

STIGMA EXPERIENCED BY PRIMARY CARE GIVERS OF PERSONS WITH EPILEPSY

Kamlesh Kumar Sahu^{1*}, Renjith R. Pillai², Soma Hazra³, Dr. A. N. Verma⁴

Abstract

Stigma is society's negative evaluation of particular features or behaviour. Cultural beliefs that define certain conditions negatively may create tainted and discounted identities for affected individuals and their families. The present study was intended to assess the presence and degree of stigma experienced by primary care givers of persons with epilepsy (PCG) and to find out the causal attribution for epilepsy among the PCG.

The study was a cross sectional hospital based study. By using purposive sampling techniques 100 Caregivers of persons diagnosed with epilepsy were taken from the OPD (Epilepsy Clinic) of CIP. Family Interview Schedule to assess both stigma and causal attribution (Sartorius et al., 1996) were administered. Median split technique was used to divide respondents into two stigma groups, low and high.

It can be seen that the socio-demographic variables (of persons with epilepsy) religion emerged as statistically significant. Hindus in our sample seemed to have higher stigma than both Muslims and Christians. It was found more stigma when persons with epilepsy were younger. There were a significantly high number of care givers of high stigma group attributive influence of depression/unhappiness as a cause of epilepsy in their family member. Although not statistically significant but it was found that stigma tended to be more when care giver's age was young.

It was also found that, those care givers who had attributed no cause it just happened or don't know for epilepsy in their family member experienced more stigma which have important implication in psycho-educational programs and intervention to dispel stigma.

Key words: Stigma, Epilepsy

Introduction

Stigma is the situation of the individual who disqualified from full social acceptance Goffman (1963). In a broader term "stigma is a social process or related experience characterized by exclusion, rejection, blame or devaluation that results from an adverse social judgment about a person or group" (Mitchell & Jayashree, 1996). However one can understand stigma that refers to any attribute, trait or disorder that makes an in-

dividual as being unacceptably different from the normal people with whom he or she routinely interacts and that some from of community sanctions. Various dimensions of stigmatized medical conditions e.g. leprosy (Opala & Boillot, 1996), cancer (Fife & Wright, 2000), mental illness (Angermeyer & Matschinger, 1994, Corrigan Penn, 1999, Phelan et al, 2000) and epilepsy (Pasternak, 1992) include the nature of an illness, its history, and attributed characteristics; sources of the creation and perpetuation of stigma; the nature of the populations who are perceived to carry the illness; the kinds of treatments and practitioners sought for the condition; and how individuals with stigmatized medical conditions cope with societal insults that endanger their personal identity, social life, and economic opportunities (Ablon J., 2002). Stigma is an important consideration for health policy and clinical practice for several reasons. It contributes to the suffering from illness in various ways and it may delay appropriate help seeking or terminate treatment for treatable health problems. For diseases and disorders that are highly stigmatized, the impact of the meaning of the disease may be as great or a greater source of suffering their symptoms regard it fundamentally a problem arising from social interaction (Mitchell & Jayashree, 1996).

Epilepsy is a chronic brain disorder characterized by transient, episodic, excessive discharge of cerebral neurons may be associated with convulsive movements or disturbances in feeling, behaviour or both. In other words, epilepsy is an altered physiologic state with a rhythmical and repetitive hyper synchronous discharge which can be observed on the electroencephalogram (Pandey, 2001).

Epileptic seizures are sudden, involuntary behavioural events associated with either excessive or hyper synchronous electrical discharges in the brain. "Seizures" it self is known as the ictus and 'epilepsy' is the current tendency to seize (Mario, 2000). A seizure is a paroxysmal event due to abnormal, excessive hyper synchronous discharges from an aggregate of central nervous (CNS) neurons. The meaning of the term seizure needs to be carefully distinguished from that of epilepsy. Epilepsy describes a condition in which a person has recurrent seizures due to a chronic, underlying process. This definition implies that a person with a single seizure, or recurrent seizure due to correctable or avoidable circumstances, does not necessarily have epilepsy. Epilepsy refers to a clinical phenomenon rather than a single disease entity since there are many forms and cause of epilepsy (Denial, 2001).

Seizure disorders are common and usually have an early onset. Epilepsy affects 20 to 40 million people worldwide (Mario, 2000). In India the prevalence rate stands at around 5/1000 population, at this rate present estimate of total epileptics in this country is about 5 million and incidence rate varies from 38 to 49.3 per 100,000 population (Ray et al., 2002).

