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SELF-MANAGEMENT BEHAVIOURS AND OUTCOMES EXPECTANCY FOR PATIENTS WITH EPILEPSY: A QUASI-EXPERIMENTAL STUDY?

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Abstract

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. **Aim:** Evaluate self-management behaviors and outcomes expectancy for patients with epilepsy. **Research Hypothesis:** The current study hypothesized that the implementation of self-management behavior guidelines will affect positively the outcomes expectancy for patients with epilepsy. **Design:** Quasi- experimental (One group pre test and post test) design was used to achieve the aim of the present study. **Setting:** The epileptic outpatient clinic at El-Demerdash hospital affiliated to Ain-Shams University hospitals. Subject: A purposive sample of 60 patients with epilepsy. **Tools:** 1-Patients' interviewing questionnaire. 2-Adult Epilepsy Self-management Measurement Instrument (AESMMI). 3- Epilepsy Outcome Expectancy Scale. **Results:** This study revealed that 33.3% of the studied patients had satisfactory level of total knowledge before implementation of the self-management behaviors guidelines, and it was improved to 85% after implementation of the self-management behaviors guidelines, and 90%, 88.3%, 85% of the studied patients had satisfactory level of total outcomes expectancy regarding treatment, seizures, and management of seizures after implementation of the self-management behaviors guidelines respectively. **Conclusion:** The implementation of self- management behaviors guidelines for patients with epilepsy has a statistically significant positive effect on outcomes expectancy which supports the stated hypothesis. **Recommendation:** Implementing the self-management behaviors guidelines for each patient with epilepsy in different settings.

Keywords: Epilepsy, Outcome Expectancy, Patients, Self-Management Behaviors.

1. INTRODUCTION

Epilepsy is a chronic disorder of the brain marked by episodes of seizures. It arises from various pathological insults and is considered heterogeneous rather than a specific disease. World Health Organisation (2022), reported that approximately 50 million patients are affected with epilepsy worldwide and most (almost 80%) reside in low and middle-income countries(1), but in Egypt the prevalence of epilepsy was estimated at 6.98/1000(2). According to Somes (2024), who defined epilepsy as a chronic brain disorder in which groups of nerve cells or neurons in the brain send the wrong signals

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and cause seizures(3). Neurons normally generate electrical and chemical signals that act on other neurons, organs, and muscles to produce human thoughts, feelings, and actions. During a seizure, many neurons send signals at the same time, much faster than normal(4). This surge of excessive electrical activity can cause involuntary movements, sensations, emotions, and/or behaviours. The disturbance of normal nerve cell activity may cause loss of awareness. Some patients recover immediately after a seizure, while others may take minutes to hours to completely recover. During this time, they may feel tired, sleepy, weak, or confused (4, 5).

Epilepsy can lead to several complications that affect both physical and mental health. One of the primary risks is injury during seizures, such as falls, head trauma, or accidents while driving or swimming. Repeated seizures may also impact memory, learning, and overall cognitive function. Additionally, patients with epilepsy often face psychological challenges, including anxiety, depression, and social isolation. These complications highlight the importance of effective self-management behaviours guidelines, which are crucial to empower patients to take control of their condition and prevent complication (6).

Self-management for patients with epilepsy refers to the “ability of patients, in conjunction with family, community and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and the psychosocial, cultural, and spiritual consequences of health conditions”(7). Patients with epilepsy face challenges in finding a job, a decrease in self-esteem, social isolation, stigmatisation, and marriage-related problems. Patients with epilepsy often experience changes in their quality of life (QoL), such as less mobility and the impact on learning, employment, relationships, and social interactions (8). Due to the chronicity of epilepsy and its significant effects on different aspects of life and health, self-management (SM) is the main component of epilepsy management. It refers to various health behaviours and activities that an individual can learn and adapt to promote seizure control and improve well-being (9). The outcome expectancy is influenced by various factors, including patients' previous experiences with epilepsy treatment and self-management, the quality of communication and information provided by health care providers, the level of support and encouragement from family, friends, and support groups. In addition, positive outcome expectancy can lead to improved medication adherence, improved self-management, better seizure control, and improved QoL (10). Nursing education for patients with epilepsy plays a vital role in promoting effective disease management and improving quality of life. Nurses should educate patients and their families about the nature of epilepsy, including its causes, types of seizures, and possible triggers. The nurse should be emphasis on the importance of medication adherence, recognizing early warning signs of seizures, and maintaining a seizures diary to track patterns. Patients should also be taught about lifestyle modifications such as getting adequate sleep, avoiding alcohol or stress, and following a balanced diet. Additionally, nurses should provide emotional support and guidance on coping strategies, safety measures at home and at work, and available community resources. This comprehensive approach empowers patients to actively manage their condition and reduces the risk of complications (11). Patients with epilepsy can face diminished social support and family function, cognitive challenges, medical and psychiatric co-morbidities,

