“Which disease affects 40 million people worldwide, yet three quarters are untreated? Paradoxically the same disease, with early diagnosis and treatment can be controlled in three quarters of those affected. The disease is epilepsy, the commonest brain disorder in every country in the world (Lancet, 1997).

Epilepsy, a chronic brain disorder characterized by recurrent unprovoked seizures, affects people of all ages. Epilepsy is a common health problem, which carries along with it a variety of medical, social, psychological and economic burdens. Epilepsy affects every sphere of the individual’s life, cutting across age, gender and social differences. Major areas of education, employment, marriage, child rearing and social functioning are often affected and the overall quality of life is hampered due to the uncertain nature of the illness and its consequences (Radhakrishnan, 2004).

The term epilepsy is derived from a Greek word ‘epilembanein’ meaning to take hold, seize or possess and epilepsy was referred to as the sacred disease by the Ancient Greeks, who believed it to be the result of possession by the Gods. In many societies however, epilepsy was thought of less benignly as the product of demonic possession and even now it often remains a misunderstood and stigmatizing disorder.

Epilepsy, with its unpredictably, episodic nature and varied manifestations was shrouded in mysticism and superstition in the ancient period as a universal phenomenon. It finds mention in the Edwin Smith Papyrus of Egypt, the Bible and the Talmud. The
ancient Greeks believed it to be a miasma cast upon the soul. It was not until 470 BC that Hippocrates, in his treatise, 'On the Sacred Disease', stressed that "epilepsy has a nature such as other disease, and a cause whence it originates, and it is curable no less than other disease", bringing about the first semblance of a scientific approach to the disorder. But lingering doubts and fears about the disorder continued (Temkin, 1945).

There is still almost universal suspicion and social, cultural and legal stigma surrounding epilepsy. The global campaign launched jointly by International League Against Epilepsy (ILAE), the International Bureau of Epilepsy (IBE) and World Health Organization (WHO) aims to "bring epilepsy out of shadows". Fisher (2005) proposed the following new definition of epilepsy: "Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological and social consequences of this condition".

Persons with epilepsy were disabled victims suffering both from the medical disorder and from the stigma and attitudes focused on them by society. The attitude of people and society determine the quality of life of persons with epilepsy. Epilepsy and society are two inseparable factors: attitudes of society can cause more serious psycho-social issues and pain than the seizures. The society can prevent such pain by giving proper treatment, appropriate psycho-social intervention, equal opportunities and changing the attitudes (de Boer, 1995).
1.1 Epilepsy in ancient India

Ayurveda, the ancient Indian system of medicine refers to epilepsy as “apasmara”. The prefix “apa” means negation or loss and “smara” means consciousness or memory. Epilepsy is a spell of unconsciousness, when the patient develops a grotesque appearance, and his memory, mind and intellect are temporarily suspended. It may be caused by perturbation of the three dosas - vatha, pitha, kapha. A vivid picture of a complex partial fit appears in our mind when we read the verse in Ashtangahrydaya (Vagbhata). The translation of which is as follows: “With hallucination, epileptic becomes unconscious and falls down. Develops convulsions of extremities, grind teeth, bite the tongue, froths from the mouth and exhibits frightening involuntary movements.” (Valiathan, 2003).

1.2 Causes of epilepsy

There are several causes for epilepsy. Birth injuries / head injuries, central nervous system infections (meningitis / encephalitis), parasitic infection / neurocysticercosis, brain tuberculosis, brain tumors, and stroke are the important causes. In majority of cases one may not be able to find a definite cause for epilepsy.

The causes of epilepsy vary in different age groups and geographical locations. Broadly speaking, congenital and genetic conditions are the most common causes in early childhood. In infancy, metabolic and pre-natal insults are the leading causes. In older children and young adults, inherited predisposition, hippocampal sclerosis, alcohol, drug abuse and trauma are important causes. In the elderly, vascular etiology is common. Tumors and sporadic infections occur at all ages, although malignant tumors are more likely above the age of 30 years (Hauser, 1990).
In a study on a population of 1804 patients with epilepsy revealed an unknown etiology in 91.6 percent, birth injury in 1.9 percent, head injury in 1.7 percent, encephalitis in 0.2 percent, cysticercosis in 0.4 percent, other infection in 0.7 percent, vascular causes in 1.1 percent, tumors in 1.9 percent and other causes in 1.0 percent (Radhakrishnan et al., 1999).

1.3 Prevalence of epilepsy

Worldwide prevalence of active epilepsy is between 4 and 10 per thousand populations (Sander and Shorvon, 1996). Variations in prevalence are often due to differences in methodological approach, rather than actual differences. Different criteria for diagnosis of epilepsy have been used. It is important to exclude pseudoseizures and syncope. Syncope was twice as common as all seizures in the Parsi community and pseudoseizures were reported commonly in young women in India (Bharucha, 2000).

Studies of the prevalence of epilepsy from the developing world have shown prevalence rates many times higher than the average prevalence rate of 5 to 6 per 1000 in developed countries (Jallon, 1997). This difference may be apparent (attributable to misdiagnosis, varying definitions of epilepsy) or real (related to geographically relevant risk factors such as poverty, illiteracy, poor sanitation, inaccessibility of medical care, birth and accident related head trauma, cerebral cysticercosis, and hot water induced seizures (Sander and Shorvon, 1996).

A comprehensive meta-analysis of all published and unpublished studies on the Indian prevalence has been carried out by Sridharan and Murthy (1999). After taking into account the study design, differences and standardizing for age, following
prevalence rates per 1000 population at 95 percent confidence interval were found an overall prevalence of 5.59 (4.15 to 7.03). Among men it was 6.05 (3.79 to 8.31) and for women it was 5.18 (3.04 to 7.32). The prevalence in the rural areas and urban areas were found to be 6.34 (3.43 to 9.25) and 4.94 (3.12 to 6.76) respectively. The rates for men were higher than those for women, though not statistically significant. One reason for this male preponderance may be because epilepsy in women is often concealed, due to associated stigma. Although urban rates were also higher than rural, there is no statistically significant different between them. Age-specific rates were higher in the first three decades of life.

