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Research Article

Impact of Structured Awareness Program on Knowledge Regarding Home Care Management of Epilepsy Among Care Givers of Selected Neurological Patients Admitted at Skims, Soura

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A B S T R A C T

Background: Epilepsy is a chronic neurological condition that requires long-term management, often placing substantial demands on caregivers and potentially leading to caregiver burden. Enhancing caregivers' knowledge through structured awareness programs is crucial for effective home care management, contributing to a holistic approach to epilepsy care.

Aim: This study aimed to evaluate the impact of a structured awareness program on the knowledge of caregivers regarding home care management of epilepsy at SKIMS, Soura.

Method: A quantitative, one-group pre-test post-test design was employed. Following ethical clearance and permissions, participants were selected using non-probability convenient sampling. A validated and reliable (r=0.88) self-structured interview schedule assessed caregivers' knowledge before and after the intervention. The pre-test was conducted on Day 1, followed by a structured awareness program delivered via PowerPoint presentation. A post-test was conducted on Day 4. Data were analyzed using descriptive and inferential statistics. Results: Of the participants, 82% were males aged 20–30 years, with 74% from rural areas. Most had graduate-level education (34%), were self-employed (42%), and belonged to nuclear families (62%). Family incomes ranged between ₹10,000–₹20,000 for 36% of participants, and 38% were caregivers other than spouses, parents, or children. The mean post-test knowledge score (45.74 ± 4.85) showed significant improvement over the pre-test score (17.62 ± 8.71), with a mean difference of 28.12 ($p = 0.000$). Statistically significant associations were found between pre-test scores and demographic variables such as occupation ($p = 0.040$) and family income ($p = 0.047$).

Conclusion: The structured awareness program effectively enhanced caregivers' knowledge about epilepsy home care management. Such programs are recommended to improve caregiver preparedness and patient outcomes in epilepsy care.

Keywords: Epilepsy, Structured Awareness Program, Home Care Management, Care Givers

Introduction

Epilepsy as defined by the International League Against Epilepsy (ILAE) is a disease of the brain that results in at least two unprovoked seizures at least 24 hours apart. It can also be defined as a condition where a person has one unprovoked seizure and has a high chance >60% of having another seizure within the next 10 years or if he has an epilepsy syndrome.[1]

The condition can be considered a spectrum disorder because of its different causes, different seizure types, its ability to vary in severity, its varying impact from person to person, and its range of co-existing conditions. When symptomatic, some people may have convulsions that can be accompanied by loss of consciousness, others may simply stop what they are doing, have a brief lapse of awareness, and stare into space for a short period of time. Some people have seizures very infrequently, while other people may experience several seizures each day[2]

Epilepsy is a global health care issue affecting up to 70 million people worldwide. This accounts for a point prevalence of active epilepsy of 6.38 per thousand persons [95% CI] 5.57-7.30), while the lifetime prevalence is 7.60 per 1,000 persons (95% CI 6.17-9.38). the annual cumulative incidence of epilepsy was 67.77 per 100,000 persons (95% CI 56.69-81.03) while the incidence rate was 61.44 per 100,000 person-years (95% CI 50.75-74.38).[3]

the incidence of the condition was found to be higher in low/ middle income countries as compared to high income countries. This distribution of the condition may be owing to the different population structure, risk factors such as greater exposure to perimeter risk factors, higher rates of CNS infections and traumatic brain injury in these regions. The diagnosis of epileptic seizures and epilepsy and ascertainment of the cause are difficult tasks, especially in low-income countries where socioeconomic and cultural constraints are obstacles to the recognition and acceptance of the disease.[4]

Though nearly 80% of people with epilepsy live in low/middle income countries up to 90% of them are not adequately treated with conventional anti-epileptic drugs. Added to this, people in remote areas often do not receive any care at all, the problem is further worsened by discrimination and stigmatization leading to inadequate opportunities of education, work and marriage.[3]

Concurrently it is estimated that there are more than 10 million people with epilepsy in India with a prevalence of 1% the population. Further the prevalence in the rural population (1.9%) was found to be higher as compared to that of urban population (0.6%).[5] In addition, with less than 2000 neurologists and an estimated 5-6 million patients with active epilepsy.[6]

Consequently, efforts for better understanding of the disease are necessary to organize comprehensive services in terms preventive, promotive, curative, and rehabilitative services for persons with epilepsy. This requires the understanding the burden, distribution, risk factors, and determinants of epilepsy through epidemiological approaches.[7]

