



Care Burden in Epilepsy: A Study from North East India

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ABSTRACT

Background: Epilepsy can affect the lives of other family members besides the persons. The caregivers of persons with epilepsy undergo severe emotional, physical, economic burden due to the nature, chronicity, disability, and stigma attached to the illness.

Aim: The aim of the present study is to assess the burden among caregivers of person with Epilepsy.

Materials and Methods: A cross sectional study was conducted at out-patient Department of Lokopriya Gopinath Bordoloi Regional Institute of Mental Health, Tezpur Assam. The sample for the current study comprised of caregivers of 30 persons suffering from Epilepsy. A semi-Structured socio-demographic data sheet, Burden Assessment Schedule, and General Health Questionnaire were administered to the caregivers.

Both genders between the age range of 18 – 50 years with duration of illness more than 1 year was included in the study

Results: The results shows that the caregivers of epilepsy were having high burden in Physical & mental Health [14.43±2.97] domain of burden assessment scheduled followed by External support [11.93±2.42], Support of patient [11.36±2.31], Caregivers routine [9.16±2.08], Persons behavior [9.38±2.3], Taking responsibility [8.10±1.84], Other relation [6.80±1.51] and spouse related [4.66±4.57]. Duration of illness has positive co-relation at 0.05 level with physical & mental health domain [$p = -0.276, p \leq 0.05$], care givers routine domain [$p = -0.178, p \leq 0.05$], Support of patient domain [$p = -0.281, p \leq 0.05$], taking responsibility domain [$p = -0.319, p \leq 0.05$] and other relations domain [$p = -0.260, p \leq 0.05$] of burden assessment schedule.

Key words: *Burden; Caregivers; Epilepsy*

Introduction

Epilepsy is a major public health problem across the world, not only because of the problem that arises as a result of seizure activities, but also due to the social & cultural stigma attached to it. It has a serious implication for the individual and the family in a various life domains, usually more serious than those of other chronic diseases. The problems that persons with epilepsy go through vary from interpersonal & emotional adjustment, family coping and adjustment within marital relationship, issues surrounding children, employment, economic burden & stigma about the

disease and treatment that exist in the society. Epilepsy can affect the lives of other family members besides the persons. The caregivers of persons with Epilepsy undergo severe emotional, physical, economic burden due to the nature, chronicity, disability and stigma attached to the illness. In a study conducted Ioannis et al [1] found that, higher number of antiepileptic drugs, poorer patient neuropsychological performance, lower patient quality of life (QOL) score, and lower caregiver education level were associated with higher care burden.

A study conducted by in India by Kumar Jaya et al. [2] to assess the burden of care giving among the caregivers of persons with epilepsy. In the study it was found that caregivers of persons experienced a greater degree of burden. A study done by Ray et al [3] reports an overall increase in the burden amongst caregivers with epilepsy compared to the control group. Researchers has found that caregivers of patients with epilepsy have high levels of strains, fears and concern about what will happen to patients in future when the caregiver will not be available to take care [4, 5]. In an Indian study recently conducted on association between quality of life, depression and caregiver burden in epileptic patients it was found that significant positive correlation was found between Beck depression inventory and Zarit burden interview. Duration of disease was not significantly correlated with Quality of life and Beck depression inventory and Zarit burden interview. It was also found that that emotional well being is most affected domain in quality of life [6].

In India many researchers have contributed in assessing family member burden in epilepsy. There is no evidence available of any study being conducted in North East Region of India in regard to care burden in diseases like epilepsy. Therefore this study is conducted to assess burden among the care givers of patient with epilepsy towards enhancing psychosocial family based interventions. Based on this study intervention can be planned for the future. Moreover, while undertaking psychosocial interventions, psychiatric social worker not only deals with patient but also with family members. So it is mandatory for the psychiatric social worker to know about the problems faced by the relatives while giving care to the patient. This study also helps to know these aspects.

Aim

- To assess the burden among caregivers of person with Epilepsy

Objectives

- To explore the burden among caregivers with Epilepsy
- To see the relationship between care burden and duration of illness

Materials & Methods

The study was conducted at out-patient Department of Lokopriya Gopinath Bordoloi Regional Institute of Mental Health, Tezpur Assam .The study aim to explore the burden among caregivers with epilepsy. Hence a cross sectional & exploratory research design was considered for the study. The caregivers were selected using purposive sampling based on inclusion and exclusion criteria set for the study .The sample for the current study comprised of caregivers of 30 persons suffering from Epilepsy. Based on the inclusion & exclusion criteria, sample was selected from the follow – up persons attending the OPD of LGBRIMH, Tezpur .Patients of both genders , between age group of 18 – 50 years with duration of illness more than 1 year were included. For caregivers between age group of 18-50 years, primarily educated, with duration of care giving more than 2 year were included. Patient with Mental retardation, Organicity and Substance abuse [excluding tobacco] were excluded .Caregivers that score 2 on the GHQ 12 were excluded. The study was approved by the Scientific and Ethical Committee of the Institute.

