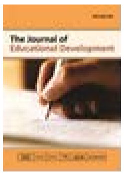
The Journal of Educational Development

JED 6 (2) 2018 : 252-264

http://journal.unnes.ac.id/sju/index.php/jed



The Effect of Applying Self- and Family-Oriented Written Education on the Management of Medicamentose, Clinical Exposure, and Quality of Life of Patient with Epilepsy

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Article Info

Article History:
Received 15 January 2018
Accepted 19 February 2018
Published 1 June 2018

Keywords:
self- and family-oriented education, clinical outcome, quality of life, epilepsy

Abstract

Epilepsy is a brain disorder characterized by a tendency to induce a continuous epileptic recurrence and neurobiological, cognitive, psychological, as well as social consequences. Epilepsy seizures are a series of signs and/or symptoms caused by abnormal neuronal activities in the brain. The purpose of this study was to prove the benefits of applying self- and family-oriented educational management to clinical outcomes, self-management, and impact of epilepsy on family, patient's quality of life, family support, and the role of doctors and family of the epilepsy patient. This is an experimental research using two groups pre and posttest design. The subjects were 80 epilepsy patients ranging from 18 to 70 years of age. All subjects had never had any epilepsy surgery. The subjects were randomly assigned to treatment and control groups; 40 subjects in the treatment group received treatment and self- as well as family-oriented education while the other 40 subjects in the control group received treatment only. Family-oriented education was conducted using written materials on pathophysiology and epilepsy management, psychological effects of epilepsy, and information about the epilepsy community. All of the subjects answered the questionnaires prior to and 3 months after treatment. The questionnaires include information on seizure frequency and seizure-free status, medication adherence, self-management, epilepsy impact on patient and family, and quality of life. The results show that self- and family-oriented education can improve medication adherence, self-management, and family roles. Family-oriented education reduces the frequency of seizures as well as the impact of epilepsy on patients and families. It was concluded that self- and family-oriented education had a positive effect on medical management, clinical outcomes, self-management, and the quality of life of patients with epilepsy.

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p-ISSN 2085-4943
e-ISSN 2502-4469

INTRODUCTION

Epilepsy is a brain disorder characterized by a tendency to cause persistent epileptic seizures and neurobiological, cognitive, psychological, and social consequences. Epilepsy seizures are a series of signs and/or symptoms due to abnormal neuronal activities in the brain. Epilepsy is a chronic disease that can occur at any age (Fisher et al., 2005, p.472).

Recent data show that approximately 50 million people around the world live with epilepsy. The incidence of active epilepsy (epileptic patients reported with persistent seizures or who are currently taking the drug) is between 4 and 10 people per 1000 population (World Health Organization, 2015).

The incidence of epilepsy in Indonesia is estimated to be 0.6% of around 220 million people. Approximately 1.5 million people in Indonesia live with epilepsy (Muttaqin, 2013, p.36). By 2014, 590 epilepsy patients treated in Dr. Kariadi General Hospital Semarang consisted of 536 outpatients, 26 inpatients, and 28 patients in the emergency department (Kustiowati, 2015).

Epilepsy is still considered a social stigma. The burden and stigma of epilepsy can be more severe than the seizure itself. Many studies show that people living with epilepsy experience a decline in annual income, low quality of life, poor education or school performance, and low self-esteem. 75% of patients with epilepsy have problems with adaptability. Epilepsy not only affects patients but also their families in their social life (Aliasgharpour, Nayeri, Yadegary, & Haghani, 2013, p.47).

Education plays a very important role in the management of comprehensive chronic diseases including epilepsy. In the management of these chronic diseases, educational programs have two main objectives, namely increasing the patient's knowledge of the disease and improving the ability and responsibility of the patient to live with minimal limitations (Ried, Specht, Thorbecke, Goecke, & Wohlfarth, 2001, p.77).

Cochrane research (1995, p.30) shows that education for epilepsy patients results in increased self-confidence, ability to self-regulate, ability to know their needs, and limitations so that they can use all available resources to fulfil their needs.

