

## Impact of an Educational Program for Adolescent and Adult Epileptic Patients and Their Families on Their Knowledge and Practices

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**Abstract:** Epilepsy remains one of the most common neurologic disorders affecting both adults and children alike. Epilepsy is a manifestation of brain neuronal hyper excitability. It is a symptom complex C. N. S disorder of a variety underlying etiologic causes. Seizures occurring across the spectrum of age, gender, race and economic background. The aim of this study is to assess the impact of an educational program for adolescent and adult epileptic patients and their families on their Knowledge and practices. **A quasi- experimental design** was used for this study. It was carried out in epileptic Out Patient Clinic of Assiut University Hospital. **Sample of this study included (150)** adolescent and adult epileptic patients and their family members or relatives (aged 18-40 year) and they were divided into two groups: study group included (50) adolescent and adult epileptic patients and their family members or relatives (50) and control group included (50) adolescent and adult epileptic patients. The exclusion criteria were those who had other chronic diseases. Data was collected during the period from the beginning of October 2009 to the end of March 2010 through using **the following tools:** 1) – A structured interview questionnaire sheet. 2)-Educational program booklet which was developed by the researchers. **Results** of this study revealed that all patients had poor knowledge scores, while about (59.0%) of them had poor practices scores with highly statistical differences between the pre-test and the post-tests 1 and 2 related to total knowledge and practices scores ( $p=0.000$ ). **Concluded** that, by implementation of the program there was remarkable improvement of adolescent and adult epileptic patients and their families knowledge and practices, it was clear in post tests results. The study **recommended**, that education for epileptic patients and their families about epilepsy and care pre, during and post seizures should be in simple Arabic and small sessions or classes using films and audio visual materials.

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**Key words:** Adolescent - Seizures

### 1. Introduction

Epilepsy is an episode of excessive and disorganized electrical activities involving the neurons within the cerebral cortex, this activity can interrupt the ongoing mental and behavioral activities of the individual (Dalrymple and Appleby, 2000). Epilepsy remains one of the most common neurologic disorders affecting both adult and children alike. Approximately, one third of new cases of epilepsy have their onset before age 20 years (Sheth, 2002). From many studies around the world it has been estimated that the mean prevalence of active epilepsy (i.e. continuing seizures or the need for treatment) is approximately 8.2 per 1,000 of the general population. In Egypt, Assiut governorate the prevalence rate was 12.9/1000 (Gilliam, 2002) and (WHO, 2004).

According to the centers for disease control, epilepsy is one of the most commonly diagnosed neurological disorders there percent, of the united states population are 2,3 million people, have epilepsy. More than 180,000 new cases are reported each year, fourteen percent, or 316,000 patient with epilepsy are under 14 years of age, 63% or 1.9 million

patients are between the ages of 15 and 64, and 29% or 549, 000 patients are older than 65 years of age (Centers for disease control and prevention, 2005).

There are multiple etiologies for a patient to develop epilepsy such as prenatal injuries, hypoxia, metabolic changes and congenital defects. Also children can experience epilepsy due to hyperpyrexia, central nervous system infections or idiopathic reasons. During adolescence, the primary cause of epilepsy is head trauma. In adulthood, a brain mass is a common cause (Schachter, et al, 2013).

The three generally recognized phases of epilepsy are aura, ictal, post-ictal. An aura occurs immediately prior to a seizure, usually lasting a few seconds. Patients often describe an aura as 'a warning' the description of an aura can be varied and may include weakness, an epigastric sensation, sense of fear, visual hallucinations, aphasia, headache, feelings of being hot or cold or sensing unpleasant odors. The ictal phase is the duration of the actual epilepsy activity, the patient experiences a proximal, uncontrolled, abnormal, excessive discharge of electrical activity in the brain. The post-ictal period is

the interval after epilepsy, the patients may experience amnesia, confusion, fatigue and /or coma (Kelley, 2014).

Parents of children or family of epileptic patients often experience frustration, hopelessness and financial difficulties. It is important for parent to address these issues so that they don't transfer their feelings to their patients. Support groups and counseling often help relieve the feelings of frustration and hopelessness (Thomas and Bindu, 1999). Management of epilepsy requires skills and sensitivity. The aim of any epilepsy nurse intervention is rapid and complete control of seizures without or with minimum antiepileptic drug side effects (Hosking, 2004).

