Effect of Self Management Guidelines for Adult Patients with Epilepsy on their Health Practices

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Abstract: The aim of this study was to evaluate the effect of self-management guidelines for adult patients with epilepsy on their health practices. A quasi experimental research design was employed. This study was conducted at the Outpatient Clinic of the Epilepsy Center at El-Hadara University Hospital, Alexandria. The subjects comprised 44 adult epileptic patients. They were equally divided into a study group for the implementation of self management guidelines and a control group who received the routine Clinic care. Two tools were used: first the epileptic patient profile was used to collect biosociodemographic data, and secondly, the Epilepsy Self-Management Scale (ESMS) that was used to assess the frequency of use of epilepsy self management practices. The results of the study showed a significant effect of self management guidelines on health practices for the study group versus their control immediately after and 2 months post the guideline implementation. It can be concluded that adult patients with epilepsy improved their self management, health practices after implementation of the guidelines. It is to be recommended that implementation of self management guidelines for patients with epilepsy is warranted and should become an integral service in the specialized epilepsy care centers.

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1. Introduction

Epilepsy is one of the most common chronic neurological conditions, that affects people all over the world and still represents a social stigma for many patients. [1] According to the World Health Organization (WHO) reports, approximately 50 million people worldwide have epilepsy. The incidence is approximately 50–70 cases per 100,000 per year, excluding febrile seizures, which have a similar incidence.[2,3]According to records of newly diagnosed patients at Alexandria Epilepsy Center it has been estimated that patients who were diagnosed,and receive medication were about 600 patients during the year 2013, nearly half of them are adults.[4]A seizure disorder during young adulthood can seriously disrupt the adult' s life who is going to or already is carrying the new responsibilities of a career, marriage or parenthood. Studies in the UK showed that epilepsy-related deaths in young adults are 3 times higher than standard age-related mortality rate.[5] Also, Shahin mentioned that sudden unexpected deaths are most frequently occurring among epileptic adult patients who have poor seizure control. He recommended that patient education is important to control seizures and accordingly prevent these deaths.[6]

Epilepsy is both a medical diagnosis and a social label that affects life physiologically, psychologically, and socially. In fact, as a group, patients are affected more strongly by social and psychological aspects related to epilepsy than by the seizures themselves, and many studies indicate that patients with epilepsy have a lower annual income, a lower quality of life, poorer school performance, social stigma, and low self-esteem. Thus, 75% of patients with epilepsy have serious adjustment problems. [7,8]

Achieving full seizure control seems to be the most important factor in decreasing psychosocial problems. Based on the scope of the reported psychological and social problems associated with epilepsy (adjustment, self-image, unemployment, financial distress, insurance issues, and stigma), it is reasonable to conclude that this disease has a major impact on the patient, his or her family, and the society as a whole. Therefore, better seizure control is essential for patients with epilepsy and the society.[8] Traditional medical care of patients with epilepsy tends to focus on seizure control through drug treatment and surgical interventions.[9] It has been widely acknowledged that comprehensive epilepsy treatment goes far beyond medication.[10] In 1997, the Centers for Disease Control and Prevention (CDC-P) began crafting a public health agenda in this area, which culminated by 2003 in Living Well with Epilepsy II Conference sponsored by the Epilepsy Foundation, CDC-P, and other epilepsy organizations. A number of priority recommendations resulting from this conference were directly related to self-management research in epilepsy.[11]

Self-management in patients with epilepsy refers to adaptive health behaviors and activities that an individual can perform to promote seizure control and enhance well-being.[1, 2] Kobau and Dilorio described behavioral and psychosocial adjustments made by patients with epilepsy to control seizures and attain a higher quality of life. Behavioral adjustments include medication adherence, adequate sleep, good nutrition, and stress reduction. Psychosocial adjustments include coping with the loss of independence, dealing with embarrassment and stigma. All these adjustments comprise self-management behaviors.[13] Patients' diligence in adhering to their medication regimen as well as non-drug-related behavioral factors such as management of information, concern for personal safety, management of the seizures themselves and lifestyle issues play an important role in the overall success of epilepsy therapy. [14]

Epileptic patients need accurate and adequate information to help them understand the nature of their illness, drug regimen and restrictive activities that lower the seizure threshold. Also, the patients should be aware of safety precautions to prevent harm during seizure and to live a normal life as much as possible. [15] The nurse assumes an important role in providing comprehensive epilepsy education. Epilepsy may occur at any time throughout life, and age-related needs necessitate an ongoing assessment and intervention. The initial approach is to formulate an individualized educational plan of care.

Significant of the study:

The goal of epilepsy self management guidelines is to provide the patient and family members with the informational tools needed to enhance their knowledge about epilepsy. The nurse can present a formal educational plan and schedule appointments to review the various aspects of self-management and reinforce their importance. Ultimately, this knowledge of epilepsy and the recommended treatment plan can lead to a greater sense of power and control necessary for self-management and an improved quality of life. [16,17] Hopefully, these guidelines will be a contribution toward the improvement of self management health practices among adult patients with epilepsy.

Aim of the study:

This study was conducted to evaluate the effect of self management guidelines for adult patients with epilepsy on their health practices.

Research hypothesis:

Adult patients with epilepsy who receive the self management guidelines have higher mean self management health practice scores than those who do not.

2. Materials and Method

Materials

Research design:

A quasi experimental study design was used to conduct this study**.**

Setting:

This study was conducted at the Outpatient Clinic of Epilepsy Center, El-Hadara University Hospital, Alexandria. This center provides diagnostic, therapeutic and follow up services irrespective of patient's age or residence. These services include EEG monitoring, and other confirming lab studies and scanning procedures, provision of the prescribed medication and follow up procedure.

Subjects:

A convenience sample of 44 adults with epilepsy of both sexes was recruited from the above mentioned setting. The Epi info program was used to estimate sample size using the following parameters:

a- population size= 50 /month
b- Expected frequency = 50%
c-Acceptable error= 5%
d- Confidence coefficient=95
e- Estimated sample size=44

Criteria for patient's inclusion included:

1-Adults aged between 20 up to 60 years

2- Able to communicate verbally and willing to participate.

