the studied patients N=100</b>		
<b>Items</b>	<b>N</b>	<b>%</b>
<b>Age (Years)</b>		
20 – < 40	79	79
40 – < 50	15	15
50 – 60	6	6
<b>Mean (SD)</b>	<b>36.8 (10.3)</b>	
<b>Gender</b>		
Male	56	56
Female	44	44
<b>Marital Status</b>		
Married	43	43
Unmarried	57	57
<b>Level of education</b>		
Uneducated	15	15
Primary	30	30
Secondary education	43	43
Higher education	12	12
<b>Occupation</b>		
Employed	35	35
Unemployed	33	33
Housewives	32	32
<b>Monthly income</b>		
Not enough	65	65
Enough	35	35
<b>Area of residence</b>		
Urban	34	34
Rural	66	66

<b>Table 2. Clinical relevant data among the studied patients N=100</b>		
<b>Items</b>	<b>N</b>	<b>%</b>
<b>Age of onset of the first attack of epilepsy (years)</b>		
< 20	53	53
20 – < 40	30	30
40 – 60	17	17
<b>Mean (SD)</b>	<b>28.9 (10.9)</b>	
<b>Family history of epilepsy</b>		
Absent	81	81
Present	19	19
<b>Type of seizure</b>		
Partial	18	18
Generalized	82	82
<b>The prescribed medication</b>		
Mono – therapy	42	42
Poly – therapy	58	58
<b>Presence of aura</b>		
Absent	74	74
Present	26	26
<b>Seizure triggers</b>		
Noncompliance with medication	30	30
Insufficient sleep or interrupted sleep	9	9
Stressors (psychological & physical)	42	42
Menstruation (in females)	12	12
Hunger	7	7
<b>Numbers of seizures in the last month</b>		
≤ 2	35	35
> 2	65	65
<b>Seizure frequency per month</b>		
≤ 2 per month	45	45
> 2 per month	55	55
<b>Duration of seizure per minute / Mean(SD)</b>	<b>3.3 (1.6)</b>	



**Figure 1. Comparison of knowledge total mean score between pre – test, 3 months post, and 6 months post**

\*: Statistically significant at  $p \leq 0.05$



**Figure 2. Comparison of self- management practices mean score between pre – test, 3 months post, and 6 months post**

\*: Statistically significant at  $p \leq 0.05$

**Table 3. Comparison of quality of life domains scores and the total mean score pre, 3 months, and 6 months post implementing the DEP**

Items	Pre – test	Immediate post	Post 6 month	Student's T – Test			
	Mean ±SD	Mean ±SD	Mean ±SD	T1	P1	T2	P2
Energy/fatigue health	30.0 ±10.7	62.3 ±10.1	58.1 ±9.9	21.952	<0.001* *	19.276	<0.001* *
Emotional well-being	28.8 ±9.3	63.7 ±4.6	58.0 ±5.4	33.637	<0.001* *	27.152	<0.001* *
Cognitive functioning	27.1 ±5.2	63.7 ±6.6	54.6 ±5.7	43.559	<0.001* *	35.383	<0.001* *
Social functioning	30.5 ±6.2	63.8 ±8.3	47.9 ±13.7	32.142	<0.001* *	11.571	<0.001* *
Medication effects	32.1 ±8.1	45.8 ±8.9	42.4 ±8.5	11.384	<0.001* *	8.772	<0.001* *
Seizure worry	33.5 ±5.4	55.9 ±12.7	54.1 ±13.5	16.231	<0.001* *	14.167	<0.001* *
Overall QOL	25.1 ±6.3	50.2 ±10.1	48.4 ±9.6	21.085	<0.001* *	20.291	<0.001* *
<b>Total QOL Score</b>	<b>28.8 ±7.2</b>	<b>60.5 ±15.9</b>	<b>52.9 ±10.3</b>	<b>18.161</b>	<b>&lt;0.001* *</b>	<b>19.177</b>	<b>&lt;0.001* *</b>

**T1: Student's T – Test performed on pre – test with immediate post,**

**T2: Student's T – Test performed on pre – test with Post 6 months**

**\*: Statistically**

**significant at  $p \leq 0.05$**

**Table 4. Correlation between knowledge, self- management practices and quality of life total mean scores pre, 3 months, and 6 months post implementing the DEP**

Items	Knowledge		Management practices		Epilepsy quality of life	
	r	P	R	P	r	P
Pre – Test						
Knowledge	-	-	0.055	0.589	0.091	0.366
Management practices	0.055	0.589	-	-	0.003	0.976

**r: Pearson coefficient**

**\*: Statistically significant at  $p \leq 0.05$**

Epilepsy quality of life	0.091	0.366	0.003	0.976	-	-
<b>3 months post</b>						
Knowledge	-	-	0.282	0.004*	0.408	<0.001**
Management practices	0.282	0.004*	-	-	0.275	0.006*
Epilepsy quality of life	0.408	<0.001**	0.275	0.006*	-	-
<b>6 months post</b>						
Knowledge	-	-	0.209	0.037*	0.229	0.022*
Management practices	0.209	0.037*	-	-	0.205	0.041*
Epilepsy quality of life	0.229	0.022*	0.205	0.041*	-	-