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stigmatization, disability, and severely reduced epilepsy self-management (ESM). Additionally, those with epilepsy also report more difficulty in employment, lower annual income, and physical limitations (12). Epilepsy affects 65 million patients around the world (13). Furthermore, the estimated number of patients with epilepsy who visited the outpatient clinic at Ain Shams University Hospital from July 2018 to July 2019 was approximately 2000 patients (14).

In this study, SM behaviours and outcome expectancy for epilepsy patients were used for the first time in Egypt to evaluate self-management behaviours and outcome expectancy for epilepsy patients in Cairo, Egypt. The current study hypothesised that the implementation of self-management behaviour guidelines will positively affect outcome expectancy for patients with epilepsy.

2. METHODS

2.1 Study Design

A quasi-experimental design (one group pre and post-test) was conducted with the objective of evaluating self-management behaviours and outcome expectancy for patients with epilepsy.

2.2 Study Setting

Research was carried out in the epileptic outpatient clinic of El-Demerdash Hospital, affiliated to the Ain-Shams University Hospitals in Cairo, Egypt. The clinic consists of the ground floor; It contains a large hall to wait for patients, a nursing room, and an administration office. The epileptic outpatient clinic room is equipped with three beds for patients and necessary devices, such as a monitor and emergency vehicle.

2.3 Study Period

Data collection was carried out from March to December 2022. The total duration of the study was approximately ten months.

2.4 Study Population

A purposive sample based on retrospective statistical data; it was found that the number of patients with epilepsy who visited the epileptic outpatient clinic affiliated with the Ain shams university hospitals in the period from July 2018 to July 2019 was 2000 patients.

2.5 Inclusion criteria

Eligible participants were a) adult patients with epilepsy aged from 20 to 65 years with epilepsy of both genders, b) who had not previously been exposed to educational instructions, c) who were able to understand instructions and were free of mental health problems, and d) willing patients.

2.6 Sample Size and Sampling

As mentioned in another study (15), the sample size was calculated using the sample size formula to estimate the mean of the population. Using a 95% confidence level, a 5%

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error margin, and the required sample size was calculated to be 60 (n=60). A purposive sample of 60 epilepsy patients was applied to select the required participants. It is an empirical interventional study used to estimate the causal impact of an intervention on the target population without random assignment, most likely to be conducted in a field setting in which random assignment is difficult or impossible due to the researcher's lack of full control over the intervention (16).

2.7 Data Collection

Data were collected using a self-administered questionnaire distributed during the morning and evening shifts from the epileptic outpatient clinic at El-Demerdash Hospital. The average time to complete the questionnaire was 20 minutes. The researcher visited different shifts to maximise response rates and clarified any ambiguities in the tool.

2.8 Study Instruments

The researcher developed this questionnaire in a simple Arabic language. The validity of the tool was tested by a jury of seven experts from the Department of Medicine and the Department of Medical-Surgical Nursing of Ain Shams University, including 4 professors, 2 assistant professors, and 1 lecturer. It is composed of three parts as outlined below.

1) Patients' interviewing questionnaire

It included six questions concerning the personal data of patients such as; age, gender, marital status, educational level, occupation, and residence. Clinical data from the patient and lifestyle: It was divided into two categories that included 10 questions (17). The questions are in the form of MCQ and "yes" or "no" questions. This contains the present medical history of the period of suffering from epilepsy, the type of epilepsy, the number of epileptic episodes that occurred in the last month, antiepileptic medications, side effects of antiepileptic drugs, and diagnostic measures.

