The Effect of Comprehensive Video-Assisted Epilepsy Education on Drug Adherence and Self-Care in People with Epilepsy

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Abstract

Background   Epilepsy is a chronic neurological disorder which needs proper drug adherence and follow-up care to control the recurrent seizure events as one of the most common reasons for "breakthrough" seizures is nonadherence to antiepileptic drugs. In addition to usual therapeutic management, patients are encouraged to involve in epilepsy self-management by understanding the nature of the disease and its control measures to prevent the complications.

Methods   A single group experimental design (pretest–posttest) was conducted to evaluate the effect of comprehensive video-assisted teaching program on self-care efficacy and level of knowledge of patients with epilepsy. Data was collected by direct interview with Epilepsy Self-Management Scale and epilepsy knowledge questionnaire. A video-assisted teaching covering all aspects of epilepsy was given on the day of pretest. At the interval of 3 months, the level of drug adherence, self-care, and knowledge level were assessed.

Results   Majority of the study participants (47.1%) belonged to the age group between 19 and 30 years, 54.3% participants were male, majority of them (70%) had tonic-clonic seizure, and 40% of them reported the onset of seizures as above 20 years. Eighty-seven percent of participants had no family history of seizures or epilepsy. Note that 38.6% of the participants had at least one seizure episode/month. Majority of the caregivers were either parents (41.4%) or spouse (48.6%). The study revealed that, following video-assisted teaching, the proportion of participants with adequate knowledge has increased from 14 to 64.3%. Similarly, the percentage of participants who had good drug adherence increased from 52 to 65% and no participant had poor drug adherence. Participants who had high level of self-care increased from 71.4 to 88.6%.

Conclusion   To overcome the poor drug adherence-related complications, people with epilepsy are to be personally educated adequately to increase the factual information about the condition and their self-care practices.

Keywords
► epilepsy
► follow-up
► neurology

Introduction

Among common neurological disorders, seizure disorder shares approximately 1% of the total burden of disease worldwide; out of which, more than three-quarters of the population live in low to lower middle income countries. In India, approximately 10 to 12 million people suffer from epilepsy.[1,2] Epilepsy is a disorder of chronic, frequent seizures in which the onset and duration of the seizure cannot be anticipated. This common disease have a notable social

stigma which leads to discrimination in the society which further disable the self-esteem of people with epilepsy. Societal stigma often caused by misconceptions, myths, and misunderstandings about the disease have been observed for thousands of years.[3,4] Social discrimination often leads to reduced interest to access medical care, and many of them try to hide their disease in view of negative stereotyping.[5,6] A range of incorrect and even harmful practices to regulate seizure are frequently embraced; for instance, keeping iron rod in the hand, rubbing irritants to eyes, holding the patient in fire, burns, and ingestion of cow urine.[7-9] It is imperative to educate about management of this chronic disease to the caregivers and patients with epilepsy to improve self-care.[10-12]

Persons with seizure disorder need to transform their lifestyle primarily focusing on drug adherence and self-care. Modification of the lifestyle and adhering to treatment regime is key for improving their quality of life. Hence, this study is focused to evaluate the self-care management educational program with the support of video, focused on disease characteristics, monitoring symptoms, management modalities, significance of drug adherence, and managing lifestyle pattern to increase patient's self-confidence by improving their understanding about the disease.

Methods

A single group experimental design (pretest–posttest) was applied to evaluate the effect of comprehensive video-assisted teaching program on self-care efficacy and level of knowledge among patients with seizure disorder. Participants who were in the age group of 18 to 65 years, who were enrolled in the institute's epilepsy clinic were included in the study. Sample size estimated was 70 with power of the study as 90% and 5% level of significance. It was calculated based on mean difference in drug adherence score before and after implementation of education program as 6.58 versus 7.53.[7] Consecutive sampling technique was used. Under Graduate Research Monitoring Committee and Institute Ethical Committee approval was obtained (JIP/IEC/2018/111).

With the help of epilepsy knowledge questionnaire and Epilepsy Self-Management Scale (ESMS), the data was collected by interview method. The ESMS has five domains which focus on safety management, medication management, seizure management, and lifestyle management. The internal consistency reliability was 0.81 to 0.86.[13] The epilepsy knowledge questionnaire has 20 items about the knowledge of epilepsy. The score ranges from 0 to 20; the higher the score, the higher the knowledge level.

A video-assisted teaching covering all aspects of epilepsy was given to the people with epilepsy on the day of pretest. At an interval of 3 months, the level of drug adherence, self-care, and knowledge level were assessed.

