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DO THE SOCIO-CULTURAL DETERMINANTS AFFECT THE TREATMENT OUTCOME? EXPLORING PEOPLE LIVING WITH EPILEPSY

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The present study has explored the cultural beliefs associated with Epilepsy in the rural areas of Bareilly, a North-West District of India the aims of the study were: to assess the local healing practices and faith-spirit possession related to epilepsy prevalent in the rural communities; to evaluate differences in variables such as sex, caste, religion, socio economic status and to evaluate the social burden in terms of care in family, economics, decision making in family, impact of treatment, employment, if any; absenteeism in patient care, treatment due, long distance of medical centre and the stigma associated with the epilepsy patients.

Keywords: Epilepsy, demography, traditional belief, disease, patient, community, family stigma.

INTRODUCTION

Epilepsy, the most common neurological disorder, affects the normal brain function. It is also known as the *Seizure disorder* and commonly known as *mirgi ki bimari* in North India. Some Epilepsy syndromes do not continue lifelong and some are confined to particular stages of childhood. Epilepsy is a syndrome with different symptoms involving episodic abnormal electrical activity in the brain (Rani, 2012). Epilepsy may develop after a particular identifiable event (e.g., asphyxia, head injury, meningitis), in which case it is called *symptomatic epilepsy*, or it may develop without any identifiable cause, and then it is called *idiopathic epilepsy* (Dekker, 2002). In India, according to the reported studies it is estimated that about 10 million people may be suffering from epilepsy (Gourie Devi, *et al*,1999, 2003,2004).

Some unreported studies from urban populations (Surya, 1964; Dube, and Varghese, 1973; Mathai, 1960) and reported from rural areas (Gopinath, 1968; Elangar, 1971; Sethi, 1971; Nandi, 1975; Carstair, 1976; Issac, 1980; ICMR-1983; Mathai, 1969; Gourie Devi, 1984; Koul *et. al.* 1986; Das *et. al.* 1989; Mani, 1991; Kokkat, 1993 and Satishchandra, 1995) screened 4,52,465 persons and observed 2,435 cases of epilepsy with an average rate of 5.38 in

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rural areas with an overall rate of 5.32 per 1000 and in West Bengal various aspects of epilepsy are reported (Pal, *et al* 1998, 1999).

A Community based study in Bangalore (Gourie Devi *et al.*, 2004), in Kerala (Pandian *et al.* 2006, Radhakrishnan K. 2000) and in rural North West India (Sureka *et al*. 2007) also reported the prevalence of the disease.

The present study has explored the cultural beliefs associated with Epilepsy in the rural areas of Bareilly, a North-West District of India, as it has District Mental Hospital and other private neuro-clinics where such patients also visit for consultation, with an aim to investigate variations in terms of the behavior, social burden of care in family, economic, decision making, education, and influence of peer groups, employment, if any, absenteeism in patient care, treatment pattern, long distance of medical centre and existing facilities. It was conducted on the patients' population visiting the city hospital and other private clinics in the district from other neighboring districts of northern India. The main objective of the study was to assess the knowledge of rural people about epilepsy, visiting the city hospital/ clinics for consultation in the district and other clinics treating cases of seizures.

MATERIAL AND RESEARCH METHODS

People with Epilepsy from the districts neighboring Bareilly seeking treatment consultations were included in the study. Purposive sampling emphasized the selection of the patients. Their care provider or accompanying persons were also included as *informants* besides the patients. A semi structured bilingual (Hindi & English) schedule was used to collects details of patients. An *informed consent* was also obtained from each patient/ care giver who was included in the study.

Limitations: There were field situational encounters while conducting this kind of field work. Most of the patients were not interested in the interview as they had to go back home as early as possible. The City hospital does not dispense the epilepsy medicine so they visit other private clinics treating epilepsy. We initially targeted for 100 epilepsy cases, but we could not achieve the target because of several field based situations — long traveling distance to the field site, patients and their care givers do not allow us to investigate, particularly among the women patients, hence women patients number is less and further social stigma associated with the disease was another additive factor imposing the constraint. Therefore they neither wished to be interviewed nor did their caregivers allow us to interview their patients.

RESULTS AND DISCUSSION

The general information about the fifty eight patients includes the age, demographic profile — sex, residence, marriage, religion, and education of patients, parents, type of family, profession and members in the family (table 1 to 3). The age of fifty eight patients ranges from 19 to 28 years. Demographic profile of People with Epilepsy reveals sex, residence, marriage, religion, and education of patients, parents, type of family, profession and members in the family (Table 2).

