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## Self-Care Behavior among Patients with Epilepsy in Sohag University Hospital

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### Abstract

**Background:** Epilepsy is one of the most prevalent neurological disorders that can cause various physical, cognitive and psychological burdens. Individuals with long-term medical conditions as epilepsy need to adhere to self-care behaviors to manage their condition and lower the risk of consequences. Therefore, assessment of patient knowledge and self-care behavior is crucial. **Aim:** to assess self-care behavior among patients with epilepsy. **Research questions:** What is the level of knowledge regarding self-care among patients with epilepsy, what is self-care behavior among patients with epilepsy?. **Methods:** A descriptive correlational study conducted over 11 months. 60 convenient patients included. Patient knowledge is assessed by epilepsy knowledge scale while self-care behavior assessed by epilepsy self-management scale (ESMS). **Results:** 56.7% were male, 51.7 were married, 45% were illiterate, and 65.0% lived in rural areas. 73.3% had generalized epilepsy, 55% had a history of head injuries. Regarding self-care behavior, 60% had poor knowledge regarding epilepsy with the mean knowledge was  $17.86 \pm 5.057$  while, 56.7% had low level of using self-care behaviors. Regarding ESMS scores, there was a highly significant positive strong relation between patient knowledge and self-care behavior ( $r=0.611$ )  $P \leq 0.000$ . **Conclusions:** The current study found that patient knowledge and self-care behaviors were poor. Moreover, patients used certain self-care behaviors more than others as patients scored higher on questions of medication rather than lifestyle and information management.

**Keywords:** *Epilepsy Knowledge Scale, Epilepsy Self-Management Scale, Knowledge, Self-care behavior.*

### Introduction

Epilepsy is one of the most prevalent neurological disorders that characterized by the occurrence of repeated seizures associated with enduring brain alterations that can lead to injury and death (Mukuku et al., 2020). Due to the erratic nature of seizure attacks, epilepsy can cause accidental injuries that impact the individual's life regarding family, education, and employment while contributing significantly to the burden of the disease as well (Hu, Zhang, Xiao, Guo, & Sun, 2020). Moreover, epilepsy results in various physical, cognitive and psychological burdens such as risk of injuries (burns, falls, fractures, drowning), related disabilities, increased hospital admission, depression, poorer quality of life, and higher mortality rates (Makkawi et al., 2023).

Epilepsy continues to be a critical condition especially in Africa due to delayed diagnosis and inadequate treatment. Even with the use of medications and the advances in the various treatment modalities in developed countries, around 40% of people with epilepsy are

resistant to pharmacological treatment and report difficult-to-control seizures as antiepileptic drugs are only moderately effective in attaining seizure control (Bilal et al., 2021). Chan et al. (2020) indicated that poor seizure control is returned to insufficient knowledge about disease, non-compliance or poor adherence to medications, inappropriate care, and difficulty creating lifestyle modifications to cope with the disease and its impacts. Poor seizure control can be conquered when care of epilepsy goes far beyond the traditional medical management which focuses on antiepileptic medications and surgical treatment into a comprehensive care that requires appropriate self-management (Ridsdale et al., 2018).

Self-management is considered as the ability of patients to adapt and adhere to the behavioral adjustments needed to reduce seizure frequency and improve overall health (Helmert et al., 2017). Self-management of epilepsy comprises medication, information, safety, seizure and lifestyle management. Good epilepsy self-care involves a range of

skills such as strict adherence to medication, precisely define and document seizures, practice safety precautions, get sufficient rest, and manage anxiety (Ahmed et al., 2023). The nurse assumes a major role in epilepsy self-care through evaluating the different aspects of self-management behavior and designing proper educational programs (Morgant et al., 2019). Perzynski et al., (2017) indicated that lack of practice of self-management behaviors can reduce patient ability to manage the disease, increase hospital admission and care costs; hence, it is essential to assess self-care behavior among patients with epilepsy.

### Significance of the study

Though epilepsy can be controlled in 60% of patients, it is the second leading cause of disability-adjusted life years accounting for 13 million/year due to uncontrolled epilepsy (Mohamed et al., 2023). Globally, epilepsy affects almost 5 million people every year where Egypt is considered the most predominant Arab countries with epilepsy as 752,000 persons are newly diagnosed with epilepsy annually (Hosny et al., 2023).

Pandey et al. (2020) stated that patients have regularly reported frustration with the insufficient information they received to address many concerns regarding epilepsy. Moreover, most PWE are not knowledgeable about their condition or not educated about the risks of epilepsy. Hence, it is critical to assess patients' knowledge to improve self-management. In our country, patients are discharged without proper education, signifying a major treatment issue. Therefore, good self-management requires appropriate knowledge of the condition, its treatment, and the necessary skills to carry out related tasks that can be achieved through self-care assessment and development of educational programs.

