EFFICACY OF GROUP INTERVENTION IN THE PSYCHO-SOCIAL CARE OF PATIENTS WITH EPILEPSY

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in Behavioural Science

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DECLARATION

I, Jayachandran.D, do declare that this thesis, "**Efficacy of group intervention in the psycho-social care of patients with epilepsy**", has not been submitted for the award of any Degree, Diploma, Title or Recognition before.

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Certificate

I, Dr K.A. Kumar, do hereby certify that this dissertation entitled ***"Efficacy of group intervention in the psycho-social care of patients with epilepsy"****, is a record of bonafide study and research carried out by Mr.Jayachandran.D., under my supervision and guidance.*

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Efficacy of group intervention in the psycho-social care of patients with epilepsy

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ABSTRACT

Key words : *Group intervention, Epilepsy, Psycho-education, Yoga- Meditation, Knowledge, Attitude and Practice, State-Trait Anxiety, Depression, Psycho-Social Effect, Self-Esteem, Locus of Control, Quality of Life.*

Topic of Research: "Efficacy of group intervention in the psycho-social care of patients with epilepsy."

Background: Epilepsy is a chronic brain disease with serious psycho-social complications. The psycho-social implications of epilepsy are more disabling than the seizures. Psycho-educational group intervention as a novel approach for patients with epilepsy and their family members has been in practice in the Centre for Comprehensive Epilepsy Care, Sree Chitra Tirunal Institute for Medical Science & Technology (SCTIMST) in Thiruvanathapuram, Kerala, India for the past 17 years. Yoga- meditation (Pranayama) has also been practiced in this center for the past 4 years with proven efficacy in seizure reduction.

Design: The study followed a prospective, randomized experimental research design involving two experimental groups (psycho-education and meditation) and a common control group.

Tools used: Eight scales / inventories were used to assess the efficacy of the interventions.Out of the eight scales, two scales namely: EPSES and QOLIE-31 are translated from English to Malayalam and standardized by the investigator using 440 patients with epilepsy (220 patients for each scale).

Subjects for Experimental Study: Thirty six patients (20 males and 16 females), age range 16 35 years with an established diagnosis of epilepsy with at least two seizures during the past one year.

Interventions: 1. Psycho-educational group sessions for patients with epilepsy and their family members. 2. *Pranayama* (Yoga- Meditation) for 20 minutes twice daily (morning and evening).

Results: Out of the 28 dependent psycho-social variables tested with different scales/ inventories there were statistically significant positive changes in more than half of the variables either in ANOVA or ANCOVA or in both in the Psycho-education group. Two variables (Trait and Total Anxiety) recorded significant change in Meditation group, which is another major finding of the study.

Conclusion: The study revealed efficacy of both intervention techniques, but Psycho-education was found to be more effective than Meditation in improving psycho-social status and Quality of Life of patients with epilepsy. The findings can have wider application in the management of epilepsy.

PREFACE

Epilepsy is a chronic, and stigmatized brain disorder with serious psycho-social and economic implications. A recent study by WHO (2002) estimated that in many developing countries the need for chronic disease will increase multi-fold in the near future. As many as one third of the chronically ill are not able to work, attend school or perform daily living activities. The impact of epilepsy is much more than that of other chronic illnesses due to stigma and misconceptions of epilepsy, which are culturally ingrained in every community throughout the world.

Globally there has been a growing interest in the use of groups in medical setting, as social support predicts better coping with the illness, improved adherence to medical regimen and positive outcome in chronically ill patients. Adequate knowledge and good information about every aspect of the illness to the patient and family may aid them making informed choices, and to retain a perception of control. This approach can promote patient autonomy, better health outcome, optimal physical and psycho-social functioning and better quality of life. This is a growth oriented and developmental approach with wider implications. However, the outcome research of such programs are very rare as pointed out by The International Association of Group Psychotherapy (IAGP) and Commission for Control of Epilepsy.

In this connection, a novel approach of psycho-educational group sessions for persons with epilepsy and their family members are practised in the epilepsy clinic of the Department of Neurology, SCIMST, Thriuvananthapuram for the past many years. The Centre has also been practicing Yoga- Meditation (*Prnayama)* as an add on therapy with proven efficacy in controlling seizures among patients with epilepsy. The present endeavor of the investigator is to translate and validate Malayalam version of two epilepsy specific tools and to use a prospective randomized experimental research design to evaluate the relative efficacy of these two intervention programs (Psycho-education and Meditation) in comparison to a control group of patients.

This Research Report is divided into five chapters. The first introductory chapter gives updated information of the various psycho-social aspects of epilepsy. The second chapter covers the review of literature with relevant studies. Chapter 3 covers the methodology with details of tools development and procedures followed for its standardization. Chapter 4 discusses the results in detail. Chapter five gives the summary and conclusion of the study.

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ABBREVIATION USED

AED	Anti- Epileptic Drug
ANCOVA	Analysis of Co-Variance
ANOVA	Analysis of Variance
ATL	Anterior Temporal Lobectomy (Epilepsy Surgery)
EPSE/PSE	Epilepsy Psycho-Social Effect
GE	Generalized Epilepsy
Group session	Psycho-educational group intervention
Group Intervention	Psycho-educational group intervention and or Meditation
HRQOL	Health Related Quality of Life
IAGP	International Association of Group Psychothersapy
IE Scale	Internal –External Locus of Control
IGE	Idiopathic Generalized Epilepsy
ILAE	International League Against Epilepsy
KAP	Knowledge, Attitude and Practice
LOC	Locus of Control
LRE	Localization Related Epilepsy
LTLE	Left Temporal Lobe Epilepsy
MFT	Multiple Family Therapy
MOSES	Modular Service Package Epilepsy
QOLIE : 31	Quality of Life in Epilepsy Inventory - 31
RTLE	Right Temporal Lobe Epilepsy
SCTIMST	Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvnanthapuram
SEE	Sepulveda Epilepsy Education
SGE	Symptomatic Generalized Epilepsy
STAI	State -Trait Anxiety Inventory
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life
YM / Meditation	Yoga - Meditation

CHAPTER - 1

INTRODUCTION

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INTRODUCTION

"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 (Markand1999). 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 (Radhakrishanan, 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 1.1Seizure Scoring System

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

(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 psycho-social problems are prevalent in persons with seizure disorder. There is no standard definition of psycho-social problems that exist among people with epilepsy. This uncertainty is complicated by the difficulty of dealing with psycho-social aspects of epilepsy in objective and reliable ways. This points to the need for developing culturally suitable and sensitive tools for understanding psycho-social issues in epilepsy (Chaplin, 1990).

Psycho-social effects of epilepsy are often as detrimental as the seizures themselves. Unfortunately, health care professional 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 life-style 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 bio-psycho-social 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 feed back 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 setting 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 (Mackonzie,1994). Gestault 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. More over 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 establised 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 sufferes (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

CHAPTER - 2

REVIEW OF LITERATURE

In this chapter a review of some of the important and relevant studies are made. It covers studies related to Epilepsy, Knowledge, Attitude and Practice (KAP), Epilepsy and Family, Epilepsy and Economic Consequences, Psycho-Social Problems of Epilepsy, Anxiety and Depression, Self-Esteem, Locus of Control, Epilepsy and Quality of Life, Meditation and Group Interventions.

2.1 Epilepsy

In a study conducted by Dijibuti et al., (2003) to identify the clinical, demographic, and socio-economic factors that are associated with a poor quality of life in patients with epilepsy in Georgia. The clinical, demographic, and socio-economic data were collected from 115 adult out-patients with epilepsy being treated in the epilepsy program at the Sarajishvili Institute of Neurology and Neurosurgery (SINN) in Georgia. Health Related Quality of Life (HRQL) was measured by the Quality of Life in Epilepsy Inventory (QOLIE:31). Multiple Regression Analysis was used to determine which variables were associated with QOLIE:31 total and sub-component scores. The mean age of the patient population was 37.9 (SD 15.8) years; 43.5% were females; 51.8% did not have a partner, 39.1% had some university education, 82.6% were unemployed. Of 115 epileptic patients 83.3% had partial, and 16.7% had generalized seizures. Overall, 32.2% of patients were seizure free, and 28.7% experienced more than 10 seizures over the past year. The variables that most strongly predicted a lower QOLIE:31 total score were low education level, high seizure frequency, and long duration of epilepsy. The QOLIE:31 all sub-component scores correlated strongly with seizure frequency.

Advanced age was a significant predictor for a low overall quality of life, Energy / fatigue, and Cognitive scores. Female sex was the factor that significantly predicted a low seizure worry score. Education level strongly correlated with overall quality of life, and cognitive and social functioning scores.

Shackleton et al., (2002) conducted a follow-up study of a cohort of 1355 consecutive patients newly diagnosed with epilepsy, between 1953 and 1967. In 1995 a random sample of 333 patients received a questionnaire asking clinical and demographic information and validated measures for psycho-social outcomes. Comparisons were made with the general Dutch population, standardized for age, sex and calendar period. The response rate was 73 percent (116 men and 127 women); 134 patients (46 percent women) were less than five years seizure free, and 81 patients (57 percent women) still had seizures in the last year. 127 patients (54 percent women) were taking anti-epileptic drugs (AEDs), of whom 51 were receiving monotherapy. Epilepsy patients have a positive health evaluation, comparable to the general Dutch population. Fewer epilepsy patients married or had children than the general Dutch population; more patients live at home with their parents, or in foster homes or institution ($P< 0.01$). Having epilepsy at school-age has a significant negative effect on learning achievement ($P< 0.01$).

Beghi (2000) conducted a study on the social aspects of epilepsy in the adult in seven European countries. Seven hundred and six patients with idiopathic or remote symptomatic epilepsy and 662 matched controls without epilepsy were enrolled by secondary and tertiary centres in seven European countries (Italy, Germany, Spain, the Netherlands, England, Portugal and Russia). The distribution of each social variable varied significantly across countries, but with few exceptions, the differences between patients and controls were fairly similar. Comparative findings from different European countries support the concept that epilepsy has a considerable impact on driving and to a less extent on education, occupation, leisure-time activities, and insurance. The social implications of epilepsy in this sample are partly related to its severity and clinical features.

A European perspective study by Baker (1999) collected clinical and demographic details and information about patient-perceived stigma using self-completed questionnaires mailed to members of epilepsy support groups. Stigma data were collected from more than 5000 patients living in 15 countries in Europe. More than 50 percent reported feeling stigmatized, with 18 percent reporting feeling highly stigmatized. The study confirms the findings of previous studies that have identified the importance of both clinical and non-clinical factors in understanding the stigma of epilepsy. The study suggests that the cross-cultural differences require further explanation, and much more research should be conducted to reduce the stigma associated with epilepsy.

Viberg et al., (1987) conducted a study on 'Epilepsy in adolescence: Implications for the development of personality'. Sixteen adolescent children with onset of epilepsy between the ages of 1 and 12 years and 16 control children were investigated by interview, Self-esteem scales, and the Thematic Apperception Test (TAT). Children with epilepsy had a significantly larger discrepancy between the self-image and the ideal self-image than did the control children. TAT indicated the body and self-image is poorer, the unknown and the risk of acting out more threatening, the self-identity was less stable, and the defense not as adaptive as the control group. Persons suffering from epilepsy are often stigmatized.

2.2. Knowledge, Attitude and Practice.

To assess perceptions of knowledge and experience with epilepsy and seizures in the U.S. population, Koban and Price, (2003) developed communication campaigns to improve the public's understanding of epilepsy. Responses were obtained from 4397 persons. Despite the low prevalence of epilepsy, results indicate that about half of all persons have witnessed an epileptic seizure either in person or on television about one third of all persons know someone with epilepsy, but relatively few are familiar with epilepsy, how to respond to a seizure, or contact with the Epilepsy Foundation for assistance. In general public has relatively little knowledge about epilepsy. Educational campaigns that inform the public about this disorder and about seizures should work through community setting to improve the general public's understanding of epilepsy.

Shulman et al., (2002) conducted a survey at older adult community centres in metropolitan phoenix, Arizona to understand their personal perceptions and attitudes about epilepsy. The survey covered 32 males and 76 females in the age group (60-99). The average age of respondents was 77. Most were familiar with seizures or epilepsy by either knowing somebody (67 percent) or having witnessed a seizure (69 percent). Twenty eight percent considered epilepsy a form of mental illness. Eight percent believed the seizures were contagious. Only 53 percent were able to correctly identify various symptoms of different seizure types. Sixty nine percent were uncertain as to how to help someone with a seizure. Several differences emerged between male and female responders regarding whom they would tell about having seizures. Thirty-seven percent of men and 25 percent of women would tell a family member. Fourteen percent of females would tell a friend. Fifty six percent of all respondents would not tell their doctor.

Radhakrishnan et al., (2000) conducted a study on prevalence, knowledge, attitude and practice of epilepsy in Kerala. They conducted a door-to-door survey covering the entire population of 238102 people residing in 43681 households in a semi-urban area in 10 panchayats of central Kerala. They evaluated knowledge, attitude and practice (KAP) toward epilepsy among 1118 subjects (439 males and 679 females; mean age, 33.3 years; age range, 15-85 years) from households without epilepsy in the study area. Through a three-phased survey, they ascertained 1175 cases (616 males and 559 females) with active epilepsy, providing a crude point prevalence ratio of 4.9 cases per 1000 people and an age-adjusted prevalence ratio of 4.7 cases per 1000 population. The highest age-specific prevalence rate of 6.5 per 1000 was seen in the age group of 10-19. Sex specific prevalence rates did not significantly differ. The proportion of generalized and localization related epilepsies were 58.8 percent and 30.6 percent respectively, Ninety nine percent of the KAP respondents had read or heard about epilepsy. Thirty one percent and 27 percent thought epilepsy was a hereditary disorder and as a form of insanity respectively. About 40 percent of the respondents felt that individuals with epilepsy could not be properly educated or employed. Eleven percent would object to their children having contact a child with epilepsy.

An assessment of epilepsy patient's knowledge of their disorder was conducted by Long et al., (2000). Two hundred and twenty epilepsy patients referred to an epilepsy center completed a knowledge questionnaire. The questionnaire included topics related to safety, compliance and legal issues of driving and employment. The investigators found that patients with epilepsy are not knowledgeable about their disorder. This is true regardless of age, educational background, or number of years with epilepsy. The study suggests that there is a need for educational intervention and the legalities of driving and employment.

DiIorio and Manteuffel (1995) examined the opinions of nurses, physicians and persons with epilepsy about their preferences for provision of patient education. The result indicated that patients preferred physicians as their main source of discussion of their diagnosis and treatment plan and perceived nurses and medical social workers in educational role for psycho-social issues. For patient education a team approach is beneficial.

Desai et al., (1998) demonstrated the role of patient's own attitudes towards the on-going treatment as an important factor in ensuring success of any epilepsy treatment program. A sample of 80 patients with epilepsy (age 30-40 years) attending a comprehensive rural health services project was interviewed. It was found that the majority of the patients were well-informed about the causes of epilepsy, and more than half had tried alternative treatment methods. Many patients had misconceptions about the goal of the treatment and the consequences of missing a prescribed drug dose. Surprisingly, few patients avoided taking medicines on days they were fasting for religious reasons. It was also noted that most patients depended on free medical supplies from the clinic dispensary and a small number of patients would stop medication, if it was not supplied free of cost. The need to understand the patient's concepts about the cause and treatment of epilepsy, the need to educate them and their families regarding the principles of modern medical treatment of epilepsy, and the need to maintain a regular supply of free medicines have been discussed.

All the above studies regarding KAP reveals that patients, family members and the general public, the knowledge regarding epilepsy are poor and misconceptions and negative attitude regarding the illness still exists in different parts of world including the highly literate State like Kerala.

2.3 Epilepsy and family:

Rosenberg et al., (1997) in a study titled 'Family factors and psycho-pathology in children with epilepsy: A literature review' When compared with control groups, families with a child with epilepsy generally fare worse on the whole range of family factors, indicating lower parent-child relationship quality, more depression in mothers, and problems with family functioning. Significant associations were apparent between distinct family factors, especially parental psychological control, parental attributions about epilepsy, and family members' satisfaction with family relationships, and psycho-pathology in children with epilepsy. They suggested future childhood epilepsy research might benefit from the examination of the simultaneous contribution of distinct family factors to child psycho-pathology, within a broad multi-factorial framework that also includes neurological and medication factors.

In a cross-sectional study conducted by Stanhope et al., (2003) on expressed emotion in the relatives of people with epileptic (n=36) or non-epileptic (n=21) seizures found that expressed emotion was significantly high among relatives of patients of non-epileptic seizure. Hostility was evident in more high- expressed emotion epilepsy than high- expressed emotion non-epileptic seizure relatives.

Ellis et.al.,(2000) conducted a study titled 'Epilepsy and family: A review of current literature'. This paper reviews the present state of family research, examining the influence of both childhood and adulthood epilepsy on the psychological and social well-being of family members. Studies indicate that epilepsy may cause high levels of psycho-social difficulties for all family members, including stigmatization, stress, psychiatric morbidity, marital problems, poor self-esteem and restriction of social activities. Studies also suggest that the family environment may be an important intervening factor between the condition and the outcome for the family unit, and a number of family factors are reviewed which have been suggested to mediate this relationship; with recommendations being made for their use in intervention studies. Shortcomings of the family studies to date are discussed and these include: concentration on examination of issues around family life, studies being based on reports from single member of the family and the selection of subjects from clinical populations. Recommendations are made concerning methodological and conceptual issues that need addressing for future research. However, all the studies indicated that the effects of epilepsy are far reaching, and are not simply confined to the biomedical or practical aspects of the condition, having negative implications for all those involved with the individual. Research is obviously needed in order to delineate the implications of epilepsy in the family unit.

Thomas and Bindu., (1999) tested parents of children with epilepsy in Trivandrum, Kerala to study the psycho-social and economic problems facing them. Parents of 50 children (age 5-16 years) suffering from epilepsy for more than 1 year were administered a structured questionnaire. It was noted that 52 percent of the children had partial epilepsy whilst the remaining had generalized epilepsy, with the median seizure frequency being 1 seizure every 6 months. The majority of the patients (86 percent) lived in villages. A decline in social activities, following the onset of epilepsy, was reported by (80 percent) of the parents, while daily routines were reported to be significantly affected by over (75 percent) of the parents. Parents experienced frustration (52 percent), hopelessness (76 percent) and financial difficulties (60 percent). Drugs and visits to the hospital were the most common costs reported. Impaired emotional status and poor social adaptation were correlated with the severity of epilepsy and low economic status of the parents.

Kerley (1992) in the paper titled 'Helping parents and children with epilepsy cope successfully: the outcome of a group programme for parents' describes a study to determine the effectiveness of a group programme for parents designed to reduce the psycho-social morbidity among children with epilepsy and their families. The participants were the parents of 108 children attending the seizure clinic at a children's hospital. The first part of the project had shown that half of the children and their families had considerable morbidity. Despite the high rate of psycho-social morbidity among these children and their families, only 35% of the parents expressed an interest in participation in the intervention programme, with only 12% attending any meetings. The latter were mainly the small number of parents whose children had severe intractable epilepsy as well as educational and family problems. Many parents did, however, request more information about epilepsy and for the provision of a counseling service. Education and counselling are likely to be most beneficial in the months following diagnosis.

The above studies on epilepsy and family underscore the need for early comprehensive epilepsy education of the patient and family to prevent various psycho-social problems.

2.4 Psycho-social Problems.

Peter et.al., (2002) reported that patients who reported any type of abuse during childhood in the psycho-social interview by the epilepsy social worker reported increased difficulty with adjustment and functioning in adulthood compared to those without an abuse history. This showed that among the patients, childhood abuse is having a long-term impact on psycho-social functioning. With the growing popularity of offering comprehensive epilepsy services, this information was useful in creating a successful treatment plan for patients that addresses not only the medical aspects of epilepsy, but also the social and emotional aspects as well.

Banerjee and Banerjee., (1995) investigated the psycho-social factors determining the first choice of health facility in 30 children with epilepsy, adolescents and adults attending the psychiatric outpatient department of a hospital. The family decision was the determining factor for the majority of patients who choose indigenous health facility was the result of a belief in the supernatural causation of epilepsy coupled with the family decision. Those who believed in the physical cause of epilepsy and took advantage of the social network in decision-making contacted the practitioners of modern medicine. The time lag between the onset of illness and first contact was short when indigenous healers were the first option. However, these patients took a long time to reach the referral center.

Psycho-social problems in adolescents with epilepsy have been concern for many years, but have been difficult to assess. Batzel et al., (1991), developed the Adolescent Psycho-social Seizure Inventory (APSI), an empirically based self-report test patterned after Washington Psycho-social Seizure Inventory, which is used to evaluate psycho-social problems in adults. After pilot work, 120 adolescents with epilepsy from five centres in the North America took the APSI and were interviewed by professional with respect to adequacy of adjustment in eight psycho-social areas. At least one parent or guardian was also interviewed. Using an item-by-item, empirically based technique, eight psycho-social scales were developed as well as three validity scales. Reliability of the scales was established by both internal consistency and test-retest procedures. Results for each adolescent are presented in profile form. These results give a visual display of the types and extent of problems that likely would be identified in a detailed professional assessment. It is anticipated that the APSI will be of value in a variety of treatment and research contexts.

Dodrill et al., (1984) conducted a comparative study on psycho-social problems in adults with epilepsy from four countries. Psycho-social problems in groups of adults with epilepsy from Canada, Finland, the German Democratic Republic and the United States were evaluated by the Washington Psycho-social Seizure Inventory. A number of similarities in psycho-social concerns were found across the four countries. At the forefront for each group were emotional problems followed by concerns pertaining to adjustment to the seizures themselves. Where far-reaching governmental support of a financial and vocational nature was lacking, difficulties in these areas were also found out. In all cases, few problems were found in matters pertaining to family relationships and to medical care. Additional factors contributing to differences in scores between the various groups have been suggested, but further investigation is required to determine which factors are of greatest importance in the international comparison of psycho-social problems in adults with epilepsy.

These studies points to the fact that psycho-social problems can vary based on childhood experiences, family atmosphere and cultural diversity. Psycho-social studies using culturally suitable and validated tools for realistic understanding of the problem are required for planning effective intervention strategies to deal with various psycho-social problems of epilepsy.

2.5 Self-esteem

Pradhan et al., (2003) conducted a study to evaluate psychopathology and self-esteem in chronic illness. 60 children and their parents were selected to participate in an open study. 30 children had epilepsy and the other 30 had thalassemia. Both the groups consisted of children randomly selected from the Epilepsy Clinic and Thalassemia Centre respectively, of a teaching general hospital. The children and their parents were interviewed and also rated on Childhood Psycho-pathology Measurement Schedule (CPMS) and Rosenberg's self -esteem scale. The data was analysed using Pearson's chi square test and Pearson's correlation coefficient. The children were seen to have high psycho-pathology on CPMS (average score : thalassemia group = 28.56, epilepsy group = 26.06). Depression was the subscale with the maximum elevation in both groups. Behavior problems were high in epilepsy. In addition, sadness and disinterest in life were common symptoms in thalassemia while irritability and panic were high in epilepsy. Children with epilepsy perceived a change in lifestyle after diagnosis. Self-esteem was moderately affected in both groups and this affected compliance with treatment in thalassemia. They concluded that chronic illness affects psychological health and self-esteem in children. Hence, in addition to the physical aspects it is necessary also, to focus on the psychological health of the child in order to ensure compliance and thus treat the child comprehensively.

Camp and Lyons, (2002) assumed that membership in a stigmatised group has negative consequences for the self-concept. Open-ended interviews and qualitative analysis were used in preference to global measures of self-esteem. It was found that although the women were aware of society's unfavourable representations of mental illness, and the effects this had on their lives, they did not accept these representations as valid and therefore rejected them as applicable to the self. The participants did not deny their mental health problems, but their acceptance of labels was critical and pragmatic. Labels were rejected when they were perceived as carrying an unrealistic and negative stereotype, when the women felt that their symptoms did not fit with the diagnostic criteria.

The research illustrates the importance of considering people's subjective understandings of stigmatised conditions and social reactions in order to understand the relation between stigma and the self-esteem.