The continuous data such as age, duration of treatment, number of seizure per last month, number of drugs, and frequency of the drugs was expressed as mean with standard deviation or median with range, whereas the distribution of nominal data including literacy, occupation status, participants' gender, marital status, domicile status, and comorbidity history was stated as frequency and percentages. Chi-square/Fisher's exact test was used to analyze the level of drug adherence with sociodemographic characteristics. ESMS domains and knowledge score before and after implementation of video-assisted teaching program was analyzed with paired t-test. The level of statistical significance $p < 0.05$ was considered as significant.

Results

Results showed 47.1% of the participants belonged to the age group between 19 and 30 years, 54.3% participants were male, 7.1% were illiterate, and majority of the participants (82.9%) were from rural (►Table 1).

Majority of the participants (70%) had generalized tonic-clonic seizure, 40% of the participants had the age of onset of seizures at above 20 years, 87% of participants had no family history of seizures or epilepsy. Note that 38.6% of the participants had at least one seizure episode/month. Majority of the caregivers were either parents (41.4%) or spouse (48.6%) (►Table 2).

►Table 3 shows the pre- and postintervention mean score and standard deviation for the level of knowledge of people with epilepsy who had undergone the educational program (video-assisted epilepsy education). It shows during pretest 12 (17.1%) of the participants had inadequate knowledge regarding epilepsy, 48 (68%) participants had moderate level of knowledge, and 10 (14.3%) participants had adequate knowledge. During posttest, 45 (64.3%) had adequate knowledge, 23 (35.7%) had moderate knowledge, and no participants had inadequate knowledge. The level of good drug adherence of people with epilepsy improved to 65% from 52% and no participant had poor drug adherence after receiving the video-assisted teaching. Similarly, the percentage of participants who had high level of self-care increased from 71.4 to 88.6% (►Tables 4 and 5). Various sub domain mean score of Epilepsy Self-Management Scale (ESMS) also improved following video-assisted education (►Table 6).

Discussion

Sociodemographic and Seizure Characteristics

This study included 70 epilepsy patients with the mean age of 33.54 ± 11.22 years. Majority of the study participants (54.4%) were male and 38.6% of the participants had at least one seizure episode per month. Note that 7.1% had comorbidities like diabetes mellitus, hypertension, and hypothyroidism. Similar mean age of participants with seizures, and male preponderance has also been observed in earlier studies.[10,11]

The average age of onset of seizure was 18 years with 7.1% of the participants suffering day time seizures. Seventy percent of them were in the category of tonic-clonic seizure. In a comparable study by Hovinga et al, it was reported that among 408 participants, the average mean age of onset was 20 years, and majority of them (57%) were reported with tonic-clonic seizures and 12% had day time seizure.[13,14]

Table 1 Sociodemographic characteristics (N = 70)

Sociodemographic characteristics	Frequency (n)	Percentage (%)	Chi-square	p-Value
Age (in y)				
19–30	33	47.1	15.457	0.000
31–45	29	41.4		
46–65	8	11.4		
Mean age: 33.54 ± 11.22 y				
Sex				
Male	38	54.3	0.514	0.473
Female	32	45.7		
Education				
Illiterate	5	7.1	14.286	0.006
Primary	24	34.3		
High school	17	24.3		
Higher secondary	13	18.6		
Graduate	11	15.7		
Occupation				
Unemployed	6	8.6	31.143	0.000
House wife	23	32.9		
Agriculture	7	10.0		
Employed	34	48.6		
Income (INR)				
Less than 1,000	5	7.1	96.200	0.000
1,000–2,000	62	88.6		
More than 2,000	3	4.3		
Marital status				
Married	51	72.9	14.629	0.000
Unmarried	19	27.1		
Domicile				
Rural	58	82.9	30.229	0.000
Urban	12	17.1		

Approximately more than half of patients in this study were on polytherapy. Similar proportions were found in other studies also.[15,16]

Level of Knowledge on Epilepsy

In the current study, the mean knowledge score of the participants increased from 10.82 ± 3.93 to 15 ± 2.59 following video-assisted education during posttest which was significant at (p = 0.000). The number of participants with adequate level of knowledge increased from 10 (14.3%) to 45 (63.3%) after the implementation of the video-assisted epilepsy education. In a related study led by May et al, it was observed that the knowledge level improved after the educational treatment and was significant (p < 0.001).[15]

Drug Adherence and Self-Care

Patients' knowledge on disease management is directly proportionate to their disease outcome, satisfaction, and quality of life. Educating patients and their caregivers in epilepsy is an important component of quality management, including improving self-care outcomes and overall epilepsy care. The pretest mean score of the participants for the level of drug adherence were 39.34 ± 7.015, during posttest it was 45.40 ± 5.417 which was highly significant (p = 0.000). The number of participants with good level of drug adherence increased from 52 (74.3%) to 65 (92.9%) after the implementation of the video-assisted teaching program which was concurrent with the studies. Frequency of the drugs per day (patients with monotherapy) associated significantly with the level of drug adherence with a p-value of 0.010.

