Original Research Article

A Studyof Knowledge Attitude and Self Perception on Epilepsy in the Persons suffering from Epilepsy and their Care Givers

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Abstract

Background: A study of Knowledge Attitude and Self Perception on Epilepsy in persons suffering fromEpilepsy and their Care Givers. **Methodology:** This study was conducted in the Department of Psychiatry, Government General Hospital, Guntur,Andhra Pradesh which has both outpatient clinics and inpatient admissions for the Epileptic patients and equipped with EEG and Brain Imaging facilities. This is a Cross Sectional, Purposive Sampling,Quantitative Study. **Results:**We have found significant differences between PWE (Patients with Epilepsy) and controls, particularly with respect to the understanding of and attitudes toward Epilepsy.Patients and Care Givers showed similar attitudes and behaviors, perhaps because they had common information and experience regarding the disorder.May be true for the average comparisons between Patients with Epilepsy and controls, we must take into account during clinical practice that these problems occur predominantly in the minority of patients with refractory epilepsy.The level of knowledge deviated significantly from the scientific data, especially in the causes of Epilepsy, safety issues, and side effects of Anti Epileptic Drugs.**Conclusion:** Disease characteristics should guide clinical decision-making in patients with Epilepsy.

Keywords: Epilepsy, Psychological Behaviour, knowledge, attitude.

Introduction

Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. Epilepsy, which is also known as Seizure Disorder, is a Chronic Neurological condition characterized by recurrent seizures. Epilepsy must always be regarded as a symptom rather than a disease and it is a sign of abnormality within the Central Nervous System (CNS) that requires further elucidation. A seizure is a finite event that occurs when there is a transient disturbance of cerebral function due to an excessive and disorderly discharge in the brain [1,2].

''Epilepsies are the conditions thought to arise from pathologic or metabolic disturbances in the brain ,which are characterized by abnormal , paroxysmal neuronal discharges , producing convulsive movements, sensory, vegetative or psychic dysfunction with or without loss of consciousness'[3].A higher prevalence is found in people with epilepsy of learning disabilities and memory problems, often caused by co-morbidities such as brain damage. Attention deficits occur during seizures, especially during absence seizures in school-children. Antiepileptic drug side-effects of drowsiness and short attention span can affect educational achievement, and are commonly exacerbated by polytherapy[4-6].

Aim: To study Knowledge, Attitude and Self Perception on Epilepsy in persons suffering fromEpilepsy and their Care Givers.

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Objectives

1. To assess Epilepsy related knowledge andattitudes in the Epileptic patients and intheir caregivers & to compare between the two groups.
2. To study the association of seizure severity with Perception of illness

Materials and Methods

Data Source

Setting: This study was conducted in the Department of Psychiatry, Government General Hospital, Guntur, A.P. which has both outpatient clinics and inpatient admissions for the Epileptic patients and equipped with EEG and Brain Imagingfacilities.

Type of the study: A Cross Sectional, Purposive Sampling , Quantitative Study.

Selection Criteria

Subjects are

1. Epileptics N= 50
2. Care Givers N= 50

Subjects for the study were recruited based on purposive sampling on the following criteria

Inclusion Criteria

- Epilepsy patients diagnosed by NeuroPhysician /General Physician / Psychiatrist.
  - Aged 18 years old and above
  - Able to either understand, read, speak or write mother tongue & Capable of answering the questions either in written form or by interview.
- Care Givers who are reliable and consistent.

Exclusion Criteria

- Mental Retardation and any other severe Cognitive Impairment.
- Substance induced / withdrawl Seizures.
- Traumatic Brain Injury (TBI) with other organic dysfunctions (prominent lobe dysfunctions)
- CVA with Aphasia and other disabilities.

- Absence Seizures.
- Medication induced seizures (eg.Psychotropics)
- Status Epilepticus
- Below 18 years age.
- Other Major Medical or Surgical disorders or procedures within 6 months.
- Care Givers with uncontrolled Chronic Medical Illnesses

Tools

- Semi Structured Intake Proforma
  a. Of Epileptics –with socio-demographic details & details about epilepsy and treatment details
  b. Of Care Givers - including the socio-demographic details &Opinion about epilepsy
- Questionnares& Assessment Scales :-
  1. Knowledge, Attitude and Practices Questionnaire (15Qs)
  2. Illness Perception Questionnare –Revised (38 Qs)
  3. Seizure severity questionnaire – Overall assessment (3 Qs)

Statistical Analysis was done with **SPSS 17.0** version.

Results and Discussion

50 patients with Epilepsy and their caregivers were taken in the study.