2) Adult Epilepsy Self-Management Measurement Instrument (AESMMI)

This tool was adopted from Escoffery et al. (18). It was used to assess the frequency of the use of self-management practices in epileptic patients. It consists of 63 items divided into eleven categories: Health care communication 13 items, treatment management 11 items, coping 10 items, social support 7 items, seizure tracking 3 items, wellness 3 items, seizure response 3 items, safety 4 items, medication adherence 4 items, stress management 2 statement and proactivity 3 items. This self-administered scale used a 5-point response scale ranging from 1 "no time" to 5 "all time" for positive statements and reversed in negative statements that include the statements "number 14, 15, 17, 18, 20, 21".

The scores of the items in each category were summarised, and the total scores were divided by the number of items in each category of the adult self-management behaviour instrument. The total score for the adult self-management scale was calculated and categorised as follows: Poor self-management behaviour less than "25% < 79 degrees". Low self-management behaviour ranged from "25% to < 50% from 79 degrees to < 158 degrees". Moderate self-management behaviour ranged from "50% to < 75% from 158 to

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< 236 degrees". High self-management behaviour was "more than or equal to 75% ≥ 236 degrees" (19).

3) Epilepsy Outcome Expectancy Scale:

This scale was adopted from Dilorio et al.(20). It was used to assess expected outcomes for patients with epilepsy. It consisted of three subscales that involved 36 statements distributed as follows. Outcome expectancy related to treatment 12 statements, outcome expectancy for having a seizure 17 statements, and outcome expectancy related to epilepsy management 7 statements.

This self-administered scale used a 5-point response scale ranging from 1 "strongly disagree" to 5 "strongly agree" for positive statements and the scale is reversed in negative statements that include statements "number 9 to 16". Higher scores for the expectancy of epilepsy outcome refer to better use of self-management behaviours. The total score of the epilepsy outcome expectancy questionnaire was 180 degrees. The total score of the epilepsy outcome expectancy was classified into two categories: "less than or equal to 70% < 126 degrees" was considered an unsatisfactory level of the epilepsy outcome expectancy. "More than 70% > 126 degrees" was considered a satisfactory level of epilepsy outcome expectancy (9, 20).

2.9 Reliability and Validity of Study Instruments

The reliability of the questionnaire was assessed using Cronbach's Alpha, with values ranging from 0.792 for the adult epilepsy self-management measurement instrument and 0.813 for the epilepsy outcome expectancy scale.

2.10 Pilot Study

A pilot study was carried out on 10% of patients 6 of the epileptic outpatient clinic at El-Demerdash hospital affiliated to Ain-Shams University hospitals to test the applicability, clarity and efficiency of the tools, as well as estimate the time needed to answer the study tools. Modification was done, some questions were added to the tools, and then the final form was developed according to the opinions of experts. The patients included in the pilot study were excluded from the actual study subjects.

2.11 Ethical Considerations

Ethical approvals were obtained from the Scientific Research Ethical Committee of the Faculty of Nursing, Ain Shams University before starting the study work. This research was approved by the Review Ethics Boards of Ain Shams University Registered number 164/2023. Additionally, written informed consent was obtained before completing the questionnaire, the patients were informed that participation in the study is voluntary, and confidentiality and anonymous of the information were confirmed.

2.12 Statistical analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS) version 25 is used for data handling and graphical presentation. Quantitative variables are

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described by mean and standard deviation, while qualitative categorical variables are described by proportions and percentages.

Pearson's correlation coefficient (r) was used to evaluate the relationships between variables. The chi-square independence test is used for categorical variables. Correlation and regression tests were conducted to examine the differences and the association was considered as follows: A p-value of less than or equal to 0.05 was considered significant.

3. RESULTS

Table 1: Socio-demographic Characteristics of the studied patients

Variables	Frequency N	Percentage (%)
Age		
20- <30	19	31.7%
≥30- <40	31	51.7%
40 or more	10	16.6%
Mean±SD	32.15±4.67	
Gender		
Male	31	51.7%
Female	29	48.3%
Level of education		
Can't read and write	16	26.7%
Read and write	32	53.3%
Intermediate education	10	16.7%
University education	2	3.3%
Marital status		
Married	19	31.7%
Not Married (single, widower)	41	68.3%
Occupation		
Worker	3	5.0%
House wife	7	11.7%
Retired	14	23.3%
Not working	36	60.0%
Residence		
Urban	19	31.7%
Rural	41	68.3%

Table 1 summarises the demographic details of the 60 patients who participated in the study. 51.7% of the studied patients their age ranged from 30-40 years with mean 32.15±4.67, and 51.7% were males. Regarding the educational level, 53.3% can read and write, and 68.3% were not married. Moreover, 60.0% of the patients were not working and 68.3% were lived in rural areas.

