

Dementia and Epilepsy

Family and Kinship care Analysis*

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Abstract. 38 interviews of epilepsy patients and 22 interviews of care givers of Dementia (Alzheimer Disease) were conducted between August 2006 and July 2007 in neuropsychiatric hospital. The content analysis of these interviews is illuminated here in the paper. The cultural dimensions of epilepsy and dementia reveal social stigma, problems of marriage, school education and employment etc. in case of epilepsy as the main issues for the parents about it as disease, how do epilepsy patients being cared in home situations, who spend most of the caring time with the patients, family structure and composition are discussed; whereas in case of dementia the care givers discuss the strains in caring the dementia patients in the family. It recommends culturally appropriate interventions in such care and relevance of voluntary organizations in creating public awareness for such neuropsychiatric behavioral problems and they can act as the catalytic agents of mass awareness and change in rural areas of National Capital Region of Delhi (NCR Delhi).

Key words: Epilepsy, Dementia culture, family, kinship care and community

Introduction

The dementia and epilepsy are neurological diseases causing the social suffering to the family and community and causing an irreparable loss. When a kinsmen suffers with any such diseases is assessed by time lived with his ability rather than by mortality, several neurological disorders appear as leading causes of suffering worldwide (Chandra, *et al.* 2006). Neuropsychiatric disorders are mental, neurological and behavioral and are growing causes of morbidity. The magnitude and burden is very high and affecting more than 450 million people in the world. It is mentioned that 33 percent of years lived with disability and 13 percent of disability-adjusted life years (DALYs) are due to neurological and psychiatric disorders, which account for four out of the six leading causes of years lived with disability.

The burden caused by these diseases is remains largely unrecognized in developing countries. Such chronic neuropsychiatric diseases are devastating the poor population living in our country. They cause the serious social suffering which made us the socially handicapped and unproductive to our best of capacity. It appears in

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loss of job or become unable to work, loss of family income; burden on family for caring, with further potential loss of wages; the cost of medications; and the need for other medical services can be expected to be particularly devastating among those with limited resources. Besides these neuropsychiatric sufferers are also frequently victims of human rights violations, stigmatization, and discrimination and hence limits patients' access to treatment. Therefore these diseases require special attention in developing countries including ours.

The anthropological view of caring focuses on the non-institutional parts of caring in context of medical pluralism and the combination of wide range of nurturing practices including the informal practices in domestic sector generally considered to be the work of the women. Anthropology of caring has been explored as new path for individuality, alterity, gender relations, and new form of sociality in every day life experiences of caregivers, spouses, children, and other relatives who provides day to day care to person with illnesses living in the home (Saillant and Genset, 2007).

This paper deals with care giver's problem and family dynamics in the family of patients of two serious neurological diseases- Dementia or Alzheimer's disease (AD) and epilepsy. Here we are illuminating case studies of Alzheimer's disease (AD) and Epilepsy, primarily focus on the family composition and their sibs in caring their family members as patients. Care giver of dementia patients were interviewed in the wards as well as in outpatients' clinic. However, the interviews of people with epilepsy were conducted in outpatients' clinic as well as through home visits at the week end and are also reported elsewhere¹ (Ravinder, *et al* 2009).

Dementia and Epilepsy : Anthropological aspects

Dementia

Dementia is a deterioration of intellectual function and other cognitive skills interfering with social or occupational functioning. AD is the most common diseases that lead to dementia worldwide among people age 65 and older, followed by vascular dementia, mixed dementia consisting of AD plus vascular dementia and dementia caused by general medical conditions. Although distinguishing AD from other causes of dementia is important, particularly for treatment with acetylcholinesterase inhibitors, the burden from all causes of dementia is similar. The role of treatable dementias in developing countries is important as it can reduce the burden of caring in families (Chandra, *et al.*2006).

The behavioral and other psychological symptoms of dementia are a major source of stress to family members providing care to patients. Training family caregivers in behavioral management techniques, including problem solving, memory training, and reality orientation, has been shown to reduce the level of Agitation and anxiety in people with dementia (Brodaty and Gresham, 1989; Haupt, Karger, and Janner, 2000). Use of low doses of antipsychotic medications, which calm the patient and reduce symptoms such as aggression and wandering, have been shown to reduce caregiver stress, but these improvements have not been quantified (Melzer, *et al* 2004). Interventions that have specifically targeted stress and depression among caregivers and have shown positive results include caregiver training, counseling and support for caregivers, and cognitive and behavioral family interventions (Marriott, *et al* 2000). Limitations to the implementation of such strategies include the need for training by specialists, which makes these strategies less suitable for developing countries. The challenge for developing countries is to develop culturally appropriate interventions that can be delivered within existing resources, such as supporting families in their role as caregivers. Treating underlying disease and risk factors for cardiovascular disease can help prevent future cerebrovascular disease that could lead to multi-infarct dementia. Other conditions, such as hypothyroidism or vitamin B12 deficiency, which could lead to or aggravate dementia, are easily treatable, and the costs of treatment are much lower than the costs of dementia care. In Western countries, the model of care for patients with moderate to severe dementia is based on skilled, long-term care in institutions. However, such long-term care institutions do not exist in developing countries, and if they were set up, they would be extremely expensive and beyond the reach of most patients and their families. Thus, the model of care in developing countries should be based on home care, along with providing training and support for family caregivers. Interventions that should not be pursued include the use of multiple medications, which can be detrimental in older age groups, particularly unproven medications such as cerebral activators and neurotropic agents.

Several prevalence studies of Alzheimer's disease (AD) and other dementias have been reported throughout the world. The prevalence of dementia has generally been found to double with every five year increase in age, from 3 percent at age 70 to 20 to 30 percent at age 85 (Henderson and Jorm 2000). Studies in developing countries have shown a prevalence of dementia ranging from 0.84 to 3.50 percent (Chandra, *et al* 1998; Hendrie, *et al* 1995; Rajkumar, Kumar, and Thara, 1997).

Several studies have reported the incidence rate of AD and other dementias in Europe and the United States (Jorm and Jolley, 1998). Compared with incidence rates in developed countries, very low age-specific incidence rates of AD and other dementias have been reported from developing countries (Chandra, *et al* 2001; Hendrie, *et al* 2001). A comparison of data from developed and developing countries raises several important questions. The reported differences in the prevalence of AD and other dementias across countries could be due to partly methodological differences or could be due to genuine differences caused by variations in diet, education, life expectancy, socio-cultural factors, and other risk factors. The low incidence reported from Ballabgarh, India, and Ibadan, Nigeria, raises the possibility of environmental factors or gene-environment interactions in the causation of AD. At the same time, multi-infarct dementia is more common than primary degenerative dementia in China which also suggests variation in risk factors across countries (*c.f.* Chandra *et al*, 2006).