Additionally, a study done by Kamau (2019) found that numerous research results showing a high correlation between self-management and medication adherence among patients with epilepsy. Consequently, practicing self-management is significant for individuals with epilepsy in order to improve medication adherence, knowledge about epilepsy, and self-care. Moreover, assessment of self-care behavior plays a significant role in epilepsy care, controlling the illness, improving clinical outcomes and quality of life (Bautista, 2017).

Hopefully that the results of the current study will allow nurses to support and empower patients with necessary skills needed for adequate self-management. Furthermore, this study will add to the nursing body of knowledge as there is no data concerning the assessment of self-care behavior of epileptic patients in Egypt so far. So, it is expected that the findings of this study might promote nursing practice and research.

### Aim of the study

The aim of the current study is to assess self-care behavior among patients with epilepsy.

### Research Questions

1. What is the level of knowledge regarding self-care among patients with epilepsy?
2. What is self-care behavior among patients with epilepsy?
3. What is the relation between knowledge and self-care behavior among patients with epilepsy?

### Subjects and Method

#### Research Design

A descriptive correlational design was utilized in the current study.

#### Research Setting

The study was conducted at the neurology department at Sohag University Hospital.

#### Research Sample

A convenient sample consisting of sixty patients were included in the study. Sample size is calculated according to the following equation;

$$n = \frac{N Z^2 \sigma^2}{Z^2 \sigma^2 + N e^2}, n = \frac{150 \times (1.96)^2 \times (0.256)^2}{(1.96)^2 \times (0.256)^2 + 150 \times (0.05)^2} = 60.253 \cong 60$$

**The inclusion criteria** included adult conscious male and female patient from >18 to 60 yrs., accepted to participate in the study, having a diagnosis of epilepsy for at least 6 months, having experienced seizures during the previous year, receiving standard treatment for epilepsy, including antiepileptic drugs. **While, the exclusion criteria;** patients scheduled for brain surgery or those who had co-occurring medical conditions such as brain trauma, mood syndromes, and related mental

impairment (mentally retarded) were excluded from the study.

### Tools of Data Collection

Data was collected using the following tools

**Tool (1): Structured interview schedule:** it was developed by the researchers. This tool consists of four parts:

**Part 1:** Demographic data, by asking patients about age, gender, residence, occupation...etc.

**Part 2:** Medical data related questions such as onset of the disease, duration of fit, number of seizures per month, types of seizure, and risk factors of disease.

**Part 3:** Data regarding patient knowledge about epilepsy such as definition, causes, triggers, treatment of epilepsy, drug adherence, causes of non-compliance and medication side effects.

**Part 4: Epilepsy Knowledge Scale (EKS):** it was adopted to assess patient knowledge about of epilepsy. It consists of 19 questions such as (symptoms, diagnosis, and medications... etc.). **Scoring system:** The patients' answers regarding the knowledge questions were scored on 3 points scale (true, false, or I don't know) ranged from zero to two. The correct answer has a score of (2) and the wrong answer has a score (1) while don not know answer has no score (0). The total score is (38). Moreover, the scale is categorized into levels considering patients who have knowledge score below 50% as having a poor knowledge level; those who have score between  $50 \leq 75\%$  were categorized as having a fair knowledge level, while those who have  $\geq 75\%$  were categorized as having a good knowledge level (May & Pfafflin, 2002).

**Tool (2): Epilepsy Self-Management Scale (ESMS):** it was developed by Dilorio and colleagues (2008) to evaluate the frequency with which persons achieve tasks that are useful in controlling their seizures. The ESMS is a useful tool for assessing self-care behavior of patients with epilepsy. The scale is categorized into five subscales which are information (8 items), lifestyle (6 items), medication adherence (10 items), safety (8 items), and seizure management (6 items). **Scoring system:** It comprises 38 items in the form of statements. Each item is rated on a 5 point likert scale ranged from 1= never, to 5= always. The tool score ranged from 38-190 with higher scores representing more repeated use of self-care behaviors. The scale was

classified as; Less than 50% = low use of self-care behaviors, 50% to less than 75 % = moderate use of self-care behaviors, and more than 75% = high use of self-care behaviors.

### Validity and Reliability

Face validity of the data collection tools was reviewed by a panel of five experts in the field of medical surgical nursing and neurology medicine. Also its reliability was statistically examined. According to reliability, the instruments were tested and demonstrated good internal reliability as Cronbach's alpha for epilepsy knowledge scale and epilepsy self-management scale were 0.89 and 0.91 respectively.

### Pilot Study

A pilot study was conducted on 10% of the sample to estimate the needed time for data collection and to judge the feasibility, objectivity, also to test the appropriateness of content, wording, and order. No modification was done; therefore the participants of the pilot study were included in the actual research participants.

### Ethical Consideration

Written approval was obtained from the Ethics and Research Committee of the Faculty of Nursing, Sohag University. Similarly, permission was obtained from hospital administrators to conduct the study. The purpose and nature of the study, as well as the importance, were explained to the participants who met the inclusion criteria. Signed consent was obtained from the patients who accepted to participate in the study. Furthermore, anonymity and confidentiality were assured through coding the data. Patients were assured that their participation is voluntary and they have the right to withdraw from the study at any time without any penalty.

