CHAPTER III

REVIEW OF LITERATURE

There is sufficient literature to suggest that epilepsy, with its unpredictability, episodic nature and varied manifestations has been historically shrouded in mysticism and superstition. It was only in 470 B.C that Hippocrates in his treatise, ‘On the sacred disease’, stressed that ‘epilepsy has a nature such as other diseases bringing about the first scientific and medical approach to the disorder (Temkin, 1971). None the less, lingering doubts and fears about the disorder continue till date.

It was only in the 20th century that a new wave of neuro-scientific enquiry swept over Europe with the emergence of anatomists, physiologists and pathologists trying to explain epilepsy in a scientific manner. Following this development there has been abundant research done to investigate the medical aspects of epilepsy. Various journals such as Epilepsia, Seizure, Epilepsy, International Journal of Neurology etc. focus on trends in treatment and new research done in the field of epilepsy. Since decades the studies that find mention in these acclaimed journals have been primarily medical in nature.
It is only recently that psychological, psychosocial and neuropsychological studies have been emphasized upon. The trend in recent research on management of epilepsy is that of a holistic nature where in most medical and paramedical practitioners believe that a comprehensive care program for epilepsy is most beneficial for people with epilepsy. A holistic intervention of this nature not only targets seizure control but also deals with the associated problems of epilepsy that are predominantly psychosocial in nature.

The following chapter attempts to highlight important studies and investigations conducted in the field of epilepsy. Since the orientation of the current research is psychosocial, studies relevant to psychological issues have been emphasized upon. There is a plethora of medical literature available focusing on epilepsy but only those studies which are relevant to the subject under study are mentioned here. Also it is important to note that for sections such as epilepsy and depression and women and epilepsy there are very few Indian studies that can be mentioned.
Contrary to these sections, there is enough Indian literature to support international claims in the fields of neuropsychology of epilepsy and epidemiological studies.

3.1: Epidemiological Studies

Epilepsy is a major health problem and a neuropsychological condition in both developed and developing countries. Globally, approximately 10% of the population will experience a seizure in some point in their lives (Hauser & Hesdeorffer, 1990). Nearly 1 in 20 of the general population will have an epileptic seizure at some point in their lives and 1 in 200 will have recurrent seizures which are commonly known as epilepsy (Sander, 1996). It is interesting to note that the prevalence rates of epilepsy are reported to be ten times that of multiple sclerosis and a hundred times that of motor neuron disease (Brown et al., 1993).

Epidemiological studies from the so called developed part of the world have revealed that epilepsy occurs with a prevalence rate of ~5/1000 in children (Cowan et al. 1989) and 4-7: 1000 in adults (Hauser & Annegers, 1993).
In the UK there are an estimated 350,000 people living with a diagnosis of epilepsy (Brown & Betts, 1994). New cases keep getting reported with the highest rates occurring in infants and young children and in the elderly (Brown et al., 1993). Although the prevalence rates of epilepsy in developing countries, India included is reported to be twice that of the developing world; this may be an erroneous estimate due to the misdiagnosis and inclusion of symptomatic seizures, single seizures, febrile seizures and inactive epilepsy (ILAE Commission report, 1997).

In India, a comprehensive meta analysis of all published and unpublished studies had been carried out highlighting epidemiological facts (Sridharan & Murthy, 1999). After taking into account the design of the study, differences and standardizing for age, the following prevalence rates per 1000 population and 95% significance rate was found.

Overall: 5.59 (4.15 to 7.03)
Men: 6.05 (3.79 to 8.31)
Women: 5.18 (3.04 to 7.32)
Urban: 6.34 (3.43 to 9.25)
Rural: 4.94 (3.12 to 6.76)
The rates of men having epilepsy were higher than those for women, though not statistically significant. Also it is often observed that epilepsy in women is concealed, due to the associated stigma (Shah, 2000). Although urban rates were also reported to be higher than rural, there is no statistically significant difference between them. The study also highlighted that age-specific rates were higher in the first three decades of life (Sridharan & Murthy, 1999).

Since the population of India is so large, it is important to study the prevalence rates of epilepsy in the different communities which might have a certain genetic predisposition towards developing seizures. Four community based surveys representing north, central and south of India have shown prevalence rates per 1000 population of 2.5 for Kashmir (Koul et al., 1988), 3.6 for Mumbai Parsis (Bharucha et al., 1988), 4.4 for Bangalore (Mani et al., 1998) and 4.9 for Kerela (unpublished data).
Also in India for a population of over 900 millions, there are only a little over 300 qualified neurologists, a prevalence ratio (neurologist/population) of 1/3 million (Mani, 1988). Over 70% of the Indian population live in rural areas, but almost all the neurologists practice in urban areas. Hence majority of people with epilepsy in India and in other developing countries are seen, treated and followed up in primary and secondary care facilities.

Studies on the prognosis of epilepsy in India are still unavailable. It is important to know whether patients who have had epilepsy for a long time, before being treated are more or less likely to go into remission. There is evidence from other countries to support the view that patients who have many seizures before initial treatment with antiepileptic drugs are more likely to develop refractory epilepsy (Kwan, 2000). Also there is no data published on the mortality of epilepsy in India. Again studies from developed countries give an indication that people with epilepsy have a 2 to 3 times greater risk of dying than the general population (Chadwick, 1994).
Therefore it is evident from the studies mentioned above that in spite of infrastructural limitations, and the geographical vastness of a country like India, medical practitioners have made the effort to scientifically investigate the prevalence rates of epilepsy consequently keeping pace with studies available in the international arena.

3.2: Epilepsy & Depression

A link between depression and epilepsy was proposed by Hippocrates (Temkin, 1971). It is the most prevalent neuro-psychiatric disorder in epilepsy. It occurs in up to 80% of epileptic patients (Robertson et al., 1987). Recent research also indicates that epilepsy is not a benign condition; on the contrary it comes with a plethora of other associated conditions (Nashef et al., 1995). Ongoing seizures have to be coped with and for some patients these may be short lived episodes but for some they are psychologically traumatic as they not only occur frequently but cause embarrassment due to bizarre behaviours and incontinence in some cases as part of their seizure activity. The need to be compliant at all times with regards to medication and following the restrictive drug regimen also contributes as a
source of additional stress especially when there are side effects such as weight gain, facial hair, acne and cognitive difficulties. People with epilepsy very often have to deal with treatment failures especially those with intractable or refractory epilepsy. All these experiences have a cumulative effect and foster a feeling of hopelessness.

