

Improving Epilepsy Patient Self-Management: An Instructional Program Evaluation

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ABSTRACT

Background: Encouraging epileptic patients to develop good self-management strategies may improve their understanding of their illness and overall well-being. The aim of this study to evaluate the effectiveness of instructional program on self-management strategies for patients with epilepsy.

Subjects and Methods: A quasi-experimental design study was conducted at Al-Najaf Al-Ashraf City, within the Al-Najaf Al-Ashraf Health Directorate, specifically at The Middle Euphrates Neurosciences Center, from August 13, 2023, to November 13, 2023. The purposive sample comprised 87 patients, divided into two groups: the study group, consisting of 44 patients exposed to the instructional program, and the control group, consisting of 43 patients not exposed to the program. The effectiveness of the instructional program was measured using the Epilepsy Self-Management Scale (ESMS), which includes 38 questions measuring 5 subscales related to epilepsy self-management. The reliability of the tools was determined through test-retest, and the instrument's validity was established through expert panel review. Descriptive and inferential statistics were employed for data analysis.

Results: Results of the study indicate that the instructional program's effectiveness regarding self-management strategies was good, with highly significant differences observed in the study group between pre- and post-tests across all items related to the self-management strategies of patients with epilepsy.

Conclusions: The study concludes that the instruction program is appropriate and effective to improve the self-management strategies of epileptic patients. Additionally, it concludes that most of patients at the Middle Euphrates Neurosciences Center have deficit self-management strategies.

Key words: Improving, Epilepsy, Self-management, Instructional Program.

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Introduction

In developing countries, epilepsy is considered as one of the chronic diseases(1), alongside conditions like diabetes mellitus(2)(3)(4)(5)(6)(7), hypertension(8) (9)(10), arthritis(11), stroke(12), heart diseases(13)(14)(15), Gastric, Duodenal ulcer, and asthma(16). In addition it is one of the most prevalent neurological disorders(17), and characterized by a persistent propensity to produce spontaneous epileptic seizures and has a variety of neurobiological, cognitive, and psychosocial effects (18).

Seizures that occur frequently and without warning can significantly lower the quality of life because they make everyday tasks more difficult to complete (19). Additionally, patients with epilepsy (PWE) are more negatively impacted by social and psychological aspects of their condition than by seizures alone(20). Consequently, epilepsy is both a medical diagnosis and a social label that profoundly affects a patient's life in all aspects (21).

Epilepsy causes numerous difficulties for those affected by the condition, as well as for caregivers and family members(22). It is impossible to overestimate the significance of effective seizure management for epileptic patients. People who have trouble controlling their seizures, especially those who have generalized tonic-clonic seizures, are more likely to develop a syndrome called "sudden unexplained death in epilepsy" (SUDEP). Furthermore, PWE with persistent seizures have various social and cultural limitations that negatively impact their way of life and overall well-being (23). Therefore, seizure control is an important preventive strategy that emphasizes the need to inform individuals with epilepsy, their families, and caregivers about the possibility of SUDEP and probable seizure trigger factors (24).

Reduced education has been linked to poor seizure control (25). Therefore, self-management strategies are considered the most effective means of reducing seizures (26). These strategies aim to enhance patients' abilities and self-efficacy in symptom monitoring, problem-solving, decision-making, goal-setting, communication, and adoption of healthy behaviors to improve health and quality of life (27).

Additionally, patients with epilepsy require a variety of educational interventions in addition to adopting numerous self-management strategies to manage their condition (28).

The everyday activities people do to reduce the effects of their illness on their physical well-being and ability to function, to control it, and to deal with the psychological effects are collectively referred to as self-management of chronic illness. Self-efficacy, or people's confidence in their ability to engage in these actions, is related to self-management. These actions include applying the necessary skills to maintain adequate psychosocial functioning, making informed decisions about care, and carrying out activities intended to manage the condition (29).

There are three domains that comprise epilepsy self-management. Prescription management, the first domain, is best described as compliance. Seizure management, which encompasses both seizure prevention and seizure response strategies, constitutes the second domain. The third domain, life management, covers methods for handling circumstances brought on by epilepsy (30).

