Indian Journal of Nursing Sciences

International Peer Reviewed Journal

Research Article

# Assessment of the Knowledge among Caregivers of Epileptic Patients Regarding Epilepsy

**Rupam Gaikwad, Sumit Khare**

Department of Psychiatric Nursing, Maharashtra Institute of Mental Health, Pune, Maharashtra, India

**Abstract**

**Aim:** Epilepsy is a spectrum of disorders with range of severities, widely differing seizure types and causes, an array of coexisting conditions and varying impacts on patients and families. Living with epilepsy patients exposes one to challenges at home, school, workplace, and other outdoor places. Awareness and understanding of epilepsy nature are, hence, critical to create a better attitude among family caregivers to provide a better care for the patients as well as improve their health-related quality of life. **Methodology:** The present study based on the quantitative approach. A research design selected for the present study was non-experimental exploratory design. Using non-probability purposive sampling 200 caregivers of epileptic patients were selected. The tool used for the data collection was semi-structured questionnaires. Pilot study was conducted from November 5, 2019 to November 13, 2019 in selected hospitals. After explaining the study purpose, objectives, role participants, benefits to the participant, and then a written consent was taken from subjects. Knowledge was assessed with the help of semi-structured questionnaire. Collected data were arranged properly and analyzed as per the objectives of the study. **Results:** The result of the study shows that 23.5% of the caregivers have poor knowledge score (0–09), 50% of caregivers have average knowledge score (10–18) and (26.5%) of the caregivers have good knowledge score (19–26). **Conclusion:** Demographic variable, educational status, and age were found to have significant association with the knowledge score.

**Key words:** Caregiver, epilepsy, hospital, seizure

**Address for correspondence:** Mr. Sumit Khare, Department of Psychiatric Nursing, Maharashtra Institute of Mental Health, Pune, Maharashtra, India.
E-mail: sumitkhare22@rediffmail.com

## Introduction

Epilepsy is the most common childhood neurological disorder. Children who suffer from seizures tend to have significant psychosocial difficulties that are more noticeable when seizures coexist with other chronic disorders. It was found that children whose onset was below the age of two years were mostly males with comorbid neurological or psychiatric conditions with a certain seizure type acting as a risk factor for refractoriness.[1] Children with epilepsy have other coexisting health conditions that significantly affect their health and intensify their parents' worries and anxiety as they require continued surveillance and are often in a state of uncertainty and apprehension. Many studies have shown that people with less awareness and knowledge about epilepsy demonstrated poorer attitudes. The magnitude of negative attitudes was shown to be aggravated by the presence of misconception of epilepsy which includes the perception of epilepsy as a form of insanity, being untreatable, contagious, and hereditary or a form of mental retardation.[2,3] Family stigma is a major challenge for parents of child with epilepsy need to special attention by health system. To manage this problem, the health system should develop supportive strategies such as enhanced familiarity to epilepsy and parent's problems.[4] Although some studies have suggested that patients and their families' attitude regarding epilepsy have become less negative over time, the problems of stigma remain widespread.[5]

| Access this article online | |
|---|---|
| Website:http://www.innovationalpublishers.com/Journal/ijns | e-ISSN: 2581-463X |
| DOI: 10.31690/ijns.2020.v05i04.005 | |

**How to cite this article:** Gaikwad R, Khare S. Assessment of the Knowledge Among Caregivers of Epileptic Patients Regarding Epilepsy. Indian Journal of Nursing Sciences 2020;5(4): 189-193.

Most research consistently demonstrated that epilepsy patients and their families do not have a comprehensive understanding of the basic information about the illness ranging from how the diagnosis was made, seizure precipitants, types of seizures, the purpose, and potential side effects of medications, safety concerns to the risks and potential consequences of seizures.[6,7] Sociocultural attitudes continue to cause a negative impact on the management of epilepsy in many African nations.[8,9] In India, there is little attention has been paid about knowledge of epilepsy to the public. At present, there are lot of myths, prejudices, bias, and social stigma about epilepsy among caregivers.[10]

The present study was carried out to assess the knowledge of caregivers of epilepsy patient regarding epilepsy in selected hospitals and to find the association between study findings with selected demographic variables.