What is even more damaging psychologically is the failure of surgical treatment which occurs in one third of the cases with epilepsy (Thomson & Grant, 2001). There are also patients who go through the lengthy procedure of pre surgical assessment only to be rejected in the final stages. All this contributes to the frustration that builds up within the individual leading to a feeling of helplessness and hopelessness and finally depression. Therefore it is not unusual that depression is the most frequently diagnosed psychiatric disorder in patients with epilepsy (Betts, 1981).
There are various aetiological factors, which contribute to the problem. Psychological factors such as social stigma attached with epilepsy and the obvious discrimination, occupational difficulties, unpredictable losses of consciousness leading to a feeling of low personal control over life are some of the contributory factors. Also anti epileptic medication may produce depression as a side effect e.g. Phenobarbital (Hirtz & Nelson, 1985). There are also dysphoric conditions directly related to seizures as pre and postictal depressive syndromes. Although they are linked to the epileptic syndrome their expression and intensity often varies with dependence of anti epileptic drugs. Another type of epilepsy related depression is the so called 'interictal dysphoric disorder' (Blumer & Altshuler, 1997). It is described as having a sudden onset and a brief duration interictally. The main symptoms are depressive mood and irritability including anger and fury. The therapeutic strategy often used to treat these types of physiological based depression is the use of anti depressant medication. At most times medication has proven to be effective within a time frame of only few days even if low doses are prescribed.
Besides anti-depressant medication interventions based on psychotherapeutic models can also be implemented, the most suitable being ‘Interpersonal psychotherapy for depression’ (Klerman et al., 1984). This psychotherapeutic model sets depressive episodes into the context of specific interpersonal tasks. According to the manual it can also be used for the treatment of post operative depressions during the rehabilitation period. Psychotherapeutic interventions can also be used in cases where depressive tendencies in epilepsy are a result of the ‘learned helplessness’ that people with epilepsy live with. In such cases cognitive behaviour therapy is more effective where in there is alteration of the pessimistic external attributional style in order to offer more confidence into self-efficacy. Therapeutic interventions for epilepsy are discussed more in detail in the last section of this chapter.

What is of importance is to diagnose and treat this associated depression because besides impairment of quality of life, there is also a high suicide risk (Barracklough, 1981).
It has been reported that suicide in people with epilepsy is approximately four to five times more common than in the general population and twenty-five times more common in people with temporal lobe epilepsy (Mathew & Barabas, 1981).

Epilepsy has also been associated with anxiety. Anxiety has been reported as a common consequence of the unpredictable nature of epilepsy (Baker, 1997). For many patients it is the diagnosis of epilepsy and the following adjustment which results in feelings of anxiety; and anxiety can also occur as an integral part of the pre ictal, ictal and post ictal aspect of an individual’s seizure (Betts, 1981).

Therefore it is important to identify and analyse the occurrence of anxiety and depression in people with epilepsy to improve the overall quality of life and more importantly for proper treatment implementation.
3.3: Neuropsychological aspects of epilepsy

Cognitive and behavioural dysfunctions are associated with children as well as adults with epilepsy. Neuropsychology which is the study of brain behaviour relationships has immense potential in terms of application in the field of epilepsy. Neuropsychological assessment, a sensitive measure of brain dysfunction, which can lateralise and localise brain damage is used effectively in the screening, treatment and rehabilitation of epilepsy patients. Several studies have described the nature of cognitive dysfunction in epilepsy in terms of deficits in intelligence, specific cognitive functions such as attention, memory and information processing deficits. The severity of the problem may amount to deficits, disabilities or even handicaps. The deficits in cognition in people with epilepsy often arise due to:

a) brain pathology responsible for seizures
b) brain damage as a result of recurrent seizures
c) the effect of anti epileptic medication including the type, dosage and number of antiepileptic drugs (AED’s).
The most commonly reported cognitive deficits in patients with epilepsy are related to attention and memory (Loiseau et al, 1983). Difficulties in comprehending fast speech, difficulty in concentrating for long periods of time and difficulty in concentrating in the presence of noise or when people are conversing in the background are common attention deficits reported by people with epilepsy. Attention deficits may also present as an inability to remember names, facts, faces or routes. Multiple tasks or even divided attention between two tasks such as writing notes while listening to a lecture is found to be difficult. Epilepsy also affects intelligence over a prolonged course of illness which is commonly reported as an inability to function in day to day activities.

Neuropsychological assessment in epilepsy has several clinical uses. The assessment is a comprehensive documentation of the working brain as it measures brain functioning while the brain is interacting with the environment. Therefore it is able to assess damage at higher levels of brain functioning.
In the case of epilepsy surgery, neuropsychological assessment is used extensively where in the prospective candidate has to undergo investigations from multiple perspectives to identify seizure focus. Neuropsychological assessment along with structural brain imaging and EEG monitoring are the chief components of this pre-surgical evaluation (Engel et al., 1996).

It is interesting to note that the cognitive behavioural side effects of AED’s can also be documented by neuropsychological assessment. It is ideal if the treatment of epilepsy can achieve seizure control with minimum cognitive and behavioural dysfunction as a result of AED’s but this is not always the case (Dreifuss et al., 1992).

With reference to the impact of epilepsy on education, children with epilepsy are often known to be at a risk of educational underachievement (Williams et al., 2001). They are often retained in school at a higher rate than expected when compared with matched controls (Farwell et al., 1985; Huberty et al., 1992).
The increased academic risk may be related to both the effects of having a chronic illness and the effects of a central nervous system (CNS) disorder. However, children with epilepsy have been found to be at a greater academic risk than children with other chronic illnesses, such as diabetes and asthma, as well as compared with children in the general population (Freeman & Hagen, 1990). There are various questions that remain unanswered about the underlying mechanisms and factors associated with academic vulnerability among children with epilepsy. Multiple factors other than the impact of seizures and medications may influence academic performance. They may include cognitive functions, environmental variables, personality and motivation of the child, family adjustment, and various social variables.

