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Impact of structured teaching program on the parent's knowledge of domiciliary management of seizure—A randomized controlled trial

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ABSTRACT

The aim of study was to assess the combined effectiveness of structured teaching program (STP) and patient information pamphlet (PIS) on caregivers' knowledge with regard to domiciliary management of seizure as compared with PIS alone. Study participants included caregivers of typically developing children aged 1–18 years with at least one episode of convulsion. The enrolled participants were allocated to either of the two groups: intervention group (STP along with PIS) and control group (PIS). The outcome was measured by a structured questionnaire — 'first-aid measures knowledge questionnaire'. Baseline knowledge scores were recorded and compared with post-intervention scores measured at one-month follow-up. The preintervention knowledge scores were comparable in the two groups ($p = 0.72$). The control group has shown no significant difference in the knowledge scores at one-month follow-up ($p = 0.58$). Postintervention knowledge scores ($p < 0.01$) and mean difference in the knowledge scores ($p < 0.01$) were significantly higher in the intervention group when compared with controls. Structured teaching program regarding first-aid measures for convulsion along with PIS was effective in improving the knowledge of caregivers than PIS alone.

1. Introduction

Epilepsy contributes a share of 1.6% of the total burden of diseases in the world [1]. It affects approximately 50 million people worldwide with more than three-fourths living in resource poor, developing countries [2]. In contrast to developed nations, major causes of epilepsy in developing countries include neurocysticercosis and perinatal asphyxia. Poor access to healthcare facilities, lack of sufficient knowledge, myths, and prejudice are some of the major limitations to care of children with epilepsy in developing countries.

The health literacy of parents is overpowered by misperceiving epilepsy to be contagious with evolution to psychosis resulting from supernatural causes [3]. In a study by Asiri et al. [4], it was observed that only 10% of mothers were aware of an antiepileptic drug that could abort a prolonged seizure at home. Moreover, one-third of mothers would prefer to wait for 15 min before taking the child to an emergency [4]. This emphasizes the need for training parents regarding domiciliary management of seizures. The home management education for children with epilepsy is essential considering the adverse neurological outcomes of prolonged seizures.

Provision of patient information pamphlets (PIS) has been shown to improve the parental knowledge regarding epilepsy [6]. However, in the context of developing countries with poor literacy rates, it is believed that such measures alone might not result in better knowledge of parents. Literature suggests a possible role of structured teaching program (STP) in enhancing knowledge of parents who have children with febrile seizure and chronic epilepsy [5–10]. However, there is limited literature on the role of STP on domiciliary management of seizures in children. Hence, the present study was designed to assess the effectiveness of combined STP and PIS in improving knowledge of caregivers in comparison with PIS alone on domiciliary management of seizures in children.

2. Methods

2.1. Design

A randomized controlled trial was carried out among caregivers of children with convulsion who attended the pediatric neurology outpatient unit of All India Institute of Medical Sciences New Delhi from September 2015 to January 2016. It is a tertiary care referral center catering to surrounding states of Haryana, Uttar Pradesh, and Bihar. The ethical clearance was obtained from Institutional Ethical Committee through IESC/T-182/01-4-2015. A written informed consent was

Abbreviations: PIS, patient information pamphlets; STP, structured teaching program; OPD, outpatient department.

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obtained prior to enrollment taking into account the confidentiality of the information given by the participants and their anonymity.

2.2. Sample and sampling techniques

Caregivers of typically developing children aged 1–18 years with at least one episode of convulsion were enrolled in the study. The exclusion criteria included the following: caregivers of children with other comorbidities such as spasticity, developmental delay, vision loss, hearing loss, or any other chronic condition and caregivers who already have read the PIS.

2.3. Study methodology

A thorough review of literature was carried out by researcher, guide, and co-guide for a period of two months resulting in a pooled dataset comprising tools to assess the knowledge of caregivers regarding first-aid measures of convulsion. A common consensus was developed regarding the various aspects of domiciliary management of seizure. The common consensus developed during discussion served as an FGD guide for the consecutive focused group discussion. The focus group formed with 5–10 caregivers along with researcher, guide, co-guide, and an expert from pediatric neurology department carried out the FGD to identify the baseline knowledge of caregivers on first-aid measures for convulsion. The consensus tool developed for the FGD was modified to an Indian context by inclusion of multiple content areas like question regarding positioning during convulsion, medications such as nasal spray, and abortive treatment for convulsion, based on the FGD. Multiple FGD were not possible as most of the caregivers were far from the site and had to depart as soon as they had outpatient department (OPD) consultation. The content validity of the tool yielded a content validity index of 0.85 (the item relevance of the tool was done by 5 experts, 2 from the Department of Pediatrics, AIIMS and 3 from the Faculty of Nursing, and the proportion of agreement among experts was determined using the content validity index). Baseline demographic variables and knowledge of each caregiver were assessed as per the structured tool developed for study. The enrolled participants were allocated to either of the two groups: intervention group (STP along with PIS) and control group (PIS alone) by sealed envelope techniques.