As far as Kerala is concerned, a crude prevalence ratio of 4.9 per thousand population was estimated by Radhakrishanan et al., (2000) in a study conducted to ascertain the prevalence, knowledge, attitude and practice of epilepsy among people of the state of Kerala covering a population of 238,102.

1.4 Diagnosis

The diagnosis of a seizure is based on the appearance of characteristic symptoms or signs. Thus, the diagnosis does not depend primarily on the results of the tests, but on the information obtained after a detailed interview with the patient and the eye-witness of the seizure and on performing a neurological examination. Once the presumptive diagnosis of a seizure is made, complementary tests are performed to confirm the diagnosis and to look for etiology.
The first step towards diagnosing epilepsy lies in identifying the type of seizure, the precipitating factors, and ruling out pseudoseizures. Certain seizures are precipitated by sleep deprivation or alcohol consumption or rarely, by sound, light or touch. Seizures cannot always be clearly distinguished from a variety of non-epileptic events. Most frequent type of pseudoseizure is the psychogenic seizure. The diagnosis of psychogenic seizures is often difficult to establish and a prolonged Video Electroencephalogram (Video-EEG) recording is often necessary to confirm it. Video-EEG monitoring has become established as a gold standard in evaluating patients suspected to have psychogenic seizures (Markand 1999). The accurate diagnosis of epilepsy at the initial stages is important not only from an epidemiological standpoint, but also from a clinical one. It is interesting that between 10 to 20 % of patients with “intractable epilepsy” do not have epilepsy (Radhakrishnan, 1999).

In the majority of patients with epilepsy, diagnosis can be made with a detailed neurologic history and examination, an Electroencephalogram (EEG), and in some cases a Computed Tomography (CT), and / or a Magnetic Resonance Imaging (MRI) Scan. However, in certain patients, diagnosis requires recording the seizures during in-patient Video – EEG monitoring. Patients who usually require this sophisticated diagnostic procedure are those in whom the clinical diagnosis is obscure or those who require precise seizure localization in order to pursue epilepsy surgery. Once the diagnosis of the type of seizures has been proposed, confirmation is sought by means of an EEG. The presence and localization of the paroxysmal activity in between seizures (interictal activity) can confirm the diagnosis and substantiate the type of epilepsy (Radhakrishnan, 1999).
The final step in the diagnosis is to determine the etiology and syndrome classifications of seizures. Many different epileptic syndromes have been described. "syndrome" being a cluster of signs and symptoms which occur together and constitute a particular medical condition. Some epileptic syndromes share a common etiology and may be grouped together as distinct diseases or "epilepsies". The various epilepsies and epileptic syndromes require classification to guide treatment and determine prognosis (ILAE, 1989).

1.5 Types of epilepsy

Epileptic seizures are classified in several different ways. Their electro-clinical features identify them as either generalized or partial. Seizures are also classified according to their etiology as either 'idiopathic' (primary, without a known cause) or symptomatic (secondary). Two thirds of cases of childhood epilepsy are idiopathic. The brain disturbances responsible for the initiation of epileptic activity and seizures are also classified as either inherited or acquired (ILAE Commission Report, 1989).

Attempts to classify epilepsy have developed over the ages. The modern classification, the 1981 ILAE classification of seizures and the 1989 ILAE classification of epilepsies and epileptic syndromes, have a common hypothesis in the differentiation of seizures into generalized and partial in the former, and the differentiation of epilepsies into generalized and localization related or partial in the later.

1.6 Seizure Scoring System

Engel et al.,(1993) recommended a focussed post-operative Seizure Scoring System (Table 1.1). A recent study effectively evaluated seizure outcome utilizing the
Seizure Scoring System. The scoring can also be used in following natural history or treatment outcome of non-surgical patients. (So, et al., 1997).

Table 1.1 Seizure Scoring System

<table>
<thead>
<tr>
<th>Seizure frequency</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizure free, off antiepileptic drug</td>
<td>0</td>
</tr>
<tr>
<td>Seizure-free, need for antiepileptic drug unknown</td>
<td>1</td>
</tr>
<tr>
<td>Seizure free, requires antiepileptic drugs to remain so</td>
<td>2</td>
</tr>
<tr>
<td>Non disabling simple partial seizure</td>
<td>3</td>
</tr>
<tr>
<td>Non disabling nocturnal seizures only</td>
<td>4</td>
</tr>
<tr>
<td>1-3 per year</td>
<td>5</td>
</tr>
<tr>
<td>4-11 per year</td>
<td>6</td>
</tr>
<tr>
<td>1-3 per month</td>
<td>7</td>
</tr>
<tr>
<td>1-6 per week</td>
<td>8</td>
</tr>
<tr>
<td>1-3 per day</td>
<td>9</td>
</tr>
<tr>
<td>4-10 per day</td>
<td>10</td>
</tr>
<tr>
<td>&gt; 10 per day but not status epilepticus</td>
<td>11</td>
</tr>
<tr>
<td>Status epilepticus without Barbiturate coma</td>
<td>12</td>
</tr>
</tbody>
</table>

(From Engel et al. (1993) by permission of Lippincot-Raven Publishers).

1.7 Chronic / Medically refractory epilepsy

Long term care of people with chronic illness and disabilities present an urgent challenge around the world. A recent study estimated that in many developing countries the need will increase by as much as 400 percentage in the coming years (WHO Global Report, 2002).
For more than a century, epilepsy was characterized as chronic disease with little chance of remission or cure. (Robin, 1977). It is now generally accepted that as many as 70 to 80 percent of persons with newly diagnosed epilepsy eventually achieve remission (Hauser, 1975 and Sander, 1996).