Education for epilepsy patients and their families includes information about the consequences of epilepsy and self-management that are important to them. Poor knowledge leads to psychosocial and emotional problems that can affect their daily lives (Ried et al., 2001, p.77).

A research study conducted by Nagarajan, Mahadevan, Franks, & Chen (2011, p.1) on American veterans suffering from epilepsy suggested that the use of modules in formal epilepsy education programs could improve the patient's knowledge of epilepsy. However, Nagarajan et al. have not studied the benefits of an educational program about clinical manifestations of epilepsy. Lua & Neni (2012, p.27) reported that the short message service (SMS), used as a medium for epilepsy patient education, resulted in increased knowledge, attitudes, and behavior of the epilepsy patients. However, this method has not been able to improve clinical outcome and patient medication compliance. May (2002) mentions that by using an educational module called Modular Service Package of Epilepsy (MOSES), clinical outcomes and patient satisfaction on the treatment they receive can be improved. However, the use of this module has not been able to improve the quality of life of the epilepsy patients (May & Pfäfflin, 2002, p.548).

In contrast to education management to improve the knowledge of other chronic diseases such as asthma and diabetes, similar management for epilepsy patients and their families has not been widely used.

Accurate information about epilepsy patients is necessary for successful management of epilepsy. The availability of information about the consequences of epilepsy and required self-management skills is an important component in the management of patient-oriented epilepsy itself. Patients and people living with them are often unaware that people with epilepsy are at risk of injury and, even worse, death. Epilepsy patients and those living with them need information about epilepsy and its implications for the patient's life. The most important information for adult epilepsy patients is on the job, handling and stress management, the effects of the hormonal system on the disease, and the possible side effects of epilepsy on pregnancy. Elderly patients need information about the increased risk of falls and the possibility of other diseases that can affect epilepsy patients (UK, Liverman, Schultz, & Strawbridge, 2012, p.327).

Patients and their families rely on information provided by health workers and also written information available on the internet. The available information often contains medical language that is not easily understood by the patient and his/her family. Based on this fact, it is necessary to develop an independent education model for epilepsy patients and their families. In this educational model, modules need to be written in simple language so that it is easy to understand it. Research on educational programs for epilepsy patients and their families has never been conducted in Indonesia. Educational modules for epilepsy patients are also unavailable in this country.

Based on the above description, it is necessary to develop independent and family education management that can support the patient's medical care. It is expected that self- and family-oriented education can improve the life quality of epilepsy patients.

The purpose of this study was to examine the effect of patient-oriented education on the medical management, clinical outcome, and quality of life of epilepsy patients.

METHODS

This is an experimental research study that is designed for two groups pre and posttest design at random. All of the research procedures have been approved by the Medical and Health Research Ethics Committee of the Faculty of Medicine Diponegoro University/Dr. Kariadi General Hospital Semarang. Patient's readiness and written information from all of the subjects were collected prior to the study.

The subjects of this study were adult epilepsy patients treated at the Neurology Clinic, Dr. Kariadi General Hospital and 2 public hospitals in Semarang equipped with Electro-Encephalography (EEG) facilities. The subjects were chosen by purposive sampling method. The inclusion criteria include patients with epilepsy or vocal epilepsy with EEG or other examinations such as Computed tomography scan (CT-Scan) and Magnetic Resonance Imaging (MRI), ages range between 18 and 70 years, and agreed to participate in the study. Patients who have had epilepsy surgery and those who have epilepsy complications that cause inability to receive education are excluded.

The number of samples was calculated using the formula for the difference in the proportion of 2 populations. A total of 80 epilepsy patients were allocated randomly into two groups: the treatment group and the control group. Subjects in the treatment group received medical treatment and self- and family-oriented education (n = 40); the control group received treatment only (n = 40).

Self- and family-oriented education are done by using written materials developed specifically for this research. The contents of the written materials include information on living with epilepsy, epidemiology, causes, and pathophysiology of epilepsy, diagnosis, therapy, prognosis, psychosocial aspects of epilepsy, self-control, family roles, and existing epilepsy issues. Two different types of written materials were developed: written materials for patients and written materials for their family. Education is delivered by doctors who have been trained by the principal investigators.