The opaque envelopes were sequentially labeled, and random numbers were assigned to each envelope as per the computer-generated random number table. Caregivers who were enrolled in the intervention group were administered STP and provided with patient information pamphlet (PIP) on Epilepsy and encouraged to read through the instructions. The caregivers in the control group were provided with PIP on Epilepsy and instructed to go through the same. The posttest knowledge level of the participants in both groups was reassessed after 1 month by the primary investigator independently without blinding.

2.4. Tool for data collection

The data were collected using two instruments; first is a demographic profile of caregivers, and second is a structured questionnaire regarding first-aid measures of convulsion. The demographic profile of the caregivers consists of 2 sections. The first section was the caregivers' demographic profile consisting of age, sex, monthly family income, types of family, and place of residence. The second section was the Kuppuswamy socioeconomic scale consisting of educational score, occupational score, and monthly family income. According to the Kuppuswamy socioeconomic status scale, the caregivers of the child with convulsion were categorized into upper class (total score = 25–29), upper middle class (total score = 16–25), middle/lower middle (total score = 11–15), lower/upper lower (total score = 5–10), and lower class (total score = <5) [11].

The second section of the tool consisted of 12 open-ended questions regarding first-aid measures of convulsion. The questions were regarding placing the child during a convulsion, how and when to give midazolam nasal spray, prevention of blockage of airway and when to call for an ambulance, position given to the child during convulsion, surface on which child to be kept during convulsion, and so on (Table 1). All the questions were open-ended requiring the participants to write their response, and the responses were analyzed by the researcher as totally correct, partially correct, and incorrect assigned with a score of 2, 1, and 0 respectively. The maximum possible score was 24, and minimum score was 0. The tool was developed in English then translated to Hindi with the help of an expert from the Hindi department of AIIMS, New Delhi and back translated to English. The reliability of the tool was established by the test–retest method. The tool was administered twice to a sample of 15 within a gap of 3 days. The test–retest reliability coefficient was determined and found to be good (Cronbach's alpha—0.86).

S. N.	Item	2	1	0
1.	On which surface will you place the child during convulsion?			
2.	In what position will you place the child while your child is convulsing?			
3.	What drugs are used for abortive treatment of convulsion?			
4.	By which route will you give midazolam to your child during convulsion?			
5.	What dose of midazolam is to be given when your child is convulsing?			
6.	Will you try to open the child's mouth during convulsion?			
7.	How long can you wait for giving nasal spray while your child is convulsing?			
8.	Will you give fluid and water to the child during convulsion if no why?			
9.	What things will you note during convulsion?			
10.	How will you protect your child's airway during convulsion?			
11.	Once the convulsion has aborted what will you do first?			
12.	What will you do if the convulsion does not stop even after 5 min?			

2.5. Procedure for data collection

Data were collected between September 2015 and January 2016. A signed informed consent was taken from the accessible population before the enrollment into the study. Patient information pamphlet was given to the caregivers of both groups on the day of enrollment. Demographic data were collected through the interview schedule using demographic data sheet, and pretest knowledge regarding first-aid measures for convulsion

Table 1
Demographic profile of caregivers in intervention (n = 32) and control groups (n = 29).

Variables	Category	Frequency		p value (95% CI)
		Intervention group (n = 32)	Control group (n = 29)	
Age (years)	21–30 year	6 (18.8%)	10 (31.3%)	0.51
	31–40 year	16 (50.0%)	14 (43.8%)	
	More than 40 year	10 (31.3%)	8 (25.0%)	
Gender	Male	18 (56.3%)	21 (65.6%)	0.44
	Female	14 (43.8%)	11 (34.4%)	
Type of family	Nuclear family	20 (62.5%)	16 (50.0%)	0.31
	Joint family	12 (37.5%)	16 (50.0%)	
Place of residency	Rural area	13 (40.6%)	8 (25.0%)	0.41
	Semiurban area	6 (18.8%)	7 (21.9%)	
	Urban area	13 (40.6%)	17 (53.1%)	
Socioeconomic status	Upper class	1 (3.1%)	4 (12.5%)	0.61
	Upper middle	11 (34.4%)	8 (25.0%)	
	Middle/Lower middle	7 (15.6%)	5 (21.9%)	
	Lower/Upper lower	13 (40.6%)	12 (37.5%)	
	Lower	2 (6.3%)	1 (3.1%)	