Controlling epilepsy, although extremely important, the goal of management of children with epilepsy should be to enable the child and the family to lead a life as free as possible from the medical and psychosocial complications of epilepsy. This comprehensive care need to go beyond simply trying to control seizure with minimal adverse drug reactions. Seizure frequency and severity is only one important outcome variable (Ronen, et al., 2003).

Nurses play a pivotal role in providing coordinate care and education to patients acting as a facilitator to assist patients to self-manage their epilepsy (Hosking, 2003) and (Hayes, 2004).

Nurse care in epilepsy is useful in assessing symptoms, diagnosis, tests and risk management (Kendall, et al., 2004). Nursing care to the epileptic patients have been many aspects as nursing role pre, during, and post seizure to keep them calm and protect from injury (Hockenberry and Wilson, 2011).

#### **Significance of the Study:**

Although the incidence of epilepsy is high in adolescents, specific services for adolescents with epilepsy are rarely provided, adolescents is a time of great change, growth into adulthood. In addition, adolescents tend to be very body-conscious and do not like to be different from their peer groups. Denial of the epilepsy may result in some teenagers taking risks. So that this study was done to assess the impact of an educational program for adolescent and adult epileptic patients and their families on their knowledge and practices.

#### **Aim of the study:**

The aim of this study is to assess the impact of an educational program for adolescent and adult epileptic patients and their families on their knowledge and practices.

#### **Subjects and Method:**

##### **Research design:**

A quasi-experimental design is used for this study.

##### **Setting:**

This study is conducted in epileptic out patients clinic at Assiut University Hospital.

##### **Sampling:**

Sample of this study includes 150 adolescent and adult epileptic patients and their family members/ or relatives aged from (18-40) years for both sexes. They are divided into two groups: Study group included (50) adolescent and adult epileptic patients and their family members /or relatives (50) and control group included (50) adolescent and adult epileptic Patients. They were selected randomly from their follow-up cards numbers (single numbers) in outpatient clinic. The only exclusion criteria is that patient should be free from other chronic diseases.

##### **Tools of data collection:**

**First tool:** A structural interview sheet which is developed by the researchers and consists of three parts:-

**Part I:** Personal characteristics of adolescent and adult epileptic patients and their family members/or relatives such as age, sex, education, occupation, marital status and residence.

**Part II:-** Questions to assess adolescent and adult epileptic patients and their family members/or relatives knowledge about epilepsy as definition, causes, types, signs and symptoms, diagnosis, treatment, complications and preventions of epilepsy.

**Part III:-** Sheet to assess patients family members/or relatives practices or care pre, during and after epilepsy seizure or attack, preventive measures taken and nutrition of their patients.

**Second tool:-** Educational program booklet.

##### **Method:-**

- A written permission to conduct the study was obtained from the head manger of Assiut University hospital and outpatient epileptic clinic.

- The purpose of the study was explained to every adolescent and adult epileptic patient and his or her

- Family member or relative participated in the study.

##### **Pilot study:**

- After the development of the tools, a pilot study was carried out on (10%) of adolescent and adult epileptic patients and their family members or relatives, to test clarity and applicability of the study tools and to estimate the time needed to complete the questionnaire. According to the results of the pilot study, the needed modifications were done. A jury acceptance of the final form was secured before actual study work from both pediatric and neurology fields to test its contents validity and the reliability was assessed by measuring its internal consistency using Cronbach's alpha coefficient method.

##### **Ethical consideration:**

- The oral consent was taken from all adolescent and adult epileptic patients and their family members or relatives participating in the study. The researchers explained the purpose of the study through direct personal communications and they were secured that the data will be confidential and will be used only for the research purpose.

#### **Field of the work:**

- The study was conducted over a period of six consecutive months from the beginning of October 2009 to the end of March 2010.