Epilepsy

Epilepsy is a disorder of cerebral function which is characterized by a pattern of repeated, sudden brief attacks of altered consciousness, motor activity or sensory phenomena known as *seizures*. It is a symptom of an underlying condition and seizures may be due to brain tumors, scar tissue from trauma to the brain, or a progressive neurological disease. It poses specific problems in day to day life among the people with Epilepsy, which is recurring unprovoked seizures affect their physiological, behavioral or cognitive consciousness. Though many such people are neurologically unaffected but they face the psychological and social consequences of the disease (Ravinder, *et al*, 2009)

Studies have been reported on the epilepsy covering the different aspects like screening of the community people, rate, wherein it is found that about 10 million people are suffering from epilepsy in our country (Gourie Devi, *et al*, 2004a, 2004b). In rural areas 452465 people have been screened and observed 2435 cases of epilepsy with an average rate of 5.38 in rural areas with an overall rate of 5.32 per 1000. Similarly another Bangalore based Community study of various neurological disorders reveals rate of these disorders, very high among children 3,057/100,000 and prevalence rate among children (<15 years) has been observed as 2653/100,000. The overall prevalence rate is higher among the women (3,617) as compared to men (2657/100,000). Further the prevalence neurological disorder is high among the rural than urban population groups of city (Gourie Devi *et al* 2004a). Another estimate based on the total projected population of India in 2001, the estimated number of people with epilepsy is about 55, 00,000. Considering rural population constitute about 74% of the Indian population, the number of people with epilepsy in rural areas will be close to 41, 00,000. In most cases however, it is idiopathic means no pathological basis for the seizures. In the other countries like USA and Canada, epilepsy is the second leading neurological disorder after stroke. The prevalence of epilepsy is about one percent but this varies widely across populations. For example, in Africa it is estimated to lie between 0.5% and 3.7% and in the United States and Canada it is estimated to be 0.5%. There is a significant level of under-reporting because of the stigma associated with seizures. There is also some indication that some sub-groups have a genetic predisposition to lower seizure thresholds and consequently a much higher prevalence than is reported within their general populations (Chandra, *et al* 2006)

Material and Methods

Sixty Epilepsy and Dementia patients' interview (38 epilepsy interviews and 22 patients of dementia) were conducted between August 2006 and July 2007. Socio-demographic detail of patients is given in Table-1. Epilepsy interviews were further substantiated through home visit during week end with prior appointment of head of family. Here, we explored traditional healing practices, if they consulted; initially we visited to complete the information which they could not give in clinical setting. Most of patients don't feel to share with the physicians in their consulting room. They think about physicians exclusively meant for diagnosis and prescription and will not pay attention to alternative healing consultations. People with Dementia and their care givers were

interviewed during their visit to OPD of hospital. People with dementia always accompanied by close care givers from the family members or other kinsmen and interviewed as a care giver.

People with Dementia and Epilepsy

Most of Dementia patients were from the different places: Sundar nagari, Gokul puri, Pandav nagar, Dilshad garden, Krishna nagar, Nehru Nagar, Shahdara, New govindpura from Trans Yamuna area where these patients came to the tertiary care, neuropsychiatric hospital, centrally located. The information which we collected through the semi structured schedule. The semi structured schedule was divided into *four* major sections: *first*, deals with the general information- address, age sex, occupation, income, residence in urban or in rural, areas, caste, community, and religion; *second*, Food habits- how many times patients in the past has been taking the meal per day, constituents of the staple diet-green vegetables, fruits consumption, spices consumption, Non/vegetarian. *Third*, Family profile, family supporting members, time spent in caring. *Forth*, the life history of the person: scholastic performance, nature of job and earning, number of hours spent in the jobs, level of satisfaction and stress of the job. Life after the retirement, marital history, family responsibilities, peer group activities in the life and important events in the life. This information we had collected in the structured schedule and unstructured interview one of us (RS) conducted with care giver. Here while writing we have restricted our interpretation to the family members or composition and how much they are giving their time in the care of the person, their sib, with dementia in the family setting. Other detail is useful for the clinical interpretation which we have not analyzed and restricted our analysis to family and kinship care and the same is given in the small case histories of these people.

Whereas most of the patients of epilepsy are from Uttar Pradesh followed by the Delhi which share similar culture, but religious practices varies according to their religion viz. Hindu and Muslim. A large number of People with epilepsy came from Alighrah, Gaziabad, Muzffarnagar, Meerut, Bulandshar, Moradabad, Gujrola, where as some of these people are from trans-yamuna areas of Delhi which includes Nanad Nagari, Sunadr Nagari, Wazirabad, Yamuna vihar, Gokul puri, Saboli extension, Ashok Nagar, including other parts of Delhi (Ravinder, *et al*, 2009). In some cases people came from other far of places- nearby districts of Haryana for the treatment to this tertiary care centre. Most of them are Hindu followed by the Muslim. In our patients most of them are from the low socioeconomic group are living in the nuclear families in Delhi whereas the people from the Uttar Pradesh belong to rural families engaged in agriculture activities (*Ibid*).

Table-1: Socio-demographic Variable of Dementia (N=22) and Epilepsy (N=38) patients

S.No	Socio-demographic Variable		Dementia(%)	Epilepsy(%)
1.	Age	<i>in Mean Range</i>	63.5	36.7
2.	Sex	<i>Male</i>	10(16.66)	22(36.66)
		<i>Female</i>	12(20)	16(26.66)
3.	Marital Status	<i>Married</i>	22(36.66)	15(25)
		<i>Unmarried</i>	01(16.66)	13(21.66)
4.	Financial Support	<i>Yes</i>	21(35)	11(18.33)
		<i>No</i>	01(1.66)	17(28.33)
5.	Religion	<i>Hindu</i>	22(36.66)	21(35)
		<i>Muslim</i>	00	17(28.33)
6.	Education	<i>Below Primary</i>	02(3.33)	12(20)
		<i>Secondary</i>	11(18.33)	17(28.33)
		<i>Above Secondary</i>	10(16.66)	09(15)
7.	State Domicile	<i>Haryana</i>	01(1.66)	00
		<i>Delhi</i>	13(21.66)	22(36.66)
		<i>Uttar Pradesh</i>	08(13.33)	16(26.66)

People with Dementia

Following case studies of nine patients, three women and six men, focus the family structure and other sibs supporting the dementia patients in the family. A genealogy of each case was made for the detail of family members. Most of the detail deliberately have not been used here as it was related to clinical assessment of cognitive impairment. We have restricted our interpretation to family members, caring dynamics and other kinsmen in care analysis (*Pseudoname used*).

Women with Dementia

1. *HKD*, 60 years, Hindu woman, came from the rural village Rehman Pur of Shamali, in Bulandshar, UP. She is illiterate housewife and look after the agriculture activities in the house as well as in the field. She had been working 12 to 17 hours every day. She had seven children four boys and three girls. All are married and well settled. All married son stay away from their ancestral village. Both parents live alone and belong to *Jat* rural community and their monthly income is about 10,000 /-pm. She had been diagnosed a case of AD at the age of 60 years. She is well build and tall. A brief history about her life style in past shows that she is married for 45 years where in she took all the responsibility of the household activity. Her husband told about her she never felt more stress. She spent her time 3 to 4 hrs. in recreational work with her peer group. Her husband claims that she is satisfied. Nothing has disturbed her. About her diet, she took staple diet 3 to 4 times a day. Diet includes the traditional food composition-cereals, pulse milk etc. with moderate spices vegetarian food. About half kilogram fruits are consumed daily besides green vegetables.