The variables measured in this study were the frequency of seizures and seizure free status, medical compliance, self-management measured using the Epilepsy Self-Management (ESM) questionnaire, the impact of epilepsy on patients and families using the Personal Impact of Epilepsy Scale (PIES) questionnaire, the quality of life using the Quality of Life Questionnaire in epilepsy-31 (QOLIE-31), and family support using the FACES III Questionnaire. Measurements were administered twice: before self- and family-oriented education and 3 months after education.

Because the data collected in this study were not normally distributed, the data were statistically analyzed using the Mann-Whitney test and the Wilcoxon test. Chi-square was used for categorical data analysis.

RESULTS AND DISCUSSION

Eighty epilepsy patients and eighty closest relatives treating patients were involved in the study. No patient dropped out of school in this study. All patients and families completed the study protocol. The study subjects consisted of 52 men (65%) and 28 women (35%). The average age of the subject is 30.3 ± 13.62 years, the youngest age is 18 years and the oldest is 70 years. Characteristics of the subjects of this study are shown in Table 1.

Table 1. Characteristics of the subjects

Characteristics	**Study Group**		**p**
	Treatment (*n*=40)	**Control** (*n*=40)	
Age (year);[§]	30.3±13.72	30.3±13.68	0.9[¥]
Age category (year); n (%)			
- ≤25	19 (47.5%)	17 (42.5%)	0.1*
- 26-45	13 (32.5%)	20 (50.0%)	
- 46-65	8 (20.0%)	2 (5.0%)	
- >65	0 (0.0%)	1 (2.5%)	
Sex; n (%)			
- Male	24 (60.0%)	28 (70.0%)	0.3*
- Female	16 (40.0%)	12 (30.%)	
Educational background			
- Elementary school	3 (7.5%)	5 (12.5%)	0.2
- Junior High School	10 (25.0%)	17 (42.5%)	
- Senior High School	16 (40.0%)	12 (30.0%)	
- Diploma	2 (5.0%)	3 (7.5%)	
- Bachelor	9 (22.5%)	3 (7.5%)	
Employment status			
- Unemployed	16 (40.0%)	11 (27.5%)	0.2
- House wife	3 (7.5%)	3 (7.5%)	
- Student	10 (25.0%)	7 (17.5%)	
- Employee	11 (27.5%)	11 (27.5%)	
- Labourer	0 (0.0%)	4 (10.0%)	
- Entrepreneur	0 (0.0%)	1 (2.5%)	
Income per month (Rupiah)			
- No income	27 (67.5%)	21 (52.5%)	0.1
- 1-2 million	2 (5.0%)	4 (10.0%)	
- 2-4 million	3 (7.5%)	10 (25.0%)	
- 4-6 million	6 (15.0%)	5 (12.5%)	
- > 6 million	2 (5.0%)	0 (0.0%)	
Marital status			
- Single/divorced	25 (62.5%)	21 (52.5%)	0.4
- Married	15 (37.5%)	19 (47.5%)	

[§] Mean ±SD
[¥] Mann-Whitney Test
* χ^2Test

As shown in Table 1, there were no significant differences in age, sex, educational background, employment status, monthly income, and marital status between the treatment group and the control group. All have p> 0.05. The characteristics of epilepsy are shown in Table 2.