2.6 Epilepsy and Economic Consequences

People with epilepsy continue to experience higher rates of unemployment and underemployment relative to people without epilepsy. The purpose of the study by Bishop and Allen, (2002) was to further the understanding of the factors that affect employability and predict employment status among adults with epilepsy. Binary Logistic Regression and chi-square analyses were used to evaluate the relationship between employment status and demographic variables, including gender, age, rural versus urban dwelling, education, and epilepsy-related variables, including seizure frequency, and epilepsy medication (AED) use, years since diagnosis and seizure type. Data for the analysis were collected from 146 adults with epilepsy. A number of variables, including gender, number of anti-epileptic drugs used, seizure frequency, and perceived interference of seizures in daily functioning were significantly associated with employment status. The results provide a comprehensive understanding of the effects of epilepsy on employment.

Kostopoulos et al., (2001) highlights the importance of studying the economic consequences of epilepsy and of interpreting the results on the international level. The results of epilepsy cost studies can provide insight into the distribution of the cost of epilepsy and the impact of epilepsy on the national expenditure on health care.

A study conducted by Guerrini et al., (2001) on the cost of epilepsy for children and adolescents in Italy revealed that the cost vary significantly according to the severity and duration of the disease. Hospital services and drugs are the major sources of costs. The setting of health care plays a significant role in the variation of the costs, even for patients in the same category of epilepsy.

Economic burden of epilepsy in India was studied by Thomas et al., (2001). Epilepsy Centers attached to University hospitals in six states of India participated in this study. Data on clinical characteristics, utilization of medical services, and costs were collected in a standardized format. There were 285 patients (mean age, 22.6 + 12.5 years) drawn from six states in this study. The annual cost of epilepsy per patient was INR 1,3755 (US$ 344) The direct cost of epilepsy per patient was INR 3,725 (US$ 93), and the indirect cost was INR 10031 (US$ 251). Direct cost included medical consultations (INR 329), laboratory services (INR 271), hospitalization charges (INR 316), and cost of travel to clinics (INR 659). The indirect cost included the cost of lost productivity due to its complications, or attendance to clinics. There are >5 million people with epilepsy in India. The economic burden due to epilepsy to the nation is to the tune of INR 68.75 billion (US$ 1.7 billion). The annual economic burden of epilepsy in India is 8.82 percent of GNP per capita and 0.5 percent of the GNP.

These studies highlight the fact that the direct and indirect cost of epilepsy differs according the severity of the disease, duration of illness number of anti-epileptic drugs used and treatment modalities adopted by individual patients.

2.7 Anxiety and depression

de Souza., (2006) in a study titled 'A psycho-social view of anxiety and depression in epilepsy' among sixty patients and 60 healthy subjects were interviewed at the out-patient clinic for epilepsy, using the Beck Depression Inventory and State-Trait-Anxiety Inventory. The objective of the semi-structured interview was to identify the patients' perception of the disease, self-concept, personal strategies, and perception of seizure control. There was a significant difference in anxiety and depression between the groups, as well as a strong relationship between perception of seizure control and depression and anxiety, independently assessed.

According to Gilliam et al., (2004) epilepsy is a chronic disorder that adversely affects social, vocational, and psychological functioning. Despite the variety and complexity of the negative clinical associations with epilepsy, depression is remarkable in prevalence and related adverse effects on health status. An estimated 30-50 percent of persons with refractory epilepsy have major depression, and depression has a stronger correlation than seizure rate with quality of life. Suicide is one of the leading causes of death in epilepsy.

Suicide rate in Kerala is increasing at alarming proportion. In a pioneering study of the dynamics of attempted suicide in Kerala, based on 60 cases admitted for attempted suicide in Kozhikkode Medical college, Jayachandran (1989) found that 32 percent of the attempted suicide were either because of bodily illness (16 percent) or because of depression (16percent). Twenty four percent of the case attempted suicide due to unemployment and remaining due to other personal reasons like love affairs (20 percent), marital problems or adjustment problems with other family members. This study using *Suicide Intent Scale* developed by Pierce (1977), further revealed that among attempters 68 percent of them the degree of *intentionality* for the attempt was only minimal to mild . This result indicated that the attempts were mainly a cry for help rather than real intention to die and psycho-social intervention has a definite role in preventing attempted suicide and suicide.

According to Lecrubicer, (2001) psychological illness is responsible for considerable disability worldwide. Different measures of disability has been used in different studies, they have consistently demonstrated that individuals with depression and anxiety disorders experience impaired physical and role functioning, more days in bed due to illness, more work days lost, increased impairment at work, and high use of health services. The disability caused by depression and anxiety is just as great as that caused by other common medical conditions, such as hypertension, diabetes, and arthritis. Co-morbidity of depression with anxiety or medical illness further increases the disability experienced by sufferers. Recognition and treatment, however, relieve the burden imposed by untreated depression on the individual, society and health services.

Piazzini et al., (2001) conducted a study on depression and anxiety in patients with epilepsy. The aim of the investigation was to study the interaction between depression/ anxiety and epilepsy. 150 individuals with partial epilepsy, 70 with idiopathic generalized epilepsy, and 100 controls were administered two self-rating mood questionnaires for the evaluation of depression and anxiety respectively. The group with left TLE appeared to have the highest levels of depression and anxiety. The final results of the study confirmed that some mood disorders are common throughout the epilepsy population, especially in patients with left TLE. No correlation was noted between the frequency of seizures and onset of epilepsy and the results of the mood questionnaires. Moreover, no differences were found in depression and anxiety between males and females among both left focus and right focus epilepsy patients.

Richard et al., (1998) studied the prevalence of psychiatric disorder and the level of cognitive function in children with epilepsy in Kerala. Children with epilepsy were identified during a population based epidemiological study of 1403, 8-12 year olds. They were compared with age, sex and social class. Matched controls on measures of reading, vocabulary, and non-verbal test, but performed worse on tests of vocabulary and reading, suggesting a specific disadvantage in the area of education. Psychiatric disorder was more prevalent in children with epilepsy.

Roth et al., (1994) conducted a study on physical exercise, stressful life experience and depression in adults with epilepsy. Adults with epilepsy completed self-report measures of exercise participation, barriers to exercise, stressful life experience, depression and general psycho-social adjustment (n-133) as part of routine out-patient visits. Descriptive statistics showed lower levels of depression among patients who exercised regularly. Structural Equation Analyses confirmed the fit of a path model that included significant direct effects of exercise and stressful life experience on depression. These effects were significant of each other, and independent of the influence of other predictor variables, such as seizure frequency, age and gender. Stressful life experience also had a direct unique effect on seizure frequency in the multivariate models. These results suggest that problems with depression, which are common in adults with epilepsy, are significantly lower among those who exercise.

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. Many 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. Certainly in considering anxiety, the context in which it is occurring has to be understood, as one cannot say that a particular degree of anxiety is pathological or not.

Williams (1979) emphasized the occurrence of short-lived dense depression as an immediate sequele of a convulsion as particularly striking, emerging from the post-ictal confusion and ending quite quickly. Gunn (1969) described depressive symptoms as being particularly common in people with epilepsy who were also in prison, and Millor et. al., (1974) described children with epilepsy as being particularly prone to depression. It may be noted that the incidence of depression in epilepsy in centers which draw upon a selected population is less than in the unselected population of mental hospitals.

These studies reveal that anxiety and depression are more common among people with epilepsy which can interfere with treatment sucess and quality of life of persons with epilepsy. This co-morbidity can further increase the burden of epilepsy.

2.8 Epilepsy and Locus of Control

To explore and delineate the relationship between biomedical (seizure frequency and number of years since diagnosis) and psychosocial predictors (LOC, social support and mood) and the HRQOL out comes of Chinese patients in Hong Kong. Lau et al., (2002) concluded that the psycho-social variables did make a significantly independent contribution to the prediction of QOL of PWE. The statistical significance of the health, LOC and the satisfaction with the social support confirmed the importance of the influence of the subjective sense of mastery of condition.

Gopinath et al., (2000) conducted a questionnaire survey about doctor-patient communication, compliance and locus of control among South Indian people with epilepsy. The subjects comprised 200 adult persons with epilepsy, 113 males and 87 females, mean age 30.5 (range 18-67) years. Over one-third of the subjects received from the doctor insufficient information about epilepsy and its treatment. There was a significant positive correlation between effective doctor-patient communication and compliance. A majority of the patients had an external locus of control, which negatively influenced the compliance. Even in a comprehensive epilepsy clinic of a model tertiary referral central in a developing country, a significant proportion of patients do not receive optimal information about epilepsy from the doctor. Knowledge about their disease will encourage people with epilepsy to make informed choices, and achieve better compliance and personal control of their problems. Educating primary and secondary care physicians about the importance of doctor-patient communication in the management of epilepsy and educating the public about the positive aspects of life in epilepsy cannot be over emphasized.

These studies on locus of control show that people with epilepsy generally have an external locus of control which interfere with their self-esteem and compliance behaviour. Good doctor - patient communication and patient empowerment are essential for developing a sense of control among patients in the management of their epilepsy.

2.9 Epilepsy and Quality of Life (QOL)

Thomas et al., (2005) studied pharmcotherapy, seizure control and QOL in person with epilepsy in one hundred and twelve patients with epilepsy (59 males and 53 females) in the R. Madhavan Nayar Centre for Comprehensive Epilepsy Care (SCTIMST), Trivandrum, Kerala .Quality of life was assessed by using Malayalam version of QOLIE:31. The study revealed frequent seizures and polytherapy have significant association with poor QOL in persons with epilepsy.

Johnson et al.,(2004) conducted a study to determine the independent effects of depression and anxiety on health-related quality of life (HRQOL) in epilepsy as well as the relative explanatory power of psychiatric co-morbidity compared with demographic and clinical epilepsy variables (e.g., seizure frequency, severity, and chronicity). It was conducted in Patients (n = 87) with temporal lobe epilepsy completed self-report measures of depression, anxiety, HRQOL, and seizure severity. Information was derived regarding subjects' seizure frequency, duration, and treatment. HRQOL status (QOLIE:89) was examined in relation to self-reported symptoms of anxiety and depression, clinical seizure features, and demographic characteristics. Depression and anxiety were independently associated with reduced HRQOL. Psychiatric co-morbidity explained more variance in HRQOL than did combined groups of clinical seizure or demographic variables. Although weaker in explanatory power than psychiatric co-morbidity, several epilepsy factors were nonetheless significantly related to HRQOL, including seizure frequency, severity, and chronicity. They concluded that inter-ictal anxiety and depression exert independent adverse effects on HRQOL. In addition, frequent, severe, and chronic seizures reduce HRQOL, but appear less powerful predictors of HRQOL than interictal psychiatric symptoms. Recognition and treatment of co-morbid depression and anxiety is an important consideration in improving quality of life in epilepsy.

Meijer et al., (2002) examined the way coping styles and locus of control contribute to the prediction of psychosocial adjustment in adolescents with a chronic illness. Psycho-social adjustment of 84 adolescents aged 13-16 years with a chronic illness was assessed with measures of social adjustment, global self-esteem and behaviour problems. Linear regressions were performed with demographic factors (age and gender) and stress-processing factors (coping style and locus of control) as predictor variables. Results indicated that coping styles were related to most aspects of social adjustment. The coping style 'depression' was a predictor for poor adjustment, viz., low social self-esteem and high social anxiety. Avoidance and locus of control were not strongly associated with psycho-social adjustment.

Cho et al., (2002) evaluated the quality of life in epilepsy (QOLIE) of 210 epilepsy adult patients. The QOLIE:31 questionnaires for self-assessment of quality of life were used for this assessment. They assessed the correlation between QOLIE concerns (Seizure worry, Overall QOL, Emotional well-being, Energy / fatigue, Cognitive function, Social function and Medication effects) and clinical parameters such as age, gender, marital status, education level, age at seizure onset, duration of illness and number of anti-epileptic drugs (AEDs). The mean sub scores of QOLIE:31 items were 54.9

(Medication effects), 52.0 (Energy-fatigue), 50.1 (Overall QOL), 42.4 (Seizure worry) 41.5 (Emotional well-being), 36.3 (Social function), and 30.9 (Cognitive function). The mean of overall health was 59.4. The items of QOLIE did not show any significant correlation with age at seizure onset or duration of illness. However, education level, economic status, number of AEDs, and frequency of seizures could be related with QOLIE. They identified several risk factors for poor QOL in patients with epilepsy. They explored different factors including cultural influences that may explain these findings. These results provide information about patients with epilepsy that may be helpful in their emotional support, as well as drug treatment.

With data from 134 adults with refractory complex partial seizures participating in a randomized controlled anti-epileptic drug (AED) trial, Birbeck et al., (2002) compared the change in HRQOL across groups having different levels of change in seizure frequency: 100 percent, 75-99 percent, 50-74 percent reduction, and 0-50 percent increase or decrease. Changes over time within each seizure-reduction group also were assessed. HRQOL was measured by the QOLIE:31, QOLIE:89, and SF-36. Subjects who became seizure free reported significantly more positive change than those who did not on the QOLIE :31, QOLIE-89 and Overall scores.

Suurmeijer et al., (2001) randomly selected 210 persons with epilepsy. During their visit to the out-patient clinic, they completed a questionnaire assessing, among other things, health perceptions and social and psychological functioning. Additional information about their medical and psycho-social status was gathered from the patient files. Data were analyzed by using a Hierarchical Regression Analysis. Because all of the variance in QOL of the patients was explained by the psycho-social functioning of the patients and the role it plays in the achievement of a good QOL. Both informal and professional support may be an adjunct to conventional treatment.

Andermann (2001) investigated the relationship of the laterality of the epileptogenic lesion to personality factors, emotional processing and the subjective experience of quality of life self -assessment in candidates for epilepsy surgery. Eighteen patients (aged 19-61 years) had localization – related epilepsy in the left temporal lobe (LTLE), and 20 were demographically matched normal subjects. The Spielberger Trait / State Anxiety questionnaire and the QOLIE:31 questionnaire for self-assessment of quality of life were used. One-way Analyses of Variance, Pearson's correlations, and Linear Regression Analyses were performed on group and anxiety levels and QOLIE variables. LTLE patients systematically showed higher levels of anxiety, and lower self-estimates of the quality of their lives when compared with Right Temporal Lobe Epilepsy RTLE patients. All anxiety measures were highly correlated with total QOL in LTLE ($P<0.05$) but not in RTLE patients; however, different parameters of QOL showed different relationships with measures of anxiety. Results of Multiple Regression Analyses suggested that the level of anxiety was relatively stable and less affected by QOL factors in LTLE as compared with RTLE patients ($P=0.03$).

Amir et al., (1999) conducted a study on self-efficacy and social support as mediators in the relation between disease severity and quality of life in patients with epilepsy. Eight-nine patients with epilepsy (58 percent men, age 36 + 12 years) were given the following instruments: Liverpool Seizure Severity Scale, Interpersonal Support Evaluation List, Epileptic Self-Efficacy Scale, Locus of Control Scale and the World Health Organization's Quality of Life questionnaire (WHOQOL). Structural equation modeling showed good fit between the research model and the data. Ninety percent of the variance of the WHOQOL was explained by a combination of disease severity, self-efficacy in epilepsy, social support, and locus of control. Mastery was found to mediate the correlation between disease severity of QOL, and social support was found to act as a mediator between disease severity and mastery. The study findings emphasize the possibility of improving QOL among patients with epilepsy by counseling and treatment aimed at reinforcing their self-efficacy and locus of control, as well as by improving their social support.

These studies on Quality of Life reveals that patients with epilepsy tend to have a poor quality of life because of seizure severity, number of AEDS, and associated psycho-social problems. Social support was found to act as mediator between disease severity and quality of life.

2.10 Group Intervention.

Gunter et al.,(2005) conducted an objective study to evaluate the impact of a comprehensive, multifaceted disease management program on self-reported quality of life (QOL) for adult patients with epilepsy. The study (1996-2000) employed a quasi-experimental research design in which primary care clinics in a South Western Integrated Delivery System were assigned to either the intervention or comparison group. The impact evaluation involved a comparison of responses to a validated QOL survey before and after a disease management intervention for adult health plan members with epilepsy. The intervention consisted of both formal provider training and associated tools and reinforcements as well as direct-to-patient interventions, including a comprehensive education booklet, a seizure diary, a patient education class, and a resource list. Pre-post analysis utilizing paired t-tests was conducted to identify any pre-post differences in QOL for both the intervention and comparison group patients, as measured by the seven specific domains of the epilepsy QOL instrument (QOLIE:31). The intervention group patients showed statistically significant positive changes in two QOL domains: Seizure worry ($P < 0.001$) and Emotional well-being ($P < 0.05$). One other domain, Overall Quality of Life, showed improvement in the intervention group that approached statistical significance ($P < 0.06$). There were no statistically significant changes for the comparison group. A well-designed, comprehensive disease management program can improve patient empowerment and coordination of care between the patient and provider, which resulted in an improvement in quality of life, one of the most central patient outcomes in this difficult disease.

Helde et al., (2005) conducted a study titled 'A structured, nurse-led intervention program improves quality of life in patients with epilepsy : A randomized, controlled trial'. The study tested the hypothesis that structured epilepsy nursing improves quality of life (QOL). One hundred fourteen adult patients with uncontrolled epilepsy were randomly assigned to either an intervention group or a control group. The intervention group was offered an interactive, 1-day group education program followed by extended nurse follow-up and counseling. The nurse was present at as many out-patient consultations as possible and performed repeated consultations by telephone. All patients completed the QOLIE:89 before randomization and after 2 years. QOL was significantly improved from inclusion to completion of study in the intervention group ($P=0.019$), mainly in the sub items for Health discouragement ($P=0.01$), Medication effects ($P=0.035$), and Physical role limitations ($P=0.05$).This is the first study to demonstrate a significant effect of a structured nurse-led intervention program in QOL of patients with epilepsy.

In an interventional study conducted by Sharif et al., (2005) on 110 patients with Chronic Liver Disease (CLD) in Shiraz Liver Transplantation Center (SLTC). Subjects with the required CLDs criteria were selected and randomly divided into experimental (55) and control (55) groups. A two-part questionnaire with 25 items concerning demographic and general information and 29 items regarding QOL was used. The psycho-educational needs of the experimental group were assessed in a session before the intervention, then the experimental group took part in 3 sessions individually and one session in groups. The questionnaires were filled in again for both groups but the control group did not receive the intervention program. Findings revealed no significant differences between the two groups from the view point of demographic characteristics such as marital status, gender, etc. ($p > 0.05$) and from the point of clinical variables no statistically significant differences were found ($p > 0.05$). Findings revealed statistically significant differences in all domain of QOL in the experimental group three months after the intervention ($p = 0.01$), while there was no statistically significant difference in the control group.

Snead et al., (1994) conducted a study regarding the development and initial implementation of a 6-week structured psycho-educational group intervention for adolescents with epilepsy and their parents. In pre intervention, the QOLIE:AD-48, Childhood Depression Inventory, and Revised Children's Manifest Anxiety Scale were administered. Educational topics included medical aspects of epilepsy, healthy lifestyle behaviors, and family and peer relationships, understanding self-image and self-esteem, and stress management techniques. Participants were introduced to a variety of cognitive-behavioral strategies, and were encouraged to share their own experiences with epilepsy. Feedback from adolescent and parent participants indicated that the intervention was relevant to their needs, helped them better understand their epilepsy, and allowed an opportunity for positive peer support. Also, post intervention outcome measurement indicated an overall positive trend for quality of life improvement in the adolescents. There remains, however, a paucity of research concerning psycho-social interventions for adolescents with epilepsy.

Ackerson et al., (2002) conducted a study on the development of a structured group intervention for adolescents with epilepsy and their parents. Nine adolescents age 13-18 years were screened. Five (2 boys and 3 girls) qualified and were enrolled. of these, one patient did not complete the program due to a family illness. After the final session, all participants completed an anonymous evaluation form including Likert type scale items and open-ended questions. Overall level of satisfaction with the group was high. Responses to open-ended questions indicated that parents and adolescents valued the interaction with other participants and the support provided by the group. In addition, several respondents indicated particular topic areas covered in the sessions as what they liked most about the groups. Both adolescent and parent participants responded positively to participation in the group sessions. Social interaction with other participants and factual information presented in groups were most commonly indicated and valued by the participants. The adolescents varied greatly in age (13-17 years) as well as development level. Overall cognitive level and degree of independence from parents may influence the applicability of the group for some adolescents.

Impact of a group intervention on the quality of life of adolescents with epilepsy was conducted by Schmitt et al., (2002). Pre and post intervention ratings of quality of life using the QOLIE were obtained from adolescents with epilepsy and at least one of their parents participating in a six-session (weekly) structured cognitive-behavioural group intervention. All of the adolescents were being treated with anti-epileptic medication while they participated in the group and some continued to experience seizures. Certain items on the QOLIE address symptoms or general health states that an intervention of this type would not be expected to impact even if successful. Therefore, before analysis of the data, the researchers identified the critical items on the QOLIE for analyses in addition to the derived sub-scales and total score. The preliminary data demonstrates a potential positive effect on adolescent quality of life as measured by the QOLIE from participation in a structural group psycho-social intervention for adolescents with epilepsy and their parents. The small size (n=4) is an obvious limiting factor of the study.

Ried et al., (2001) conducted on educational program for patients with epilepsy and their relatives. According to them, the knowledge of patients with epilepsy about their own condition is poor, and thus the need for educational programs for people with epilepsy has long been recognized. However, no such programs have been established in their routine care. The Modular Service Package Epilepsy (MOSES) now tries to fill this gap for patients in German speaking countries. The program was developed by a multidisciplinary group (neurologists, non-medical professional helpers, and representatives of national epilepsy associations) for people with epilepsy older than 16 years, independent of the kind and severity of their epilepsy. MOSES is designed for group education and can be used among in-patient and out-patient settings in epilepsy centers in clinics and by neurologists in private practice. The program aims to help patients achieve a better understanding of their disease to gain more self-confidence, and to take over responsibility, thus supporting patients to become experts in managing their own illness. Being modular in structure, MOSES includes nine units: living with epilepsy, epidemiology, and basic knowledge, diagnostics, therapy, self-control, prognosis, psycho-social aspects and network epilepsy, MOSES consists of a workout manual for patients and a trainer manual. For potential trainers, special "train-the trainer seminars" are offered and considered mandatory. About 400 patients have participated in a MOSES training in Germany, Switzerland and Austria. The efficacy of the program is currently been evaluated.

Outcomes for negative symptoms over a one year period were examined in two groups of schizophrenic patients, one receiving psycho-educational multiple family group treatment standard care was conducted by Dyck et al., (2000). A total of 63 out-patients aged 18 to 45 years, with DSM-IV diagnoses of schizophrenic disorders were randomly assigned to standard care or multiple family group psycho-education treatment at a large mental health center in Washington. Treatment assignment was stratified by whether patients were taking typical or atypical anti-psychotic medications. When the analysis controlled for baseline negative symptoms, participants in the multiple family group experienced significantly reduced negative symptoms compared with those receiving standard care. The study demonstrated that a psycho-educational multiple family group intervention was more effective than standard care in managing negative symptoms over a 12-month period.

Reiter and Andrews (2000) conducted a study on neuro-behavioral approach for treatment of complex partial epilepsy. This is a retrospective study of the efficacy of a short- term comprehensive multidisciplinary neuro-behavioral treatment approach for complex partial epilepsy. Eleven patients were treated intensively for five consecutive days followed by 6 months of weekly telephone contact and an additional 6 months of monitoring of seizure logs and journals. Weekly data was analyzed at least 24 months after initiation of treatment. Pretreatment seizure frequency ranged from 1 to 15 per month. Post-treatment seizure frequency was zero per months for the nine patients who experienced less than four seizures per month for the other two patients. Additional benefits of the treatment program were improved levels of professional achievement in the arts and computer sciences and reduction of medication dosages.

A psycho-educational approach by Ogata and Amano, (2000) was taken with 174 epileptic patients. Using this approach, no family problems were recognized among patients with idiopathic generalized epilepsy (IGE) or among those with symptomatic generalized epilepsy (SGE) and 1 patient with non-temporal lobe epilepsy (non-TLE), did exhibit family problems indicating that such problems involving IGE or SGE cases can be prevented through educational programs using psycho-educational approach. This fails, however to prevent such problems for TLE or non-TLE cases. Furthermore, small group psychotherapy was given to 10 patients with intractable TLE. They were directed to make self-evaluations regarding therapeutic factors specially modified for these particular patients. Relatively high evaluations were given on every factor when compared with the results of individual psychotherapy.