Twenty to thirty percent of persons with epilepsy do not achieve any substantial remission and continue to have epileptic seizures regardless of treatment with anti-epileptic drug (Radhakrishanan, 1999). They have chronic epilepsy and constitute the unfortunate patients with intractable or medically refractory epilepsy. Patients with uncontrolled seizures or those who develop intolerable side effects that interfere with their quality of life, despite maximally tolerated trial of one or more anti-epileptic drugs (AEDs) are considered to be having refractory epilepsy. Patients expectation, degree of disability due to seizure or AED toxicity, aversion to AED intake and other factors such as employment, marriage and difficulty to obtain driving licence have to be considered in the decision making process. In general, patients who continue to exhibit two or more disabling seizures per month for a period two years or more despite supervised trials (six months each) twice with monotherapies and once with polytherapy are candidates for detailed evaluation in a comprehensive epilepsy program for considering epilepsy surgery. Psycho-social problems are more in people with chronic epilepsy (Radhakrishanan, 1999).

1.8 Psycho-social issues in epilepsy

Although the predicament... might have come about because of epilepsy, relief of epilepsy need not necessarily relieve the predicament (Taylor, 1987).
Modern Medicine has progressed a lot in controlling seizures, but at the end of treatment patients are saddled with numerous psycho-social problems which pose several obstacles on their path to treatment, recovery, social functioning and rehabilitation. Social stigma, feeling of inferiority, low self-esteem and lack of confidence can aggravate disturbance that people with epilepsy have (Jayachandran, 2000).

Due to misconceptions and negative attitude of society, people with epilepsy may experience social, emotional or psychological stress. Each person who has epileptic seizures experiences them in a different way. Some of the major psycho-social areas that may be affected in persons with epilepsy are summarized by Devinsky (1993) as follows:

**General issues**
- Self-esteem
- Dependence
- Cognitive problem
- Behavioral problem
- Embarrassment of seizures
- Fear of seizures

**Stigma and discrimination**
- Perceived Vs Actual
- Misconceptions about epilepsy
Education

- Learning difficulties
- Social interactions

Employment

- Discrimination
- Unemployment and under employment
- Inability to perform job functions

Insurance

- Health
- Life
- Disability

Home

- Family relationship
- Social activities

Recreations

- Sports
- Hobbies
- Alcohol consumption
- Reproductive behavior
The psycho-social consequences of epilepsy remain debilitating and are observed in both developed and developing countries. According to the United States Commission on Epilepsy (1977), "Possibly the least understood and most neglected aspect of epilepsy is the social, psychological and the behavioral problems that are so common. Knowledge and adequate support in this area are important because these psycho-social sequelae largely determine what it means for the person concerned "to have epilepsy"; even after complete seizure control has been achieved.

The reasons for maladaptive psycho-social adaptation to epilepsy have typically been traced to its omnipresent anxiety, perceived stigma and discrimination, increased level of condition-specific life stressors, and also unwitting use of denial. Coping styles and strategies that have been empirically found to be associated with successful psycho-social adaptation to epilepsy include learned resourcefulness, self-efficacy, planful problem solving, and cognitive restructuring. Coping strategies that have been linked to poor psychosocial adaptation to the condition include wishful thinking, avoidance, and self-blame (Livneh, et.al., 2001).

Although people suffering from different illness face similar issues, there is also a large degree of diversity inherent in diseases that affect psycho-social adjustment. The psycho-social aspects of epilepsy, which varies from culture to culture, have been long recognized as crucial to a comprehensive understanding of the condition. A scientific understanding of the psycho-social implications of epilepsy becomes essential for guiding effective treatment and rehabilitation approaches (Andermann, 1993).
Epilepsy is often a secondary handicap. It is not so much having fits which constitutes the problem for many people with epilepsy. The attitude of people around them can be a great deal more important. The epilepsy literature shows that psychosocial problems are prevalent in persons with seizure disorder. There is no standard definition of psychosocial problems that exist among people with epilepsy. This uncertainty is complicated by the difficulty of dealing with psychosocial aspects of epilepsy in objective and reliable ways. This points to the need for developing culturally suitable and sensitive tools for understanding psychosocial issues in epilepsy (Chaplin, 1990).

Psycho-social effects of epilepsy are often as detrimental as the seizures themselves. Unfortunately, health care professionals often find themselves providing more care in less time and may not be able to thoroughly address these psychosocial needs. Directing patients toward available reliable resources can help the time constraint of the professionals. They should ensure that patients need for epilepsy education and psycho-social support are adequately met (Radhakrishnan, 1999).

The diversity in educational standards, social customs, beliefs and cultural backgrounds of the Indian society is unmatched. The problem of educating the public is therefore a challenging one, and requires not only knowledge and skills but also an implicit understanding of the special needs of individual patients. Educating the patients, family members and the community, and giving them proper perspective of the disease will help in inculcating healthier attitudes and consequently better adaptations and socialization of the patient (Radhakrishnan, 2004). Persons with epilepsy are likely to have a more External Locus of Control or learned helplessness. They often fail to
pursue social, educational or employment opportunities and may end up as underachievers (Dilorio and Manteuffel, 1995).

1.9 Epilepsy and the Family

Although family and social support system have been found to improve coping, adjustment and outcome of illnesses, the negative attitudes and approaches of the family can also hinder outcome and increase disability. Family reactions to epilepsy may range from over protection, scapegoating and rejection. Families show reactions like disbelief, guilt, fear, anger, sadness, shock, anxiety, embarrassment, confusion, depression and avoidance. Various behaviors have been associated with reactions like ostracism, permissiveness, over indulgence, poor compliance in administering medications, alterations in family activities, jealousy in siblings and decreased parental expectations of the child with epilepsy. Other developmental problems like guilt, concealment, adaptation of sick role, suppression of normal responsibilities, withdrawal, denial, dependency and low self-esteem are the problems of the children with epilepsy (Ellis et al., 2000).