Table 2. Characteristics of epilepsy

Characteristics	**Study Groups**		**p***
	Treatment (*n*=40)	**Control** (*n*=40)	
Period of suffering from epilepsy			
- 1-3 years	7 (17.5%)	15 (37.5%)	0.09
- 3 - 5 years	5 (12.5%)	6 (15.0%)	
- > 5 years	28 (70.0%)	19 (47.5%)	
Type of seizures			
- SF	3 (7.5%)	6 (15.0%)	0.5
- CF	10 (25.0%)	10 (25.0%)	
- GTCS	27 (67.5%)	24 (60.0%)	
Therapy			
- Carbamezepin	4 (10.0%)	4 (10.0%)	0.2
- Fenitoin	7 (17.5%)	11 (27.5%)	
- Carbamezepin + Fenitoin	3 (7.5%)	7 (17.5%)	
- Other	7 (17.5%)	9 (22.5%)	
- Carbamazepin + Others	6 (15.0%)	1 (2.5%)	
- Fenitoin + Other therapy	12(30.0%)	6(15.0%)	
- Carbamazepin + Fenitoin + Other	1(2.5%)	2(5.0%)	
Medication side effects	0 (0.0%)	0 (0.0%)	-

* χ^2test

GTCS=*General Tonic Clonic Seizure*; SF=*Simple Focal Seizure*; CF=*Complex Focal Seizure*

As shown in Table 2, there was no significant difference in epilepsy, seizure type, therapy, and therapeutic side effects between the study group and the control group. All scores p> 0.05.

As shown in Table 3, all patients take medication as recommended by doctors (p = 0.3). There are significant differences in the section, which is about the fun of taking medicine every day and forgetfulness of taking medication. In the treatment group, the frequent and regular patients taking the drug at the same time each day were larger than the control group (p = 0.002). In the treatment group, patients who never or rarely forgot to take the drug were significantly higher than the control group (p <0.001).

Table 4 shows that the frequency of seizures in the treatment group after self-oriented and family-oriented education was significantly lower than the control group (p <0.001). The self-management skill score of the treatment group is much higher than that of the control group. The impact of epilepsy score of the treatment group was significantly lower than that of the control group (p <0.001). The quality of the treatment group's life score was much lower than that of the control group (p <0.001). Table 5 shows that the impact of epilepsy scores on treatment groups was significantly lower than that of the control group (p = 0.01). The family support scores in the treatment group did not differ significantly from support in the control group.

Table 3. Comparison of medical compliance between the study groups

Patients compliance to take medication	**Study groups**		p
	Treatment (n=40)	**Control** (n=40)	
Medication taken as recommended by doctor			
- Never	0 (0.0%)	1 (2.5%)	0.3
- Seldom	0 (0.0%)	1 (2.5%)	
- Sometimes	0 (0.0%)	2 (5.0%)	
- Often	5 (12.5%)	7 (17.5%)	
- Always	35 (87.5%)	29 (72.5%)	
Medication taken at the same time everyday			
- Never	0 (0.0%)	1 (2.5%)	0.002
- Seldom	0 (0.0%)	4 (10.0%)	
- Sometimes	2 (5.0%)	12 (30.0%)	
- Often	21 (52.5%)	10 (25.0%)	
- Always	17 (42.5%)	13 (32.5%)	
Forget to take medicationresearch			
- Never	20 (50.0%)	4 (10.0%)	<0.001
- Seldom	20 (50.0%)	21 (52.5%)	
- Sometimes	0 (0.0%)	13 (32.5%)	
- Often	0 (0.0%)	1 (2.5%)	
- Always	0 (0.0%)	1 (2.5%)	

* χ^2test

Table 4. Clinical outcomes, self-management skills, the impact of epilepsy, and life quality of the study subjects by treatment group.

Epilepsy related outcomes	**Study groups**		
	Treatment (n=40)	**Control** (n=40)	p$^{¥}$
Frequency of seizures within three months			
- Before	3.4±3.37	4.6±3.61	0.1
- After	1.4±1.87	4.9±3.65	<0.001
p (before vs. after)$^{\$}$	0.001	0.2	-
Scores of self-management skill			
- Before	128.9±12.72	122.5±14.68	0.08$^{¥}$
- After	137.8±13.20	119.9±14.63	<0.001$^{£}$
p (before vs. after)$^{\$}$	<0.001	<0.001	-
Impact of epilepsy scores			
- Before	28.5±14.65	27.8±12.98	0.8
- After	21.9±12.95	29.2±13.08	0.01
p (before vs. after)$^{\$}$	<0.001	<0.001	-
Quality of life scores			
- Before	63.0±14.98	69.1±12.34	0.1$^{¥}$
- After	70.8±12.73	65.5±14.38	0.1$^{¥}$
p (before vs. after)$^{\$}$	0.01	0.4	-