Group 1 consists of Patients with Epilepsy (PWE)

Group 2 consists of the caregivers (CG) of above mentioned epileptics

Table 1 : Depicts Sociodemographic data across the two groups

Variable	Epileptics N (%)	Caregivers N (%)	Test (CHI Square)	Significance
1) Gender				
Male	29 (58.0)	30 (60.0)	0.04	0.84
Female	21 (42.0)	20 (40.0)		
2) Socioeconomic Status				
Lower	24 (48.0)	24 (48.0)	0.001	1.001
Middle	21 (42.0)	21 (42.0)		
Upper	05 (10.0)	05 (10.0)		
3) Education				
Illiterate	21 (42.0)	22 (48.0)	5.91	0.12
Primary	09 (18.0)	09 (18.0)		
Secondary	13 (26.0)	05 (10.0)		
Graduate and Above	07(14.0)	14(28.0)		
4) Employment				
Unemployed	12 (24.0)	01 (02.0)	17.47	0.004**
Housewife	15 (30.0)	11 (22.0)		
Labourer	10 (20.0)	21 (42.0)		
Part Time Job	08 (16.0)	07 (14.0)		
Full Time Job	04 (08.0)	10 (20.0)		
Others	01(02.0)	0 (0)		
5) Domicile				
Rural	17 (34.0)	17 (34.0)	0.001	1.001
Semi Urban	13 (26.0)	13(26.0)		
Urban	20 (40.0)	20(40.0)		
6) Marital Status				
Unmarried	13(26.0)	06(12.0)	4.38	0.11
Married and Living Together	36 (72.0)	44 (88.0)		
Separated or Divorced	01 (02.0)	0 (0)		
7) Living Situation				
Living with Parents	15 (30.0)	06(12.0)	9.44	0.001***
Living with Spouse& Children	28(56.0)	42(84.0)		
Dependent on Children	07(14.0)	02(04.0)		
8) Religion				
Hindu	31 (62.0)	31 (62.0)	0.001	1.001
Muslim	19 (38.0)	19 (38.0)		
9)Family Type				
Nuclear	27 (54.0)	27 (54.0)	0.001	1.001
Joint	23 (46.0)	23 (46.0)		

Table 1 depicts socio demographic data across both groups.

Gender

As shown in table 1each group consists of 50 subjects which are matched in sex with each group consists of 29 male and 21 female epileptics and 30 male and 20female caregivers with no statistical significant difference across both groups with p value **0.84.**

Socio-Economic Status

As per table 1 most of the subjects belongs to low class socio-economic status were found to be similar in both groups (p value **1.001**).Thus two groups were comparable with respect to socio-economic status.

Education

As per education was concerned most of the epileptics and their caregivers were illiterates and had primary school education which

was same in both groups(p value **0.12**).Hence both groups were matched in educational level.

Employment

Among the subjects 12% of the Epileptics are unemployed when comparing with 01% of caregivers ; among rest of the epileptics 20% earning through labour work while 30% are housewives when comparing with 42% labourers and 22% housewives in caregiver group with statistical significance of **p value 0.004**, indicating significant difference in the employment status between the groups[6,7].

Religion

As shown in table-1each group consists of 50 subjects which are matched in religion with 62% of Epileptics & caregivers are HINDUs and 38% of Epileptics & caregivers are MUSLIMs with no statistical significant difference across both groups with p value 1.001.

Family Type

High proportion of patients from both groups about 54% belongs to nuclear family .There was no statistical difference between the two (p value 1.001)