In the Family and its support, all sons stay away from the parents, particularly from the patient mother, father most of the time mobile visiting their sons and daughter. Mother remains back in her house. Often sons contribute economically to the parents. But physically they hardly stay long with them. It is apparent that parents living alone in the village setting. Most of the time husband cares his wife; none of the daughters-in-law stay together though their children often stay back with grandmother. Financially children support the parental family. Their sons are well educated and settled well in their life. Patient is illiterate and satisfied with her household work. Married life is very satisfactory and supportive to each other in their life for 45 years. As the mother *HKD* cared well her children, home and enjoyed happy married life in company of husband and children and grand children.

2. *KR* is another woman, above 60 years, presented as the case of AD/Dementia diagnosed in Neurobehavioral clinical OPD. She had been complaining the memory loss, failing to recognize the sibs and kins in the family during the early November and December 2006 her family members treated her with local trained doctors in Baraut. But there was no cure till Jan. 2007. Meanwhile she further rapidly lost the memory and she reached here through referral in the Neurobehavioral Clinic where she was diagnosed as dementia of AD type. *KR* is brought by her daughter married in Delhi. She further adds that *KR* has four children and a husband. One already married and three sons- one of them is married. Married son had been living together till October, 2006, just before these symptoms of memory loss appeared. *KR* used to love to much this married elder son Ashok and his children and till then *KR* was very active in the home chore activities of the house. As the patient began to exhibits the symptoms as mentioned earlier, she now requires more time for her care and sympathy of other family members. During this time, Ashok, a married son, refused to take care of her mother and his wife also refused to look after her mother-in-law. Her husband also refused to care her in such a situation and even did not help for her treatment as the wife. Then her unmarried two sons in the state of dilemma transferred her to their elder sister's house in Delhi for care and treatment. Both unmarried sons are looking after the economic expenditures of patients- their mother. In sum, married daughter is looking after her AD mother whose physical situation is further deteriorated much. Patient belongs to the high socio economic and high hierarchical stratum of a rural village where a married daughter ideally does not keep her parents in her in-laws house. Two unmarried sons supporting the economic needs and seek the social support from their married sister.

3. Mrs. *SK* is 71 years old Hindu woman, housewife. She had three children –one son and two daughters and both daughters are married off and one married son is living on the top floor of the three storied house. First floor is sold off and *SK* and her husband are living on the ground floor. Her only married son has two children living separately on top of the house. Her husband further adds that he runs his family life on the pension of Rs 3000/-pm and his son hardly supports them even they support as his son's family. Their son does not earn much and it becomes difficult to support his own family...

Men with dementia

4. *B S* is illiterate agriculturist Hindu Khastryia from Gorakhpur district in eastern UP and diagnosed for the vascular dementia. He used to consumed a staple diet 3 to 4 times a day which comprised of the *chapti*,

seasonal vegetable and pulses. Basically vegetarian and consume half kilogram seasonal fruit a day. He earns 5000/pm.

Personal: He is using tobacco chewing daily and had worked very hard in the agricultural field. Earlier he had a job of motor driving in Calcutta for 17 years and forced to lost his driving job due to gastric problem and again reassumed the agricultural work. He had more than 40 years of married life and blessed with five children: two daughter and three sons. His wife supports in his endeavors and children occasionally help him. His all sons are settled in Delhi. Patient is second among his sibs and he cared all sibs himself and did his best for his brother and sisters and he felt that he did not did much for his own children whereas his younger brothers hardly cares him now it is this hurts and make sometimes sad.

Kinsmen/Sibs: He belongs to extended family of 10 to 11 family members. His wife cares him very well. His two sons work, elder works as auto driver in Delhi and both remain away from their ancestral residence where their parent stays alone. Most of the care giver is the wife. Children are away from the caring work, he is brought in Delhi for the treatment. BS hardly gets any support of care from the secondary kinsmen, particularly his younger brothers and their children. He took all the responsibility of his family and made house for them, settled them, social obligation they also met.

5. SC is male of 65 years and a post graduate from Govind Pura of Trans Yanmuna Area suffering with dementia. He is retired from the Pay and Account Office where he worked for nearly 33 years as account Officer and getting a pension of Rs 6000/pm as his wife tells. In Family care all are living in the joint family of the SC which is comprised of two married son and their three and two children respectively. Their two younger sisters are married away. Families of both son stay with SC and both run the electricity goods shop. Wife of SC is main care giver. House of SC is three storied. Eldest son and his family stay on the top floor, younger son and his family stays on the first floor and SC with his wife stay on the ground floor. Two married sons staying with SC on two different floors- layered structured house where their bonds are weak with old parents. Both sons hardly interact in the day and they are busy in their personal families after the hectic day at the shops. Wife of SC further adds that often some unpleasant issues are discussed in his presence which hurt him more. Such incidents make SC to think about some jobs or to earn money for which is they are looking towards the married sons. However he has been retired from the government office where he performed the mental calculation and kept himself active in life. He tried some pity shop in the house but still it is his wife run now, as does not enjoy any more this work. Prior to it he tried another shop of sweet making, *halwai ki dubkan*, but he gave up after sometime. SC tried in many engagements to earn money after the retirement but failed. His wife looks after for his care. As far as daughter-in-laws are concern they hardly care him. Reasons are very different in this case as wife tells, he is not able to maintain his normal body dressing and often he forgets to wear undergarments which put other care givers away in the family, particularly the daughter-in-laws and their children or even their own sons hardly pay attention the *personal care* of their father. It left to the wife alone.

6. FS, 58 years man, is matriculate and has been retired as sub-Post master from the government services after serving for the more than 20 years and now living in his own house in Delhi. He is living on the pension. He had been diagnosed for Alzheimer Disease (AD) in 2004 and under treatment since then. He is married for more than 40 years had three sons, elder one is married and separated from the parental home and living separately with his wife and two children. FS and his wife stay on the top floor and FS is not aware about separation of his elder son form his family. As far as care of FS concern it is his wife who pays most of the time on the caring job who is supported their *two unmarried sons*. Though they could not give much time for care his father as they are busy in jobs and though stay with the parents. As wife further adds that FS cannot manage his normal behavior and is cool and calm but needs the direction for the self management. Often *he stare women, young girls and put off his garments, particularly the lower one*. Such frequent episode forced his wife in embarrassing situation to keep him separate from other family members. Their monthly pension is about 9000/-pm. FS expects much attention from his eldest married son who is living separately with his two children. His food habits in the past have been includes the vegetarian food including the egg but not other strong non-vegetarian items. Often fruits are taken in the diet but alcohol seldom consumed.

7. SS 70 years male, 70 years old Hindu male is a casual agricultural labor from a rural village in Muzzafarnagar, UP. He is illiterate and is unmarried among six married brother and sister three each. All are well settled and living with joint family members. He is being looked after by the elder brother and his wife and their children. His other brothers also pay attention to him. In his life he has seen many ups and down. He has huge amount of debit and sold off a piece of his agricultural land and tried several menial works which had caused much suffering and put in depression. Prior to onset of the AD dementia he used to earn at least Rs. 1500/- pm. But he now is dependant up on the brothers and their family as one of his brother admits. He is looking after the children of his brother and on of the younger sisters. Sometimes SS

He had been vegetarian and morning diet comprised of the routine *chapatti, rice, dal* etc. Fruits are very rarely consumed and more often whatever is available usually consumed. He is not able speak much. Previously he used to meet relatives at different places houses.