This scenario highlights the need for awareness programmes regarding the disease and the home care management of the patients that can intern enable improvement in the general outlook toward the disease and bring about better outcomes in the care aspects of this patient group. In view of the same November 17 is observed every year as "National Epilepsy Day'' to create awareness about epilepsy in India by the epilepsy Foundation of India.[8]

Need For the Study

Epilepsy is one of the most common neurological diseases that affect people of all ages, races, social classes, and geographical locations. Epilepsy is a disease of the brain characterized by an enduring predisposition to generate seizures and bring about the neurobiological, cognitive, psychological, and social consequences of seizure recurrences.[4]

In India epilepsy is the second most common and frequently encountered neurological condition that imposes heavy burden on individuals, families, and also on healthcare systems[7]. As per a recent study by Department of Epidemiology, Centre for Public Health, National Institute of Mental Health and Neurosciences, Bangalore, Karnataka, India. Epilepsy has a median prevalence of 1.54% (0.48-4.96%) for rural and 1.03% (0.28-3.8%) for urban cities in developing countries. With a conservative estimate of 1% as prevalence of epilepsy, there are more than 12 million persons with epilepsy (PWE) in India, which contributes to nearly one-sixth of the global burden.[7]

In a multi-centre cross-sectional, observational study conducted on 800 patients at New Delhi, India in 2022, it was found that, a majority (69.0%) had generalized onset seizure in the six months before enrolment. The median age at epilepsy onset was 20.0 (1.0–64.0) years; 40.0% of the patients were females, 48.5% were married, 99.1% were literate, and 67.0% belonged to the lower or upper-middle socioeconomic class[9].

Zhu X et al (2018)[10] reported a high risk of anxiety and depression in caregivers of adult patients with epilepsy and its negative impact on patient quality of life showed. Caregiver anxiety was significantly associated with poorer adult PWE QOL scores. Caregiver depression was significantly associated with poorer adult PWE QOL. Caregiver depression was an independent predictor of the QOLIE-31 total score and five subscales: seizure worry, emotional wellbeing, energy/fatigue, cognitive, and

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medication effects. are givers of adult PWE are at high risk of experiencing anxiety and depression.

A quasi-experimental study conducted by Aruljothi M (2018)[11] in Neuro OPD of Vinayaka Missions Medical College Hospital. Highlighted most of the family members had inadequate knowledge (48%) in pretest. After structured teaching programme, 84% had adequate knowledge and 16% of them had moderately adequate knowledge about epilepsy. Masoodi D[12] et al 2016 conducted a study in Hazratbal Community Block Srinagar, Kashmir on 47 cases of epilepsy, where there was a male to female ratio of 1:0.88. Majority of the cases were in the age group of 20-39 years followed by 40-59 years. Neuroinfection was the predominant cause of seizures with encephalitis accounting for 12.63%. Other causes included cerebrovascular accidents (25.53%), metabolic (17.02%), miscellaneous (8.51%) and idiopathic (12.76%) conditions. Higher incidence of seizures was observed in the age group of 20-29, followed by 40-49 and 30-39 age groups.

Seizure episodes can present dangers to the patients in the form of severe injuries or can be life threatening accompanied by falls or road accidents. There can also be psychological effects of the condition on both the patients and the care givers. The situation can be complicated by the already existing lack of awareness and misconceptions related to the illness. Further, stigmatization with in the society, that is often experienced by these patients can bring about withdrawal from the society and social isolation. This can be a leading cause for the emerging psychological effects in these patients that often present as anxiety or depressive disorders. This further complicates the condition and increases the demand on the family care giver task performance. it further necessitates the provision of multi-faceted care in these patients that tends to their physical, physiological, psychological and social needs. This can be challenging for the already overburdened care giver role to take up these extra demands. Care giver needs to be assessed for existing capabilities, care demands and provided the necessary assistance in the form of supportive awareness programmes. Individuals living in the community with neurological conditions receive the majority of their care from informal caregivers. The purpose of this research study is to explore and enhance the awareness of caregivers of neurological patients regarding home care management of epilepsy. The caregiver's assessment is very important in the wellbeing of the neurological patients.