Table 2: Distribution of the studied patients regarding present medical history

Variables	Frequency (N)	Percentage (%)
Onset of epilepsy		
Less than a year	12	20.0%
From one to five years	40	66.7%
More than five years	8	13.3%

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Variables	Frequency (N)	Percentage (%)
Seizure type		
Generalized seizures	44	73.3%
Partial seizures	16	26.7%
Seizure frequency during the last month		
Once or more a day	20	33.3%
Once or more a week	24	40.0%
Once or more a month	16	26.7%
Did the illness cause you any complications?		
Yes	60	100.0%
What are these complications?		
Burns	14	23.3%
Bleeding	4	6.7%
Wounds	31	51.7%
Fractures	11	18.3%
Take medication for epilepsy		
Yes	60	100.0%
Duration of taking antiepileptic medication		
Less than one year	9	15.0%
From one to five years	33	55.0%
More than five years	18	30.0%
Have side effects of their medication		
Yes	53	88.3%
No	7	11.7%
Side effect of medication		
Forgetfulness	6	11.3%
Feeling sleepy	27	50.9%
Blindfolded	10	18.9%
Inability to concentrate	10	18.9%
Diagnostic measures done before diagnosis		
Yes	60	100.0%
Diagnostic measures that had done		
Computed axial tomography (Brain CT)	13	21.6%
Electro Encephalography (EEG)	25	41.6%
Blood electrolytes such as calcium, Magnesium	2	3.4%
Magnetic resonance imaging (MRI)	20	33.4%

Table 2 shows that 66.7% of the study patients had seizures from one to five years, 73.3% of them had generalized seizures, and the frequency of seizures was more than once a week in 40% of the patients.

Regarding the complications of epilepsy, 51.7% had wounds and 23.3% had burns. It also illustrated that 55% of patients took medication for epilepsy from one to five years and 88.3% of them had a side effect from this medication.

The side effects of the medication included feeling sleepy in 50.9% of the patients, blindfolded, and inability to concentrate in 18.8% of them. In addition, 41.6% and 44.3% of the patients were diagnosed with EEG and MRI, respectively.

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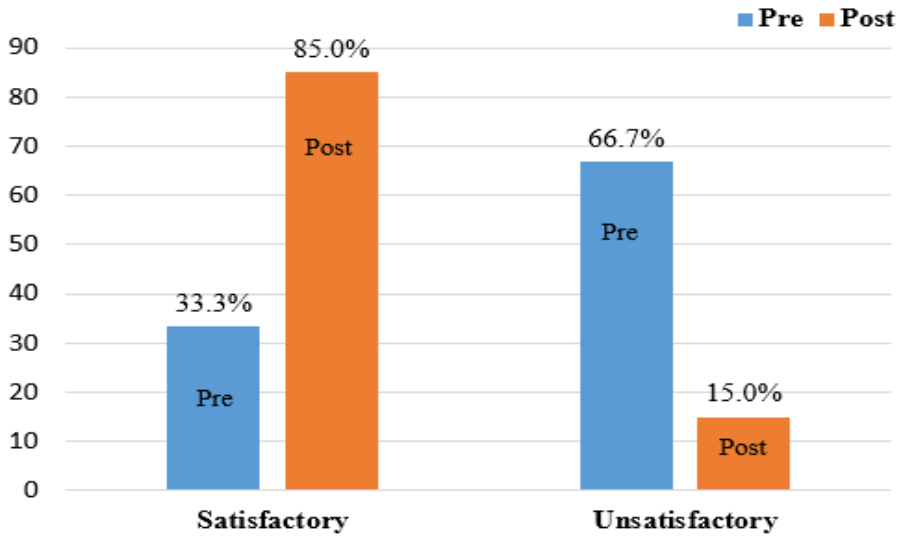

Figure 1: Total satisfactory and unsatisfactory level of knowledge pre and post implementation of the self -management behaviour guidelines among the studied patients

Figure 1 shows that 33.3% of the patients studied had a satisfactory level of total knowledge pre implementation of the self- management behaviours guidelines, and it was improved to 85% after implementation of the self- management behaviour guidelines.