Epilepsy is a disorder with biological and functional consequences that affects on different areas of social adoption. Seizures and the postictal phase impose restrictions on the performance of different activities, because transient cognitive impairment, loss of motor control, and loss of sensory input is potential risk of accidents and injuries. The impact of epilepsy on social functioning has been explored through different studies using Quality of Life Questionnaire show poor health related quality of life in children, adolescents and adults with epilepsy. Community based longitudinal studies indicate that poor social adoption is common among patients with epilepsy. In studies based on patient's reports shows, specific difficulties in different aspect of their social life usually are encountered (Antonia, 2001). Epileptic seizures are associated with many psychosocial problems. Seizures may be the primary problems in epilepsy; they generate secondary problems in both the psychological and behaviour of the patient and family. Social attitudes towards epilepsy cause more distress to the patient and his/her near and dear ones, than the disease itself. The major psychosocial issues related to epilepsy are: Quality of medical management, overprotection, education, employment, marriage and pregnancy. Inadequate treatment is the major reason involved in psychosocial issues. Constant over protection and pampering leads to behavioural pattern which makes epileptic patient dependent for ever. Education is hampered in epileptic persons. Teachers and students should have proper information regarding seizures. If seizures are well controlled, job opportunities increase. Employers and employees need to be educated about epilepsy. Self-employment is the best in epileptic patients. Regarding marriage, each patient is to be judged on individual merits and type of epilepsy. Society needs to be educated about the facts and consequences of epilepsy. Risk of anti-epileptic drug's usage is very insignificant compared to risk of seizures in pregnancy. So girls are advised to seek medical advice before pregnancy and during follow-up. With more and more support from the society, persons with epilepsy (PWE) will have the courage and confidence to speak about themselves and their illness. It is only then that we will realise that PWE are 'normal' or 'near-normal' and this will break the vicious cycle of stigma (Shah P., 2002).

Epilepsy is a socially noticeable disorder, over the ages it is always been associated with stigma perhaps because the condition is not easy to understand. Despite improved education and increasing awareness the problem of stigmatization has not disappeared (Pasternak, 1992).

In most developing countries, epilepsy seems to be a heavy burden. In some African countries the condition is strongly associated with death. (Gerrit, 1986; Nkwi, 1988). Vernacular name for epilepsy in some countries is equivalent to that for death. This may be due to the fact that epilepsy is more related to accidental death; especially in communities where as great deal of the social life takes place around open force (Gerrit, 1986; WHO, 1979). The people with epilepsy tend to live below their potential because of overprotection by family members and society, and because less is expected from them, they may judge their potential to be less than that of people without epilepsy (Ziegler, 1981). Because of nature of the epileptic seizure, the social stigma attached to epilepsy is a major handicap to person with epilepsy, compared with the disability associated with seizures or the side effects from medication (Fong et. al., 2002).

Although great studies have been made in public understanding about epilepsy, reports continue to surface to remind as that there is a stigma attached to epilepsy (Antonia, 2001). According to some studies the negative impression that individuals in society may feel about epilepsy, may not be as important in social adaptation as felt stigma (Collings, 1995). Even if this is the cues, both types of stigma are highly interrelated; the development of self stigma is, in part, proportional to the negative experiences that people with epilepsy have encountered through their life that is in these situation where enacted stigma has been noticed (Antonia, 2001). Pilo (1993) say, epilepsy and psychiatric illness are also similar in that they cause restriction in terms of activities and employment opportunities because of the associated stigma and prejudice. Various studies are conducted on different areas related to epilepsy; very few studies are assessing how much the family members of a person with epilepsy are stigmatized. In view of the fact that high prevalence of epilepsy is in the country (5 per 1000, Ray et al, 2002), the studies related to stigma are relatively less. This kind of study is very much relevant and required for planning and executing programmes aimed to alleviate stigma in the society.

Method and Materials

The present cross sectional hospital based study was intended to assess the presence and degree of stigma experienced by primary care givers of persons with epilepsy (PCG), to find out the causal attribution for epilepsy among the PCG and to examine the associations between attribution and socio-demographic and clinical variables with stigma experienced by PCG. 100 subjects were drawn purposively among the primary care givers (by definition the person living with the persons with epilepsy in same house hold for at least one year and spend maximum time and effort in caring for him) of PWE attending the OPD (Epilepsy Clinic) of Central Institute of Psychiatry, Kanke, Ranchi, India.