In view of the findings of the above studies and the investigators own experiences where he has come across many cases of neurological patients with or at risk of epilepsy being managed at home by informal caregivers. It was observed that these patients are usually left unattended in the home care environment and are at risk of considerable morbidity and mortality. So, the investigator felt the need for a study that explores and enhances the caregiver's ability to cater to the demands of neurological patients and thus help in reducing the complications. This can be achieved only through adequate knowledge of caregiver's regarding the different aspects of care of patient to enhance the same, a structured awareness program among care givers of selected neurological patients was developed and administered.

Methodology

The research design used in this study was "quasi-experimental One Group Pre-test, Post-test design. Permission was obtained from the concerned authorities to conduct the final study. Ethical clearance was obtained from Institutional Ethical Committee (IEC) to conduct the study using non-probability convenient sampling technique on 50 care givers of selected neurological patients admitted in Neurology & Neurosurgery wards at SKIMS, SOURA, Srinagar. Pilot study was conducted to find the feasibility of the study.

A self-structured interview schedule was administered to study subjects as a pre-test measure and intervention was given after 10 minutes of break, The whole intervention was explained through lecture cum discussion method in local i.e., Urdu language with the help of power point presentation (PPT) followed by post-tested on every 4th day of intervention following the same procedure as in the pre-test

Assessment of knowledge scores was categorised into various levels based on the scale developed by Aruljothi M (2018)[11] in his study effectiveness of structured teaching program on knowledge on home care management of epilepsy among family members of patients with epilepsy. Knowledge score <25% indicates inadequate knowledge, 25-50% indicates moderately adequate knowledge and >75% indicates adequate knowledge.

Results and Discussion

Findings related to the demographic and clinical variables:

Majority of the study subjects were males (82%) in the age group of 20-30 years, Majority (74%) of study subjects belonged to rural areas, Maximum number of study subjects (34%) had qualification as graduation, Majority of study subjects (42%) were self-employed, Majority (62%) were from nuclear families, Most of study subjects (36%) had a family income less than 10,000 & 11000-20000 rupees per month respectively, Majority (38%) of care givers were members other than spouse, parent and child, Majority (84%) patients did not have any seizure episode, Maximum number of study subjects (80%) had care giver role of less than one year. (Table 1)

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The findings of the present study are comparable to the findings of the study done by Kissani N, Moro M, Arib S (2020)[13] where the mean age of caregivers was 40 years and 5 months. 66% caregivers were women, 50% were from rural areas. 41 % were illiterate.

The findings of the present study are consistent to the findings of the study done by Kumar R, Khakha D, Gulati S, Kaushik J (2019)[14] the results showed that 56.3% were males, 62.5% were belonging to nuclear family, 40.6% study subjects were rural.

The findings of the present study are consistent to the findings of the study done by Shewangizaw Z, Teferi J (2015)[15] the results showed that 76.2% of the participants were rural dwellers and 23.8% were urban, maximum number 54.1% were males

Findings related to knowledge score of study subjects

The pre-test knowledge score (Mean ± SD) of the study subjects was (17.62±8.719). In the pre-test knowledge, most of the study subjects i.e, 62% had moderately adequate knowledge, while as 26% subjects had inadequate knowledge and 12% subjects had adequate knowledge. These findings revealed that most of study subjects had moderate knowledge regarding home care management of epilepsy among care givers of selected neurological patient. (Table 2)

These findings of the present study are in conformity with the findings of the study conducted by Musekwa O, Makhado L, Maphula A (2023)[16] (n=519) conducted a survey among family members of patients with epilepsy in rural South Africa Limpopo, and Mpumalanga province. The study findings revealed that most respondents from both provinces had moderate knowledge of epilepsy (54.7%), with a mean of 16.57±3.34.

The post-test knowledge scores revealed that majority of the study subjects 49 (98%) had adequate knowledge,1 (2%) of the study subjects had moderate knowledge, while none of study subjects had inadequate knowledge. The post-test (Mean ± SD) knowledge score was (45.74±4.852). The findings revealed that most of the study subjects had developed adequate knowledge in the post-test regarding home care management of epilepsy among care givers of selected neurological patients. (Table 2)

These findings of the study are consistent with findings of the study conducted by Aruljothi M (2018)[11] (n=50) to assess the effectiveness of structured teaching program on knowledge on home care management of epilepsy among the 50 family members of patients with epilepsy in at Puducherry Tamil Nadu. The study findings revealed that in the post-test knowledge score 84% were having adequate knowledge and 16% of them had moderately adequate knowledge about home care management of epilepsy.