It has also been investigated that epilepsy is associated with learning disability. Individuals with learning difficulties commonly suffer from various concomitant conditions, epilepsies constitute up to 35% (Staufenberg & Brown, 1994).
Although, it is unfortunate that the prevalence of epileptic syndromes in learning disabled people is less well documented. Due to this lack of work being done in the field it is often the epileptic patient with learning disability that suffers in spite of the entire work dedicated individuals do involved in their care. The aims of high quality care for people with epilepsy and learning disabilities are the same as those for epilepsy alone, i.e. increased quality of life and more effective and efficient use of resources (Hannah & Brodie, 1998). Those involved in the therapeutic process are not just health professionals but also families, carers, social service, employment and educational agencies and people in the voluntary sector.

Neuropsychology also extends its application to neuropsychological rehabilitation which is useful in the treatment of cognitive dysfunction in epileptic patients whose seizures are well controlled (Bharathi, 1999). In India, work in the filed of neuropsychology is at par with the West. Methodologically sound studies have been conducted at the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India.
These studies have been conducted both in adult and child patients with epilepsy. Studies have been done in the field of neuropsychological assessment of cognitive deficits. A study conducted by Agnihotri et al (1972) researched cognitive deficits in 59 patients with generalised or partial seizures. Results indicated disturbances in intelligence, concentration, memory, abstraction, simple learning and attention. The impairment of attention was associated with impairment in all other functions. Kapur (1981) compared the neuropsychological functioning of 35 patients with epilepsy and 65 normal controls on a battery of tests to measure organic dysfunction. The results showed that epileptic patients were slower in their speed of performance on various tasks. Learning of new material was impaired while memory of previously learnt material was adequate.

Neuropsychological rehabilitation as a treatment procedure where in the neuropsychological deficits associated with brain damage are treated through psychological means has also been implemented in the Indian settings.
During the course of rehabilitation cognitive retraining is given to brain damaged patients in order to improve their cognitive functioning. The rationale is that change in behaviour of the patient arises due to deficient primary cognitive processes. The deficient cognitive processes are improved through graded tasks, which address the functions. Retraining is given continually till the patient reports symptomatic improvement (Rao, 1991). A recent study has utilised neuropsychological rehabilitation for treating cognitive dysfunctions in epilepsy. 56 patients with generalised or complex-partial seizures were divided into two groups of 28 each. Common complaints of the patients included cognitive dysfunction in attention and memory domains. The treatment group underwent cognitive retraining on a daily basis to improve attention, categorisation, information processing, planning and organisation. The retraining program lasted for 45 days on a daily basis for an hour. Compared with the control group the treatment group not only improved on cognitive functions but also on psychosocial functions. The study clearly highlighted the importance of neuropsychological rehabilitation in the treatment of epilepsy.
The importance of neuropsychological assessment in epilepsy is amply demonstrated by the studies carried out in our country. The studies have indicated that neuro-cognitive and neuro-behavioural dysfunction is prevalent in epileptic children and adults.

Therefore it can be concluded that the field of neuropsychology of epilepsy in India has kept pace with the developments in the international field. A continued recognition of the application of neuropsychology would further the treatment beyond mere seizure control for the person with epilepsy instead of restricting it to seizure occurrence.

3.4: Women and Epilepsy

Marriage, family and reproduction are important aspects of a woman’s normal life. Women with epilepsy are often denied this privilege in many parts of the world. This is often due to the stigma associated with epilepsy and the consequent marginalization (Chary, 2000).
In India till the late 90’s the law also rendered a marriage null and void and this could be used as grounds for divorce if either spouse had epilepsy. It is a known fact that this law was used more against women than men as marriage and childbirth were not an easily available option for several women with epilepsy in India (Singhal, 2000). To contribute to this problem there are doubts about the sexual adequacy of a woman to conceive children, fear of inheritance of epilepsy, issues related to antiepileptic medication and malformations and breast feeding further complicated the issue.

Catamenial epilepsy is very common amongst women with epilepsy. In this kind of epilepsy seizures may take place shortly before menstruation, during or immediately after it. Studies reveal that premenstrual and ovulatory phases are associated with highest seizure frequency (Devinsky, 2002). Controlling seizures that occur mainly around the time of menstruation is a difficult problem. It has been reported that for women who have regular menstrual cycles, a slight increase in the dosage of the antiepileptic drugs before the time of increased seizure frequency might be helpful (Singhal, 2000).
Some doctors prescribe an additional epileptic drug while some advocate the use of hormonal agents such as progesterone or birth control pills for women with Catamenial epilepsy. It must be pointed out that the effectiveness of this kind of hormonal therapy remains to be established.

Epilepsy in women is of much concern even in the child bearing years. The fears and apprehension that accompany pregnancy are often compounded for people with epilepsy and more so for women with epilepsy. In recent years attention has been focused on epilepsy in women of childbearing age. According to Devinsky (2002) it has been researched that there are higher rates of unplanned pregnancies among young women with epilepsy as some antiepileptic drugs may reduce the effect of birth control pills. It is also known that 90% of women with epilepsy will have healthy babies but this is provided all the steps to reduce the risks for seizure occurrence for mother and child have been taken before the pregnancy begins and there is good communication among the couple, the neurologist and the obstetrician.
Risk of developing a seizure disorder in children of parents with epilepsy is only marginally higher than that of the general population which is 3% (if the mother has epilepsy the risk is estimated at 5% and if the father has epilepsy it is 3% similar to that of the general population) if both the parents have epilepsy the risk is higher (Devinsky, 2002).

It has been researched that 25 -33% of women with epilepsy are likely to experience an increase in their seizures after conception. Sabers et al (1998) found that 21% had increased seizure frequency during pregnancy and mostly due to the sub therapeutic levels of the anti epileptic drugs (AED's). These sub therapeutic levels of AED's were due to deliberate noncompliance for fear of possible adverse effects of AED's on the foetus. The risk of birth defects also increases for women with epilepsy. It has been estimated that the healthiest woman will have a 2.5% chance of having a baby with a birth defect. This chance increases to approximately 6% in women with epilepsy. The use of anti epileptic drugs before and during epilepsy, especially in the first trimester is a major contributory factor to this increased risk.
Common obstetric problems of women with epilepsy are vaginal bleeding, abnormalities of the placenta (the organ that most importantly provides nourishment to the baby) and complications around the time of birth, such as high blood pressure (pre-eclampsia) and premature delivery.

