

Effectiveness of an Epilepsy Education Programme on the Self-Management among Patients with Epilepsy

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Abstract: The purpose of this study is to determine the effectiveness of an epilepsy education programme on self-management among patients with epilepsy. The methodology adopted was a randomized controlled trial wherein patients were assigned to the study and control groups based on the inclusion and exclusion criteria. Pretest on self-management was conducted on the first day. On the 15th day the study group received the Epilepsy Education Programme and the Epilepsy Information Booklet. The control group received the routine care. This was followed by 1st reinforcement at one and a half months. The posttest I was carried out at the end of the third month for both the groups. The second reinforcement was conducted at four and a half months following which the posttest II was carried out at the end of the sixth month for both the study and control groups. The study began with 175 participants in each group but at the end of the sixth month, the study group had 169 patients with epilepsy and the control group had 167 respectively. The findings revealed that the overall self-management scores of the study group had increased from 2.97, 3.39 to 3.79 compared to that of the control group which showed a minimal difference from 3.46 at pretest, 3.42 at third month to 3.46 at the end of the sixth month. The type of epilepsy had an impact on self-management.

Key words: Epilepsy Education Programme, Patients with epilepsy (PWE), Self-management

I. Introduction

The prevalence of epilepsy in different states of India showed that in Kolkata, in a door-to-door survey among a population of 52,377, the prevalence was found to be 309 and the incidence was 66 active cases of epilepsy, after standardization the Average Annual Incidence Rate (AAIR) was found to be 572.8 (509.79-641.54) per 100,000 and 27.27 (21.03-34.80) per 100,000 per year.[1] The incidence of epilepsy in rural community of West Bengal, India identified 38 cases in a population of 20,966. The age adjusted average annual incidence rate was 42.08 per 100,000 people per year. The common cause being cerebral infection. [2] A three-phased survey among a population of 238,102 in a semi-urban locality of central Kerala identified 1,175 cases (616 males and 559 females) with active epilepsy. The crude point prevalence ratio was 4.9 cases per 1,000 people and an age-adjusted prevalence ratio of 4.7 cases per 1,000 people. The age-specific prevalence rate was highest between 10 and 19 years being 6.5 per 1,000. The proportion of generalized and localization-related epilepsies was 58.8% and 30.6% respectively. [3]

Epilepsy accounts for 0.75% of global disease burden. This includes the Disability Adjusted Life Years (DALY's) that accounts for the years of life lost due to premature mortality, number of days lost in less than normal, healthy social and economically productive living, without taking into account that caused due to the effects of stigma. The causes, signs and symptoms, management and the impact of seizures vary across individuals. It is mostly idiopathic in onset and is seen in 6 out of 10 PWE, with an underlying genetic basis. [4]

A survey regarding the challenges that were faced by PWE in managing their condition carried out among 101 clinical, academic and human service professionals revealed that 30% of the respondents had personal experience with epilepsy. The psychological and emotional impact of epilepsy were challenging for the patients with epilepsy. The significant outcomes were seizure control and Quality of Life. The clinicians had constraints of time to be spent with the PWE. The challenges identified were Quality of care and stigma. [5]

It is imperative to integrate self-management in chronic illness. Epilepsy is one such chronic health problem that affects the physical, psychological, social and economic well-being of an individual. The difference between the other chronic conditions and epilepsy is its sudden occurrence that could cause injury to the individual and discomfort to those around him. Epilepsy is otherwise known as the hidden condition. This in turn causes prejudice about the condition and affects the individual in terms of education, employment, marriage and family. The level of knowledge and social acceptance has significantly improved but these need to be integrated into the day-to-day life of the PWE and their caregivers. Information needs of individuals with epilepsy varies at different points of time and is based on the severity, frequency, age, impact of the condition, gender, marital status and social outlook of the problem.

The researcher during interaction with patients with epilepsy found that they had varied questions as how long to take the medications, the reason for drowsiness, bone pain, impact of the condition on marriage and child birth, reduced or sluggish activities, memory problems, frequent anger and irritability. The PWE were not only coping with the condition and its effects but also with the treatment and its effects which were significant. This formed the basis for the objective of the study which was to assess the effectiveness of an Epilepsy Education Program on Self-management among Patients with Epilepsy (PWE).

