

CAREGIVERS LEVEL OF BURDEN AND COPING STRATEGIES AMONG PATIENTS WITH EPILEPSY: AN EXPLORATORY STUDY

Ms. Agnes Monica .V

Lecturer, Psychiatric Mental Health Nursing,
King Saud Bin Abdul Aziz University for Health Sciences,
Riyadh, Kingdom of Saudi Arabia.
yoguddi@gmail.com

ABSTRACT:

Background: A neurological disorder characterized by recurrent seizures, which are sudden surges of electrical activity in the brain is epilepsy. It tends to arise suddenly, as it has highly random character and high psychological impact. Epilepsy occurring in a public place can lead to embarrassing and sometimes dangerous situations. It may occur in a workplace or in a social setting, where the patients along with the caregivers experience a lack of understanding and stigma on epilepsy.

Objectives: The main objective of the study level of burden among caregivers of patients with epilepsy, explore the coping strategies used by family members of patients with epilepsy and to associate the level of burden between caregivers and selected demographic variables. **Methods:** Descriptive research design was adopted to achieve the objectives of the study. The study was carried out in the Neuro Center clinic in Chennai, India. A total of 40 consecutive pairs of subjects and their main caregivers were initially joined in the study. The samples are selected using purposive sampling technique. Participants were asked to complete three part questionnaire including demographic data questionnaire, caregivers burden inventory and coping strategies scale among caregivers of patients with epilepsy. The investigator explained the education to the patients and caregivers reassuring them that their privacy would be firmly endangered and the questionnaires are administered to the participants. Self-introduction of the invigilator was made on the meeting day; the caregivers were primarily invited into a designated interview room for privacy. They were delivered with a detailed description on the study purposes and its procedure as written in the Family Caregiver Information Sheet. The Written consent form was later signed upon contribution agreement by the participants. The information was assigned and analyzed using Statistical Package of Social Studies (SPSS) version 21.0. **Results:** Majority (37.5%) was under the age group of 21-30 years, (72%) female, married (55%) and joint family (52.5%).

Around 95% of the subjects were literate and 70% of the Subjects from a city background and almost three fourth belonged to the middle class family.

KEYWORDS: CAREGIVERS, BURDEN, COPING, EPILEPSY.

I.INTRODUCTION

Epilepsy is the fourth most common neurological disorder and affects people of all ages, also known as Seizure disorders [6]. A neurological disorder characterized by recurrent seizures, which are sudden surges of electrical activity in the brain is epilepsy [15]. Epilepsy tends to arise suddenly, as it has highly changeable character and high psychological impact.

Epilepsy occurring in a public place can lead to embarrassing and sometimes dangerous situations. It may happen in a workplace or in a social setting, where the patients along with caregivers experience a lack of understanding to cope with the situation on epilepsy. It has a significant impact on quality of life of patients [2, 10, 11], are inflicted with a condition which tends to occur suddenly.

The most difficult thing to further accept the condition has always related with different, spoiled identity [9]. Moreover, caregivers from the patient's family require support from rehabilitation team to cope with many adjustments and qualms which accompany the diagnosis of epilepsy. Appropriate resources can be provided to the caregivers in the form of knowledge to enhance better understanding and coping to continue as a support. Basically, they need to improve self-management skills to increase the self-efficacy level for better compliance and coping technique in managing epilepsy patients [4]. Caregiver's level of burden includes emotional, psychological, physical and economic impact as well as related distressing feelings like embarrassment, anger,

feeling of guilt and self-blame [1].

Additionally, many family caregivers of patients with epilepsy are continually concerned about the long-term costs of treatment and care maintenance. Also, they get worried about the inadequate health insurance or low-income flow in the family [13]. Epilepsy is similar to other chronic diseases in terms of the economic burden. The financial part of patients ultimately contributes to the stress level of family caregivers. It includes the resources consumed by family caregivers for patient diagnosis, treatment and follow-up and also the loss of cost of unemployment, decreased productivity to perform their jobs or work at home[3].

Currently, there are very few statistics and available studies available on caregiver's burden among patients with epilepsy which raise an urgent need to conduct research studies among the population to gain an insight into that global growing concern.