Primary Caregivers (of persons with epilepsy with either sex, below 65 years of age diagnosed according to ILAE 1981, without any co-morbid psychiatric disorders, not presented with pseudo seizures and without any chronic physical illness) with either sex between 18-65 years who had given consent were included in the study. Primary care givers with chronic physical illness, substance dependence, having any other family member with a psychiatric or chronic physical illness and scoring more than 1 on General Health Questionnaire - 5 (GHQ-5) (Shamsundar et. al., 1986) were excluded. Relevant demographic and clinical data was then obtained. Family Interview Schedule (FIS) to assess both stigma and causal attribution were then administered with primary care givers. Family interview schedule used in the International Study of Schizophrenia (ISOS, WHO, Sartorius et al., 1996) also adopted for study How Stigmatizing Schizophrenia in India by Thara and Srinivasan, (2000). In the current study for the assessment of stigma, the Stigma Section of FIS was used. The stigma assessment section comprised of 14 questions on various items like – difficulties with neighbours, marriage, and fear of the fact of mental illness being revealed to others, feeling of shame, embarrassment, guilt & depression. The degree of stigma on each of the items is scored on a four point scale (0 - 3) ranging from 'not at all' to 'is a lot'. The total stigma score was compiled by adding the score on the 14 items of the questionnaire care givers experience of 'high' stigma was differentiated from those having 'low' stigma. For the assessment of attribution items of Attribution Section were taken from the above mention FIS. This 24 attribute items, was scored on 5 point scale (1-5), ranging from 'very unlikely' to 'very likely' was used to assess the attribution/causes for the illness. Since the other stigma scale could not be traced to assess stigma and causal attribution specifically for epilepsy this

tool (which had been modified and standardized especially for the study of PWE and used in an unpublished dissertation, submitted to Ranchi University, Ranchi conducted at CIP, Kanke, Ranchi (2003); entitled, "A Study of Psycho-Social Factors in Married People with Epilepsy" by Suman DC) has been taken.

Result and Discussion

Studies (Janzik, 1988; Scambler, 1980 & Ratsepp, 2000) were mainly conducted with the aim of assessing how the PWE felt or perceived stigma and how caregivers felt or perceived stigma due to their relative's epilepsy. The strength of the present study is in assessing stigma experienced rather than felt or perceived by patients who are presumably the recipients with epilepsy and their caregiver are relatively more stigmatized.

High and Low Stigma Group

Median split technique was used to divide respondents into two stigma groups, low and high. In the socio-demographic variables (Table 1) of PWE, religion emerged as statistically significant. Hindus in our sample seemed to have higher stigma than both Muslims and Christians. Stigma was found to be more when PWE were younger. None of the socio-demographic variables were significant for primary care givers.

There were a significantly high number of care givers of high stigma group attributing the influence of depression/unhappiness as a cause of epilepsy in their family member.

It was also found that, those care givers who had attributed no cause, it just happened or don't know for epilepsy in their family member experienced higher stigma.

Correlation between Stigma and Attribution (Table 2)

A significant positive correlation at the 0.01 level found between attribution item 'Brain injury' and stigma item 'helped other people to understand' ($r = .284$) and 'felt it might be your fault' ($r = .304$). It indicates that those who attributed epilepsy more logically experienced low stigma. A significant positive correlation ($r = .207$) at the 0.05 level found between 'substance abuse' and 'felt it might be your fault'. It explained the awareness about harmful effects of the substance. PCG believe that substance taking may be one cause of epilepsy. A significant negative correlation at the 0.05 level found between attribution items

'faulty biological function' ($r = -.227$) and 'Faulty nutrition habit' ($r = -.236$) and stigma item 'sought out families with a person, with
National Journal of Professional Social Work Vol.-10 No: 1-2, Jan. - Dec.2009 22