8. AD, 75 years, old Hindu illiterate woman has five married children and the husband who look after her for the four years. Four years ago she developed the dementia and lost to no work. AD remains the part of family and being cared by the well settled married five sons and a daughter. Her daughters- in- law and their children care much. She had been a active housewife an used to work 8 to 10 hrs. She takes the different smoking means, traditional *bukka, chilim, tobacco* and *bidi*. She does not earn herself. As far as her part on the responsibility of bring up children which did nicely and had their own house, settled well all children and still pay attention to the social responsibility. Occasionally she spends times with her pear group. As her younger son tells that she thinks much of the past unpleasant incidences

9. IJS, 66 yrs. old Sikh male living with his wife and a married son and two grand children. His wife supports much to his care and Rs 2000/- pm he manage to earn from his factory. He had been trained as fitter and hence set up his own factory and used to work for 15 to 20 hrs. a day. He was very satisfied form his job. They live in their own house. He care him as they are living together and daughter is already is married and does not support much. IJS used to run a factory and supervise the fellow workers. Gradually he forgets things and subsequently fails to recognize his workers in the factory and fail to do minor calculation. Still he is on the treatment. He often goes to his factory with the son and tries to do thing under supervision.

People with Epilepsy

Here we give brief narratives of five school children, three cases of married women and a case of married man reaching for the tertiary level treatment(*pseudo name*)

School Children with Epilepsy

1. VK, 16 years, another school child of 12 class preparing the board examination. His mother narrates about his seizure began when he was eight years old. Toady nearly eight years passed in the treatment for the seizure. During past eight years, some traditional healers treated him for one year in his maternal uncle house in Himanchal Pradesh. These healers used, as his mother narrates further, *tabeej, mantra rituals and scared thread etc.* but VK had no cure in his maternal uncle house. He visited the different places for the traditional treatment including the well known big hospital in Delhi. Initially, as his mother tells that *she did not know it is a disease*, while one doctor treating him then told her that it is a disease, epilepsy, and doctor referred him to this hospital and VK re-assumed the treatment in the tertiary care neuropsychiatric center. Further she adds about VK that he feel shyness or hesitates in visiting to the hospital after an interval of fifteen days. His mother admits the trouble in bringing him here in outpatient department for the routine checkup. He does not want to come very frequently, she continues further that his friends and neighbor make fun of him by saying that his treatment is going on from this hospital, and feels it. As his mother says:

“Main usko chupake lati hun taki padosi bhi nahi jante ke eska ellaz yaban se ho raba he aur vikas ko ye achha nahi lagta ki usko bar bar yaba ana achacha nahi lagta he!” (I bring him hospital in the hiding, he does not like to visit the hospital frequently, even his friends and our neighbor do not know about the treatment. It is only we the family know the about it and we do not share his treatment with other).

However his treatment continues from the hospital. His seizures are under controlled.

2. KV, 13 years boy, study in primary class in his home town Moradabad, having the complaints of seizures since 2007 and on 27 May 2007 he had 9 episodes of seizures and followed by 3 seizure on the next day. Because of the complaints neither he was not allowed to appear in the examination nor he appeared and finally he dropped a year in the fifth class. KV stays with his uncle in Moradabad and his father work in Gajrola where he is *Patwari* visit him at the weekend and could not pay attention to his academic activity. In the class situation has classmates tease him due to *Caste* Status and often pass the derogatory remarks due to his *caste* and it creates tension and always haunt him. He requested his father to change school due to this. KV feels disturbed in home could not concentrate on the studies. Common shouting or asking with harsh word to get thing done cause ultimately seizures (?). This patient was referred on the advice of the some relative to this hospital.

3. SNZ, 12 years girl from the Muslim lower socioeconomic status from the Tahirpur village near to our hospital, she has been diagnosed for the seizure for the five years. She had first episode of the seizure at the age of seven years, in the school and it continues to the next few days. As first episode of the seizure her took her to the local healer of their community, *Mohvie*, and for the 6 months she remains under his treatment but her parents visited again another healer, *Ojha* but nothing cured her illness, and her father visited in the hopeless situation to Pediatrician, who advised her father for the proper neurological treatment and referred to our hospital. She had reduced the frequency after the treatment much from every day to week, then in ten days to once in a month within a year and her seizures were under the control. Her school teacher advised her not to attend the school and parents though continue her treatment. She lost the precious years of school education due to this disease.

4. SND, 18 years male, a 9th class student in the Aligrah has been suffering the seizure disorders for the past three years and discontinued his studies because of seizure and though he used to cycle 6 km one way to go to school. He had first episode of seizure at the age of 15 years and his family members took the treatment form the local healers in Chachera, Aligrah, UP. He also went to *Vaid* Rajvir Singh who is also well known as *Bhagatji* who had claimed the cure of several cases of the epilepsy. *Snd* was given the treatment for the one year and it forced his studies and the *vaid* treatment gave no relief to him. Though the cost of herbal medicinal treatment was Rs. 42/- per month. He was also treated by Traditional healers' for epilepsy. While he was being examined for the diagnosis in the OPD then his father planned for another visit in Anupshare near Blundshar. But a neighbor, who had been taking the treatment from the hospital, the advice his father, had advice to visit this hospital for the treatment. His treatment continues now from the hospital but still his family members are looking for the alternative healing, *Snd* wants to continue his studies but his parents prevented him due to fear and social stigma felt in school as well as in neighborhood areas of to his house. It seems that family feel the stigma in the society.

5. USH, 16 years girl from Nand Nagari, Delhi. She is the student of 8th class and recently complaining the seizures for four years. She continued the treatment straight from this hospital. Her seizures subsequently controlled. Seldom episode of mild episode of seizure disturbed her and these may occur in the school. Here she expresses that their teachers and class mates help at the time of the seizures. She felt that both teachers and other students are helping her at the time need. She suffers and she says:

“*Kash mai mar jaun, babut ho gaya es bimari se, har samay dar laga rahata he*”(If I could die, it is enough of seizures. Every time I am afraid of seizures)

She further released the economic strain of expenditures on this disease made her sicker as she says:

“*babut paise kburch ho gaye, lekin kuch tik nahin hota,acha hota ki mai mar jaun! Na tik se pad sakete he, Na kbel sakete he!*” (Much has been spent on this disease; nothing turns right to my disease. It would be better if I die. Neither I can not study well nor can play well)

Ush has developed a guilt which is giving her more suffering than the disease.

Married Women: A Hidden voice or Voiceless narration?