II. Review

Support systems are important in self-management, in order to identify the support providers who aid in self-management efforts among 153 PWE the number of support providers ranged from 0 to 6, 12% had no support. were the most common supporters were the parents and significant others. The emotional and instrumental support including support for medication intake self-management could be encouraged. [6] The self-management that was preferred among PWE who had depressive and cognitive complaints was face-to-face individual or group interaction that was led by an epilepsy professional and trained peer leader. This included 6 to 8 sessions for 60 minutes in a week with focus on disability management, medical care, socializing on a budget, healthy lifestyle and emotional coping strategies [7] The relationships among medicine symptom distress, self-efficacy, patient-provider relationship, and medication compliance in 357 patients with epilepsy in northern Taiwan revealed that the health care providers of patients with epilepsy paid more attention to factors as co morbid chronic disease, self-driving, seizure after a missed dose, and self-efficacy and they were significantly associated with medication compliance.[8] Overall management, information management and safety management were better than medication, seizure, and lifestyle management. Self-efficacy, depression, social support, stigma, desire for control, and outcome expectations were higher with higher socioeconomic status. Higher levels of self-efficacy and social support was directly proportionate to higher self-management [9] An European survey on the level of satisfaction of patients and physicians in the management of epilepsy found that patients wanted more information on treatment options [10] A pilot study of an integrated cognitive-behavioural and self-management intervention for youth with epilepsy and caregivers: Coping Openly and Personally with Epilepsy (COPE) identified that among nine youth aged 10–15, parents rated significant improvements in their children's coping skills, self-efficacy for seizure management and knowledge of epilepsy. The suicidal ideation also decreased following the intervention. [11] The assessment of the feasibility of a telephone-based self-management program for people with epilepsy among 22 adults wherein the intervention group received intervention by a nurse trained in Motivational Interviewing (MI) counseling. Out of the five sessions the first one was an in person interview and the remaining four sessions were conducted over phone. Ninety-five percent of the 55 planned MI sessions and the 44 planned courtesy calls for those in the control group were completed showing acceptance of the telephone based self-management programme.[12] The extent of behavioral, social, and affective factors contributing to self-reported epilepsy self-efficacy revealed that self-management, depressive symptoms, and seizure severity had an impact on self-efficacy whereas patient satisfaction and stigma were of less importance. Self-efficacy was not influenced by social support and regimen-specific support . [13] Individuals with low self-efficacy would get benefited from the interventions that increase self-efficacy beliefs to enhance their ability to adopt and maintain good self-management. [14]

III. Methodology

3.1 **Study Design:** A randomized controlled trial was adopted to determine the effectiveness of an epilepsy education program on self management among patients with epilepsy. Data were collected from the patients after obtaining permission from the institutional ethical committee. Informed written consent was obtained from the patients after identification of patients based on the inclusion criteria.

3.2 **Sample:** The inclusion criteria included PWE who had at least one seizure during the last six months, were between 21 and 60years of age, of both gender, able to understand and respond to questions in English or Tamil, regular follow up at the tertiary care center, and willing to participate in the study They were then assigned randomly to either the study or control groups. PWE having cognitive impairment, cerebral infections or tumors and pregnant women were excluded from the study

3.3 **Intervention:** The patients in the study and control groups were assessed for their self -management on the first day. On the 15th day the study group received the **Epilepsy Education Programme** that included explanation, discussion and clarification about epilepsy, causes, types of seizures, family's role, common diagnostic measures, medications and their effects, foods to be included, facts about epilepsy, activities that a person can do and the activities that are to be avoided and special consideration in women. The teaching was given using the epilepsy **information booklet** which was later handed over to the patients. The session lasted for about 25 minutes. Group teaching was given for a group of 3 to 5 patients. The **first reinforcement** was given at one and a half months along with clarification of individual patient's doubts, following which the

posttest I was done on the third month for both the groups. After the first posttest the **second reinforcement** was given at four and a half months along with the routine care that included regular consultation and medications. Follow-up was encouraged by telephonic reminders. The posttest II was carried out at the end of sixth month for both the groups. PWE in the control group received the routine care which included regular consultations and medications from the physician. The pretest, posttest I and II were carried out for the control group. After the posttest II they received epilepsy education and the Epilepsy Information Booklet. The sample size at the end of the sixth month during Posttest II was 169 for the study group and 167 for the control group.

3.4 Data collection tools

3.4.1 Background data including:

The demographic variables included age, gender, education, occupation, monthly family income, residence, marital status and type of family. The social variables identified were the caregivers relationship, dependence and medical expense management and the clinical variables included age at onset of epilepsy, duration of epilepsy obtained from patient’s response and type of epilepsy as obtained from the patient’s records. The time of occurrence of seizure was obtained from the patient’s response.