epilepsy not crazy'. It indicates that PCG believe that crazy people (mentally ill) have disturbed biological function and faulty nutrition habit. A significant positive correlation was found between stigma item 'possessed by sprits' and attribution items 'Effort to keep as secret' ($r = .145$ at the 0.05 level) and 'worried about taking him/her out' ($r = .262$ at the 0.01 level). It indicates that those who attributed more magico – religious cause for epilepsy experienced high stigma. A significant negative correlation ($r = -.238$) at the 0.05 level found between 'Effect of the moon' and 'worry that neighbours would avoid'. It again indicates that those who attributed more magico – religious cause for epilepsy experienced high stigma. A significant negative correlation at the 0.05 level found between stigma item 'character or life style' ($r = -.203$) and 'insecurity' ($r = -.227$) and attribution by care givers 'worry that neighbours would avoid'. It indicates that those who attributed character or life style as a cause for epilepsy or those who had feeling that insecurity is a cause for epilepsy experienced high stigma. A significant negative correlation at the 0.05 level found between 'difficulties in intimate relationship' and 'marriage' ($r = -.227$) and 'spend time worrying' ($r = -.207$. and also a significant negative correlation ($r = -.298$) at the 0.01 level found between 'jealousy' and 'marriage'. This is no unexpected finding especially in our cultural setting, wherein, the question of marriage assumes over powering importance even when the girl becomes an adolescent. Over 90% of the marriages being still arranged by the families, the fact of epilepsy poses to be a heavy burden on the entire family. This is also reflected in the finding that worry about marriage was reported by (56%) of the family members (Thara and Sreenivasan, 2000). A significant negative correlation at the 0.05 level found between 'jealousy' and 'neighbours would treat differently' ($r = -.221$) and 'effort to keep as secret' ($r = -.135$). It indicates that those who attributed jealousy as a cause for epilepsy experienced high stigma. A significant negative correlation ($r = -.209$) found between 'specific precipitating events' and 'helped other people to understand', 'worried about taking him/her out' ($r = -.233$) and total score on stigma item ($r = -.215$). A significant correlation ($r = .212$) at the 0.05 level between 'homelessness' and 'need to hide fact'. A significant negative correlation ($r = -.198$) at 0.05 level was found between 'No cause it just happened and total score on stigma item. It indicates that those who attributed 'no cause, it just happened' in their family member experienced more stigma. It was also supported in group

comparison between low and high stigma group on attribution items. Absence of knowledge about cause could shield the family from

feeling guilty of being involved in the causation of the illness or failing to take preventing measures.

Conclusion & Implication

Conclusions drawn from this study are that the caregivers of persons with epilepsy experienced a great degree of stigma, which may have detrimental effects in the recovery and reintegration of PWE in the community. Caregivers are additionally overburdened, by such stigmatizing experiences. Differences in causal attribution between both groups, that is the low and high stigma groups indicates that causative factors about epilepsy differ between both groups, which have important implication in psycho-educational programs of intervention to dispel stigma.

Table 1 Socio-demographic & Clinical Variables between Low & High Stigma Groups

Variables	Low Stigma Group Mean \pm SD/n (%)	High Stigma Group Mean \pm SD/n (%)	χ^2/ t	df	p
Age (in years)	22.02 \pm 10.33	17.67 \pm 10.65	2.07	98	.041*
Sex : Male Female	33 (64.7%) 18 (35.3%)	27 (55.1%) 22 (44.9%)	.960	1	.327
Education (in yrs.)	7.201 \pm 4.42	5.57 \pm 4.75	1.771	98	.080
Religion: Hindu Muslim Christian Others	25 (49.0%) 15 (29.4%) 03 (05.9%) 08 (15.7%)	39 (79.6%) 06 (12.2%) 01 (02.0%) 03 (06.1%)	10.156	3	.017*
Category: General OB SC ST	14 (27.5%) 25 (49.0%) None 12 (23.5%)	17(34.7%) 18 (36.7%) 03 (06.1%) 11 (22.4%)	4.435	3	.218
Marital Status: Unmarried Married	38 (74.5%) 13 (25.5%)	41(83.7%) 08 (16.3%)	1.265	1	.261
Residence Area: Rural Urban Semi-urban	27 (52.9%) 21 (41.2%) 03 (05.9%)	25 (51.0%) 22 (44.9%) 02 (04.1%)	.260	2	.878
Occupation: Student Farmer Business Home maker Service Unemployed/Other	21 (41.2%) 06 (11.8%) 01 (02.0%) 07 (13.7%) 01 (02.0%) 15 (29.4%)	18 (36.7%) 06 (12.2%) 02 (04.1%) 06 (12.2%) None 17 (34.7%)	1.727	5	.889

Family Income (Monthly in Rs.): 0 - 2000 2001-5000 > 5000	13 (25.5%) 18 (35.3%) 20 (39.2%)	15 (30.6%) 17 (34.7%) 17 (34.7%)	0.375	2	.829
Type of Family: Nuclear Joint	35 (68.6%) 16 (31.4%)	32 (65.3%) 17 (34.7%)	0.125	1	724
Type of seizure: Partial Primary Generalized Secondary Generalized	15 (29.4%) 16 (31.4%) 20 (39.2%)	17 (34.7%) 15 (30.6%) 17 (34.7%)	.361	2	.835
Age of onset of seizure (in years)	14.31 ± 8.55	10.57 ± 8.12	2.243	98	.027*
No. of Seizure (in last six months)	90.90 ± 85.69	82.33 ± 74.99	0.514	98	.609
Duration of Seizure (in months)	46.84 ± 62.06	41.96 ± 53.26	0.532	98	.596
Duration of treatment (in months)	46.84 ± 62.06	41.96 ± 53.26	0.422	98	.675

* p < .05 level (2-tailed).