## Discussion

Epilepsy is one of the most prevalent neurological disorders, that has various physical and psychosocial consequences, which can have adversative impact on the patient's QOL.<sup>(45)</sup> Inadequate education is one of the most frequent reasons and considered a wide problem for medication non-adherence producing 'break through' seizures.<sup>(46)</sup> Thus, education for the patient with epilepsy is consider the main and primary supports in order to improving their knowledge, practices, coping and enhancing QOL.<sup>(47)</sup> So, this study aimed to evaluate the effect of a DEP on QOL among patients with epilepsy.

Regarding socio-demographic characteristics, the current study reveals that, the mean age among the studied patients was 36.8 (10.3), this finding supported by **Mohamed et al., (2023)**<sup>(48)</sup> who reported that, epilepsy was more prevalent in young age, and the neoplasms and cerebrovascular diseases are the most common risk factors associated with new-onset epilepsy in adults aged 20–49 years, followed by intellectual disability, alcohol,

substance misuse, and traumatic brain injury. These conditions may be linked to common risk factors of epilepsy at this young age.

The current study shows that, more than half of the studied patients were males, which is consistent with the findings by **Abdel-Whahed, Shaheen, Thabet, and Hassan, (2022); Peterson, Piccenna, and Williams, (2021); Mersal, Qalawa, and Algharib, (2021)**,<sup>(8,49&50)</sup> reported that, the occurrence of epilepsy was higher in men than women. In contrast, the results by **Reddy et al., (2021); Al Rumayyan et al., (2023)**<sup>(51&52)</sup> revealed that, the higher prevalence of epilepsy was among females than males, from their point of view that, women exhibit greater fluctuations in seizure susceptibility including catamenial seizures associated with the menstrual cycle, in addition to, gender differences of epileptic seizures are related to endogenous inhibitory neurosteroids and steroid hormones.

The current study represents that, about two thirds of the studied patients do not have sufficient monthly income, and live

in rural area. These findings came in the same line with the results of the studies conducted by **Zydan, Abo-Elkheir, and Osman, (2022)**; **Sehlo et al., (2022)**,<sup>(9&53)</sup> revealed that, overall the prevalence of epileptic diseased was higher in the rural area and in patients suffered from low socioeconomic status. From the researchers' point of view, this result could be attributed to several factors including inadequate access to healthcare in rural areas, high rate of birth trauma, intracranial infections, asphyxia and genetic factors that are more common in rural areas due to consanguineous marriage. These factors are thought to be the most common risk factors for epilepsy. Regarding clinical relevant data, the current result portrays that, the majority of the studied patients had generalized type of seizure and more than half of them exposure to epilepsy attack at age 1 to less than 20 years. This finding was in agreement with the study conducted by **Rizou, De Gucht , Papavasiliou, Maes, (2017)**<sup>(54)</sup> illustrated that, high prevalence of generalized epilepsy in patient who had the first attack of epilepsy at age less than 20 years old.

This finding might be explained by the fact that, whereas other forms of epilepsy might present with nebulous symptoms, generalized epilepsy is the most severe kind that prompts the family to seek treatment right away. Concerning the prescribed drug, the current study demonstrates that, over half of the patients were taking poly-therapy of anti-epileptic drugs that is in agreement with **Verrotti et al.,(2020)**,<sup>(55)</sup> who pointed that antiepileptic multi-therapy may be indicated in patients

with drug-resistant epilepsy in order to achieve the optimal therapeutic response.

**Concerning H1**, the current study reveals that, there are high significant differences throughout the different phases of implementing the DEP in total score of patient's knowledge, with total score slightly decline compared between three and six months post the DEP implementation. This result was in accordance with **Fontaine et al., (2023)**<sup>(56)</sup> who emphasized that, patients knowledge pre educational program about epilepsy concept improved after application of educational program. From the researchers point of view, the lack of knowledge in patient with epilepsy may be attributed to the deficiency of facilities and absence of standardized educational protocol for those patients.

This point of view is supported also by the finding of **Mohamed et al., (2023)**<sup>(48)</sup> who confirmed that, there is a significance of conducting a researches on epilepsy for developing countries to raise the level of awareness and understanding about the disease among patients with epilepsy. On the other hand, the researchers' opinion regarding the decline of the knowledge level at 6 months post DEP implementation compared to 3 months may be attributed to that, the patients with epilepsy had psychological, cognitive, and emotional insult. For this reason, For this reason, they are in dire need of a continuous source to give them information in a simple manner to ease and help them understand the disease and how to deal with it.