Table 1
Age of the Epilepsy Patients (N =58)

Sl no.	*Age Range(ys)*	*No (58)*	*% age*
1.	<20	28	48.0
2.	21-25	27	46.6
3	26-30	03	5.2

There are 70.7 percent male and 29.3 percent female patients. About 60 percent patients live in the rural area as compared to 39 percent patients in the urban town/city. More than ninety percent (54) people with epilepsy are unmarried as compared to six percent (4) married. 63 percent PWE are Hindus, 32 percent Muslim and 3.4 percent were Christian. The education of the patients indicates that most of the patients are well educated — 43.1 percent patients are educated up to 10th class followed by 36.2 percent who are above 10th class. Parents of the patients are also educated; particularly the fathers of 56.9 percent are educated above 10th class followed by 32 percent who are illiterate. Similarly more than 50 percent mothers are educated up to 10th class followed by 27.6 percent mothers who are as illiterate. 62 percent of the patients are living in nuclear families when compared to 37.9 percent patients who stay in joint families. Most patients are agriculturists (41 percent), 56.9 percent patients are in service and 1.7 percent patients were students (Table 2).

FAMILY BASED CARE AND TREATMENT PATTERN

The traditional beliefs, treatment pattern and family based care pattern are explored in this section. The following tables show the age of the patient at the first seizure, how long in years patients have been suffering from epilepsy and the treatment pattern and associated knowledge about epilepsy.

Age at the first seizure: 34.5 percent patients expressed the first episode of seizure between 16 to 20 years followed by 29.3 percent when they were between 11 and 15 years of age, 20.7 percent felt first seizure when they were below 5 years and 15.5 percent patients mentioned about the first seizure when they were between 6 and 10 years of age.

Duration of Seizure: The duration of epilepsy suffering among the people with epilepsy show that about 39.7 percent patients were suffering for five

Table 2
Demographic profile of People with Epilepsy (N= 58)

Variable		*No.*	*%*
Sex			
	Male	41	70.7
	Female	17	29.3
Residence	*Rural*	35	60.3
	Urban	23	39.7
Marriage	*Married*	04	06.9
	Unmarried	54	93.1
Religion	*Muslim*	19	32.8
	Hindu	37	63.8
	Christian	02	03.4
Education of Patient			
	Illiterate	12	24.7
	<10th class	25	43.1
	>10th class		
Father of Patient			
	Illiterate		
	<10th class		
	>10th class		
Mother of Patient			
	Illiterate		
	<10th class		
	>10th class		
Family			
	Nuclear	36	62.1
	Joint	22	37.9
Patient Profession			
	Agriculture	24	41.4
	Service	33	56.9
	Student	01	1.7

years, followed by 29.3 percent for the last six to ten years. The patients suffering for 11 to 15 years are 18.7 percent and 12.1 percent patients suffered about 20 years with epilepsy.

Treatment and Knowledge about Epilepsy: PWE revealed pattern of treatment and knowledge about the disease and what they thought about marriage. None of them sought the community treatment. 44.8 percent people took ayurvedic or homeopathic treatment whereas 38 percent patients took allopathic treatment. More than 86 percent had heard about epilepsy in contrast to 13.8 percent patients who had never heard about this. About 62 percent patients consider it as a mental or physical disease and still 37.9 percent patients believe it as a supernatural disease. 79.3 percent feel that it can be treated like other diseases whereas 20.7 believe it cannot be treated. Epilepsy has disturbed the daily routine among 46.7 percent patients whereas about 53 percent do not have disturbance in day to day activities. 51.7 patients do not want to marry because of epilepsy whereas 44.8 patients think they can marry despite the disease and 3.5 percent people are indecisive about marriage.

Traditional Healing Pattern for Epilepsy

Traditional healing pattern explores the treatment sought from the *masjid, peer, tabeej, sacred thread etc.* to treat Epilepsy. About 31 percent patients sought the treatment from the *Maulvi* of *Masjid* whereas 69 percent patients did not visit such healers nor seek their treatment. Further there are other diseases for which 31 percent patients also visited the religious sites — *masjid, mazar etc.* for healing of diseases like anemia.