The value in the table were mean ±SD
¥ Mann-Whitney test
$ Wilcoxon test

Table 5. Impact of epilepsy on family and family support according to treatment group

Impact of epilepsy and family support	Study groups		
	Treatment (n=40)	**Control** (n=40)	p¥
Impact of epilepsy scores			
- Before	28.4±14.65	27.4±13.12	0.8
- After	23.6±17.00	29.3±13.34	0.01
p (before vs. after)$	<0.001	<0.001	-
Family support scores			
- Before	4.8±0.92	4.8±0.87	1.0
- After	4.9±0.88	4.8±0.87	0.9
p (before vs. after)$	0.4	1.0	-

The value in the table was mean ±SD
¥ Mann-Whitney test
$ Wilcoxon test

Table 5 shows that the impact of epilepsy scores on treatment groups was significantly lower than that of the control group (p = 0.01). The family support scores in the treatment group did not differ significantly from support in the control group.

Epilepsy is a neurological disorder that can affect all age groups. Patients with epilepsy may experience recurrent seizures, psychosocial disorders and emotional disturbances that lead to limitations in everyday life (May & Pfäfflin, 2005, p.186).

Research on the benefits of education for self-management of epilepsy patients has often been conducted (Bautista, 2017, p.10). However, there has been no research that assesses the benefits of education management for patients and families that has been conducted so far. In this study, it turns out that the group of epilepsy patients who received standard medicines and education using self- and family-oriented written educational management manuals decreased the frequency of recurrence, increased the number of seizure-free subjects, increased self-management abilities, decreased epilepsy impact, and improvement of patient's quality of life. In addition, the provision of education using self- and family-oriented written educational management manuals also decreases the impact of epilepsy on the family. After the provision of education using self- and family-oriented written educational management manuals, the role of the family also becomes better. Before and after research the role of the doctor has been and remains good.

In this study, the provision of education using self- and family-oriented written educational management manuals can decrease the frequency of recurrence and increase the number of seizure-free patients. The results of this study are supported by previous research results that also provided education to epilepsy patients, i.e. research on Modular Service Package Epilepsy (MOSES). In the MOSES study, educational management was administered twice a week, 2 hours at each meeting, for 4 weeks (Ried et al., 2001, p. 79). The MOSES study results also indicate a decrease in the frequency of recurrence in the education group (May & Pfäfflin, 2002, p 546). The biological direct link to the effects of educational management with the decreasing frequency of recurrence as found in this study has not been explained. However, this is thought to be related to the observance of research subjects in taking medication. The results of previous studies indicate an increase in adherence to taking medication to groups who received educational programs. In this study, medication adherence was assessed by measuring the drug levels in the blood of the subjects. However, in the study, there was no assessment of the frequency of recurrence (May & Pfäfflin, 2002, p.191). In this study, the decrease in the frequency of the recurrence is thought to be related to the increase in Epilepsy Self-Mangement score (ESM). The self- and family-oriented written educational management leads to the better introduction of the patient to the trigger factors so that the occurrence of the relapse can be avoided. The results of a study by

Lewis et al showed that increased knowledge of epilepsy led to improvements in the ability of patients to manage themselves and become more responsible to themselves (Lewis, Noyes, & Mackereth, 2010, p.11). The increasing number of seizure-free subjects in this study was related to improved self-management of illnesses including the introduction of precipitating factors and medication adherence. Similar to the MOSES research, the measurement of an antiepileptic drug in blood in this study was not conducted so that the decrease in the frequency of recurrence and the increase in the number of seizure-free subjects has not been proven objectively.