3- Having a diagnosis of epilepsy for at least 1 year

4-Receiving standard treatment for epilepsy, including antiepileptic drugs

5- Having experienced seizures during the previous year

Criteria for patient's exclusion included mentally retarded patients.

The participants were equally and sequentially recruited to the study and control groups as follows:

A-Study group I (Intervention) (N=22): received implementation of self management guidelines.

B- Control group II (N=22): received the usual epilepsy care and support offered by the clinic.

The participants in the intervention group were divided into four subgroups (5 to 6 patients in each). Each subgroup received a one month self management guidelines comprising eight sessions.

Tool:

Two tools were used to collect the necessary data**.**

Tool one: Epileptic Patient Profile:

This tool was developed by the researcher after review of relevant literature.It was used to collect biosociodemographic data and it was divided into:

Part one: This part comprised patient's sociodemographic data, including age, gender, marital status, occupation status and education

Part two: This part involved subjects clinical data including type of epilepsy, causes, attack frequency,

the time since the last attack and the number of prescribed anti-epileptic drugs.

Tool two: Epilepsy Self-Management Scale (ESMS):

This tool was adapted from Dilorio *et al.* (2008) [18] and developed based on a thorough review of current related literature. [1,13,14] It aimed to assess the frequency of use of epilepsy self management practices. It included 38 items rated on a 5-point Likert scale from "never" (1) to "always" (5). Only one item about drinking alcoholic was replaced by I drink a lot of coffee and smoke cigarettes because alcohol consumption is not accepted in the Egyptian culture. Content validity was assessed. Internal consistency, reliability ranged from 0. 81-0. 86. [10,19] The 38-items regarding epilepsy self management practice scale were factored,analyzed, yielding 5 factors: Medication, Information, Safety, Seizure, and Lifestyle Management [20].

Ratings were summed to obtain scores for the 5 subscales of Epilepsy Self Management Practice Scale as follows:

A- Medication management subscale: This subscale is a sum of 10 items related to adherence to medication

B- Information management subscale: This subscale contains 8 items related to record of how and when a seizure occurs, wearing or carrying identification card, physician notification about side effects of seizure medication and talking about epilepsy with others.

C- Safety management subscale: This subscale includes 8 items related to dangerous activities such as swimming alone, using power tools, climbing objects, tub bathing, and using high temperature at home.

D- Seizure management subscale: This subscale is composed of 6 items related to what situations tend to precipitate their seizure, the method used to take seizure medication, and monitoring serum level of antiepileptic drug.

E- Lifestyle management subscale: This subscale includes 6 items related to stress management, sleep, exercise and eating behavior.

The total scores of the scale ranged from 38 to 190 with higher total scores indicating more frequent use of self-management health practices. The mean percentage total score and subscale scores were classified as follows: Less than 50% = low use of self-management health practices, 50%-less than 75 % = moderate use of self-management health practices and more than 75% = high use of self-management health practices.

Method

1- A written approval was obtained from the director of the Epilepsy Center at El-Hadara University Hospital in Alexandria to collect the necessary data.

2- Tool I was developed by the researcher. Tool I and II were translated into Arabic and tested for content validity by 5 experts in the field of Medical Surgical Nursing and Neurological Medicine. Accordingly, some items were modified.

3- Epilepsy Self-Management Scale (ESMS) (tool II) was tested for its reliability using the Cronbach' s alpha coefficient test. The reliability result was 0.99 which indicates the high reliability of the tool.

4- A pilot study was carried out on 6 patients to test the applicability and feasibility of the study tool and the necessary modifications were performed.

5- **Data collection**:

Data were collected in three phases: assessment, implementation and evaluation.

I- *Assessment phase:* During this phase, an exploratory visit was done to Epilepsy Outpatients Clinic in order to estimate the rate of admissions and suitable time for data collection.

Personal various communications were done with staff nurses and physicians to explain the purpose of the study and gain their best possible cooperation. Patients who met the study criteria were included in the study after explaining the nature and purpose of the study and obtaining their consent. Patients' information needs were assessed and baseline data were obtained.

- Developing the guidelines:

- The objectives and contents of the guidelines were established based on a thorough review of related literatures [1,5,6,21,22]. Patients' information's were obtained from the collected data. It was then designed to be introduced to patients in Arabic.

The objective of the guidelines:

These guidelines aimed to enhance self-management of health practices for adult patients with epilepsy.

- Contents of the guidelines:

The guideline content was delivered through 8 sessions, as follows:

- **The first session**: This session consisted mainly of theoretical aspects of epilepsy, including the definition of epilepsy, causes, and descriptions of the different types of seizures, seizure observation, diagnostic procedures, different types of auras and what to do.

- **The second session**: This session provided information about prescribed antiepileptic drugs, including drug actions, side effects, and their interaction with other drugs, toxicity and the need for routine assessment of serum drug level. Also, patients were encouraged to take medication daily as

prescribed and provided strategies to remember to take antiepileptic drugs.

- **The third session:** This session provided information about patients' seizure type and its manifestations, what they do during and after the seizure, documentation of seizures, carrying a medical identification card or wearing a medical information bracelet and reporting any adverse effects or change in well-being. Also, patients were encouraged to tell others what to do during a seizure. Personal interactions with others through participation in social activities and interactive discussions were also emphasized.
- **The fourth session:** Patients were taught to avoid situations that tend to precipitate their seizure, such as stress, fatigue, anxiety, fear, loss of sleep and drinking coffee and smoking. Also, patients were taught to obtain medical attention immediately if seizure frequency and duration increases.
- **The fifth session**: This session provided information about home and work safety as the risk of being burned by touching a hot stove or spilling boiling water. Also, patients were taught to take showers rather than tub bath to avoid drowning, never swim alone and avoid activities that required alertness and coordination e.g. driving a car, operating machinery.
- **The sixth session**: Patients were instructed to eat regular meals, well balanced and healthy diet. Patients were encouraged to practice physical exercise in groups, develop regular sleep patterns to minimize fatigue and insomnia and maintained personal hygiene especially oral hygiene.
- **The seventh session**: Patients were taught to manage stress by using techniques, such as relaxation therapy, guided imagery and self hypnosis.
- **The eighth session**: Patients were implemented safety measures during seizure, including maintain patent airway, protect the patient's head, turn the patient to the side, loosen constrictive clothing, ease patient to the floor if seated, do not restrain the patient and do not place any objects in the mouth.

