Stigma Experienced By Primary Care Givers of Persons with Epilepsy and Mental Illness : A Comparative Study

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ABSTRACT

Stigma is society's negative evaluation of particular features or behaviour. Various medical conditions are stigmatized. The goals of the study were to assess and compare the stigma experienced by Primary Care Givers (PCG) of persons with epilepsy and mental illness and to find out the relationship between stigma and attribution. The study was a cross sectional hospital based study used purposive sampling techniques and sampled 100 caregivers of each group; persons with mental illness and persons with epilepsy from the outpatient department (OPD) of Central Institute of Psychiatry (CIP), Ranchi, India. Family Interview Schedule to assess stigma and causal attribution was used. Result reveals that the primary caregivers of persons with mental illness experienced a greater degree of stigma than the primary caregivers of epilepsy. Difference in causal attribution of these two illnesses by the PCG may have important implication in psycho-educational programs of intervention to dispel stigma.

Key words : Stigma, epilepsy, mental illness, attitude, discrimination

INTRODUCTION

Social stigma is the severe disapproval of or discontent with a person on the grounds of characteristics that distinguish them from other members of a society. Stigma is the situation of the individual who is disqualified from full social acceptance (Goffiman, 1963). In a broader term "stigma is a social process or related personal experience characterized by exclusion, rejection, blame or devaluation that results from an adverse social judgment about a person or group" (Weiss & Ramakrishna, 1996). Varied 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, Sahu et al., 2009) 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 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, 2002). These different stigmatized conditions are also associated with specific features of stigma, which may be locally rationalized with reference to condition-specific ideas about those conditions, their social implications, and why they are considered socially unacceptable. Exaggerated concerns about the risk of contagion may promote the stigma of some infectious diseases, such as HIV/AIDS and Tuberculosis (TB). Physical deformities (e.g., edematous limbs or scrotum with lymphatic filariasis); unacceptable scratching with onchodermatitis; exaggerated concerns about dangerousness with schizophrenia/mental illness; or moral condemnation that blames people with leprosy, epilepsy or HIV infection may all be distinctive features of condition-specific stigma. It appears to be closely associated with the experience, meaning, and behaviour associated with the disease among affected persons and unaffected persons in the community who have either no idea or very blurred ideas about it (Weiss et al. 2001).

Epilepsy is a chronic brain disorder characterized by transient, episodic, excessive discharge of cerebral neurons which 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). 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 persons with epilepsy in this country is about 5 million and incidence rate varies from 38 to 49.3 per 100,000 population (Ray et al., 2002).

Mental illnesses refer to disorders generally characterized by dysregulation of mood, thought, and/or behavior, as recognized by the Diagnostic and Statistical Manual, 4th edition (DSM-IV), of the American Psychiatric Association (2000). A mental illness can also be defined as a health condition that changes a person's thinking, feelings, or behavior

(or all three) and that causes the person distress and difficulty in functioning. The mental and behavioral disorders account for about 12% of the global burden of diseases (WHO, 2001). Depression, alcohol use disorders, schizophrenia and bipolar disorders constitute the top 10 conditions contributing to the global burden of disease among the age group of 15-44 years. Mental and behavioral disorders are present, in about 10% of the adult population, at any given point of time (Demyttenaere et al., 2004). A meta analysis of available Indian studies carried out by Reddy and Chandrasekhar (1998) revealed the overall prevalence of mental disorders as 5.8% among the population in India. A review analysis of 15 epidemiological studies by Ganguli (2000) on the prevalence of mental disorders in India estimated the national prevalence of all mental disorders as 70.5 per 1000 in the rural and 73 per 1000 in the urban population.