Enhance their understanding of their condition and helping epileptic patients adopt healthy self-management practices may overall health. Also, it can improve a patient's sense of self-efficacy and capacity for disease management. An epileptic patient can effectively regulate his condition if he has a thorough understanding of it. The patient learns how to manage stressful situations, limit alcohol consumption, quit smoking, get enough sleep, rest adequately each night, drink enough water, take medication as directed, and not change the dosage without first consulting a physician (31).

S0, enhancing patient knowledge can improve patients' quality of life and enable successful self-management (32).

Finally, epilepsy self-management is the information and resources that individuals with epilepsy and their families need to develop skills and behaviors that enable them to actively participate in patient-centered care (33)..

Subjects and Methods

A quasi-experimental design study was conducted at the Middle Euphrates Neurosciences Center in Al-Najaf Al-Ashraf Health Directorate from August 13th, 2023, to November 13th, 2023.

A non-probability (purposive) sample was selected to obtain representative and accurate data. From the initial pool of 97 patients at the Middle Euphrates Neurosciences Center, 10 patients were excluded for the pilot study. Therefore, the total number of patients participating in the study was 87 in order to obtain accurate data and a representative sample. The sample was divided into two groups: 43 patients were assigned to the control group, and 44 patients were assigned to the study group.

The study instrument consists of one part, which includes the publicly available ESMS questions from Dr. Colleen DiIorio (34). These questions were used in data collection to evaluate the instructional program for patients with epilepsy. A pre-test was administered to both the study and control groups as part of the data collection process.

The questionnaire of patients with epilepsy consisted of (38) items, was administered to both study and control groups. The test was adapted to evaluate the instruction program of patients with epilepsy and contained the following domains.

First domain: medication management (10 items).

Second domain: seizure management (6 items).

Third domain: safety management (8 items).

Fourth domain: information management (8 items).

Fifth domain: lifestyle management (6 items).

The patient is asked to rate how often do these items on the basis of 1-5 points ("never", "rarely", "sometimes", "most of the time" and "always").

In order to ensure linguistic equivalence between the Arabic translation and the original English version of the ESMS patient questionnaire, and the Arabic version of the modified ESMS, the instrument was translated from English to Arabic by two English language specialists. The back-translation of the instrument was done by an Iraqi native speaker who is proficient in both languages, and the two translations were finalized after comparing both translations with the original English version.

Following this, we presented the tool to a panel of (12) experts all of whom had over five years of experience in their respective fields. Their task was to evaluate the tool and assess the degree of each item's relationship to the phenomenon. The Content Validity Index was calculated as 0.9.

Inclusion criteria:

Include adult patients (both male and female) who can read and write at least, have a diagnosis of generalized epilepsy for at least 1 year, have experienced seizures during the previous year, are receiving antiepileptic drugs, and patients who come to the Middle Euphrates Neurosciences Center and who have agreed to participate in the study.

Exclusion criteria:

Patients with partial seizures, refractory epilepsy, and those experiencing status epilepticus, as well as individuals who cannot read or write or are unable to communicate, will be excluded from the study population. Additionally, patients who refuse to participate in the study will also be excluded.

Statement of Ethics:

The studies involving human participants were reviewed and approved by the Ethical Committee of the Nursing College, University of Baghdad. The patients signed a consent form to acknowledge their voluntary participation, with no coercion, and with the assurance that their data will be used for research

purposes only.

Statistical Analysis:

Before statistical analysis, the main studied domain (Self-Management Strategies) and its sub-domains for both the study and control groups pre-test means are tested for statistical normal distribution using Kolmogorov Smirnov Test. This part is essential before analyzing data to determine which statistical methods will used (parametric or non-parametric statistics). The normality results indicate that the data are not normally distributed. After the data are prepared for statistical analysis, the descriptive and inferential statistics are employed for data analysis using the Statistical Package of the Social Sciences (SPSS), version (IBM 22).

Results

The results of Table 1 depict the assessment of the study sample (study and control groups) responses toward Self-Management Strategies at the pretest stage. The study results indicate that the participants in both the study and control groups provided poor responses across all sub-domains, except for safety management strategies, which were rated as fair.