6. Two Sisters, *Arth* (19) and *Smit* (17), identified for the *seizures disorders*. There are three sisters; all suffer of

seizure disorders, among four children of poor parents from Hathas in Aligrah, UP. About two years before this visit, as her mother informs that the elder two sisters were under the treatment of local healers. As she narrates further the episodic drama and the treatment procedures of healers: *pir*, *mulaji*, *tantrik*, etc. in Hathras. A *Mulaji*, a Muslim religious healer, treated these sisters in Gahaziabad who administered some herbal medicine and massaged the Sunflower oil on the whole body of both and it continues for the nearly two months. Their mother noticed no relief from the local treatment. She was totally lost to hope. A closed relative told about these symptoms as epilepsy and direct for the treatment. This relative stay in Delhi and is well educated in the often interact the family. These two married sisters were referred and presented themselves in the OPD and treatment follows.

Meanwhile elder sister *Arth* was married off in the state of hopelessness of epilepsy cure and *Svit* visits the hospital with her mother for the treatment and *Arth* also come along when she need medicine. *Arth* never come with her husband and she try to make *her way* out to the hospital. On the each visit 15 days medicine are given to her and hence it seems she visits her mother every two weeks and stay till she gets her medicine. Her mother informs that it was told in advance to her husband and his parents' i.e. in-laws. But it seems *not so* (?). As she continues to narrates episode of seizure during the marriage of *Arth*, her elder daughter marriage she narrates while *Arth* was about to take the *phere* – in Hindu ritual of marriage both husband and wife take seven scared rounds of fire in presence of the all the relatives, then patient had an attack of *seizure* in the special room and the *phere* were delayed for one hour then it was managed to carry out the *phere* with much of the defense to the groom relatives.

Their mother while narrating the suffering caused due to the disease she expressed her agony:

“*Ya to bhagwan mujhe uthale, ya mere tino batiyo ko tik kar de!*” *barma jeevan nark ban gaya be!*” (Let the God give me the Death or Give the cure of all my three daughters, our life has become the hell!).

She became sad and said there is nothing enjoying in my life and she broke to weep before me. I consoled her and advice them for future.

7. *Yasda*, 26 years, married woman from Nand Nagari who is suffering *seizure disorder* for the last thirteen year. As her care giver accompanied her to OPD where I probe them. She had injuries on the forehead near left eye. She had been treated for it in GTB Hospital first in emergency after she was referred to here with her husband. I saw her feeling uneasy and dizziness and relaxing the on the chairs near to Clinical examination room and I offered her and my room where she relaxed on the stature and her Husband and her Parents sat outside the room and I conducted informal interviews of her parents.

They narrate that *Yasda* had a history of Seizure disorders three to four every day for the past several years. Initially her parents treated her for the seizure in Bareilly and Neeraj Clinic in Haridwar for three years and her parents' recall that about 1.5 lakh has been spent on her treatment in these clinics. She was treated in RML Hospital, and some antiepileptic drug reacted and her situation turned very worse. Her parents became hopeless of the treatment of these seizures in hospitals of Delhi –Dr RML hospital, GB Pant hospital etc.

She started her treatment again in our hospital and frequency reduced to *one or nil per day* as tells her husband. Because of the treatment she stays with her husband and two children with her parents in Nand Nagari. Her husband works in private factory earn very merge amount salary and is very difficult to support her treatment in private clinical setting. Her husband mentions that he stay with her in-laws in order to cares her and our children.

8. *Sumi*, 25 years married woman who resides with her parents in Radha Vihar, Saboli extension, Delhi and she had been married in the Meerut. She had developed the complained of seizure just after her 3rd child. Prior to this she developed inability to pronounce the words and failed to express herself and gradually she lost the recognition to all the family members. Her husband who resides in Meerut left her with three children in her parents' house in Delhi where she is living as deserted woman for five years and taking the treatment. Initially she took treatment from the *molvie* and *bhagat* in Delhi, Meerut and Gaziabad and no cure for the disease and none of these healers told her about her disease. They were treating her for the

supernaturally: her parents think it is *upri hawa*, heavenly punishment, as she had experiences of the disturbed her speech dysfunction, could not recognize proper words and failing to recognize the family members and what to say. Her parents stay in Delhi and she had been married for years and had three children staying with her as her husband left her because of the disease. She visited LNJP Hospital (formerly Irwin hospital) where she took treatment for the seizure but did not get the cure. But a local *mohvee*, a local Muslim healer told her about this disease and directed them to hospital which is very near to her house. She visited the hospital with her brother. *Sumi* had a diagnosis of General Tonic clonic Seizures (GTCS) and her treatment had been started for one and half years. Since then the treatment has been very effective and frequency has reduced much. Earlier seizures used to be for an hour or more but after the treatment at least it is reduced for 5 to 10 minutes. In marital family life her husband left her due to seizure and her husband does not care her and their children. Her parental family members are supporting her and her children. Her brothers are looking after the treatment part from the hospital. It is told that her brother took loans and claimed expenditure of Rs 25,000/- for her treatment till now. *Sumi* is second among four children, two brothers and two sisters. She had one elder sister who is married and has normal children, then a brother who is married and has normal children and then *Sumi*, a third child of her parents followed by a married brother with normal children. *Sumi* has one elder son and two daughters. She is being cared by her two brothers in most of the time and her father also cares her. *Sumi* is taking care of her children during the day but during nights she had seizures in night sleep.

Epileptic Married man and his mental Agony?

9 *KA*, 30 years, married and living in the Kastalakasambad, Railway station, Ghaziabad. He had been blessed six children but now two children, one boy and a girl, alive and is living with his wife in the same vicinity where his other five married brothers are living. *KA* being the eldest in the family and earlier he used to support the family. But after the seizure disorder he lost his job and failed to support economically his family. Prior to this he used to work in the grill-gate, Iron Gate welder in the local shop and used to earn good amount to support his family and brothers too. But after the diagnosis of this problem, he is under the treatment from our hospital and his neighbor comments on his behavior as the *pagal* (mad). His intimate relationship with his wife has become stressful. His wife presses him to stay separate from his other brothers. But *KA* refuses to his wife as he thinks that during the seizure who will help him? He stressfully mentioned me that because of the disease I will remain here together. He expresses his suffering as

“mujhe lagta he ke mai mar jaunga, mere family members mere dek-bhal nahi karte, lekin mai bahar bhi rah sakta hu par mujhe es rog ke karan yaha rahna padta he, kyuki parivaar ke log mere dek bhal karege yadi mai yaha rahna hu to” (I feel that I will die because my family members do not care me. I can stay outside this house but I have to live here so that they will definitely care me, therefore I do not leave or separate from my parents).

He further felt that

Ye bimari mujhe buri lagti he na jane kab keya ho jaye? Mai keya karu? (This disease I do not like much, it is not clear when and what can happen? What should I do now?)

Says that his old parents support him at the time of seizure and *KA* need more care during this time. His wife supports the old parents in laws in the care of her husband. But other of his brothers and their wives do not support them in the care. Further his younger brothers curse him as he is not contributing economically. *KA* took the traditional treatment from the local healers in different places with his parents. He further also adds about the places where he had been treated for the seizure. He went to Meerut with his parents to traditional healer who told his parents *“kuch kara rakha he apke ghar me!”* (Some body has done something to your house). This and many other healer gave him several *tabeej* (amulets) to tie on upper arm, but it did not cure the disease, as felt *KA*. Then he also went to Gondi sarai, a village near Hapur in Gaziabad where he is receiving the treatment while getting the treatment in the tertiary care hospital. Moreover his parents have already planned a visit to *dargah* (Muslim religious shrine) / *manjaar* in Roorkee and Naurangabad for the treatment. However *KA* is well aware about this hospital treatment and admits the benefits-reduced the frequency seizures now to once in two to three months which was earlier reverts-two or three episodes in one month. Parents still have faith that religious cure from the *manjaar* in Roorkee and

Naurangabad, UP will fully cure the seizure of their son.