II. OBJECTIVES

1. Assess the level of burden among caregivers of patients with epilepsy
2. Explore the coping strategies used by family members of patients with epilepsy
3. Associate the level of burden between caregivers and selected demographic variables
4. Associate the between caregivers coping strategies and selected demographic variables
5. Correlate the relationship between caregiver's level of burden and coping strategies.

III. CONCEPTUAL FRAMEWORK:

The conceptual framework identified for this study based on Sr. Callista Roy's Adaptation Model [RAM]. Roy's adaptation model views a person as unified bio psychosocial adaptive system in constant interaction with the external and internal environment. The environment is the source of a variety of stimuli that either threaten or promote the Peron's wholeness [25]. The concepts of this model were control processes, effectors and adaptive and ineffective response. Effectors identify factors on physiologic, self-concept, role function and inter dependence. These concepts were modified and utilized for the current study.

It is hypothesized that output behaviors have a constructive coping mechanisms which include spiritual support, family support, acceptance, relaxation, and problem solving and negative copings like denial and anger.

IV. REVIEW OF LITERATURE

A study proposed to explore the needs and problems of epilepsy family caregivers of epilepsy patients encountered during the caregiving process in Malaysia. Fifteen Muslim family caregivers between the age of 19 and 66 years participated. Most were females (53%), married (67%), and with education level at secondary school or equivalent (73%) and some are homemakers (40%). In particular, respondents expressed the need for extra support from their family members and experts regarding physical (care relief), mental, and financial aspects. They concluded that the experiences while taking care of their loved ones regarding feelings, beliefs and needs exposed the difficulties in caregiving, causing substantial emotional pressure which could later lead to poor quality of caregiving [28].

Similar to the incident another cross-sectional study was undertaken to assess the burden between family caregivers of patients having Schizophrenia and Epilepsy in India. It was aimed to compare the burden on families of schizophrenia and compare the same with patients having a physical disease requiring long-term management. Data was collected on sixty participants and the findings revealed that the caregivers of both long term physical illness like intractable epilepsy and mental illness like schizophrenia experience a high level of burden in the areas of; patient care, finance, physical and emotional burden, family relations and occupation. No significant difference was found in both groups of caregivers and in total burden score between male and female caregivers of both the groups. The study highlights the need for family interventional programs in follow-up clinics to address the specific concern, related to burden of caregivers [29].

V. METHODOLOGY

The selection of the research approach is the basic procedure for the conduct of research inquiry.

An exploratory approach was considered to be the most appropriate and adopted for the study to explore the level of burden and coping strategies used by the caregivers of patients with epilepsy.

The research design refers to the researcher's overall plan for obtaining an answer to the research questions and spells out coping strategies that the researcher adopted to develop information that is accurate. Descriptive research design was adopted to achieve the objectives of the study.

Table – 1 Schematic representation of Research Methodology

RESEARCH APPROACH	EXPLORATORY
RESEARCH DESIGN	NON-EXPERIMENTAL DESCRIPTIVE
SETTING	NEURO CENTER, CHENNAI, INDIA
POPULATION	CAREGIVERS OF PATIENTS WITH EPILEPSY
SAMPLE	40 CAREGIVERS OF PATIENTS WITH EPILEPSY
SAMPLING TECHNIQUE	PURPOSIVE SAMPLING TECHNIQUE
TOOL	STRUCTURED SCHEDULE QUESTIONNAIRE
DATA ANALYSIS	DESCRIPTIVE AND INFERENCEAL STATISTICS
INTERVENTION	COPING STRATEGIES TO THE CAREGIVERS

The study was carried out in the Neuro Center in Chennai, India. A total of 40 consecutive pairs of subjects and their principal caregivers were initially joined in the study. A primary caregiver was defined as any person who, without being a professional or belonging to a social support network, usually lives with the patient and, in some way, is directly implicated in the patient's care or is directly affected by the patient's health problem. The neuro center is one of the well-equipped centers for care of epileptic patients and OPD facility. An Outpatient consultation conducted on Monday, Wednesday and Friday of every week. The caregivers of patients with epilepsy who accompanied their relatives for the follow up care were identified by the invigilator. The samples are selected by purposive sample technique based on feasibility, availability of subjects and invigilators familiarity with the setting. The data was collected by the invigilator

on all the above mentioned three days in a period of four weeks.