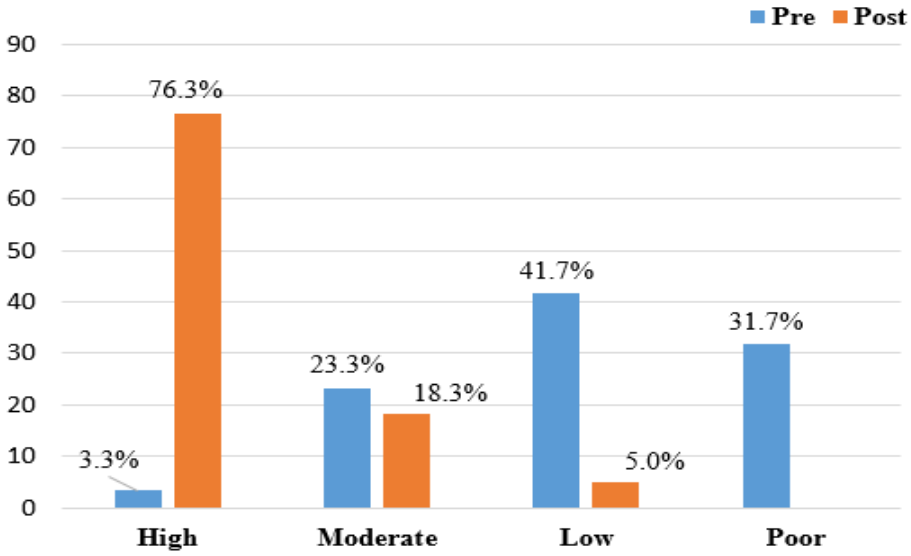

Figure 2: Total level of self-management behaviour among the studied patients pre and post-implementation of the self-management behaviour guidelines

Figure 2 shows that 3.3% of the studied patients had a high level of total self-management behaviour prior to the implementation of the self-management behaviour guidelines, while

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76.3% of the patients had a high level of self-management behaviour after the implementation of the guidelines.

Table 3: Total satisfactory and unsatisfactory level of outcomes expectancy among the studied patients post implementation of the self-management behaviour guidelines

Items	Satisfactory		Unsatisfactory	
	N	(%)	N	(%)
Outcome expectancy for treatment	54	90	6	10
Outcome expectancy for seizures	53	88.3	7	11.7
Outcome expectancies for management of seizures	51	85	9	15

Table 3 showed that 90%, 88.3%, and 85% of the studied patients had a satisfactory level of total outcome expectancy in terms of treatment, seizures, and management of seizures, respectively.

Table 4: Correlation between total knowledge and total self-management behaviour pre-implementation of the self-management behaviour guidelines

Pre	Total knowledge	
	R	P-value
Total self-management behavior	0.695	<0.001*

Table 4 revealed a statistically significant positive correlation between the total knowledge of the study patients and their total self-management behaviour, with a P-value <0.001.

Table 5: Correlation between total knowledge, total outcome expectancy, and total self-management behaviours post implementation of the self-management behaviour guidelines

Post	Total knowledge		Total self-management behaviours	
	R	P-value	R	P-value
Total adult epilepsy self-management behaviours	0.798	<0.001*		
Total outcome expectancy for patients with epilepsy	0.755	<0.001*	0.793	<0.001*

Table 5 reveals a positive and statistically significant correlation between total knowledge, total self-management behaviour, and total outcome expectancy after the implementation of the self-management behaviour guidelines, with a p-value of <0.001. Furthermore, a positive and statistically significant correlation was found between the total self-management behaviour and total outcome expectancy post-implementation of the self-management behaviour guidelines, with a p-value of <0.001.