Table 2: Comparision of KAP Among Two Groups

Groups	Yes N(%)	No N (%)	Chi Square value	P Value
1. Is epilepsy a mental illness?				
PWE	16(32.0)	34(68.0)	1.27	0.26
CG	11(22.0)	39(78.0)		
2. Is epilepsy a hereditary disease?				
PWE	12(24.0)	38(76.0)	0.001	1.001
CG	12(24.0)	38(76.0)		
3. Is epilepsy a contagious disease?				
PWE	11(22.0)	39(78.0)	0.250	0.62
CG	09(18.0)	41(82.0)		
4. Do you think epilepsy is caused by ancestor's sin?				
PWE	25(50.0)	25(50.0)	0.644	0.422
CG	21(42.0)	2958.0)		
5. Do you think that epilepsy is a hindrance to a happy life?				
PWE	37(74.0)	13(26.0)	0.77	0.39
CG	33(66.0)	17(34.0)		
6. Is it possible for an epilepsy patient to lead a married life?				
PWE	35(70.0)	15(30.0)	0.46	0.50
CG	38(76.0)	12(24.0)		
7. Can epilepsy patients lead a normal sexual life?				
PWE	35(70.0)	15(30.0)	0.20	0.66
CG	37(74.0)	13(26.0)		
8. Do you think that epilepsy affects the education of a person?				
PWE	35(70.0)	15(30.0)	0.71	0.40
CG	31(62.0)	19(38.0)		
9. Do you think that epilepsy patients can be employed?				
PWE	45(90.0)	05(10.0)	0.100	0.75
CG	44(88.0)	46(12.0)		
10. Do you think society discriminates against persons with epilepsy?				
PWE	38(76.0)	12(24.0)	0.050	0.82
CG	37(74.0)	13(26.0)		
11. Would you allow your child to play with a child with epilepsy?				
PWE	49(98.0)	01(02.0)	0.001	1.001
CG	49(98.0)	01(02.0)		
12. Do you think allopathic treatment is beneficial for epilepsy?				
PWE	48(96.0)	02(04.0)	0.35	0.56
CG	49(98.0)	01(02.0)		
13.Do you think ayurvedic treatment is beneficial for epilepsy ?				
PWE	48(96.0)	02(04.0)	0.35	0.56
CG	49(98.0)	01(02.0)		

Table-3: Illustrates the Knowledge, Attitude and Practices regarding epilepsy among the 100 subjects (epileptics N=50 and caregivers N=50) .As per the table KAP regarding Epilepsy in the both groups is almost similar as further explanation follows:*Though 100 % subjects known about disease as "EPILEPSY" – 32 % of the epileptics considered it as a type of Mental Illness while 22% of caregivers go with the same opinion with no statistical significance (p value 0.26)

*Regarding the cause and spread of Epilepsy -24% of both the groups considered it as Hereditary disease (all those are with positive family history of Epilepsy) with p value 1.001; while 11% of Epileptics and 09% of caregivers assuming of Epilepsy is Contagious disease with p value 0.62 and 25 % of epileptics and 21 % of caregivers still believing Epilepsy is their fate due to ancestor's sin with p value 0.422 without statistical difference between the two groups[8].

*74% of Epileptics and 66% of caregivers considered Epilepsy is a hindrance to happy life without statistical significance (p value 0.39)

*Regarding Marriage & Sexual Life, 70% of the Epileptics and around 74% of caregivers responded positively without statistical significance with the opinion of that Epileptics can lead happy married life (p value 0.50) with normal sexual activities (p value 0.66) in spite of epilepsy.

*Among all 70% of Epileptics and 62% of caregivers thought that Epilepsy effects the Education of the sufferer without statistical significance (p value 0.40)
*Almost 90% subjects in both the groups accepted without statistical significance (p value 0.75) that Epileptics can be EMPLOYED.
*With no statistically significance (p value 0.82) 76% of the epileptics and 74% of the caregivers assuming that still society Discriminating the Epileptics .
*Almost all subjects(98%) with no statistical significance (p value 1.001) has no fear in allowing their children to play with the Epileptics.
*Regarding the treatment efficacy about 96% to 98% of subjects in the both group without any statistical significance (p value 0.56) thought that both Allopathic and Ayurvedic treatments are beneficial in controlling Epilepsy though almost all of the Epileptics currently on Allopathic Treatment only.
People's illness perceptions bear a direct relationship to several important health outcomes, including their level of functioning and ability, utilization of health care, adherence to treatment plans laid out by health care professionals, and even overall mortality.In fact, how a person views his illness may play a bigger role in determining his health outcomes than the actual severity of his disease [8-12].

Table 3(A): Correlations:Epilepsy Severity and Perception

SpearmansRHO		IP Time Line	IP Consequences	IP Personal Control	IP Treatment Control	IP Illness Coherence	IP TimeLine Cyclical	IP Emotional Representation
Severity	Correlation Sig. (2-tailed)	0.234 0.101	0.348 0.013*	-0.233 0.103	-0.214 0.136	0.019 0.896	0.210 0.143	0.415* 0.003
Bothersome	Correlation Sig.(2-tailed)	0.242 0.091	0.420* 0.002	-0.275 0.050*	-0.228 0.111	-0.102 0.480	0.301 0.034*	0.480* 0.001
Epilepsy Duration(Years)	Correlation Sig. (2-tailed)	0.483 0.001**	0.304 0.032	-0.409* 0.003	-0.449* 0.001**	-0.184 0.201	-0.008 0.958	0.003 0.986
Seizure Frequency (per Month)	Correlation Sig. (2-tailed)	0.103 0.478	0.244 0.088	-0.044 0.764	-0.056 0.701	0.034 0.816	0.214 0.137	0.362* 0.010**
Treatment Duration (Months)	Correlation Sig. (2-tailed)	0.254 0.075	0.239 0.095	-0.201 0.161	-0.192 0.181	-0.007 0.959	0.253 0.076	0.212 0.139
No. of AED s	Correlation Sig. (2-tailed)	0.478* 0.001	0.297* 0.036	-0.401* 0.004	-0.434* 0.002	-0.171 0.235	-0.008 0.956	-0.003 0.985