3.4.2 Epilepsy Self-management Scale (ESMS)

This scale was developed by DiIorio et al. (2004) It has 38 items divided under five components as

Information management (IM)	: 8
Medication management (MM)	: 10
Safety management (SM)	: 8
Seizure management (SeM)	: 6
Lifestyle Management (LM)	: 6

Score interpretation

The scale is a five point rating scale with never being 1, rarely 2, sometimes 3, most of the time 4 and always 5. There were twelve negatively worded items for which the score was taken by reverse coding, and then the total score was obtained. The higher the score the better the self-management. The mean score for each component was calculated. The mean score of the whole scale was obtained by the sum of all items divided by the total number of items. The tool was translated into the local language and back translated.

The reliability of the scale was determined by the test- retest method. The reliability value obtained was $r = 0.81$.

3.5 Statistical analysis: The collected data were analyzed using descriptive and inferential statistics. Frequency, percentage and chi square was used to determine the homogeneity of the samples. Mean, standard deviation, independent t test and RM ANOVA were used to determine the effectiveness of epilepsy education programme on self- management between the two groups.

IV. Results

A total of 350 patients were selected with 175 PWE in the study and 175 PWE in the control group respectively. The baseline demographic characteristics were collected following which the intervention was given to the study group and the posttest I and II were carried out at the end of the third and sixth month respectively.

4.1 Patient characteristics

Table. 1 Summary of sociodemographic variables at baseline

Demographic Variables	Study group Percentage (N=175)	Control group Percentage (N=175)	Chi square
Age (in years)			
a. 21-40	76.6(134)	119(68)	0.07
b. 41-60	41(23.4)	56(32)	
Gender			
a. Male	55.4 (97)	60.6 (106)	0.330
b. Female	44.6 (78)	39.4 (69)	
Education			
a. Non formal	14.3(25)	22.9(40)	0.067
b. Primary	46.9(82)	43.4(76)	
c. Secondary	29.7(52)	21.1(37)	
d. Graduate	9.1(16)	12.6(22)	
Occupation			
a. Employed	17.7(31)	9.1(16)	0.096
b. Self-employed	.6(1)	2.9(5)	
c. Unemployed	23.4(41)	29.1(51)	
d. Daily wages	37.1(65)	34.9(61)	
e. Housewife	19.4(34)	22.9(40)	
f. Agriculture/other	1.7(3)	1.1(2)	

Family income (in Rs/ month)				
a.	<2500	59.4(104)	66.9(117)	0.485
b.	2501-5000	30.9(54)	26.3(46)	
c.	5001-7500	5.7(10)	4.6(8)	
d.	>7501	4.0(7)	2.3(4)	
Residence				0.015
a.	Urban	82.9(145)	72.0(126)	
b.	Rural	17.1(30)	28.0(49)	
Marital status				0.826
a.	Married	60.6(106)	61.7(108)	
b.	Unmarried	39.4(69)	38.3(67)	
Type of family				0.889
a.	Joint family	17.7 (31)	18.3(32)	
b.	Nuclear	82.3(144)	81.7(143)	
Accompanied by care giver				0.517
a.	Yes	41.1(72)	44.6(78)	
b.	No	58.9(103)	55.4(97)	
Dependent on				0.021
a.	Independent	30.3(53)	37.1(65)	
b.	Mother/Father	33.1(58)	25.1(44)	
c.	Sister/ Brother	.6(1)	5.7(10)	
d.	Husband/ Wife	30.9(54)	25.7(45)	
e.	Friends / Other	5.1(9)	6.3(11)	
Medical Expenses taken care of by				0.652
a.	Self	33.1(58)	35.4(62)	
b.	Others	66.9(117)	64.6(113)	

Table 1. illustrates that the study and control groups were homogenous with regards to age, 76.6% in the study group and 68% in the control group were in the age group of 21-40 years, gender 55.4% in the study group and 60.6% in the control group were males, and with regards to education 46.9% and 43.4% had primary level of education in the study and control groups respectively. In occupation 37.1% in the study group and 34.9% in the control group were in the category of daily wages. The family income in rupees per month revealed that 59.4% and 66.9% had an income of below Rs.2500 in the study group and control groups respectively. The findings with regards to residence depicted that 82.9% in the study group and 72% in the control group belonged to the urban area which was significant at $p < 0.05$. The marital status revealed that 60.6% in the study group and 61.7% in the control group were married.

The social variables revealed that 82.3% in the study group and 81.7% in the control group belonged to the nuclear family. 58.9% in the study group and 55.4% in the control group were not accompanied by a caregiver but 41.1% and 44.6% were accompanied by a caregiver. In the study group 58 were dependent on their mother / father and in the control group 45 were dependent on the husband/wife. This was significant at $p < 0.05$. In relation to the healthcare expenses it was found that for most of the PWE 66.9% in the study group and 64.6% in the control group the medical expenses were met by other family members.