The studies of children with epilepsy and of normal adolescents suggest that support of autonomy is another potential target of intervention. Boys with epilepsy whose mothers support their autonomous problem solving behaviors have fewer behavior problems in schools than whose parents who are less supportive of autonomy. (Pianta and Lothman, 1994). Adolescents' autonomous behavior when interacting with their parents predicts successful adjustments in later years (Allen et al.,1996).
It is generally agreed that persons with epilepsy have a lower rate of marriage than persons without epilepsy (Radhakrishnan, 2004). Social isolation and withdrawal are also common. Frequent hospitalizations interfere with opportunities for social interaction and contribute to social isolation. Lack of self-esteem, reduces the person’s opportunity to learn appropriate social interaction skills (Rodin, 1977).

1.10 Psychiatric aspects of epilepsy

People with epilepsy as a group have a high prevalence of psychological, psychiatric and behavioral disturbances, more so among patients with medically refractory chronic epilepsy (Dodrill et al., 1980). Vuilleumier and Jallon (1998) estimated that 20 - 30% of patients with epilepsy have psychiatric disturbances. Anxiety is a common consequence of the unpredictable nature of some epilepsy. Some patients may have seizures that are associated with, or precipitated by anxiety. People with epilepsy are more prone to depression than are those without epilepsy. In addition, suicide in people with epilepsy is 4 to 5 times more common than in the general populations. (Reynolds and Trimple, 1981).

Anxiety, however, does have a complex relationship with epilepsy. A study of this is made difficult to measure, and the differentiation of normal from abnormal anxiety is not easy. Studies also fail to distinguish between ‘state’ anxiety (ie. What the person is feeling at this moment) from ‘trait’ anxiety (the level of anxiety that a particular subject usually feels). The two are not necessarily the same, as some people normally have a higher degree of everyday anxiety than others, and people respond to the same stressful situation with differing degrees of anxiety (Barraclough, 1981).
Due to overestimated fears of being rejected, many people choose not to disclose their epilepsy to friends, neighbors and colleagues. This may result in the permanent psychological pressure of being embarrassed by a seizure in public. Psychological interventions including stress-reduction techniques, anxiety management, and group intervention to learn adequate disclosing strategies have been used only in small numbers of people with epilepsy and need to be administered and evaluated in larger patient populations. Psychotic episodes occur mostly in people with longstanding active epilepsy and underscore the need for an improvement in seizure control. However, even in people who finally become seizure free, a history of psychotic episodes highlights the need for increased awareness of psychiatric aspects during the rehabilitation process (Piazzini et al., 2001).

The self-esteem of epilepsy patients also is found to be significantly lower than that in those without epilepsy (Lau et al., 2001). Stress and emotional agitation experienced by persons with epilepsy can precipitate the onset or increase the frequency of seizures.

1.11 Epilepsy and Quality of Life

The impact of epilepsy may be greater than that of some other chronic conditions, partly because of the unpredictability of seizures, and partly because of the associated stigma. In recent years, there has been a growing recognition that assessing the impact of epilepsy must extend beyond counting seizures. The benefit of treatment is commonly measured from a caregiver's perspective that often includes seizure frequency, occurrence of adverse effects and other laboratory measures. The impact of epilepsy on the life of the patient, particularly in the psycho-social realm is not adequately represented in such estimates (Thomas, 2005).
Recently, Quality of Life measures have been included to supplement other outcome measures with the patient's perspective also (Thomas, 2005). Quality of life in epilepsy evaluation passed through several phases before it reached the current concepts (Hermann, 1995). Consequently there have been a number of instruments to measure the QOL of people with epilepsy. Several tools have been developed to estimate QOL in epilepsy in different settings such as drug trials and epilepsy surgery programs, such as QOLIE:31 (Cramer, 1998). The treatment of epilepsy vis-a-vis QOL has not been adequately audited in developing countries including India. It needs standardized culturally specific and sensitive tools to scientifically measure the QOL in different languages and cultures.

The primary goal of epilepsy management is to enable the patient to lead a lifestyle as free from the medical and psycho-social complication of seizures as possible. This approach benefits a patient's QOL as well as his/her family and society. Though treatment with antiepileptic drugs is the primary therapy for epilepsy, physical and psycho-social issues must also be addressed. Since QOL in epilepsy patients is improved with successful management, the indirect costs of epilepsy may decrease, as the medical and psycho-social aspects of the disease are successfully managed (Markand, 1999).

Improvement in the medical course of a disease does not automatically improve QOL, since the psychological, social and occupational consequence of the illness often continue to remain even after seizures are controlled. Epilepsy may result in early retirement, unemployment or employment for which the individual is overqualified. Such people need a comprehensive approach to diagnosis, treatment and counseling (Silfvenius, 1999).
An important implicit aim of the surgical treatment of medically resistant epilepsy has always been to improve the individual's well-being. Outcome measures, however, until recently have been focused mainly on seizure relief. It is clearly important that evaluation of surgical outcome should include an assessment of the effects of seizure relief or reduced seizure frequency on the individual's psycho-social functioning and well-being, often termed Health Related Quality of Life (Markand, 1999).