Table 2 Correlation between Stigma and Attribution Items

Stigma Attribution	S 1	S 2	S 3	S 4	S 5	S 6	S 7	S 8	S 9	S 10	S 11	S 12	S 13	S 14	S 15
A1	.045	-.004	.016	.284**	.089	-.019	.091	.031	-.080	.028	.042	.172	-.007	.304**	.115
A2	-.041	.020	.016	.109	-.083	-.035	.071	.037	-.120	-.077	-.005	-.050	-.007	.120	-.029
A3	-.002	-.128	-.082	.026	-.127	-.110	.136	.119	.020	-.122	-.149	.021	.099	.115	-.023
A4	.106	.076	.090	.041	-.064	.156	.034	.046	.049	-.108	.052	-.110	.068	.124	.107
A5	-.063	.032	-.016	.161	-.136	-.004	.044	-.053	-.020	-.153	.033	-.026	.108	.054	.010
A6	-.001	.013	.041	-.065	-.157	-.065	.054	-.034	-.158	-.169	.021	-.163	-.007	.207*	-.067
A7	-.069	-.046	-.098	.056	-.152	.014	.054	.000	-.098	-.163	.014	-.055	-.033	-.075	-.083
A8	.185	-.077	-.045	-.060	-.067	.169	-.137	.066	-.045	-.072	-.048	-.108	.114	.058	.027
A9	-.034	-.158	-.164	.045	-.061	-.039	-.005	.075	.025	-.035	.133	-.051	.022	.008	-.012
A10	.145	.073	.161	-.094	.041	.025	-.074	.164	-.005	-.079	.124	-.061	-.134	.121	.065
A11	.080	-.016	.012	-.059	-.167	.068	.170	-.096	-.110	-.156	-.160	-.142	-.095	.018	-.085
A12	.067	-.012	.063	-.018	-.051	.109	.107	.023	-.081	-.110	-.036	-.227*	-.034	.119	.003
A13	.129	-.050	-.015	-.022	-.122	.018	.094	.066	-.112	-.169	-.002	-.236*	.039	.117	-.023
A14	.014	.093	.111	-.017	.108	.176	-.175	.145*	.262**	-.120	.015	-.077	.106	.071	.156
A15	-.044	.004	.031	.089	.001	.041	-.061	.117	.127	-.238*	.004	-.049	.012	.003	.026
A16	.058	-.088	-.062	.005	.023	.008	.012	-.067	.015	-.203*	.041	-.029	.107	.043	-.004
A17	.170	-.168	-.113	.072	-.102	.066	.083	-.034	-.070	-.227*	-.052	-.049	.051	-.025	-.054
A18	-.009	-.227*	-.170	-.134	-.207*	-.085	-.085	.079	-.101	-.194	-.083	.080	.093	.060	-.135
A19	-.063	-.298**	-.221*	-.021	-.133	-.128	.055	-.135*	-.098	-.047	.003	.030	.000	.094	-.161
A20	.034	-.109	-.004	.030	-.103	-.099	.212*	-.033	.078	-.032	.019	.145	-.120	.014	-.023
A21	.086	.024	.078	.065	.060	-.008	.009	-.064	.079	.065	.128	.092	.000	.086	.087
A22	-.167	.043	.033	-.018	-.187	-.153	-.131	-.073	.075	-.179	-.093	.063	.045	-.119	-.110
A23	-.095	-.088	-.078	-.209*	-.142	-.132	-.173	-.123	-.233*	-.073	-.005	-.001	.000	-.179	-.215*
A24	-.135	-.062	-.072	-.085	-.100	-.082	-.138	-.073	-.179	-.146	-.078	.111	-.123	-.175	-.198*

* Correlation is significant at the 0.05 level. ** Correlation is significant at the 0.01 level.

Attribution Items

A1=Brain injury, **A2**=Inherited from parents, **A3**=Stress (unspecified) **A 4**=Stress home, **A 5**=Stress at work, **A 6**=Substance abuse, **A7**=Bereavement, **A8**=Influence of Depression/Unhappiness, **A9**=Influence of Social Environment, **A10**=Financial worries, **A11**=Childhood experience, **A12**=Faulty biological function **A 13**=Faulty nutrition habit, **A14**=Possessed by sprits, **A15**=Effect of the moon, **A16**=Character or life style, **A17**=Insecurity, **A18**=Difficulties in intimate relationship, **A19**=Jealousy, **A20**=Homelessness, **A 21**=Age, **A22**=Don't know, **A 23**=Specific precipitating events, **A24**=No cause it just happened.