In this study, there was also an increase in self-management in the group of patients educated using self- and family-oriented written educational management manuals. The results of this study were supported by previous studies which also found an increase in self-management of epilepsy patients (Aliasgharpour et al., 2013, p. 50). In his study, education management is given in the form of 2-hour classroom instructions using PowerPoint for 4 meetings in a month. The learning materials were medical aspects of epilepsy and self-management including the lifestyle of epilepsy patients. In the Aliasgharpour study, self-management was also measured using self-management questionnaires on self-management of epilepsy patients which similar to this study (Aliasgharpour et al., 2013, p.49). The results of Aliasgharpour’s study also showed an increase in self-management score before and after education. Educational management really improves the patient's ability to better manage himself by identifying the illness, its management, and lifestyle that is more appropriate for epilepsy patients. According to Bautista (2017, p.7), self-management of epilepsy patients is the patient's ability to adjust the behavior needed to reduce seizures and improve overall health. At the individual level, self-management aims to improve the patient's ability and confidence in recognizing symptoms of epilepsy, solving problems, making decisions, setting goals, communicating, and accepting healthy lifestyle behaviors to improve health status and quality of life. Self-management is a partnership between patients and physicians, by combining patient’s desires and goals and making patient-centered management. Self-management facilitates healthy behaviors that include physical, mental, and social aspects aimed at improving the patient well-being. At the population level, self-management of epilepsy patients is a support to the health services of the patients and surrounding communities aimed at assisting the patients in understanding and overcoming epilepsy and assisting them in the treatment of their illness (Helmers et al., 2017, p.221). Good self-management of epilepsy patients includes a set of skills including medication adherence, ability to recognize seizures and vigilance against seizures, adequate rest, and participation in managing stress levels generated by employment (Bautista, 2017, p.7).

Self-management is closely related to the ability of self-efficacy. The ability of self-efficacy is defined as the patient's ability to organize and perform actions necessary to achieve treatment goals such as taking medication, self-care, and involvement in other treatment (Hixson, 2017, p 55).

This study did not measure the ability of self-healing. However, the results of this study indicate an increase in the ability of self-management of epilepsy patients. This is followed by a decrease in the frequency of recurrence and an increase in the number of seizure-free subjects.

The results of the study conducted by Gurumurthy, Chanda, & Sarma, 2017, p.100) on epilepsy patients in Singapore show several factors that influence patient adherence to taking medication. One of the most influential major factors is forgetfulness in taking the drug, difficulty in remembering when to take medication, feeling worse and feeling that there is some improvement. The encountered factors are conditions that can be avoided by the increasing ability of self-management of the epilepsy patients. It reinforces the notion that the decreasing frequency of recurrence and the increasing number of seizure-free patients is due to improved self-management abilities.

The results of the study conducted by Clark et al. (2010, p.256) show that medication adherence is the most common action of epilepsy patients in terms of self-management. However, it is not the most important challenge in the management of patients with epilepsy. Clark, et al. found that the main challenge in the self-management of the epilepsy patients is effective health services accessible to the patients. This demonstrates the need for the participation of health care providers, especially the Ministry of Health and professional organizations such as the Indonesian Doctors Association (IDI) to add and expand health services for people with epilepsy. The ability of self-management needs to be supported by the ease of accessing quality health services.

This study also found a decrease in epilepsy scores on patients who are educated using self- and family-oriented written educational management manuals. The effects of epilepsy on patients are due to seizures, side effects of medical treatment, and presence of comorbid illnesses such as depression (Robert S. Fisher, Nune, Roberts, & Cramer, 2015, p. 140).

This study used a Personal Impact of Epilepsy Scale (PIES) questionnaire to assess the impact of epilepsy on epilepsy patients. PIES questionnaire can measure the impact of epilepsy on the life of the patient as a whole. The questionnaire assessed seizures and their characteristics, side-effects of medical treatment, comorbidities and quality of life in general (Fisher et al., 2015, p.143).