Table1: Assessment of Patients' Self-Management Strategies for both Study and Control Groups at the Pre-test.

Studied Sub-Domains	Levels	Statistics	Groups		Total
			Study	Control	
Medication Management Strategies	Poor	Freq	43	38	81
		%	97.7%	88.4%	93.1%
	Fair	Freq	1	5	6
		%	2.3%	11.6%	6.9%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Seizure Management Strategies	Poor	Freq	43	41	84
		%	97.7%	95.3%	96.6%
	Fair	Freq	1	1	2
		%	2.3%	2.3%	2.3%
	Good	Freq	0	1	1
		%	0.0%	2.3%	1.1%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Safety Management Strategies	Poor	Freq	6	14	20
		%	13.6%	32.6%	23.0%
	Fair	Freq	37	28	65
		%	84.1%	65.1%	74.7%
	Good	Freq	1	1	2
		%	2.3%	2.3%	2.3%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Information Management Strategies	Poor	Freq	44	43	87
		%	100.0%	100.0%	100.0%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Lifestyle Management	Poor	Freq	44	39	83
		%	100.0%	90.7%	95.4%

t Strategies	Fair	Freq	0	4	4
		%	0.0%	9.3%	4.6%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%

Poor (Mean 1-2.33), Fair (Mean 2.34-3.66), Good (Mean 3.67-5), F= Frequency, %= Percent.

Table (2) displays the assessment of the study sample (study and control groups) responses toward Self-Management Strategies at post-test. The study results indicate that the study group participants' responses are good across all sub-domains, while the assessment of self-management strategies among the control group participants is poor in all sub-domains except for safety management strategies, which are rated as fair.

Table 2: Assessment of Patients’ Self-Management Strategies for both Study and Control Groups at the Post-test.

Studied Sub-Domains	Levels	Statistics	Groups		Total
			Study	Control	
Medication Management Strategies	Poor	Freq	0	39	39
		%	0.0%	90.7%	44.8%
	Fair	Freq	0	4	4
		%	0.0%	9.3%	4.6%
	Good	Freq	44	0	44
		%	100.0%	0.0%	50.6%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Seizure Management Strategies	Poor	Freq	0	41	41
		%	0.0%	95.3%	47.1%
	Fair	Freq	0	1	1
		%	0.0%	2.3%	1.1%
	Good	Freq	44	1	45
		%	100.0%	2.3%	51.7%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Safety Management Strategies	Poor	Freq	0	16	16
		%	0.0%	37.2%	18.4%
	Fair	Freq	0	26	26
		%	0.0%	60.5%	29.9%
	Good	Freq	44	1	45
		%	100.0%	2.3%	51.7%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Information Management Strategies	Poor	Freq	0	43	43
		%	0.0%	100.0%	49.4%
	Good	Freq	44	0	44
		%	100.0%	0.0%	50.6%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Lifestyle Management Strategies	Poor	Freq	0	40	40
		%	0.0%	93.0%	46.0%
	Fair	Freq	0	3	3
		%	0.0%	7.0%	3.4%
	Good	Freq	44	0	44
		%	100.0%	0.0%	50.6%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%

Poor (Mean 1-2.33), Fair (Mean 2.34-3.66), Good (Mean 3.67-5), F= Frequency, %= Percent.

Table (3) indicates that the overall assessment of the study group participants' self-management strategies at the pre-test is poor. Additionally, the overall assessment of self-management strategies among the control group participants is also poor. At the post-test the overall assessment of the study group participants self-management strategies is good, while the overall assessment of self-management strategies among the control group participants is poor.

Table 3: Overall Assessment of Patients' Self-Management Strategies for both Study and Control Groups at Two Periods of Measurements Pre-test and Post-test.