1.12 Epilepsy and Locus of control

The concept of Locus of Control (LOC) refers to an individual tendency to perceive events either as controlled by personal influence (Internal Locus of Control) or by external forces (External Locus of Control, Rotter, 1966). In epilepsy, the repeated loss of personal control is a central problem and has to be addressed directly. Persons with epilepsy spent a great deal of time focusing on seizure episodes and the negative consequences of epilepsy (Hermann et al. 1990). Individuals with epilepsy, as a group exhibit a more external locus of control relative to other chronic illness groups. Several studies have shown that epilepsy is associated with externality of control. Externality of control and learned helplessness have been implicated as casual factors in the development of psycho-social problems in epilepsy (Vellis et al., 1980, Zeigler, 1981, Ferrari et al.1983 Amir et.al., 1999, Hermann et al., 1990). Moreover, elevated external LOC is associated with depression in adults with epilepsy (Hermann and Wyler, 1989).

After exploring and delineating the relationship between biomedical (seizure frequency and number of years since diagnosis) and psycho-social predictors (LOC, social support and mood) and the HRQOL outcomes of Chinese patients in HongKong, Lau et al (2002) concluded that the psycho-social variables did make a significantly
independent contribution to the prediction of QOL of patient with epilepsy. The statistical significance of the health, LOC and satisfaction with the social support confirmed the importance of the influence of the subjective sense of mastery of condition and QOL (Gopinath et al., 2000).

1.13. Epilepsy Management

Management of epilepsy is multifaceted. Broadly it can be divided into medical and surgical. The medical management involves medical and psychosocial management and both are important to control seizures. Full seizure control is always the primary goal.

1.13.1 Medical treatment of epilepsy

Medical management refers to treatment with anti-epileptic drugs. What to start with, how to start, in what dosage, how to stop and how long to continue treatment? Management of epilepsy and treatment consists of appropriate counseling for the patient and family about the diagnosis. Questions concerning schooling, employment, driving, parenting children and the cost of medical and surgical management should be addressed. The assistance of medical social worker in the counseling process is very valuable (Radhakrishnan et al., 1999).

There was a long tradition of using several AEDs simultaneously for the treatment of epilepsy. The approach to pharmacologic treatment of epileptic disorders has changed substantially in the past two decades all over the world with emphasis on mono therapy over poly therapy. However, a majority of patients with epilepsy in developing countries are treated by clinicians without specific training and expertise in the disorder. The drug
prescribed depends on the seizure type. In the most common type of seizure - Generalized Clonic-Tonic Seizure – Phenobarbitone (PB), Phenytoin (PHT), Carbamazepine (CBZ), or Sodium Valproate (VPA) are equally effective as far as seizure control is concerned. This is a point of practical importance in rural epilepsy control program in developing dosage for an individual. (Radhakrishanan, 2003). Non-compliance is a major factor contributing to sub-optimal control of epileptic seizures (Leppik et al., 1988). As many as 30 to 50 percent of persons with epilepsy are reported to be non-compliant to the extent of interfering with optimal treatment. A significant factor that may lead to non-compliance is insufficient education regarding medication regimen and apprehension regarding AED adverse effects (Radhakrishnan 1999).

1.13.2 Epilepsy Surgery

Over the last two decades, there is a resurgence of interest in epilepsy surgery due to improvements in the pre-surgical localization of seizure focus with video-EEG telemetry, MRI and application of micro-surgical techniques. The most common surgical procedure performed is anterior temporal lobectomy along with amygdalohippocampectomy (Rao, 1999).

More than 700 patients had undergone surgical treatment of epilepsy in the R. Madhavan Nayar Centre for Comprehensive Epilepsy Care in SCTIMST so far. If patients are properly selected, nearly 60 percent to 70 percent of patients become seizure-free after ATL and almost 80 to 90 percent of patients achieve substantial reduction in seizure frequency. The patients who are totally seizure-free after ATL appreciate a significant improvement in their quality of life. A well-defined unilateral temporal interictal EEG spike focus, MRI detected lesion in the temporal lobe, presence
of abnormal pathology in the surgical specimen, and absence of disabling seizure during the first year ATL have been shown to be associated with a long-term seizures-free outcome after surgery (Sylaja et al., 2004).

1.13.3 Psycho-social care of epilepsy

The psycho-social management of epilepsy refers to maintenance of regular, moderate lifestyle, which has minimum possible stress level and both the patient and nearest family learn how to cope with it with positive thoughts and positive emotions. This reduces the impact of provoking factors and thus minimizes frequency and severity of seizures. (Shah 2006). Globally the misunderstanding about epilepsy and the resulting social stigma and discrimination often cause more suffering to persons with epilepsy than the seizures themselves (de Boer, 1995). Therefore proper education of the patients, caregivers and the general public and giving them proper perspective and psycho-social support are important aspects of epilepsy care. The psycho-social aspects of epilepsy, which varies from culture to culture, have been long recognized as crucial to a comprehensive understanding of the condition. A scientific understanding of the psycho-social implications of epilepsy becomes essential for guiding effective treatment and rehabilitation approaches (Andermann, 1993).

Within comprehensive therapeutic management of chronic disease, educational programs for patients are considered extremely important. Such educational programs have two aims: to increase the relevant knowledge about their disorder, and to strengthen the responsibility of the patients for themselves (Pfafflin et al., 1997).
1.14 Psycho-social Therapy

Psycho-social functioning of the person with epilepsy can be described as multivariate and over determined. There are many causes and many needs and it is influenced by culture in combination with the individuals’ personality, as determined in partly by family relationship. The success or failure of a person with epilepsy in psycho-social functioning depends to a large extent on the manner in which his/her psycho-social needs are met (Wright, 1975).

Psycho-social therapy is a form of psycho-therapeutic practice in which the biopsychosocial knowledge of human and societal behavior; skills in relating to individuals, families, groups and communities to help persons to alter their personality, behaviour or situation in a manner that will contribute to the attainment of satisfying, fulfilling human functioning within the framework of their own values and goals and the available resources of society. Various psycho-social therapeutic approaches and group interventions are effective in handling psycho-social problems of epilepsy (Yalom, 1995).