Variables are concepts which can take on different qualitative values at various levels of abstractions that are measured, manipulated and controlled in the study. Two types of variables are used in the study. The research variables used are caregiver's level of burden and coping strategies.

Demographic variables in the present study are age, gender, marital status, religion, education, type of family, occupation, family income, socioeconomic status, and relationship with the patient.

The target population of the present study comprises of caregivers of epilepsy patients who accompanied the patient during the health check-up at selected Neuro Centre, Chennai. The population referred to as the target population, which represents the entire group of subjects that meet the criteria for inclusion in the study.

Sample refers to the portion of the population that is selected to participate in a particular study. A Sample size of the present study consists of 40 caregivers of patients with epilepsy who accompanied the patient during the health check-up at selected neuro center in Chennai.

The samples are selected by using purposive sampling technique, Neuro Center, Chennai, Tamil Nadu, India.

Inclusion criteria:

- Caregivers of epilepsy patients who are willing to participate in the study
- Caregivers with patients who are attending the Neuro Clinic, Chennai
- Caregivers of epilepsy patients who can understand Tamil and English

Exclusion criteria:

- Caregivers of epilepsy patients who are not willing to participate in the study.
- Caregivers who are not accompanied by the patients.
- Caregivers of epilepsy patients who can understand Tamil and English.

The tool consists of mainly three parts.

Part-one: Demographic data questionnaire

It consists of 10 items; Socio-demographic questionnaire were collected from both of patients and of caregivers, namely age, gender, marital status, religion, family type, place of residence, education, occupation, family income,

relationship to the patient, and the other persons who help for the patient.

Part-two: Caregivers burden inventory

To assess the level of burden among caregivers and to associate with selected demographic variables the self-report questionnaires were compiled in the waiting room. Caregiver Burden Inventory (CBI) is a 24-item multi-dimensional questionnaire in which five sub-scales explore five different dimensions of caregiver burden. It consisted of as follows:

- objective burden : the amount of time keen to caregiving [items 1–5]
- developmental burden: the caregiver's sense of being left over, unable to delight in the similar prospects and chances as his or her peers [items 6–10]
- physical burden: feelings of fatigue and chronic health problems [items 11–14]
- social burden, which results from a perceived conflict of roles [items 15–19]
- emotional burden, which originates from awareness of negative feelings towards the patient that can be induced by the patient's bizarre and unpredictable behavior [items 20–24].

Scoring/Interpretation:

Subjects were asked to rate each item on a 5-point Likert scale ranging from 0 [not at all disruptive] to 4 [very disruptive]. Eight of these pairs did not return the questionnaires, while another five were excluded because they [n = 3 patients, n = 2 caregivers] failed to complete them. Therefore, the final study participants were neuro out patients who are 40 caregivers . All the caregivers escorted the patients.

Subjects were asked to rate each item on a 5-point Likert scale ranging from 0 [not at all disruptive] to 4 [very disruptive]. All of the scores on the 24-item scale are summed, and a total score >36 indicated a risk of "burning out" whereas scores near or slightly above 24 indicated a need to seek some form of respite care.

Part-three: Coping strategies scale among caregivers of patients with epilepsy.

It consists of 46 items and was internally reliable [$\alpha=0.91$] and had highest reliability [$r=0.81$].

To assess the coping used by the caregivers, a coping scale was adapted. It was developed by Matheson k and

Anisman H in the year 2001 and got published by British Journal of health psychology in the year 2006.

VI. DATA COLLECTION:

A formal permission from the Director of Neuro centre, was obtained from Chennai, Tamil Nadu, India.