Stigmatization not only affects those who possess a stigmatized condition, it also impacts others. Research has shown people associated with stigmatized individuals (e.g., family, friends, caregivers) are routinely devalued purely as a result of their connection with someone with a stigmatized condition (Hebl & Mannix, 2003; Neuberg, et al, 1994). Stigma is a topic that began to interest social scientists a mere five decades ago. More recently it has become an important topic for health social sciences concerned with the burden of illness and the social determinants of disease control. Stigma may contribute to suffering, delay help seeking, and encourage non-adherence to treatment of people with stigmatized conditions. Its social impact may also disrupt families and lessen support for services, community programmes, and research. Number of studies revealed that stigma is attached with mental illness and epilepsy, studies also focus various dimensions or aspects of stigma related to these two illnesses but very few studies compare it. Comparative study may give an insight on varied dimensions of stigmatized mental illness and epilepsy.

OBJECTIVES

The present study was intended to assess and compare the presence and degree of stigma experienced by primary care givers (PCG) of persons with mental illness and epilepsy, to find out the causal attribution for mental illness and epilepsy among the PCG.

METHOD AND MATERIALS

It was a cross sectional hospital based study. It sampled equal number of two outpatient groups purposively, 100 persons with a mental illness (with psychotic symptoms, since this is considered to found only in major and severe mental illnesses) diagnosed according to International Classification of Mental and Behavioral Disorders (ICD-10) version 10 (ICD-10; WHO, 1992) and 100 persons with epilepsy according to International League Against Epilepsy (ILAE, 1981) with either sex, between 18 to 65 years of age and attending OPD of Central Institute of Psychiatry, Kanke, Ranchi, India were taken for the study. Persons with mental illness or epilepsy having any co-morbid diagnosis or presented with pseudo seizures or with any chronic physical illness were excluded. Primary care givers living with the persons with mental illness or epilepsy in same house hold for at least one year and spend maximum time and effort in caring for their ward with either sex between 18-65 years and who had given consent were interviewed. Primary care givers with chronic physical illness, substance dependence, having any other family member with a psychiatric or neurological or chronic physical illness or 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. Hindi version of Family Interview Schedule (FIS) to assess both stigma and causal attribution were then administered with primary care givers. Tool had been translated, modified and standardized in earlier works (Sahu, et al., 2009; Suman, 2003;) especially to make it relevant in epilepsy group. FIS used in the International Study of Schizophrenia by WHO (Sartarius 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. For the assessment of attribution/causes for the illness attribution items of attribution section were taken from the above mentioned FIS. This 24 attribute items, was scored on 5 point scale (1-5), ranging from 'very unlikely' to 'very likely'.

RESULT AND DISCUSSION

SOCIO-DEMOGRAPHIC AND CLINICAL PROFILE

Table 1. Socio-demographic and Clinical Profile of the Persons with Epilepsy and Mental illness

Variables	Epilepsy Mean ± SD/n N = 100	Mental illness Mean ± SD/n N = 100		df	p
Age (in years)	19.89 ± 10.66	3w4.66 ± 11.87	-9.225	198	000***
Sex Male Female	60 40	59 41	.021	1	.885

Variables	Epilepsy Mean ± SD/n N = 100	Mental illness Mean ± SD/n N = 100		df	p
Education (in yrs.)	6.40 ± 4.64	8.80 ± 4.53	-3.702	198	000***
Religion					
Hindu	64	93	34.687	1	.000***
Others	36	3			
Category					
General	31	33	.092	1	.762
Reserved	69	67			
Marital Status					
Unmarried	79	36	37.831	1	.000***
Married	21	64			
Area of Residence					
Rural	49	46	.180	1	.777
Urban	51	54			
Occupation					
Unemployed	88	80	2.318	1	.123.
Employed	12	20			
Family Income					
(Monthly in Rs.)					
0 - 2000	28	25	.400	2	.819
2001-5000	35	39			
> 5000	37	36			
Age of onset (in years)	12.48 ± 8.51	27.82 ± 11.67	-10.623	198	000***
Duration of Illness (in months)	86.70 ± 80.33	67.23 ± 69.10	1.837	198	.068#
Duration of treatment (in months)	44.45 ± 57.68	63.84 ± 66.44	-2.204	198	.029*