Spector et al., (1999) conducted a study on reduction in seizure frequency, following a short-term group intervention for adults with epilepsy. A preliminary investigation of the efficacy of a group intervention combining a range of psychological approaches and techniques for seizure management in adults with poorly controlled epilepsy. An uncontrolled AB group design was employed. Seven adults with intractable seizures took part in 8, weekly group sessions, which included providing information, employed cognitive-behavioral techniques and addressed emotional difficulties. Participants kept weekly seizure logs during the intervention and the following 3 months. Five questionnaires were administered before and after the intervention and the following 3 months. Seizure frequency and scores on the questionnaires were used as outcome measures. There was a significant reduction in seizure frequency in the group, which persisted at follow-up. There were no significant changes on any of the questionnaires. The results suggest that a group-based intervention incorporating a range of psychological techniques may be effective for improving seizure control.

Sally et al., (1999) conducted a study on Meta-analyses of medical self-help groups. In particular medical self-help groups often promoted by hospitals as viable treatment alternatives, have no systemized database from which to draw conclusions about overall effectiveness compared to traditional group therapies. A preliminary assessment of this area is presented using a meta-analysis of articles called from a comprehensive review of the literature from 1970 to 1997. Results indicate that although the post treatment analysis produced no significant differences between active and control conditions, pre to post-treatment scores indicated that self-help groups produced higher patient improvement when compared to the control group.

An effective open-ended therapy group for persons with serious mental illness can be organized around a problem-solving format. Such a group focuses on identifying problems, defining them in a solvable form, generating alternative solutions, evaluating the alternatives, selecting an alternative for implementation, and determining the effectiveness of the problem-solving plan. Descriptions of problem-solving groups that are based on this model are available (Bendell and Lennok, 1997).

To compare outcomes in psycho-educational multiple family group treatment vs. psycho-educational single-family treatment, McFarlane et al., (1995) selected a total of 172 acutely psychotic patients, aged 18 to 45 years, with DSM- III Schizophrenic disorders were randomly assigned to single or multiple family psycho-educational treatment at Sir Public hospitals in the state of New York. Psychotic relapse, symptom status, medication compliance, re-hospitalization and employment were assessed independently during 2 years of supervised treatment. The multiple family groups yielded significantly lower 2 year cumulative relapse rates than did the single family modality (16 percent vs 27 percent) and achieved markedly lower rates in patients whose conditions had not remitted at index hospital discharge (13 percent vs 33 percent). The relapse hazard ratio between treatment was 1:3. The relapse rate was less than half the expected rate (65 percent to 80 percent for two years) for patients receiving individual treatment and medication. Re-hospitalization rates and psychotic symptoms decreased significantly, and medication compliance was high, to an equal degree in both modalities. Psycho-educational multiple family groups were more effective than single family treatment in extending remission, especially in patients at higher risk for relapse, with a cost benefit ratio of up to 1:3.

To test whether the statistically significant results of a randomised clinical trial of an in-patient family intervention were clinically significant for hospital practice, Eriksen et al., (1994) conducted a study on physical exercise in women with intractable epilepsy. Fifteen women with pharmacologically intractable epilepsy were given physical exercise (aerobic dancing with strength training and stretching) for 60 min., twice weekly, for 15 weeks. Seizure frequency was recorded by the patients for 3-7 months before the intervention, during the intervention period, and for 3 months after the intervention.

Medication and other known seizure-influencing factors were kept as constant as possible. Self-reported seizure frequency was significantly reduced during the intervention period. The exercise also led to reduced level of subjective health complaints, such as muscle pains, sleep problems and fatigue. The exercise reduced plasma- cholesterol ratio and increased maximum oxygen.

Glick et al., (1993) re-analysed outcome data using a measure of clinical significance based on the extent to which patients had recovered during the course of the intervention. A total of 169 hospitalised subjects and their families were randomly assigned to a psycho-educational inpatient family intervention or to a comparison group. Patient and family outcome measures were assessed at admission, discharge and six and 18 months after admission. Analyses of statistically significant differences in outcome suggested that inpatient family intervention was effective for certain patient sub-groups identified by gender and diagnosis. The re-analysis confirmed that in-patient family intervention was associated with clinically significant improvement at discharge, especially for female patients and patients with chronic schizophrenia and bipolar disorder. These effects were maintained six months after admission before attending at 18 months. Inpatient family intervention results in clinically meaningful outcomes for certain subgroups of patients and their family.

Hogarty et al., (1991) demonstrated earlier that a novel family psycho-educational approach and an individual social skills training approach designed for patients living in high expressed emotion households each reduced schizophrenic relapses by one half when compared with medication controls in the 1st year after hospital discharge. The combination of treatments resulted in no relapse. Results have now been obtained after 2 years of continuous treatment. By 24 months, a persistent and significant effect of family intervention on forestalling relapse was observed, but the effect of social skills training was late in the 2nd year. There was no additive effect on relapse that accrued to the combination of treatments. Beyond 2 years, however, the effect of family intervention was likely compromised as well.

Hoberman et al.,(1988) conducted a study on group treatment of depression. The study attempted to identify patient characteristics predictive of individual outcome in a psycho-educational group treatment for uni-polar depression. Forty participants meeting Research Diagnostic Criteria for depressive disorders were assessed on demographic and psychological variables at both pre and post treatment and on participation variables during treatment. The treatment modality was the coping with depression course. At the end of treatment, 85 percent of the subjects no longer met diagnostic criteria for depressive disorders. A step-wise multiple regression analysis attained a multiple correlation of 0.92, accounting for 85 percent of the variance in post treatment depression level. The results suggest that the most robust predictors of outcome are pre treatment levels of depression, social functioning, perceived mastery over events, and early positive perception of group cohesiveness.

Hegelson et al., (1990) evaluated the efficacy of the Sepulveda Epilepsy Education Program (SEE), using a controlled outcome design. SEE is a 2-day psycho-educational treatment program designed to provide medical, educational and psycho-social therapy. 38 outpatients, matched according to seizure type and frequency were randomly assigned to treatment (N-20) or waiting list control (N-18) groups. The major outcome measures used were a 50-item true-false test specifically designed to evaluate the SEE program, the Washington Psycho-Social Seizure Inventory, the Beck Depression

Inventory, Lubin's Depression Adjective checklist, the State-Trait Anxiety Inventory, the Acceptance of Disability Scale, and Sherer's Self-Efficacy Scale. Significances between the two groups were found on the three major subscales of the 50 item, true-false test. The treatment group demonstrated a significant increase in overall understanding of epilepsy, a significant decrease in fear of seizures, and a significant decrease in hazardous medical self-management practices. In addition, an objective measure of blood levels of anti-epileptic drugs (AEDs) showed the treatment group to have a significant increase in medication compliance.

Family participation in the long-term treatment and rehabilitation of persons with serious mental disorders taps into an important resource available to psychologists working with these clients. Dysfunctional patterns of family interaction can be remediated by the use of social skills training, thus reducing stress experienced by the client. Also, the supportive aspects of families can be incorporated into the client's treatment. A problems-solving- oriented methods of multiple family therapy (MFT) was first developed by Anderson et al., (1986), which also facilitated supportive social network development among families. This treatment is based on a psychological model of psycho-education. Problem solving and social network development for the treatment of persons with schizophrenia. The original model was adapted for use in a rehabilitation oriented program of treatment and has been described in detail elsewhere (Bendell et al., 1994).

According to Mayer and Gutjahar (1977), in a Pilot study on theme centred groups with patients with epilepsy, the meaning of group therapy to the patients who took part was the possibility of interaction with others. They consider out-patient care in real life situations, with its possibilities for the reduction of a conflict situation, to be at least as sensible and perhaps less costly than short-term confinement of the patients in rehabilitation centres, which build up hopes that are quickly shattered in the reality and lack of understanding of society, forcing the patients back into their loneliness.

Several surveys indicate that relatives need more information about the disease and how to deal with it more effectively. The research of Brown and co-workers (1958) and the further work on the concept of "expressed emotion" by Vaughn (1986) strongly support the importance of psycho-educational work with relatives of schizophrenia patients. Relatives involved are experiencing severe emotional and economic strain and often suffer from various health problems.

These results points out the importance of providing such psychotherapeutic approaches as group psychotherapy and self-help groups in addition to psycho-educational programs involving family groups to deal with various psycho-social problems and to enhance the quality of life of patients with epilepsy and their families.

2.11 Meditation

Deepak et al., (1994) conducted a study on Meditation, which improves clinico-electro-encephalographic measures in drug resistant epileptics. A group of 11 adults with drug resistant epilepsy was given training in meditation, while another group of adults served as the control group. All patients were given anti-epileptic drugs, and their serum drug levels were monitored regularly. Patients in the experimental group were given training in meditation, and they practised meditation 20 minutes / day for a year. There was a significant reduction in seizure frequency and duration, an increase in the dominant background EEG frequency, reduction in mean spectral intensity of the 0.7-7.7 Hz segment, and an increment in mean spectral intensity in the 8-12 Hz segment of the EEG. All changes were statistically significant. The control group did not show significant changes in seizure frequency and duration during the observation period of 1 year. Findings indicate that continuous meditation can substantially improve the clinico-electro-encephalographic picture in drug resistant epileptics.

Rajesh et al., (2006) conducted a study to assess the efficacy of yoga-meditation protocol as an adjunctive treatment in patients with drug-resistant chronic epilepsy. 20 patients (14 males and 6 females) with medically refractory epilepsy meditation (*Pranayama*) intervention for three months. At three months, a reduction in seizure frequency was noted in all except 1 patient, in the 16 patients who continued the yoga meditation for 6 months a progressive decline seizure frequency was observed and all the 8 patients who continued meditation further for one year there was significant seizure reduction.

The review of relevant literature covering various medical and psycho-social aspects and available treatment options for epilepsy and group intervention studies has enabled the investigator to adopt a suitable research methodology and research design for the present study regarding the efficacy of group interventions (Psycho-education and meditation) in the psycho-social care of patients with epilepsy.

CHAPTER - 3

METHODOLOGY

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METHODOLOGY

Department of Neurology, Sree Chitra Tirunal Institute for Medical Science and Technology (SCTIMST), Thiruvanathapuram, Kerala. pioneered a novel psycho-educational approach through group sessions for epilepsy patients and their family members. Epilepsy patients who are called by appointments and their family members are assembled in a hall prior to the epilepsy clinics, which are conducted for one hour on every Wednesday and Friday.

The center was also practicing Yoga - Meditation (*Pranayama* - controlled breathing exercise) for people with epilepsy as an add on therapy along with anti epileptic drug regimen with proven efficacy in significant seizure reduction (Rajesh et al., 2006). The present study endeavors to evaluate the efficacy of psycho-educational group intervention and meditation techniques in the psycho-social care of patients with epilepsy.

Statement of the topic

The study is entitled "Efficacy of group interventions in the psycho-social care of patients with epilepsy."

3.1 OBJECTIVES OF THE STUDY

1. To translate and validate a Malayalam version of Epilepsy Psycho-Social Effect Scale (EPSES developed by Chaplin-1990) and to use the scale among patients who attend the group intervention programs.
2. To translate and validate a Malayalam version of Quality of Life in Epilepsy Inventory (QOLIE-31, Version 1.0), developed by Cramer (1993).

3. To prepare counseling / training module for conducting the group sessions for patients with epilepsy.
4. To find out the effectiveness of the group intervention among different types of patient groups with epilepsy.
5. To find out whether the effectiveness of the group sessions has got any impact, if the seizures are controlled with medicines or remain intractable.
6. To assess the quality of life of patients who are attending the group sessions
7. To evaluate the present method of conducting the group sessions and to explore possibility of improving its practice.

3.2 HYPOTHESIS

1. Quality of life of the patients who are attending the group sessions are more when compared to those who are not attending the group sessions.
2. The more the number of times a patient attend group sessions the more will be the quality of life.
3. Intervention is effective irrespective of whether seizures are controlled or continue to be intractable.

3.3 Sample of the study

The total sample of the study for the standardization of the two scale / inventory and the experimental study together consist of 476 patients. The first part consists of Malayalam translation and standardisation of two epilepsy specific scales:1. Epilepsy Psycho-Social Effect Scale developed by Chaplin (1990), 2. Quality of Life in Epilepsy Inventory developed Cramer, (1993). A random sample of 440 epilepsy patients were selected (220 for each scale). The Malayalam version of the scales were then administered to four groups of patients (55 in each group) speaking Malayalam, English and bilinguals and patients from the epilepsy outreach centres for finding the reliability and validity following a test retest procedure. The scale validation study was conducted during 12 month period from March 2003 to March 2004.

The second part consists of evaluation of the efficacy of the two interventions (psycho-education and meditation) in the psycho-social status and quality of life of patients with epilepsy by a prospective, randomized pre-post design using two experimental groups and a common control group.The experimental study was conducted on 36 subjects:12 were in the psycho education group, 12 in the meditation group and the remaining 12 in the control group. The sample of the study was selected from the epilepsy clinic of R Madhavan Nayar Centre for Comprehensive Epilepsy Care, Department of Neurology, Sree Chitra Tirunal Institute of Medical Sciences and Technology. Thiruvanathapuram.

The inclusion criteria were:

- Patients registered in SCTIMST and diagnosed with epilepsy.
- Patients in the age group between 16 to 35
- Patients belonging to Thiruvananthapuram District
- Patients with a minimum of two seizures during the past one year

The exclusion criteria

- The patients who have already attended the psycho-educational group session or meditation earlier
- Patients with mental retardation

- Patients with other chronic physical illness
- Patients with major psychiatric illness.

All the 36 patients and family member selected for the experimental study were informed about purpose and nature of the study and the need for regular participation and requirement of written consent for voluntary participation in the study,

The whole sample for the experimental study was called for a meeting on a pre-scheduled day and was grouped into three groups of 12 patients each for psycho education, meditation and control groups using a Lottery Method of random sampling. Patients in the control group were informed that they are in the waiting list for both the intervention programs (Psycho-education and Meditation). The experimental study was conducted during 6 months period from May 2004 and November 2004.

3.4 Variables

The social and demographic characteristics of the patients analysed in this study include : age, sex, religion, education, occupation, marital status, type of family, number of family members, place of residence and atmosphere in the family. Type of seizure, disabling effect of AED, age at onset of the first seizure, family history of seizure disorder, seizure type, time of occurrence of seizure, duration of illness, number of seizure during last one year are taken as the clinical characteristics of the patients. Depression, State anxety, Trait anxiety, Total anxiety, Knowledge Attitude Practice, Self - esteem, Locus of control, Quality of Life (7 Components) and Epilepsy Psycho-Social Effect (14 components) are taken as dependent variables.

3.5 Tools and methods

The various psycho-social parameters of the three study groups namely, the psycho-education group, the meditation group and the control group were assessed using the following scales/inventories.

1. Knowledge Attitude and Practice Questionnaire (KAP)
   (Radhakrishanan & Jayachandran, 1995).
2. Depression Inventory (Kumar and Kumar, 2002).
3. State -Trait Anxiety Inventory (Mohandas & Kumar, 1994).
4. Self - Esteem Inventory (Thomas & Raj,1990).
5. Locus of Control (IE) Scale (Kumar & Immanuel, 1992).
6. Epilepsy Psycho-Social Effect Scale (EPSES)
   (Translated and standardized as part of this research).
7. Washington Psycho-Social Seizure Inventory (WPSIQOL) - Dodrill 1988.
   (Malayalam adaptation Thomas, 1977).
8. Quality of life in Epilepsy Inventory (QOLIE:31)
   (Translated and standardized as part of this research).

The investigator interviewed the patients and their family members and collected relevant personal and family information with the help of a pre-tested structured interview schedule. A pilot study was conducted among 20 patients with an established diagnosis of epilepsy who attended the epilepsy clinic of SCTIMST. The interview schedule was then modified after analyzing the results of the pilot study. The Epilepsy Counseling/ Training Module developed by the investigator was used for comprehensively educating the patents and their family members of the psycho-educational group. The patients in the meditation and control group were not given any educational intervention.

3.6 Standardization of the Tools

Out of the eight scales used in this study six of them were translated into Malayalam and adapted by different authors. The Psycho-Social Effect Scale (EPSES) and Quality of Life in Epilepsy Inventory (QOLIE:31) were translated and standardized by the researcher (Ref. Appendix) The standardization procedure and the reliability and validity of the various scales/ inventories used for the study are discussed below.

3.6.1 Depression Inventory

Depression Inventory used in this study was developed by Kumar and Kumar, (2002). The inventory consists of 15 items and was designed to measure the depth of depression. Its items were selected on the basis of observation, their attitudes and the symptoms characteristic of depressed patients.

Administration and scoring

The following instructions were given to the subjects. "A number of statements that people used to describe themselves are given below. Read each statement and put a tick mark in the appropriate space provided in the response column to indicate how you feel. There is no right or wrong answer." In the response column against each statements there were four choices namely. A, B, C and D denoting *almost never, sometimes, often and almost always* respectively. The scoring is done as follows. A score of 4, 3, 2, 1 are given to the category A, B, C, D for a positive statement and a score of 1, 2, 3, 4 are given to the category A, B, C, D for negative item respectively. The scores are then summed up to obtain the depression score of an individual. The maximum score will be 60 and minimum 15.

Reliability

The test-retest method is used to find out the reliability of the depression inventory. A group of 70 subjects were selected for calculating the test–retest reliability and administered the test after a week. The test was again administered to same group and a second set of score was obtained. The correlation coefficient thus obtained from the depression inventory was 0.91. Therefore the higher correlation value shows the higher rate of reliability of the depression inventory.

Validity

To find out the validity of the depression inventory, concurrent validity method was used. For this, the scores of depression inventory were validated against the concerned medical practitioner's rating of the patient on depression using five point rating scale. The correlation value thus obtained was 0.73.

3.6.2 Self – Esteem Inventory

Thomas and Raj (1990) developed the Self-Esteem Inventory. The test consists of 20 items. Ten items were positive and 10 items were negative. It is a five-point scale.

Administration and scoring

The following instructions were given to the subjects." Some statements are given below, indicate how much you agree with each statement. There are five response categories viz. A, B, C.D, and E. 'A' denotes 'strongly agree' and ' B" denotes ' agree, 'C' denotes 'undecided' 'D' denotes 'disagree' and 'E' denotes 'strongly disagree'. After reading each statement mark your answer with an 'X" mark in the appropriate circle. Select 'C' only when you can't say clearly whether you either agree or disagree with a statement. Do not omit any statement. Your responses will be kept confidential".

A score of 5, 4, 3, 2, and 1 is given to the category A, B, C, D and E for a positive item, while the scores are in reverse order for negative item. The final score is assigned by counting all the points. All the items in the scale are in the form of self-evaluative and self–descriptive statements. There are equal numbers of positive and negative items that are arranged in a random order.

Reliability

The Self-Esteem Inventory was administered on one hundred subjects and their scores for odd and even items of the inventory obtained. The split-half reliability coefficient calculated was 0.95 by using Spearman Brown Prophecy Formula. The test–retest reliability obtained in a sample of one hundred and twenty secondary school pupils is 0.90. Both these coefficients were significant at 0.01 levels.

Validity

Correlation between overall ratings of the subjects of forty postgraduate students about their self-worth (how do you evaluate yourself on a scale ranging from 0 to 100 about overall worthiness) and the scores on self-esteem inventory was found to be 0.67.

Scoring

A score of 5,4,3,2 and 1 was given to the category A, B, C, D, and E for a positive item and while the score in the reverse order is given for a negative item. The final score was assigned by counting all the points. All the items in the scale are in the form of self-evaluative and self-descriptive. There are equal numbers of positive and negative items, which are arranged in a random order.

3..6.3 State-Trait Anxiety Inventory

Speilberger's State-Trait Anxiety Inventory was adapted into Malayalam language by Mohandas and Kumar (1994). The test was used to measure the state anxiety and trait anxiety and total anxiety. The test consists of 36 items. The first 18 items are related with the state anxiety and the remaining 18 items were related with trait anxiety. It is a four-point scale. The total score of state and trait anxiety gives the total anxiety score of the subject.

Split - half Reliability

The test was administered to a sample of 70 students (35 graduates and 35 postgraduates) with males and females. The split-half reliability of the inventory was found to be 0.89 for State Anxiety and 0.79 for Trait Anxiety.

Test re-test reliability

In the test re-test reliability the State Anxiety was found to be 0.81 and 0.70 for Trait Anxiety.

Validity

The Concurrent Validity was found to be 0.84 for State Anxiety and 0.86 for Trait Anxiety.

Administration and Scoring

The subjects were given the following instructions "There were four response choices. The individual response was to be made by marking 'X' mark against the item which is selected.

3.6.4 Locus of Control (IE) Scale

Locus of control refers to the degree of control the individual think they have over what happens to them, that is it refers to the extent to which the individual feel that things which happened to them are determined by internal locus of control (Under their own control or external locus of control i.e., not affected by their behaviour). The internal–external scale (IE -Scale) that measures locus of control was developed and popularized by Rotter (1966).

The original scale contained 23 item forced choice statements. The present scale that consists of 15 items (dyads) was prepared, translated and standardized into Malayalam by Kumar and Thomas (1992).

Scoring

Scoring is done with the help of a scoring key. The scoring is in the direction of internal locus of control, i.e., higher scores indicate high internality. A weight or score of '1' is given to each internal statement the subject responded. For the other statement '0' mark is given. The score obtained by the subject out of the total score of 15 items is taken as the IE score of the subject.

Reliability

The split-half reliability of the test estimated using 100 subjects was found to be 0.69. This is high and significant indicating that the test has significant reliability.

Validity

The test is modeled after the well-known test for measurement of locus of control popularized by Rotters, (1966). Examinations of the nature of the items included in the scale gives ample evidence for the face validity and contend validity of the scale.

3.6.5 Knowledge, Attitude and Practice Questionnaire (KAP)

The survey questionnaire comprised of twenty four questions, prepared in Malayalam (Radhakrishnan and Jayachandran, 1995). The questionnaires were initially selected and standardized through a gallop poll survey in U.S.A. The questionnaires were designed to cover knowledge, attitude and practice towards epilepsy. All the questions were simple with' 'yes' or 'no' responses. The questionnaire had been field tested in a pilot study before the first epidemiological survey of epilepsy was conducted in three districts of Kerala in 1995 and the results were documented (Radhakrishnan et al., 2000).

3.6.6 Washington Psycho-Social Seizure Inventory Quality of Life (WPSIQOL)

The development of the WPSIQOL Scale was presented at the 21st International Epilepsy Congress in Sydney, September 1995. It was based on the total score for the Quality of Life in Epilepsy–31 Inventory, and the item which selected were those which correlated.40 or greater with the QOLIE:31 total score. For 204 adults referred to neuropsychological evaluation, the average score was 10.83 on the scale (SD =5.42). The sum of the 21 items correlates .83 with the QOLIE:31 total score using the same 203 subjects. Washington Psycho-Social Effect Scale Quality of Life (WPSIQOL)- by Dodrill (1988) The was translated and adapted to Malayalam by Thomas (1997) and it is in use in SCTIMST for the past many years and its sensitivity is documented through publications (Jayachandran 1999, 2002).

3.6.7 Epilepsy Psycho-Social Effect Scale

The Epilepsy Psycho-Social Effect Scale (EPSES) was originally developed for the investigation of psychosocial issues within the National General Practice Survey of Epilepsy in the United Kingdom in 1989 (Chaplin, 1990). The investigator translated it into Malayalam and cross-culturally validated.

The objective of the scale was to quantify the main psycho-social effects of epilepsy. It is used in adult population and has been used in populations of people with recent onset of epilepsy, patients with chronic epilepsy and rehabilitation clients. The EPSES contains forty-two statements derived from in-depth interviews with patients attending an epilepsy clinic in London. Statements are categorized into 14 domains of psycho-social effect. When completing the questionnaire, the person with epilepsy responds to each statement by indicating the level of agreement in a five point scale (Chaplin, 1990). Fourteen domains of Epilepsy Psycho-Social Effects Scale are : 1. Attitude towards accepting attacks, 2.Fear of having seizures, 3.Fear of stigma in employment, 4. Fear of confidence in future, 5.Lack of confidence about traveling, 6. Adverse reaction in social life, 7. Adverse reaction in leisure pursuits, 8. change of outlook on self, 9. Difficulty in communicating with family, 10. Problem in taking medication, 11. Distrust of medical profession, 12. Depression or emotional reaction, 13. Feeling of increased isolation, 14. Lethargy / lack of energy.