The caregivers who accompanied their relatives for the follow-up care were identified by the invigilator. The sample was selected by purposive sampling technique. The data collection was structured interview schedule. An appropriate instrument to elicit the response from the caregivers and it was developed on caregivers burden and coping strategies. The investigator explained the study to the patients and caregivers [comforting them that their confidentiality would be strictly endangered] and the questionnaires were directed to the participants.

A self-introduction of the invigilator was made on the meeting day; the caregivers were initially asked into a chosen meeting area for privacy. They were provided with a thorough clarification of the study determinations and its process as written in the Family Caregiver Information Sheet. The Written consent form was earlier signed upon participation contract by the participants.

A semi-structured interview was conducted to convey the planned questions and stance additional reviews to the caregivers. The questionnaires on Demographic data, Caregivers burden inventory and Coping Strategies scale among caregivers of patients with epilepsy was administered. The data was collected from each family members who accompanied with them. Eight of these pairs did not return the questionnaires, though alternative five were excluded because they [n= 3 patients, n = 2 caregivers] failed to complete them. Therefore, the final study participants were 40 pairs of caregivers. All the caregivers escorted the patients.

All the specified data were collected in the course of arranged time periods. The investigator spent time with each family member during the data collection. The difficulties and the queries encountered by the caregivers to fill the questionnaire were identified and were clarified then and there. Each family took around more than 20 minutes to answer the given questionnaires.

VII. DATA ANALYSIS

Statistical analysis was performed using descriptive statistics for socio-demographic variables and caregiver measures, and differences were analyzed using nonprobability Chi Square test [χ^2]. Data was presented using descriptive statistics in the form of frequencies and percentages. Interval and ratio variables were presented in the form of means and standard deviations. Possible

correlations between variables were tested using Pearson’s correlation coefficients. The data was imputed and analyzed using Statistical Package of Social Studies [SPSS] version 21.0. The level of statistical significance was kept at $p < .05$.

The plan of data analysis is as follows:

Descriptive statistics:

- ✍ The responses of the item in part-one demographic variables was planned and summarized in number and percentage.
- ✍ Caregiver’s burden inventory and coping strategies scale were assigned as mean, standard deviation and mean percentage.

Inferential statistics:

- ✍ Chi-square value was used to work out in order to find out the association between the demographic variables and the caregiver’s age, gender, marital status, religion, family type, place of residence, education, occupation, family income, relationship to the patient, and the presence of other persons who help care for the patient.
- ✍ Karl Pearson correlation coefficient was planned and computed in order to find out the correlation between the caregivers burden among patients with epilepsy and coping strategies used by them.

VIII. RESULTS

The data was collected from the care givers of 40 consecutive in-patients receiving follow-up care in the neuro center. The sample included 17 male and 23 female care givers. The Majority [37.5%] was under the age group of 21-30 years, [72%] female, married [55%] and joint family [52.5%]. Around 95% were literate and 70% of the subjects from a city background and almost three fourth belonged to a middle-class family. Fifty-six percent of the care givers were the primary earning members of the family as well. All the caregivers that satisfied the inclusion criteria decided to participate in the study. The mean age of the applicants was 46.23 ± 6.52 years. The mean age of the female caregivers was 42.04 ± 5.54 , while that of male caregivers was 47.21 ± 4.32 . There was no significant difference between the male and female caregivers [$t=3.12, p=0.19$].

Table- 2 Socio-demographic Data of the Participants [n = 40]

Variables		Frequency	Percentage [%]
Age	20-30 years	15	37.5
	31-40 years	8	20.0
	41-50 years	11	27.5
	51-60 years	6	15.0
Gender	Male	17	42.5
	Female	23	57.5
Marital status	Married	22	55.0
	Unmarried	13	32.5
	Divorced	5	12.5
Religion	Hindu	20	50.0
	Christian	13	32.5
	Muslim	7	17.5
Education	Post-Graduate	3	7.5
	Graduate	11	27.5
	Diploma	20	50.0
	School Education	6	15.0
Occupation	Government	19	47.5
	Private	13	32.5
	Dependent	8	20.0
Family type	Nuclear family	19	47.5
	Joint family	21	52.5
Place of residence	Urban	28	70.0
	Rural	12	30.0
Monthly income	Rs.10,000-15,000	5	12.5
	Rs.15,000-20,000	13	32.5
	>Rs. 20,000	22	55.0
Relationship with the	Son/daughter	16	40
	Spouse	11	27.5
	Son-in-law	7	17.5
	Daughter-in-law	6	15.0