Nowadays, seizures in epilepsy patients is a very important clinical variable. If therapy can not decrease the frequency of seizures, then preventing prolonged seizures, falls, and trauma is necessary (Wirrell, 2006, p 81). The next factor that negatively affects the epilepsy patient is the side effects of the drug. Unlike intermittent seizures, the side effects of the drug tend to last longer although their effects may be fluctuating (Fisher et al., 2015, p. 141). Epilepsy comorbidities, such as depression, anxiety, social limitations, driving restrictions, work problems, schools, and social relations are fundamental problems for epilepsy patients (Fisher et al., 2005, p 471).

The effect of self-educational management on epilepsy patients has not been previously reported. The decrease of self-epilepsy impact scores on groups educated using self-education using self- and family-oriented written educational management manuals is related to the decrease of seizure frequency and the increase of self-management abilities.

The impact of epilepsy on the patients is not only physical but also psychological (Morell, 2001, p 294). Physical, social, and psychological impacts greatly affect the quality of life of the patients. Seizures and drug side effects lead to the decrease of physical function that can influence their daily life. Disruption of the social function, lack of support for the family and the surrounding community will disrupt relationships within the family, surrounding community, and working partners. Epilepsy is also known to have an effect on cognitive function either directly or indirectly as a drug side effect. Emotional distress, depression, anxiety, and decreased self-satisfaction affect the patient's wellbeing (Baker, 2001, p 67).

The results of this research also show a decrease in the impact of epilepsy not only on the patients but also on their families. The results of research conducted by Karakis et al. (2014, p.5) indicates that the patient's family, especially those providing care to the patient, is affected by epilepsy suffered by the members of their family.

This study found an improvement in the quality of life of the patients who received education using self- and family-oriented written educational management manuals.

In recent years, attention to the quality of life of epilepsy patients has continued to increase. The research results show that epilepsy patients had a worse quality of life than the general population (Norsa'adah, Zainab, & Knight, 2013, p. 1). The mean score of QOLIE-31 in this study was 70.8 ± 12.73 higher than the mean score of QOLIE-31 of epilepsy patients in Malaysia, i.e. 68.9 ± 15.9 (Norsa'adah et al., 2013, p. 3). This is probably due to different ways of measuring the quality of life. In this study, quality of life was measured after the administration of education, while in Malaysia the measurements were performed in the general population of epilepsy patients. The mean score of QOLIE-31 in the control group was 69.1 ± 12.34 approximately equal to the mean score in the Malaysian population.

The results of the study by Djibuti & Shakarishvili (2003, p 572) suggest that high seizure frequency and prolongation of epilepsy are major factors affecting the quality of life of the epilepsy patients. The study also found that lack of education is the most influential predictor of low quality of life. The Djibuti research results explain the results of this study. Educational management provides improvements in the quality of life of the patients through physical effects in the form of decreased frequency of recurrence and an increase in the number of patients who are free from seizures. Educational management also enhances self-efficacy of epilepsy patients and decreases the impact of epilepsy on the patient.

This study also observed the impact of epilepsy on the patient's family. The results showed that the provision of education using self- and family-oriented written educational management manuals can reduce the impact of epilepsy on the family.

Karakis et al. (2014, p.5) reported the impact of patients with epilepsy on their families. The impact on the patient's family is primarily psychological and physical. The results of the analysis indicate that there are three factors related to the impact of the patients on their family that is the amount of anti-epilepsy drugs used, the cognitive function, and the quality of life of the patient. Family factors include the education level of the family members and the length of time that the family members spend with the patient.

Accurate information about the family of epilepsy patients, especially about the consequences of epilepsy and the development of self-management abilities, is an important component to help the patient's family to be a good partner in the patient-centered care (England et al., 2012, p.327).

Previous research has shown that epilepsy patients and their families require education on epilepsy, particularly those related to the diagnosis and treatment of the patients. Epilepsy patients and their families may have anxiety and even fear when the diagnosis of epilepsy is made (Hills, 2007, p.10). Early epilepsy during childhood can be very frightening. When a parent sees a child having a seizure, he/she may believe that his or her child life is in danger. Children and adults with epilepsy are also afraid of their mental health conditions, injuries, and death. In order to overcome such fear and prevent anxiety, epilepsy patients and their families need complete and accurate information about the risk of epilepsy-related comorbidities and mortality, including sudden death from epilepsy (Sudden Unexpected Death in Epilepsy/ SUDEP), suicide, injuries related to seizures, and the risk of prolonged seizures such as epilepticus status (England et al., 2012, p.331). Family support in the form of consultation and education can eliminate the impact of epilepsy on the family and have a reciprocal effect on the quality of life of the patient (Karakis et al., 2014, p.7).