The endeavor of the investigator has been to satisfy the pertinent need to prepare a culture–specific inventory to quantify psycho-social effects among people with epilepsy in Kerala, India. It is rather a pre-requisite for the further research and outcome evaluation of psycho-social interventions among people with epilepsy.

3.6.7.1 Translation and Standardization of EPSE Scale into Malayalam Procedure

The translation of EPSES into Malayalam followed an interactive process of translation and back translation. The translation into Malayalam was conducted by a five-member team of bilinguals. The back translation into English was done by a different team of bilinguals. A subsequent modification of the wording and phrasing of the instrument was done after discussion of each item by a team of experts.

The final version was tested in a pilot study among twenty patients with epilepsy attending the Epilepsy clinic of the SCTIMST. In line with the principle that the translation should follow the method of the original, the researcher also used the procedure adopted in U.K by Chaplin, (1990). The weightings assigned in the original instrument was determined in accordance with the relative importance of statements within each dimension, as judged by professionals (Chaplin, 1990, Chaplin and Malmgren, 1999) As in the original study, a paired comparison study (Nunnally, 1981) was conducted, in which statements were presented in dyads. Professionals concerned with epilepsy were asked to identify which of the two statements indicated the greatest problem with adjustment to epilepsy. Cumulative judgments for each statement were converted into percentages and were divided by 10 providing actual weighting for each item. The English and Malayalam weightage of each of the forty-two items are shown separately in Table 3.3.

Table 3.1
Epilepsy Psycho-Social Effect Scale - English and Malayalam weightages

Domain No	Domains	Q.No.	English Weightings	Malayalam Weightings
D1.	Attitude towards accepting the attacks	1	2.42	0.74
		15	5.08	4.98
		29	2.50	4.31
D2.	Fear of having attacks	2	1.72	2.57
		16	6.02	2.15
		30	2.27	5.31
D3.	Fear of stigma in employment	3	2.33	2.65
		17	5.50	2.73
		31	2.17	4.64
D4.	Lack of confidence in the future	4	3.39	3.07
		18	3.79	4.39
		32	2.82	2.32
D5.	Lack of confidence about traveling	5	4.96	4.15
		19	2.28	1.24
		33	2.76	4.56
D6.	Adverse reaction on social life	6	2.48	2.98
		20	3.95	3.23
		34	3.57	3.73
D7.	Adverse reaction on leisure pursuits	7	3.65	3.23
		21	1.75	1.16
		35	4.60	5.56
D8.	Change of outlook on life/ self	8	4.09	2.32
		22	2.13	4.06
		36	3.78	3.56
D9.	Difficulty in communicating with the family	9	2.71	1.99
		23	4.10	4.23
		37	3.20	3.73

D10.	Problems with taking medication	10	3.03	2.57
		24	4.34	4.31
		38	2.62	3.07
D11.	Distrust of the medical profession	11	3.64	2.32
		25	2.25	2.73
		39	4.11	4.81
D12.	Depression or emotional reactions	12	3.71	3.56
		26	3.55	2.40
		40	2.74	3.98
D13.	Feeling of increased social isolation	13	2.77	2.07
		27	5.77	5.56
		41	1.95	2.32
D14.	Lethargy / lack of energy	14	2.77	2.73
		28	4.96	4.06
		42	2.27	3.15

Scoring

The subject's response to each of the forty-two statements was noted down in a 5-point Likert Scale. The values for options are as follows: 0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = almost always / always. The individual score given by each subjects were multiplied by the Malayalam weightage and thus the score in each subscale were obtained.

Reliability

Reliability was established utilizing a test–retest procedure (Anastasi, 1988). The Malayalam version of the full questionnaire was administered to 110 subjects (55 from the outpatient epilepsy clinic of SCTIMST and 55 pateints in the epilepsy outreach centers twice with an interval of one month. The results from the first administration were compared against those of the second to determine whether the questionnaire produced consistent results. Completion of the questionnaire was carried out on an individual basis, and the investigator interfered in no way with their response.

Pearson's correlation coefficient was calculated and the overall correlation was found to be significant. The result thus indicated good reliability. Average overall reliability score for the whole questionnaire was found to be 0.85, and that of the original scale was 0.64 (Chaplin, 1990). The individual domain reliability figures are given in Table 3.4.

Table 3.2
EPSES - Pearson's Correlation Analysis (Domain reliability)

Domain No	Domains	Correlation Coefficient
D1.	Attitude towards accepting the attacks.	0.72
D2.	Fear of having seizures.	0.77
D3.	Fear of stigma in employment	0.67
D4.	Lack of confidence in the Future	0.74
D5.	Lack of confidence about traveling.	0.56
D6.	Adverse reaction on social life	0.82
D7.	Adverse reaction on leisure pursuits	0.65
D8.	Change of outlook on life / self	0.64
D9.	Difficulty in communicating with the family	0.66
D10.	Problems with taking Medication	0.55
D11.	Distrust of the medical Profession	0.47
D12.	Depression or emotional reactions.	0.73
D13.	Feeling of increased social isolation.	0.72
D14.	Lethargy / lack of energy	0.79
	Overall domain reliability	0.85

Validity

The criterion related validity is most appropriate for local validation studies. The Malayalam version of the scale was validated against the original English version of Epilepsy Psycho-Social Effect Scale, where the original English version is taken as the 'Gold

Standard'. The English version was first administered to 55 adult patients from Kerala attending epilepsy clinic of SCTIMST who were well versed in English language. This English scale was re-administered to the same group after an interval of one month. The Malayalam version of the scale was administered to another group of 55 patients and English version was administered to a different group of 55 patients. Product moment correlation obtained was 0.49 (N=55) and is presented in Table 3.5. Criterion –related validity of the original scale was assessed from comparison of the results of subjects against judgments of medical staff closely associated with those subjects. Spearman's rank correlation analysis was conducted which revealed an overall mean validity for the scale 0.38.

Table 3.3:
EPSES - Spearman's correlation coefficient (Domain Validity)

Domain. No.	Correlation Domains	Coefficient
D1.	Attitude towards accepting the attacks	0.45
D2.	Fear of having seizures	0.35
D3.	Fear of stigma in employment	0.71
D4.	Lack of confidence in the future	0.70
D5.	Lack of confidence about traveling	0.62
D6.	Adverse reaction on social life	0.57
D7.	Adverse reaction on leisure pursuits	0.59
D8.	Change of outlook on life / self	0.50
D9.	Difficulty in communicating with the family	0.42
D10.	Problems with taking medication	0.49
D11.	Distrust of the medical profession	0.19
D12.	Depression or emotional reactions.	0.68
D13.	Feeling of increased social isolation	0.38
D14.	Lethargy / lack of energy	0.49
	Overall domain validity	0.38

3.6.8 Quality Of Life in Epilepsy Inventory (QOLIE:31 - Version 1.0)

An understanding of the assessment of quality of life of persons with epilepsy becomes essential for guiding effective treatment and for health outcome measurements. Development of culturally sensitive and suitable measures of quality of life is a need of the hour. The present endeavor is to translate and standardize a quality of life in epilepsy inventory in Malayalam language in Kerala, India among epilepsy population. Over the last 20 years, the study of quality of life (QOL) has assumed central importance in assessing outcome of medical and social interventions (Gill et.al., 1994).

The QOLIE :31 was developed in effort to assess health related quality of life in patients with epilepsy. The original questionnaire contains 31 items, 16 of which were drawn from existing scores, which included in other questionnaires (Brazier, 1993, Hadon, 1991,Nelson, 1990, Stewart, 1992, Vickrey, 1993) and 15 were developed by the QOLIE development Group. The QOLIE:31 contains seven multi-item sub-scales covering diverse aspects of QOL. The QOLIE:31 has one visual analogue scale of overall quality of life and 30 questions pertaining to diverse aspects of epilepsy QOL. Each aspect, the number of questions under that aspect and the range score for that aspect were as follows: Seizure worry (5,0-8), Overall quality of life (2,0-14), Emotional well being(5,0-15), Energy or fatigue (4,0-12), Cognitive functioning(6,0-27), Medication effect(3,0-3) and Social function (5 ,0-21), Total score(30,0-100). A higher score indicates better quality of life and a lower score indicates poor quality of life.

Scoring

The scoring procedure for the QOLIE:31 converts the raw pre-coded numeric values of items 0-100 scores, higher scores always reflecting better quality of life. An overall score may be obtained by using a weighted average of the multi-item scores. This scale is standardized and available in U.S. English, Dutch, Danish, German, Canadian, French, Italian, Swedish Spanish and U.K., English. The cross- cultural translation into nine other languages makes it feasible to use the scale in multinational clinical trials after validation in each population .

3.6.8.1 Translation and standardization of QOLIE:31 into Malayalam.

Procedure

The adaptation of QOLIE:31 into Malayalam included translation into Malayalam and back translation into English. The translation into Malayalam was done by a five-member team of bilinguals. A different team of other 5 members back translated the Malayalam version again into English. After this a panel of bilingual experts discussed each item and wording. Some of the questions were modified for e.g. the question number 20 regarding *the problem with driving.* As in this part of India all people do not drive, the question was modified as "Do you drive / travel alone". The question number 31 was deleted, as many could not understand the question. The area of this question was covered by other questions in the inventory. The final version was then tested in a pilot study among 20 patients with epilepsy attending the epilepsy clinic of SCTIMST, which confirmed a high level of item comprehension.

Reliability

The Malayalam version of the questionnaire was then administered into two groups of 55 adult epilepsy patients each attending the epilepsy clinic of Sree Chitra Tirunal institute of Medical Sciences and Technology and 55 patients attending the out reach epilepsy clinic of the Institute in Malappuram and Trissur Districts. The test was re-administered to the same group after an interval of one month to assess the test-retest reliability of the scale.The overall reliability was found to be 0.84.

Table 3.4
QOLIE : 31 - Reliability (Test-retest) SCTIMST Sample
(Malayalam - Malayalam)

	QOL Domains	Malayalam- Malayalam
1	Seizure Worry	0.69
2	Overall Quality of Life	0.75
3	Emotional Well being	0.70
4	Energy/ Fatigue	0.51
5	Cognitive Functioning	0.87
6	Medication Effect	0.61
7	Social Functioning	0.62
	Overall Score	0.84

Table 3.5
QOLIE : 31 - Reliability (Test-retest) Out-reach Clinic sample
(Malayalam - Malayalam)

	QOL Domains	Malayalam - Malayalam
1	Seizure Worry	0.78
2	Overall Quality of Life	0.77
3	Emotional Well being	0.67
4	Energy / Fatigue	0.64
5	Cognitive Functioning	0.58
6	Medication Effect	0.66
7	Social Functioning	0. 82
	Overall Score	0.83

Validity

The original English version was first administered to 55 adult patients from Kerala attending epilepsy clinic of SCTIMST who were well versed in English language. The English scale was repeatedly administered to the same group after a period of one month.The Pearson's correlation analysis showed a validity of 0.76 The validity was assessed by giving the Malayalam and original English version to a different group of 55 bilingual adult epilepsy patients from SCTIMST, where the English version was considered as the 'Gold Standard'.

Table 3.6
QOLIE : 31 - Validity SCTIMST Epilepsy Clinic sample
(English - English)

	QOL Domain	English -English
1	Seizure Worry	0. 81
2	Overall Quality of Life	0.77
3	Emotional Well being	0.63
4	Energy/ Fatigue	0.63
5	Cognitive Functioning	0.65
6	Medication Effect	0.76
7	Social Functioning	0.72
	Overall Score	0.76

Table 3.7
Validity SCTIMST Epilepsy Clinic sample
(English - Malayalam)

	QOL Domain	English - Malayalam
1	Seizure Worry	0.82
2	Overall Quality of Life	0.81
3	Emotional Well being	0.83
4	Energy/ Fatigue	0.78
5	Cognitive Functioning	0.88
6	Medication Effect	0.6 4
7	Social Functioning	0.73
	Overall Score	0.93

The overall reliability was found to be 0.84 and validity 0.93. The translation and cross-cultural validation showed significant reliability and validity comparable to the original English version of the scale.

3.6.9 Epilepsy Counseling / Training Module

The investigator prepared an Epilepsy Counseling / Training Module (Jayachandran, 2001) in English and Malayalam languages with a view to comprehensively educate the patients, family members, health professionals, teachers and public about epilepsy (Ref. Appendix).

The module consists of medical and social aspects of epilepsy.

Medical aspects :

- What is epilepsy?
- Types of epilepsy,
- Causes of epilepsy,

- First aid for epilepsy,
- Diagnosis and treatment of epilepsy.

Social aspects :

- Epilepsy and education,
- Epilepsy and employment,
- Epilepsy and marriage,
- Epilepsy and quality of life,
- Do's and don'ts in epilepsy.

The module has been in use in the Epilepsy Center in SCTIMST, Trivandrum for educating various target groups for the past five years. Educating with the module enabled the educator to have a control over the information being disseminated through the psycho-educational group sessions, facilitating the outcome evaluation of the psycho-educational group intervention.

3.7 Pilot Study

A pilot study was conducted among 20 patients with an established diagnosis of epilepsy who attended the Epilepsy Clinic of SCTIMST using all the tools selected for the study and the structured interview schedule. The data of the pilot was analyzed and feasibility of the study was confirmed. Based on the observations of the pilot study suitable modification were made in the interview schedule.

3.8 Administration of tools

The whole sample for the experimental study consisting of 36 patients was called for a meeting on a pre-scheduled day and was randomized into three groups of 12 patients each for psycho-education, meditation and control. The randomization was done using a Lottery Method of random sampling. Patients in the control group were informed that they are in the waiting list for both the intervention programs (psycho education and meditation). The pre-assessment (baseline) of all the patients was done on the day of the first gathering. The patients and their family members were interviewed by the investigator personally and collected relevant personal and family information with the help of a pre-tested structured interview schedule. The instructions for filling the scales and inventories were separately given to each patient. During the post-assessment at 3 months and 6 months the data collection was done separately for each group.

3.9 Social and demographic characteristics of the sample of the Experimental Study

The Sample of the study for the experimental group was selected from the Trivandrum District. The pouplation of the Trivandrum District consists of 3234356 comprising of 1569917 males and 1664439 females. Amoung the population 2202112 (66.09%) are Hindus 431512 (13.84%) are Muslims and 595563 (18.4%) are Christians The average family size of the population is 4.26. The literacy rate of Trivandrum District is 89.36. The male literacy is 92.36 and female literacy is 86.26. The total literacy level rate of the State of Kerala is 90.92 percentage (Census of India - 2001).

Age, sex, religion, education, occupation, marital status, type of family, number of family members and place of residence were taken as social and demographic characteristics.

Age is an important aspect as far a person with epilepsy is concerned. Age has a major role in shaping the individuality, behaviour and adjustment of a person with epilepsy. Generally people have specific behaviour patterns at different age groups. So age was taken as an important variable in this study. Age of the sample was from 16 to 35 years. Among the thirty six patients 38.89 percent were in the age group (31-35), 30.66 percent in the age group (16-25), 16.67 percent were in the age group (21-25) and 13.89 percent in the age group (26-30). The group were in the productive age group composed of adolescents and adults.

Table 3.8
Percentage distribution of patients by their and socio - demographic characteristics

Characteristics	**No**	**Percent**
Age	16-20	11 (30.56)
	21-25	6 (16.67)
	26-30	5 (13.89)
	31-35	14 (38.89)
Sex	Male	20 (55.56)
	Female	16 (44.44)
Religion	Christian	3 (8.33)
	Hindu	30 (83.34)
	Muslim	3 (8.33)
Education	School	21 (58.33)
	College	11 (30.56)
	PG/Professional	4 (11.11)
Occupation	Students	13 (36.11)
	Unemployed	5 (13.89)
	Employed	13 (36.11)
	Professional	5 (13.89)
Marital status	Married	14 (38.89)
	Unmarried	22 (61.11)
Type of family	Nuclear	19 (52.78)
	Extended	17 (47.22)
Family members	<=4	21 (58.33)
	5-7	15 (41.67)
Place of residence	Rural	23 (63.89)
	Urban	13 (36.11)

To a greater extent the individuals attitudes, belief system, life style and behaviour are influenced by religion. More than Eighty Eight percent of the subjects belonged to Hindu religion, 8.33 percent were Christians and 8.33 percent of the respondents belonged to Muslim religion.

Gender is an important factor as far as patients with epilepsy and their social situation are concerned. Psycho-social problems are reported to be more for women patients with epilepsy. Out of the thirty-six subjects selected for study 55.56 percent are males and 44.44 percent are females.

According to the locale of the residence of patients were divided into three namely, those belonging to panchayat, corporation and municipality. Sixty four percent of the patients belonged to Panchayat areas, 27.78 percent from corporation area and 8.33 percent belonged to municipality.

Education and occupation have been found to be potential factors in the adjustment and behaviour of patients with epilepsy. More than 58 percent of the patients were school-educated, 30.56 percent were college-educated and remaining 11.11 percent were postgraduates or professionally qualified. The occupational status of the patients showed that 36.11 percent were students, another 36.11 percent were employed, 13.89 percent were unemployed and 13.89 percent were professionals.

As far as the type of family is concerned, 52.78 percent were found staying in nuclear families and 47.22 percent were in extended families. There was no patient from joint families. Regarding the number of persons residing with the respondents it was found that 58.33 percent of patients were from families having less than or equal to four members and 25 percent of the patients came from families with members between five to seven. The marital status of the patients showed that 38.89 percent were married and 61.22 percent were unmarried.

3.9.1 Clinical Characteristics of the patients

Atmosphere in the family, disabling effect of AED, age at onset of the first seizure, family history of seizure disorder, time of occurrence of seizure and duration of illness, number of seizure during last one year were taken as the clinical characteristics of the patients. Table 3.2 shows the percentage distribution of the patients with regard to their clinical characteristics.

Table 3.9
Percentage distribution of the Patients by their Clinical Characteristics

Patient Characteristics	No	Percent
Atmosphere in family	Healthy	22 (61.12)
	Unhealthy	14 (38.88)
		100.00
Disabling effect of AED	Have disabling effect	11 (30.56)
	Have no disabling effect	25 (69.44)
Family history of seizure disorder	Have family history	8 (22.24)
	Have no family history	28 (77.78)
Family history of mental disorder	Have family history	1 (2.78)
	Have no family history	35 (97.22)
Previous history of mental illness of the Patients	Have history of mental illness	1 (2.78)
	Have no history of mental illness	35 (97.22)
Frequent time of occurrence of seizure	Early morning	4 (11.11)
	Within 2 hours of waking	4 (11.11)
	Only during night	5 (13.89)
	Any time the day	23 (63.89)
Duration of illness (Years)	1-10	14 (38.89)
	11-20	17 (47.22)
	21-30	5 (13.89)
Age at first seizure (Years)	<=5	8 (22.22)
	6-15	19 (52.78)
	16-30	9 (25.00)
Seizure frequency (in an Year)		
Engel score 5	<11	27 (75.00)
Engel score 6	11+	9 (25.00)

3.9.2 Atmosphere in the family

Atmosphere in the family in terms of mutual cooperation and acceptance was recorded from the respondents. Epilepsy patients' family atmosphere plays a crucial role in psycho-social adjustment and developing coping strategies. Table 3.2 shows that 61.48 percent of the respondents described the family atmosphere as healthy, 38.48 percent reported that the family atmosphere to be unhealthy.

3.9.3 Disabling effect of AED

Patients who take anti-epileptic drug for long duration can develop side effects of varying nature and some of them are disabling which can interfere with the their daily functioning. Among the study sample, 30.56 percent of the patients reported disabling effect of the AED while 69.44 percent reported no side effect of the drugs.

3.9.4 Age at onset of the first seizure

Early onset of seizures, especially seizure occurring at infancy and continuing throughout childhood and adolescence can negatively affect the psycho-social development and personality make up of the person. Table 3.2 indicates that 22.22 percent of the subjects reported the onset of their first seizure before 5 years, 52.78 percent reported that the first seizure started between 6- 15 years and 25 percent reported the first seizure between 16-30 Years. The result indicates that in majority (81percent) of the patients' seizure started during their childhood or early adolescence.

3.9.5 Family History of Seizure disorder

Some of the epilepsies are genetic in origin, with the proportion being higher in epilepsies of childhood onset (Mathew, 2005). From Table 3.2 it can be seen that 22.22

percent of the patients had positive family history of seizure disorder among close relatives while 77.78 percent reported no family history of seizure disorder.

3.9.6 Time of occurrence of seizure

Time of occurrence of seizure is important as far as the patient's coping to the disease and their psycho-social adjustments are concerned. For majority of the patients Seizure can occur at any time of the day. Some patients develop seizure only at sleep and some others when sleep is disturbed. Table 3.2 shows that 63.89 percent of patients reported that the time of occurrence of the seizure are unpredictable and could occur at anytime of the day, 13.89 percent reported seizure occurrence only during sleep and others reported seizure within 2 hours of waking up in the morning.

3.9.7 Duration of illness

Since epilepsy is a chronic disorder, long duration of epilepsy can lead to various psychosocial problems. From Table 3.2 it can be seen that 47.22 percent of patients reported a seizure duration of 11 to 20 years and 38.89 percent the seizure duration of 1 year to 10 years and 13.89 percent reported seizure duration of 21 to 30 years. Thus it can be seen that the majority of the sample under study had more than 10 year's history of seizure disorder.

3.9.8 Number of Seizure during last one year

Seizure frequency is an important factor determining the success of the treatment, the psycho-social functioning and the quality of life of persons with epilepsy. Only patients with a minimum of two seizures during the last one-year were included in the study. Patients who develop up to 11 seizures an year were considered as patients with controlled seizures and included in Engel score 5, Similarly patients who had more than 11 seizures in an year were considered as patients with uncontrolled or intractable seizures and included in Engel score 6 in this study. Table 3.2 shows that 75.00 percent patients came *in* Engel score 5 and the remaining 25.00 percent in Engel score 6.

3.10 Consolidation data

The relevant data from the subjects using the structured interview schedules and the eight scales/inventories were entered and processed with the help of a personal computer. The data was analysed using suitable statistical tools.

3.11 Statistical techniques used

The important statistical techniques used in the present study were descriptive statistics, ANOVA, ANCOVA and Linear Multiple Regression Analysis.

3.12 Method of analysis

Changes in the scores of the scales / inventories were noted at three different times namely before the intervention (baseline), at three months and six months. One-way ANOVA was used for assessing the changes in the scores of scales/inventories of the three groups independently as a preliminary analysis. Since the sample size of the groups was not sufficiently large, the absolute change in the scores of the scales / inventories of psycho-education and meditation groups were studied by comparing with that of the control group at pre-assessment and at three month and six month using ANCOVA. ANCOVA measures the difference of scores at two different point of time after adjusting for the initial differences.

3.13 Limitations of the study

The major limitation of the experimental study is its small sample size. In an experimental group research design like this, it is difficult to have more than 12 members in each group. This is because of the fact that there is a chance of diminishing collateral relationship and tendency among participants of the group to depend on the therapist rather than group member for support. The other limitation is that patients could be selected only from a tertiary referral centre from Thiruvanathapuram district of Kerala State as the facilities for conducting psycho-education sessions and meditation are currently available only in this centre. Moreover, Patients if selected from long distances had to travel repeatedly to attend the sessions.

3.14 Organization of Report

The report of the investigation is presented in 5 chapters. Chapter 1 highlight about epilepsy, psycho-social problems, treatment and group interventions. Chapter 2 contains a review of literature covering relevant studies about epilepsy, psycho-social issues and group interventions.Chapter 3 contains a detailed description of Methodology of the study including sample, objective of the study, hypothesis, tools used, tool development and standardization procedures. data collection, statistical techniques used for date analysis. Chapter 4 consists of results and discussion and in Chapter 5 summary and conclusions of the study and scope for further research are presented. Bibliography and appendicies are presented as annexure.