The above table.2 depicts the total score of each Caregivers burden inventory [CBI] sub-scale [Time Dependence, developmental, physical, social, emotional] was calculated and expressed as a relative percentage of the total CBI score. The 40 caregiver’s interview scored 54% in the physical burden, 34% in the Time Dependence burden, 21% in the social burden, 16% in the developmental burden and 8 % in the emotional burden.

The Table.2 shows that the physical burden has the highest occurrence of burden based on the aggregation of the scores from all study participants. Gender differences were also examined: independent samples t-test analysis failed to reveal any statistical difference

between caregiver burden perceived by men, mean value 29.51 SD 13.50 and by women, mean value 27.18 [SD 12.94] at the level of $p = 0.72$.

Table- 3 Mean and standard deviation of caregivers level of burden among patients with epilepsy [n=40]

CBI	Mean ± SD	% Mean score
Time Dependence	5.35±1.25	66.8
Developmental	3.25±.06	65
Physical	3.13±1.24	62.6
Emotional	2.88 ±1.55	57.6
Social	3.55±1.68	50.7
Total	18.15 ±3.61	60.5

As presented in the table.3 exploration of the caregiver's responses to the burden inventory, the most highly reported sub-scale was physical burden with a mean score 66.8 [SD 1.25] and followed by time dependence with a score of 65 [SD 1.06].

Table- 4 Level of burden among caregivers of patients with epilepsy [n=40]

Level of burden	No. of caregivers	%
Mild	8	20
Moderate	26	65
Severe	6	15

Table. 4 represents the level of burden among caregivers of patients with epilepsy showed a remarkable result on the mild level of burden at 20% [8], the moderate level at 65% [26] and a severe level of 15% [6].

Table- 5 Mean and standard deviation of coping strategies used by the caregivers of patients with epilepsy: [n=40]

Intervention	Number	Min -	Mean ± SD	% of Mean
Coping	40	0-138	80.45±10.93	58.3

Table.5 shows the overall percentage of coping strategies adopted by the caregivers of patients with epilepsy. On an average, the caregivers were having 58.3% of coping among them.

Table- 6 Level of coping strategies score

Level of coping	No. of caregivers	%
Low coping	12	30
Moderate coping	28	70
High coping	0	0

Table.6 mentioned about the caregivers classified into three categories which are according to the level of coping strategies adapted by them during the same period. It showed 28[70%] of caregivers had moderate level of coping and only 12 [30%] had low coping. This indicates that the caregivers do use some coping mechanisms to adjust with the disturbances in current situation.

Table- 7 Association of selected demographic variables with caregivers level of burden and coping strategies used by them [n=40]

Variables	X2 p	Variables
Age		
20-30 years	6.72 0.03	5.79 0.01
31-40 years	S	S
41-50 years		
51-60 years		
Family type		
Nuclear family		
Joint family	7.11 0.02	NS
Monthly income		
Rs.10,000-15,000		
Rs.15,000-20,000	6.47 0.03	4.56 0.03
>Rs. 20,000	S	S

Relationship with the patient Spouse Son/daughter Son in law Daughter in law	6.82 0.03 S	NS
Education Post- Graduate Graduate Diploma		
School education	NS	3.90 0.05

Analysis of data in table.7 revealed that there is a significant association between the age, monthly income, type of family and caregivers relationship with the level of burden, also the significant association between the age, education, and monthly income with the coping strategies. This shows the people more familiar with the patient living in a joint type along with financial assistance have more coping ability than others.

Table- 8 Correlation between the caregivers level of burden among patients with epilepsy score and coping strategies score (n=40)

Correlation	Mean SD	Karl Pears on correlation
Caregivers burden	18.15 3.61	r= -0.25 p= 0.05
Coping strategies	80.45 10.93	

Table.8 shows the correlation score which showed a significant negative correlation between the caregivers level of coping among Patients with epilepsy with coping strategies. In other words when the caregivers level of burden increases, the coping level decreases and when the caregiver’s level of burden is decreased, the coping level increases.

r= -0.25, p=0.05 where the p-value shows significant at $p \leq 0.05$.