#### **Program design:**

A pre-test was conducted for the adolescent and adult epileptic patients and their family members or relatives to assess their knowledge and practices pre, during and post epileptic seizures. After that Preparation of the educational program was done in a form of an Arabic booklet after reviewing of relevant literature (nursing textbooks, journals and internet resources). The program was revised by pediatric nursing and medical neurology specialists and the final form was modified according to the given comments.

#### **Implementation of the program:**

The program was implemented on the study group by the researchers in about four months (about 60 hours) divided to (20 hours) theoretical and (40 hours) practical, they are divided into (10) small groups, each group include about (5) adolescent and adult epileptic patients and their family members or relatives, each group had about (10) sessions, each ranged between 45 to 60 minutes and each of them had a copy of the program booklet. Methods of teaching were through a modified lecture, group discussion, demonstration and re demonstration, suitable teaching aids were prepared such as a mannequin of an adolescent or adult.

Post test was done immediately after the program (post test 1) and after 3 months (post test 2) to evaluate the effectiveness of the program.

#### **Scoring system:**

Patient and their family members or relatives knowledge

A score of one was given for correct answer and zero for incorrect answer and for family members or relatives practices, a score of one for done and zero for not done. For each part, the scores of the items were summed up and the total divided by number of items, giving a mean score for the part, these scores were converted into a percent score. The patients and their family members or relatives knowledge and practice scores less than 40% of the total were considered poor, scores between 40-70% were considered fair and a score more than 70% were considered good.

#### **A statistical analysis:**

The obtained data were coded, analyzed and tabulated. Descriptive statistics as frequency percent, mean, standard deviations, were calculated using computer, also T- test and chi- square were used, p value less than 0.05 level considered as statistical significant.

### **3. Results**

**Table (1)** Shows distribution of the studied patients according to their personal characteristics. It was found that about 38% of patient's age was between 18 to 21 years while 34.0% were between 22 to 40 years and 28% of patients more than 40 years. According to sex, it was found that 62.0% of patients were males while 38.0% of them were females. Also results revealed that more than three quarters (78.05%) of patients were from urban areas while 22.0 % were from rural areas. Regarding education, most of the studied patients (64%) were illiterate while 36.0 % of them were educated. As regards studied patients occupation, it was found that the majority (88%) were do not work and according to marital status, two thirds (70%) of patients were single.

**Table (2)** Presents distribution of the family members or relatives according to their socio -demographic characteristics. It was found that about 74.0% of relatives, ages were between 20 to 40 years while 26.0% of them were more than 40 years. According to sex, it was found that about two thirds (71%) were females and one third (29%) were males. Regarding education, 64.0% of relatives were illiterate while 36.0% were educated. As regards to occupation, it was found that 28% of relatives were do not work while 72.0% are working. As regards marital status, two thirds (70%) were single and one third (30.0%) were married. Regarding degree of relatives, it was found that 74.0% were from first degree while 26.0% of them were from the second degree.

**Table (3)** demonstrate the mean scores of adolescent and adult epileptic patients and their families knowledge about epilepsy related to pre and post educational program tests. Findings revealed that there were highly statistical significant differences between the pre-test and post-test, and between the pre-test I and the post -test 2 related to all items of knowledge (P=0.0001).

**Table (4)** illustrates the mean scores of relative's practices pre, during and after adolescent and adult epileptic patient's seizure or attack of epilepsy in pre and post educational program tests. Highly statistically significant differences were found between pre and post-test I, the majority (82%, 80%, 80%) of relatives performed some practices during post -test I such as observe patient after attack to prevent apnea, elevate head to prevent suffocation, left patient until attack stop respectively, while more than

three- quarters (78%) of them performed practices as putting cotton between teeth, calm the patients and avoid asking him what happened, meanwhile there was a decrease in scores of post –test 2 related to the same items.

**Table (5)** describes the total scores of adolescent and adult epileptic patients and their family's knowledge about epilepsy in the pre and post educational program test. Highly statistically significant differences was found between the pre and post tests related to knowledge about epilepsy ( $P=0.0001$ ), the majority of studied patients and their families (88%) had poor scores of knowledge in the pre –test while only (12%) had fair scores and none of them had good scores while these scores have all increased at the post program tests reaching 60% had good scores in knowledge, 32% had fair scores, only (8%) had poor scores.