1.15 Theoretical background of the study

According to Taylor (1997) the application of sociological perspective to health and health care suggest that the social influence play an important role in helping to explain both the distribution of health, experience of illness and how health care is organized and delivered.

Becoming ill is a social process. Illness is not only a biological state but a social process state. The concept of sick role focuses on the social expectations and sanctions (Clarke, 2000).
The bio-psycho-social model developed by Engel (1977) observed that actions at the biological, psychological and social levels are dynamically interrelated and these relationship affect both the process and outcome of care. To understand human being in health and disease, there is a need to understand and treat patients as psycho-social entities. The bio-psycho-social model perspective involves an appreciation that disease and illness do not manifest themselves only in terms of patho-physiology, but also may simultaneously affect many different levels of functioning from cellular to organ system to persons to family to society. This model provides a broader understanding of the patient including effect of doctor-patient relationship (Frankel, 2003).

The family health model is an emerging holistic practice orientation focusing on the physical, mental, emotional, cultural and spiritual dimensions of health. Many behaviors related to health are developed within the context of family system (Baird et al., 1990). The work of Minuchin (1974) developed a direct link between physical illness, psycho-social problems and family. Specifically families which are enmeshed, overprotective rigid and lacking in conflict resolution foster psychosomatic diseases. Although family and support system have been found to improve coping, adjustment and outcome of disease, the negative attitude and approaches of the family can hinder outcome and actually increase disability. The families also influence the way the illness is perceived and experienced on their health status and contribute to the functional part of the individual, family and community (Jayachandran, 2005).

Schneider et al.,(1981) suggests two models for epilepsy, the medical and sociologic model, to understand the classification of factors that may contribute to the development of psychopathology in people with epilepsy. The medical model assumes
that the severity of problems associated with epilepsy is directly dependent on the severity of the medical condition alone. Different from the medical model sociologic model assumes that the severity of psycho-social problem is mediated by individual or social factors such as person's self-perception of his or her condition or social stigma.

The health behaviour of a population can also be explained using health belief model developed by Purola (1972). In this model the basic setting for healthy use of health care services is firstly, the disease in the medical sense and secondly, the perceived illness as an originator of behavior reactions. Thirdly, the predisposing and enabling factors act as modulations of the person's behaviour reactions. The persons reactions to symptoms of illness are modified by various factors like motivation, the experienced threat of illness and coping factors. The model included an interesting concept namely "cue for action", which means that cues, information or recommendation may act as the final stimulus to behaviour carried out, Eg. An encounter with a Physician. According to Deep (1999) the individuals subjective experience determine the extend of their illness and the impact it has on their Quality of Life.

1.15.1 Theoretical Background of Group intervention

Groups can be used for therapeutic or educational purposes or a combination of the two. Some groups deal primarily with helping people make fundamental changes in their ways of thinking, feeling and behaving. Other groups, those with psycho-educational focus, teach members specific coping skills. A well functioning group can serve the important task of helping towards building a bridge over the limitations between one group member and another or within the group as a whole, thereby contributing to the strength and quality of work of the group (Yalom,1995).
A freely interactive group, with few structural restrictions, will, in time, develop into a social microcosm of the participant members. The social microcosm concept is bi-directional: not only does outside behaviour become manifest in the group but behaviour learned in the group is eventually carried over into the patients' social environment, and alterations appear in patients interpersonal behaviour outside the group. Gradually an adaptive spiral is set in motion, at first, inside and then outside the group. As the patient's interpersonal distortions diminish, his or her ability to form rewarding relationship is enhanced. Social anxiety decreases, self-esteem rises; the need for self-concealment diminishes, others respond positively to this behaviour and show much approval and acceptance of the patient, which further increases self-esteem and encourages further change. The patients are enormously helpful to one another in the group therapeutic process. They offer support, reassurance, suggestions, and insight: they share similar problems with one another. Not infrequently group members will accept observations from other members far more readily than the group therapist (Yalom, 1995).

Research by (Matta and Winton, 1990) emphasizes the importance many members place on working through relationship with others rather than with therapists. The group members through feedback from others and self-observation, become aware of significant aspects of their interpersonal behaviour, their strengths, their limitations, their interpersonal distortions and the maladaptive behaviour that elicits unwanted response from other people.

According to Kepner (1980) the group is regarded not only as a collection of individuals but as a potent psycho-social environment which profoundly affects the
feelings, attitudes and behaviors of the individuals in that system. In groups, there are many clients present, and the interactional possibilities increase exponentially at interpersonal, intrapersonal and system level. The therapist now has the opportunity of being manager of learning and awareness processes. She / he can function as a therapist for an individual, as a facilitator of interpersonal process or as consultant to the group as a system.

1.16 Group Size

Opinions differ concerning the exact number in a group. As for instance some therapists prefer six, while others are prepared to go as far as twelve (Fulkerson et al., 1981). What has to be borne in mind is that, as the group increases in size, collateral relationships often get weakened. The tendency to depend on the counselor rather than upon one another becomes increasingly evident. Clinically, ten members seem to be the upper limit for productive work in a psychodynamic group. However, it is well accepted by experts in International Association of Group Psychotherapy (Weinberg, 2006) that psycho-educational groups can comfortably accommodate more numbers.

Ongoing groups should have a balance of men and women. Often, women seeking treatment significantly outnumber men. In such instances, it is possible to begin a group with a preponderance of women. For instance, if the therapist's goal is eight members, the group might begin with five women and whatever number of men is available. The remaining seats would be reserved for additional men (Rutan and Stone, 2001).
1.17  **Group psychotherapy**

Group Psychotherapy is still a very young field but with a bright future. It is indeed sad to realize that the average person in most places is not even aware of the clinical application of many forms of group therapy. The importance of group dynamics has been recognized in certain hospital settings in relation with staff interaction, work with in-patients and out-patients. Some major teaching hospitals with well-equipped Consultation Liaison units promote homogenous group psychotherapy in clients in eating disorder units, mother / baby units, personality disorder units, of those with breast cancer and renal dialysis units (Rustomjee, 2000).