Table 2 Seizure characteristics (*N* = 70)

Seizure characteristics	Frequency (*n*)	Percentage (%)	Chi-square	*p*-Value
Type of seizure				
Generalized tonic-clonic seizure	49	70	116.286	0.000
Complex partial seizure	6	8.6		
Absence seizure	1	1.4		
Myoclonic seizure	1	1.4		
Others	3	18.6		
Age of onset				
Before 5 y	15	21.4	9.200	0.027
6–12 y	11	15.7		
13–20 y	16	22.9		
After 20 y	28	40.0		
Mean age of onset: 18.81 ± 13.14 y				
Family history				
Yes	9	12.9	38.629	0.000
No	61	87.1		
Duration of treatment				
Less than 5 y	32	45.7	5.171	0.075
6–10 y	17	24.3		
More than 10 y	21	30.0		
No of drugs per day				
One drug	29	41.4	33.086	0.000
Two drugs	29	41.4		
Three drugs	11	17.7		
More than three drugs	1	1.4		
Drug resistant epilepsy				
No	70	100	–	–
Frequency of drugs per day				
1 time	5	7.1	26.429	0.000
2 times	25	35.7		
3 times	40	57.1		
No of seizure per last month				
No seizure	27	38.6	31.571	0.000
One seizure	22	31.4		
2 seizures	13	18.6		
3 seizures	6	8.6		
More than 3 times	2	2.9		
Usual time of seizure occurrence				
Day time	5	7.1	47.857	0.000
Night time	15	21.4		
No specific time	50	71.4		
Caregiver				
Parents	29	41.4	17.686	0.000
Spouse	34	48.6		
Others	7	10.0		

(*Continued*)

Table 2 (*Continued*)

Seizure characteristics	Frequency (n)	Percentage (%)	Chi-square	p-Value
Comorbidity				
No	65	92.9	51.429	0.000
Yes	5	7.1		
CT/MRI findings				
No changes	62	88.6	41.657	0.000
Changes	8	11.4		
Hypodensity in frontal lobe	1	1.4		
Parietal lobe calcification	2	2.8		
Frontal lobe calcification	1	1.4		
Ischemic vessel changes	1	1.4		
Small size of right hippocampus	1	1.4		
Right temporal horn prominence	1	1.4		
Right mesotemporal sclerosis	1	1.4		
EEG findings				
No changes	69	98.6	66.057	0.000
Epileptoform activity	1	1.4		

Abbreviations: CT, computed tomography; EEG, electroencephalogram; MRI, magnetic resonance imaging.

Table 3 Knowledge on epilepsy (*N* = 70)

Knowledge	Pretest			Posttest			p-Value
	Frequency (n)	Percentage (%)	p-Value	Frequency (n)	Percentage (%)	p-Value	
Inadequate	12	17.1	0.000	–	–	0.017	0.000
Moderate	48	68.6		25	35.7		
Adequate	10	14.3		45	64.3		
Total	70	100		70	100		
Mean	10.8286			15.000			
Standard deviation	3.93414			2.59004			

Table 4 Level of drug adherence (*N* = 70)

Level of drug adherence	Pretest			Posttest			p-Value
	Frequency (n)	Percentage (%)	p-Value	Frequency (n)	Percentage (%)	p-Value	
Poor	1	1.4	0.000	–	–	0.000	0.000
Average	17	24.3		5	7.1		
Good	52	74.3		65	92.9		
Total	70	100		70	100		
Mean	39.34			45.40			
Standard deviation	7.015			5.417			

Table 5 Self-care level (N = 70)

Self-care level	Pretest			Posttest			p-Value
	Frequency (n)	Percentage (%)	p-Value	Frequency (n)	Percentage (%)	p-Value	
Low	–	–	0.000	–	–	0.000	0.002
Average	20	28.6		8	11.4		
High	50	71.4		62	88.6		
Total	70	100		70	100		
Mean	130			154			
Standard deviation	15.893			19.114			

Table 6 Self-care domains (N = 70)