CHAPTER - 4

RESULTS AND DISCUSSION

CHAPTER - 4

RESULTS AND DISCUSSION

Psycho-educational group intervention and Yoga-Meditation (YM) are being practised among patients with epilepsy in the Comprehensive Center for Epilepsy Care in SCTIMST, Thiruvanathapuram, India to deal with epilepsy and various psycho-social problems. The present endeavor is to scientifically evaluate the effectiveness of both the programs by comparing the results with a control group of patients who are not attending any intervention programs. This experimental research follows a pre-post test experimental research design involving two experimental group (Psycho-education and Meditation) and a common Control group.

The various psycho-social parameters of the three study groups namely, the psycho education group, the meditation group and the control group were assessed using the following scales / inventories :

1. Knowledge Attitude and Practice Questionnaire (KAP) (Radhakrishanan & Jayachandran, 1995).
2. Depression Inventory (Kumar and Kumar 2002).
3. State -Trait Anxiety Inventory (Mohandas & Kumar, 1994).
4. Self -Esteem inventory (Thomas & Raj,1990).
5. Locus of Control (IE) Scale (Kumar & Immanuel, 1992).
6. Epilepsy Psycho-Social Effect Scale (EPSES), (Translated and standardized as part of research).
7. Washington Psycho-Social Seizure Inventory(WPSIQOL) –Dodrill 1988 (Malayalam adaptation Thomas, 1977).

8 Quality of life in Epilepsy Inventory (QOLIE:31.

(Translated and standardized as part of research)

4.1 Change in scores of scales / inventories during intervention (ANOVA)

Observed changes in the values of the scales / inventories at three different times of assessment are presented in this section.The three times of assessment were before the intervention (pre-assessment), at three months and six months after intervention. One-way ANOVA was used for assessing the changes in the scales / inventories during the intervention.

4.1.1 Knowledge, Attitude and Practice (KAP)

Knowledge, Attitude and Practice Scale (Malayalam version) related to epilepsy developed by Radhakrishanan and Jayachandran (1995) was administered to the patients of all the three groups prior to the sessions and after three and six months of the intervention. Higher score in KAP scale indicated better knowledge, attitude and practice about epilepsy. The score of KAP at pre-intervention were found to be 19, 19.25 and 18.92 for psycho-education group, meditation group and control group respectively. At the third month after intervention the KAP scores of psycho-education group became 20.42. (Table 4.1). The score then increased to 21.83 at sixth month after interventions. This change in the KAP score of psycho-education was found to be statistically significant (P=0.006). At the same time no significant improvement was noticed in the Meditation and Control group, where no educational or cognitive inputs were given.

The marked increase in KAP after the third psycho-educational session (See Fig 1.1) can be attributed to efficacy of the psycho-educational group intervention. This results indicated that patients after attending three educational sessions developed greater rapport and support between the group members and therapist and they got sufficient time to think and utilize their knowledge and awareness to develop positive attitude and healthy practices about epilepsy. Similar result was observed by Jayachandran et al., (2002) using the KAP questionnaire among 103 patients who attended the sessions against KAP results of 1118 patients during the epidemiological study of epilepsy.

This result is also supported by a study conducted by May and Pfafflin (2002) to find out the efficacy of an educational treatment program for patients with epilepsy (MOSES), which showed significant improvement in KAP along with all the assessed parameters of participants of the educational program. Another study conducted by Jayachandran et.al (2001) among 60 patients using a structured questionnaire to asses knowledge and positive attitude attending psycho-educational group sessions also found that the mean scores improved significantly ($P<0.01$) from the baseline after the group sessions.

The findings of the study regarding the improvement in KAP has greater significance in the light of the observations made by the Commission for Control of Epilepsy and its Consequences (1977), that the understanding an individual has about any disability is directly related to the success of the individual in coping with their disability.

Fig. 4. 1
Average score of KAP of the three groups of patients at three-time interval

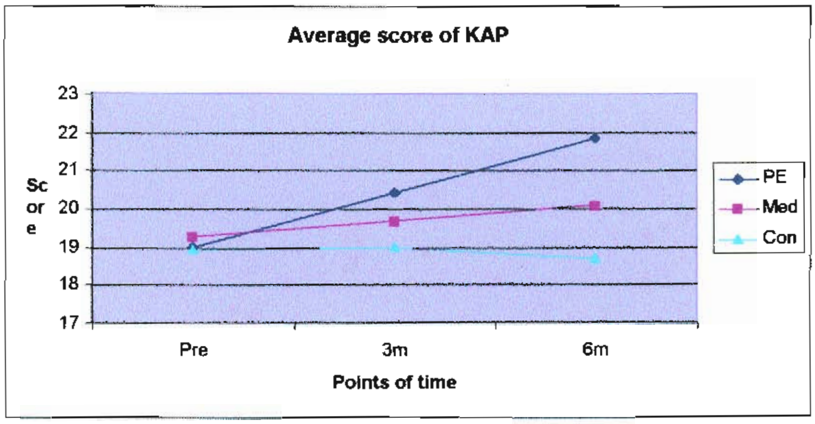


Table 4.1
Average score of KAP of three groups of patients at three points of time along with values of F-test

Groups	Pre	3m	6m	F	Sig.
PE	19.00	20.42	21.83	6.086	0.006
Med	19.25	19.67	20.08	0.374	0.691
Con	18.92	19.00	18.67	0.081	0.923

PE = Psycho-education group, Med = Meditation group, Con = Control group
Pre = Pre - Invervention, 3m = 3 months after intervention, 6m = 6 months after intervention

4.1.2 Depression

Depression is a major health concern not only because of personal distress, excess mortality, impaired interpersonal relationships and restrictions of work activities but also because of economic burden it imposes (Meager,1977). Depression can occur in up to 30 percent of people with epilepsy. The risk of suicide in depressed patients is believed to be 13 percent (Karceski, 2005).

The depression inventory developed by Kumar and Kumar (2002) was administered to the three groups of patients at three time intervals. The inventory contains 15 questions. Higher score indicated more depression and lower score indicated improvement in depressive state.

The averages of depression scores are presented in Table 4.2.The table showed that the average depression scores before the intervention were 38.25, 29.58 and 25.83 for psycho-education, meditation and control groups respectively.

At six months after intervention, the scores reduced to 26.08 in psycho-education and 27.17 in meditation groups. The reduction of score was found to be statistically significant (P= 0.014) for the psycho-education group. The changes in the scores of meditation were not significant. The control group also did not show any significant pre-post difference in depression score. The result revealed that group intervention is effective in reducing depression in patients with epilepsy who repeatedly attend the psycho-educational group sessions. A possible explanation for the reduction is depression score in the psycho-education group is that after educational interventions cognitive changes might have occurred among these patient facilitating desirable mood changes. This cognitive change did not occur in meditation and control groups as there was no additional educational or cognitive inputs given for these patients.

In a similar effort to evaluate the effectiveness of two day Sepulveda Epilepsy Education program. Hegelson et al. (1990) could not find a statistically significant reduction in depression score. This could be attributed to the short duration of the intervention as against the present intervention study were the three psycho-educational interventions were conducted over a period of three months. The result was also supported by a study conducted by Hoberman et.al., (1988) on group treatment of depression. The study attempted to identify patient characteristics predictive of individual outcome in a psycho-educational group treatment for uni-polar depression. Forty participants meeting Research Diagnostic Criteria for depressive disorders were assessed on demographic and psychological variables at both pre and post-treatment and on participation variables during treatment. The treatment was the coping with course. At the end of treatment, 85% of the subjects no longer met diagnostic criteria for depressive disorders. A stepwise Multiple Regression Analysis attained a multiple correlation of 0.92, accounting for 85% of the variance in post-treatment depression level.

Fig. 4.2
Showing Average Score of Depression of three groups of patients at three points of time

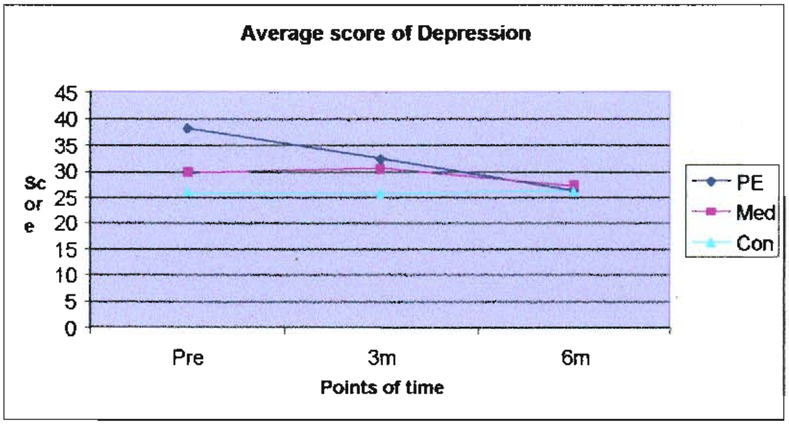


Table 4.2
Average score Depression of three groups of patients at three points of time along with values of F-test

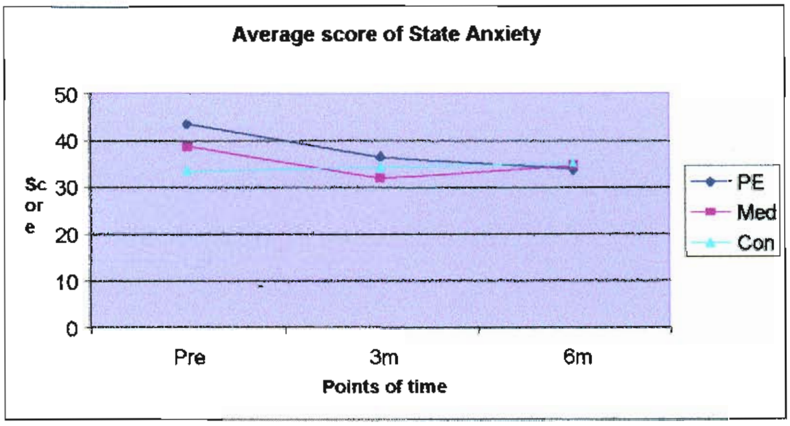
Groups	Pre	3m	6m	F	Sig.
PE	38.25	32.17	26.08	4.851	0.014
Med	29.58	30.33	27.17	0.411	0.666
Con	25.83	25.58	26.25	0.037	0.964

PE = Psycho education group, Med = Meditation group, Con = Control group
Pre = Pre assessment, 3 months after intervention 6m = 6 months after intervention

4.1.3 State -Trait Anxiety

The present study evaluated the effectiveness of psycho-education and meditation in reducing state and trait anxiety using State-trait anxiety scale developed by Spielberger (1970). Many researchers worldwide are interested in this scale, and it has been translated into 20 languages (de Souza, 2006). The scale translated and standardized in Malayalam by Mohandas and Kumar (1994) was administered to all the three groups prior to intervention and after 3 months and 6 months after intervention. Higher the score in the scale indicated more state / trait anxiety and lower score indicated improvement in the condition. The baseline (pre intervention) scores were 43.67, 38.92 and 33.42 for psycho-education group, meditation group and control group respectively. At three month, the scores changed to 38.33, 32.17 and 34.33 and at six month (Third assessment), the scores were 33.75, 34.83 and 36.43 respectively for psycho-education group, meditation group and control groups. (Table .4.3). The results showed significant reduction in state anxiety score (P = 0.050) in the psycho-education group. The scores in the meditation group also showed a declining trend at three and six months but the results were not statistically significant.

Fig. 4.3
Average score of state-trait and total anxiety of three groups of patients at three points of time



4.1.3.1 Trait Anxiety

The score in trait anxiety also showed a declining trend in psycho-education group, but the results were also not statistically significant. In the meditation group also the score declined at three months and slightly increased at six months, which indicated that the effect was not well sustained.

Table. 4.3
Average score of state-trait and total anxiety of three groups of patients at three points of time along with values of F-test

STAI Variables	Groups	Pre	3m	6m	F	Sig.
State anxiety	PE	43.67	36.33	33.75	3.159	0.050
	Med	38.92	32.17	34.83	1.866	0.171
	Con	33.42	34.33	35.42	0.191	0.827
Trait anxiety	PE	46.17	41.92	39.42	1.368	0.269
	Med	39.50	34.67	35.92	1.360	0.271
	Con	35.00	35.75	37.00	0.226	0.799
Total anxiety	PE	89.83	78.25	73.17	2.402	0.106
	Med	78.42	66.83	70.75	1.780	0.184
	Con	68.42	70.08	72.42	0.224	0.800

PE = Psycho education group, Med = Meditation group, Con = Control group
Pre = Pre assessment, 3m = 3 month after intervention, 6m = 6 months after intervention

4.1.3.2 Total Anxiety

The change in the total state and trait anxiety score also was not statistically significant in psycho-education and meditation group. The control group did not show any significant difference in pre-post assessment.

The finding showed that group intervention was effective only in reducing state anxiety of patients with epilepsy who regularly attended the psycho-educational group sessions and there was no noticable change in the meditation and control groups. This change in state anxiety can be atributed to the fact that for every reduction in anxiety state there should be a strong precussor and the participation in psycho-educational group session might have acted as a strong precussor to make a change in their cognitive level, which does not occur in meditation and control group.

4.1.4 Self- Esteem

In epilepsy, symptoms may result or exacerbated by psychological reactions including response to the unpredictability of seizures and restrictions on normal activities, resulting in low self-esteem, stigmatization and social rejection (Vasques et al. 2003). Social stigma, feeling of inferiority, low self- esteem and lack of confidence can aggravate disturbance that people with epilepsy have (Jayachandran, 2000). The self-esteem of epilepsy patients is found to be significantly lower than those without epilepsy (Lau et al, 2001).

Table 4.4
Average score of Self-esteem of three groups of patients at three points of time along with values of F-test

Groups	Pre	3m	6m	F	Sig.
PE	59.25	66.5	65.67	0.908	0.413
Med	71.58	80.17	76.83	1.337	0.277
Con	79.17	79.25	78.5	0.017	0.983

PE = Psycho education group, Med = Meditation group, Con = Control group
Pre = Pre assessment, 3m = 3 month after intervention, 6m = 6 months after intervention

4.1.5 Internal-External Locus of Control

Many are the exigencies or internal / external demands that are appraised as overburdening an individual's personal resources (de-Souza, 2006). Individuals with epilepsy, as a group, exhibit a more external locus of control relative to other chronic illness groups. The concept of Locus of Control (LOC) refers to an individual tendency to perceive events either as controlled by personal influence or by external forcer (Rotter). In epilepsy, the repeated loss of personal control is a central problem and may be important to address directly. Gramstad et.al., (2001) hypothesized that negative and positive affectivity, self-efficacy and Health Locus of Control (HLOC) are important for psychosocial adjustment in patient with epilepsy. Studies have shown that epilepsy is associated with externality of control. Externality of control and learned helplessness has been implicated as casual factors in the development of psycho-social problems in epilepsy (de Vellis et al., 1980).

The Malayalam version of the Rotters (1966) Internal-External Locus of Control Scale translated and standardized by Kumar and Thomas (1992) was administered to all the three groups prior to attending group sessions and meditation. Higher the score indicated more internal locus of control and lower score shows external locus of control. Results did not show any significant change in any of the three groups indicating that group session and meditation are not effective in changing the locus of control for person with epilepsy with three psycho-educational sessions or three months of yoga meditation. However, there was a trend towards internal locus of control in both psycho-education and meditation groups (Table.4.5), which indicated that with more number of sessions or long duration of meditation they may further improve.

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Table 4.5
Average score of Internal-external locus of control of three groups of patients at three points of time along with values of F-test

Groups	Pre	3m	6m	F	Sig.
PE	9.50	10.92	11.58	1.113	0.341
Med	10.00	11.00	11.75	0.913	0.411
Con	12.42	12.42	11.58	0.390	0.680

PE = Psycho education group, Med = Meditation group, Con = Control group
Pre = Pre assessment, 3m = 3 months after intervention, 6m = 6 months after intervention

4.1.6 Epilepsy Psycho-Social Effect

The Psycho-Social Effect Scale originally developed by Chaplin in U.K (1990) was translated and standardized in Malayalam by the researcher and administered to the psycho-education, meditation and control groups of patients prior to intervention and at three and six months after intervention.

The scale consists of the following 14 subscales: 1. Attitude towards accepting the attacks, 2. Fear of having seizures, 3. Fear of stigma of employment, 4. Lack of confidence in future, 5. Lack of confidence in travel, 6. Adverse reaction in social-life, 7. Adverse reactions in leisure pursuits, 8. Change of outlook on life/self, 9. Difficulty in communicating with family, 10. Problem with taking medication, 11. Distrust of medical profession, 12. Depression or emotional reaction, 13. Feeling of increased social isolation, 14. Lethargy / lack of energy.

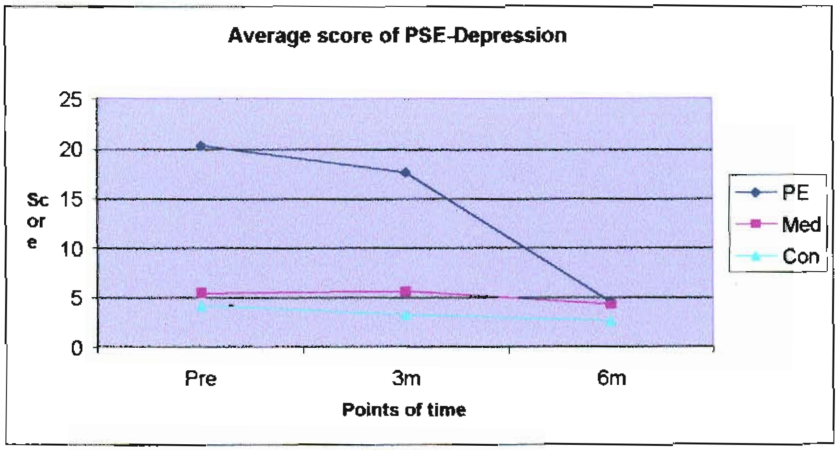
The statistical analysis of the scores at three and six months after intervention in the three groups of patients revealed significant reduction in three subscales of the psycho-education group viz. Depression / emotional reaction (P= 0.02), Feeling of increased isolation (P=0.04), Lethargy / lack of energy (P=0.01) ·

Table. 4.6
Average score Psycho-Social Effect (PSE) of three groups of patients at three points of time along with value of F test.

		Pre	3m	6m	F	Sig.
Depression or emotional reaction	PE	20.32	17.63	4.57	4.35	0.02
	Med	5.50	5.60	4.31	0.07	0.94
	Con	4.05	3.26	2.62	0.22	0.80
Feeling of increased social isolation	PE	16.01	12.71	3.57	3.70	0.04
	Med	8.22	5.73	4.24	0.47	0.63
	Con	6.60	5.95	5.29	0.07	0.94
Lethargy/ lack of energy	PE	23.01	15.16	7.38	5.67	0.01
	Med	7.79	7.68	7.36	0.01	0.99
	Con	9.60	9.33	8.28	0.06	0.95

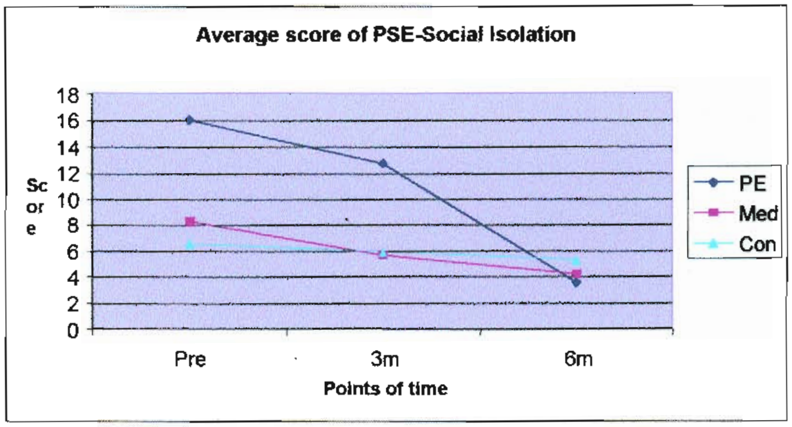
PE = Psycho education group, Med = Meditation group and Con = Control group
Pre = Pre assessment, 3m = 3 months after intervention, 6m = 6 months after intervention

Fig.4.4
Average score of PSE- Depression / Emotional reaction in three groups



The scores of PSE Depression / emotional reaction of the psycho-education group were 20.32, 7.63, and 4.57 at pre intervention, and three and six months after intervention respectively. (Table 4.6).The results indicate that among psycho-education group, Depression / emotional reaction decreased steadily during the study period.

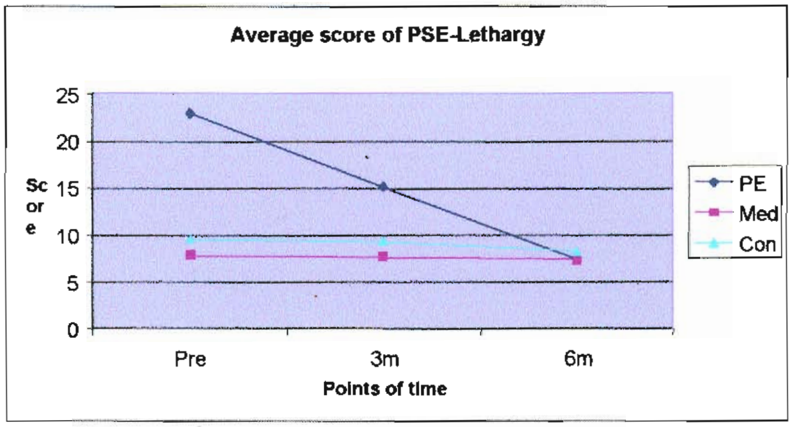
Fig.4.5
Average score of PSE – Increased Social Isolation in three groups



In PSE- Feeling of increased social isolation the baseline score was 16.01 and at three month it was 12.71 and it changed to 3.57 at six month for the psycho-education group. This change is statistically significant (p= 0.04). In the case of PSE-Lethargy / Lack of energy the initial score was 23.01 for psycho-education group. The score then changed to 15.10 and 7.38 respectively at three and six months after intervention (Table. 4.6). This shows the stability and sustainability of treatment gains with psycho-educational group sessions.

Change in the value of score of PSE-Lethargy / lack of energy was found to be statistically significant (P= 0.01). This can be explained as a treatment gain of the psycho-educational sessions which have probably removed the social inhibition because of the theraupeutic communication and social support occured among the group members and the therapist. In the case of meditation group and control group, both Feeling of increased social isolation and Lethargy / Lack of energy did not show any significant change (Table 4.6).

Fig 4.6
Average score of PSE -Lethargy / lack of Energy in three groups



In the areas of PSE-Feeling of increased social isolation and Lethargy / lack of energy there was statistically significant reduction in score following psycho-educational group intervention. In the case of meditation group and control group, there were no significant change in these two areas of PSE.

4.1.7. Quality of life

In recent years, there has been a growing recognition that assessing the impact of epilepsy must extend beyond counting seizures. Consequently there have been a number of instruments to measure the QOL of people with epilepsy. (Thomas et al,. 2005). In this study two scales were used to assess the quality of life of patients in the three groups. The scales used were WPSIQOL and QOLIE: 31 with seven subscales.

4.1.7.1 Quality of life (WPSIQOL)

Washington Psycho-Social Effect Scale Quality of Life (WPSIQOL) is a short scale containing 21 'Yes' or 'No' questions developed by Dodrill (1995). Malayalam adaptation was done by Thomas (1997). This scale was administered to the Psycho-education, Meditation and Control groups before intervention and at 3 and 6 months after intervention.

The analysis of results showed statistically significant improvement in quality of life of psycho education group patients (P= 0.012). The mean score for the psycho-education group at three time intervals were 9.08, 12.5, 15.17 and for the meditation group 13.50,14.08 and 15.67 and for the control group 13.92, 13.75 and 15.25 respectively (Table.4.7).

A similar result was obtained in a study using WPSIQOL conducted by Jayachandran (1999) among 67 adult persons with epilepsy who had attended the psycho-educational group intervention when compared it with 47 patients who did not attend the sessions. He found significant improvement (P=0.01) in quality of life of persons who attended the group sessions. There was a positive correlation between the quality of life and the number of visits to the sessions. The change in the quality of the life can be attributed to the increasing awareness and positive attitude, mutually empowering and support building interactions between the group members and therapist.