Findings related to comparison of pre-test and post-test knowledge scores of study subjects regarding home care management of epilepsy of selected neurological patients

In comparing pre-test and post-test knowledge scores, the post-test (Mean ± SD) knowledge score was (45.74 ± 4.85) it was found to be significantly higher than the pre-test (Mean ± SD) knowledge score (17.62 ± 8.71) which was found to be statistically significant (p=0.000) at 0.05 level of significance so it can be inferred that mean difference of 28.12 or increase in post-test knowledge score of study subjects. (Table 3 & Fig 1). The findings of the present study were consistent with the study conducted by Alharbi R, Kaki A, Tabassum S (2023)[17] (n=206) to assess the effectiveness of an educational intervention on status epilepticus among 206 care givers of children with Epilepsy in King Fahad Medical City, Riyadh, Saudi Arabia. The findings revealed that the mean (±SD) score of total knowledge was 12.3/20 (±2.6) before the intervention which increased to 15.7/20 (±3.1) after the intervention, and the difference was found to be statically significant (p = 0.001).

Findings related to association of pre-test knowledge score among care givers with selected demographic/ clinical variables

The findings of the present study revealed that there was significant association between the pre-test knowledge score of care givers and demographic/clinical variables i.e. occupation (p=.040), family monthly income (p=0.047) while as no significant association was found with other demographic/clinical variables i.e. age (p=0.991), gender(p=0.948), residence(p=0.381), educational qualification(p=.485), type of family(p=0.852), relationship with patient(p=0.395), seizure episodes(p=.809), duration of care givers role(p=0.183). the calculated chi-square values were less than the table value at the 0.05 level of significance. (Table 4)

The findings of the study are consistent with findings of the study conducted by Musekwa O, Makhado L, Maphula A (2023)[16] (n=519) to assess the knowledge among 519 family members of patients with epilepsy and epilepsy related seizures in rural South Africa Limpopo, and Mpumalanga province. Findings of the study revealed that there was significant association of the pre-test knowledge score with the demographic variable (occupation) Employment or work status (p=0.001).

The findings of the study are consistent with findings of the study conducted by Kissani N, Moro M, Arib S (2020)[13] (n=100) to assess the knowledge, attitudes, and traditional practices specifically among relatives and caregivers of

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patient with epilepsy in our community, in order to better evaluate their educational needs at outpatient neurology clinic of the Mohammed 6 University Hospital, a tertiary referral center in Marrakesh, Morocco. The Findings of the study revealed that there was significant association of knowledge score with the demographic variable income level (p=0.008). the study results revealed that there was no significant association with educational qualification (p=0.091), age (p=0.301) and gender (p=0.363) as the findings of the present study.

Table 1.Frequency and percentage distribution of study subjects according to demographic/clinical variables

n=50

Demographic/clinical variable		Frequency	Percentage%
Age	20-30	20	40.0%
	31-40	18	36.0%
	41-50	6	12.0%
	51-60	6	12.0%
Gender	Male	41	82.0%
	Female	9	18.0%
Residence	Rural	37	74.0%
	Urban	13	26.0%
Educational status	Illiterate	8	16.0%
	Primary school	13	26.0%
	Secondary school	12	24.0%
	Graduation	17	34.0%
Occupation	Govt/private employee	8	16.0%
	Self-employed	21	42.0%
	Unemployed	14	28.0%
	Student	7	14.0%
Type of family	Nuclear	31	62.0%
	Joint	17	34.0%
	Extended	2	4.0%
Family monthly income	<10000	18	36.0%
	11000-20000	18	36.0%
	21000-30000	3	6.0%
	>30000	11	22.0%
Relationship of care giver with patient	Spouse	6	12.0%
	Parent	14	28.0%
	Child	11	22.0%
	Any other	19	38.0%
Seizure episodes patient had	5 and more	2	4.0%
	Less than 5	6	12.0%
	Zero	42	84.0%
Duration of care givers role	<1yr	40	80.0%
	1-2yr	5	10.0%
	3-4 yr	1	2.0%
	>5yr	4	8.0%

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Table 2.Frequency and percentage distribution of study subjects according to Pre-test and post-test knowledge scores

n=50

Pre-test & post-test knowledge score	Number of subjects in pre-test		Number of subjects in post-test	
	Frequency (f)	Percentage (%)	Frequency (f)	Percentage (%)
Inadequate (0-13)	13	26%	0	0%
Moderately adequate (14-25)	31	62%	1	2%
Adequate (26-50)	6	12%	49	98%