* $p < .05$ *** $p < .001$ level (2-tailed). # trend

CAREGIVERS' SOCIO-DEMOGRAPHIC CHARACTERISTICS

In comparison of socio-demographic and clinical variables of persons with mental illness and epilepsy (Table 1), the age, education, religion, marital status, age of onset ($p < .001$ level) and duration of treatment ($p < .05$ level) emerged as statistically significant. Persons with epilepsy are much younger (19.89 ± 10.66) than persons with mental illness (34.66 ± 11.87) and their age of onset of illness is also early

(12.48 ± 8.51 than 27.82 ± 11.67). So it is obvious that duration of illness is more in persons with epilepsy than persons with mental illness but surprisingly duration of treatment is more in persons with mental illness than persons with epilepsy which indicates that their treatment started very late. Persons with epilepsy are having less years of education which could be because of their illness which has started at early age so that they can't study. Young onset and long duration of illness could be also attributed as a reason for less number of married persons with epilepsy in comparison with persons with mental illness. Hindus in our sample seemed to have higher number of persons with epilepsy in comparison to persons with mental illness.

Table 2. Socio-demographic Characteristics of the Care Givers

Variables	Epilepsy Mean ± SD/n N = 100	Mental illness Mean ± SD/n N = 100	χ^2/t	df	p
Relationship					
Parents	57	43	5.662	2	.129
Spouse	19	22			
Others	24	35			
Age (in years)	38.99 ± 12.96	42.36 ± 13.87	-1.1775	198	.077[#]
Sex					
Male	67	69	.267	1	.605
Female	33	29			
Education (in years)	9.14 ± 4.71	8.30 ± 5.76	1.128	198	.261
Marital Status					
Unmarried	16	23	6.082	1	.048*
Married	84	77			
Occupation					
Unemployed	83	63	1.282	1	.000***
Employed	17	37			

* p < .05 *** p < .001 level (2-tailed). # trend

In group comparison of socio-demographic profile of primary care givers of the persons with epilepsy and mental illness (Table 2), marriage (p < .05 level) and occupation (p < .001 level) emerged as statistically significant. More number of care givers of persons with epilepsy were married and unemployed than

care givers of persons to mental illness. Although not statistically significant but it was found that age of care givers of persons with epilepsy tended to be younger than care givers of persons to mental illness.

COMPARISON OF STIGMA EXPERIENCED BY THE PRIMARY CARE GIVERS

Table 3. Group Comparison of Stigma

Stigma items		Mean ± SD/n (N = 100)				
		Epilepsy	Mental Illness	χ^2/t	df	p
Neighbours would treat differently	Not at all	48	15			
	Sometime	33	40	40.080	3	.000***
	Often	16	15			
	A lot	3	30			
Spend time worrying	Not at all	53	07			
	Sometime	27	50	63.552	3	.000***
	Often	17	14			
	A lot	03	29			
Need to hide fact	Not at all	55	04			
	Sometime	26	38	80.784	3	.000***
	Often	15	13			
	A lot	4	45			
Helped other people to understand	Not at all	51	37			
	Sometime	37	17	30.733	3	.000***
	Often	10	29			
	A lot	02	17			
Effort to keep as secret	Not at all	54	00			
	Sometime	13	15	1.028	3	.000***
	Often	29	28			
	A lot	04	57			
Worry that neighbors would avoid	Not at all	60	04			
	Sometime	18	21	92.565	3	.000***
	Often	18	21			
	A lot	04	54			
Explaining to others that he/she is not crazy	Not at all	64	59			
	Sometime	25	06	26.585	3	.000***
	Often	11	27			
	A lot	00	08			
Worry that you would be blamed	Not at all	66	30			
	Sometime	19	22	39.262	3	.000***
	Often	14	21			
	A lot	01	27			