IX. DISCUSSION

The association between the caring for patients below the

age of 20 and high burden was inconsistent with Martin’s-Yellow report [13] among caregivers of schizophrenic patients. He found that those who cared for patients in the age group of 21- 45 years were the most burdened. It is possible that caring for younger patients may be more stressful. They also recommended that this is the stage when children and adolescents are expected to be in school and if needed seizure is poorly controlled the children will spend time away from the school. It is needed that the caregivers may be forced to stay at home with patients. (Fig.2)

In this study, Table 7 shows monthly income was found to be associated with higher level of burden. In patients who have the illness for a long time, the burden experienced by caregivers may be the cumulative effects of the disease over the years. A period without seizure may be an indication of severe illness. Seizure attacks which occur may challenge the coping ability of the caregiver. It includes the frequent hospital visits, using high doses of anticonvulsant drugs, close monitoring of patients at home with less time for other work, receiving visitors at home due to stigma and fear of what future holds for the patient. These were some of the concern experienced by the caregivers when there is a family history of epilepsy. The burden experienced by caregivers are the total burden of caring for more than one in the same family which is associated with stigma. And the inability to meet financial expenses along with family commitments which supports the first objective to explore the caregiver’s burden among patients with epilepsy.

Caregivers living outside the city of Chennai also had a mild burden in this study. There is a similar study on the same perspectives among caregivers of patients with schizophrenia in Nigeria who lived in rural areas [13, 21, and 25]. Indeed, rural people who live outside the city are more likely to be poorer than the urban, and they have very inadequate access to physical and mental health care. The main factor is the distance patients, and their caregivers travel to cover for the follow-up treatment to the hospital. Some of the patients along with their caregivers travel more than 30kms to attend the clinic, some travels a day before the clinic appointment and have to sleep in their relatives place after the clinic to avoid night journey back home and this, will also worsen their economic restraints and increase the overall burden which is supported by the first objective under the demographic variables.

Coping status of caregiver burden among patients with epilepsy explains a high percentage of variation in caregivers. They found that the same between coping and health-related quality of life (HRQOL) among seizure patients [24]. Other studies on coping among caregivers of patients with the chronic disease show comparable

results. The patients with Huntington's disease found a positive correlation between caregiving and general life satisfaction among HRQOL caregivers. Caregivers' understanding of the situation had a significant influence on safety than other characteristics [19,22] found that 15–27% of variance in psychological functioning of caregivers among patients with epilepsy could be explained by coping strategies as mentioned in table.3. Thus, the second objectives to explore the coping strategies used by the caregivers among patients with epilepsy were supported.

The third objective was the association between the caregivers level of burden and selected demographic variables among patients with epilepsy has shown a significance in some of the demographic variables like age, family type, monthly income and relationship with patients of epilepsy in table.7 which was supported by a group of people in their study on the burden experienced by family caregivers of patients with epilepsy attending the government psychiatric hospital [7]. The results of this study showed that about 52% of our subjects experienced a high level of the burden while caring for their relatives. It was associated with some of the factors like caring for patients who were unemployed, had a longer duration of illness, lived outside the city and had a family history of epilepsy and short seizure-free periods.

The fourth objective of the study reveals the association between the Coping strategies used by the caregivers of patients with epilepsy with the selected demographic variables. A similar type of study on Coping style and health-related quality of life in caregivers of epilepsy patients investigated health-related quality of life (HRQOL) and coping style of both patients and caregivers and their interaction. They showed significant associations between patient and caregiver HRQOL scores. Also, they recommended that improving caregiver HRQOL through interventions on coping style might benefit patients as well. And they insisted the need to recognize personal coping styles of both patient and caregiver as a part of a patient-oriented approach in treatment [13].