### Procedure

Data collection was conducted over a period of 11 months from beginning of January 2023 to the end of November 2023 after an official permission from the Research Ethical Committee in Faculty of Nursing, Sohag University was granted. All patients with epilepsy who were admitted at Neurology department during the period of data collection and met the inclusion criteria were included in the study. The investigator met the patients at Neurology department by

introducing herself to every patient who enrolled in the study, explained the purpose and nature of the current study. Informed consent of patients or their relatives who were willing to participate in the study was taken and anonymity was assured. Confidentiality and privacy were asserted.

It took from 30 to 45 minute to interview each patient individually starting with data related to **demographic and medical related part** which was obtained through interviewing the patient using the first tool (structured interview schedule) then data related to **patient knowledge** was attained to assess their knowledge about epilepsy by asking each patient involved in the study about the definition, causes, risk factors, risks of the disease, symptoms occur before the seizure attack, how to deal before and after epileptic fits, antiepileptic medications and its side effects. After that, data related to **Epilepsy Knowledge Scale** was completed to evaluate patient's level of knowledge by asking each patient about work that can be done, activities, diagnostic test for epilepsy, medications, symptoms, job, and sports, if epilepsy is associated with mental illness and driving related questions. Then data related to **Epilepsy Self-Management Scale** was collected to assess frequency of using epilepsy self-care behavior through asking questions related to epilepsy information, lifestyle, medication, safety, and seizure management.

### Data Analysis

Data entry and analysis were done using Statistical Package for Social Science (SPSS) software version 20. Descriptive results were in the form of mean, SD, frequency, and percentage. Correlation was tested using Pearson bi-variate. Chi-Square test was used to clarify the association between qualitative variables. The Cronbach alpha test was used to assess the reliability of the developed tools. The probability level of 0.05 was adopted as the level of significance for all statistical tests done.

### Results

**Table (1)** represented that 43.33% of the patients having their age ranging from more than 18 to 30 years with the mean age of patients was  $34.01 \pm 11.36$ . 56.7% of the patients were male and 51.7% were married. As regard to residence, 65% of the patients were from rural areas, 45% of the patients

were illiterate, while, 66.7% of the patients were unemployed.

**Table (2)** displayed that 73.3% of the patients suffered from generalized epilepsy, 46.7% of the patients have been diagnosed with epilepsy since 1 to 5 years. Regarding seizure duration and frequency, seizure attack lasted up to 3 minutes in 21.66% while, 21.66% of the patients complained of having seizure 1 time or more per day. Concerning related risk factors, 55% of patients had a history of head injuries.

**Table (3)** Regarding patient knowledge about epilepsy, the above table shows that only 8.3%, 0%, 10%, 5%, 11.7%, 8.3%, and 1.7% were able to correctly mention the definition, causes, triggers, symptoms, risks, and measures to do before and after the fit respectively. As regards to patient knowledge about antiepileptic drugs, 93.3% of the patients believed that epilepsy can be treated with medications. 83.3% understand that medications treat the disease and prevent fits. However, 40% of the patients are not committed to treatment. 8.3%, 6.7% were able to correctly recall causes of drug non-commitment and side effects of AEDs respectively. Concerning level of knowledge of the patients, 70 % had poor level of knowledge with mean of  $8.63 \pm 3.65$ .

**Based on table (4)**, the questions with the most correct answers were that "doctors can control epileptic seizures with medication" (76.7%), and "If a patient expects a seizure, he/she should take an additional dose of AED" (50%). The questions with the least correct answers were that "An EEG can always prove the diagnosis of epilepsy" (5%) and "Every seizure destroys a number of nerve cells in the brain" (5%). Regarding level of knowledge, 60% of the patients had poor knowledge regarding epilepsy with the mean was  $17.86 \pm 5.057$

Regarding information management, **table (5)** showed that only 1.7% of the patients always had a record of seizure frequency, 3.3% always had a record of seizure types, 25% always called the doctor when having side effects. Moreover, 88.3% never traced drug side effects. 100% of the patients never worn medical ID or participate in support group. 98.3% never talked with other epileptic patients, 86.7% never shared seizure information with family. Concerning lifestyle management, 83.3% of the patients never practiced relaxation to manage stress or avoid

seizure, 58.3% had sufficient sleep, only 5% exercised regularly, 65% had regular meals. About medication management, 71.7% of the patients never change dose time or frequency when medications run out, 60% always took medications as doctor ordered at the same time. 80% never stop medication due to cost, 78.3% never skipped drug dose due to side effects, 68.3% never missed dose due to forgetfulness, 26.7% sometimes missed clinic appointments, 25% rarely refilled drugs before running out, and 21.7% sometimes skipped drug doses.