Various teaching methods were used in the form of group discussion, demonstration and case histories of patients facing the challenges of epilepsy. Teaching aids and guides, including powerpoint slides and handouts were purpose prepared and utilized.

- Content validity of the guidelines was tested through experts' opinions. These experts included five experts in Medical Surgical Nursing and two experts in Neurological Medicine, Alexandria University.
- Data were collected in five months, starting from July 2014 to November 2014.

II- ***Implementation phase:***

During the implementation phase, patients and caregivers were interviewed in the conference room. During the interview the purpose of the study was explained, handouts were provided for each patient in the intervention group separately and explained through modified lectures, interactive discussions, and demonstrations. The self management guidelines were implemented in 8 successive sessions. Each session lasted approximately 45-60 minutes, 2 times per week at the morning shift for one month duration, where patients were divided into four groups (5 to 6 patients each).

- A follow up card was developed for the purpose of the study, for each epileptic patient under the study to record the date, time of seizure occurred, duration of attack and description after attack throughout the two month follow up.
- Phone contact was maintained between researchers and patients to ensure meetings and follow up visits in outpatient clinics to complete data collection during follow up period.

III- ***Evaluation phase:***

Post- implementation of the guidelines, reassessment were done using the same pre-guidelines tools, immediately after implementation of self management guidelines and after two months for the two groups.

Administrative and ethical consideration

An ethical permission was obtained to conduct the study. An official approval was obtained to conduct the study from the director of the Epilepsy Center at El-Hadara University Hospital in Alexandria. Patients' verbal consents were obtained after explaining the aim of the study and assuring them complete confidentiality and that they can withdraw at any phase of the study.

Statistical analysis of the data

Data was fed to the computer and analyzed using IBM SPSS software package version 20.0. [23] Qualitative data were described using numbers and percent. Quantitative data were described using mean and standard deviation for normally distributed data. Comparisons between the two groups regarding categorical variables were tested using the Chi - square test. When more than 20% of the cells have expected count less than 5, correction for chi-square was conducted using Fisher's Exact test or Monte Carlo correction. To calculate the mean percent score of each subscale and the total scales the next equation was used:

Mean percent score =

(actual raw score – lowest possible raw score) x 100

Raw score range

For normally distributed data, comparisons between study and control subjects were done using independent t-test. Comparisons between different

periods were identified using ANOVA with repeated measures and Post Hoc test was assessed using Bonferroni adjusted. The significance of the obtained results was judged at the 5% level. [24]

Table (1): Distribution of the study and control subject group according to their socio-demographic data and epilepsy history.

Socio- demographic data and epilepsy history		Study (N = 22)		Control (N = 22)		Test of sig.	p
		No.	%	No.	%		
Age (years)	20 – <40	15	68.2	19	86.4	χ^2= 2.071	0.150
	40 – 60	7	31.8	3	13.6		
	Mean ± SD.	38.50 ± 12.66		32.32 ± 11.04		t= 1.726	0.092
Sex	Male	16	72.7	11	50.0	χ^2= 2.397	0.122
	Female	6	27.3	11	50.0		
Marital	Single	3	13.6	8	36.4	χ^2= 3.613	^{MC}p = 0.165
	Married	18	81.8	14	63.6		
	Divorced	1	4.5	0	0.0		
Type of work	Housewife	6	27.3	11	50.0	χ^2= 3.394	0.183
	Doesn't work	7	31.8	7	31.8		
	Manual work	9	40.9	4	18.2		
Education	Read and write	12	54.5	16	72.7	χ^2= 4.925	^{MC}p = 0.138
	Primary /Preparatory	5	22.7	6	27.3		
	Secondary	9	13.6	0	0.0		
	University	2	9.1	0	0.0		
Type of Epilepsy	Partial	3	13.6	6	27.3	χ^2= 1.257	^{FE}p = 0.457
	General	19	86.4	16	72.7		
Duration of epilepsy (in years)	<5 y	2	9.1	3	13.6	χ^2= 7.343	^{MC}p = 0.057
	5 – <10 y	8	36.4	4	18.2		
	10 – <15 y	4	18.2	0	0.0		
	≥15 y	8	36.4	15	68.2		
	Mean ± SD.	16.23 ± 9.60		17.95 ± 8.14		t= 0.644	0.523
Causes	Traumatic accident	5	22.7	4	18.2	χ^2= 0.315	^{MC}p = 1.000
	Childhood Fever	2	9.1	2	9.1		
	Unknown	15	68.2	16	72.7		
Seizure frequency (In month)	1 –< 4 times	8	36.4	2	9.1	χ^2= 5.566	^{MC}p = 0.055
	4 – <6 times	5	22.7	4	18.2		
	≥6 times	9	40.9	16	72.7		
	Mean ± SD.	14.27 ± 37.74		11.47 ± 15.99		t= 0.320	0.750
Last time seizure has occurred	< 7 days	5	22.7	8	36.4	χ^2= 5.818	^{MC}p = 0.104
	7 – <15 days	7	31.8	7	31.8		
	15 – <21 days	0	0.0	3	13.6		
	≥21 days	10	45.5	4	18.2		
	Mean ± SD.	18.0 ± 12.30		11.20 ± 11.16		t= 1.921	0.063
Number of anti-epileptic drugs	One	13	59.1	10	45.5	χ^2= 0.820	0.365
	Two or more	9	40.9	12	54.5		

χ^2: Chi square test MC: Monte Carlo test FE: Fisher Exact test
t:Studentt-test

3. Results:

Table (1) shows the distribution of the study and control group subjects according to their socio-demographic data and epilepsy history. It was found that the ages of more than half of subjects of both groups ranged from 20 to less than 40 years old, with mean ages of (38.50 ± 12.66, 32.32 ± 11.04 years) for study and control group subjects, respectively. Most of the studied groups were males, married and were able to read and write. Concerning type of work, it was noticed that (40.9%) of the study subjects were performing manual works, compared to (18.2%) of the control.