Group counseling tends to be growth-oriented in that the emphasis is on discovering internal resources of strength. The participants may be facing situational crisis and temporary conflicts, or they may be trying to change self-defeating behaviors. The group provides the empathy and support necessary to create an atmosphere of trust that leads to sharing and exploring these concerns. Group members are assisted in developing their existing skills in dealing with interpersonal problems so that they will be better able to handle future problems of a similar nature. Group counseling is often carried out in a variety of institutional settings, such as schools, university counseling centres, community mental health clinics and other human service agencies (Fuhriman and Burlingame, 1994).

The group counsellor uses verbal and non-verbal techniques as well as structured exercises. Common techniques include reflection (mirroring the verbal and non-verbal messages from a group member), classification (helping members understand more clearly what they are saying or feeling) role-playing and interpretation (connecting present
behaviours with past decisions). Basically, the role of group counselor is to facilitate interaction among the members, help them learn from one another, assist them in establishing personal goals and encourage them to translate their insights into concrete plans that involve taking action outside of the group. Counselors perform this role largely by teaching members to focus on the 'here' and 'now' and to identify the concern they wish to explore in the group (Mackenzie, 1994). Gestalt Therapy group further popularizes this concept.

The group offers understanding and support, which foster the members' willingness to explore the problems they have brought with them to the group. The participants achieve a sense of belonging, and through the cohesion that develops they learn ways of being intimate, of causing and of challenging. In this supportive atmosphere members, can experiment with alternative behaviours. As they practice their behaviours in the group, they receive encouragement as well as suggestions on how to apply what they are learning in the outside world. Ultimately, it is up to the members, themselves to decide what changes they want to make. They can compare the perceptions they have of themselves with the perceptions others have and then decide what to do with this information. In essence, the members get a clearer glimpse of the kind of person they would like to become and they come to understand what is preventing them from becoming that person (Fuhriman and Burlingame, 1994).

1.18 Psycho-educational approach

Psycho-educational approach usually focuses on the common areas of concern, notably depression, anxiety, relationships, anger, stress-management (Young, 1999). Psycho-educational groups are structured in such a way as to help people to develop
specific skills, understand certain themes, or go through difficult life transitions. Although the topics obviously vary according to the interest of the group leader and the clientele, such groups have a common denominator of providing members with increased awareness of some life problems and tools to better cope with it. Psycho-educational groups are suited for all age populations (Fuhriman and Burlingame, 1994).

Families with a member afflicted with a serious illness need help to cope with this burden and related personal stress. Mental health professionals have hoped that well-informed relatives could act as co-therapists and might thus help to improve patient's compliance (Corrigan et al., 1990). Most of the interventions for relatives can be subsumed under the category of "Psycho-education" or at least contain psycho-education as an essential component. "Psycho-education" is the most common collective designation for an intervention that combines the imparting of information with therapeutic elements and the term is internationally acknowledged (Walz et al., 2001).

In sum, a group approach can help people meet almost any need. One of the main reasons for this popularity is that the group approach is frequently more effective than the individual approach. Effectiveness stems from the fact that group members can practice new skills both within the group and in their everyday interactions outside it. Moreover members of the group benefit from the feedback and insights of other group members as well as those of the practitioner. Groups also offer many opportunities for modeling. Members learn how to cope with their problems by observing others with similar concerns. There are practical reasons for popularity of groups such as, lower costs and broader distribution of the available counselors and therapists. Group approach is economical and effective in dealing with various psycho-social and interpersonal issues in patients with epilepsy (Jayachandran, 2001).
1.19 Psycho-educational group Intervention in SCTIMST

Sree Chitra Tirunal Institute for Medical Science and Technology, (SCTIMST), Thiruvananthapuram is a tertiary referral center with advanced facilities in Cardiology and Neurology (Valiathan, 2004). The institute has a special center for epilepsy namely : R. Madhavan Nayar Centre for Comprehensive Epilepsy Care established in 1998. There are about 15000 epilepsy patients registered in the epilepsy clinic. Approximately 800 to 900 persons with epilepsy are enrolled in this center every year and 60 persons with medically refractory epilepsy are operated every year with 70-80 percent success rate (Rao et al., 2000). It runs two epilepsy clinics every week on Wednesdays and Fridays regularly. 50- 60 patients are called by appointment to every clinic (Thomas, 2005). The centre is running two outreach epilepsy clinics one in Anasar Hospital Perumpilavu, Trissur and other in Primary Health Centre Changranmkulam, Malappuram on third and first Sunday of every month regularly for the past ten years. Fifty to sixty patients are seen and counseled in the clinic by a neurologist and a medical social worker from SCTIMST (Radhakrishnan, 2004).

The institute pioneered a novel approach through psycho-educational group sessions for epilepsy patients and their family members (Jayachandran, 1999) Epilepsy patients who are called by appointments and their family members are assembled in a hall prior to the epilepsy clinics, which are conducted on every Wednesday and Friday. This technique has been very popular in this center for the past 17 years and has many potential advantages. The therapist opens the discussion followed by description of each patient’s experience with the illness. This helps in elicitation of the psychosocial problems which the patients or family member had to face while living with epilepsy. While participants share their experience, the therapist encourages group dynamics.
through group interaction and group facilitation. The therapist reinforces the positive attitudes, approaches and achievements of the participants, besides providing information on various aspects of epilepsy. This facilitates other members of the group to think independently and discover effective methods to cope with the disease in their daily living. This type of open discussion reveals to the patients and their family members that there are many people with similar problems; and that they are not the only sufferers (Jayachandran, 2001).