On the subject of safety management, 33.3% always stayed late at night, 53.3% always swam alone, 26.7% always used unsafe power tools, 50% always took shower instead of bath, 85% always keep water temperature low to not get burned, 23.3% never checked doctors before taking other medications, 20% never climbed objects as ladders, 43.3% always drunk a lot of coffee or smoked cigarettes. Relating to seizure management, 66.7% of the patients never avoid situations or thing that cause seizure, 35% always took seizure medications when leaving home,

38.3% always called doctor when having more seizure, 31.7% never have a way to remind take seizure medications, 30% always had blood tests done when ordered by physician. As regards level of self-care behavior, 56.7% of the patients have low level of using self-care practices with the mean  $108.53 \pm 21.29$

**Table (6)** revealed that there was a highly significant relation between level of patient education and their knowledge regarding epilepsy management and self-care behavior.

**Table (7)** showed that there was a positive strong relation between patient knowledge regarding epilepsy management and patient epilepsy knowledge as measured by EKS ( $r=0.548$ ), a positive strong relation between patient knowledge and self-care behavior as measured by ESMS ( $r=0.611$ ) and a positive strong relation between patient epilepsy knowledge and their self-care behavior ( $r=0.625$ ) at  $P \leq 0.001$ .

**Results****Table (1) Frequency and Percentage Distribution of Subject's Demographic Data (N=60):**

Variable	No	%
<b>Age</b>		
- > 18 to 30	<b>26</b>	<b>%43.3</b>
- 31 to 40	15	%25
- 41 to 50	10	%16.7
- > 51	9	%15
<b>Mean ± SD</b>	34.01±11.36	
<b>Gender</b>		
- Male	<b>34</b>	<b>%56.7</b>
- Female	26	%43.3
<b>Marital status</b>		
- Single	25	%41.7
- Married	<b>31</b>	<b>%51.7</b>
- Divorced	2	%3.3
- Widow	2	%3.3
<b>Residence</b>		
- Rural	<b>39</b>	<b>%65.0</b>
- Urban	21	%35.0
<b>Level of education</b>		
- Illiterate	<b>27</b>	<b>%45</b>
- Read and write	3	%5.0
- Basic education	4	%6.7
- Secondary education	15	%25
- University	10	%16.7
- Master	1	%1.7
<b>Occupation</b>		
- Non-working	<b>40</b>	<b>%66.66</b>
- Farmer	4	%6.66
- Machinery	7	%11.66
- Office work	6	%10
- Retired	3	5.0%

\* Basic education = primary and preparatory

Table (2) Frequency and Percentage Distribution of Subject's Medical Data (N=60):

Variable	No	%
<b>Type of epilepsy</b>		
- Generalized	<b>44</b>	<b>%73.3</b>
- Focal	16	%26.7
<b>Onset of the disease (in years)</b>		
- 1 to 5	<b>28</b>	<b>%46.7</b>
- >5 to 10	14	23.3%
- >10 to 15	9	15%
- > 15 to 20	9	15%
<b>Mean ± SD</b>	8.05± 6.46090	
<b>Variable</b>	<b>No</b>	<b>%</b>
<b>Duration of the attack (per minute)</b>		
- Up to 1 min	4	%6.66
- Up to 2 min	10	%16.66
- Up to 3 min	<b>13</b>	<b>%21.66</b>
- Up to 4 min	12	%20
- Up to 5 min and more	<b>21</b>	<b>35%</b>
<b>Mean ± SD</b>	3.6± 1.3	
<b>Frequency of seizures</b>		
- Less than 1 time per week	23	%38.33
- 1 time per week	15	%25
- 2 times per week	6	%10
- 3-5 times per week	3	%5
- 1 time or more per day	<b>13</b>	<b>%21.66</b>
<b>Mean ± SD</b>	13.65± 21.48	
<b>History of related risk factors</b>		
- Meningitis	1	%1.7
- Head injuries	<b>33</b>	<b>%55.0</b>
- Fever	12	%20
- Stroke	14	%23.3

**Table (3) Frequency and Percentage Distribution of Subject's Knowledge about Epilepsy and Anti-epileptic Drugs (N=60):**