**Concerning H2**, the current study reveals that, there are high statistically significant differences were found throughout the



implementation phases in total score of self- management practices, with total score slightly decline at 6 and compared to 3 months post DEP implementation. The study results are supported by **Streltzov et al., (2022) & Zeglam, (2020)**<sup>(57&36)</sup> stated that, the majority of participants had incompetent practices regarding epilepsy management before applying the educational program. From the researchers point of view, lack of awareness and economic status among the studied patients are important variables affecting the practice of patients with epilepsy.

**Concerning H3**, the results of the present study discloses that, there were highly significant improvement in all domains of QOL (Fatigue/ energy, emotional, cognitive, social, medication effect, seizure worry, and the overall QOL) among the studied patients post implementing the DDP. The current findings came in accordance with **Rabiei et al., (2022)**<sup>(58)</sup> who proved that education and support intervention are significantly effective in improving the self-efficacy, self-esteem, which positively reflected on QOL of patient with epilepsy.

**With the extension of H3:** considering patients' energy/fatigue, the study conducted by **Gündoğdu et al., (2023)**<sup>(59)</sup> **Seid and Mebrahtu (2022)**<sup>(60)</sup> reported that, patients with epilepsy frequently experience feeling of tiredness and fatigue. Furthermore, the majority of participants report that fatigue is a further complication of their condition that is linked to depression and is thought to be a factor that can trigger seizures. In addition, they emphasized that, the effect of fatigue should be taking into account with the aim

of enhancing the management and QOL of patients with epilepsy.

Regarding the social activities domain of QOL, it was found that, there was an improvement in this domain post DEP implementation compared to pre- test. The study carried out by **Stotaw et al., (2022)**<sup>(61)</sup> in the same line with the results of the current study showed that, because of fear of seizures, stigma, and in addition to the lack of confidence, patients with epilepsy are more likely to experience changes in their everyday activities, to engage in social or recreational activities. In addition, the current study finding reveals that, there was a lack of medication management practices pre implementing the DEP implementation compared to post implementation. This may be because the patients not committed to taking medications on time, didn't follow the physician's order regarding the prescribed drug therapy.

In this respect, **Mula, (2023)**<sup>(62)</sup> proved that, symptoms of depression, anxiety, and attention deficit hyperactivity disorder in patients with epilepsy are on of the side effects caused by epilepsy treatment. This is in agreement with **Tu et al., (2022)**<sup>(63)</sup> who stated that, the recurrent seizures can affect patients' QOL. In a similar studied conducted by **Ayele, Wondiye and Bogale, (2023); Mroueh et al., (2022)**<sup>(64,65)</sup> demonstrated that, although QOL is influenced by numerous determinants, seizure worries have the greatest impact on QOL in patients with uncontrolled epilepsy.

In this regard, the study conducted by **Mersal et al., (2021)**<sup>(50)</sup> suggested that, enhancing the psychological, physical, and perceived levels of support among

epileptic patients and their families would be very essential. It is also obvious that there educational training programs on how to enhance their QOL and daily living activities accompanied by supportive family dynamics are necessary that can help epileptic patients manage and cope with their condition to the fullest level possible. From the perspective of the researchers, educational protocol including lifestyle changes, self-management awareness, and appropriate coping mechanisms with regards to all seizures aspects play a critical role in preventing seizures and helping patients overcome anxiety, tension, and anger as well as sleep difficulties, ultimately improving their QOL.

**Concerning H4**, This study shows that, there were significant positive correlation between the knowledge and practices among studied patients and their QOL at 3 months and 6 months post DEP implementation. This result was supported by **Fatima et al., (2022)<sup>(66)</sup>** who carried out the study about " Knowledge, Attitude and Practice of Epileptic Patients Towards Their Disease" reported that, there was a positive correlation between knowledge and practices among participants and their QOL. This may be attributed to that effective patient education influence patient motivation and consequently affected their health behaviors leading to improvement of their QOL.

### **Conclusion**

It can be concluded from the current study that, there was an improvement in the total score of knowledge, self- management practices, and QOL among the studied patients post implementing the DEP. On the other hand, the current study revealed

that, there was a significant positive correlation between the total score of knowledge and self- management practices among the studied patients and their QOL total score.

### **Recommendations**

The following recommendations are proposed based on the study findings:

- The designed educational protocol should be planned in a continuous manner and applied on regular basis to patients with epilepsy.
- Implementing educational programs for patient with epilepsy and evaluate its impact on the QOL on long-term process
- Displaying the information and practices contained in the educational protocol on a display screen for patients and their families in all health settings to improve their health awareness
- Applying of evidence-based guidelines manual for patient with epilepsy in the hospitals and evaluate its effect on their QOL.
- Evaluating the psychosocial factors along with epilepsy related factors and implementing psychological interventions as an adjunctive treatment for patients with epilepsy in order to enhance health-related QOL
- Assessment of patient adherence to intervention protocol and evaluate its effect on their quality of life.
- Further studies are needed to assess the factors contributing to reduced QOL in patients with epilepsy with a greater number of interventions designed to address this critically important issue

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