Family Burden

Family burden was assessed and it was noticed that 65.5 percent patients and their families are economically capable *to some extent* and 6.9 percent *much more* capable to care for their epilepsy patients in the family whereas 27.6 percent are not at all economically capable to care for such patients. 60.3 percent patients are also responsible *to some extent* for the family economic needs whereas 29.3 percent patients are much *more responsible* for the family's economic needs and only 10.3 percent patients are *not at all responsible* for the family economic needs. Family members are also worried about the economic responsibilities in future of the patients. 58.6 percent patients' families are worried about the future *to some extent* whereas 31.1 percent patients' families *much more* worried and 10.3 percent patients' families *do not worry at all.* 48.3 percent families remain disturbed economically *to some extent,* 15.5 percent families are much *more* disturbed economically and 36.2 percent are *not at all* disturbed economically. 51.7 percent patients are not at all disturbed about the jobs, 27.6 are disturbed *to some extent* followed by 20.7 percent patients who are much more disturbed about the job.

HOW DO THE PATIENTS ARRIVE AT THE HOSPITAL?

Arrival of patients explores the places from where they come to visit the hospital, how they reach — vehicle, expenditure incurred on travelling etc. Patients visit the city hospital from different districts — Bareilly, 44.8 percent; Barabanki, 24.1 percent; Shahjanpur,15.5 percent; Badaun, 5.2 percent; followed by Unnav, Pilibhit, Sitapur, 3.4 percent each. 32.4 percent patients reach within one hour of their journey whereas 22.4 percent patients take at least 2 hours to reach the hospital; 17.2 percent patients take between 2 and 3 hours to reach the hospital and 27.6 percent patients take more than three hours to come to the hospital. More than 51 percent patients spend more than 150 rupees to visit the hospital; 20.3 percent patients spend between 100 and 150 rupees followed by 17.2 percent patients who spend between 50 and 100 rupees.

Patients are accompanied by the core family members. 51.7 patients are accompanied by the father followed by 24.1 percent patients accompanied by the mother, 17.2 by brother but none is accompanied by sister of the patients. Only 6.9 percent of the patients were accompanied by another relative for the hospital visit. 41.4 percent of the patients are referred by the Doctor followed by 29.3 percent referred by relatives and 24.1 percent referred by neighbors. More than 65 percent patients visited the hospital for the first time for consultation.

About 65.8 percent patients have been visiting for five months followed by 13.8 percent patients visiting the hospital for between 5 and 10 months and 20.7 percent patients have been visiting the hospital for more than 10 months. Nearly 57 percent patients have benefited from the treatment as compared to 43.1 percent who said that there was no benefit from the treatment. Further 48.3 percent patients felt treatment benefit was much more whereas 37.9 percent patients felt benefit was less. The frequency of the hospital visit of the 51.7 percent patients is once in a month, 19 percent patients visit twice in a month and 29.3 percent patients visit the clinic whenever they require the need for consultation. 86.1 percent of the patients do not feel any problem in the hospital as compared to 13.9 percent patients who mentioned problems in the hospital which chiefly related to the late arrival of Doctor, non availability of medicine for patients, long waiting for consultation, and late registration. 62.1 percent of the patients visit hospital by bus, 25.9 percent by rail and 12.1 by their own means of transport.

IMPACT ANALYSIS OF TREATMENT

Utilization Time

All patients are taking the treatment for epilepsy for some time. On being asked whether they were not using their time usefully before the treatment, 32.8 percent and 24.1 percent patients *strongly disagree* and *disagree* respectively which indicate that more than 50 percent (56.9 percent) patients were utilizing their time in a useful manner. Only about the 39.7 percent patients (*agree* 27.6 percent and *strongly agree* 12.1 percent) agreed that they were not utilizing their time in a useful manner before the treatment. Similarly as the treatment began 48.3 percent patients (32.8 + 15.5) used their time usefully with the treatment as compared to 48.3 percent who did not use their time usefully. Precisely, with treatment 48.3 percent patients did utilize their time and equivalent percent patients did not utilize their time in a useful manner.

Stigma in the Family and Community

Stigma is normally associated with such Patients or PWE. They face stigma in the life time. PWE expressed their opinion about the stigma which they felt due to epilepsy. More than 56 percent people with epilepsy (PWE) expressed that they did not feel any stigma in the community or in the neighborhood area before the treatment; in contrast about 36.4 percent PWE felt stigmatized in the community. Similarly about 53.4 percent PWE did not feel any stigma in the family before the treatment whereas 41.3 percent PWE people expressed discrimination experienced due to the disease in the family before the treatment.

Understanding About Epilepsy

Knowledge about the disease is an important factor in caring for the PWE in the family situations. It plays an important role in the life of the Patient. Families of more than fifty three percent PWE did not have better understanding about the disease whereas 41.2 percent of the family members of PWE have an understanding about the disease and its consequences before the treatment (table 3). As the treatment and consultation began with Doctors then 44.9 percent families of PWE still did not know about the disease as compared to 46 percent of families of PWE have expressed that their families have understood the disease as the treatment began.