Variable	No	%
<b>Definition of epilepsy</b>		
- Correct complete answer	5	8.3%
- Correct incomplete answer	24	40%
- Incorrect answer or don't know	31	51.7%
<b>Causes of epilepsy</b>		
- Correct complete answer	0	0%
- Correct incomplete answer	19	31.7%
- Incorrect answer or don't know	41	68.3%
<b>Triggers of epileptic fit</b>		
- Correct complete answer	6	10%
- Correct incomplete answer	32	53.3%
- Incorrect answer or don't know	22	36.7%
<b>Symptoms that occur before epileptic fit</b>		
- Correct complete answer	3	5%
- Correct incomplete answer	30	50%
- Incorrect answer or don't know	27	45%
<b>Variable</b>	<b>No</b>	<b>%</b>
<b>Measures to do when feeling symptoms of epileptic fit</b>		
- Correct complete answer	5	8.33%
- Correct incomplete answer	20	33.33%
- Incorrect answer or don't know	35	58.33%
<b>Risks that can occur during epileptic fit</b>		
- Correct complete answer	7	11.7%
- Correct incomplete answer	34	56.7%
- Incorrect answer or don't know	19	31.7%
<b>Measures to do after epileptic fit</b>		
- Correct complete answer	1	1.7%
- Correct incomplete answer	47	78.3%
- Incorrect answer or don't know	12	20%
<b>Epilepsy can be treated</b>		
- Yes	56	93.3%
- No	4	6.7%
<b>Best treatment of epilepsy</b>		
- Medications	56	93.3%
- Others as herbs, religion, cupping	4	6.7%
<b>Benefit of anti-epileptic drugs</b>		
- Treat and prevent fits	50	83.3%
- Useless	10	16.7%
<b>Commitment to treatment</b>		
- Yes	36	60%
- No	24	40%
<b>Causes of drug non-commitment</b>		
- Correct complete answer	5	8.3%
- Correct incomplete answer	27	45%
- Incorrect answer or don't know	28	46.7%
<b>Side effects of antiepileptic drugs (AEDs)</b>		
- Correct complete answer	4	6.7%
- Correct incomplete answer	18	30%
- Incorrect answer or don't know	38	63.3%
<b>Level of knowledge</b>		
- Poor knowledge	42	70%
- Fair knowledge	16	26.7%
- Good knowledge	2	3.3%
<b>Mean ± SD</b>	8.63± 3.65	

**Table (4) Study Subject's Knowledge Level as Measured by Epilepsy Knowledge Scale (N=60):**

Items	Correct answer		Incorrect answer		Don't know	
	No	%	No	%	No	%
People with epilepsy should avoid strenuous work because this provoke seizures (false)	10	16.7%	41	68.3%	9	15%
An EEG can always prove the diagnosis of epilepsy (false)	3	5%	37	61.7%	20	33.3%
People with epilepsy are as capable as other people (true)	23	38.3%	31	51.7%	6	10%
All people with seizures should avoid working with open machineries (false)	10	16.7%	41	68.3%	9	15%
Every seizure destroys a number of nerve cells in brain (false)	3	5%	19	31.7%	38	63.3%
People with epilepsy should not swim without an accompanying person (true)	25	41.7%	33	55%	2	3.3%
All people with epilepsy should avoid flashing or strobing lights (false)	6	10%	36	60%	18	30%
In most cases, doctors can control epileptic seizures with medication (true)	46	76.7%	9	15%	5	8.3%
If your seizures are controlled for some months, you can reduce the dose of AEDs (false)	27	45%	16	26.7%	17	28.3%
All people with epilepsy have similar symptoms (false)	17	28.3%	6	10%	37	61.7%
If a patient expects a seizure, he/she should take an additional dose of AED (false)	30	50%	9	15%	21	35%
On job application, a patient should always disclose his/her epilepsy condition (false)	11	18.3%	41	68.3%	8	13.3%
People with epilepsy can take an active part in sports (true)	17	28.3%	25	41.7%	18	30%
An epileptic seizure always results in loss of consciousness (false)	18	30%	28	46.7%	14	23.3%
People whose seizures only happen during sleep may hold a driver's license (true)	13	21.7%	14	23.3%	33	55%
Everyone can have a seizure given the appropriate circumstances (true)	13	21.7%	13	21.7%	34	56.7%
Blood samples can be used to measure concentrations of AED in the body (true)	26	43.3%	5	8.3%	29	48.3%
Epilepsy is a symptom of mental illness (false)	5	8.3%	20	33.3%	35	58.3%
If persons with epilepsy drive, they must inform driving authorities about condition. (false)	11	18.3%	30	50%	19	31.7%
<b>Level of knowledge</b>						
- Poor knowledge	36	60%				
- Fair knowledge	23	38.3%				
- Good knowledge	1	1.7%				
<b>Mean ± SD</b>	<b>17.86± 5.057</b>					