Fig.. 4.7

Average score of WPSIQOL at three-time intervals

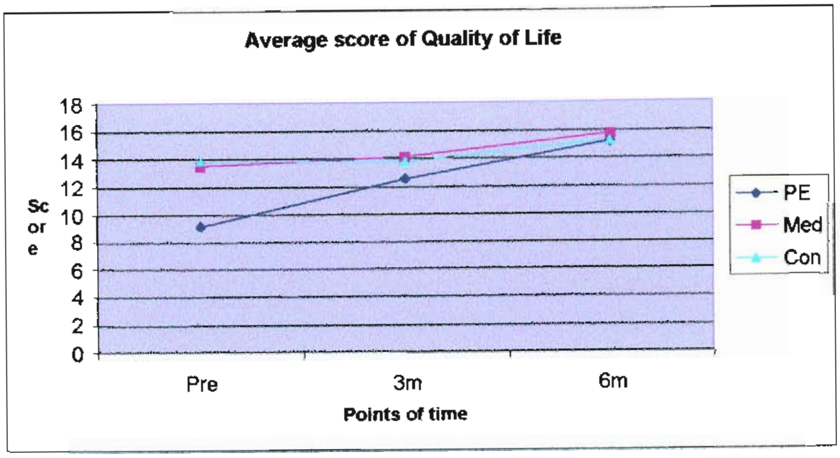


Table 4.7
Average score Quality of life (WPSIQOL) of three groups of patients at three points of time along with value of F test

Groups	Pre	3m	6m	F	Sig.
PE	9.08	12.5	15.17	5.061	0.012
Med	13.50	14.08	15.67	0.708	0.500
Con	13.92	13.75	15.25	0.823	0.448

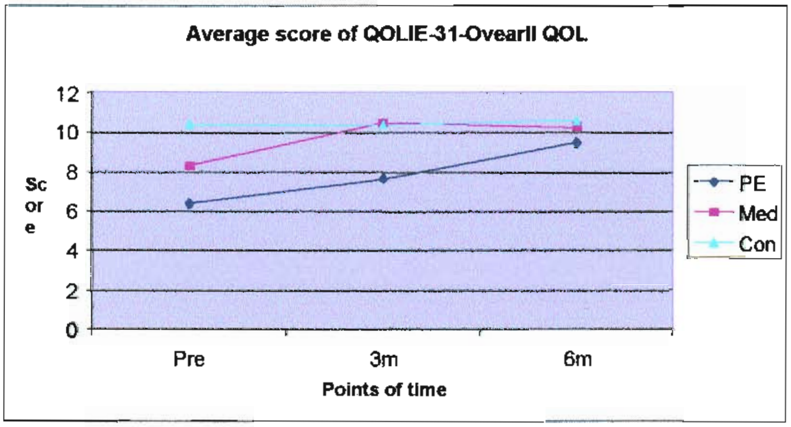
PE = Psycho education group, Med = Meditation group , Con = Control group
Pre = Pre assessment, 3m = 3 months after intervention, 6m = 6 months after intervention

4.1.7.2 Quality of life (QOLIE : 31)

This long scale was developed by Cramer (1993) originally contains 31 questions. This scale was translated into Malayalam language and standardized by the researcher. It contains 30 questions after standardization and was administered to all the three groups of patients before and after intervention. This scale consists of following 7 subscales; 1. Seizure worry, 2. Overall quality of life, 3. Emotional well- being, 4. Energy / fatigue, 5. Cognitive functioning, 6. Medication effects and 7. Social functioning.

Fig. 4.8

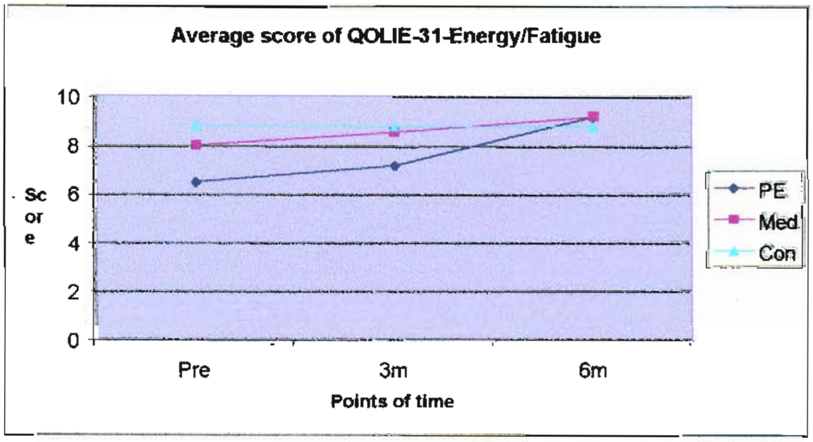
Average score QOLIE:31- Overall QOL of the three groups



The statistical analysis showed significant improvement in three sub-scales areas and in overall score of QOLIE:31 among psycho-education group. The sub-scales which showed significant improvement (Table No.4.8) were 1. Overall Quality of life, (P=0.04), 2. Energy / fatigue (P= 0.03) and 3. Medication effect (P = 0.00).

Fig 4.9

Average score of QOLIE:31– Energy / fatigue of the three groups



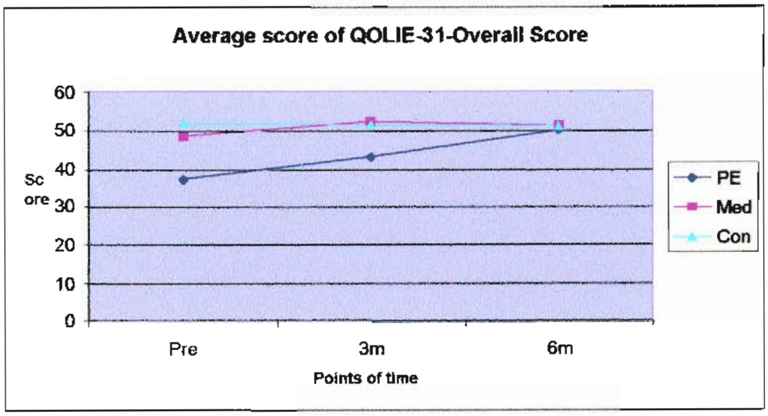
In QOLIE:31-overall QOL the mean score for this component at three time intervals (pre, 3m and 6 m) were 6.34, 7.81 and 9.48 respectively. For QOLIE:31 Energy / fatigue mean scores were 6.50,7.15 and 9.20 at pre 3 months and six months and for QOLIE:31-Medication effect with mean scores were 1.17, 1.64 and 3.26 at pre , 3 months and six months The P value for the overall score was 0.02 and the mean scores were 37.17, 43.06 and 50.11 respectively at pre, 3 months and six months. (Table 4.8).The group session were found to be effective in improving quality of life of patients who were attending the sessions repeatedly in the above three areas where statistically significant results were obtained. However there was no significant change in any of the other areas of QOLIE:31 among meditation and control groups. However QOLIE:31 - Seizure worry reached near signficant level (0.07).

The above finding were supported by a study conducted by Schmitt et. al., (2002). They studied the impact of a group intervention on the quality of life of adolescents with epilepsy. Pre and post intervention ratings of quality of life using the QOLIE were obtained from adolescents with epilepsy and at least one of their parents participating in a six-session (weekly) structured cognitive-behavioural group intervention The preliminary data demonstrated a potential positive effect on adolescent quality of life as measured by the QOLIE from participation in a structural group psycho-social intervention for adolescents with epilepsy and their parents. The small size is an obvious limiting factor of both this study and the present experimental study.

Table.4.8
Average score QOLIE:31 of three groups of patients at three points of time along with value of F -Test

QOLIE:31. Variables	Groups	Pre	3m	6m	F	Sig.
Seizure worry	PE	3.89	5.27	5.83	2.85	0.07
	Med	5.84	6.23	6.15	0.12	0.89
	Con	5.74	5.80	5.68	0.01	0.99
Overall quality of life	PE	6.34	7.61	9.48	3.47	0.04
	Med	8.28	10.47	10.21	2.14	0.13
	Con	10.35	10.41	10.59	0.02	0.98
Emotional well-being	PE	6.23	7.24	7.87	1.14	0.33
	Med	8.48	7.76	7.21	0.75	0.48
	Con	9.13	9.03	8.26	0.49	0.62
Energy/ fatigue	PE	6.50	7.15	9.20	3.81	0.03
	Med	8.00	8.55	9.15	0.82	0.45
	Con	8.85	8.75	8.75	0.01	0.99
Cognitive functioning	PE	1.52	1.27	0.69	1.74	0.19
	Med	0.42	0.29	0.29	0.45	0.64
	Con	0.47	0.35	0.40	0.19	0.83
Medication effects	PE	1.-17	1.64	2.36	7.78	0.00
	Med	2.19	2.22	2.19	0.00	1.00
	Con	1.83	1.80	1.69	0.08	0.92
Social functioning	PE	11.51	12.89	14.68	1.69	0.20
	Med	15.13	16.58	16.05	0.60	0.56
	Con	15.45	15.47	15.68	0.02	0.98
Overall Score	PE	37.17	43.06	50.11	4.30	0.02
	Med	48.35	52.10	51.26	0.57	0.57
	Con	51.82	51.6	51.05	0.02	0.98

Fig 4.10
Average score of QOLIE:31- Overall score at three points of time



In summary, the analysis of the results showed significant and progressive improvement at three months and six months compared to pre-assessment values in the areas of KAP, Depression, and state anxiety of psycho-education group. In EPSES significant changes were seen in three subscale areas viz. Depression or emotional reaction, Feeling of increased isolation and Lethargy / lack of energy. In quality of life Washington Psycho-Social Inventory (WPSIQOL) Scales showed statistically significant improvement. In QOLIE:31 significant improvements were observed in three areas viz, Overall quality of life, Energy / fatigue and Medication effect and in Overall score. There was no significant change in the scores of control group and meditation group. The improvement in three areas of QOLIE-31 can be attributed to the potential advantages of the psycho-educational intervention in the clinic setting, where 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 problems among themselves and explore suitable solutions under professional guidance of the therapist. In addition, the therapist provides information about psycho-social, educational, and employment aspects of epilepsy, thereby improving their awareness, positive attitude and quality of life of the participants (Jayachandran,1999).

4.2 Change in scores of scales / inventories due to intervention (ANCOVA)

Actual changes (after adjusting for the initial difference among experimental and control groups) in the values of the scales / inventories at three different times of assessment are presented in this section. The three times of assessment were before the intervention (pre-assessment), at three months and six months after intervention. The statistical method of ANCOVA was used for assessing the changes in the scales /inventories due to interventions among Psycho-education and Meditation in comparison with Control group.

4.2.1 Knowledge, Attitude and Practice (KAP)

The Knowledge, Attitude and Practice (KAP) questionnaire administered for the psycho-education group after controlling the initial difference during pre-intervention and on completion of three months after the initial intervention, which was then compared with the control group at three months revealed statistically significant ANCOVA result much higher (F = 9.54) than the table value of 4.32, whereas the KAP results (Table 4.9) after six months showed a still higher significant value (F = 15.29). These results showed that the KAP values increased considerably after the third session and effect of psycho-educational intervention sustained for three months after stopping the sessions at three months.

Table 4.9.
Average score KAP of Psycho - education and Meditation patients at three points of time along with F-value calculated by ANCOVA

Groups	Pre	3m	F	6m	F
PE	19.00	20.38	9.542	21.82	15.294
Con	18.92	19.03		18.68	
Med	19.25	19.53	0.351	20.06	2.104
Con	18.92	19.14		18.69	

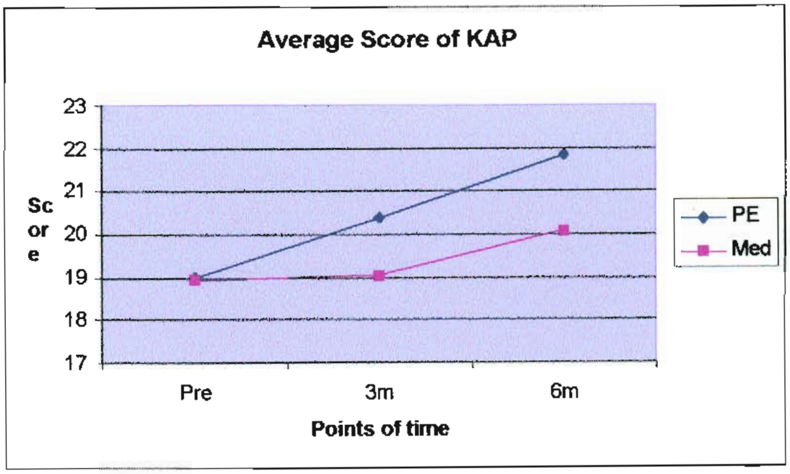
PE = Psycho education group, Med = Meditation group, Con = Control group
Pre = Pre assessment, 3m = 3 months after intervention, 6m = 6 months after intervention
(Table value= 4.30, score above the table value is significant at 5 percent level)

The ANCOVA results of the meditation group test scores during the same time interval when compared with the control group did not show any statistical significance. It may be noticed here that the meditation or control group do not have any package or program to improve the knowledge, Attitude and Practice (KAP) of the participants. From the above analysis it can be inferred that Psycho-educational group sessions were effective in imparting progressive education for patients with epilepsy attending group sessions as it has enhanced their knowledge, attitude and practice with stability and consistency and as they attended for three group sessions.The effect of the sessions sustained for three months after the last group session at third assessment. It is interesting to note that similar result was obtained from ANOVA also. The results established the effectiveness of psycho-educational intervention in imparting knowledge and improving positive attitude and practice about epilepsy among the patients who attended the sessions.

Compared with individual education or group training with traditional lectures, a different level of perception can be reached more successfully by learning and training within a small group with the possibility of discussions and sharing personal experience (Lewis, 1991). The psycho-educational program here aims to help patients achieve a better understanding of their disease, to gain more self-confidence, and to take over responsibility, thus supporting patients to become experts in managing their own illness (Jayachandran et al,. 2001).

Reid et al., (2001) further observed that within a group session of structured educational program, questions arising can be answered and an exchange with the trainer and with other participant is possible The success of medical therapy is strongly related to the patient's medication compliance, and this can be enhanced by improving the patient's knowledge about his or her disorder.

Fig. 4.11
Average score of KAP of the Psycho - education and meditation of patients at three points of time



In a related study with MOSES (Modular Service Package Epilepsy) involving 199 patients revealed that the acceptance of the program was excellent (Thorbecke,1997). MOSES had many positive effects on the patient's involvement in the treatment process: for example, they asked for many questions about their epilepsy and doctor rounds, they continued to discuss various related topics among themselves, they made contacts with self–help groups, they asked for more written information concerning epilepsy. Reid et al. (2001) conducted another study among 400 patients who participated in a MOSES program in Switzerland and Austria. Independent of the duration of their illness, all participants gained from the program. They further observed that there will be more systematic results on the effect of MOSES on the **participant's behaviour** from the ongoing evaluation studies (Reid et al., 2001).

The psycho-educational program under investigation here has many similarity to the MOSES as this also is using a educational package - The Epilepsy Counseling / Training Module. But the group here is different as it involves the family members which it is open, interactive and part of the weekly epilepsy clinic for one-hour.

4.2.2 Depression

The ANCOVA results of the depression scores of the psycho-education group after adjusting for the initial difference during pre assessment and after three months when compared with control group of patents did not show any statistical significance (F = 0.11). When it was retested after six months it showed positive changing trend with a relatively higher value (F = 1.69) than the first assessment, but this also was not statistically significant (Table 4.10).The test results of the meditation group during the same time interval when compared with the control group also did not show any significant improvement (F = 0.23). This results show that neither the meditation nor the group intervention is effective in dealing with depression of patents with epilepsy attending these programs.

Hegelson et al., (1990) evaluated the efficacy of the Sepulveda Epilepsy Education Program (SEE), using a controlled outcome design. SEE is a 2-day psycho-educational treatment program designed to provide medical, educational and psycho-social therapy. The treatment group demonstrated a significant increase in overall understanding of epilepsy, a significant decrease in fear of seizures, and a significant decrease in hazardous medical self-management practices. In this study also depression score did not show any significant pre-post difference.

Table. 4.10
Average score Depression of Psycho - education and meditation patients at three points of time along with value of F-Test calculated by ANCOVA

	Pre	3m	F	6m	F
PE	38.25	28.49	0.106	23.87	1.689
Con	25.83	29.26		28.46	
Med	29.58	29.04	0.969	26.18	0.228
Con	25.83	26.87		27.24	

PE = Psycho education group, Med = Meditation group, Con = Control group
(Table value= 4.30, score above the table value is significant at 5 percent level)

4.2.3 Self - Esteem

The analysis of scores of self-esteem at pre and three months for psycho-education group showed a statistically significant F-value of 4.42. The analysis of the scores of pre and six months gave a statistically insignificant F value of 0.38 for psycho-education group. The empowerment and social support among the members of the group and Therapist and the increasing awareness about the disease and the self through group sessions can be attributed to the change in self-esteem. However, to sustain the effect of the session it need reinforcement through attendance in more number of sessions repeatedly (Table. 4.12). For the meditation group the results where higher at six months when compared with the psycho-education group (F = 2.12) indicating that meditation was relatively more sustainable than the psycho-educational group session for dealing with self- esteem of patients with epilepsy even though the ANCOVA value for meditation was not statistically significant (Table .4.11).

Table 4.11
Average score Self-esteem of Psycho - education and meditation of patients at three points of time along with value of F-Test calculated by ANCOVA

	Pre	3m	F	6m	F
PE	59.25	76.49	4.42	73.46	0.378
Con	79.17	69.26		70.71	
Med	71.58	82.87	3.798	79.63	2.120
Con	79.17	76.54		75.71	

PE = Psycho education group, Med = Meditation group, Con = Control group
(Table value= 4.30, score above the table value is significant at 5 percent level)

4.2.4 Internal – External Locus of control

The Internal–External Locus of control (IE-Scale) test scores administered during pre-assessment and three months showed a statistically significant ANCOVA result (F=7.51). When it was retested after six months by comparing with the control group, patients showed positive trend with F = 3.72 (which is not significant at 5 percent level of significance) for the psycho-education group indicating that the effect of the group session sustained to some degree even though it was not statistically significant. In meditation group, the result after six months was almost similar (F = 3.52) to that of psycho-education group.(Table.4.12). The results indicated that group session is effective in changing the locus of control of patients with epilepsy from external to internal. However the effect attained at three months was not well sustained at six month. The meditation programs also showed a changing trend towards internal locus of control.

The change towards internal locus of control can be attributed to the overall improvement in KAP and self – esteem due to psycho-education and resultant mutual empowerment following attendance in three support building psycho-educational group intervention programs.

In this connection by Schneider (1981) stated that those who feel in control of the stressful events of life usually have fewer health problems. How people face their disease is not directly related to the severity of seizures, but to the strategies through which they define their personal and social reality. After evaluation of a situation as stressful, the tendency to choose certain strategies depends on the individual's repertoire and experiences reinforced through his/her lifetime. The psycho-educational sessions being practised here for persons with epilepsy and their family members aims at empowering the individual patients ability to enhance their self–esteem and to facilitate internal locus of control. Internal locus of control enables the patients for better adherence to medication compliance (Gopinath et al. 2001).

Table 4.12
Average score Internal-external locus of control of Psycho - education and meditation of patientsat three points of time along with value of F-Test calculated by ANCOVA

	Pre	3m	F	6m	F
PE	9.50	12.33	7.513	12.80	3.723
Con	12.42	11.00		10.36	
Med	10.00	12.05	1.163	12.64	3.528
Con	12.42	11.36		10.69	

PE = Psycho education group, Med = Meditation group, Con = Control group
(Table value= 4.30, score above the table value is significant at 5 percent level)

4.2.5. State- Trait Anxiety Scale - State Anxiety

The ANCOVA results of the State Anxiety in the State Trait anxiety scale for the psycho-education group after three months did not show a significant change (F= 2. 72). The retest result after six months also did not show any significant change (F= 2.98) in the state anxiety score in psycho-education group. However the change in scores shows that there was a positive trend at three months, which got sustained steadily after six months. Meditation group results for the state anxiety after six months when compared with the control group showed F value of 1.58, which was not significant.

Fig. 4.12
Showing average scores Trait Anxiety of the psycho-education and meditation groups at three points of time

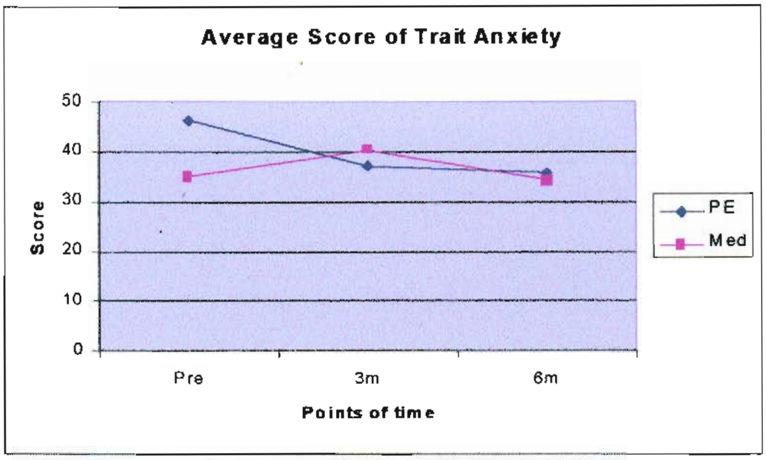
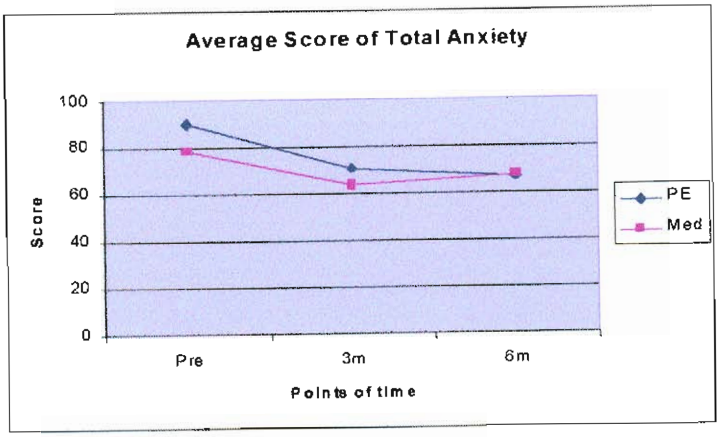


Fig. 4.13
Showing average score of Total Anxiety of the psycho-education and meditation groups at three points of time



4.2.5.1. Trait Anxiety

Even though the trait anxiety score of the psycho-education group did not show a significant change at three months (F = 2.25), it had a significant change at six months (F = 4.67). This result showed that there existed a positive trend at third month which sustained and increased to a significant level at sixth months. For meditation group F values at third and sixth months were 4.71 and 6.57 respectively and were found to be statistically significant at 5 percent level of significance. The results showed that both psycho-education and meditation were effective in dealing with trait anxiety of persons with epilepsy. It is encouraging to note that both the intervention program (psycho-education and meditation) has achieved **significant stable and sustainable reduction in trait anxiety**.

4.2.5.2 Total Anxiety

The F value of total state-trait anxiety score for psycho-education group at third month was 2.39 and at sixth months it was 4.42 and for Meditation group they were 3.42 and 4.31 respectively. The result showed that psycho-education and meditation are effective in dealing with state-trait anxiety of epilepsy patients. Among the two types of interventions meditation was found to be more effective than psycho-education in reducing total state-trait anxiety (Table.4.13).

Table 4.13
Average score of Anxiety of Psycho - education and meditation of patients at three points of time along with F-value calculated by ANCOVA

STAI Variables	Groups	Pre	3m	F	6m	F
State Anxiety	PE	43.67	32.94	2.723	31.36	2.984
	Con	33.42	37.73		37.81	
	Med	38.92	30.77	2.470	33.43	1.579
	Con	33.42	35.73		36.82	
Trait Anxiety	PE	46.17	37.29	2.252	35.59	4.669
	Con	35.00	40.37		40.82	
	Med	39.50	32.97	4.712	34.49	6.570
	Con	35.00	37.45		38.42	
Total Anxiety	PE	89.83	70.40	2.390	66.76	4.422
	Con	68.42	77.93		78.83	
	Med	78.42	63.71	3.419	67.75	4.306
	Con	68.42	73.21		75.42	

PE = Psycho education group, Med = Meditation group, Con = Control group
(Table value= 4.30, score above the table value is significant at 5 percent level

4.2.6 Epilepsy Psycho-Social Effect

The test scores of the Psycho-Social Effect Scale of the psycho-education group during pre-assessment and post-assessment at sixth months when compared with the test results of the control group showed statistically significant average change (Table 4.14) in scores only for two subscale areas of the EPSES namely Fear of stigma of employment (F = 4.58) and Lack of energy / lethargy (F = 4.64).