Table 3.Comparison of pre-test and post-test knowledge scores of study subjects regarding home care management of epilepsy of selected neurological patients

-	Mean	n	S. D	t value	df	P value
Pre-test knowledge score	17.62	17	8.719	-21.096	49	.000***
Post-test knowledge score	45.74	46.50	4.852			

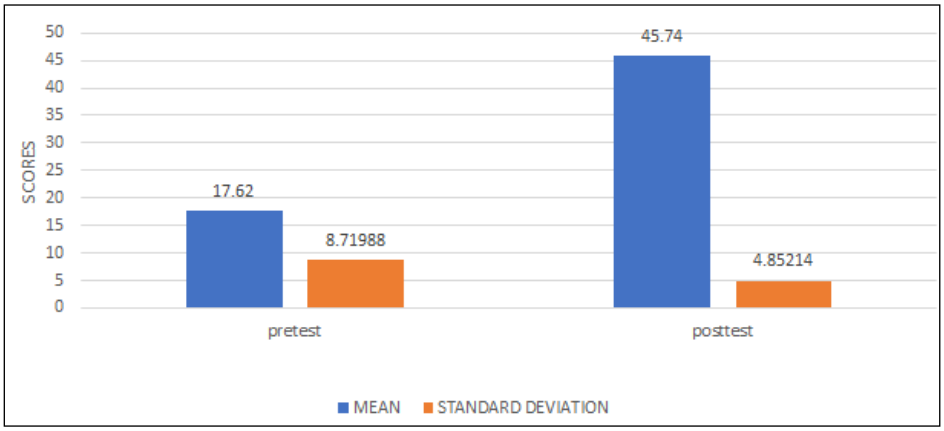

Figure 1.Bar diagram showing comparison of pre-test and post-test mean knowledge scores

Table 4.Association of pre-test knowledge score among caregivers with selected demographic/clinical variables

Variable	Category	Inadequate knowledge	Moderately adequate	Adequate knowledge	Chi-square	P value
Age	20-30	5	13	2	.843	0.991
	31-40	5	11	2		
	41-50	2	3	1		
	51-60	1	4	1		
Gender	Male	11	25	5	.106	.948
	Female	2	6	1		
Residence	Rural	8	25	4	1.928	.381
	Urban	5	6	2		
Educational status	Illiterate	1	7	0	5.474	.485
	Primary school	4	8	1		
	Secondary school	4	5	3		
	Graduation	4	11	2		

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Occupation	Govt/private employee	1	5	2	13.183	.040*
	Self employed	8	12	1		
	Unemployed	4	10	0		
	Student	0	4	3		
Type of family	Nuclear	8	19	4	1.354	0.852
	Joint	5	10	2		
	Extended	0	2	0		
Family monthly income	<10000	4	13	1	12.734	0.047*
	11000-20000	4	13	1		
	21000-30000	1	0	2		
	>30000	4	5	2		
Relationship With patient	Spouse	0	4	2	6.257	.395
	Parent	5	8	1		
	Child	2	7	2		
	Any other	6	12	1		
Seizure episode	5 and more	0	2	0	1.599	.809
	Less than 5	2	3	1		
	Zero	11	26	5		
Duration of care givers role	<1yr	11	26	3	8.842	.183
	1-2yr	0	3	2		
	3-4 yr.	1	0	0		
	>5yr	1	2	1		

Conclusion

The following conclusions were drawn on the basis of findings of study:

- Pre-test findings revealed that most of study subjects had moderate knowledge regarding home care management of epilepsy among care givers of selected neurological patient. So, there is a need to educate them regarding home care management of epilepsy
- Post-test findings showed that 98% of the study subjects had adequate knowledge, 2% of the study subjects had moderate knowledge, while none of study subjects had inadequate knowledge, after implementation of structured awareness programme on knowledge regarding home care management of epilepsy. So, showed that most of the study subjects had developed adequate knowledge and the structured awareness programme was effective in increasing the knowledge score among care givers of selected neurological patients regarding home care management of epilepsy.
- Significant association between pre-test knowledge score of care givers and demographic/clinical variables i.e. occupation (p=.040), family monthly income (p=0.047) while as

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Conflict of Interest: None

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