Stigma Items

S1=Felt grief or depression, **S2**=Marriage, **S3**=Neighbors would treat differently, **S4**=Helped other people to understand, **S5**=Spend time worrying, **S6**=Ashamed / Embarrassed about it, **S7**=Need to hide fact, **S8**=Effort to keep as secret, **S9**=Worried about taking him/her out, **S10**=Worry that neighbors would avoid, **S11**=Explaining to others that he/she is, **S12**=Sought out families with a person, with epilepsy not crazy, **S13**=Worry that you would be blamed, **S14**=Felt it might be your fault, **S15**=Total score on stigma item.

References

1. Ablon J. The nature of stigma and medical conditions. *Epilepsy Behav* 2002; 3 (6s2): 2-9.
2. Angermeyer MC, Matschinger H. Lay beliefs about schizophrenic disorder: the result of a population study in Germany. *Acta Psychiatria Scand* 1994; 89: 39-45.
3. Antonak FF, Rankin PR. Measurement and analysis of knowledge and attitude towards epilepsy and persons with epilepsy (1982). As cited in Levin R, Banks S, Berg B. Psychosocial dimensions of epilepsy: A review of literature. *Epilepsia* 1988; 29 (6): 805-816.
4. Antonia GN, Dilar GD. The Social Impact of Epilepsy: Keeping out Patients 'In the Closet'. In: Alan BE, Anderes MK (eds.). *Psychiatric issues in Epilepsy: A practical guide for diagnosis and treatment*. Philadelphia Lippincott Willans and Wilkens 2001: 289-296.
5. Baker GA, Brooks J, Buck D, Jacoby A," The stigma of epilepsy: A European prospective." *Epilepsia* 1999; 41 (1): 98-104.

6. Baker GA. People with epilepsy: what do they know and understand, and how does this contribute to their perceived level of stigma? *Epilepsy Behav.* 2002; 3(6S2):26-32.
7. Canveness WF, Gallup GH. A survey of public attitudes to ward epilepsy in 1979 with an indication of trends over the past thirty years. *Epilepsia* 1980; 21:509-518.
8. Collings JA. Correlates of well being in a New Zealand epilepsy sample. *N Z Hed J* 1990; 103 (892): 302-303.
9. Collings JA. Life fulfilment in an epilepsy sample from the United States: Samples from United States. *Soc Sci Med* 1995; 40: 1579-1584.
10. Corrigan PW, Penn DL. Lessons from social Psychology on discrediting psychiatric stigma. *Am Psycho* 1999; 54: 765-776. As cited by Link BG, Phelan JC. Conceptualizing stigma. *Annu rev Social* 2001; 27: 363-385.
11. Danesi MA Patient's prospective on epilepsy in a developing country. *Epilepsia* 1994; 25 (2): 184-190.
12. Daniel HL. Diseases of the Central Nervous System. In Braundawald D, Hanser S, Longo DL, Jameson JL (eds.). Harisons' 15th edition: Principles of International Medicene. New York: Mc Growhill Medical Publishing Devison 2001; 2354-2416.
13. Dispelling Myths about Epilepsy (2003). [online]. Available: URL <http://www.baptistonline.org> [Accessed on 28/01/05].
14. Edwards, 1974. As cited in Suman DC. A study of psycho-social factors in married people with epilepsy. An unpublished dissertation, CIP, Kanke, Ranchi, 2000; 5.
15. Epilepsy Foundation (2004). Myths & Statistics Epilepsy in African Americans: Facts and Figures [online]. Available: URL <http://www.epilepsyfoundation.org/answerplace/info.cfm> [Accessed on 28/01/05].
16. Fife BL, Wright ER. The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav* 2000; 41: 50-67. As cited in Link BG, Phelan JC. Conceptualizing stigma. *Annu rev Social* 2001; 27: 363-385.
17. Fisher RS, Vickrey BG, Gibson p, Hermsnn B, Penovich P, Scherer A, Walker S. the impact of epilepsy from the patients' perspective:

- A descriptions and subjective perceptions. *Epilepsy Res* 2000; 41 (1): 39-51.
18. Fong CY, Hung A. A Public awareness attitudes and understanding of epilepsy 2002; 43 (3): 311-316.
 19. Gerrit C. Epilepsy Care in a Non-clinical Setting; A medical anthropological study among Bassa and Kpelle in rain forest of West Africa. Presented at the international seminar on medico-social problems of epilepsy. Indian Epilepsy Association, Bangalore Chapter. October 1986.
 20. Goffman E. *Stigma: Notes on the Management of spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall 1963.
 21. Gupta ML, Shama DD. *Sociology*, (5th ed.) Sahitaya Bhawan Agra, India, 1995. 361.
 22. Hasan A., Akhtar SW, Hasan KZ. Epilepsy in Pakistan: stigma and psychosocial problems. A population-based epidemiologic study *Epilepsia*. 1997; 38 (10):1069-73.
 23. Herodes M, Oun A, Haldre S, Kaasik AE. Epilepsy in Estonia: a quality-of-life study. *Epilepsia*. 2001 Aug; 42(8):1061-73.
 24. Hill MD, Baker PG. relationship among the epilepsy, social stigma, and social support. *J Epilepsy* 1992; 5 (4):231-238.
 25. ILAE. As cited in Commission of the International League against Epilepsy. Proposal for revised clinical and electroencephalographic classification of epileptic seizures. *Epilepsia* 1981; 22:489-501.
 26. Information Library Common Myths Associated with Epilepsy [online]. Available: URL www.epilepsyontario.org [Accessed on 28/01/05].
 27. Jacoby A, Barker GA, Steen N, Potts P, Chadwick DW. The clinical course of epilepsy and its psychosocial correlates: findings from a U.K. Community study. *Epilepsia* 1996; 3 (2): 231-238.
 28. Jacoby A. Felt versus enacted stigma: a concept revisited: Evidence from a study of people with epilepsy in remission. *Social Sci Med* 1994; 38 (2): 268-274.
 29. Jacoby A. Stigma, epilepsy, and quality of life. *Epilepsy Behav.* 2002 Dec; 3(6S2):10-20.
 30. Janzik HH, Schnitz I, Geiger G, Mayer K. correlation between, self esteem and social and professional factors. In Meinardi H, Reason

- AJ (eds). *Advances in Epileptology*. As cited in Levin R, Banks S, Berg B. *Psychosocial dimensions of epilepsy: a review of the literature*. *Epilepsia* 1988; 29 (6): 805-816.
31. Jones E, Farina A, Hastorf AH, Markus H, Miller DT, Scott RA et al. *Social Stigma: The Psychology of Marked Relationships*. New York: WH Freeman and company, 1984.
 32. Latest African American Newswire Releases (2005). 2.5 Million Americans With Epilepsy Are About To Be Heard [online]. Available: URL http://www.epilepsy.com/newsfeed/pr_1098970205.html [Accessed 28/01/05].
 33. Link BG, Phelan JC. Conceptualizing stigma. *Annu rev Social* 2001; 27: 363-385.
 34. Mario R, Mendez. Neuopsuchiatric Asoects of Epilepsy. In: Kaplan RS, Sadock VA, (eds). *Comprehensive Textbook of Psychiatry*. Philadelphia: Lippincott William and Wilkins 2000: 375-385.
 35. McQueen AH, Swartz L. Reports of the experience of epilepsy in rural South African Village. *Soc Sci Med* 1995; 40 (6): 859-865.
 36. Mitchell GW, Jayashree R, intervention research in stigma. 1996. As cited in Suman DC. *A study of psycho-social factors in married people with epilepsy*. An unpublished dissertation, CIP, Kanke, Ranchi, 2000; 5.
 37. Morrell MJ. Stigma and epilepsy. *Epilrpsia Behaviour* 2002; 3 (6s2): 21-25.
 38. Myths & Misconceptions. [online]. Available: URL www.whosea.org/LinkFiles/Information_and_Documents_myths.pdf [Accessed 25/01/05].
 39. Nkwil NP. The Epileptic among the Bamilele of Mahan in the Nde Division West Proision of Cameron, conference on Ethno medical Systems in Sub Saharan Africa. Leiden: Institite of Cultural and Social Studies 1988.
 40. Opala J, Boillot F. leprosy among the limba: illness and healing in the contex of world view. *Soc Sci Med* 1996; 42: 3-19. As cited in Link BG, Phelan JC. *Conceptualizing stigma*. *Annu rev Social* 2001; 27: 363-385.