A detailed Indian perspective on pregnancy and epilepsy is still not readily available. Although several major cities have initiated their pregnancy/epilepsy services, formal long term studies have not been conducted as compared to longitudinal studies performed in the West. The Sree Chitra Tirunal Institute in Trivandrum, Kerela has a pregnancy registry and encourages any woman with epilepsy or any physician caring for a woman with epilepsy to register with them. Centres in Mumbai, Bangalore, Hyderabad and Delhi run excellent epilepsy services which include care of women with epilepsy services which include care of women with epilepsy but the work done has not been scientifically documented to that great an extent (Singhal & Nag, 2000).
3.5: Epilepsy and Law

Laws and legislations for people with epilepsy were made many decades ago when there was no adequate treatment and poor seizure control. Today with effective anti epileptic medication almost 90 percent of the cases can have effective control of seizures for long periods and 70 percent can even be withdrawn of drugs (Mani, 1999). In spite of this medical development the laws remain the same thereby imposing restrictions that are unwarranted for people with epilepsy.

As we know epilepsy is a neurological disorder which may, may not be accompanied by disabilities. The common disabilities are uncontrolled movements of limbs and actions, characteristic of a tonic clonic seizure and an altered state of consciousness during which period the person with epilepsy may perform activities with any control and may have no memory of it after recovery. Therefore from a legal perspective it is not only important to control seizure but equally important for the individual with epilepsy and the treating physician / neurologist to be aware of the laws and the restrictions that it imposes on people with epilepsy.
For example in many countries it is against the law to carry certain types of drugs over a certain quantity without prescription. Therefore it is important to carry prescription papers especially when traveling to other countries. It has also been reported that people with epilepsy are arrested for being drunk or disorderly or for resisting arrest where in actuality they are having a seizure or post seizure confusion. Hence most local epilepsy organizations e.g. even the Indian Epilepsy Association’s Mumbai chapter provides for identifications with the disease mentioned and insist that people with epilepsy wear it (Shah, 2000).

Although epilepsy is an illness and not necessarily a disability, it is highly stigmatized and people with epilepsy experience the discrimination and differential treatment from as early as their school days. For individuals with well controlled epilepsy most milestones of life are easily achievable but for individuals with intractable of refractory epilepsy where seizures are uncontrolled every milestone is either more difficult than the previous one or simply unachievable.
Therefore it is important that government provide for certain sanctions for people with epilepsy in spheres of education, employment and legal protection to ensure a better quality of life for them. For example in USA, AMERICANS WITH DISABILITY ACT (ADA) protects all disabled people and epilepsy is mentioned as one of them. In India efforts are being made to lobby for epilepsy as a disability but the realization of such an act is a long way ahead.

In India one of the most recent achievements of people crusading for epilepsy has been the removal of epilepsy as a cause for annulment of marriage in 1999 (Mani, 1999). With respect to epilepsy in a supreme court judgment the word ‘epileptic insanity’ was pronounced as state of mind not responsible for its activities during period of automatisms (interpreted by court as temporary insanity). Also according to the Hindu Marriage act of 1955 that covers Hindus, Buddhists, Jains and Sikhs, it stated that a person subject to recurrent attacks of ‘Insanity of Epilepsy’ cannot have a legally valid marriage.
Although this law was exploited more by men to annul their marriage and remarry for dowry; it was only after 25 years of appeals and court cases that the government of India finally agreed to remove the term epilepsy as a cause for annulment.

Another area where quality of life for the person with epilepsy is gravely affected is that of employment. People with epilepsy often face the dilemma of whether they should or should not disclose that they have epilepsy in fear of losing their job or getting a job in the first place. A recent research conducted in the United Kingdom surveyed employers attitudes towards people with epilepsy and highlighted the employment problems that they encounter (Jacoby et al. 2005). It is interesting to note that in spite of changing legal, medical and social context of epilepsy, employers continue to be skeptical when it comes to employing a person with epilepsy. According to the findings of the study, seizure severity, frequency and controllability were all considered important features of epilepsy in the context of employment.
Also it was noted that there were concerns linked to work related accidents and that employers were uniformly of the view that even if the epilepsy was treated and the person was in remission, the individual should disclose their condition to the prospective employer. The only positive finding was that employers were willing to make accommodations like job sharing, temporary reassignments of duties and flexible working hours although this was influenced by company size and type and previous experience of employing people with epilepsy. In India unfortunately the employment scenario for people with epilepsy is very grim. With no legal backing, the person with epilepsy if more often than not left at the mercy of family and relatives to employ them and when this is not possible they are treated as any other financially dependent member of the family. Also there are no structured guidelines for organisations to hire people with epilepsy and therefore this complicates matters even more when PWE have struggled to educate themselves and then again face frustrating uphill battles to find suitable employment.
Epilepsy and driving is another issue which is under legal debate in India. Ideally legislations governing issue of driving license should balance the excess risks of driving against social handicap to people with epilepsy. In UK 'THE DRIVING AND VEHICLE LICENSING AGENCY' (DVLA) has its own medical advisory panel which is empowered to decide on fitness to issue driving licenses. It is therefore obligatory for a driver who develops a seizure to inform voluntarily the DVLA and surrender his driving license with adequate information. It is also the legal obligation of the family physician to inform him about the law (Besag, 2004). In USA during the past decade there has been a significant trend away from across the board seizure free period and to reduce the period when required. While most states in the US insist on a one year seizure free period, other states will allow exceptions with accepting shorter seizure free periods.

In India the motor Vehicles Act of 1939 specifically disallows driving license to epileptics at any point in life.
The Motor Vehicles Act of 1988 has modified this law allowing referral of epileptic applicant for driving license to authorized registered medical practitioner for fitness to drive although no guidelines with regards to the qualification of the doctor are stipulated.

Although these are only a few aspects of the law discussed which affect the life of the person with epilepsy, there are various other aspects such as education and employment that are completely ignored by the Indian legal system which are covered for in the West as epilepsy has been included in their disability act.

3.6: Psychotherapeutic Interventions for Epilepsy:

Epilepsy being a chronic illness although neurological in nature has enormous psychosocial implications. There is ample literature to support the view that depression, lack of self esteem, poor family relations and anxiety disorders are not uncommon to those living with epilepsy and their care givers.
These research investigations provide for a base explaining the need for various psychotherapeutic interventions leading to an overall improvement in the quality of life for the person with epilepsy and their family. The following section deals with the psychosocial implications of epilepsy emphasising on the use of psychotherapeutic interventions for the effective management of epilepsy.