Table 2. Summary of the clinical variables at baseline(N=350).

Clinical Variables	Study Group	Control group	Chi-square
	%(N=175)	%(N=175)	
Age at onset of Epilepsy (in years)			
≤ 5	9.7(17)	5.7(10)	0.556
6-15	17.1(30)	16.6(29)	
16-25	32.0(56)	33.7(59)	
≥ 26	41.1(72)	44.0(77)	
Duration of diagnosis of epilepsy (in years)			
≤ 5	41.7(73)	42.3(74)	0.092
6-10	31.4(55)	21.1(37)	
11-15	12.0(21)	18.3(32)	
≥ 16	14.9(26)	18.3(32)	
Type of Epilepsy			
Focal	3.4 (6)	1.7(3)	0.023
Generalized	56.0(98)	43.4 (76)	
Unclassified	40.6(71)	54.9(96)	
Time of occurrence of seizure			
Day	12.0(21)	12.0(21)	0.644
Night	36.0(63)	31.4(55)	
Anytime	52.0(91)	56.6(99)	

Table 2 illustrates that 41.1% in the study group and 44% in the control group had the age at onset of epilepsy at ≥ 26 yrs. With regard to the duration of epilepsy 41.7% in the study group and 42.3% in the control group had the duration of ≤ 5 yrs. The type of epilepsy revealed that in the study group 56% had generalized epilepsy and 43.4% in the control group belonged to the unclassified category respectively which was significant at $p < 0.05$.

The time of occurrence of seizures showed that 52% in the study group and 56.6% in the control group had their seizures at any time i.e., both at night or day. The second most frequent time of occurrence of seizures was found to be at night or early morning for 36% in the study group and for 31.4% patients in the control group.

4.2 Epilepsy education on self-management

Table 3. Effectiveness of an epilepsy education programme on the Self-management between the study and control groups.

Self-management	Pretest			Posttest I			Posttest II		
	Study	Control	p value	Study	Control	p value	Study	Control	p value
	Mean±SD	Mean±SD		Mean±SD	Mean±SD		Mean±SD	Mean±SD	
IM	1.39±.21	1.44±.20	0.043	1.61±.22	1.43±.20	0.0005	2.48±.22	1.55±.17	0.0005
MM	4.62±.27	4.61±.25	0.654	4.58±.31	4.50±.26	0.021	4.71±.21	4.53±.26	0.0005
SM	4.73±.12	4.83±.14	0.0005	4.77±.15	4.80±.14	0.057	4.82±.12	4.80±.14	0.184
SeM	2.48±.23	4.04±.25	0.0005	3.20±.25	4.03±.25	0.0005	4.11±.24	4.03±.25	0.004
LM	1.59±.21	2.35±.26	0.0005	2.76±.38	2.33±.25	0.0005	2.82±.35	2.38±.24	0.0005

The baseline assessment reveals that the control group had higher mean for IM (1.44), SM (4.83), SeM (4.04) and LM (2.35) which were statistically significant, but at three months the study group showed an increase in the mean for all components of Self-management as IM (1.61), MM (4.58), SM (4.77), SeM (3.20) and LM (2.76). At the sixth month the study group had a significant increase in the mean for all the components and safety management was the same for the study group and the control group. The study group showed an increase in components as IM (2.48), MM (4.71), SeM (4.11) & LM (2.82) of self-management which was statistically significant at $p = 0.0005$. (Table.3)

Table 4. Repeated measures of the overall self-management for the study and the control group.

Overall Self-management	Pretest		Posttest I		Posttest II		p value
	Study group	Control group	Study group	Control group	Study group	Control group	
	Mean ±SD	Mean ±SD	Mean ±SD	Mean ±SD	Mean ±SD	Mean ±SD	
	2.97 ±.11	3.46 ±.12	3.39 ±.15	3.42 ±.12	3.79 ±.15	3.46 ±.12	.0005

The changes in the overall self-management among the study and control groups at different periods of time showed that there was an increase in the self-management for the study group from baseline 2.97 to 3.39 at third and at the sixth month to 3.79, the control group showed the baseline mean as 3.46 which decreased to 3.42 at third month and then again an increase to 3.46 at the sixth month the 'f' value showed that it was significant at $p = 0.0005$.