Regarding, the type of epilepsy, (86.4% and 72.7%) for study and control subject group, respectively, reported having a generalized type of epilepsy. The duration of epilepsy ranged from less than 5 years to more than 15 years with mean durations of (16.23 ± 9.60, 17.95 ± 8.14 years) for the study and control subject group, respectively. The cause of epilepsy was unknown, as reported by more than half of the studied group. As regards frequency of seizure in a month, (40.9%, 72.7%) of the study and control subjects reported having more than six seizures a month. More than half of the study subjects (59.1%) were on monotherapy, compared to (45.5%) of the control group.

Table (2): Displays the comparison between the study group pre and post implementation of guidelines with the control in relation to information self

management. There were no significant differences between the two groups before implementation of the guidelines (P =0. 917), while, significant differences were detected between study and control groups immediately after and 2 months post guidelines implementation, in relation to information management, where (P<0.001). The mean percentage subscale scores of information management between the study and control subjects were (2.27±5.64, 2.41±2.88) indicating **low** practice of information self management before the guidelines. This, however, increased immediately after and 2 months after implementing the guidelines for the study group (90.06±7.99, 90.34±7.71), respectively, indicating **high** practices of information self management. For the control subjects these values remained low immediately after and 2 months (2.56±2.83, 1.0 ± 1.49) respectively.

Table (2): Comparison between the study group pre and post implementation of the guidelines with the control in relation to information self management.

Information self management items	Study			p_1	p_2	Control			p_1	p_2	p_3	p_4	p_5
	Before	Immediately after	2months later			Before	Immediately after	2months later					
	Mean± SD	Mean± SD	Mean± SD			Mean± SD	Mean± SD	Mean± SD					
1- I write down how often I have seizures and when they occur.	1.0±0.0	5.0±0.0	5.0±0.0	-	-	1.0±0.0	1.0±0.0	1.0±0.0	-	-	-	-	-
2- I call my doctor when I think I am having side effects from my seizure medication	1.0±0.0	4.82±0.59	4.73±0.70	<0.001*	<0.001*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	-	<0.001*	<0.001*
3- I keep a record of the types of seizures I have.	1.0±0.0	4.45±1.41	4.45±1.41	<0.001*	<0.001*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	-	<0.001*	<0.001*
4- I keep tracking of the side effects of my seizure medication.	1.18±0.59	4.91±0.43	4.91±0.43	<0.001*	<0.001*	1.09±0.29	1.05±0.21	1.09±0.43	0.986	1.000	0.520	<0.001*	<0.001*
5- I wear or carry information stating that I have epilepsy.	1.0±0.0	5.0±0.0	5.0±0.0	-	-	1.0±0.0	1.0±0.0	1.0±0.0	-	-	-	-	-
6- I talk with other people who have epilepsy.	1.36±0.79	4.27±0.77	4.36±0.66	<0.001*	<0.001*	1.27±0.55	1.63±0.58	1.32±0.57	0.486	0.986	0.660	<0.001*	<0.001*
7- I participate in social activities.	1.18±0.59	4.18±0.59	4.23±061	<0.001*	<0.001*	1.27±0.46	1.27±0.46	1.09 ± 0.29	-	0.486	0.570	<0.001*	<0.001*
8- I practice what to do during a seizure with my family and friends	1.0±0.0	4.18±0.59	4.23±0.61	<0.001*	<0.001*	1.14±0.35	1.14±0.35	1.05±0.21	-	0.986	0.083	-	-
Total subscale score (degree = 40)	8.73±1.80	36.82±2.56	36.91±2.47	<0.001*	<0.001*	8.77±0.92	8.82±0.91	8.32 ± 0.48	1.000	0.199	0.917	<0.001*	<0.001*
Average subscale score (degree = 5)	1.09±0.23	4.60±0.32	4.61±0.31			1.10±0.12	1.10±0.11	1.04±0.06					
Mean % subscale score** (degree = 100)	2.27±5.64	90.06±7.99	90.34±7.71			2.41±2.88	2.56±2.83	1.0 ± 1.49					

p_1: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with immediate post guidelines in each of study and control group

p_2: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with follow up guidelines in each of study and control group

p_3: p value for Student t-test for comparing between study and control pre guidelines

p_4: p value for Student t-test for comparing between study and control immediate guidelines

p_5: p value for Student t-test for comparing between study and control follow up guidelines

*: Statistically significant at $p \leq 0.05$ **: Mean percentage of subscale score classified as the following

<50% low information self management health practices 50 – <75% moderate information self management health practices

≥75% high information self management health practices

Table (3): Comparison between the study group pre and post implementation of the guidelines with the control in relation to lifestyle self management.

Lifestyle self management items	Study			p_1	p_2	Control			p_1	p_2	p_3	p_4	p_5
	Before	Immediately after	2months later			Before	Immediately after	2months later					
	Mean± SD	Mean± SD	Mean± SD			Mean± SD	Mean± SD	Mean± SD					
1. I practice stress reduction techniques such as relaxation, guided imagery, and self hypnosis	1.18±0.59	4.95±0.21	4.91±0.29	<0.001*	<0.001*	1.0±0.0	1.05±0.21	1.0±0.0	0.986	-	0.162	<0.001*	<0.001*
2- I get enough sleep	1.59±1.01	5.0±0.0	4.68±0.48	<0.001*	<0.001*	2.36±0.95	2.55±0.86	2.77±1.19	0.486	0.176	0.225	<0.001*	<0.001*
3-I do things that I enjoy helping manage stress.	1.23±0.53	4.95±0.21	4.95±0.21	<0.001*	<0.001*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	0.057	<0.001*	<0.001*
4-I maintain personal hygiene, especially oral hygiene.	1.18±0.59	5.0±0.0	4.41±1.40	<0.001*	<0.001*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	0.162	-	<0.001*
5-I get enough exercise.	1.0±0.0	5.0±0.0	4.91±0.29	-	<0.001*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	-	-	<0.001*
6-I eat regular meals.	2.82±1.10	5.0±0.0	4.82±0.39	<0.001*	<0.001*	3.14±0.71	3.27±0.63	3.23±0.69	0.557	1.000	0.260	<0.001*	<0.001*
Total subscale score (degree = 30)	8.95±2.08	29.91±0.43	28.68±1.36	<0.001*	<0.001*	9.50±1.01	9.86±0.71	10.0±1.20	0.264	0.257	0.278	<0.001*	<0.001*
Average subscale score (degree = 5)	1.49±0.35	4.98±0.07	4.78±0.23			1.58±0.17	1.64±0.12	1.67±0.20					
Mean % subscale score ** (degree = 100)	12.31±8.67	99.62±1.78	94.51±5.66			14.58±4.22	16.10±2.96	16.67±4.98					

p_1: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with immediate post guidelines in each of study and control group

p_2: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with follow up guidelines in each of study and control group

p_3: p value for Student t-test for comparing between study and control pre guidelines

p_4: p value for Student t-test for comparing between study and control immediate post guidelines

p_5: p value for Student t-test for comparing between study and control follow up guidelines