Table 4 (A)– illustrates linear relationship between Epilepsy details and perception of illness.
*Seizure Severity has strong POSITIVE linear relationship with IP Consequences (r=0.348)with p value 0.05 and IP Emotional Representation (r=0.613) with p value 0.003. There was no linear relationship between Seizure SEVERITY scores and other IP subcomponents.

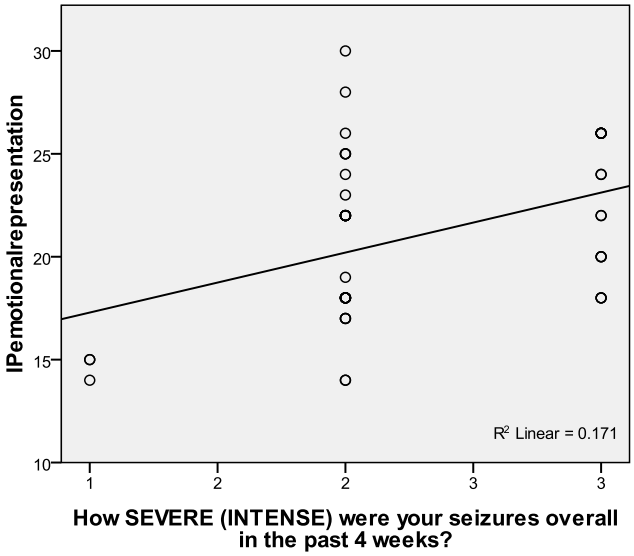

Figure 1: Scatter plot

Bother some due to Epilepsy has strong Positive linear relationship with IP Consequences (r=0.844) with p value 0.002, IP Emotional Representation (r=0.480) with p value 0.001, and with IP Timeline Cyclical (r= 0.301) with p value 0.034.

Bothersome due to Epilepsy has strong NEGATIVE linear relationship with IP Personal Control (r= - 0.275) with p value of 0.05.

There was no linear relationship between BOTHERSOME due to Epilepsy and other components.

* Duration of Epilepsy in years has strong POSITIVE linear relationship with IP Timeline (r=0.483) with p value of 0.001 ,with IP Consequences (r=0.304) with p value of 0.05 has Negative linear relationship with IP Personal Control (r= - 0.409)and Treatment Control(r= - 0.449) with p values of 0.003 and 0.001 respectively[7]. There was no linear relationship with other components.

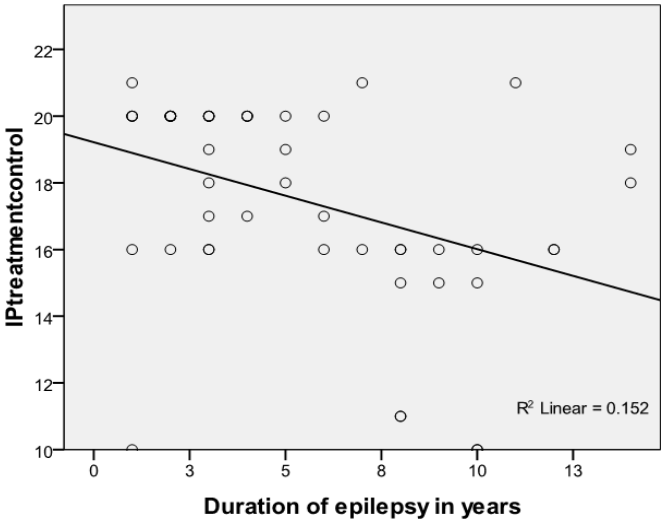

Figure 2: Scatter plot

Frequency of seizures has strong Positive linear relationship with IP Emotional Representation (r=0.362)with p value of 0.01. There was no linear relationship with other components.

* Treatment Duration in months has no linear relationship with IP components.

* Number of AEDs using has strong POSITIVE linear relationship with IP Timeline (r=0.478)with p value of 0.001 , with IP Consequences (r=0.297) with p value of 0.036 . Number of AEDs using has strong Negative linear relationship with IP Personal control (r= -0.401) and IP Treatment Control (r= -0.434) with p values of 0.001 and 0.003 respectively

There was no linear relationship with other components.

