Original Research Article

Psychosocial problems in epilepsy patients in sub-urban Hyderabad

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Abstract

Background: Epilepsy is a common disorder with co-morbidities. It affects physical, emotional, psychological, social, financial and cognitive functioning of the patients. Identification and management of psychosocial problems are important in holistic treatment of epilepsy. There is paucity of literature in psychosocial functioning in epilepsy.

Aim: To find out the occurrence of psychosocial problems in patients with epilepsy.

Materials and methods: One hundred consecutive patients attending the OPD of Internal Medicine were evaluated with a questionnaire subserving seven domains of psychosocial functioning with inclusion and exclusion criteria.

Results: The occurrence of depression, emotional instability, inter personal relationship and vocational difficulties were higher in patients with epilepsy.

Conclusion: Psychosocial co-morbidities are higher in patients with epilepsy and are likely to be missed unless carefully evaluated.

Key words

Epilepsy, Depression, Anxiety, Emotional instability, Interpersonal relationship, Vocational status, Compliance, Psychological problems, Social problems.

Introduction

Epilepsy is a common heterogeneous group of disorders of brain leading to morbidity. It is

characterised by recurrent (two or more) epileptic seizures with more than 24 hours apart, unprovoked by any immediate identified cause

[1]. It has long lasting neurobiologic, cognitive, psychological and social consequences [2]. It is still considered as a social stigma in our society [3]. The incidence of epilepsy is 49.3/100,000 in India. There are about 10 million patients in India suffering from epilepsy making a fifth of worldwide burden [4]. The frequent comorbidities of epilepsy are neuropsychiatric manifestations viz., depression, anxiety, suicidal psychotic tendencies and behaviour Identifying and addressing these issues has great impact on health outcomes of epilepsy patients. Various scales to assess the psychological and social issues are available in the literature [6]. Washington Psychological Seizure Inventory (WPSI) is one of them [7]. Most of the studies are on prevalence of psychiatric complications in epilepsy. The present study was undertaken to assess the psychosocial problems among epilepsy patients.

Materials and methods

One hundred patients diagnosed as suffering from epilepsy as per ILAE 2014 criteria attending the medical out-patient department of Malla Reddy Institute of Medical Sciences, Hyderabad were analysed. This study got Ethics Committee approval of the Institute.

Inclusion criteria

- Diagnosed as suffering from epilepsy as per ILAE criteria.
- Age >15 years.
- Patients on Anti Epileptic Drugs (AED) for > 6 months
- Informed consent

Exclusion criteria

- Age >60 years
- Patients not taking AED.
- AED usage of <6 months.
- Patients having neurological deficit or mental retardation.
- Patients having gross intra cranial lesions: stroke, brain trauma, tumour or brain surgery.
- Patients having drug toxicity.

A questionnaire based on time tested WPSI scale was given to the patient under his/her consent in the language of their preference viz., Telugu, Hindi or English by the Principal investigator (PI) under the supervision of the guide. Psychosocial evaluation was done in the following way. A total number of 24 questions under 7 domains were given to the patients.

- 1. *Home environment:* whether the patient grew up in a secure and loving parents or guardians.
- 2. *Emotional stability:* whether the patient has anxiety, depression, emotionally upset and cope up with problems of daily life.
- 3. *Interpersonal relationship:* whether the patient can confide in others, maintaining good relationship, level of comfort in social situations, interacting with new people easily and whether maintains enough social contacts.
- 4. *Vocational status:* whether adjusted with employment or lack of it. Whether epilepsy is interfering in job.
- 5. *Financial issues:* whether the patient has any financial difficulties and how much it is impacting his life.
- 6. Adjustment to epilepsy: whether the patient has resentment of having epilepsy, feels low in esteem and whether he is accepted in society.
- 7. Adjustment to treatment: whether the patient is compliant in taking medicines, understands need for taking medicines, has confidence in his treating doctor.

Details are given in **Appendix - 1**. The following scores were given depending on the involvement of different parameters of 7 domains.

"1" was marked if there is involvement of the parameter.

"0" was marked when there is no involvement.

Demographic information of the patients like age, sex, residence, occupation, monthly income

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and educational status were noted. Additional data like age of onset, type of seizures, seizure count per month, details and number of AED,

duration of medication, EEG and C.T. scan of brain were also obtained.

Appendix-1

Pro-forma of Psychosocial evaluation

1. Home environment

- (a) Whether the patient grew up in loving home environment
- (b) Whether the patient had good relationship with parents/guardians

2. Emotional stability

- (a) Whether the patients feels depressed / discouraged
- (b) Is the patient free from worries / tensions
- (c) Is the patient gets easily upset emotionally over petty issues
- (d) Is the patient able to cope with the problems of daily living

3. Interpersonal relationship

- (a) Does the patient find people in whom he can confide
- (b) Does the patient able to maintain relationships in society
- (c) Does the patient finds himself comfortable in social situations
- (d) Does the patient finds himself comfortable in meeting new people
- (e) Does the patients have enough social contacts

4. Vocational status

- (a) Is the patient happy about having / not having a job
- (b) Does the patient feel that epilepsy is interfering in getting a job
- (c) In job whether the patient needs any special counselling in view of epilepsy

5. Financial issues

- (a) Does the patient have financial problems
- (b) Does the patients worries a lot about financial resources

6. Adjustment to epilepsy

- (a) Does the patient resent a lot of having epilepsy
- (b) Does the patient feels low in self esteem of having epilepsy
- (c) Does the patient has embarrassment of having epilepsy
- (d) Does the patient feel accepted in the society in spite of having epilepsy