*: Statistically significant at $p \leq 0.05$

**: Mean percentage of subscale score classified as the following

<50% low lifestyle self management health practices

50 – <75% moderate lifestyle self management health practices

≥75% high lifestyle self management health practices

Table (3): Presents the comparison between the study group pre and post implementation of guidelines with the control in relation to lifestyle, self management. Statistical significant differences emerged between study and control subject group immediately after and 2 months after implementation of guidelines in relation to lifestyle self management, where (P<0. 001). The mean percentage subscale score of lifestyle, self management between the study and control subjects was (12.31±8.67, 14.58±4.22) respectively, indicating **low** practices of lifestyle, self management before the guidelines, then it significantly increased immediately after and 2 months post guidelines for the study subjects were (99.62±1.78, 94.51±5.66) respectively, indicating **high** practices of lifestyle self management. For control subjects these values were low (16.10±2.96, 16.67±4.98) immediately after and 2 months post guidelines, respectively.

Table (4): Demonstrates the comparison between the study group pre and post implementation of the guidelines with the control in relation to medication self management. It was found that there were no significant differences between the both groups before guideline implementation were (P=0.066). However, significant differences were detected between the both groups immediately after and 2 months post implementation of guidelines, where (p<0. 001& <0.001), respectively. The mean percentage subscale score of medication self management before implementation of guidelines between the both groups were moderate (57.73±11.77, 50.57±13.29) respectively, then it significantly increased immediately after and 2 months post guidelines implementation among study subjects (99.55±2.13, 96.48±3.05), respectively. Compared to, the control group,it was moderate (51.02±11.82) immediately after and decreased after 2 months (47.39±13.70).

Table (4): Comparison between the study group pre and post implementation of the guidelines with the control in relation to medication self management.

Medication self management items	Study			p1	p2	Control			p1	p2	p3	p4	p5
	Before	Immediately after	2months later			Before	Immediately after	2months later					
	Mean± SD	Mean± SD	Mean± SD			Mean± SD	Mean± SD	Mean± SD					
1- I spread out the time between doses, when my seizure medication is running out,.	3.45±1.14	5.0±0.0	4.77±0.43	<0.001*	<0.001*	2.95±0.84	3.64±0.73	1.64±0.58	0.612	1.000	0.107	<0.001*	<0.001*
2- I take less medication at each time, when my seizure medication is running out..	3.64±1.14	4.91±0.43	4.50±0.51	0.001*	0.009*	3.14±1.04	3.27±1.12	2.50±1.37	0.557	0.066	0.135	<0.001*	<0.001*
3- I take my seizure medication the way my doctor orders it.	4.23±1.41	5.0±0.0	5.0±0.0	0.054	0.054	3.50±1.41	3.0 ± 1.15	3.55±1.47	0.051	1.000	0.094	0.002*	<0.001*
4-I take my seizure medication at the same time each day.	3.18±1.59	5.0±0.0	4.86±0.35	<0.001*	<0.001*	3.23±0.92	3.59±1.14	3.18±1.30	0.086	1.000	0.908	<0.001*	<0.001*
5-I have to put off having my seizure medication refilled because it costs too much money.	2.82±1.14	4.91±0.43	4.64±0.49	<0.001*	<0.001*	2.32±1.09	2.68±1.25	2.27±1.39	0.086	1.000	0.144	<0.001*	<0.001*
6-I miss doctor or clinic appointments.	3.32±0.95	5.0±0.0	4.82±0.39	<0.001*	<0.001*	3.09±0.68	2.68 ± 1.25	3.36±1.09	0.218	0.249	0.366	<0.001*	<0.001*
7-If I had side effects from the seizure medications, I would skip a dose without asking my doctor.	2.50±0.86	5.0±0.0	5.0±0.0	<0.001*	<0.001*	3.0±1.11	2.73±0.46	3.05±1.50	0.114	1.000	0.076	<0.001*	<0.001*
8- I plan ahead and have my seizure medication refilled before I run out	3.77±1.63	5.0±0.0	5.0±0.0	0.006*	0.006*	3.59±0.91	3.45±0.96	3.82±1.30	0.284	0.782	0.651	0.001*	<0.001*
9-I miss doses of my seizure medication because I do not remember to take it.	2.91± 1.15	5.0±0.0	5.0±0.0	<0.001*	<0.001*	2.55±0.67	2.64±0.85	2.55±0.67	1.000	1.000	0.0207	<0.001*	<0.001*
10-I skip doses of seizure medication	3.32±1.04	5.0±0.0	5.0±0.0	<0.001*	<0.001*	2.86±0.47	3.05±0.72	3.05±0.72	0.640	0.640	0.072	<0.001*	<0.001*
Total subscale score(degree = 50)	33.09±4.71	49.82±0.85	48.59±1.22	<0.001*	<0.001*	30.23±5.32	30.41±4.73	28.95±5.48	1.000	0.363	0.066	<0.001*	<0.001*
Average subscale score(degree=5)	3.31±0.47	4.98±0.09	4.86±0.12			3.05±0.53	3.04±0.47	2.90±0.55					
Mean % subscale score**(degree = 100)	57.73±11.77	99.55±2.13	96.48±3.05			50.57±13.29	51.02±11.82	47.39±13.70					

p_1: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with immediate post guidelines in each of study and control group

p_2: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with follow up guidelines in each of study and control group

p_3: p value for Student t-test for comparing between study and control pre guidelines

p_4: p value for Student t-test for comparing between study and control immediate post guidelines

p_5: p value for Student t-test for comparing between study and control follow up guidelines

*: Statistically significant at $p \leq 0.05$**: Mean percentage of subscale score classified as the following:<50% low medication self management health practices 50 – <75% moderate medication self management health practices ≥75% high medication self management health practices

Table (5): Comparison between the study group pre and post implementation of the guidelines with the control in relation to safety self management.