Table 3. Group Comparison of Stigma

Stigma items		Mean ± SD/n (N = 100)		χ²/t	df	p
		Epilepsy	Mental Illness			
Worried about taking him/her	Not at all	58	30	74.832	3	.000***
	Sometime	27	22			
	Often	13	21			
	A lot	02	27			
Ashamed / Embarrassed about it	Not at all	54	13	39.267	3	.000***
	Sometime	26	57			
	Often	16	21			
	A lot	04	09			
Sought out families with a person with epilepsy/mental illness	Not at all	65	00	1.705	3	.000***
	Sometime	27	00			
	Often	07	76			
	A lot	01	24			
Felt grief or depression	Not at all	11	00	67.416	3	.000***
	Sometime	21	00			
	Often	25	04			
	A lot	43	96			
Felt it might be your fault	Not at all	72	28	48.788	3	.000***
	Sometime	21	38			
	Often	07	10			
	A lot	00	24			
Total Score in Stigma Items		10.14 ± 6.11	25.25 ± 4.90	-19.30	198	.000***

*** $p < .001$ level (2-tailed).

Comparison of total mean score in stigma item of both groups reveals that primary care givers of epilepsy (Table 3) group scored 10.14 ± 6.11 whereas care givers of mental illness group scored 25.25 ± 4.90. It means primary care givers of persons with mental illness were having much stigma than primary care givers of persons with epilepsy. Significant group difference was found between these two groups in all stigma items which indicates difference in nature of stigma experienced by them.

If we consider the positive response in stigma items it is very evident that, a feeling of grief or depression because of the illness (mental illness or epilepsy) in the PCG was highest one in stigma items, seen among 100% and 89% of the care givers respectively. The other issue which was highly disturbing to the care givers was the marriage of their ward (56% and 100% in PCG of persons with mental illness and epilepsy respectively). Effort to keep (illness) secret was the concern of all PCG of persons with mental illness whereas only 45% PCG of persons with epilepsy had this concern. Sought out families with a person with epilepsy (98%), fears that need to hide fact (96%), worried about taking him/her out (96%),

worry that neighbors would avoid (96%) was the concern of most of the PCG of persons with mental illness whereas majority of the PCG of persons with epilepsy having the fear that neighbours would treat differently (52%). Most (92%) of the PCG of persons with mental illness spend time worrying whereas only 47% PCG of persons with epilepsy having the same. Again, large majority of the PCG of persons with mental illness felt ashamed / embarrassed about

it (87%), neighbours would treat differently (83%) and it might be their fault (72%) in comparison to their counterpart in the same domains respectively (46%, 40% and 28%). Majority of the PCG of persons with mental illness were worrying that they would be blamed (70%) and 63% helped other people to understand about the mental illness in comparison to their counterpart in the same domains respectively (34% and 49%).