**Table (5) Study Subject's Self-Care Behaviors as Measured by Epilepsy Self-Management Scale (ESMS) (N=60):**

Items	Never		Rarely		Sometimes		Most of time		Always	
	No	%	No	%	No	%	No	%	No	%
<b>Information management</b>										
I write down how often I have seizures and when they occur.	54	90%	2	3.3%	3	5%	0	0%	1	1.7%
I call my doctor when I think I am having side effects from my seizure medication.	24	40%	5	8.3%	11	18.3%	5	8.3%	15	25%
I keep a record of the types of seizures I have.	54	90%	2	3.3%	2	3.3%	0	0%	2	3.3%
I keep track of the side effects of my seizure medication.	53	88.3%	2	3.3%	5	8.3%	0	0%	0	0%
I wear or carry information stating that I have epilepsy.	60	100%	0	0%	0	0%	0	0%	0	0%
I talk with other people who have epilepsy.	59	98.3%	1	1.7%	0	0%	0	0%	0	0%
I participate in a support group for persons with epilepsy	60	100%	0	0%	0	0%	0	0%	0	0%
I practice what to do during a seizure with my family and friends.	52	86.7%	1	1.7%	5	8.3%	2	3.3%	0	0%
<b>Lifestyle management</b>										
I do things such as relaxation, and guided imagery to manage stress.	50	83.3%	7	11.7%	1	1.7%	1	1.7%	1	1.7%
I make sure I get enough sleep.	5	8.3%	11	18.3%	2	3.3%	7	11.7%	35	58.3%
I do things that I enjoy to help manage stress.	45	75%	8	13.3%	2	3.3%	2	3.3%	3	5%
I do things such as relaxation, and guided imagery to keep myself from having a seizure.	50	83.3%	7	11.7%	1	1.7%	1	1.7%	1	1.7%
I get enough exercise.	13	21.7%	19	31.7%	20	33.3%	5	8.3%	3	5%
I eat regular meals.	4	6.7%	5	8.3%	4	6.7%	8	13.3%	39	65%
<b>Medication management</b>										
When my seizure medication is running out, I spread out the time between doses.	43	71.7%	3	5%	10	16.7%	4	6.7%	0	0%
When my seizure medication is running out, I take less medication at each time.	43	71.7%	5	8.3%	10	16.7%	2	3.3%	0	0%
I take my seizure medication the way my doctor orders it.	1	1.7%	10	16.7%	10	16.7%	3	5%	36	60%
I take my seizure medication at the same time each day.	1	1.7%	10	16.7%	10	16.7%	3	5%	36	60%
I have to put off having my seizure medication refilled because it costs too much money.	48	80%	6	10%	4	6.7%	1	1.7%	1	1.7%
I miss doctor or clinic appointments.	30	50%	5	8.3%	16	26.7%	8	13.3%	1	1.7%
If I had side effects from the seizure medications, I would skip a dose without asking my doctor.	47	78.3%	2	3.3%	7	11.7%	1	1.7%	3	5%

Items	Never		Rarely		Sometimes		Most of time		Always	
	No	%	No	%	No	%	No	%	No	%
I plan ahead and have my seizure medication refilled before I run out.	2	3.3%	15	25%	17	28.3%	4	6.7%	22	36.7%
I miss doses of my seizure medication because I do not remember to take it.	41	68.3%	2	3.3%	10	16.7%	4	6.7%	3	5%
I skip doses of seizure medication.	37	61.7%	2	3.3%	13	21.7%	6	10%	2	3.3%
<b>Safety management</b>										
I stay out late at night.	20	33.3%	9	15%	8	13.3%	3	5%	20	33.3%
I would go swimming alone.	18	30%	3	5%	5	8.3%	2	3.3%	32	53.3%
I use power tools such as electric saws, or electric knives without an automatic shutoff.	27	45%	5	8.3%	11	18.3%	1	1.7%	16	26.7%
I take showers instead of baths.	10	16.7%	2	3.3%	14	23.3%	4	6.7%	30	50%
I keep temperature of water in home low enough so I do not get burned.	0	0%	0	0%	4	6.7%	5	8.3%	51	85%
I check with my doctor before taking other medicines.	14	23.3%	4	6.7%	17	28.3%	5	8.3%	20	33.3%
I climb objects such as high stools, chairs, or ladders.	12	20%	4	6.7%	2	3.3%	16	26.7%	26	43.3%
I drink a lot of coffee and smoke cigarettes	10	16.7%	5	8.3%	4	6.7%	15	25%	26	43.3%
<b>Seizure management</b>										
I stay out of situations that cause a seizure.	40	66.7%	5	8.3%	11	18.3%	2	3.3%	2	3.3%
If I am going away from home, I take my seizure medication with me.	9	15%	6	10%	19	31.7%	5	8.3%	21	35%
I call my doctor if I am having more seizures than usual.	9	15%	11	18.3%	11	18.3%	6	10%	23	38.3%
I have a way to remind myself to take my seizure medication.	19	31.7%	8	13.3%	12	20%	9	15%	12	20%
When the doctor orders blood tests, I have them done.	7	11.7%	9	15%	18	30%	8	13.3%	18	30%
I stay away from things that make me have seizures.	40	66.7%	5	8.3%	11	18.3%	2	3.3%	2	3.3%
<b>Level of self-care behavior</b>										
- Low use of self-care behaviors			34	56.7%						
- Moderate use of self-care behaviors			25	41.6%						
- High use of self-care behaviors			1	1.7%						
<b>Mean ± SD</b>	<b>108.53± 21.29</b>									

**Table (6) Association between subject's level of education and their Knowledge Regarding Epilepsy Management and Self-Care behavior (N=60):**

Level of education	Subject Epilepsy knowledge			Self-Care Behavior			P value
	Poor	Fair	Good	Low use	Moderate use	High use	
Illiterate	24	3	0	20	7	0	0.000**
Read and write	2	1	0	2	1	0	
Basic	3	1	0	3	1	0	
Secondary	5	10	0	7	8	0	
University	2	8	0	2	8	0	
Master	0	0	1	0	0	1	

Chi-Square test, \*\* highly significant  $P \leq 0.01$

**Table (7) Relationship between Patient Knowledge regarding Epilepsy Management and Self-Care Behavior (N=60):**

		EKS	ESMS
Patient Knowledge	R	0.548	0.611
	P value	0.000**	0.000**
EKS	R		0.625
	P value		0.000**