Safety self management items	Study			p_1	p_2	Control			p_1	p_2	p_3	p_4	p_5
	Before	Immediately after	2months later			Before	Immediately after	2months later					
	Mean± SD	Mean± SD	Mean± SD			Mean± SD	Mean± SD	Mean± SD					
1- I stay out late at night.	3.73±1.16	4.91±0.43	4.86±0.35	0.001*	0.001*	4.27±0.77	4.23±0.75	4.32±0.65	-	0.127	0.074	0.164	0.757
2-I go swimming alone	1.55±0.91	5.0±0.0	4.45±1.41	<0.001*	<0.001*	1.09±0.43	1.0±0.0	1.0±0.0	0.986	0.986	0.352	-	<0.001*
3-I use power tools such as electric saws, electric hedge trimmers, or electric knives without an automatic shutoff	2.27±1.28	4.77±0.43	4.45±0.51	<0.001*	<0.001*	1.68±0.57	1.77±0.75	1.50±0.67	0.986	0.311	0.057	<0.001*	<0.001*
4- I take showers instead of baths	4.59±1.05	4.82±0.85	4.64±1.18	1.000	1.000	5.0±0.0	5.0±0.0	5.0±0.0	-	-	0.083	0.329	<0.001*
5-I keep the temperature of the water in my home low enough so I do not get burned	1.41±0.80	4.95±0.21	4.95±0.21	<0.001*	<0.001*	1.18±0.59	1.18±0.59	1.18±0.59	-	-	0.288	<0.001*	0.162
6-I check with my doctor before taking other medicines	1.09±0.29	4.95±0.21	4.95±0.21	<0.001*	<0.001*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	0.162	<0.001*	<0.001*
7-I climb objects such as high stools, chairs, or ladders.	2.14±0.83	5.0±0.0	4.86±0.35	<0.001*	<0.001*	2.05±0.65	2.09±0.61	1.77±0.75	0.986	0.230	0.689	<0.001*	<0.001*
8-I drink a lot of coffee and smoke cigarettes	1.14±0.64	4.41±0.50	4.18±0.59	<0.001*	<0.001*	1.59±0.96	1.68±1.09	1.86±1.28	0.986	0.745	0.072	<0.001*	<0.001*
Total subscale score (degree = 40)	18.55±3.58	38.82±0.96	37.36±1.59	<0.001*	<0.001*	18.23±2.41	18.36±2.24	18.14±2.25	1.000	1.000	0.731	<0.001*	<0.001*
Average subscale score (degree = 5)	2.32±0.45	4.85±0.12	4.67±0.20			2.28±0.30	2.30±0.28	2.27±0.28					
Mean % subscale score** (degree = 100)	32.95±11.2	96.31±2.99	91.76±4.97			31.96±7.53	32.39±6.99	31.68±7.04					

p_1: Stands for adjusting the Bonferroni p - value for ANOVA with repeated measures for comparison between pre with immediate post guidelines in each of study and control group

p_2: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with follow up guidelines in each of study and control group

p_3: p value for Student t-test for comparing between study and control pre guidelines

p_4: p value for Student t-test for comparing between study and control immediate post guidelines

p_5: p value for Student t-test for comparing between study and control follow up guidelines

*: Statistically significant at $p \leq 0.05$

**: Mean percentage of subscale score classified as the following

<50% low safety self management health practices

50 – <75% moderate safety self management health practices ≥75% high safety self management health practices

Table (6): Comparison between the study group pre and post implementation of the guidelines with the control in relation to seizure self management.

Seizure self management items	Study			p1	p2	Control			p1	p2	p3	p4	p5
	Before	Immediately after	2months later			Before	Immediately after	2months later					
	Mean± SD	Mean± SD	Mean± SD			Mean± SD	Mean± SD	Mean± SD					
1- I stay out of situations that might cause a seizure (as stress, anxiety, fear).	1.0±0.0	4.95±0.21	4.95±0.21	<0.00*	<0.00*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	-	<0.001*	<0.001*
2. I take my seizure medication with me when going away from home,	1.0±0.0	5.0±0.0	5.0±0.0	-	-	1.0±0.0	1.0±0.0	1.0±0.0	-	-	-	-	-
3- I call my doctor if I am having more seizures than usual.	1.09±0.43	4.82±0.59	4.91±0.43	<0.00*	<0.00*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	0.329	<0.001*	<0.001*
4-I remind myself to take my seizure medication	2.45±1.47	5.0±0.0	5.0±0.0	<0.00*	<0.00*	2.50±1.60	2.59±1.68	2.50±1.57	0.486	1.000	0.922	<0.001*	<0.001*
5-I do blood tests as the doctor orders.	3.73±1.16	5.0±0.0	5.0±0.0	<0.00*	<0.00*	3.82±0.66	3.95±0.49	3.86±0.64	0.799	1.000	0.752	<0.001*	<0.001*
6-I stay away from environmental factors that precipitating seizures (as flash light, noise)	1.32±0.65	4.95±0.21	4.95±0.21	<0.00*	<0.00*	1.0±0.0	1.0±0.0	1.0±0.0	-	-	0.162	<0.001*	<0.001*
Total subscale score (degree = 30)	10.59±2.13	29.73±0.94	29.82±0.18	<0.00*	<0.00*	10.32±1.70	10.55±1.79	10.36±1.71	0.404	1.000	0.940	<0.001*	<0.001*
Average subscale score (degree = 5)	1.77±0.36	4.95±0.16	4.97±0.14			1.72±0.28	1.76±0.30	1.73±0.28					
Mean % subscale score** (degree = 100)	19.13±8.88	98.86±3.90	99.24±0.76			17.99±7.09	18.94±7.47	18.18±7.11					

p_1: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with immediate post guidelines in each of study and control group

p_2: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with follow up guidelines in each of study and control group

p_3: p value for Student t-test for comparing between study and control pre guidelines; p_4: p value for Student t-test for comparing between study and control immediate post guidelines

p_5: p value for Student t-test for comparing between study and control follow up guidelines; *: Statistically significant at $p \leq 0.05$