3.6a: Family Therapy

Family and marital therapy which is an adjunct of the same is conducted with diverse theoretical orientations (e.g. learning theory, systems theory, psychodynamic theory) and various combinations of methodologies (behavioural strategies, paradoxical approaches, structural interventions, clarification of communication and insight). More importantly the terms family or marital treatment describe modalities but do not imply a unitary method of intervention. For the purpose of definition family therapy can be defined as a form of psychotherapy in which sessions are attended by family members from two or more generations (Wolberg, 1981).
It has been estimated that 20% of the patients with epilepsy are refractory (non responsive) to medication. Hence the illness not only becomes chronic in nature but the impact of epilepsy on a person's quality of life is tremendous (Murthy, 1999). The experience of a chronic illness dramatically changes an individual's life and the life of the immediate family, which is often the primary care giver. In addition to a physical or cognitive disability, which could be an outcome, a chronic illness impacts one's emotional well-being, financial status and interpersonal relationships amongst other things. It is not uncommon to hear that people with epilepsy often ask, "Why me?" or as in the case of the family 'Why my family member?' Therefore emotions such as anxiety, sadness, guilt and anger are not uncommon in people and families where someone suffers from a chronic illness.

Children with epilepsy see the disorder through the window of their parent's eyes. How will epilepsy affect the child often depends on how the epilepsy affects the parents.
On hearing the diagnosis of epilepsy parents are likely to go through a series of emotional response e.g. shock, bewilderment, disappointment, hopelessness, guilt, anger and grief. Family therapy as a form of intervention can help parents realize that life goes on and that the child with epilepsy and the family can enjoy life and flourish if the parents take a positive outlook towards the illness (Devinsky, 2002).

Epilepsy as a disease can be disabling due to the unexpectedness of the occurrence of a seizure. The restrictions imposed by it cause the individual with epilepsy and their family to re-evaluate their lives therefore the intervention for not only the afflicted member but for the whole family becomes even more important. The problems associated with epilepsy such as behaviour disturbances, overprotective and fearful attitude of the family, non supportive attitude of school authorities affect the individual and the family in a tremendous manner (Shah, 2000). Regardless of the severity of the condition, children with epilepsy need special attention to ensure they have a positive outlook and their self esteem is intact (Devinsky, 2002).
The role of family intervention is crucial in the management of epilepsy as various psychosocial issues such as over protectiveness of parents, education, employment, marriage and pregnancy haunt the person living with it. When it comes to parenting a child with epilepsy, there is a fine line between healthy caution and over protectiveness. Parents have a strong and natural tendency to direct their child’s behaviour. For children with epilepsy this may become exaggerated. Parents are often unaware of their directive behaviour or they fiercely defend it. Even in the Indian setup it has been observed in many families there is a case of over protection and ‘smothering’ instead of mothering for the handicapped and the chronically sick child. Consequently their emotional growth and development are stunted resulting in immature and irresponsible behaviour (Shah, 2000). In this case it is important to educate the family and teach new parenting skills which will help modify the behaviour of the epileptic child and improve family relationships.

Understanding epilepsy is also equally important if not more for parents with an epileptic child.
Very often certain types of seizures are mistaken for behavioural problems (Devinsky, 2002). For example parents may think their child is misbehaving where in actuality the problems are caused by absence seizure, partial seizures or other disorders such as tics. When they behaviour is justified on grounds of diagnosis of epilepsy, parents feel guilty for scolding the innocent child. Therefore family intervention programs require adding a knowledge element to it making parents aware of the facts regarding their child’s illness.

Apart from awareness programs, continual support to the individual and family is needed which can be found in support groups. Just as it is important for individuals with epilepsy to interact with other epileptic children, it is also helpful for parents to join a parents group or to have other parents talk with and share experiences occasionally. In support groups parents can share problems, frustrations, coping strategies, achievements and joys as well as information on doctors, medications and educational and recreational programs. In this process the parents build strong bonds. A case study of one such support group is attached as an annexure (Annexure 1).
An experience of chronic illness also requires major lifestyle changes and at times the debilitating effect can remove people from the mainstream of life. If the illness is stigmatised the effect is even worsened. Very often once the child’s epilepsy is diagnosed and treatment has begun and adequate time has passed for the family to understand and accept the disorder it is time for the parents to move. But in the case of intermittent seizures and adverse side effects of medication, resuming normalcy in life is a great challenge. To deal with this it is often recommended that parents must accept the condition and the associated disorders for what they are. They also need to understand the needs of the child with epilepsy and the other children if they have any and their own needs and those of their partner. The happiness and soundness of other relationships in the family will positively affect the child with epilepsy. It has been documented that divorce is much more common among parents who have children with developmental disorders as compared to couples in normal. Therefore an element of marital therapy is also essential in the family intervention program (Devinskly, 2002).
In the case of epilepsy patients the first step of intervention for the family is often done by the general physician or family physician as in the case of the Indian set up. It has been researched that knowledge of the disease, preparation in advance of the progress of the disease significantly helps to alleviate distress (Wilcock et al., 1991). It is known that early intervention for the family i.e. before a crisis point is reached is best but often this is achieved only when the general physician is sensitised to the carer’s burden. It is important to mention that the Indian medical set up which is unorganised in the rural sector and where basic health and hygiene facilities are at times difficult, specialised care in terms of intervention appears to be a distant reality.

Studies conducted by Faison et al. (1999) have found that there is a positive correlation between increased activities of care performed by the caregiver and caregiver burden. This includes both the provision of direct care such as bathing and indirect care such as running errands, preparing meals, and performing housework.
Interestingly it has been found that sons, as caregivers, reported significantly less burden than did daughters or other relatives. Community health and home health nurses working with families in a care-giving situation, by taking over certain responsibilities can help reduce caregiver burden. For this it is important that the assessment of the care-giving environment is done and appropriate plans for early intervention are implemented upon. New intervention programmes such as education and training for the carers have proved beneficial (Ehrlich & White, 1991). In the West services such as day care and relief admissions to homes and hospitals have also been researched and have found to relieve the overall stress of the carer, as in the case of epilepsy this is limited only to patients with severe mental and physical handicaps. It has been a known fact that psychotherapy helps the caregiver to accept the patient and their vulnerable status therefore lessening the distressing effect of the illness. Interventions developed by Marriot et al (2000) involved carer education, stress management and coping skills training based on the stress vulnerability family coping skills model and involved detailed assessment of both carer and
patient behaviour. Significant reductions in distress and depression in the intervention group has been reported as well as reductions in behavioural disturbance post treatment.