41. Our Health. [online]. Available: URL <http://www.napsnet.com/aframer/43963.html> [Accessed on 28/01/05].
42. Pandey S. behavioural Management in Epilepsy. An unpublished dissertation, CIP, Kanke, Ranchi 2001
43. Pasternak 1992. As cited in Suman DC. A study of psycho-social factors in married people with epilepsy. An unpublished dissertation, CIP, Kanke, Ranchi (R.Univ). 2000; 5.
44. Phelan JC, Link BG, Stueve A. Pescosolido B. Public conceptions of mental illness in 1950 and 1960: What is mental illness and it to be feared. *J Health Soc Behav* 2000; 41: 188-207. As cited in Link BG, Phelan JC. Conceptualizing stigma. *Annu rev Social* 2001; 27: 363-385.
45. Pilo L. The psychiatric complications of epilepsy. *Singa Med J* 1993; 34 (4): 349-350.
46. Placencia M, Farmer PJ, Jumbo L, Sander JW, Shorvon SD. *Neuroepidemiology*. 1995; 14(3):147-54.
47. Ratsepp M, Oun A, Haldre S, Kaasik AE. Felt stigma and impact of epilepsy on employment status among Estonian people: exploratory study. *Seizure* 2000; 60 (9): 394-401.
48. Ray BK, Bhattacharya S, Kundu TN, Saha SP, Das SK. Epidemiology of epilepsy-India perspective. *J Ind Med Assoc* 2002; 100 (5): 322-326.
49. Ryan R, Kempner K, Emlen AC. The stigma of epilepsy as a self-concept. *Epilepsia* 1980; 21 (4):433-444.
50. Sartorius N, Gulbinar G, Harrison GL. Long term follow up Schizophrenia in 16 countries. *Social Psychiatry Epidemiol* 1996; 31:249-258.
51. Scrambler G, Hopkins A. Social class, epileptic activity and disadvantage at work. *J Epidemiol Community Health*. 1980; 16: 34: 129-133.
52. Shah P. Psychosocial aspects of epilepsy. *J Indian Med Assoc*. 2002; 100 (5): 295-800.
53. Shamsundar C, Sriram TG, Muralirey SG, Shamughaml. Validity of a short versin of GHQ. *Ind. J Psychiatry*, 1986; 28 (3): 217-219.
54. Stavem K, Loge JH, Kaasa S. Health status of people with epilepsy

- compared with a general reference population. *Epilepsia* 2000; 58 (2A): 214-220.
55. Suman DC. A study of psycho-social factors in married people with epilepsy. An unpublished dissertation, CIP, Kanke, Ranchi (R.Univ). 2000; 50.
 56. Suurmeijer TP, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning and quality of life in epilepsy. *Epilepsia* 2001; 42 (9):1160-1168.
 57. Thara R, Srinivasan TR. How stigmatizing in schizophrenia in India. *Indian J. soc Psychiatry* 2000; 46 (2): 135-141.
 58. Westbrook LE, Bauman IJ, Shinnar S. Applying stigma theory to epilepsy: a test of a conceptual model. *J Pediatr Psychol* 1992; 17 (5): 633-649.
 59. Westbrook LF, Silver Ej, Coupey SM, Sinnar S. Social Characteristics of adolescents with idiopathic epilepsy: A comparison to chronically ill and non chronically ill peers. *J Epilepsy* 1991; 4 (2): 87-94.
 60. WHO Study Group. Epilepsy in Developing Countries. *WHO Chronicle* 1979; 33: 183-186.
 61. Ziegler FG. Epilepsy: Individual Illness, human predicament and family dilemma. *Fam. Rel* 1982; 31; 435-444. Cited by Levin R, Banks S, Berg B. Psychosocial dimensions of Epilepsy: a review of literature. *Epilepsia* 1988; 29 (6): 805-816.
 62. Ziegler RG. Impairment of Control a Competence in Epileptic Children and their Families. *Epilepsia* 1981; 22: 339-346.

.....

1. Mr. Kamlesh. Kumar Sahu, Programme Coordinator, PARIPURNATA 1912, Panchasayar Road P.O Panchasayar, Kolkata – 700094 (India)
2. Mr. Renjith R. Pillai, Ph.D. Scholar and Junior Consultant, Department of Psychiatric Social Work, NIMHANS, Bangalore.
3. Ms. Soma Hazra, Lecturer, Department of Psychology, Bangabasi College, 19, Rajkumar Chakraborty Sarani, Kolkata - 700009
4. Dr. A. N. Verma, Associate Professor, Department of Psychiatric Social Work, RINPAS, Kanke, Ranchi – 834006

* Correspondence: withkamlesh@gmail.com