Tools of data collection:

The following Schedule and Scales are used for data collection -

1. Socio – demographic data sheet:

A semi-Structured socio-demographic data sheet was prepared by the researcher to gather personal data of the respondent as well as other details. The sheet includes information such as age, sex, marital status. Occupation, etc about the caregivers and patient.

2. Burden Assessment Schedule by Thara et al [7]

This scale measures the Burden of care among family member/care givers. This scale is composed of nine factors or sub scale: spouse related burden, physical and mental health burden, burden related to external support, burden on care givers routine, burden to support patient , burden related to taking responsibility, burden on other relations, burden due to persons behavior and care givers strategy due to burden of care. The Sub scale of spouse related, care givers routine, taking responsibility, patient's behavior and care givers strategy related burden has constituted of 4 items each. The physical and mental health burdens, burden related to external support sub scale

comprised of six items each, burden to support patient sub area has 5 items and burden on other relations sub scale comprised 3 items. A total 40 items are there in the scale. On each items of scale the minimum possible score is 1 and maximum of 3. The responses could be very much scored as 3, to some extent scored as 2 and not at all scored as 1. 15 items of the scale that is item no.1,8,11,13,15,17,18,24,25,29,34,35,36,39 and for item no 40 the scoring is reversed as 1 for very much, to some extent as it is and not at all measured as 3. The scale was translated to local language according to prescribed translation procedures.

3. General Health Questionnaire-12 [8]

It is a self report instrumental questionnaire to screen psychiatric morbidity in normal subjects. It consists of 12 items, each assessing the mental problem over the past few weeks. The original consists of 60 items. The items have been scored as zero or one. The higher the scores, the higher was the distress. The instrument has been translated into Hindi, Bengali & Kannada.

Statistical analysis

Statistical analysis of data using descriptive techniques such as mean, standard deviation, frequency etc was done. Pearson correlation was used to find out the degree of association between the scales & background variables.

Results

Table 1: Age of caregivers and patients

N=60

Variables	Epilepsy n=30	
	Mean	SD
Age of caregivers	39.60	9.37
Age of patient	28.96	8.72

The above table shows mean age of caregivers of persons with Epilepsy and it was found that the mean age of the care givers was 39.60 with SD=9.37 and for the patient the mean age was 28.96 with SD=8.72.

Table 2: Duration of illness

Variables	Mean	SD
Duration of illness	3.16	1.11.
Age of onset	26.56	8.66

Mean age of duration of illness was 3.16± 1.11 and age of onset was 26.56 ± 8.66 among the patients.

Table 3: Socio demographic profile of care givers

		Epilepsy N =30
Gender of caregiver	Male	17(56.6%)
	Female	13(43.3%)
Religion	Hinduism	25(83.3%)
	Islam	5(16.6%)
Education	Illiterate	1(3.3%)
	Primary	8(26.6%)
	Middle	6(20%)
	High School	9(23.3%)
	Higher Secondary	3(10%)
	Degree	3(10%)
	Post Graduate	0
Occupation	Business	6(20%)
	Agriculture	9(30%)
	Housewife	12(40%)
	Others	3(10%)
Marital Status	Married	29(96.6%)
	Unmarried	1(3.3%)

The above table shows that majority of the caregivers were male (56.6%), Hindu by religion (83%), majority of the caregivers were educated up to primary level (26.6%). In occupation majority of the female care givers were house wife (40%) and male caregivers were engaged in agriculture activities (30%). Majority of the caregivers were married (96%).

Table 4: Socio Demographic profile of persons with epilepsy

		Epilepsy
Variables		n=30
Gender	Male	20(66.6%)
	Female	10(33.3%)
Religion	Hinduism	25(83.3%)
	Islam	5(16.6%)
Occupation	Unemployed	2(6.6%)
	Business	3(10%)
	Student	3(10%)
	Agriculture	11(36.6%)
	House wife	7(23.3%)
	Others	(13.3%)
Education	Illiterate	0
	Primary	4(13.3%)
	Middle school	10(33.3%)
	High school	14(46.6%)
	Higher Secondary	1(3.3%)
	Degree	1(3.3%)
Marital Status	Married	16(53.3%)
	Unmarried	14(46.6%)
Family type	Nuclear	20(66.6%)
	Joint	10(33.3%)

The above table shows that majority of patients were male (66.6%), Hindu by religion (83%), majority of the patients were educated up to high school level (46.6%). In occupation majority of them were engaged in agriculture activities (36.6%). Majority of the patients were married (53%). Majority of the patients are hailing from nuclear family background (66.6%).