It has been observed that the most effective caregiver is well informed, prepared and will ask for help and support from all resources that are available.

There is a greater risk of psychological problems for the patient and the family when there are other stressors and limited coping resources (Northouse, 1995). It has been researched that supportive families that are intimate with each other and share their distress are least likely to develop psychological problems (Kissane et al. 1994).

It is evident that when family dynamics are positive and healthy, people with a chronic illness can derive immense benefit from the support of those who love them. It has also been suggested that it is important for the health care professionals to develop a relationship with the patients’ families and it not only helps them to cope better but also facilitates treatment compliance and management (Bluglass, 1991).
Therefore it is important that although the medical professional usually aims at treatment of the patient it is important that effective communication skills involve the family as well. It is not possible to work effectively with patients in isolation and forget the fact that extended family is in the background that has an important influence as care-givers.

As stated earlier the stress of dealing with a family member's chronic illness is compounded by economical, social and psychological factors. Therefore it becomes important that appropriate interventions, which could be in the form of individual or group counseling, or support groups, are planned so that psychosocial management of any chronic illness is easier.

With reference to the Indian perspective, not much importance is given to family therapy in India. In the absence of appropriate and timely medical intervention for majority of the population, psychosocial intervention with the patient's family appears to be a distant reality.
Also where specialists do conduct family therapy, the choice of a particular therapy is more often determined on the ideology and resources of the consultant instead of systematic application of research findings on generally accepted clinical guidelines.

3.6b: Role of Cognitive behaviour therapy (CBT) in management of epilepsy

There is adequate evidence to support the view that people with refractory seizures have an increased risk of disorders of cognitive functioning, such as memory, language or difficulties of attention. Therefore psychotherapeutic interventions are extremely effective for some patients to manage their epilepsy better. This need is not only a perceived need by the medical and paramedical staff working with epilepsy patients and their families. In a recent study it was found that 19 percent of patients attending an epilepsy clinic requested more contact with a psychologist (Chaplin et al. 1998).
Also evidence exists to show that majority of patients require more information about epilepsy and this is best provided by someone with agreed expertise and more importantly has time to discuss issues in depth (Reid et al, 2001 & Huber et al. 2001).

Parents, siblings, grand parents and teachers provide children with role models, advice, guidance and support. They very often also offer a nurturing environment and a positive outlook but the fact remains none of them have epilepsy. It is not uncommon that despite the best intentions and loving support they do not ask questions:
‘How do you feel about having epilepsy?’
‘How do you think other children react to you because you have epilepsy?’
‘Do you understand what the doctor says?’
‘Are you scared about having epilepsy?’

If the diagnosis and treatment of epilepsy are confusing for the parents they will certainly be bewildering to the child. Also the social impact of epilepsy is often psychologically painful for the child.
Most children with epilepsy require education about the disorder and help in learning to adjust to it. Therefore counselling can be an effective support for children with epilepsy.

The counsellor provides the outside perspective which is often lacking. A successful counsellor can help ‘open’ the part of the child that epilepsy can hide. The essence of counselling is to provide understanding and help the person cope with the medical and psycho social impact of the disorder.

Psychotherapeutic interventions such as CBT are also highly efficient in the management epilepsy cases when stress is associated with increasing frequency of seizures (Devinsky, 2002). Negative or unpleasant emotions associated with stress such as worry, fear, depression, frustration, anger etc can lead to sleep deprivation or disrupted and fragmented sleep therefore precipitating seizure activity in the brain. Stress and anxiety also trigger hyperventilation i.e. increase in breathing rate which is a well recognised means of provoking seizures for some individuals with epilepsy.
Negative emotions such as worry or fright can have a direct effect on the brain and therefore can cause seizures. Since there is an obvious connection of stress and increased seizure patterns, the use of therapeutic techniques like CBT are extremely beneficial for the person with epilepsy. If stress appears to provoke seizures it may be helpful to learn some form of relaxation techniques. Therefore there is enough evidence to support the view that occurrence of seizures is not limited to neuropsychological or biochemical processes but is related to a complex interaction with epileptic individual and their environment.

Research evidence also suggests the possibility of using treatments based upon psychological principles to reduce seizure occurrence in people for whom other invasive approaches, such as neurosurgical removal of an epileptic focus are not possible or for whom antiepileptic medication offers only inadequate seizure control (Goldstein, 2001). Although it is only recently that the possibility of controlling seizures through psychological interventions has received any systematic study (Dahl, 1992).
There is increasing consensus that most seizures do not occur in vacuum. Dahl et al (1988) have proposed that an organic predisposition including brain damage might be the basis of seizure occurrence in an individual but not necessarily 'cause' their occurrence. They suggest that any event in the person's life can influence seizure occurrence. Dahl (1992) indicates that seizure occurrence can become associated with contextual events and the consequences of the seizures through the conditioning process i.e. once a seizure occurs it can change from being in classical conditioning terms, an 'unconditional response' to a 'conditioned response' when it has repeatedly occurred in a similar situation. This can lead to a person subsequently expecting a seizure to occur in a particular situation. This accounts for the tendency for people with epilepsy to be able to identify specific seizure precipitating factors (Spector et al. 2000).
Also as observed in many people with epilepsy, if a seizure has positive consequences for a person (for e.g. they can avoid certain situations, or they receive a lot of attention) then operant learning processes act to increase likely seizure frequency, until the consequences of the seizures are modified therapeutically or otherwise.

These maladaptive behaviour patterns associated with seizure activity can also be explained under the ABC Model (Antecedents, Behaviours and Consequences) model which can be used in the functional analysis of behaviour (Yule, 1987). Studies of people with poorly controlled epilepsy have indicated that such individuals can often identify likely seizure triggers and there is a greater degree of consistency with which stress, anxiety and tension are identified as these seizure triggers. Based on the RET model, Cognitive restructuring has also been used as a therapeutic strategy to deal with emotional maladjustment (Thomson et al., 2001). In this strategy the negative aspects of the illness are accepted but the positive aspects are emphasised upon and an individual’s unrealistic beliefs and goals are altered accordingly.
For e.g. most people with epilepsy confess to having recurrent thoughts of them not being normal because they have an illness. The self talk they indulge in is 'I am not normal because I have epilepsy'. This therapeutically can be altered to 'I am not inferior because I have epilepsy, it gives me something extra, something special and most people i.e. people who count feel it has made me a better person'.