**: Mean percentage of subscale score classified as the following

<50% low seizure self management health practice

50 – <75% moderate seizure self management health practice

≥75% high seizure self management health practice

Table (5): Shows the comparison between the study group pre and post implementation of the guidelines with the control in relation to safety, self management. It was found that there were significant differences between study and control group immediately after and 2 months after implementation of guidelines.In relation to safety self management health practices, (P<0.001).The mean percentage subscale score of safety self management health practices between study and control subjects group was low (32.95±11.2, 31.96±7.53) respectively, then it significantly increased immediately after and 2 months after implementing the guidelines among the study subjects (96.31±2.99, 91.76±4.97) respectively. For control subjects,these values remained low (32.39±6.99, 31.68±7.07) immediately after and 2 months post guideline implementation.

Table (6): Depicts the comparison between the study group pre and post implementation of the guidelines with the control in relation to seizure self management. There were significant differences between study and control groups immediately after and 2 months post implementation of the guidelines (P<0. 001, ‹0. 001), respectively.

The mean percentage subscale score of seizure self management between both groups was low (19.13±8.88, 17.99±7.09) respectively, then it significantly increased immediately after and 2 months post guideline implementation for study subjects were (98.86±3.90, 99.24±0.76) respectively. For the control group, this value was low (18.94±7.47, 18.18±7.11) immediately after and 2 months post the guidelines.

Table (7): Displays the comparison between the study group pre and post implementation of the guidelines

with the control in relation to epilepsy self management total score. There were no significant differences between the study and control groups before implementation of the guidelines (p=0.182). Also, there were highly significant differences between before,and immediately after as well as between before and after 2 months (p<0.001, <0.001),respectively, for the study group. However, there was no significant difference between before and 2 months later in the control group (p = 0.085,0.079). Moreover, there were highly significant differences between study and control groups in relation to self management total score immediately after as well as after 2 months of post implementation of the guidelines (p <0.001, <0.001), respectively, infavour of the study group.

Table (7): comparison between the study group pre and post implementation of the guidelines with tcontrol in relation to epilepsy self management total score.

Total score of epilepsy self management	Study			p_1	p_2	Control			p_1	p_2	p_3	p_4	p_5
	Before	Immediately after	2months later			Before	Immediately after	2months later					
	Mean± SD	Mean± SD	Mean± SD			Mean± SD	Mean± SD	Mean± SD					
Total score (degree = 190)	79.91±8.31	185.09±3.48	181.36±3.54	<0.001*	<0.001*	77.05±5.36	77.59±6.12	79.91±8.10	0.085	0.079	0.182	<0.001*	<0.001*
Average score (degree = 5)	2.10±0.22	4.87±0.09	4.77±0.09			2.03±0.14	2.04±0.16	2.10±0.21					
Mean % score** (degree = 100)	27.57±5.47	96.77±2.29	94.32±2.33			25.69±3.53	26.05±4.03	23.68±2.28					

p_1: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with immediate post guidelines in each of study and control group

p_2: Stands for adjusted Bonferroni p-value for ANOVA with repeated measures for comparison between pre with follow up guidelines in each of study and control group

p_3: p value for Student t-test for comparing between study and control pre guidelines

p_4: p value for Student t-test for comparing between study and control immediate post guidelines

p_5: p value for Student t-test for comparing between study and control follow up guidelines

**: Mean percentage of total scale score classified as the following

<50% low self management health practice

50 – <75% moderate self management health practice

≥75% high self management health practice

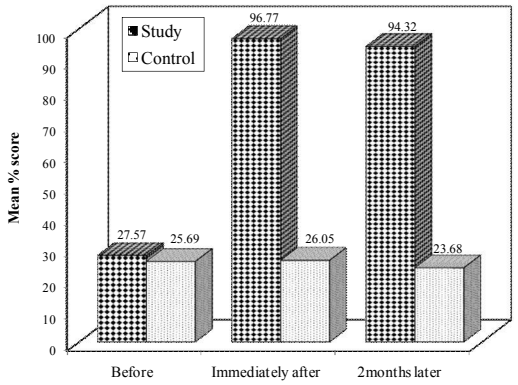

Figure (1): Comparison between the study group pre and post implementation of the guidelines with the control in relation to mean percent score of epilepsy self management.

Figure (1): Illustrates the comparison between the study group pre and post implementation of the guidelines with control in relation to mean percent score of epilepsy self management. The mean percentage total score of epilepsy self management before implementation the guidelines was low in both groups (27.57±5.47, 25.69±3.53) respectively, then it increased markedly immediately after and 2 months post implementation of the guidelines for the study subjects (96.77±2.29, 94.32±2.33), respectively. For control subjects, these values were **low** (26.05±4.03, 23.68±2.28) immediately after and 2 months post guideline implementation.

4. Discussion

Self management guidelines are important in the achievement of seizure control, increase adherence. They improve satisfaction, lower cost of treatment, reduce morbidity and mortality, enhance quality of life and empower patients and families to increase their autonomy[25-28]. A study done by Shafer recommended that instructional guidelines which address patient and family knowledge, attitude, beliefs and behaviors, including interventions to increase the person's feeling of self efficacy, offering regimen specific support were also highly emphasized to increase the effectiveness of self management practices. [29]

Concerning, the sociodemographic data of the study and control subjects, it was found that the level of education of the majority of subjects, were able to read and write.These findings could be explained by the school difficulties they met, by repeated epileptic attacks and antiepileptic drugs, which have an impact on their cognitive abilities. These results are in line with a study done by Moran, who found that the major impacts of epilepsy on life were school, work and

social life difficulties. These impacts no doubt, vary with the disease severity and age.[30] This also explains why most of the subjects in the present study were manual workers.