The fifth objective of the study revealed the caregiver's perceived burden while caring for the child with a mental illness supported by the coping patterns of Chinese parents of a child with a mental illness. They used limited coping arrangements to maintain a purposeful family life. Also, a significant negative correlation found between the caregiver burden and the way of coping. Caregiver physical health and the child's educational level were the best predictors of the way of coping [16]. Findings recommend that effective nursing involvements should be established to help parents of a child with mental illness cope with caregiver burden while maintaining a functional family life.

X.NURSING IMPLICATIONS

Nursing Practice

The nurse can utilize the intranet e - learning facility and plan for group teaching sessions for patients as well as caregivers and family members to reinforce learning during the follow-up period. It is crucial for nurses to involve family members to enhance their knowledge on treatment adherence and its important contribution to improve the quality of life. The booklet can be used as a ready reckoner to teach patients with minimal instructions on how to deal with patients who are undergoing treatment in their clinics.

Nursing Education

Nursing care of epileptic patients is a clinical challenge for nursing students during the clinical training experience. A well-defined lecture during pre-clinical education with demonstration and will inspire confidence and ensure better patient care and outcomes.

As technology shape education in all disciplines, e-learning is beneficial in enhancing nursing skills in nursing students. Incorporating comprehensive nursing strategies into nursing curriculum would benefit the nursing students.

Nursing Administration

Orientation can be done for nurses about e -learning availability of booklet information for effective utilization. Periodical assessment of the interaction between improved patient's satisfaction and nurse's job satisfaction could be explored. Intuitively, satisfaction within one or both groups is likely to engender and reinforce satisfaction in the other.

Nursing research

Research seeks to provide definite answers to important questions, which can inform clinical practice, enabling evidence-based patient care. Dissemination of research findings is the prerequisite for the implementation of research findings in nursing practice that yield significant health benefits to all populations and across all health care settings.

The use of Journal club, research seminars, and research workshops are some of the enabling processes to increase the dissemination of knowledge. Nurse researchers can enroll themselves in nursing Ph.D. society and organize conferences to communicate research findings either in oral form or in written form.

XI. RECOMMENDATIONS

The Experimental study can be done to understand better how caregiver's burden, expectations influence their depression and anxiety and their recovery also helps to understand better how expectations change over time.

Phenomenology study can be done to find out the barriers to adherence to rehabilitation and find out the factors to overcome the same for adherence.

Long term follow-up study could be done for sustaining the benefits. The combination of physiological parameters and other psychosocial interventions can be investigated for future purposes.

The study can also be replicated in different cultural groups, urban areas and in larger samples in different settings.

A multicenter study may be carried out applying the same interventions. A Comparative study can be done among various epileptic patients and their caregiver's burden in various settings.

CONCLUSIONS

Caring for patients with epilepsy is really challenging, and it is associated with enormous burden. The study predicts high burden are high levels of emotional distress among caregivers, long duration of epilepsy, poor seizure control and living far away from the treatment center. We, therefore, recommend that all efforts should be made to control seizure in epileptics and to make health care readily available to the entire population at an affordable price.

Based on the findings of this study, the following recommendations are suggested:

- Replicate the current study on larger sample size using a combined quantitative and qualitative research approach to better understand the caregiver's level of burden and coping strategies
- Develop awareness programs specific for the school and college students and other high-risk groups about the importance of caring the epilepsy patients along with the caregivers are urgently needed to meet those groups unique needs
- Conduct regular "stress management" programs for the epilepsy patients along with the caregivers to help them to cope with life stressors

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XIII. CONFLICT OF INTERESTS:

The author declares that they have no conflict of interests with any organization regarding the materials discussed in this manuscript.

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schizophrenia in Katsina, Nigeria. *South African Journal of Psychiatry*. 15(2):43–47.

AUTHORS PROFILE



Ms. Agnes Monica V post graduated in Psychiatric Mental Health Nursing, currently employed in King Saud Bin Abdul Aziz University for Health Sciences Riyadh, Kingdom of Saudi Arabia. Actively involved in teaching practical Nursing for the 16 years and currently teaches Psychiatric Mental Health Nursing theory and clinical courses