Family and Kinship care Analysis

Dementia

On focusing the detail of family, sibs and other possible care givers in the kinship network, it seems from these brief case histories wherein we have restricted the use of the family detail and where they are living and possible resources are available for care and treatment of dementia and epilepsy. In case of dementia the clinical symptoms appear when a person cross the age of 50 year or above, in our analysis the average age is 63.5 years, here at age this nobody is around the grand old person with dementia except the spouse. The children by this time get married off and stay away or separated from their parents. The poor persons with dementia remain behind and don't know with whom he is living with. They as caring kin people knows well what he or she is to us but the person with dementia is *now* in a different personhood in the family where very less number of kin or sibs or spouse remain.

Before we give the brief observation of our analysis in people with dementia in the families in the northern part of India, we give synoptic view of the family and kinship caring ties of the African-American caregivers to the person with dementia then follows our own analysis.

A review article of Hargrave(2006) emphasis on the features of family and kinship ties of the African-American caregivers to the person with dementia mentioned that the nature of the relationship between the dependent elder and his/her caregiver vary across ethnic group. White caregivers are more likely to be spouses, whereas African-American caregivers are more likely to be adult children, extended relatives, or friends. Several studies emphasizing the care giving aspects among the African-American are well reported in caring the people with dementia among black and white people-a comparison of adaption, adjustment, and service utilization for the Care of dementia in Black and white caregivers (Hinrichsen and Ramirez,1992), different issues of race, ethnicity, and culture in care giving research(Dilworth-Anderson, Williams , Gibson,2002), dynamics of care giving of demented elder among black and white families(Lawton , *et al* 1992), and an analytical review of racial, ethnic, and cultural differences in dementia care givers(Connell and Gibson,1997).

In general, African-American caregivers as compared to white caregivers are more likely to be younger, unmarried, with less formal education, and fewer financial resources. Because of their lower income and higher poverty rates, the financial stress of care giving may pose a greater emotional burden on African-American caregivers (Hargrave, 2006).She elaborately mentioned in detail that African-American caregivers, as compared to white caregivers, are more likely to provide more hours of care, higher-intensity care, and are more likely to report more unmet needs in terms of support and access to services (*ibid*). Many African-American caregivers are also actively caring for other people in addition to the frail elderly, such as minor children, grandchildren, and other family members. Even though African-American caregivers are caring for severely debilitated elders and other family members, they are less likely than white caregivers to use formal care services like nursing homes (Haely, *et al* 1996).

Numerous studies have reported that African-American family caregiving of dependent elderly persons is performed within a collectivistic structure composed of different people with varying levels of involvement in daily caregiving activities (Dilworth-Anderson , Williams, Cooper,1995; Burton , Dilworth-Anderson ,1991). Since kinship ties are a very powerful force in African-American families, many investigators thought that African-American caregivers receive significant support from their network of family members. However, more recent studies suggest that prior research may have overestimated the availability and extent of support that African-American caregivers receive from other family members (Hinrichsen and Ramirez ,1992; Cox and Monk, 1996; Fox , Hinton , Levkoff, 1999). These studies suggest that adult children of dependent elderly persons may be adversely affected by the other commitments in their own lives, which may severely limit the amount of assistance they can offer frail African-American elderly. In the midst of an extended family network, one primary caregiver emerges who bears the burden of being the sole decision maker, and has few opportunities for shared responsibility and shared decision making (Fox , Hinton , Levkoff, 1999).

In our analysis too, we observe that among people with dementia remains with their spouse – either husband or

wife. Only unmarried children, daughters or sons remain to support. Most of the children married, particularly son and their wife either prefer to stay away from the parental house or staying together then they remains *functionally away* from the care giving mechanism though they are living together with their families-wife and the children spatially at different space within the same parental house. Such are the sons who are forced to stay with as they cannot go outside to live. Like in case of HKD have seven married children, four sons and three daughters. Daughters are away and outside the kinship care network as they remain with the in laws. Her sons hardly find time for the care their mother and whole responsibility remains with father, who is entirely for her care besides other home chore.

In contrast KR another woman from the rural area of Baruat near Delhi and her husband who is refused to care her. She also denied care by her elder married son and separated from the parental family and start living separately with his wife and children and do not care much to his mother. Remaining unmarried sons under the stress approach the elder sister in Delhi for help in her treatment, as *dutiful daughter* she took all responsibility for her mother treatment. However the unmarried younger brothers economically support her elder sisters in the treatment. Married daughter and her husband are taking care of KR.

Here it reminds us the reference of a film "*complaints of a dutiful daughter*" by Deborah Hoffman and the Taylor's article(2008) "*On Recognition, Caring and Dementia*" and the *Politics of care*, a commentary of Lawrence Cohen on the latter article. In this film a tag appears "What's, a daughter to do when her mother ask: "how exactly are we related?" (cf Cohen, 2008).

Similarly, parents, either father or mother left behind uncared by their sons in their home setting. Their sons are doing the job in far off cities, as in case BS, father, left behind to mother alone in their village. Their sons working in Delhi and up knowing the situation of the father they brought him in Delhi for his treatment as one (RS) of us was interviewing the son as well as his father being treated for dementia in the in ward patients. It is planned after the discharge BS would be sent back to his village in a district of eastern UP where his wife will look after again. However other lateral kinsmen-brothers of BS and their wives and children will remain functionally away from the caregiving system. Similarly, AD, a woman of 75 years being treated for dementia who is well received and being cared well not only by her sons but by their wives and her grand children also caring the grandmother. The care of elderly person with dementia pose a different stress to the care givers- usually the spouse either husband or wife- least supported by the eldest married sons, however younger unmarried sons always extend their help. The family and Kinship caring analysis of dementia is different in many respect to epilepsy- clinical symptoms of dementia are irreversible.

Epilepsy

Let us see the how do people- children with epilepsy, married women and married man experiences living with epilepsy in the family and deal with disease. First we summarize the coping strategies by these groups, as we had already reported elsewhere in the World Congress followed by the latter analysis¹.

There is much variability in the analysis of the description in interviews. Some major themes were evident from the data. Attitudes to epilepsy were in some cases dominated by a marked non-acceptance, where in other cases the diagnosis appeared to be a fairly well-integrated part of life. In most of the cases patients elaborately described their experiences the manifestations of the epilepsy. They feel as the epilepsy is disease of uncertainty and disappointment. After having had a seizure were clearly expressed. One of the patients said that he always believed the most recent seizure to be the last and he experienced an enormous disappointment and sadness after each new seizure. Medical treatment makes these patients more curious about the medicine how long these will be continued. There were expressions of a negative self-image and even of self-destructive tendencies, as we had seen in case of *Ush* and two sisters *Arth* and *Svit* whose mother expresses a state of hopelessness due to the disease. There is similar expression in many other cases. The feeling of insecurity was however often present. Perceptions of the reactions of other people to epilepsy emerged as another problem area. Several interviewees demonstrated some difficulties dealing with the reactions of other people: what other people say or think about their disease. Almost all declared that they had sometimes met a negative attitude or lack of understanding from other people.