Chi square test, #: Fisher's exact test. CI — confidence interval.
Note: Nuclear family — family including caregivers and only their child, Joint family — family including caregivers, their children, and parents, Rural area — village, Semiurban area — town, Urban area — city, Upper class — caregivers who have scores 26–29 in Kuppuswamy socioeconomic scale, Upper middle — score 16–25, Middle/Lower middle — 11–15, Lower/Upper lower — 5–10, Lower — <5.

was collected from the caregivers of both groups. The caregivers who were enrolled in the control group were provided PIS and asked to go through that, and caregivers who were enrolled in the intervention group were provided STP regarding 'first-aid measures for convulsion' along with PIS. Posttest data were collected from both groups on 1-month follow-up using the same questionnaire.

2.6. STP

The STP to create an awareness regarding general knowledge of convulsion and first-aid measures during and after convulsion was given. The STP was conducted in small groups of a maximum of 3 caregivers in a separate room in pediatric neurology OPD of AIIMS, New Delhi. The teaching was given by researcher, showing the slides to the caregivers followed by discussion and clearing of their doubts if any. A laptop (Dell Inspiron 15) was used to show the slides. The duration of the intervention was approximately 20 min according to the level of understanding of the caregivers, and the medium of instruction was Hindi. After the intervention, feedback was taken from all subjects, and their doubts were cleared. The STP was developed in English then translated to Hindi with the help of an expert from the Hindi department of AIIMS, New Delhi and back translated to English. The slides that have been used to give intervention in this study had content in both Hindi and English.

The main content of STP included the following: Placing the child — safe/soft/flat surface/ground, Putting the child on his/her side, Recovery position as soon as possible, Midazolam nasal spray or diazepam suppositories as abortive treatment, Dose — no. of puff/spray as doctors' advice, Do not try to open the child's mouth, Do not put anything in the child's mouth, Time to give nasal spray, Do not offer food or water to the child during convulsion, Noting time, duration and type of convulsion and making a video record, if possible, Protecting the child's airway, Loosening the cloths around the neck, Protecting the child from possible hazards (fall/trauma), Staying with the child until he/she is fully recovered, Shifting the child to emergency as early as possible, Shifting the child to emergency immediately if convulsion does not stop after 5 min, Treating fever with paracetamol, clobazam for prophylaxis for initial 3 days of febrile episode (on doctor's advice only), and carrying an epilepsy card by the child.

2.7. Statistical analysis

Categorical variables were expressed as Numbers (proportions) whereas continuous variables were expressed as Mean standard deviation (SD) or Median interquartile range (IQR). The knowledge scores between the two groups were compared using the Mann–Whitney test, and the knowledge scores within the group (comparison of pretest with posttest knowledge of the same group) were compared using the Wilcoxon signed-rank test. A value of less than 0.05 was considered significant for analysis.

3. Results

A total of 137 caregivers were screened for enrollment in the study. Among these, 64 eligible participants were randomized into two groups of 32 (Fig. 1). Two participants in the structured teaching group and 6 participants in the PIS group were lost to follow-up at 1 month (Fig. 1). Baseline demographic characteristics were comparable between the two groups (Table 1). Baseline knowledge scores were comparable in the two groups ($p = 0.72$). There was no significant difference in the knowledge scores in the control group at one-month follow-up ($p = 0.58$). Postintervention knowledge scores ($p < 0.01$) and mean difference in the knowledge scores ($p < 0.01$) were significantly higher among those who were subjected to STP as compared with those who were administered PIS alone (Table 2).