Psycho-social issues are discussed, debated, tackled and researched throughout these sessions. In addition, information about psychosocial, educational and employment aspects of epilepsy are provided (Radhakrishnan, 1999, 2004). This psycho-educational method is also used to impart appropriate health education particularly regarding the need for regular medication, suitable life-style, and general precautions to be taken by a person with epilepsy and his/her family members (Jayachandran, 2002).

This occasion is also utilized to emphasize the need to augment these positive attitudes and approaches in the patient to achieve better social functioning and rehabilitation. Group sessions can be conveniently organized in any clinic setting. This method can be of wider application in developing countries because it involves saving of professional time. The group session also helps to identify patients with deeper psycho-social problems requiring further evaluation and treatment. The group approach in a clinic setting has many potential advantages. The problem relevant to most patients can be discussed within a short time. The living example of well-controlled and successful patients will provide inspiration to others. The participants can discuss their problems among themselves, to develop new ideas and explore suitable solutions under professional guidance (Jayachandran, 2002).
1.20 Yoga-Meditation Group Intervention

The Department of Neurology, SCTIMST has also been practicing Yoga-Meditation (YM) for the past 4 years to patients with Intractable epilepsy, as an add on therapy along with anti-epileptic drug regimen. The efficacy of YM in significantly reducing seizure frequency has been proved in a clinical trial among patients with intractable epilepsy (Rajesh et.al., 2006).

1.20.1 Yoga-Meditation Technique

An expert in Yoga-Meditation instructed the patients and supervised the yoga-meditation sessions. Patients are taught to sit in a relaxed posture over a mattress with legs crossed (sukhasana), breathe in a slow, deep and controlled manner (nadisodanapranayama). Nadisodhana refers to "cleansing of the nadis" The subject had to inhale and exhale through alternate nostrils, maintaining a ratio of 1:1 without holding the breath. The pranayama began with a deep expiration through both nostrils followed by slow and smooth inhalation through the left nostril (the right being closed with the thump) followed by exhalation through the right nostril (with the left nostril being closed with the ring and little finger). This was followed by exhalation through the right nostril (left closed) and exhalation through the left nostril (right closed) to complete one cycle. The subjects maintained the time ratio of 1:1 by mentally counting numbers. Pranayama was practiced for 5-7 minutes at a time. This was followed by silent meditation by concentrating over the region between the eyebrows. Mantras (sound phrases) were not used. Patients were required to meditate for 20 minutes daily at home both in mornings and evenings. They had to attend supervised sessions every month during the intervention period of three months. Patients had to maintain a seizure diary and have strict drug compliance (Rajesh et.al., 2006).
1.21 Need for the study

Children and adolescents with epilepsy frequently experience poor psycho-social outcomes due to numerous factors such as perceived stigma, behavior problems, academic difficulties, and depression. Health psychology research has documented the effectiveness of psycho-educational interventions aimed at improving psycho-social outcomes for individuals with a variety of health conditions. With increasing numbers of adolescents living with epilepsy, interest in improving the quality of life of this particular population has grown. There remains, however, a paucity of research concerning psychosocial interventions for persons with epilepsy (Snead et al, 2004).

The primary goal of epilepsy management is to enable the patient to lead a lifestyle as free from the medical and psycho-social complications of seizures as possible. This approach benefits a patient's quality of life as well as his or her family and society. Though, treatment with antiepileptic drugs is the primary therapy for epilepsy, physical and psycho-social issues must also be addressed. The indirect costs of epilepsy are related to the patient's ability to function. Since quality of life in epilepsy patients is improved with successful management, the indirect (and possibly the total) costs of epilepsy may decrease as the medical and psycho-social aspects of the disease are successfully managed (Schachter, 2000). In India, we severely lack facilities to deal with psycho-social issues in health care. The epilepsy clinics in the Indian situation have to cater to a large clientele with limited skilled personnel. Often there are no trained psychologists or professional social workers to attend to their psycho-social problems. To overcome this, counseling in groups can be practiced as an effective and economical method (Jayachandran, 2000).
As the patients' knowledge and understanding is related to her or his success in coping with the disease, the need for and importance of epilepsy education was emphasised by The Commission for the Control of Epilepsy and its Consequences (1977). But only a few educational programs have been developed in the past (Hegelson et al., 1990, Oousterhuis, 1994 and Reid, 2001). The Commission further stated that almost no research is being done on the delivery or effectiveness of services for people with epilepsy.

A variety of approaches to brief group treatment have been developed in recent years. Even though a number of group therapy and group intervention programs are being practised in different parts of the world, there is little research on the outcome of these programs. In an era of increasingly limited resources brief group treatment, which are effective and economical, remains under utilized (Rosenberg and Wright, 1997). In India organized group therapy activities are relatively rare and to the best of the investigator's knowledge, this is a pioneering work among patients with epilepsy involving their family members.

Through working with psycho-educational groups of patients with epilepsy and their family members for the past about 17 years, the investigator has observed that patients after attending a few psycho-educational sessions undergo a series of positive psychosocial and behavioural changes. Most of them become regular in their life style with timely medication and good compliance, regular sleep, facilitating seizure control and improvement in quality of life. Most of them are found to be increasingly happy and successful in their adjustment to the disorder after attending few sessions (Jayachandran, 1999).
Group counseling here provides the individual to work through problems in a social context. Since patients with epilepsy often experience their difficulties in isolation, the psycho-educational group program exposes them to the feelings, concerns and experience of others which facilitate them to improve their self-image, self-esteem and quality of life (Jayachandran, 2002).

The present attempt is to systematically and scientifically evaluate the psycho-social and behavioural outcome of this psycho-educational group therapy on patients with epilepsy using experimental research design with two experimental groups (psycho-education and meditation) and a control group. This research follows an experimental pre-post test research design.
CHAPTER - 2

REVIEW OF LITERATURE