## Conceptual Framework

The conceptual framework selected for the present study is based on the Callista Roy's adaptation model on which will explain the concepts related to this study.[11] Callista Roy's adaptation model has evoked much interest and respect since its inception in 1964 by Roy as part of her graduate work at the University of California. Theory consists of four essential elements: The person who is the recipient of nursing care, the concept of environment, and the concept of health and nursing. In this study, person is a family members of the epileptic patients were included, environment is impact of mentally challenged on their family members especially the first degree relatives such as parents and siblings of epileptic individuals, health speaks about the social, spiritual, financial, psychological and physical problems of the family members of mentally challenged individuals and nurses role in identifying problems, and adopting coping strategies and take steps to improve it.

## Research Design and Sampling

In the present study, research design was non-experimental exploratory descriptive research design. The purpose of descriptive studies is to observe, describe, and document aspects of situation as it naturally occurs, and sometimes to serve as a starting point for hypothesis generation or theory development.[12] The setting of the study was selected hospitals of the city. Target population of present study was caregivers of epilepsy patients in selected hospitals from Maharashtra. In the present study, accessible population was caregivers of epilepsy patients in selected hospitals, study samples were selected caregivers of epilepsy patients in selected hospitals. The non-probability purposive sampling was used, because this technique was found to be appropriate for the present study. The sample size for the present study was 200 caregivers of epilepsy patients. They were selected purposively to suit the study.

Variables are the characteristic, quality or attribute of a person or objects that the experimenter manipulates controls or observes. Variables can be changed and these changes were studied. In the present study, demographic variables were age, gender, religion, marital status; educational status was taken up as demographic variables.

## Criteria for Sampling

Following criteria were set for the selection of sample

### Inclusion criteria

The caregivers, who were:
1. Willing to participate in the study
2. Staying with Epileptic Patients
3. Able to understand English and Marathi Language.

### Exclusion criteria

The caregivers, who
1. Participated in the pilot study
2. Absent during the period of data collection.

## Scoring Key and Procedure

To assess the level of knowledge, the score was grouped in to the category such as poor, average, and good based on the percentages of the scores.

Scoring key of knowledge of caregivers of epileptic patients

| Level of Knowledge | Percentage | Actual score |
|---|---|---|
| Poor | 1–33 | 0–9 |
| Average | 34–67 | 10–18 |
| Good | 68–100 | 19–26 |

## Pilot Study

Pilot study was conducted from November 5, 2019 to November 13, 2019 in selected hospital of city. Twenty samples were collected for the pilot study and same samples are excluded in main study.

## Data Collection and Data Analysis

Before collection approval was obtained from Institutional Ethical/research committee, written permission was obtained from medical officer. Permission was obtained from authorities of the selected hospitals. The purpose and nature of study were explained to the authority to gain co-operation. The data collection was done from December 1, 2019, to December 31, 2019. During this study, the investigator collected data.

In this study, data were presented in the form of tables, bar diagrams, and pie charts. Data were analyzed by computing mean, standard deviation, *P*-value, and ANOVA.

## Data Interpretation

1. Data pertaining to the demographic characteristics of the people with respect to age, gender, religion, marital status, educational qualification, and the study child psychology in their educational program.

Percentage wise distribution of caregivers of epilepsy patients according to their age depicts that majority 100 (50%) of the samples were from age group 21 to 30 years, 49 (24.50%) of them were from age group of 31 to 40, 32 (16%) of the samples were in the age group of 41–50 years, and 19 (9.50%) of them were from age group 50 years and above [Table 1.1].

Percentage wise distribution of caregivers of epilepsy patients according to their gender depicts that 105 (52.50%) of them were males and 95 (47.50%) of them were females [Table 1.2].

Percentage wise distribution of caregivers of epilepsy patients according their religion depicts that 129 (64.50%) of them was Hindu and 41 (20.5%) of them were Muslim [Table 1.3].

Percentage wise distribution of caregivers of epilepsy patients, according to their marital status, depicts that the majority 121 (61.50%) were married and 70 (35%) were unmarried [Table 1.4].

Percentage wise distribution of caregivers of epilepsy patients, according to their educational status, depicts that 100 (50%) of them had education up to graduation, 69 (34.50%) of them had education up to secondary, 25 (12.50%) of them had primary education, and 6 (3%) of them were illiterate [Table 1.5].

Distribution of demographic data of samples in group according to the study of child psychology in their educational program (*n* = 200)

Percentage wise distribution of caregivers of epilepsy patients, according to their study of child psychology in their educational program, depicts that the majority 72 (36.00%) of the respondents had study of child psychology in their educational program and 128 (64.00%) of the respondents did not study child psychology in their educational program [Table 1.6].