Relationship of PWE with others

43.2 percent PWE expressed that their relationship with others was not affected because of the disease whereas 39.6 percent mentioned that their relationship has been affected due to the disease before the treatment. As the treatment began then relationship of 51.4 percent of PWE with others does not have any positive effect and 37.9 PWE percent expressed the positive impact on the relationship with others. It appears that treatment doesn’t have any positive impact on the relationship, rather it may have negative impact as PWE become more visible after the treatment (table 3).

Capacity to Work

Generally such people are scared to do work because of their disease. 34.4 percent of PWE were working easily without any trouble due to the disease whereas 60.4 percent PWE expressed their fear to do work before the treatment

Table 3
Impact Analysis of Epilepsy Treatment (percent)

Indicators	*SD*	*D*	*A*	*SA*	*DK*
Not using time usefully before treatment	24.1	32.8	27.6	12.1	3.4
Not using time usefully with treatment	32.8	15.5	34.5	13.8	3.4
Before treatment felt stigmatized in community	31	25	19	17.2	6.9
Before treatment felt stigmatized in family	8.6	44.8	24.1	17.2	5.2
Family understood the Disease before treatment	32.8	20.7	17.1	24.1	5.2
Family understood the Disease with treatment	19	25.9	31	15	8.6
Relationship with others affected due to Disease	27.6	15.6	22.4	17.2	17.2
Positive impact on relationship with treatment	36.2	15.5	20.7	17.2	10.3
Afraid to do work before treatment	10.3	24.1	19	41.4	5.2
Afraid to do work with treatment	10.3	41.4	3.4	27.6	17.2
Income increase with treatment	32.8	29.3	19	6.9	12.3
Treatment expenditure is difficult	10.3	44.8	19	17.2	8.6
Difficulty to visit the clinic/hospital	19	44.8	10.3	22.4	3.4

(Table 3). More than fifty percent (51.7 percent) of PWE said that they do not fear while doing any work as compared to 31 percent PWE who reveal that they are still afraid to do work because of the disease.

Income, Expenditure and Hospital Visit

There is no increase in the income of 62.1 percent of PWE on the treatment of the disease whereas 25.9 percent of PWE expressed that their income has increased due to the treatment. About 55.1 percent of the PWE said the treatment of the disease is not much difficult as compared to 36.2 percent PWE who revealed difficulty in meeting the treatment expenditure of the disease. Further these people also expressed the difficulty in visiting the clinic or the hospital from the neighboring districts. More than 55 percent of the PWE do not have any difficulty in visiting the hospital or the clinic whereas 32.7 percent of the PWE expressed difficulty in visiting the hospital (table 3).

PWE and Community Involvement

There are problems associated with PWE in interaction with other people in the family as well as in the community. We tried to find out the pattern of their involvement in the community (table 4). More than Fifty percent PWE do not interact with community people. About 17 percent of the PWE each involve themselves more than normal and less than normal where as 13.8 percent PWE involve normal time in the community before the treatment. But 31 percent each of the PWE involve *not at all* and their *normal time* in the community and 22.4 percent PWE involve *less than normal* time in the community and 15.5 percent of the people involve their time *more than normal* after the treatment (table 4).

Table 4
Pattern of Normal involvement in the Community

Patient Pattern of Normal involvement	*Before Treatment*		*After Treatment*	
	No.	*%*	*No*	*%*
Not at all	30	51.7	18	31
A normal amount of time in the community	8	13.8	18	31
Less than normal amount of time in community	10	17.2	13	22.4
More than normal amount of time in community	10	17.2	9	15.5
Total	58	99.9	58	99.9

In conclusion we feel the PWE have many problems dealing with their daily life: on one hand they are stigmatized in the family as well as in the Community and on the other hand, remain in the state of fear to do daily routine work. The disease itself is unpredictable and needs more continuous and longer period of medication. At the family level it appears that all members are disturbed due to his disease, particularly of its uncertainty and longevity of treatment. Further there is scope for advanced research, which could not be carried out because of the time constraints, in 'Narrative of their suffering' as PWE, 'Medicine and its compliance'- how people think about its medicine, whether they take medicines as advised to them, etc. Further it also can be explored how they live as married people and carryy out their duties/ daily mundane work. Similarly, another aspect that can be explored is 'Epilepsy: Women, Pregnancy and children.' Children with epilepsy and their social problems in school, family and other peer groups etc. could be a good exploration. There is further vast scope for research on the diverse issues. During this piece of research we realized while reading on epilepsy later that there are critical issues that must be explored systematically on a larger scale.

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