* Seizure Severity scores has strong Positive linear relationship with Bothersome (r=0.844), FREQUENCY of seizures (r=0.826), number of AEDs using (r=0.600), PSS score (r=0.621) and CBI score(r=0.613) with p value 0.001 for all . There was no linear relationship between Seizure Severity scores and duration of both illness and treatment[8].

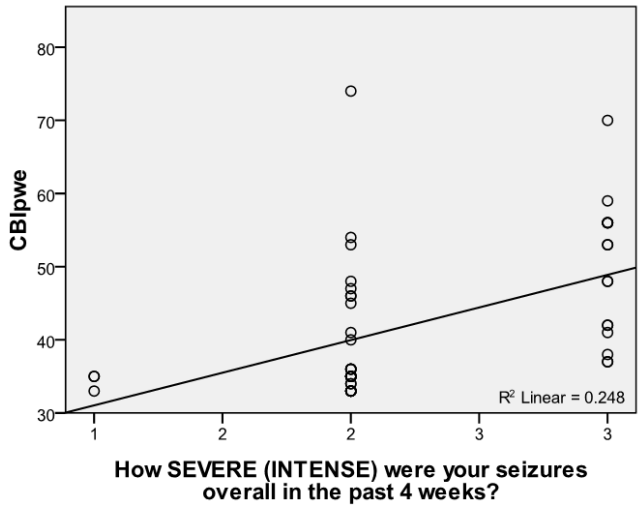

Figure 3: Scatter plot

Duration of Epilepsy in years has strong Positive linear relationship with Treatment Duration in months (r=0.994) with p value of 0.001 and has Negative linear relationship with Frequency of seizures (r = - 0.276) with p value of 0.053.There was no linear relationship with Seizure Severity, Bothersome due to Epilepsy, number of AEDs using, PSS score and CBI score.

* Frequency of seizures has strong Positive linear relationship with Seizure SEVERITY (r=0.826), BOTHERSOME due to Epilepsy (r=0.722), number of AEDs using (r=0.498), PSS score(r=0.508) and CBI score (r=0.638) with p value of 0.001 and has Negative linear relationship with Duration of Epilepsy (r = -0.276) with p value of 0.053. There was no linear relationship with Treatment Duration in months.

Treatment Duration in months has strong Positive linear relationship with Duration of Epilepsy (r = 994) and CBI score (r=0.452) with p value of 0.001. There was no linear relationship withSeizure Severity, Bothersome due to Epilepsy, FREQUENCY of seizures, number of AEDs using, PSS score and CBI score.

* Number of AEDs using has strong Positive linear relationship with Seizure SEVERITY (r=0.600), Bothersome due to Epilepsy (r=0.649), FREQUENCY of seizures (r = - 0.498), with p value of 0.001 and with PSS score (r=0.433) with p value of 0.002 . There was no linear relationship with Duration of Epilepsy, Treatment Duration and CBI score.

*PSS score has strong Positive linear relationship with Seizure Severity (r=0.621), Bothersome due to Epilepsy (r=0.635), Frequency of seizures (r = - 0.508),CBI score (r=0.743) with p value of 0.001 and withNumber of AEDs (r= 0.433) with p value of 0.002. There was no linear relationship with Duration of Epilepsy, Treatment Duration.

* CBI score has strong Positive linear relationship with Seizure Severity (r=0.613), Bothersome due to Epilepsy (r=0.574), Frequency of seizures (r = - 0.638), Number of AEDs(r= 0.433) and withPSS score (r=0.743) with p value of 0.001. There was no linear relationship with Duration of Epilepsy, Treatment Duration[9-11].

The unexpected seizures and to gain better understanding about causes of Epilepsy, people searchfor answers from within their own knowledge base which may include Western scientificunderstanding of the illness and/or their culture-specific beliefs and attitudes about Epilepsv.

Theirknowledge base may also contain information drawn from persistent culture-specific myths about causes of Epilepsy [12].

Knowledge alone is not adequate to deal with epilepsy and its consequences as patients still need to learn to cope with its misfortunes [13].

Conclusion

In general, among the Epileptic and caregivers, Knowledge and Attitude was only moderate and could still be improved especially regarding causes.Knowledge, attitude (KA) and perceptionlevels seemed to influence the Patients with Epilepsy (PWE) in dealing with their illness suggesting that, efforts in improving KA level should be combined with appropriate strategies to provide better health outcomes in Epilepsy management.

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