Table 5: Caregivers experience on burden between two groups

Burden domains	Epilepsy n=30	
	Mean	S D
Spouse related	4.66	4.57
Physical & mental Health	14.43	2.97
External support	11.93	2.42
Caregivers routine	9.16	2.08
Support of patient	11.36	2.31
Taking responsibility	8.10	1.84
Other relation	6.80	1.51
Persons behavior	9.83	2.3
Caregivers strategy	9.10	1.64

The table shows that the caregivers of epilepsy were having high burden in Physical & mental (14.43±2.97) Health domain of burden assessment scheduled followed by External support (11.93±2.42), Support of patient (11.36±2.31), Caregivers routine(9.16±2.08), Persons behavior (9.38±2.3), Taking responsibility (8.10±1.84), Other relation (6.80±1.51) and spouse related (4.66±4.57).

Table 6: Correlation with duration of illness & Burden Assessment Schedule

Burden assessment schedule	Duration of illness
Spouse related	.118
Physical & mental health	.276*
External support	.211
Caregivers' routine	.178*
Support of patient	.281*
Taking responsibility,	.319*
Other relations	.260*
Patient behavior	.190
Caregivers strategy	.209

* P<0.05

The above shows the co-relation of duration of illness with various domains of burden assessment schedule. Duration of illness has positive co-relation at 0.05 level with, physical & mental health domain (p=.276, p≤ 0.05), care givers routine domain (p=.178, p≤ 0.05), Support of

patient domain ($p=-.281$, $p\leq 0.05$), taking responsibility domain ($p=-.319$, $p\leq 0.05$) and other relations domain ($p=-.260$, $p\leq 0.05$) of burden assessment schedule.

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Discussion

The results of this study show that caregivers experienced high level of burden while caring for their relatives. The results shows that the caregivers of epilepsy were having high burden in Physical & mental Health domain of burden assessment scheduled followed by External support, Support of patient, Caregivers routine, Persons behavior, Taking responsibility, Other relation and spouse related .Studies have reported that caregivers of persons with Epilepsy have high levels of strains [4,5].The burden experienced by caregivers may be the cumulative effect of the disease over the years. Frequent relapse & repeated seizure attacks challenges the coping and problem solving ability of the caregiver. This also involves frequent hospital visits, using high doses

of psychotropic drugs which are expensive, close monitoring of persons at home. In the present study it was found that Burden assessment schedule has significant co-relation with duration of illness. Duration of illness has positive co-relation at with, physical & mental health domain, care givers routine domain, Support of patient domain, taking responsibility domain and other relations domain of burden assessment schedule. Studies of caregivers of chronic patients have found levels of burden to be associated with greater severity of illness symptoms and longer duration of illness [9]. In addition, it has been shown that relatives who care for persons with epilepsy have higher burden of care than control groups [2,10]. In a study conducted by Folorunsho et al [11] more than half of the care givers (51.9%) had high burden. High burden was significantly associated with patients aged less than 20 years, patient's unemployment, and long duration of epilepsy, short seizure-free period, and family history of epilepsy. Caregivers play a vital role in supporting family members who are sick, infirm or disabled [12]. The main limitation of the study was the size of the sample, the other were that only family burden was studied in the present study areas like Family home environment, support system expressed emotion, family interaction pattern, family coping skill should be taken for study in order to understand the true burden of care.

Conclusion

The implications from this study are that it will help us to understand the burden of illness existent in caregivers of patients with a chronic mental illness such as epilepsy in a north eastern society. There is often a perception that the burden of care existent in a traditional society like in Assam may be different from other parts of the country. It is also known that social support services are inadequate and stigma associated with treatment of chronic illnesses is seen to be more in traditional and in developing societies. Knowledge about burden perception and enhancement of social support services goes a long way in improving the quality of life of patients and their families and also towards management of chronic illnesses like epilepsy. Caring for patients with epilepsy is really challenging and it is associated with enormous burden. Various inputs in the psychosocial area can be planned based on knowledge gained.

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