Until now, the best format of education for epilepsy patients and their families has not been practiced widely. Educational materials and information need to be made to meet the needs and circumstances of the patients both orally and in writing. Couldridge, Kendall, & March (2001, p 611) found that some studies support information provided in written form, instead of spoken one because spoken information can be a challenge for epilepsy patients who may also have memory dysfunction.

Written information about epilepsy, seizure type, treatment, and medical treatment of epilepsy is reported as essential for epilepsy patients and their families (England et al., 2012, p.331). This supports the results of this study demonstrating the benefits of education using self- and family-oriented written educational management manuals for the patient’s family.

Family support and function for epilepsy patients in this study was measured by FACES III questionnaire. The results showed an increase in FACES III score in the treatment group. However, the increase was not significant while in the control group there was no change.

About the support and functions of the family in both groups, only a few are within the category of balanced, some are included in moderate balanced, and most are in mid-ranged; there is no family that is included in the extreme category. This indicates that most families are not functioning properly. The results of this study are similar to those of Wirrell et al. (2006, p. 132) who also found that only a small percentage of families were categorized as well-balanced (balanced and moderate balanced).

The explanation of the results of this study is based on the assumption of the type of relationship between the family providing care and the patient. In this study, most family members who provide care to the patients are parents, namely, mother and father.

The provision of education using self- and family-oriented written educational management manuals cause the family to be able to perform its role and function in accompanying and becoming the main supporter of the patient in facing the disease. This explains that family support for the subjects of the study in the treatment group was similar to the support for the control group. The relatively short period of treatment, i.e. for 3 months, may not yet be able to clearly alter the family support, so longer-term follow-up research is needed so that it can change the supported behavior and function of the epilepsy family.

In this study, the role of physicians is categorized to be good, both before and after treatment. This is most likely due to the existence of health service standards in the form of permanent management of epilepsy so that the entire role of doctors in the management of epilepsy patients is in the good category.

After being educated using self- and family-oriented written educational management manuals, the role of most families is better, especially in taking appropriate action in the event of relapse. This is because all family members in the treatment group have knowledge about epilepsy.

The strength of this research is that it is a randomized clinical trial. The design of this study is the best design to assess the clinical benefits of a new management method for patients. Research on a clinical trial using educational management for epilepsy patients has not been conducted so much that this research has novelty both in national and international levels. This study involves not only epilepsy patients but also doctors treating the patients and families of the patients so that the results of this study are comprehensive and applicable to the patients, doctors, and patients' families.

The limitation of this study is that the observation was only done for 3 months, a relatively short period of time to measure the psychosocial changes. Longer-term studies are needed to find out the benefits of education management for epilepsy patients. In addition, this study has not measured the concentration of drugs in the blood as an indicator of patient compliance to take anti-epilepsy drugs.

CONCLUSION

Self- and family-oriented education provide good results in medical management, clinical outcomes, self-management, and quality of life of patients with epilepsy. Patients who receive self- and family-oriented education experience a decrease in frequency of seizure. The decrease in seizure frequency may result from better medication compliance and improved self-management. Lower seizure frequency results in better clinical outcomes and improves quality of life.

Self- and family-oriented education using two different written materials for patients and their families have shown to be effective in improving knowledge about epilepsy. Patients with epilepsy and their families should be aware of the key factors for the success of the epilepsy treatment including medication compliance, seizure prevention, and what to do if their family has a seizure.

In addition, self- and family-oriented education can contribute to a better awareness of epilepsy. Health institutions and the community can work together to support the increasing awareness of epilepsy by ensuring that all health facilities are accessible to all specifically those with epilepsy and their family.

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