Regarding the frequency of epilepsy attacks, most of subjects in both groups reported having more than six seizures a month. This interestingly indicates that they have active epilepsy and poor seizure control, which could be explained by the fact that the majority of the studied subjects have generalized type of seizure which makes them liable to injury during active attacks. Amin reported a monthly seizure frequency of one to less than ten in nearly three quarters of his study subjects.[22] A similar study done by Aliasgharpour et al reported that 46.7% of the studied sample had one seizure per year.[31] Our current study observed high frequency of attacks which might be due to lack of specific knowledge about prevention and safety measures to be taken in between attacks.

The study results revealed that there were no significant differences between both groups before implementation of the guidelines, however, significant differences were detected between study and control groups immediately after and 2 months post guidelines, in relation to information on self management. This indicates that they lack applying these informations in their self management before implementing the guidelines. Present results are consistent with the study done by Amin, who found that only (4%, 6%) of the participant were carrying an ID with personal information, and keeping a calendar with seizure description. [22] This could be attributed to the lack of knowledge of the patients about the importance of these items.

The current results indicated low practices of lifestyle, self management before implementation of the guidelines. This could be explained by the fact that all the patients reported that stress is the most common precipitating factor of their seizures and that they cannot do anything to manage it. In most of times these patients attributed their stress and thereby emotional strain to economic hardship. These results are in line with Frucht *et al.* and Nakken *et al.* who found that approximately 25% of people with epilepsy said that emotional stress was their most frequent precipitating factor.[32,33] Furthermore, studies have shown that progressive relaxation training was effective and an easily learned adjuvant therapy that encourages people to take an active role in controlling their seizures.[34,35]

Sleep behavior is the second important dimension in the lifestyle management. Evidence suggests that having epilepsy and the occurrence of seizures as well as some antiepileptic drugs are associated with significant sleep disturbance. [36] Accordingly, it is important for many people with epilepsy to avoid sleep deprivation or poor sleep to minimize their seizures. Also, it has been observed that almost all the patients were not practicing any type of physical exercises and took large amounts of caffeine. The interpretation of these results could be explained by the fact that the healthful lifestyle management is neglected most of the times on the part of health care workers, probably due to lack of time, over responsibilities, staff shortage, especially health care settings in Egypt, which is necessary for the prevention and treatment of chronic diseases.

The findings of the current study revealed that patients in both groups with epilepsy have moderate practices of medication self management than other health aspects related to epilepsy, before implementation of the guidelines. Most of the subjects in the present study complied with their seizure medication as prescribed.These results are consistent with previous studies which indicated that epilepsy patients may be adherent to medication therapy, but do not have healthy lifestyle behaviors.[25,26] These results are in line with the findings of Kobau et al who reported that a larger proportion of persons with epilepsy reported higher self efficacy for medication management behaviors than for healthy lifestyle behaviors.[13] This behavior is a reflection of drug compliance, that individuals with chronic diseases often present. The interpretation of these results is that patients receive counseling about medication adherence more extensively than other aspects of epilepsy management. As a matter of fact, most practitioners tend to spend more time discussing medication adherence and side effects than discussing other social and safety issues related to epilepsy.

The results indicated a lack of using safety, self management practices before implementing the guidelines. These results could be related to lack of patients' knowledge and practice about the importance of safety self management. These results are in agreement with the study done by Esheiba who found that the epileptic school student lack knowledge about safety precautions. [37] The majority of our patients in both groups were following the safety precautions,as regards bathing only. This could be explained by the fact that most of the subjects in the present study have a generalized type of seizure which leads to loss or impaired consciousness. So, safety precautions were followed as taking showers instead of a bath to avoid the risk of drowning.

The results of this study revealed a low practice of seizure self management before the guideline implementation. This could be explained by the fact that most of the subjects in the present study did not avoid situations as stress, fear, anxiety, loss of sleep and environmental factors as flashlights and noise

which precipitate seizure frequency. This reflected the importance to teach patients and his or her families about situations that trigger the seizure frequency. Our results are in line with the study done by Amin, who recommended that teaching healthier behaviors can maintain patient safety and prevent complications. [22]

The results of present study showed that there were no significant differences between both groups before implementation of the guidelines, while, immediately after and 2 months post implementation of the guidelines, there were highly significant differences between study and control groups.This indicates that the self management guidelines had a positive impact on healthy practices of self management among the study group. Implementation of self management guidelines has helped the current study subjects to become self-confident, competent in self-management, aware of their needs, and able to access resources to meet their needs.In other words, it has helped them become better partners in patient-centered care.Having accurate, in-depth information about epilepsy helps people better understand the disorder, prevents misconceptions, and reduces concerns about stigma. These results are consistent with a study done by Jacoby et al who concluded that self management guidelines had improved seizure control and quality of life of people with chronic illness.[38] Also, these results are in accordance with a study done by Aliasgharpour *et al.* who showed that the participants in the intervention group reported higher self-management practices at follow-up compared to baseline.[31] In addition, the current study findings are not congruent with those Dilorio *et al.* and Pramuka *et al.* who showed that their educational guidelines did not led to improvement in their intervention group.[39,40]

The results of the current study correspond to those of other studies of educational programs for a variety of chronic diseases, including diabetes and coronary artery heart disease. The participants in these studies showed improved self-management behaviors. [41,42] Also, these studies recommended that for healthy practices of self-management of chronic diseases and prevention of adverse health outcomes, individuals require continuing information and education about their illnesses and strategies to deal with the impact of these illnesses on their day-to-day lives. To accept the diagnosis and understand the behavioral changes needed for effective self-management, these individuals require appropriate educational support. [14,36]

Conclusion

Based on the findings of the current study, it can be concluded that there is a significant effect of self management guidelines on healthy practices of self management in adult patients with epilepsy immediately after and 2 months post guidelines.

Recommendations:

As a result of this study, the following recommendations are suggested:

- Implementation of self management guidelines for patients with epilepsy is warranted and should become an integral service in the specialized epilepsy care center.
- Standard of care for epileptic patients should be developed and updated annually.
- A comprehensive health education program for patients with epilepsy in outpatient clinics with simplified printed guidelines through leaflets, brochures or booklets explaining how to use self management practices should be conducted.
- Nurses working in the epilepsy center should be oriented with updating inservice training program on how to encourage patients' participation in self management strategies.

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