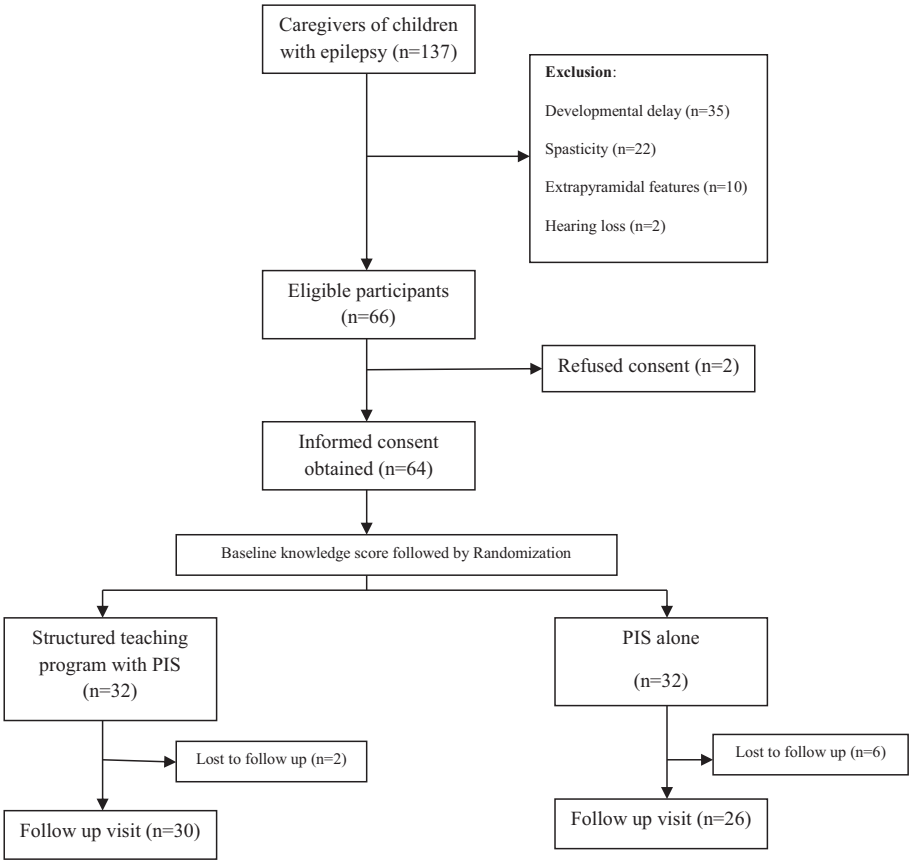

Fig. 1. Figure depicting study flow of patients.

Table 2
Table depicting knowledge scores before and after intervention.

	Structured teaching program with PIS (n = 32)	PIS alone (n = 29)	p value (95% CI)
Baseline knowledge scores	7.28 (3.42)	6.97(3.73)	0.72
Postintervention knowledge scores	18.0 (5.95)	6.55 (4.08)	<0.01[8.809, 14.091].
Mean difference in knowledge scores	10.71 (6.11)[8.2949, 13.1451].	−0.24 (1.93)[−1.6364, 2.4764].	<0.01

CI — confidence interval.

4. Discussion

Home management of seizure is mandatory for all caregivers of children with epilepsy. This study indicates that STP leads to improved knowledge in caregivers of children with epilepsy. The results showed a significant difference in the knowledge scores before and after the intervention revealing better postintervention scores among those who received STP.

Comprehensive care of children with epilepsy requires individual training on domiciliary management of seizure. In order to prevent status epilepticus-related adverse outcome, training on home management of seizure is essential. Caregivers require information and education on strategies to deal with seizures at home and to minimize the impact of seizure on the day-to-day functioning. Living with multiple episodes of seizures at home has an impact on quality of life of parents [11]. Neurologist often focuses on medical management of seizures leaving the limited scope of information on dealing with seizures at home. Various educational programs have been developed to enhance knowledge of caregivers of child with epilepsy.

The educational programs have demonstrated improved self-management among adult patients with epilepsy when compared with controls [12]. Educational intervention including mailed pamphlets and educational program has demonstrated significant improvement in parents' knowledge and attitude regarding febrile seizures [10]. There was a significant improvement in the knowledge, attitude, concerns, and anticipatory practice of febrile convulsion among those randomized to educational intervention as compared with controls [10]. Simulation-based discharge teaching on seizure recognition, medication administration, and postmedication seizure management has also demonstrated improvement in postintervention performance scores [7]. In addition to parents, educational programs have also focused on school teachers [13]. These study findings emphasize the need for creation and dissemination of seizure teaching.

Another interesting finding in the present study was a lack of improvement in the knowledge scores among controls who were encouraged to read PIS alone. The present study represents a study population with low literacy rate. Considering comparable demographic characteristics of the study population, the present study adds to the importance of additional STP in the context of poor literacy study setting. The strengths of the study include a robust study design. The sample was practical, suited the convenience, and provided credibility to our results. Development and assessment of knowledge score based on culture specific concerns add to the strength of the study. The duration of follow-up was one month, so the long-term efficacy of intervention and the actual care given when the children had a seizure after the study intervention have not been addressed. Moreover, the small sample size and marginal follow-up loss add to the limitations of the study. Hence, future research could focus on larger sample size adopting methods to reduce the attrition rates and long-term follow-up to determine the effectiveness of intervention in the long run in order to have a predictive validity for a better knowledge score found through the study.

The present study shows that the STP was effective in improving the knowledge of caregivers regarding the domiciliary management of seizures in children.

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Conflict of interest

There is no conflict of interest.

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