2. Analysis of data related to knowledge of caregivers of epilepsy patient regarding epilepsy.

The figure shows that 23.5% of the caregivers have poor knowledge score (0–09), 50% of caregivers have average knowledge score (10–18) and (26.5%) of the caregivers have good knowledge score (19–26) [Table 2].

3. Analysis of data to find the association between demographic variables and study findings.

**Table 1.1:** Distribution of demographic data of samples according to their age (*n*=200)

| Age | Frequency | Percentage |
|---|---|---|
| 21–30 years | 100 | 50.00 |
| 31–40 years | 49 | 24.50 |
| 41–50 years | 32 | 16.00 |
| 50 years and above | 19 | 09.50 |

**Table 1.2:** Distribution of demographic data of samples according to their gender (*n*=200)

| Gender | Frequency | Percentage |
|---|---|---|
| Male | 105 | 52.50 |
| Female | 95 | 47.50 |
| Transgender | 00 | 00 |

**Table 1.3:** Distribution of demographic data of samples according to their Religion (*n*=200)

| Religion | Frequency | Percentage |
|---|---|---|
| Hindu | 129 | 64.50 |
| Muslim | 41 | 20.50 |
| Christian | 14 | 07.00 |
| Others | 16 | 08.00 |

**Table 1.4:** Distribution of demographic data of samples according to their Marital status (*n*=200)

| Marital status | Frequency | Percentage |
|---|---|---|
| Married | 121 | 61.50 |
| Unmarried | 70 | 35.00 |
| Separated | 6 | 03.00 |
| Widow/Widower | 3 | 01.50 |

**Table 1.5:** Distribution of demographic data of samples in group according to their Educational status (*n*=200)

| Educational status | Frequency | Percentage |
|---|---|---|
| Primary | 25 | 12.50 |
| Secondary | 69 | 34.50 |
| Graduation | 100 | 50.00 |
| Illiterate | 06 | 03.00 |

**Table 1.6:** Distribution of demographic data of samples in group according to their Educational status (*n*=200)

| Study of child psychology in their educational program | Frequency | Percentage |
|---|---|---|
| Yes | 72 | 36 |
| No | 128 | 64 |

**Table 2:** Analysis of data related to knowledge of care givers of epilepsy patient regarding epilepsy

| Knowledge Score | Frequency | Percentage |
|---|---|---|
| Poor knowledge (0-9) | 47 | 23.5 |
| Average knowledge (10-18) | 100 | 50 |
| Good knowledge (19-26) | 53 | 26.5 |

Age 0.030 (<0.05) this found to have significant association with knowledge score [Table 3.1]

Gender 0.844 (Greater than 0.05) this found to have no significant association with knowledge score [Table 3.2].

Educational status 0.000 (<0.05) this found to have significant association with knowledge score [Table 3.3].

Study of child psychology in their educational program 0.289 (Greater than 0.05) this found to have no significant association with knowledge score [Table 3.4].

## Discussion

A preliminary study was conducted Austin and Shore on the seizures and epilepsy education program for families of patient with epilepsy. They investigated the usefulness of the seizures and epilepsy education program in improving quality of life, management of the seizure condition, and health-care utilization in families having a patient with epilepsy.[13] Considering the same, the present study, based on the quantitative research approach. The accessible population was caregivers of epilepsy patients in selected hospitals. In Section I of the study, distribution of subjects in relation to demographic data was assessed. There were total six demographic variables assessed in this study. A total of 200 caregivers of epileptic patients were selected for the study. In findings related to age, 100 (50%) of the samples were from age group of 21 to 30 years, 49 (24.50%) of them were from age group of 31 to 40, 32 (16%) of the samples were in the age group of 41–50 years, and 19 (9.50%) of them were from age group 50 years and above. In findings related to gender. 105 (52.50%) of them were males and 95 (47.50%) of them were females. In findings related to religion. 129 (64.50%) of them were Hindu and 41 (20.5%) of them were Muslim. In findings related to marital status. Marital status depicts that the majority of 121 (61.50%) were married and 70 (35%) were unmarried, in findings related to educational status 100 (50%) of them had education up to graduation, 69 (34.50%) of them had education up to secondary, 25 (12.50%) of them had primary education, and 6 (3%) of them were illiterate and in findings related to study of child psychology in their educational program depicts that the majority of 72 (36.00%) of the respondents had study of child psychology in their educational program and 128 (64.00%) of the respondents did not study child psychology in their educational program.