**Table (6)** presents the total scores of practices of relatives of adolescents and adult epileptic patients in the pre and post educational program tests. Highly statistically significant differences were observed between the pre and post tests regarding to relatives practices ( $P<0.001$ ). The scores of practices among relatives were generally low in the pre –test however these scores reached statistical significant difference after the educational program to 70% with good scores, 30% had fair scores and none of them had poor scores in their practices.

**Table (1): Distribution of studied adolescent and adult epileptic patients by their personal characteristics**

Items	No (n=50)	%
<b>Age</b>		
18-22 years	19	38%
23-40 years	17	34%
More than 40 years	14	28%
<b>Sex</b>		
Male	31	62%
Female	19	38%
<b>Residence</b>		
Urban area	39	78%
Rural area	11	22%
<b>Education</b>		
Illiterate	32	64%
Educated	18	36%
<b>Occupation</b>		
Not work	44	88%
Work	6	12%
<b>Marital status</b>		
Single	35	70%
Married	15	30%

**Table (2): Distribution of studied patients family members or relatives by their socio-demographic characteristics.**

Items	No (n=50)	%
<b>Family member / Relatives Age:</b>		
20 – 40 years	37	74.00%
More than 40 years	13	26.00%
<b>Family members / Relatives Sex</b>		
Male	16	29.00%
Female	34	71.00%
<b>Family members / Relatives Residence</b>		
Urban area	39	78%
Rural area	11	22%
<b>Family members / Relatives Education</b>		
Illiterate	32	64%
Educated	18	36%
<b>Family members / Relatives Occupation</b>		
Not work	14	28%
Worker	36	72%
<b>Family members / Relatives Marital status</b>		
Single	35	70%
Married	15	30%
<b>Degree of consanguinity</b>		
First degree	37	74%
Second degree	13	26.00%

**Table (3) The mean scores of adolescent and adult epileptic patients and their families knowledge about epilepsy in the pre-test and post- tests.**

Items of knowledge	Pre test	Post - test 1	TI	Post - test 2	T2	PV
Definition	0.40±0.20	0.35±0.86	8.37	0.49±0.60	4.95	0.0001
Causes	0.48±0.24	0.99±2.74	18.55	0.95±2.42	16.02	0.0001
Types	0.42±0.22	0.72±1.36	9.97	0.50±1.54	14.3	0.0001
Diagnosis	0.40±0.20	1.75±2.12	24.75	0.69±2.18	18.93	0.0001
Signs and symptoms	0.64±0.38	1.56±6.38	26.38	1.88±5.56	17.61	0.0001
Treatment	0.46±0.30	0.80±3.08	20.16	1.07±3.28	17.51	0.0001
Complication	0.40±0.20	0.96±2.74	17.04	1.56±3.34	13.84	0.0001
Prevention	0.45±0.28	0.92±3.08	19.6	1.46±3.68	16.05	0.0001

**Table (4) The mean scores of family members or relatives practices in the pre –test and post –tests.**

Items of practice	Pre-test		Post- test 1		Post - test 2	
	No	%	No	%	No	%
1. Elevate his /her head	9	18%	40	80%	31	62%
2. Put cotton between teeth	7	14%	38	78%	31	62%
3. Avoid open mouth if closed	5	10%	35	70%	31	62%
4. Open his/ her clothes	6	12%	34	68%	34	68%
5. Lie the patient down	6	12%	33	66%	29	58%
6.Remove any dangerous object	8	16%	33	66%	27	54%
7.Remove the secretion from mouth	6	12%	37	74%	33	66%
8. Avoid put water on head or any part of body	7	14%	38	76%	32	64%
9.Wait until attack stop	9	18%	40	80%	28	56%
10.Ensure good ventilation	5	10%	37	74%	32	64%
11. Avoid give drug or food during sleep	6	12%	38	76%	32	64%
12.Avoid pressure on abdomen	8	16%	38	76%	34	68%
13. Observe the patient after attack to prevent apnea	5	10%	41	82	32	64
14. Calm the patient after attack and avoid asking him what happen	6	12%	39	78%	33	66%
15. Report the doctor and referral if prolonged attack	8	16%	38	76%	38	76%