Table 4.14

Average score of two sub-scales of PSE of Psycho - education and meditation of patients at three points of time along with F-value calculated by ANCOVA

EPSES Variables	Group	Pre	3m	F	6m	F
fem	PE	22.24	14.06	1.321	8.53	4.578*
	Con	13.18	16.36		15.99	
	Med	10.26	8.76	0.566	7.02	2.513
	Con	13.18	11.44		11.89	
lac	PE	23.01	10.22	2.186	4.73	4.638*
	Con	9.60	14.28		10.93	
	Med	7.79	8.08	0.045	7.62	0.013
	Con	9.60	8.93		8.01	

*Significant at 5 percent level

(Table value= 4.30, score above the table value is significant at 5 percent level)
fem=Fear of stigma of employment, lac=Lethargy/lack of energy
PE = Psycho education group, Med = Meditation group, Con = Control group

There was an increasing positive trend in few other areas like PSE - Attitude towards accepting attacks, Fear of having seizure, Feeling of increased social isolation, Adverse reaction in leisure pursuits. However the results were not statistically significant. The scores of other areas of EPSES did not show any noticeable change due to intervention.

Fig. 4.14
Average score of PSE- Fear of stigma of employment of the psycho-education and meditation groups

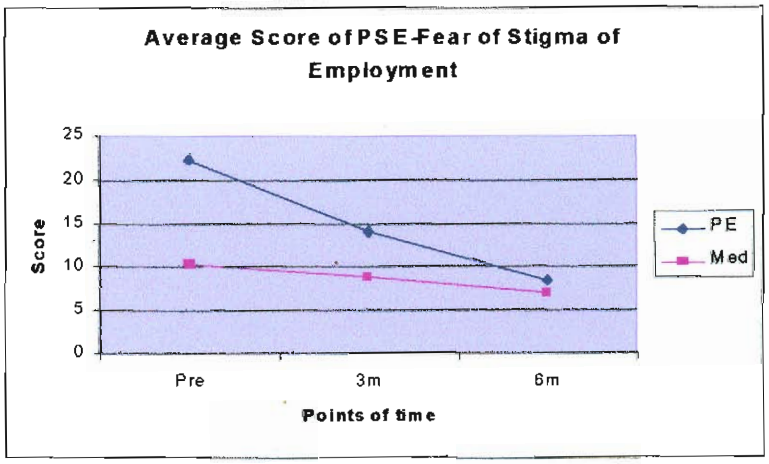
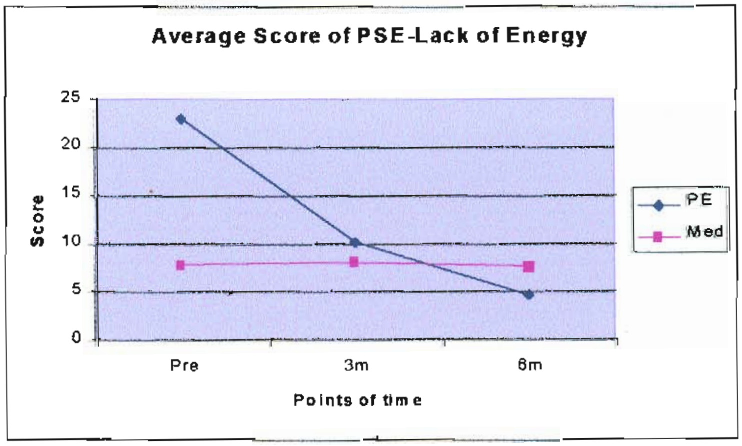


Fig. 4.15
Average score of PSE-Lack of Energy of the psycho education and Meditation groups



4.2.7. Quality of life

Quality of life is the ultimate measure in health outcome assessment. Psycho-social factors affecting quality of life are many for patients with epilepsy. Because of the misconceptions, social stigma and negative social reactions people with epilepsy generally tend to have a poor quality of life. Considering the increasing significance of QOL in epilepsy management a short-scale (WPSIQOL) and a long scale (QOLIE:31) were used in this study.

4.2.7.1 Quality of life (WPSIQOL)

The comparative test scores of Washington Psycho-Social Inventory Quality of Life (WPSIQOL) of psycho-education group and control group during pre-assessment and post-assessment at third and sixth months were 2.94 and 1.96 respectively. In meditation group the corresponding F values were 0.511 and 0.142 respectively. (Table 4.15). These values were not statistically significant at 5 percent level of significance, which indicated that both type of interventions were not effective in improving the quality of life of patients with epilepsy when they were administered with three psycho-educational interventions and three months of meditation. However it has to be specially noticed here that changes observed were due to two psycho-social interventions and 3 months of yoga-meditation. However the trend in changes indicated that with more number of psycho-educational session and long-duration of mediatation the extent of changes may further improve.

Table 4.15
Average score WPSIQOL of psycho - education and meditation patients at three points of time along with F-value calculated by ANCOVA

Group	Pre	3m	F	6m	F
PE	9.08	14.32	2.937	16.27	1.962
Con	13.92	11.93		14.14	
Med	13.50	14.29	0.511	15.76	0.142
Con	13.92	13.55		15.16	

PE = Psycho-education group, Med = Meditation group, Con = Control group
(Table value= 4.30, score above the table value is significant at 5 percent level)

4.2.7.2 Quality of life (QOLIE:31)

The score of Quality of Life in Epilepsy Inventory (QOLIE:31) in the psycho-education group at the third month of post assessment did not show any significant improvement. At sixth month the analysis showed statistically significant change in the area of QOLIE - 31 - Medication effect (F = 15.33). In meditation, group results did not show statistical significance in any of the seven areas of quality of life even though there was an increasing trend at cognitive level (Table 4.16). This revealed that psycho-education was effective in improving Medication effect in quality of life of patients with epilepsy. The meditation group patients did not show significant change in improving quality of life of the epilepsy patients attending the meditation program for three months

Table.4.16

Average scores of QOLIE:31 of Psycho - education and meditation patients at three points of time along with value of F-Test calculated by ANCOVA

QOLIE Variables	Group	Pre	3m	f	6m	F
sew	PE	3.89	5.95	2.921	6.41	3.133
	Con	5.74	5.12		5.10	
	Med	5.84	6.19	0.351	6.12	0.326
	Con	5.74	5.84		5.72	
voq	PE	6.34	8.99	0.002	10.31	0.173
	Con	10.35	9.03		9.75	
	Med	8.28	11.19	0.325	10.71	0.381
	Con	10.35	9.70		10.10	
emw	PE	6.23	8.18	0.016	8.32	0.292
	Con	9.13	8.08		7.81	
	Med	8.48	7.99	0.971	7.37	0.798
	Con	9.13	8.79		8.11	
enf	PE	6.50	8.12	0.586	9.61	2.135
	Con	8.85	7.78		8.34	
	Med	8.00	8.91	0.856	9.36	2.611
	Con	8.85	8.39		8.54	
con	PE	1.52	0.86	0.292	0.50	0.181
	Con	0.47	0.75		0.59	
	Med	0.42	0.30	0.090	0.29	0.428
	Con	0.47	0.34		0.40	
mee	PE	1.17	1.88	2.479	2.56	15.334*
	Con	1.83	1.56		1.49	
	Med	2.20	2.08	0.304	2.05	0.676
	Con	1.83	1.93		1.83	
sos	PE	11.51	14.51	1.339	15.23	0.004
	Con	15.45	13.85		15.13	
	Med	15.13	16.66	2.055	16.07	0.083
	Con	15.45	15.39		15.66	
overall	PE	37.17	48.43	0.840	54.22	3.743
	Con	51.82	46.23		46.94	
	Med	48.35	53.27	1.273	52.03	0.365
	Con	51.82	50.43		50.28	

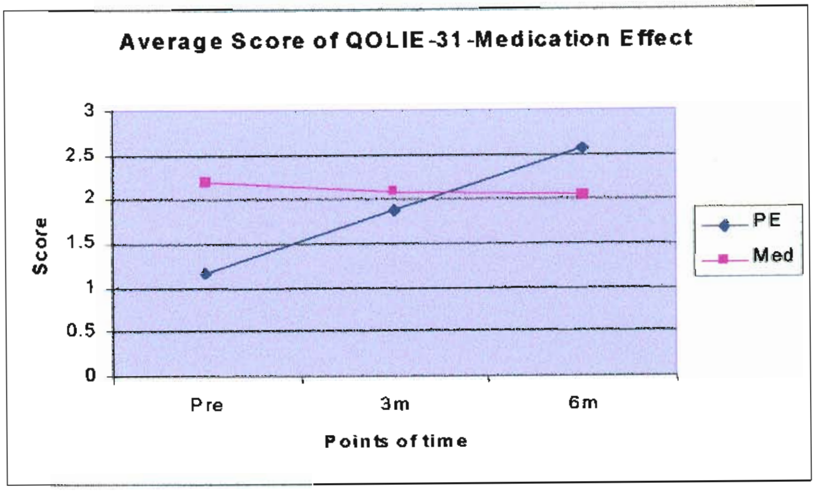
* Significant at 5 percent level

(Table value= 4.30, score above the table value is significant at 5 percent level)

sew = Seizure worry, voq = Overall Quality of Life, emw = Emotional well- being, Enf =Energy/fatigue, con = Cognitive functioning, mee = Medication effect, sos = Social functioning, overall –Overall Score. PE = Psycho education group, Med = Meditation group Con = Control group

Fig.16

Average score of QOLIE :31 – Medication Effect of psycho-education and meditation groups at three points of time



4.3 Effect of socio-demographic characteristics on intervention

In the present study the effect of socio-demographic characteristics of the patients on variables related to epilepsy, which showed significant change due to the intervention detected by ANCOVA was analyzed by the Multiple Regression Analysis. The difference in the scores between three months after intervention and pre-intervention (baseline) were taken. The variables were age, sex, education, type of epilepsy, and duration of illness, Engel's score (seizure frequency), AED side effect and age at onset of seizure. Regression analysis was used to estimate the difference in the scores of each variable by controlling the effect of other variable at their average value. In a study conducted by Johnson et al., (2004) also performed a similar series of hierarchical regression analyses to identify the proportion of variance accounted by clusters of demographic factors (age, gender, education), clinical features (duration, antiepileptic drug polytherapy, seizure frequency and severity) and psychiatric co-morbidity (anxiety and depression).

4.3.1 Effect of socio-demographic and clinical characteristics on psycho - education (ANCOVA)

In the present study the variables, which showed significant change due to psycho -education detected through ANCOVA, were selected in this section. Trait anxiety, total anxiety, PSE - Fear of stigma of employment and Lack of energy / lethargy and self – esteem and internal - external locus of control (IE) and KAP were the variables found to have significant change due to the effect of psycho-educational session.

4.3.1.1 Trait Anxiety

The average changes in the scores of trait anxiety calculated with the help of regression analysis for different age groups showed that the reduction of trait anxiety was high (-8.75) among patients in the adolescent age group of less than 20 years. Among patients in the age group (21-30), the reduction in the score of trait anxiety was -4.75 and for elder age group (30+) it was -1.75. (Table 4.17)The result indicated that as age of the patients with epilepsy increased, the average reduction of trait anxiety due to the effect of psycho-education decreased. This leads to the conclusion that psycho -education is more effective among younger patients in reducing their trait anxiety.

Regarding the effect of gender of patients on the reduction of trait anxiety due to psycho-education, male patients showed more reduction (-7.03) than female patients (-0.36).

Among the different educational groups of patients, the school-educated group showed a better improvement of trait anxiety (-9.30) than the college-educated group (-0.64) due to the effect of psycho-education. The result indicated a negative impact of education on the efficacy of psycho-education in reducing trait anxiety among patients with epilepsy.

Regarding the impact of different seizure types on the efficacy of psycho-education in reducing the score in trait anxiety of patients with epilepsy, it was found that the average reduction of trait anxiety scores was comparatively high(-9.25) among the LRE group than among GE group (0.75). Since the severity of disorder is more among GE group than the LRE group, there can be seen a negative relationship between severity of disorder and effectiveness of psycho-education in reducing trait anxiety among patients with epilepsy. From the results it can be inferred that GE group may require more number of psycho-educational sessions or other psycho-therapeutic measures to achieve the desired effect.

While considering the duration of epilepsy and change in the scores of trait anxiety due to psycho education, it was observed that the average change of score was more (-6.58) for the chronic illness group (>15 years) than the less chronic group (-2.58). Since the psycho-social problems are more among chronic patients with epilepsy, the result indicated a positive relation between duration of illness and effectiveness of psycho-education in reducing the trait anxiety.

It was interesting to note that a similar relationship could be seen between seizure frequency and the reduction in trait anxiety score due to psycho-education. The average reduction of trait anxiety was found to be more (-11.91) for patients with difficult to control seizures than those with relatively controlled seizure patients (+3.42). This finding supports the hypothesis that psycho-educational sessions are effective irrespective of seizure frequency.

The reduction of trait anxiety score was found to be more for patients with AED side effects (-7.75) than patients without side effect (-3.08). Here also, it can be seen that when the problems related to epilepsy due to medication complication are more, the effect of psycho-education on reducing trait anxiety also is more.

Regarding the age at onset of seizure and effect of psycho-education on average trait anxiety it was found that the reduction in scores was more for patients with late age at onset of seizure (-5.33) than for patients with early onset of seizure (-1.00). Psycho-social problems are reported to be more and intense for patients with early age at onset of seizure. At the same time reduction of trait anxiety score was more among patients with late age at onset of seizure. The result reveals a positive relation between age at seizure and effectiveness of psycho-education. The implication of the result is that two psycho-educational sessions are less effective for patients with early age at onset of seizure, who generally tend to have more psycho-social problems. The change in score indicated that the latter group can further improve with more number of sessions.

As far as family atmosphere was concerned more reduction in trait anxiety (-6.08) was found more among patients who reported unhealthy family atmosphere than those with healthy family atmosphere (-2.14).

In short, it can be inferred from the above findings that psycho-educational group sessions was effective in reduction of score in trait anxiety in major areas which are prone to develop more psycho-social problems like longer duration of epilepsy, patients with high seizure frequency, AED side effect, and unhealthy family atmosphere. The reasons for these changes can be attributed to the impact of psycho-educational group intervention which facilitates mutual empowerment and social support which might have acted as a powerful cognitive precussor in reducing the trait anxiety. Moreover patients with deeper problems are found to be more receptive to these type of interventions.

4.3.1.2 Total Anxiety

The regression analysis on total anxiety score of state-trait anxiety scale showed a considerable average reduction in total anxiety scores of patients in the adolescent age group (-21.83) as compared to other age groups. For the age group (30+) the average change was –8.54 followed by the age group (21-30) with average change of –7.40. The result indicated that the psycho-educational sessions have benefited more for the younger patients with epilepsy to reduce their total anxiety (Table 4.17).

Regarding the impact of gender on psycho-educational group sessions in reducing total anxiety score, it was found that average reduction in score was more for the males (-18.75), whereas in the case of females the change in the score was only –1.56. A marked gender difference with a male preponderance in the effectiveness of psycho-educational sessions was visible in reducing the total anxiety of patients with epilepsy.

It was also found that there was more change in the score of total anxiety among school-educated patients with epilepsy (-25.19) than that of the college-educated patients (-1.86). The result indicated an inverse relationship between level of education of the patients and the effectiveness of the psycho-educational group sessions in reducing their total anxiety.

While studying the impact of type of seizure on the effectiveness of the psycho - education sessions in reducing the total anxiety of the patients, it was found that there was more reduction in score of total anxiety among patients with LRE (-24.94) than that of patients in the GE. The average change in the total anxiety score of the patients in GE showed an increasing trend (+1.78), which indicated a negative impact. The result showed an inverse relationship between the extent of severity of illness and effect of psycho-educational session in reducing the total anxiety of the patients with epilepsy.

Among the chronic epilepsy patients with longer duration (>15 years) of epilepsy, the change in the score of total anxiety was -13.66 and for the patients with relatively shorter duration of epilepsy the corresponding score was -10.09. The change of scores in both the groups was found to be statistically significant. The results clearly indicated that the psycho-educational group sessions are effective in both the groups of patients in reducing total anxiety associated with epilepsy. However the effect was found to be more for the group with longer duration of epilepsy.

Regarding the impact of seizures frequency in changing the total anxiety of patients with epilepsy, it was found that the reduction of total anxiety score was more for patients with more frequent seizures (Engel Score 6). The average score for patients with Engel Score 6 was -32.27 and that for patients with less frequent seizures (Engel Score < 5) was +9.11. This result clearly showed a negative relationship between the effects of psycho-education in reducing total anxiety of patients with their seizure frequency.

A clear reduction in score in total anxiety (-22.11) was also observed among patients with AED side effect and the score for patients without AED side effect was –

8.07. It was encouraging to note that psycho-education was found to be effective in reducing the total anxiety of patients with epilepsy who were also affected with medication side effects.

It was also seen that patients with late onset of seizure the average change of total anxiety score was -14.07 and for patients with age of onset of illness before 10 years the score was -4.11. It was noted that patients with early onset of seizure can have concomitant psycho-social problems of greater magnitude, the effect of psycho-education in reducing their total anxiety was very much less compared to patients with late on set of seizure. However the trend in change in score indicated that there can more positive changes with more number of psycho-educational sessions .

Regarding family atmosphere and impact of psycho-educational sessions in reducing anxiety in patients with epilepsy, it was found that for patients from unhealthy family atmosphere the average change in the total anxiety score was -17.8 and for patients from healthy family atmosphere the score was -5.34.

In short, it can be inferred that the patients likely to have maximum psycho-social problems like adolescent age group, males, less educated patients with long duration of epilepsy, high seizure frequency, patients with AED side effect and patients coming from unhealthy family atmosphere were benefited more from the psycho-education group intervention in reducing their total anxiety. These results in anxiety reduction suggest that psycho-educational group sessions are effective in psycho-social care of epilepsy patients, especially in reducing trait and total anxieties. The above result is supported by a related study conducted by Hegelson et al.(1990) in a two-day psycho-educational treatment program (Sepulveda Epilepsy Education) using a controlled outcome design. The treatment group demonstrated a significant increase in overall understanding of epilepsy, a significant decrease in fear of seizure and increase in medication compliance as revealed in AED blood levels. In another related study conducted by Williams et al. (1979) who reviewed the treatment of 37 patients with epileptic and non-epileptic seizures. Their seizure disorder seems to be exacerbated by stress and they received at least two sessions of a psychiatric intervention. At the end of treatment and follow up at six months, over half of the patients were improved or were seizure free and patients with partial seizures (LRE) were more likely to show a good response to group sessions than patients with GE.

These findings gain importance in the light of the observations made by Lecrubicer (2001) that psychological illness is responsible for considerable disability worldwide. Different measures of disability has been used in different studies, they have consistently demonstrated that individuals with depression and anxiety disorders experience impaired physical and role functioning, more days in bed due to illness, more work days lost, increased impairment at work, and high use of health services. The disability caused by depression and anxiety is just as great as that caused by other common medical conditions, such as hypertension, diabetes, and arthritis. Co-morbidity of depression with anxiety or medical illness further increases the disability experienced by sufferers. Recognition and treatment, however, relieve the burden imposed by untreated anxiety and depression on the individual, society and health services. A chronic illness such as epilepsy can be an important stress factor and inability to deal with this condition can bring psychological difficulties and emotional discomfort. Dealing with these stressful situations demands cognitive and behavioural efforts that may or may not be efficient (de Souza, 2006).

Based on the above observations and findings among different socio-demographic and clinical characteristics of epilepsy patients suitable psycho-educational program can be planned tailor made targeting each affected category of patients.

4.3.1.3 PSE – Fear of stigma of employment

In the case of Fear of stigma of employment in PSE of patients with epilepsy, it was found that patients in the age group (21-30) got maximum reduction (-10.01) in the area of Fear of stigma of employment in PSE. The average change in score for the age group 30+ was -5.34. The score in the age group <20 showed an increase of +4.72, which indicated a negative impact of the psycho-educational group sessions on this age group in reducing PSE Fear of stigma of employment (Table 4.17). The result indicated that it was difficult to achieve desirable changes in this area of psycho-social effect for this younger group with two psycho-educational sessions. This result further indicated that this resistant group may require either more psycho-educational sessions or additional psycho-therapeutic strategies for overcoming their psycho-social hardships.

It was also seen that males showed a better average reduction in score (-7.65) than the females (+1.12) who registered a slight increase in PSE score. The average changes in the PSE scores observed in school-educated patients was (-4.60) and the corresponding score for the college-educated group was -3.56. Here an inverse relationship can be seen between the level of education and reduction in PSE score due to psycho-educational sessions.

While analyzing the impact of seizure type on the effectiveness of psycho-education in reducing PSE score of patients with epilepsy, it was found that the average change in score was more for the LRE seizure type (-12.90), and the change of score for the GE seizure type was +4.91. The result indicated a negative relationship between illness severity and the effectiveness of psycho-education in reducing the psycho-social effect of epilepsy on patients.

Regarding the impact of seizure frequency on the effectiveness of psycho-education it was found that the average change in PSE score was more for patients with high seizure frequency (-11.23). For patients with lesser seizure frequency the change in the score was found to be increaseing (+3.24).

While analyzing the impact of AED side effects after psycho-education in reducing PSE- Fear of stigma of employment score, it was found that reduction in score was more among patients who reported no side effect (-8.38). The scores for patients having AED side effect had shown an increase of +9.17 which indicated that two psycho-educational sessions are not effective in dealing with psycho-social problems of patients having AED side effects.

Regarding the impact of age at onset of illness on the effectiveness of psycho-educational sessions in changing the PSE- Fear of stigma of employment, it was found that early onset of seizure group showed more reduction in scores (-8.26) than patients whose seizures started after 10 years of age (–2.57). As psycho-social problems are reported to be more for patients whose seizure begins early in life this finding support the view that group sessions are effective in psycho-social care of patients especially in this area of psycho-social effect namely- Feeling of stigma of employment. This trend in changes of scores further indicated that the patients can improve further with more number of sessions.

Regarding the impact of family atmosphere on the effectiveness of psycho-educational sessions in dealing with PSE - Fear of stigma of employment, it was also found that those with unhealthy family atmosphere the average reduction in score was more (-10.70) when compared to those who reported healthy family atmosphere. The score for the latter group was +3.72, showing an increase in PSE- Fear of stigma of employment. From the results it can be inferred all the socio- demographic and clinical variables, which are prone to create more psycho-social problems, were found to show more average reduction in scores in this area of psycho-social effect due to the psycho-educational group interventions.

4.3.1.4. Self- esteem

The relationships of the various demographic and clinical variables with changes in score of self-esteem due to psycho-educational group sessions were analyzed using regression. It was found that the patients below 20 yeas of age showed more average reduction in scores of self-esteem (-9.31) due to the effect of psycho-educational sessions, which indicated a negative effect. The maximum improvement of self-esteem (21.58) was found in patients with age group 21-30 followed by those 30+ age group (8.37). This result indicated that it is difficult to effect desirable changes in self-esteem with two psycho-educational group sessions among younger patients (Table 4.17).

Table 4. 17 Average difference of score at three month from the score at pre - intervention of the variables exhibited significant change due to intervention (ANCOVA) in psycho-education group.