\*\* Highly significant  $P \leq 0.01$ , EKS= Epilepsy Knowledge Scale, ESMS= Epilepsy Self- Management Scale

## Discussion

Related to the demographic results, the findings of the current study revealed that more than one-third of patients had their age below thirty with a mean of age  $34.01 \pm 11.36$ . Above half of the studied sample were males. The results of the current study were in accordance with the results of a study conducted by **Eldesoky, Habiba, and Abouelala (2023)** to evaluate the effect of structured educational package on self efficacy on one-hundred epileptic patients which revealed that above half of the sample were male with mean age was  $34.68 \pm 9.90$ . The researchers agreed that the increased incidence of epilepsy among adult males might be a result that, males being exposed frequently to stressors as finding a suitable job, having satisfactory income, family demands, occupation hazards, and others risk factors, such as head trauma which could cause epilepsy. In addition, steroid hormones as progesterone have antiepileptic effects; this might explain why females had a lower incidence than males.

Regarding marital status, above half of the studied sample were married. A similar finding was found by **Babaei et al (2023)** who conducted a study on 335 epileptic patients to assess self-management and its predictors revealed that most of the patients were married. The researchers explained that the increased incidence of epilepsy among married individuals might be due to the stressful life and

responsibilities of marriage such as financial issues, fear of genetic predisposition of the disease, or family and children burdens. Regards to the residence, around two-thirds of the studied sample lived in rural areas. This might return to low socioeconomic status, and lack of access to medications and health care services. Correspondingly, the results of the current study were in agreement with the results of **Ahmed et al. (2023)** and **Abd Elnaser, AbdAllah, Ali, and Metwally (2018)** as reported that the greatest percentages of epileptic patients were males, married, and lived in rural areas.

Concerning educational level and employment, the present study revealed that almost half of the patients were illiterate and two-thirds of them were unemployed. This was supported by **Espinosa-Jovel et al. (2019)** who emphasized the high illiteracy rate of patients with epilepsy from developing countries that is characterized by low education, and unemployment. Furthermore, **Rabiei, Lotfizadeh, Karimi, and Masoudi (2022)** conducted a study on 70 epileptic patients in Iran and found that around two-thirds of the studied sample were married and unemployed. Moreover, a study done by **Willems et al. (2023)** found that epilepsy was strongly related to higher unemployment rates ( $p < 0.0001$ ), and job discharges ( $p = 0.001$ ). The researchers believed that causes of unemployment might return to; low educational levels, qualifications, and being ashamed of the

disease at the workplace. In addition, being vulnerable to injuries would cost the employer a financial burden of treatment.

Related to medical data of the studied sample, the current study revealed that about half of the patients have been diagnosed with epilepsy for 1 to 5 years where generalized seizure type was found in around three-quarters of the studied sample. The results of the current study were compatible with the results of the study conducted by **Tigistu, Azale, Kebebe, and Yihunie (2018)** to assess the frequency of seizure attacks and found that the majority of the patients had generalized epilepsy of recent onset from one to five years. Regarding seizure duration and frequency, almost one-quarter of the patients had seizure attacks that lasted up to 3 minutes and complained of having seizures 1 time or more per day. Concerning related risk factors, above half of the patients had a history of head injuries. This was congruent with the results of **Makkawi et al. (2023)** where generalized epilepsy was found to be the most prevalent and head injuries were considered as primary causes of epilepsy. Moreover, a study carried out by **Kishk et al. (2019)** on 1000 epileptic patients in Egypt revealed that head injuries were the most common underlying etiological cause of chronic epilepsy, with males being at a greater exposure risk.

It is well known that appropriate knowledge is required to alter health behavior but is not sufficient by itself (**Helmers et al., 2017**). Consequently, assessment of patient knowledge and self-care behavior is crucial. As regards patient knowledge, the majority of the studied sample had a poor level of knowledge; patient knowledge about epilepsy revealed that the majority were unknowledgeable of definition, causes, triggers, symptoms, risks, and measures to do before and after the fit. None of them knew the causes of epilepsy which stressed the role of the nurse in providing adequate education. Unawareness of general information about epilepsy might return to their educational level, being discharged without appropriate education, absence of medical follow-up, living in rural areas where poverty and lack of care are predominant, could hamper epileptic patients from having sufficient knowledge. The present study matched the results of **Mohammed and Abou Zed (2020)** who found that there was a lack of knowledge about epilepsy in the majority of patients.

In contrast, patient knowledge about antiepileptic drugs revealed that the majority of the patients

believed that epilepsy could be treated with medications emphasizing its importance in managing the disease. However, above third of the studied patients are not committed to treatment which was in agreement with the result of **Bilal et al. (2021)** who mentioned that nearly 40% of patients continue to experience seizures despite receiving treatment. Non-adherence to medication could be due to inadequate counseling, forgetfulness, depressed mood, high cost or lack of access to AEDs, drug side effects, and misunderstanding of prescribing instructions which was supported by **Makasi et al. (2023)** who reported that patients failed to take AEDs regularly because of drug deficiency from their providers. Similar findings were found by **Rathor et al. (2017)** who conducted a study to appraise the knowledge, attitude, and practices of epilepsy patients and revealed that most epileptic patients did not know their disease however, the majority were aware that it can be treated with drugs.