Cognitive behaviour therapy (CBT) is also an approach that claims to change maladaptive thoughts and behaviours and introduces more adaptive coping styles. CBT is one of the most widely used therapies world wide. It has proved extremely efficient in the treatment of anxiety disorder (Durham et al., 1997) also it has been known to be a better treatment for anxiety than medication as its effects last longer and it is not associated with undesirable side effects or any withdrawal symptoms (Andrews, 1990). Unfortunately there has been little research published focussing on application of CBT approaches in epilepsy. Thomson et al (1992) attempted to alter coping strategies employed by people with epilepsy.
Positive changes and greater improvement in emotional well being were observed in the treatment groups receiving regular sessions as compared with untreated controls. CBT has also been used successfully in the treatment of seizure phobia in conjunction with a generalised anxiety disorder (Newsom-Davis, et al. 1998). This involved graded exposure to anxiety inducing situations and challenging maladaptive or unfounded ideas with the objective of changing them. It was observed that the patient’s levels of anxiety were greatly reduced post treatment and were maintained even on monthly follow ups. Hence the application of CBT in epilepsy can focus on the development of active coping strategies thereby enhancing feelings of control and thus reducing feelings of passivity which is not uncommon for most people living with epilepsy.

A lot of work has been done using psychotherapeutic interventions in the management of seizure control. Oosterhuis (1994) treated a group of patients using the psycho educational approach that incorporated information about epilepsy and seizure management techniques based on behaviour therapy.
Spector et al. (1999) also treated a group of individuals only on similar therapeutic premise which was an 8 week programme, conducted in 12 stages. The sessions consisted of an introduction, sessions on support and dealing with stigma, understanding epilepsy and anti epileptic drugs, recognising auras, recognising and avoiding seizure triggers, channelling negative emotions into productive outlets dealing with stress and finally an evaluation session.

Therefore there is enough consensus and sufficient literature to support the consideration of psychotherapeutic treatments for patients with intractable epilepsy. Although some of this literature has methodological weaknesses or constraints, it still appears to have possible benefits that are derived from non invasive treatment approaches. More importantly they also improve the patient’s psychological well being consequently improving their quality of life.
3.6c: Yoga Therapy

Yoga is often referred to as a mindful way of living. Yoga is an age-old traditional Indian psychophysiological-cultural method of leading one's life, that alleviates stress, induces relaxation and provides multiple health benefits to the person following its system. It is a method of controlling the mind through the union of an individual's dormant energy with the universal energy. Commonly practiced yoga methods are 'Pranayama' (controlled deep breathing), 'Asanas' (physical postures) and 'Dhyana' (meditation) admixed in varying proportions with differing philosophic ideas. A review of yoga in relation to epilepsy encompasses not only seizure control but also many factors dealing with overall quality-of-life issues (Yardi, 2001).

The three main constituents of Yoga as a way of life are firstly transference of skills learned through yoga techniques to daily routine activities which include physical posture with appropriate body alignment in static and dynamic states, relaxed and un-tensed musculature and efficient, well coordinated, integrated movement of the whole body.
Another important skill set to be learnt is that of breathing i.e. cost effective breathing movement and breathing pattern free from habit. Also it is important in yoga to be aware of ones mind which includes a mindful way of talking and experiencing. The second constituent is that of appropriate sleep and diet. This includes adequate and sound sleep at proper time and consideration of quantity, quality, regularity and way of eating food (calories, micronutrients and fibres). The third component is that of attitudinal change along with emotional culturing. This includes positive and constructive emotions and efforts to overcome the feelings of isolation, helplessness and hopelessness and fear.

Yoga as a form of therapy is practiced in the form of techniques and exercises and comprises of three main constituents which are Asanas, Pranayama and Dhyana or meditation practices. Asanas are physical practices which involve manipulation of musculoskeletal and visceral organs, proprioceptive and visceroceptive awareness and conscious intervention in the conditioned habitual reflex pattern of postural and visceral functions.
Pranayama refers to breathing practices which involve manipulation of breathing activities which influence viscero-vesceral reflexes or those operating through central nervous system i.e. regulatory mechanism of the body. Dhyana or meditational practices are those which comprise of increased concentration and heightened awareness-quiet observation of mental activities; equanimity in presence of disturbed stimuli through constant re-examination of perception of stimuli situation and the opening up of the mind to the higher states of consciousness.

Yoga is undoubtedly therapeutic in nature. It is a holistic approach which tries to address all the causal factors and their interaction in the pathogenesis of an illness. It includes both the yogic techniques as well as a mindful way of living. A general approach common to all patients is that of a process of relaxation, stretching of muscles and ligaments while maintaining relaxation, postural awareness and integrated way of whole body movement, conscious and relaxed pattern of breathing and quietening of mind.
A selective approach specific to individual requirements is based on a selection of techniques and exercises is made keeping in mind the nature and extent of pathology in each individual case. Appropriate modifications in yogic practices are made according to the limitations and abilities of each individual. Safety in performance of these exercises is achieved by ensuring parameters such as no extreme range of movement, no sudden muscular movement, no overloading of the spinal segment in an inappropriate way (as it could happen in inverted postures), no wrong alignment in any spinal segment, no other adverse effects on any system in presence of retinal pathology, glaucoma, hypertension, ischemic heart condition, hiatus hernia, obesity etc.

Sound Therapy or the use of ‘Om’ is extremely prevalent in yoga. It has been well documented in ancient texts that mantras have been a part of India’s culture for centuries. Musical renditions of words, phrases, couplets, mantras, bhajans or hymns (all these compositions are generically called spiritual music), from the ancient Indian scriptures have shown remarkable results on the physical, emotional,
spiritual and mental state of the human body. The obvious effects of this music are common to many especially those who experience peace of mind or a state of deep rest or relaxation listening to slow soothing music. According to Vedic science, sound can cure the body and mind of various illnesses. According to Ayurveda, problems connected with the different chakras (nodal energy points) can be solved with the chanting of various mantras and Om is a very powerful chant that has helped cure many ailments according to most sound therapists.