In Section 2 of the study, the knowledge of caregivers of epilepsy patient regarding epilepsy in selected hospitals was assessed. The results show that 23.5% of the caregivers

**Table 3.1:** Significance association of knowledge score with regard to age

| Demographic variable | Knowledge score | Tabulated F-value | Calculated F-value | P-value (0.05) |
|---|---|---|---|---|
| Age | | | | |
| 21–30 years | 1490 | 2.71 | 5.49 | 0.030 Significant |
| 31–40 years | 639 | | | |
| 41–50 years | 453 | | | |
| 50 and above | 222 | | | |

**Table 3.2:** Significance association of knowledge score with regard to gender

| Demographic variable | | Knowledge score | Tabulated F-value | Calculated F-value | P value (0.05) |
|---|---|---|---|---|---|
| Gender | Male | 1422 | 3.10 | 1.46 | 0.122 Not significant |
| | Female | 1350 | | | |
| | Transgender | 00 | | | |

**Table 3.3:** Significance association of knowledge score with regard to educational status

| Demographic variable | | Knowledge score | Tabulated F-value | Calculated F-value | P value (0.05) |
|---|---|---|---|---|---|
| Educational status | Primary | 323 | 2.71 | 5.48 | 0.000 Significant |
| | Secondary | 1013 | | | |
| | Graduation | 1380 | | | |
| | Illiterate | 88 | | | |

**Table 3.4:** Significance association of knowledge score with regard to study of child psychology in their educational program

| Demographic variable | | Knowledge score | Tabulated F-value | Calculated F-value | P-value (0.05) |
|---|---|---|---|---|---|
| Study of child psychology in their educational program | Yes | 1021 | 3.95 | 1.29 | 0.289 Not significant |

have poor knowledge score (0–09), 50% of caregivers have average knowledge score (10–18) and 26.5% of the caregivers have good knowledge score (19-26). In Section 3 of study, the data to find the association between demographic variables and study findings were analyzed. The results demonstrated that demographic variable, educational status, and age were found to have significant association with the knowledge score.

## Conclusion

The outcomes of the study found that demographic variable, educational status, and age were found to have significant association with the knowledge score.

## References

1. England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: Promoting health and understanding. A summary of the institute of medicine report. Epilepsy Behav 2012;25:266-76.
2. Kwan P, Brodie MJ. Early identification of refractory epilepsy. N Engl J Med 2000;342:314-9.
3. Begley CE, Famulari M, Annegers JF. The cost of epilepsy in the United States: An estimate from population based clinical and survey data. Epilepsia 2000;41:342-51.
4. Shafiq M, Tanwir M, Tariq A, Kasi PM, Zafar M, Saleem A, *et al*. Epilepsy: Public knowledge and attitude in a slum area of Karachi, Pakistan. Seizure 2007;16:330-7.
5. Saengpattrachai M, Srinualta D, Lorlertratna N, Pradermduzzadeeporn E, Poonpol F. Public familiarity with, knowledge of, and predictors of negative attitudes toward epilepsy in Thailand. Epilepsy Behav 2010;17:497-505.
6. Hasan SS, Wei WW, Ahmadi K, Ahmed IS, Yong AK, Anwar M. Knowledge and attitudes toward epilepsy among Malaysian Chinese. Int J Collab Res Intern Med Public Health 2010;2:361-76.
7. Kolahi A, Abbasi-Kangevari M, Bakhshaei P, Mahvelati-Shamsabadi F, Tonekaboni S, Farsar A. Knowledge, attitudes, and practices among mothers of children with epilepsy: A study in a teaching hospital. Epilepsy Behav 2017;69:147-52.
8. Shaba B, McLachlan M, Carr SC, Ager A. Palliative versus curative benefits regarding tropical. Epilepsia 1884;25:184-90.
9. Chilopora GC, Kayaange NM, Nyirenda M, Newman PK. Epilepsy as traditional and medical attributions. Cent Afr J Med 1993;39:165-7.
10. Amudhan S, Satishchandra P. Epilepsy in India I: Epidemiology and public health. Ann Indian Acad Neurol 2015;18:263-77.
11. Kozier B. Kozier and Erb's Fundamentals of Nursing: Concepts, Process, and Practice, 8th ed (With DVD). Pearson Education India; 2008. p. 296-308.
12. Basavanthappa BT. Nursing research 2nd. Jaypee Brothers medical publishers, New Dheli. 2007. p. 146.
13. Shore CP, Perkins SM, Austin JK. The Seizures and Epilepsy Education (SEE) program for families of children with epilepsy: a preliminary study. Epilepsy Behav 2008;12:157-64.