**Table (5) Total levels of knowledge scores among adolescents and adult epileptic patients and their families about epilepsy in the pre and post-tests.**

Knowledge level	Pre - test		Post - test	
	No	%	No	%
Poor knowledge (<40 %)	44	88	4	8
Fair knowledge (40-70%)	6	12	16	32
Good knowledge (< 70)	0	0	30	60
Total	50	100	50	100

$\chi^2 = 100.0$  P. value = 0.000 (0.001)

**Table (6) Total levels of practices scores among family members or relatives for their adolescent and adult epileptic patients in the pre and post –tests.**

Levels of practices	Pre-test		Post – test	
	No	%	No	%
Poor practices (<40%)	50	100	0	0
Fair practices (40-70%)	0	0	15	30
Good practices (>70%)	0	0	35	70
Total	50	100	50	100

$\chi^2 = 100.0$  P. value = 0.000 (P > 0.001)

#### 4. Discussion:-

Epilepsy is a common serious neurological condition to affect both adolescents and adults.<sup>(4)</sup> and has an estimated prevalence of 0.6%. More importantly, the lifetime incidence of seizures is estimated to be approximately 10%. Thus, seizures and epilepsy are encountered in every clinical practice. Furthermore, untreated or uncontrolled epilepsy is a costly disorder that may result in severe injuries, morbidity and death. Therefore proper identification and management of seizures are important for all medical disciplines, (Rakel and Bope, 2004) so that this study was done to assess the impact of an educational program for adolescent and adult epileptic patients and their families on their knowledge and practices.

Results of the present study showed several age ranges, more than one third (38%, 34%) of epileptic patients age were between (18-22, 23-40 years old), about two thirds (62%, 64%, 70%) were males, illiterate and single respectively, two thirds were lived in urban areas and most of them not work. These findings are in agreement with Mittan, (2009) who found that sixty percent of epileptic patients age were between 18-25 years old, more than half (61.7%) were single, Fifty percent were females and less than half (41.7%) were employed and similar as Marbet, et al., (2004) who reported that most respondent patients were single, male and half of them were illiterate and also with Emad, (2004) who found that epilepsy show unequal sex distribution among epileptic patient with male predominance while these findings are in contrast with Lena, et al., (2003) who found that gender did not relate significantly to different seizure type but there was a tendency for girls to have more seizures.

As regard, epileptic patients level of education, current study demonstrated that about two thirds (64%) of them were illiterate. This finding was in accordance with A guiar, et al., (2007) who reported that children with epilepsy are prone to educational underachievement as a result of co-morbid learning and behavioral problems. Hence education is an important indicator that may directly or indirectly influence quality of life of epileptic patients because well educated patients are better educated about the disease and more aware of self-management practices and also know that regular treatment can help them avoid seizures leading to normal life. Also reviewing the studies of the psychosocial consequences of epilepsy indicated that these problems may be reflected in lower rates of marriage, under and unemployment, lower rates of academic achievement and greater social isolation.

It is also important to consider the impact of epilepsy on the life of the adolescent and to minimize the isolation and stigmatization that the teenager may feel at a time when being part of an approving peer group (Besag, 2007). These issues are of interest in the Arab world because few psychosocial studies on epilepsy showed that rates of anxiety and depression are higher among people with epilepsy, and adverse effects on education, marriage and occupation are common (Al-Khateeb and Al-Khateeb, 2014).

As regard the studied patients, family members or relatives socio-demographic characteristics, results shows that more than two thirds (71%, 74% and 72%) of them respectively were females, aged between 20-40 years old, and worked. These findings are in consistent with Kendall, et al., (2004) whom found that among 70 carers, there were slightly more female careers (57.7%) than male (42.3%). Many were in work as well as being careers while in contrast with him regarding their ages that ranged from 30 to over 60 years.

Regarding educational level, marital status, residence, and consanguinity of family members or relatives, results revealed that about two thirds and more (64%, 70%, 78% and 74%) of them respectively were illiterate, single, from urban areas and had first degree consanguinity or relation to patients. These results were incongruent with Myeong and Byeong, (2003) who found that the rural residents of his study were usually less educated than those in urban areas and congruent with Mahmoud, (2009) and Sander, (2003) who reported that, rural social habits like marriage of the relatives increase the risk of developing epilepsy.