According to Dr. Salvi, sound therapist, the effects of chanting Om have been researched extensively and have known to result in a marked decrease in the their cholesterol and blood sugar levels and an increase in their lung capacities (Garg, 2001). A mantra is said to be an energy based sound that actually produces physical vibrations. Derived from two Sanskrit words mantras stands for manas or ‘mind’ or trai’ meaning to free from. Therefore the word mantra literally means ‘to free from the mind’.
Therapists who use mantras to cure the body of ailments believe that all the parts of the human body (various organs, tissues, bones) are in a state of harmonious vibration. When one of our parts vibrates at a different rate, it is diseased. Correcting the vibration of the body and its organs through sound is the basic concept behind healing through spiritual music. Various mantra therapists provide a number of chants for both physical and mental disorders along with detailed procedures on how to listen to or chant the mantras. The West has also awoken to the benefits of such therapies. Brain wave technology that is used to measure brain wave frequencies corresponding to one's mental state at any given time has been used to measure the effect of sound rhythms on the frequency of currents flowing through neural pathways in the brain, the effect of sound on the brain (and consequently the state of mind) is determined. It has been researched that chanting Aum, the brain waves for from Beta (random thought) to Alpha (meditative thought) and finally Theta (trance where outer sensations become quiet and the inner intelligence awakens.
The four common brain frequencies that are noticed are Beta-for mental states of alertness, concentration, focus, cognition; Alpha-for mental states of relaxation, visualisation, creativity; Theta-for mental states of intuition; Delta- for mental states of deep sleep, healing and detached awareness. The effects of the changing brain waves due to soothing music or meditative mantra music can also be exemplified in the fact that sleep (a relaxing and energising activity) causes the brain to slow down, going from Beta to Alpha to Theta and then Delta frequencies and in the reverse order when we awake. Excessive activity causes the Beta pattern, but when an individual takes time out to relax or indulges in creative activity the Alpha pattern is produced. Meditation produces Theta waves and sleep, Delta. Brain wave technology has proven that listening to spiritual music and vedic chants can effect the Delta frequencies – a pattern also resulting from sleep. This explains why most people listening to chants experience extreme states of restfulness.

Stress is considered an important precipitating factor for seizures. Yoga is believed to induce relaxation and stress reduction.
The effect of yoga on the EEG and the autonomic nervous system has been documented (Panjwani et al., 1996) and therefore yoga would be an attractive therapeutic option for epilepsy (if proved effective), in view of its nonpharmacological nature, minimal side effects and international acceptance (Ramaratnam & Sridharan, 2000). Yoga has been used as a form of therapy in the current study as one of the three therapeutic approaches to manage epilepsy. The literature available to support the view that yoga is beneficial for people with epilepsy especially chronic epilepsy is enough to validate its use. It is important to mention that yoga has been taught on a weekly basis to patients with intractable or refractory epilepsy since the past three years at the Samman group, which is a support group of the Mumbai chapter of the Indian Epilepsy Association. Although not scientifically researched anecdotal evidence is available to support the view that when patients experience an aura (an unusual but definitive sensation that warns the individual that a seizure is about to being) they perform breathing techniques or pranayam (breathing technique emphasizing on creating harmony within the individual concentrating on how one inhales and
exhales using maximum capacity of lungs) as it is known and have been able to successfully stop the onset of a seizure. Recently a yoga meditation protocol was used as a form of an add on treatment for patients with medically refractory epilepsy and was researched to have positive results (Rajesh et al., 2006). The findings of this study suggest that not only did majority of the participants have a decrease in frequency of seizures and conclude that a yoga protocol like this may become a cost-effective and adverse effect-free adjunctive treatment in patients with drug-resistant epilepsies.

There are a number of methodological issues relating to patient selection, randomization, blinding, type of intervention, outcome measures and analysis which are highlighted in various studies (Yardi, 2001; Ramaratnam, 2001). These issues will hopefully be taken care off in methodologically sound studies in the years to come.
Therefore one can conclude this section on the review of literature by reiterating the fact that the studies mentioned above are clearly indicative of the fact that epilepsy is a global problem and the population living with epilepsy is not miniscule enough that it can be ignored. The epidemiological studies conducted in India and internationally have clearly indicated the need for timely treatment so that the development of refractory epilepsy can be restrained. The importance of neuropsychological assessment in epilepsy is also extensively demonstrated by the studies carried out in our country. The studies have indicated that neuro-cognitive and neuro-behavioural dysfunction is prevalent in epileptic children and adults. Neuro rehabilitation appears to be a silver lining where in cognitive retraining can be done for patients with cognitive deficits such as memory and attention problems associated with epilepsy. Women with epilepsy also appear to be a marginalised group which requires focussed interventions. This is often due to the stigma, and the myths and misconceptions that are associated with it.
Also for individuals with well controlled epilepsy most milestones of life are easily achievable but for individuals with intractable of refractory epilepsy where seizures are uncontrolled every milestone is either more difficult than the previous one or simply unachievable. Therefore it is important that government provide for certain sanctions under its legal system for people with epilepsy in spheres of social rights, education, employment and legal protection to ensure a better quality of life for them. Thus the future of epilepsy which reference to research investigations appears bright. Not only are interventions being planned and documented but better psychosocial assessment and counselling are emerging as new trends in the field.

In India there has been a general consensus amongst researchers that a large majority of chronically ill patients live with their families. Compared to the West, a small percentage of the chronically ill are institutionalised or live in any other form of custodial care. Family is often seen as the primary caregiver for the chronically ill.)
Although the issues vary from one illness to the other; caregiver burden, which is often experienced by the family due to the compounded stress, is common to all illnesses. Hence, most studies conclude that supporting the family is just as important as supporting the patient.

Research shows that care for the carers, or intervention programs often involve individual or family therapy, group counselling in the form of support groups and education regarding the illness.

Therefore it is indicative from the various studies mentioned above that the goal of treating and helping individual’s with epilepsy should be to attain the best quality of life with the fewest seizures (hopefully none), the fewest number of medicines, and the fewest side effects. It is evident from most studies that the population suffering from epilepsy is achieving only a miniscule part of this goal where the overall quality of life and the escape from side effects are still uphill battles. More importantly psychosocial gains will be greater and psychosocial difficulties especially psychiatric complications less if factors relevant for psychosocial prognoses are accounted for in interventions planned for
management for epilepsy. This kind of comprehensive care model would include a multi-professional team which helps the patient to discard the sick role and to make use of potentials for maturation and for a life of 'normalcy'.