Pre-Test					
Main Studied Domain	Levels	Statistics	Groups		Total
			Study	Control	
Overall Patients' Self-Management Strategies	Poor	Freq	44	42	86
		%	100.0%	97.7%	98.9%
	Fair	Freq	0	1	1
		%	0.0%	2.3%	1.1%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%
Post-Test					
Main Studied Domain	Levels	Statistics	Groups		Total
			Study	Control	
Overall Patients' Self-Management Strategies	Poor	Freq	0	42	86
		%	0.0%	97.7%	48.3%
	Fair	Freq	0	1	1
		%	0.0%	2.3%	1.1%
	Good	Freq	44	0	44
		%	100.0%	0.0%	50.6%
Total		Freq	44	43	87
		%	100.0%	100.0%	100.0%

Poor (Mean 1-2.33), Fair (Mean 2.34-3.66), Good (Mean 3.67-5), F= Frequency, %= Percent.

Table (4) results indicate that there is a significant difference between Self-Management Strategies, at pre-test and post-test (p-value less than 0.05). Additionally, there is a high effect between Self-Management Strategies at pre-test and post-test (Cohen's d value more than 0.8).

Table 4: Differences (Wilcoxon Signed Ranks Test) in Self-Management Strategies of the Study Group at Two Periods of Measurements Pre-test and Post-test.

Self-management Strategies	Statistics	N	Mean Rank	Sum of Ranks	Z	p-value	D
Medication Management Strategies	Negative Ranks	0	0.00	0.00	5.792	0.001	10.41
	Positive Ranks	44	22.50	990.00			
	Ties	0					
	Total	44					
Seizure Management	Negative Ranks	0	0.00	0.00	5.792	0.001	9.16

Strategies	Positive Ranks	44	22.50	990.00			
	Ties	0					
	Total	44					
Safety Management Strategies	Negative Ranks	0	0.00	0.00	5.789	0.001	3.68
	Positive Ranks	44	22.50	990.00			
	Ties	0					
	Total	44					
Information Management Strategies	Negative Ranks	0	0.00	0.00	6.385	0.001	54.64
	Positive Ranks	44	22.50	990.00			
	Ties	0					
	Total	44					
Lifestyle Management Strategies	Negative Ranks	0	0.00	0.00	5.787	0.001	9.83
	Positive Ranks	44	22.50	990.00			
	Ties	0					
	Total	44					
Overall Patients' Self-Management Strategies	Negative Ranks	0	0.00	0.00	5.778	0.001	18.47
	Positive Ranks	44	22.50	990.00			
	Ties	0					
	Total	44					

D Cohen's value (less than 0.2 no effect, 0.2 small effect, 0.5 moderate effect, 0.8 and more high effect).

Table (5) Differences (Wilcoxon Signed Ranks Test) in Self-Management Strategies of the Control Group at Two Periods of Measurements Pre-test and Post-test

Self-management Strategies	Statistics	N	Mean Rank	Sum of Ranks	Z	p-value	D
Medication Management Strategies	Negative Ranks	10	6.90	69.00	1.653	.098	0.063
	Positive Ranks	3	7.33	22.00			
	Ties	30					
	Total	43					
Seizure Management Strategies	Negative Ranks	6	4.08	24.50	.923	.356	0.091
	Positive Ranks	2	5.75	11.50			
	Ties	35					
	Total	43					
Safety Management	Negative Ranks	4	4.50	18.00	.681	.496	0.062

Strategies	Positive Ranks	3	3.33	10.00			
	Ties	36					
	Total	43					
Information Management Strategies	Negative Ranks	1	1.00	1.00	1.000	.317	0.213
	Positive Ranks	0	0.00	0.00			
	Ties	42					
	Total	43					
Lifestyle Management Strategies	Negative Ranks	8m	4.56	36.50	1.669	.095	0.119
	Positive Ranks	1n	8.50	8.50			
	Ties	34					
	Total	43					
Overall Patients' Self-Management Strategies	Negative Ranks	17	10.00	170.00	2.433	.015	0.127
	Positive Ranks	3	13.33	40.00			
	Ties	23					
	Total	43					

D Cohen's value (less than 0.2 no effect, 0.2 small effect, 0.5 moderate effect, 0.8 and more high effect).