COMPARISON OF CAUSAL ATTRIBUTION BY THE PRIMARY CARE GIVERS

Table 4. Causal Attribution by Primary Care Givers

Attribution / Causes	Epilepsy Mean ± SD N = 100	Mental illness Mean ± SD N = 100	t df=98	p
Brain injury	.59 ± .49	.54 ± .50	.710	.478
Bereavement	37 ± .48	92 ± .27	-9.882	.000***
Childhood experience	. 31 ± .46	.55 ± .50	-3.516	.001***
Influence of Depression/Unhappiness	.40 ± .49.	.88 ± .33	-8.124	.000***
Influence of Social Environment	.32 ± .47.	.83 ± .38	-8.473	.000***
Financial worries	.31 ± .46	.84 ± .37	-8.935	.000***
Homelessness	.17 ± .38	.51 ± .50	-5.244	.000***
Inherited from parents	.52 ± .50	.74 ± .44	-3.322	.001***
Insecurity	.26 ± .44	.72 ± .49	-7.222	.000***
Jealousy	.14 ± .35	.40 ± .49	-4.172	.000***
Stress (unspecified)	.46 ± .50	.90 ± .30	-4.107	.000***
Stress home	.46 ± .50	.86 ± .35	-7.457	.000***
Stress at work	.46 ± .50	.80 ± .40	-6.384	.000***
Possessed by sprits	.32 ± .47	.63 ± .49	-5.235	.000***
Effect of the moon	.32 ± .47	.25 ± .44	1.023	.308
Difficulties in intimate relationship	.21 ± .41	.76 ± .43	-9.019	.000***
Character or life style	.27 ± .45	.36 ± .48	-1.377	.170
Age	.06 ± .24	.64 ± .48	-10.608	.000***
Substance abuse	.43 ± .50	.70 ± .46	-3.932	.000***
Faulty biological function	.32 ± .47	.46 ± .50	-2.016	.045*
Faulty nutrition habit	.28 ± .45	.54 ± .50	-3.750	.000***
Specific precipitating events	.05 ± .22	.87 ± .34	-19.934	.000***
No cause it just happened	05 ± .22	.27 ± .45	-4.458	.000***
Don't know	.03 ± .17	.23 ± .42	-4.363	.000***
Other cause	.00 ± 00	.00 ± 00	-	-

* p < .05 *** p < .001 level (2-tailed).

Group comparison between primary care givers of the persons with mental illness and epilepsy (Table 4) in causal attribution items reveal significant difference in almost all items except brain injury, effect of the moon and character or life style.

Table 5. Rank order of Causal attribution items

Causes of Psychosis/ Epilepsy	Causal Attribution	
	Psychosis	Epilepsy
Bereavement	92	37
Influence of Depression/Unhappiness	88	40
Financial worries	84	31
Influence of Social Environment	83	32
Stress (unspecified)	82	46
Specific precipitating events	79	5
Stress home	78	46
Stress at work	73	46
Difficulties in intimate relationship	69	21
Inherited from parents	68	52
Insecurity	66	26
Substance abuse	64	43
Age	58	6
Possessed by sprits	57	32
Childhood experience	55	31
Brain injury	54	59
Faulty nutrition habit	49	28
Homelessness	46	17
Faulty biological function	42	32
Jealousy	36	14
Character or life style	33	27
No cause it just happened	25	5
Effect of the moon	23	32
Don't know	21	3
Other cause	1	0

If we see the rank order of attribution for mental illness and epilepsy (Table 5), almost all (92%) PCG of persons with mental illness had attributed bereavement as a cause for mental illness whereas the largest number of PCG of persons with epilepsy had attributed brain injury (59%) as cause of epilepsy in their family member. Second most frequent attribution for mental illness was influence of depression/unhappiness (84%) and inherited from parents (52%) was for epilepsy. The common causes for mental illness were : influence of social environment (83%), unspecified stress (82%), specific precipitating events (79%), stress at home (78%), stress at work (73%), difficulties in intimate relationship (69%), inherited from parents (68%), insecurity (66%), substance abuse (64%), age (58%), possessed by sprits (57%), childhood experience (55%) and brain injury (54%). Whereas for epilepsy, stress unspecified or from either source home or work (46%) were attributed by the PCG. Substance abuse (43%), influence of depression/unhappiness (40%), bereavement (37%), and influence of social environment, faulty biological function, possessed by sprits, effect of the moon is equally (32%) attributed causes. Other causes are less preferred by PCG.

CONCLUSION AND IMPLICATION

It can be concluded from this study that the primary caregivers of persons with mental illness experienced a greater degree of stigma than the primary caregivers of epilepsy, which may have detrimental effects in the recovery and reintegration of persons with mental illness in the community. Differences in causal attribution between both groups indicates that causative factors about mental illness differ from epilepsy, which have important implication in psycho-educational programs of intervention to dispel stigma. It was also observed that primary caregivers of epilepsy also experienced stigma though it was lesser in comparison of what persons with mental illness experienced.

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