A number of interviewees had the experience of being harassed at school because of epilepsy, which they said had had a strong negative impact on their lives. When discussing their employment situation and leisure time activities, the attitudes of others often emerged as the greatest problem. Some individuals felt restricted at work because they couldn't take part in certain tasks, due to the risks involved or because they did not have a driving license. There were also a number of interviewees who felt they were excluded from employment because of the disease as we had seen in case of *KA*, a married man lost his job and added to parental family as burden.

Cognitive problems were commonly reported in the interviews. As in case of *KV*, we saw this school boy who not only suffered from the seizures disorders but also facing the *caste* discrimination in the class from the classmate as well as from the teachers and faced to discontinue his studies, as in case of *SNZ*, 12years, a Muslim girl from lower socio economic group also faced the social discrimination in the class due to disease. School going children with epilepsy mostly complain concerned to their memory, but a few interviewees experienced speech difficulties or attention difficulties. Feelings of fatigue or of being easily exhausted were also frequently reported.

Married Woman often pose different problem. We have seen in case of *Yasda*, 26, who is being accompanied by her husband who stay in house of father-in-law for her better care as their house is near to the hospital. Her husband does some work in private factory and hardly his personal family expenditure. Similarly case of *Svit*, an elder sister of *Arth* who is married and taking treatment from the hospital and periodically visit our hospital with her mother who brings both the sisters. These aspects give a deeper insight about the how the problem is being felt in the family members. Cognitive problems were commonly reported in the interviews. Mostly the complaints concerned memory problems, but a few patients experienced speech difficulties or attention difficulties.

Family and kinship care analysis of school children with epilepsy, most them are cared by their parents, besides maternal and paternal uncle, as in case of *VK* and *KV*, where as school going girls remains under the supervision of mothers and visit hospital for the treatment and also their parents take decision about their children, boys or girls, where to go for the treatment and parents are around them most, rarely other kinsmen care them for long. Married women, *Arti* and *Svit*, remains with their mother despite of their marriage they frequently visit hospital with their mother rather than their husband or their in laws. Their husband and his other family members are not involve in their care or treatment and kept away from the caring job. Perhaps due to the stigma associated to the disease. In contrast, case of *Yasda*, another married woman who is being cared well even her husband had searched a job in order to stay near to her in the house of in-laws who are staying very near to the treatment site in Delhi. Her husband care his wife and her children even he visited us and presented her case along with the in- laws. Still another aspect of the husband as care givers we observe that one husband has left his wife and their three children back to the parents of his wife in Delhi where she is being given care by the younger brothers and parents and managing her treatment and the children. It is this aspect which becomes the burden to the parental family and people are living with it or they have learned to with such diseases. Married epileptic man still looks for parental support besides wife and his children. These are the uninvited suffering added to one who is living to gather just because of being *affinal kins* or sibs in but this burden of care being carried along in the life.

In sum, school children are entirely depend upon the parents who are occasionally supported by close relatives, married women present differently- husband as caring, not caring or even not aware of the diseases of their wife suffer or take treatment whereas men has different perspective to view the epilepsy and its suffering.

Conclusion

The behavioral and psychological symptoms of dementia and epilepsy are major causes of stress to family and kinsmen providing care to people with epilepsy and dementia. Above interpretation from the Family and Kinship care analysis show that is family still central of caring? But the caring in the dementia differs from the epilepsy. In case of former, old people suffer only whereas in epilepsy anybody can suffer or any available kinsmen can care the epileptic person but in case of dementia it is, in most of cases, the spouse-either wife or husband. The training family caregivers in the management of these diseases, including problem solving, memory training, and reality orientation, can reduce the level of agitation and anxiety in people with dementia.

The challenge for developing countries is to develop *culturally appropriate interventions* that can be delivered within existing resources, such as supporting families in their role as caregivers. Here it is medical anthropological intervention are required which has not been yet utilized.

We feel about a care giving model for the north Indian population groups which should be home based care coupled with regular training given to the family members of both the diseases. They should be provided material and other relevant information. In many developing countries, people with dementia are still thinking it as the *madness* and consult the traditional healers. The latter is more common in people with epilepsy and reported elsewhere in this World congress¹. A simple model for the management of dementia and epilepsy, neurological disorders, must be based by existing community-based health care providers, trained to provide such services can reduce the burden of the diseases in the family.

In the last, we feel the need to focus the on the following areas that we must plan our services to:

- develop *cheaper and more efficacious medicines*. Many currently available medications have significant side effects and are too expensive for many patients in developing countries. Newer medications need to be developed with lower costs, fewer side effects, better efficacy, and less frequent dose schedules(Chanadra *et al*, 2006)..
- Use *Indigenous systems of medicine*. Many people in developing countries use local indigenous medicines. More research needs to be done on the pharmacological properties of those medications (*Ibid*). We as the medical anthropologist need to examine that how the traditional healers can be helpful to such health care providers. There should be regular programme for the local healers- who must be taught the new advancements in caring, particularly people with dementia and epilepsy in this region. *Rastriya Manav Sangharalya*, (National Museum of Man) in Bhopal, Madhya Pradesh has conducted some workshops of Tribal healers or traditional healers of various tribal areas in the country(personal communication).
- Eradicate the *stigma associate with disease*. The stigmatization of patients with living with epilepsy or dementia or any other, neurological disorders and of their families is still prevalent, particularly in rural and remote areas of the North India and because of this they are often prevents the patients from seeking and obtaining appropriate medical care. Develop an open communication and a good working relationship with the key informant from the patient's support network in the community rural areas or in residential welfare association in urban areas. Information to the caregivers about the etiology, treatment, and disease course of dementia and epilepsy must be supplied regularly to the general public of this region, north Indian rural people, who are ignorant about such disorders and relates such diseases to supernatural causes. Volunatry organisation can play a role in brining the catatlytic changes in the attitude of the people.
- Provide the family with clear educational materials about dementia and epilepsy- including, pamphlets in local language, do's and don'ts for the care givers of these care givers training.
- Educate north Indian caregivers of dementia and epilepsy about long-term care with social support groups².

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Notes:

1. A paper "*People living with Epilepsy: Narrative of OPD patients.*" By Ravinder Singh, Kiran Bala, R K Jha and Upmesh K. Talwar(Unpublished), submitted in the Panel on Public Health and Anthropology, of the 16th World Congress of The International Union of Anthropological and Ethnological Sciences (IUAES 2008) 27th to 31st July 2009 in Kunming, Yunnan, China has included these cases studies which two of us(*RS and RKJ*) have done during the home visits.