4. DISCUSSION

This study aimed to evaluate self-management behaviours and outcome expectations for patients with epilepsy in El-Demerdash Hospital, Ain Shams, Cairo, Egypt. Regarding the total satisfactory and unsatisfactory level of knowledge of the studied patients about epilepsy pre and post the implementation of the self-management behaviour guidelines,

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the current study revealed that one third of the studied patients had a satisfactory level of total knowledge pre the implementation of the self- management behaviours guidelines, which improved to the majority of patients post the implementation of the self-management behaviour guidelines.

From the researcher's point of view, this could be attributed to the success of training programme to transfer information to patients with different educational level, the stability of the content and effectiveness of educational media that were used. All these factors help to improve knowledge and empower patients to better manage their disease and related problems. This finding is supported by Turan et al. (21) who reported that educational interventions have a high and beneficial effect on the level of knowledge about epilepsy in adult with epilepsy and parents; and they can be used as an effective intervention in the management of epilepsy.

Regarding the satisfactory total level of self-management behaviour pre and post the implementation of the guidelines among the patients studied, the current study revealed that few of the studied patients had a high level of total self-management behaviour before the implementation of the guidelines, which was improved to three quarters of the patients after the implementation of the self-management behaviour guidelines. From the researcher's point of view, this could be attributed to the success of training programme to transfer information to patients with different educational levels, suitability of content and effectiveness of educational media used, increased patient's empowerment, and enhancing patient-provider communication. This finding is supported by Bahiraei et al. (22) a study in Iran that stated that the self-management training programme has a positive effect on improving stress management, seizure rate, adherence to treatment, medication side effects and improving self-efficacy in people with epilepsy.

In relation to the total satisfactory level of outcome expectancy with respect to treatment, seizure and its management for the studied patients after implementing the self - management behaviour guidelines, the current study revealed that the majority of the studied patients had a satisfactory level related to the total outcome expectancy for treatment, seizure and management of seizures. The researcher believes that education is an important component of quality of care and is considered a therapeutic outcome for patients with epilepsy. This result is supported by Aliasgharpour et al.(23) who stated that the educational programme had beneficial effects on self-management behaviours in patients with epilepsy in a study in Zanjan, Iran.

Concerning the correlation between total knowledge and total self-management behaviour after implementation of the self-management behaviour guidelines, the current study revealed that there was a positive statistical significant correlation between total knowledge and total self-management behaviour. From the researcher’s point of view, this connection can be attributed to several factors such as patients with a higher level of knowledge are more likely to make informed decisions about care, leading to better self-management. Knowledge also empowers patients and increase their confidence in managing symptoms and treatment plans. This finding is in agreement with a study in the United States by Escoffer et al. (18) showing that adult ESM programmes can improve

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knowledge and behaviour outcomes, problem solving and symptom monitoring, and reduce seizure frequency. Regarding the correlation between total self-management behaviour and total outcome expectancy post implementation of the self-management behaviour guidelines, the current study showed a highly statistically significant positive correlation between total self-management behaviours and total outcome expectancy. This may be due to the fact that self-management behaviours determine the health status of patients with epilepsy and the expected outcomes of their behaviours when patients with epilepsy under study follow the most important strategies to control seizures, such as receiving and adhering to prescribed therapies, and making the appropriate lifestyle adjustments. Their expected outcome improved significantly. Therefore, the needs of epilepsy patients should be assessed, managed and taught to adopt many self-management behaviours to control their condition and promote their life. These findings are in agreement with Rabiei et al. (9) who found that self-management education had significant positive effects on self-efficacy, self-esteem, and QoL among epilepsy patients.

The main limitation of the current study includes obstacles faced by the researcher, such as some patients taking more time than expected to collect data due to their health and psychological conditions, which affects the overall duration of data collection. However, the current study is a quasi-experimental design (one group pre- and post-test) design, the study provides a detailed assessment of self-management behaviours and outcome expectations for patients with epilepsy at El-Demerdash Hospital, Ain Shams, Cairo, Egypt.

5. CONCLUSION

In conclusion, there was a highly statistically significant difference at ($P \leq 0.001$) pre and post-implementation self-management behaviour guidelines among study patients. The implementation of self-management behaviour guidelines for patients with epilepsy demonstrated a statistically significant positive effect on the outcome expectancy, which is consistent with the stated hypothesis.

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