Table (5) shows the study results at control group indicate that there is no significant difference among all sub domains of self-management strategies, while there is a negative significant difference in overall Self-Management Strategies at pre-test and post-test (p-value less than 0.05). So, there is no effect between self-management strategies at pre-test and post-test (D Cohen's value less than 0.2).

Discussion

Table 1, 2:

The study findings concerning medication management strategies indicate that the patients had low level of assessment in pre-test when respond to the scale items. According to the total score of patient's medication management strategies, they had a poor level of medication management strategies.

While the study shows that the patients had a good level of assessment in the study group at the post-test for all items of the scale, according to the total score of patients' medication management strategies, they had a good level of management strategies. However, the control group indicated, as shown, that the patients had a poor level of assessment in both the pre- and post-test when responding to the scale items. According to the total score of patients' medication management strategies, they had a poor level of management strategies. Also, the researcher confirms that the patients in the control group did not change from pre- to post-test; they remained stable in all measures (35) (36).

Regarding seizure management strategies, the results indicated a deficit in the pretest in both the study and control groups. The instructional program for seizure management strategies is associated with a significant increase in management strategies in the study group, while the control group did not change from pre- to post-test; they remained stable in all measures. This result is in agreement with studies indicating that providing education to patients can be successful in increasing patients' seizure management strategies (37).

The results indicated that safety management strategies were fair in the pretest for both the study and control groups. The instructional program for safety management strategies is associated with a significant increase in safety management strategies in the study group, while the control group did not change from pre- to post-test; they remained stable in all measures. This result is supported by studies showing that providing education to patients can be successful in increasing patients' safety management strategies (38).

According to the information management strategies, the results indicate a deficit in the pretest for both the study and control groups. The instructional program for information management strategies is associated with a significant increase in safety management strategies in the study group, while the control group did not change from pre- to post-test; they remained stable in all measures. This result is supported by a study indicating that providing education to patients can be successful in increasing patients' information management strategies (39).

Regarding lifestyle management strategies, the results showed deficits in the pretest for both the study and control groups. The instructional program for lifestyle management strategies is associated with a significant increase in safety management strategies in the study group, while the control group did not change from pre- to post-test; they remained stable in all measures. This result is in agreement with a study that indicates providing education to patients can be successful in increasing patients' lifestyle management strategies (37).

Regarding the overall assessment of self-management strategies in table 3, there was a deficit in the pretest for both the study and control groups. The instructional program for self-management strategies was associated with a significant increase in self-management strategies in the study group, while the control group did not show any changes in the pre-posttest. This result aligns with a study that found that the study group had a lower mean at the pretest compared to the control group, but the study group demonstrated an increase in the posttest, which was nearly equal to the control group mean (39). Additionally, another study showed that more than half of the participants had a poor level of self-management (40).

According to the table 4 shows that, there is a highly significant different at $P < 0.001$ between pre-and posttest of study group with high effect, this result supported with studies that there were significant differences between pre-and posttest of epileptic patients 'self-management scores in the study group, indicating that after participating in the program, the participants' self-management has improved (26).

Regarding to the table 5 show that there are significant negative differences at $P = 0.015$ between the two periods (pre-Post Tests) with no effect in the control group. These results disagree with the study that found that there were non-significant differences in the control group (P value = 0.594). (26)

The results indicated that patients' self-management strategies were at a low level before the beginning of an instructional program and became high after the program (posttest) in the study group, while they became worse in the control group. This result reflects that patients' self-management strategies are affected by the instructional program and worsen without the program

Conclusion

The study confirmed the effectiveness of the instructional program on self-management for epileptic patients. Furthermore, there is a significant influence of an instructional program in enhancing the self-management strategies of patients with epilepsy.

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Author contributions:

Sarah Kareem Buraihi and supervisor Dr. Widad Kamil Mohammed contributed to the original drafting, editing, supervision, and critical review of the manuscript. Sarah Kareem Buraihi undertook data collection, analysis, and manuscript structuring. Sarah Kareem Buraihi was involved in drafting and revising the manuscript. All authors reviewed and approved the final manuscript for publication.

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Conflict of Interest

The authors declare that they have no conflict of interest.

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