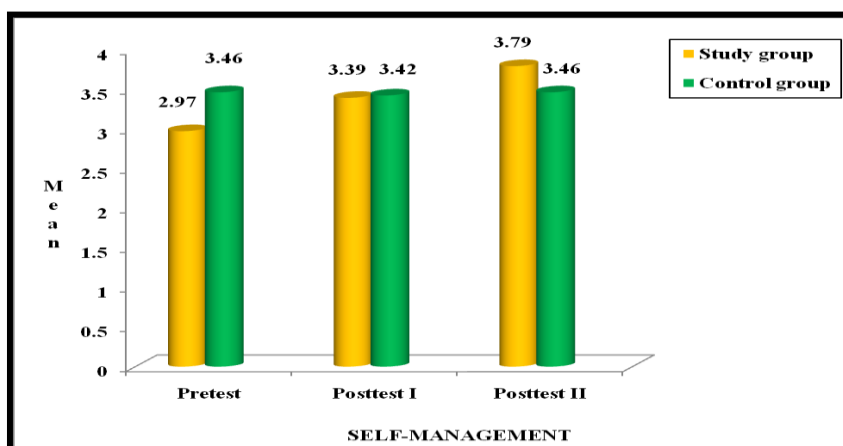


Figure 1. Comparison of the overall self-management of the study and control groups.

4.3 Discussion: At pretest the study group had a mean of 1.39 for IM, 4.62 for MM which was quite high against a total score of 5, 4.73 for SM, 2.48 for SeM and 1.59 for LM. The posttest II showed an increase in the mean of 2.49 for IM, 4.71 for MM, 4.82 for SM, 4.11 for SeM and 2.82 for LM.

At pretest the control group had a mean of 1.43 for IM, 4.61 for MM, 4.83 which was high for SM, 4.04 for SeM and 2.35 for LM. The control group showed better self-management for components as IM, SM, SeM and LM than the study group. In MM both the groups had the same mean 4.62 and 4.61 respectively. The posttest II showed an increase in the mean of 1.55 for IM but all the other components did not show any increase from the pretest mean as 4.53 for MM, 4.80 for SM, 4.03 for SeM and 2.38 for LM.

The individual components as IM, SM, SeM and LM showed a statistically significant difference at pretest. At posttest II the study group showed an increase for all the components and was statistically significant at $p = 0.0005$ for all components except for MM where both the groups were equal and it had the highest value of 4.82 and 4.80 for the study and control groups respectively.

These findings are similar to that of Kobau and DiIorio (2003) where the participants had higher self efficacy for medication management than for healthy life style behaviours that may be enhanced by good self-management. [15]

On comparison, the overall self-management mean score was found that at pretest the study group had a lower mean of 2.97 as compared to that of 3.46 in the control group, but the study group showed an increase in posttest I to 3.39 which was nearly equal to the control group mean of 3.42. On posttest II the study groups overall self-management score was 3.79 and higher than the control group mean of 3.46. The study group showed an incremental increase in the self-management whereas the control group mean values remained the same. This was statistically significant at $p < 0.0005$ McAuley, McFadden, Elliott & Shneker (2008) in order to characterize the self-management behaviours and to assess if the behaviors differed depending on the level of seizure control reported that among 50 patients the mean overall Epilepsy Self-Management Scale (ESMS) question score was 3.72 ± 0.41 . The mean question scores on the ESMS subscales Medication Management, Information Management, Safety Management, Seizure Management, and Lifestyle Management were 4.4, 2.7, 3.9, 4.0, and 2.6, respectively. Information Management and Safety Management subscale scores were higher in the patients continuing to have seizures. The Morisky scale on medication-taking behavior revealed that patients fell into either the low ($n = 2$), medium ($n = 27$), or high ($n = 21$) adherence category in medication intake. The researchers concluded that self-management skills are to be emphasized. [16]

The ANOVA to determine the association of the self-management with the type of epilepsy showed that there was no significant association between the type of epilepsy and the self-management at pretest and posttest I for the study and control groups. The study group did not show any difference at posttest II but there was a significant difference in the self-management with the type of epilepsy for the control group at $p = 0.040$, the self-management among the focal and unclassified groups was better than the self-management among the patients with generalized epilepsy.

V. Conclusion

5.1 Clinical implications: The medication management and safety management was high for both the groups but information management, seizure management and lifestyle management needed improvement. The study showed that there was a significant difference in the self-management among patients with epilepsy who participated in the epilepsy education programme hence self-management among patients with epilepsy can be enhanced by education programmes

5.2 Limitations: The medication dosage reduction was not taken into account as it was very negligible

Acknowledgements

The author would like to thank DiIorio, C., for permitting the use of the epilepsy self-management scale and thank the participants and staff of the Neurology Outpatient Department of Sri Ramachandra Hospital for their support throughout this study.

Conflict of Interest: None

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