7. Adjustment to treatment

- (a) Does the patient take medicines regularly as prescribed
- (b) Does he understand the need to take medicines regularly and on long term basis
- (c) Does he like his treating doctor
- (d) Does he have confidence in his doctor

Results

A total 104 patients were screened. Four patients were excluded from the study as could not understand the questionnaire. Finally 100 patients satisfying the inclusion/exclusion criteria were included in the study. The age range was 15 to 57 years (mean age 22 years). The male

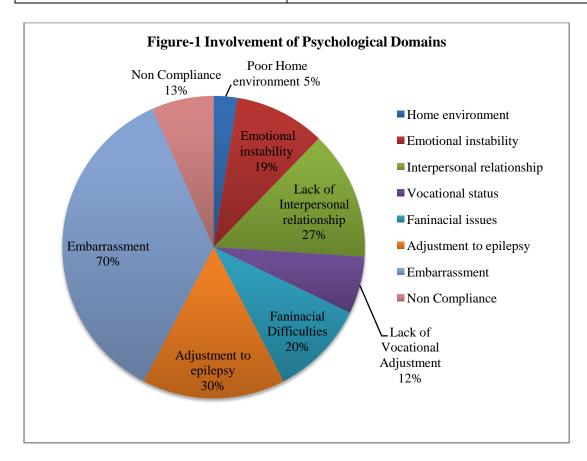
female ratio was 7:3.All patients hailed from sub-urban areas of Hyderabad. Their educational background was: Uneducated = 42, Secondary schooling = 38, Graduation = 19 and Post graduation = 1. The age of onset was between 3 to 52 years (mean 27 years). The duration of illness was: < 1 year was 20%, 1 to 5 years was 36%, >5 years was 44%. Monotherapy was in

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42% polytherapy (two or more AEDs) in 58%. calcific lesions. Nearly sixty percent had normal On CT scan brain only 18% had minor incidental EEG vide **Table - 1**.

<u>**Table – 1:**</u> Demographic profile (n=100).

Age	15-57 years (Mean 22)
Male: Female ratio	7:3
Education	Uneducated = 42
	Secondary schooling = 38
	Graduation = 19
	Post graduation = 1
Age of onset	3-52 years (Mean 27)
Duration of illness	<1 year 20
	1-5 years =36
	>5 years = 44
AEDs	Monotherapy= 42
	Polytherapy= 58
EEG abnormal	40



On psychosocial evaluation the following observations were made as per **Figure - 1**.

- 95% had loving, caring parents and guardians and grew in a secure environment.
- 2. Under the emotional aspect domain, only 19% had depressive symptoms and upset in coping up various aspects of daily living. However majority of them had anxiety, embarrassment (70%), mental tension (62%), emotional upset (62%)

- and difficulty in coping with problems of daily life (78%).
- 3. 70-88% had difficulties in maintaining inter-personal relations.
- 4. Majority of the patients (88%) were comfortable in jobs, but 44% felt that epilepsy comes in way of getting jobs or maintaining them. Only 12% required counselling in jobs.
- 5. 80% did not face any financial difficulties.
- 6. 30% had resentment of having epilepsy, felt low in self-esteem, however majority had embarrassment of impending seizures (70%).
- 7. 87% were compliant of taking medicines and understood the need for long-term treatment.

Discussion

The management of epilepsy is primarily focused on the pharmacological treatment with little importance given to the social functioning of the patient [8]. As per World Health Organisation the incidence of depression in general population is 3.5% to 5.0%. Most of the studies mainly highlight on psychiatric issues like depression [9] and anxiety [10]. Various studies have reported the occurrence of anxiety in epilepsy patients when compared to general population to be 22.8% (controls 11.2%), major depression 17.4% (controls 10.7%), mood disorders 34.2% (controls 19.6%) [10]. One study from Japan has removed subject selection bias by reporting the incidence of depression in Internal Medicine OPD patients to be 7.4% [11].

The present cross-sectional study has taken many psychosocial domains into consideration. Usage of AED was one of the inclusion criteria to maintain the uniformity among study group and remove the bias of effects drugs on psychological functioning. Nearly two third (70%) of patients had embarrassment of having epilepsy and had difficulty in maintaining inter personal relations which was not reported in literature. This is a major social issue which forces epilepsy patients

to social isolation, which in turn will have a cascading effect on social behaviour of the person. One third (30%) had resentment of having the disease. Quite a significant number (27%) had difficulty in establishing new contacts, maintain them, tried to avoid social gathering and often find difficult to confide in others, to share their problems. Irritability and getting upset with petty things was seen in 19% of patients. Only 12% patients found difficulty in getting and maintaining jobs in view of absenting due to seizures. They often had phobia of impending seizure at work place. Most of the patients (87%) were compliant in taking medicines and understand the need for prolonged period might be because majority received basic education. Almost all had confidence in the treating physician. We have not come across suicidal tendencies in any of our patients.

Almost all of the patients felt they are in a secure and loved family environment. Financial burden was not felt in 80% of patients interviewed, may be because they were young (22 years) without much responsibilities. These factors may be attributed to closely knit joint family structure in India.

When compared internal medicine OPD and population at large, the occurrence of psychosocial problems are more in patients suffering from epilepsy, which need special attention for holistic management of epilepsy.

Conclusions

The Psychosocial functioning in epilepsy is adversely affected more than what is reported in literature, in a complex manner involving physical, psychological, social, occupational, financial aspects of life. The present observation acts as pilot study reflecting only the tip of the iceberg.

Strength of the study

 Several domains of psychosocial functioning are evaluated.

Limitations of the study

- Number of subjects evaluated is small.
- Long-term follow up would have been better.

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