Self-care domains	Pretest		Posttest		
	Mean	Standard deviation	Mean	Standard deviation	p-Value
Medication management	39.34	7.01	45.4	5.41	0.000
Information management	22.28	7.92198	24.87	5.81	0.000
Self-management	28.21	4.21	32.10	4.585	0.000
Seizure management	23.13	5.464	25.00	4.700	0.000
Lifestyle management	17.63	4.69	20.31	5.199	0.533

Dash et al have shown similar results where the level of drug adherence was increased after epilepsy health education ($p < 0.001$). The pretest mean score (ESMS) of the participants for the level of self-care was 130 ± 15.89, during posttest it was 154 ± 19.11 which was significant ($p = 0.002$).[7] In the present study, the number of participants with high level of self-care increased from 50 (71.4%) to 62 (88.6%) after implementation of the video-assisted teaching program which was concurrent with the previous studies. In a comparable study, which showed similar results, the mean score of self-care increased from 2.97 ± 0.11 to 3.39 ± 0.15 after epilepsy education and was significant ($p = 0.0005$).[16]

Conclusion

Educational program to the people with epilepsy is the need of the hour to enhance awareness about disease management and self-care which would improve the outcome of the treatment regimen. Further, this kind of programs helps the patient and their caregivers to overcome the myth and prejudiced lifestyle practices related with this chronic disease. The present study demonstrates that video-assisted epilepsy education improves the knowledge, drug adherence, and self-care in people with epilepsy.

Conflict of Interest
None declared.

References

1 World Health Organization, Atlas: Epilepsy Care in the World. Geneva, Switzerland: WHO; 2005
2 Paul P, Agarwal M, Bhatia R, Vishnubhatla S, Singh MB. Nurse-led epilepsy follow-up clinic in India: is it feasible and acceptable to patients? A pilot study. Seizure 2014;23(1):74–76
3 Ibinda F, Mbuba CK, Kariuki SM, et al. Evaluation of Kilifi epilepsy education programme: a randomized controlled trial. Epilepsia 2014;55(2):344–352
4 Das AM, Ramamoorthy L, Narayan SK, Wadwekar V. Barriers of drug adherence among patients with epilepsy: in tertiary care hospital, South India. J Caring Sci 2018;7(4):177–181
5 Baybaş S, Yıldırım Z, Ertem DH, Dirican A, Dirican A. Development and validation of the stigma scale for epilepsy in Turkey. Epilepsy Behav 2017;67:84–90
6 Goel S, Singh N, Lal V, Singh A. Evaluating the impact of comprehensive epilepsy education programme for school teachers in Chandigarh city, India. Seizure 2014;23(1):41–46
7 Dash D, Sebastian TM, Aggarwal M, Tripathi M. Impact of health education on drug adherence and self-care in people with epilepsy with low education. Epilepsy Behav 2015;44:213–217
8 Jansen P, Neininger MP, Bernhard MK, et al. Knowledge and attitudes about epilepsy: a survey of high school students in Germany. Seizure 2017;51:139–144

9 Singh AJ, Arora AK. Knowledge, attitude and practices of relatives of epileptics towards epilepsy. Nurs Midwifery Res J 2005;1:77–81

10 Yang A, Wang B, Zhu G, et al. Validation of Chinese version of the Morisky medication adherence scale in patients with epilepsy. Seizure 2014;23(4):295–299

11 Aliasgharpour M, Dehgahn Nayeri N, Yadegary MA, Haghani H. Effects of an educational program on self-management in patients with epilepsy. Seizure 2013;22(1):48–52

12 Tang F, Zhu G, Jiao Z, Ma C, Chen N, Wang B. The effects of medication education and behavioral intervention on Chinese patients with epilepsy. Epilepsy Behav 2014;37:157–164

13 Dilorio C, Faherty B, Manteuffel B. Self-efficacy and social support in self-management of epilepsy. West J Nurs Res 1992;14(3):292–303, discussion 303–307

14 Hovinga CA, Asato MR, Manjunath R, et al. Association of non-adherence to antiepileptic drugs and seizures, quality of life, and productivity: survey of patients with epilepsy and physicians. Epilepsy Behav 2008;13(2):316–322

15 May TW, Pfäfflin M; Modular Service Package Epilepsy. The efficacy of an educational treatment program for patients with epilepsy (MOSES): results of a controlled, randomized study. Epilepsia 2002;43(5):539–549

16 Seethalakshmi A, Shankar V, Samson R. Effectiveness on epilepsy education programme on self-management among patients with Epilepsy. IOSR-JNHS 2015;4:35–41