Regarding patients and their families knowledge, the present study revealed that generally, epileptic patients and their families had poor scores (88%) in their knowledge related to epilepsy in all items such as definition, causes, types, signs and symptoms, diagnosis, treatment, complications and prevention of recurrence of seizures before application of the program which improved after application of the program with highly statistically significant difference ( $P = 0.0001$ ) between the pre and post-tests. These findings are consistent with those of Dilorio, et al., (2009) in which the efficacy of epilepsy education and support programs was tested. Also Mittan, (2009) reviewed 14 such programs, of these programs, six demonstrated improved knowledge. Furthermore, Helde, et al., (2003)<sup>(12)</sup> reported that a principal element of comprehensive care of chronic disease is to increase the patients factual knowledge about the specific disease and Nordeli, (2001) stated that, In addition to prescribing medication, other important

parts of the therapeutic management involve education, counseling, support and advocacy care.

Concerning family members or relatives practice of epilepsy care pre, during and after their epileptic patients seizure or attack. Highly statistically significant differences were found between epileptic patients families or relatives practices in the pre test, and immediate post- test and three months post program ( $P = 0.0001$ ). Inappropriate practices were found before application of the program regarding significant items of care as elevate his or her head to prevent suffocation, put cotton or an object between the teeth, wait until attack stop, observe the patient after attack to prevent apnea, calm patient after attack and avoid asking him or her what happen while these items were significantly improved after the educational program. This can be explained by that practices related to epilepsy were affected by family members or relatives illiteracy, age in which they are not old enough and that they work beside caring for their epileptic patients, also epilepsy management is long term and can be life – long, people with epilepsy usually need regular medication and daily lifestyle management to eliminate or minimize seizure activity. (Robinson et al, 2007)<sup>(30)</sup>

Regarding patients and their families total scores of levels of knowledge and practices, finding of the present study revealed highly statistically significant differences between pre test and post test regarding total levels of knowledge and statistically significant differences were noticed regarding levels of family members or relatives practices. This indicate the efficacy of the educational program in improving patients and their family members or relatives knowledge and practices regarding epilepsy care, these finding are in accordance with Mesfin, (1997) a study results from rural community in Jimma, Ethiopia on the knowledge, attitude and practice related to epilepsy reveal that poor knowledge as well as inappropriate attitude and practice were observed in the community and also with El-Sayed, (1993) who reported that knowledge acquired may be retained for longer time if the learner applies this knowledge in the real situation, remember ninety percent of what they do, thirty percent of what they see and twenty percent of what they hear. Thus highlights the importance of improvement of knowledge, attitudes, awareness and practices for families of epileptic patients in attempt to ensure health related quality of life.

### Conclusion

The study concluded that generally the educational program had significantly improved the adolescent and adult epileptic patients and their family members or relatives knowledge and practices concerning epilepsy care whilst not marginal

significance in family members or relatives practices. The present study spot lashes on the significant role played by the patients family, as secondary care provider, for epilepsy patients during epilepsy attack especially those in adolescence period.

### Recommendations:

#### The following suggestions were recommended:-

- 1- Proper identification and save management of seizures should be a standard of services in comprehensive epilepsy care.
- 2- Continued development of brief, Arabic, simple and inexpensive educational programs for patients with epilepsy and their families can decrease the economical burdens of treatment, injuries, morbidity and mortality rates of epilepsy.
- 3- Films and audiovisual conferences about the practices pre, during and after epileptic seizure or attack for patients and their families.
- 4- Psychological and social standard out – patient care on seizure control for adolescents with newly diagnosed epilepsy.
- 5- Developing special teenage clinics in order to meet the needs of adolescents with chronic disorders like epilepsy must be a growing interest in our in developing countries.
- 6- Adequate books, which include materials related to epilepsy and care of the attack should be available in epileptic units of the hospitals.
- 7- Further researches are needed to explore the nature and severity of injuries in connection with seizures.

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