2 We run an epilepsy clinic in the afternoon and group meetings are held wherein old patients of epilepsy and their care

givers usually meet with the care givers of new cases of epilepsy with their family members. Some of the our colleagues Ravi Kishen Jha, Dr Sushama Kumari, Himanshu K Singh, Psychiatric Social Workers, facilitates this group meeting and often one us(RS) attend such meeting as the non-participant observer. Here both, new as well as old epilepsy pateints and their care givers exchange their experiences of caring epilepsy patients in their family situations. After sometimes they become friends and among themselves they find solution of their day to day problems related to caring their pateints. We encourage such frequent meetings of the caregivers to participate and form the support groups and to reduce caregiver burden and to learn new effective coping strategies during these meetings. This is an empowering approach to the people living with epilepsy.

References

- Burton LM, Dilworth-Anderson P(1991) The intergenerational family roles of aged black Americans. *Marriage and Family Review* ;16:311-322.
- Brodaty, H., and M. Gresham(1989). “Effect of a Training Programme to Reduce Stress in Cares of Patients with Dementia.” *British Medical Journal*, 299 (6712): 1375–79.
- Cohen, Lawrence (2008). Politics of care: commentary on Janelle S Taylor’s“ On Recognition Caring, and Dementia”. *Medical Anthropology Quarterly*, Vol.22 , Issues 4 pp. 336-339
- Chandra, V., M. Ganguli, R. Pandav, J. Johnston, S. Belle, and S. T.DeKosky(1998). “Prevalence of Alzheimer’s Disease and Other Dementias in Rural India: The Indo-U.S. Study.” *Neurology*, 51 (4): 1000–8.
- Chandra, V., R. Pandav, H. H. Dodge, J. M. Johnston, S. H. Belle, S. T.DeKosky, and others(2001).“Incidence of Alzheimer’s Disease in a Rural Community in India The Indo-U.S. Study.” *Neurology*, 57 (6):985–89.
- Chandra,V., R. Pandav, R. Laxminarayan,C.Tanner, B.Manyam, S. Rajkumar, D. Silberberg, C. Brayne, J.Chow, S.Herman,F. Hourihan, S. Kasner, L. Morillo, A. Ogunniyi, W.Theodore, and Z. Zhang(2006). *Neurological Disorders*. Chapter-32 in Mental health Disorders. The International Bank for Reconstruction and Development / The World Bank, 2006
- Connell CM, Gibson GD(1997). Racial, ethnic, and cultural differences in dementia care giving: Review and analysis. *Gerontologist*;37:355-364.
- Cox C, Monk A(1996). Strain among caregivers: Comparing the experiences of African American and Hispanic caregivers of Alzheimer’s relatives. *Int J Aging Hum Dev*, 43:93-105.
- Dilworth-Anderson P, Williams SW, Cooper T(1999). Family care giving to elderly African Americans: Caregiver types and structures. *J Gerontol B Psychol Sci Soc Sci* ,54(4): S237-S241
- Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *Gerontologist*, 42(2):237-272.
- Fox K, Hinton W, Levkoff S(1999). Take up the caregiver’s burden: Stories of the care for urban African American elders with dementia. *Culture, Medicine, Psychiatry*, 23:501-529.
- Gourie-Devi,M, G.Gururaj, P Satishchandra and D K Subbhakrishna(2004a).Prevalence ofNeurological

disorders in Bangalore, India: A Community- Based Study with a comparison between Urban and rural Area. *Neuroepidemiology*, 23:261- 268

Gourie-Devi, M, G. Gururaj and P Satishchandra (2004b). Delivery of Epilepsy Care to the Community: Towards the national Epilepsy control Programme. In *Mental Health-An Indian perspective(1946-2003)* Ed. S P Aggarwal, DGHS, Ministry of H & FW, GOI, New Delhi.

Haley WE, Roth DL, Coletton MI, (1996). Appraisal, coping, and social support as mediators of well-being in black and white family caregivers of patients with Alzheimer's disease. *J Consult Clin Psychol*, 64:121-129.

Hargrave, Rita (2006) Caregivers of African-American Elderly with Dementia: A Review and Analysis. *Annals of Long-Term Care*, Vol:14

Haupt, M., A. Karger, and M. Janner. 2000. "Improvement of Agitation and Anxiety in Demented Patients after Psychoeducative Group Intervention with Their Caregivers." *International Journal of Geriatric Psychiatry*, 15 (12): 1125–29.

Henderson, A. S., and A. F. Jorm. 2000. "Definition of Epidemiology of Dementia: A Review." In *Dementia*, ed. M. Mario and N. Sartorius, 1–34. West Sussex, U.K.: John Wiley.

Hendrie, H. C., B.O. Osuntokun, K. S. Hall, A.O. Ogunniyi, S. L. Hui, F.W. Unverzagt (1995). "Prevalence of Alzheimer's Disease and Dementia in Two Communities: Nigerian Africans and African Americans." *American Journal of Psychiatry* 152 (10): 1485–92.

Hendrie, H. C., A. Ogunniyi, K. S. Hall, O. Baiyewu, F. W. Unverzagt, O. Gureje. (2001). "Incidence of Dementia and Alzheimer Disease in 2 Communities: Yoruba Residing in Ibadan, Nigeria, and African Americans Residing in Indianapolis, Indiana." *Journal of the American Medical Association*, 285 (6): 739–47.

Hinrichsen GA, Ramirez M (1992). Black and white caregivers: A comparison of their adaptation, adjustment, and service utilization. *Gerontologist*, 1992;32:279-381.

Jorm, A. F., and D. Jolley. (1998). "The Incidence of Dementia: A Meta- Analysis." *Neurology*, 51 (3): 728–33.

Lawton MP, Rajagopal D, Brody E, Kleban MH (1992) The dynamics of caregiving for a demented elder among black and white families. *Journal of Gerontology*, 42:S156- S164.

Marriott, A., C. Donaldson, N. Tarrier, and A. Burns. 2000. "Effectiveness of Cognitive- Behavioural Family Intervention in Reducing the Burden of Care in Carers of Patients with Alzheimer's Disease." *British Journal of Psychiatry* 176 (1): 557–62.

Melzer, D., K. Pearce, B. Cooper, and C. Brayne. 2004. "Alzheimer's Disease and Other Dementias." Department of Public Health and Epidemiology, University of Birmingham, U.K. <http://hcna.radcliffeoxford.com/dementiaframe.htm>.

Rajkumar, S., S. Kumar, and R. Thara. 1997. "Prevalence of Dementia in a Rural Setting: A Report from India. *International Journal of Geriatric Psychiatry* 12 (7): 702–27.

Ravinder Singh; Kiran Bala, R K Jha and U K Talwar (2009). *People Living with Epilepsy- Narratives of OPD patients*. Unpublished paper submitted to Panel on Public Health and Anthropology, 16th World Congress of The International Union of Anthropological and Ethnological Sciences (IUAES 2008) 27th to 31st July 2009 in Kunming, Yunnan, China.

Saillant, Francine and Serge Genset (2007). *Medical Anthropology-Regional Perspective and Shared Concerns*, ed. Page-27. Blackwell Publishing.

Taylor, J. S. (2008) . On Recognition Caring, and Dementia, *Medical Anthropology Quarterly*, 22(40): 313-335