Assessment of patient knowledge as measured by the epilepsy knowledge scale showed that about two-thirds of the studied sample had a poor level of knowledge besides many misconceptions about epilepsy; almost one-third of the patients incorrectly thought that every seizure destroys a number of nerve cells in the brain, and believed that epilepsy is a symptom of mental illness. This was compatible with **Epilepsy Foundation (2024)** which reported these elements as the main misconceptions among epileptic patients. In addition, more than two-thirds of the patients wrongly believed that all people with seizure should avoid strenuous work or working with open machinery which was reflected in the current study as about half of the sample perceived themselves as less capable than others and only one-quarter stated that they can take an active part in sports. Similar findings were found by **Kaddumukasa et al. (2018)** who reported work and sport as restriction misconceptions.

Nearly half of the patients mistakenly believed that an epileptic seizure always results in loss of consciousness. Similarly, half of the patients believed that they do not need to be supervised when swimming which was in accordance with **Faraj et al. (2023)**. Approximately two-thirds of the patients falsely thought that all people with epilepsy should avoid flashing or strobing lights. This finding was supported by **Newman (2021)** who explained that only people with photosensitive epilepsy are at risk of seizure when viewing strobing lights. Likewise, two-thirds incorrectly believed that EEG can always

prove the diagnosis of epilepsy. Fortunately, the majority of the patients believed that doctors can control epileptic seizures with medication; about half of them believed that they could not reduce the dose when seizures are controlled or take an additional dose of AEDs when seizures are more frequent, blood samples can be used to measure the concentration of AEDs in the blood. These results were matched with a study done by **Mohamed, Shehata, AboZead, and abdAlmageed (2018)** which revealed similar findings to the current study regarding elements of epilepsy diagnosis and treatment.

Regarding self-care behavior assessment, it revealed that above half of the studied sample had a low level of utilizing self-care practices especially regarding information management as none of the patients wore medical IDs or participated in support groups, likewise, the majority of them never documented seizure, talked with other epileptic patients, or shared seizure information with family. The researchers agreed that these findings might result from inadequate patient knowledge and limited social network. Similarly, lifestyle management revealed that the majority of the studied sample never practiced relaxation to manage stress or avoid seizures, and only three patients exercised regularly. However, almost two-thirds of them had a healthy lifestyle with respect to sufficient sleep and regular meals. This was in accordance with **Quon et al. (2020)** who reported low lifestyle behaviors as epileptic patients had difficulty managing stress, sleep, and exercise.

Self-care behavior regarding medication management revealed good medication adherence as the majority of patients took drugs at the same time as prescribed, without changing doses, never stopped medication by themselves due to cost, or side effects. The results of the current study were in congruence with the results of **Bautista (2017)** which found that patients use certain self-care behaviors more than others as patients scored higher on questions of medication rather than on questions of lifestyle and information management. Low use of self-care behavior regarding safety management was noticed; almost half of patients stayed late at night, always climbed objects as ladders, always drank a lot of coffee or smoked cigarettes, always swam alone, and used unsafe power tools. This may be because patients were not familiarized or educated about the importance of safety precautions. Concerning seizure management, two-thirds of studied sample never avoided situations or things that cause seizures.

This could be explained as majority of patients suffered from endless stresses that did not know how to be managed.

As regards the correlational data, the findings of the current study revealed that there is a highly significant relation between the level of patient education and epilepsy knowledge and self-care behavior. This was supported by **Abuhamdah, Naser, and Abualshaar (2022)** who found that patients with higher levels of education had more epilepsy knowledge. Moreover, a study carried out by **Khachian et al. (2017)** on 100 patients to determine how people with epilepsy self-manage the disease, showed that there is a significant difference between education level and self-care behavior ( $P < 0.01$ ). Furthermore, there was a highly significant positive strong relation between patient knowledge and self-care behavior which was consistent with **Babaei et al. (2023)** who revealed that self-management had a significant positive correlation with patient knowledge. The researchers also agreed that educated people can manage and control the disease more than others.

### Conclusion

The current study found that patient knowledge and self-care behaviors adopted were poor. Moreover, patients used certain self-care behaviors more than others as patients scored higher on questions of medication rather than lifestyle and information management. Therefore, individuals who have chronic medical conditions as epilepsy need to adhere to self-care behaviors to manage their condition and lower the risk of consequences.

### Recommendations

1. Additional researches are required to support the current results for generalization.
2. Advancement of educational programs where issues such as documentation of seizures, stress management, triggers, and safety concerns need to be addressed.
3. Include education in the patient care plan and provide educational handouts about epilepsy and self-care behaviors.

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