Patient Charactaristics		Trait Anx	Total Anx	PSE Fem	Self Esteem	IE	KAP	PSE Lack of energy
Age	<20	-8.75	-21.83	4.72*	-9.31	1.79	-0.30	11.16
	21-30	-4.75	-7.40	-10.01*	21.58	1.58	2.97	-23.78
	30+	-1.75	-8.54	-5.34*	8.37	1.15	1.50	-9.39
Sex	Male	-7.03	-18.75	-7.65*	8.94	2.15	1.58	-9.55
	Female	-0.36	-1.56	1.12*	4.89	0.39	1.19	-5.47
Education	School	-9.30	-25.19	-4.60*	17.21	2.49	0.71	-20.15
	College	-0.64	-1.86	-3.56*	0.13	0.65	1.92	0.93
Type	General	0.75	1.78	4.91*	4.41	2.24	0.76	-0.20
	LRE	-9.25	-24.94	-12.90*	10.09	0.59	2.07	-15.50
Duration of illness	1-15	-2.58	-10.09	-10.13*	8.44	1.30	1.57	-11.48
	16	-6.58	-13.66	4.60*	5.58	1.58	1.21	-2.78
Engel score	5	3.42	9.11	3.24*	3.58	1.40	1.10	4.01
	6	-11.91	-32.27	-11.23*	10.92	1.43	1.73	-19.71
AED effect	Yes	-7.75	-22.11	9.17*	-0.43	1.56	-0.39	-9.31
	No	-3.08	-8.07	-8.38*	9.81	1.37	2.02	-7.36
Age at onset	<10	-1.00	-4.11	-8.26*	11.20	1.56	2.43	-16.82
	10+	-5.33	-14.07	-2.57*	5.93	1.37	1.08	-4.86
Family atmosphere	Healthy	-2.41	-5.34	2.72*	1.19	0.96*	0.82	-0.11
	Not healthy	-6.08	-17.82	-10.70	13.31	1.87*	2.02	-15.59

* p value < 0.05

Trait Anx = Trait anxiety, Total Anx= Total anxiety, PSE Fem = Psycho-Social Effect Scale – Fear of stigma of employment, IE= Internal external locus of control, KAP= Knowledge attitude and practice, PSE Lack of energy= PSE – Lack of energy/ lethargy.

Among male / female gender the males (8.94) made more improvement in self-esteem than the females (4.89) by following application of psycho-educational sessions.

As far as the impact of level of education on psycho-educational sessions in making averages changes in score it was found that more improvements was observed among school - educated patients (17.21), whereas for college-educated patients the average change of score was +0.13. There exists a negative relationship between educational level and impact of group intervention in self-esteem.

Regarding the impact of seizure type on the psycho-educational group sessions it was found that improvement was more for those who have LRE seizure type (10.09), where as the GE group the score was 4.41. With the given two sessions, the changes in self-esteem were more for patients having relatively less illness severity (LRE seizure type)

Regarding the duration of illness on the effectiveness of psycho-educational group sessions in changing self-esteem of patients with epilepsy, the change in average scores was high for patients with shorter duration of epilepsy (8.44) and less for patients with chronic epilepsy (5.58). The results indicated that there can be more changes with more number of psycho-educational sessions.

Regarding the impact of seizure frequency on the effectiveness of psycho-educational sessions in this area of self-esteem it was found that the average improvement in score was more for patients with high seizure frequency (10.92), The score for patients with less seizure frequency the score was 3.58. The result indicated the effectiveness of psycho-educational sessions in improving self-esteem of patients with epilepsy was irrespective of seizure frequency. but it is more with higher frequency of seizures.

Regarding the impact of side effect of AED on the effectiveness of psycho-educational sessions, it was found that there was improvement in self-esteem among patients without side effect (9.81) whereas in the case of patients with AED side effects the change was found to be negative (-0.43).

Regarding the impact of age at onset on the effectiveness of the psycho-educational group session in improving the self-esteem of patients with epilepsy, it was found that improvement in score was more (10.20) for patients with early age at onset of seizure. The score for patients with relatively late onset of seizure was 5.93. This also is a significant finding of the study as persons with early onset of seizure generally tend to have more psycho-social problems and low self-esteem.

While studying the impact of family atmosphere on the effectiveness of psycho-educational group sessions in improving the self-esteem of patients with epilepsy it was found that patients with unhealthy family atmosphere the average increase in score was more (13.31) indicating a desirable and positive change where as the score of those patients who reported healthy family atmosphere the change in score was minimal (1.19).

From the above results it is evident that psycho-educational group sessions are effective in improving self- esteem of patients with epilepsy and the changes are more evident in patients who are prone to develop more psycho-social problems like patients with more frequent seizures, with AED side effects, early onset of seizure and unhealthy family atmosphere.

According to Amir et al. (1999) Social withdrawal and non-confrontational behaviour may reinforce self-criticism, self- rejection and internal stigma. More adaptive strategies emerged, such as searching for social support, medical treatment and spiritual help. These strategies can be powerful in that they can help those with chronic condition maintain acceptable level of well-being. Confrontation and positive attitudes towards life are associated with better prognosis, satisfaction, and well- being. Mutual empowerment social support are the strategies used by people to cope with the disease and is fundamental in reducing the impact of the stressor due to epilipsy. One of the major goals of the psycho-educational group intervention program here is building of social support from among group members and the conductor of the sessions (Jayachandran et al., 2000).

The above results are supported by the study of Kaul and Bender (1986), which reviewed group psycho-therapy literature, selecting studies that used experimental design with random assignment and control or matched alternative group treatment groups. In both reviews the majority of studies reported significant differences between group-treated clients and non-treated control groups on a variety of self-esteem measures, including self-rating of self-actualization, self-linking and other self-evaluation measures.

4.3.1.5 Locus of Control

The regression analysis of the impact of age on psycho-educational sessions in changing locus of control (IE scale) revealed that all the patients irrespective of their age group showed improvement in average score (Table 4.17). As far as the gender of the patients was concerned, males made better change (2.15) than females (0.39). Among the educational groups, college -educated group made better change (1.92) than the school -educated group (0.71). In the case of seizure types the LRE type epilepsy group made better change (2.07) than the GE group (0.76).

The different groups in the areas like duration of epilepsy, seizure frequency, AED side effects, and age at onset of seizure did not make any noticeable change in the score of the locus of control, but all the groups made uniform positive change irrespective of the differences within and between the groups. The change in locus of control towards internal was more among patients who reported unhealthy family atmosphere than those with healthy atmosphere and the changes were statistically significant.

The above findings gains further momentum in the light of the observations made by following authors. According to Seligman (1986) Psycho-social variables that might contribute to learned helplessness , such as decreased satisfaction with family relationship, negative attitudes towards illness, and unknown and external locus of control were associated with depression among persons with epilepsy. In epilepsy, the repeated loss of personal control is a central problem and may be important to address directly. Moreover elevated external LOC is associated with depression in adults with epilepsy (Hermann and Wyler, 1989. The Knowledge about their disease will encourage people with epilepsy to make informed choices, and achieve better compliance and personal control of their problems. Active patient and family education about epilepsy can heighten patients and family's sense of their internal "Locus of control" which fosters positive adjustment (Dunn, 1999). The positive changes observed among different groups mentioned in the present study can be attributed to improvement in KAP, reduction in trait and total anxiety and consequent improvement in self- esteem following attendance psycho-educational group sessions.

4.3.1.6 KAP

The estimated difference in the scores of selected variables using multiple regression analysis is presented in Table 4.17. The table showed that in the case of age of the patients, the age group 21-30 got the maximum positive changes in the KAP scores followed by the age group (30+). But in the case of the age group <20 the average difference is found to be negative which indicated that the adolescent patients are relatively more resistant and their KAP cannot be easily changed with two psycho-educational groups sessions alone.

As far as the gender of the patients was concerned the score of KAP registered a positive change among males and females. The score was higher among males than females. Impact of education was also found to have negative effect in the change in the KAP score. Among the different educational groups maximum positive change was seen among the school-educated group.

While analyzing the type of epilepsy and KAP changes it was noticed that LRE got the more benefit than the GE group. Regarding seizure frequency of the patients and change in KAP score it was found that the controlled epilepsy and uncontrolled epilepsy group as per Engel's score did not differ much. Among those patients with or without disabling side effects of anti-epileptic drugs (AED), it was found that those with disabling side effects patients did not change their KAP with two or three psycho-educational group sessions. There was positive change among those patients whose first epilepsy started before 10 years of age as compared to those whose disorder started later.

While analyzing the KAP changes with respect to family atmosphere those with unhealthy family atmosphere were found to make more positive changes after Psycho-educational group sessions .

The age group (21-30) got the maximum positive changes in KAP scores. The score was higher among males than females. The positive changes were also noticed for the school-educated group, LRE patients, patients with controlled seizure frequency, those without AED side effects and patients whose epilepsy started early age at onset. The above changes observed in differnet goups are due to psyco-education. In this connection It is significant to note the findings of Jain et al.(1993) who while reporting on 493 patients attending hospital epilepsy clinics, found greater than 90 percent of the interviewed patients wanted to receive more information about epilepsy than had already been given to them. Jarving et al.(1993) demonstrated that patients with epilepsy tend to know more about the medical rather than social consequences of their condition, but even the knowledge about the medical conditions was limited.

The observations made by the following authors also support the need for effective methods to promote awareness and positive attitude towards epilepsy among different groups. 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). Patient education is urgently needed (Scantilli et al., 1993) because the knowledge of patents with epilepsy has been shown to be poor regarding the illness and its treatment. (Schneider,1993). Dawkins et al.(1993) found that patients with epilepsy knew no more than those without epilepsy about the disorder. The results indicated that the psycho-educational group intervention involving family members is a positive beginning.

4.3.1.7 PSE – Lethargy / lack of energy

The results of regression analysis indicated that due to the effect of psycho education, the Lack of energy/lethargy among patients in the age groups (21-30) and (30+) decreased and they were found to be -23.78 and -9.39 respectively. At the same time for the patients with age less than 20 years, the average difference was +11.16. From this it can be inferred that to change the attitudes of patients with two psycho-educational group sessions was more difficult among patients with age below 20 years than older patients (Table 4.17).

When considering the gender of patients, it can be seen that the maximum desirable change was seen among the males (-9.39) and for the females the corresponding change is -5.47, which indicated the relatively high susceptibility of males to change following psycho-education.

Between the two educational categories the lower educated group had the maximum reduction in Lack of energy / lethargy (-20.15) while among patients with higher education the average change was +0.90. The result indicated a slightly negative effect of education on the effectiveness of psycho-education as effectiveness reduced with increasing education.

Between the two different seizure types patients with LRE was found to show more reduction in score of Lack of energy / lethargy (-15.50) due to the effect of psycho education. The patients from the GE the score was only -0.20.

Regarding the duration of illness and reduction in PSE score due to psycho - education, it was found that those with less than 15 years history of epilepsy had more average reduction in scores (-11.48) and for those with long duration of epilepsy a score of (-2.78). In the case of seizure frequency patients with more frequent seizure (Engel's score 6) the reduction in Lack of energy / lethargy was (-19.71) through psycho-education and the effect was negative (+4.01) for patients with less frequent seizures (Engel score 5).

While analyzing the impact of AED side effect on the change of Lack of energy / lethargy through psycho-education, it was found that the score of Lack of energy / lethargy has reduced more (-9.31) in patients with AED side effects than those who did not have any AED side effect (-7.38). The result showed a positive indication that psycho-education can alleviate the Lack of energy/lethargy problems among patients suffering from AED side effects.

Regarding the impact of age at onset of seizures on the change in the Lack of energy / lethargy due to psycho education, it was found that psycho-education sessions were more effective (-16.82) among those who have early onset of seizures (<10 years of age) than for those patients with relatively late onset of epilepsy (>10 years).

As far as the family atmosphere and change in Lack of energy / lethargy due to psycho-education was concerned, patients from unhealthy family atmosphere were more benefited (-15.59) than patients (-0.11) who had reported to have healthy family atmosphere. Since the reduction in Lack of energy / lethargy was higher among patients from unhealthy family atmosphere, it can be inferred that psycho-educational sessions were effective in dealing with psycho-social problems arising from unhealthy family atmosphere.

In this areas of PSE maximum reduction was seen among patients in the age groups (21-30), male patients, school-educated group, LRE, high seizure frequency, patients with AED side effects, patients with early age at onset of epilepsy, and patients from unhealthy family atmosphere.

4.3.2 Effect of socio-demographic characteristics on meditation

The meditation group in this experimental study was given meditation by the Yoga Expert 420 minutes each everyday in the morning and evening for three months. The pre-post results were analyzed using regression method. The analysis of the data of the meditation group showed reduction in score both in trait and total anxiety in State -trait Anxiety scale.

4.3.2.1 Trait anxiety

Among the three different age groups maximum reduction in trait anxiety scores were found among 21-30 age group (-9.73) due to the effect of Yoga - Meditation, The change in score was -2.29 for the patients in the 30+ age group and changes were minimal (-0.62) among the patients with < 20 years of age. The reduction in anxiety score was high for males (-10.69) than for females (-1.91), There is marked sex difference in the effectiveness of meditation in trait anxiety (Table 4.18).

Regarding the impact of education it was found that both school-educated and college-educated patients made improvement. Regarding the type of seizure it was found that score reduction was more (-4.11) for patients who have GE than (-3.44) patients with LRE. This observation is different from the findings in psycho-education group .

Contrary to the observations in psycho-educational group sessions, the patients with lesser seizure frequency (-15.27) showed reduction in trait anxiety through meditation. Whereas the change in score for patients with high seizure frequency was showing a negative effect with an increase in trait anxiety scores.

The reduction in trait anxiety score was found to be more for patients with AED side effects (-6.89), patients with late seizure onset (-7.06) and patients who reported unhealthy family atmosphere (-8.22).

Maximum reduction in trait anxiety scores were found among patients in the 21-30 age group, male patients, GE patients, and patients with less seizure frequency, Patients with AED side effects, late age at onset of epilepsy, and patients from unhealthy family atmosphere.

Table 4.18
Average score of meditation in Trait Anxiety and Total Anxiety among different socio-demographic and clinical variables

Patient Characteristics		Trait Anx	Total Anx
Age	<20	-0.62	12.19
	21-30	-9.73	-35.47
	30+	-2.29	-3.47
Sex	Male	-10.69	-27.03
	Female	-1.91	-3.86
Education	School	-4.94	-11.78
	College	-4.28	-10.61
Type	General	-4.11	-13.81
	LRE	-8.44	-0.47
Duration of illness	1-15	-5.54	-20.42
	16 +	-3.43	6.08
Engel score	5	-15.27	-45.42
	6	2.62	12.58
AED effect	Yes	-6.89	-20.17
	No	-2.78	-3.00
Age at onset	<10	-2.61	-7.17
	10+	-7.06	-16.00
Family atmosphere	Healthy	-1.44	-5.25
	Not healthy	-8.22	-17.92

Trait Anx = Trait Anxiety, Total Anx = Total Anxiety

4.3.2.2 Total Anxiety

In the total anxiety the maximum reduction in scores was found in the age group 21-30 (-35.47), followed by 30+ age group (-3.47). Whereas in the younger age group patents with less than 20 years the total anxiety score was showing an increasing trend indicating a negative effect following psycho-educational group sessions. (Table 4.18).

Regarding the gender the reduction in score was found more among male patients (-27.03) than the change among female (-3.47) As in the case of trait anxiety in total anxiety also there is a marked sex difference in the effectiveness of meditation.

The patients in the two educational group showed almost uniform improvement irrespective of their educational level (school-educated group -11.78 and college educated group -10.61). Among the seizure type more reduction in total anxiety was found among GE (-13.81), whereas in the LRE group the changes were minimal (-0.47). This finding also is contrary to the observation in psycho-education group.

Regarding duration of epilepsy also it was found that the effect was more for shorter duration of epilepsy patients (-20.42), The chronic epilepsy patients the score was showing an increasing trend indicating a negative effect. This observation was also against the changes observed in psycho-educational groups.

Another significant observation was the changes in score obtained for patients with less frequent seizures (-45.42) The scores for the patients with high seizure frequency was showing an increasing (+2.62) trend indicating a negative effect due to meditation. This result also is quite different from that of the psycho-educational group were the effectiveness of the sessions were more among the high seizure frequency patients.

More reduction in total anxiety score was also observed for patients with AED side effects (-20.17), late onset of epilepsy (-16.00) and patients with unhealthy family atmosphere (-17.02) and these changes were almost similar for both meditation and psycho education groups.

In the total anxiety the maximum reduction in scores was found in the age group 21-30, male patients, GE pateints, short duration of epilepsy, patients with less frequent seizures, AED side effects patients, patients with late age at onset of epilepsy and patients from unhealthy family atmosphere. Jerving et al., (1992) proved that a yogic meditation technique called Transcendental Meditation has been shown to reduce respiratory rate, enhance endogenous dopamine release, increased blood flow to certain regions in brain and improved alpha activity as shown in EEG. The above results are also supported by the study conducted by Panjawani et al., (1995) for stress reduction among patents who practiced *Sahaja Yoga* meditation.

Yoga-meditation has been practiced in SCTIMST as an add-on therapy along with other anti-epileptic drug regimen with significant seizure reduction (Rajesh et al. 2006) The present study have now proven that meditation is effective in reducing trait and total anxiety also among the meditation group in this study. In this connection Acevado (2006) observed that the search for a cure for epilepsy has been pursued for thousands of years, there are records of the use of Complementary and Alternative Medicines (CAMs) in India, Asia, America and Europe. Epilepsy programs may be more successful if CAMs and traditional medicines are used in tandem. Different studies have concluded that this may guarantee compliance with the traditional therapies, without modifying or abandoning AED prescriptions.

The reduction observed in **trait anxiety** and **total anxiety** following meditation in an important finding of the study which can have far reaching implications in epilepsy care.

4.3.3 Effect of socio-demographic and clinical characteristics of patients on variables showed significant change during Psycho - Educational Meditations interventions *(ANOVA)*

In the present analysis the changes during intervention in the selected variables were studied initially by the statistical method ANOVA, KAP,. Depression, state anxiety, EPSES (subscales) : Depression / emotional reaction and Feeling of increased social isolation, Lathargy / lack of energy, WPSIQOL, and QOLIE:31 (subscales) : Energy fatigue and Medication effect showed significant change among patients who attended psycho-educational sessions. Among patients in meditation group, no variable was found to have significant change during the period of intervention.

4.3.3.1 KAP

While analyzing the impact of age on the changes in the KAP through psycho-education, it was found that the younger age group patients (<20) showed a negative impact. The result indicated that the KAP of this groups couldn't be easily changed with few psycho-educational sessions. All other age group of patients showed uniform improvements in KAP. Regarding seizure frequency and KAP it was found that patients with lesser frequency again showed a negative change where as for patients with higher seizure frequency the change in score for KAP was positive. A positive change was also noticed for patients with AED side effects, patients with early (<10) years of age at onset of seizures and for patients who reported unhealthy family atmosphere.

4.3.3.2 Depression

While analyzing the impact of age on the change in the depression through psycho-education, it was found that adolescent group (<20 years) the average change in scores was +4.95, which indicated an increase in the depression score. At the same time the changes in the depression scores of patients in the (21-30) and (30+) age groups are -8.21 and -10.53 respectively. The result indicated that depression has reduced more among patients who were relatively older (Table .4.19).

The impact of sex on the change in depression during the study period was found to be the same for both males and females. In the case of educational status of the patients, the maximum change in depression score was noticed for the school-educated group (-13.40) than the college-educated group (-0.86), which indicated an inverse relationship.

As far as the type of epilepsy is concerned, it was found that maximum reduction in depression score was for the LRE (-17.74). Regarding the duration of illness and change in depression score during the period of group intervention it was found that those patients with <15 years history of epilepsy had a better reduction in depression scores (-9.52) than patients with longer duration (> 15 years) of epilepsy group (-1.29).

While analyzing the seizure frequency and change in depression score among psycho-education group, it was found that those with frequent seizures (Engel's score 6) showed maximum reduction in average score (-17.74). The patients with less frequent seizures (Engel's score 5) showed a negative impact in depression score (5.57).

Regarding AED side effect and average depression scores, it was found reduction in scores was more for patients with AED side effect than those without AED side effect. Regarding the age at onset it was found that those with early onset of epilepsy the reduction in depression score was more (-10.79) when compared with late onset epilepsy (-4.51).

When comparing the patients from family with healthy atmosphere and unhealthy atmosphere it was found the reduction in depression score is higher among those with unhealthy family atmosphere.(-10.58) than those from healthy family atmosphere.

The result indicated that the average reduction in depression score was more among patients who are relatively older and the effect was negative for adolescent age group The school-educated patients <15 years history of epilepsy, patients with AED side effects, early age at onset of illness and patients from unhealthy family atmosphere there was more reduction in depression scores.

In a related study Becu et al., (1993) found that a self-help group approach with group psycho-therapy focusing on psycho-social difficulties and encouraging anticonvulsant compliance reduced depression scores. The findings of the study has greater significance in the light of the following observations made in this connection by different authors. Hermann et al., (1990) suggested that psycho-social factors are better predictors of depression than biological variables. Hermann et al., (1990) He found the attributional style for depression in epilepsy. More over the cognitive and behavioural model proposes that psychological disorders come from a misconceived or dysfunctional way of perceiving events influencing affection and behaviour (Beck et al.,1979). From the above findings and observations it can be inferred that psycho-educational support building program like this is effective in dealing with depression among patients with epilepsy mainly because of the educational and cognitive inputs.

4.3.3.3 State Anxiety

While analyzing the impact of age on change in the State-Anxiety scores through psycho-education, it was found that the state anxiety score showed more reduction (-13.08) among patients in the younger age group of (<20 years). Even though for the other two age groups there was reduction in score of state anxiety, the magnitude of change is comparatively lesser. Considering the gender of patients it was found that the males had better reduction of state anxiety score (-11.72) than the females (-1.19). Among the educational groups, the school educated group showed more reduction in score (-15.89) than the college-educated patients (-0.86). When the type of seizure was considered, the LRE group was found to have more reduction in state anxiety scores (-15.69) than GE (+1.03). From the results it can be seen that duration of epilepsy had no significant impact on the change in the score of state anxiety due to psycho education (Table 4.19).

For patients with higher seizure frequency (Engel score 6) the reduction in state anxiety score was more (-20.35) than those with Engel score <5. Anxiety score reduction was about 10 point more (-14.37) for those patients with AED side effect than for patients without AED side effects (-4.99). The effect of group intervention was more (-8.74) for those with late onset of seizures (<10 years) than early onset (>10 years). Regarding family atmosphere of patients those who reported unhealthy family atmosphere, the anxiety reduction was more following group intervention.

While analyzing the impact of age on change in the State Anxiety Scores through psycho-education, it was found that the State Anxiety Score showed more reduction among patients in the younger age group of (>20 years), male patients, patients with less education, LRE seizure type, high seizure frequency, patients with AED side effects, later age at onset of seizure, and patients from unhealthy family atmosphere. The results among different demographic and clinical variables it showed that psycho-educational session have made expected change in major areas which are more prone to cause psycho-social problems.

4.3.3.4 PSE- Depression / emotional reaction

In area of PSE- Depression / emotional reaction in EPSES, the reduction in score due to psycho-educational group intervention was more(-13.16) for adult age group (21-30) followed by (30+) age group. (Table. 4.19) Among the young adult group (<20) the change in scores were found to increase (8.44) indicating that it was difficult to change Depression or emotional reaction with 2 psycho-educational group interventions in this group. Considering the gender of the patients the reduction in PSE-Depression or emotional reaction score was slightly better for the males (-5.42.) than the females (1.14). Among the educational group the college-educated group showed more reduction in PSE-depression score (-3.96) than the school-educated group (-0.90).

Regarding the type of epilepsy the LRE group showed better reduction in scores (-16.94). The score for the GE were found to increase (10.05) during the intervention. Regarding duration of illness and effect in PSE - Depression or emotional reaction it was found that the PSE score reduced more for patients with relatively shorter duration of illness than chronic epilepsy group with more than 15 years history of epilepsy. Regarding seizure frequency patients with more frequent seizures (Engel's score 6) showed more reduction in scores (-5.08) than those with less frequent seizures (-0.29) It was also noticed that the reduction in average score was more for patients who reported a unhealthy family atmosphere.

In area of Depression or emotional reaction in EPSES, the reduction in score due to psycho-educational group intervention was more for adult age group (21-30) followed by (30+) age group. Male patients, higher educated patients, patients with shorter duration of epilepsy, LRE seizure type, patients with high seizure frequency and patients who reported unhealthy family atmosphere also showed reduction in scores indicating a positive change. From the above findings it can be inferred that patients with more psycho-social problems appeared to be more suseptible and receptive to psycho-educational intervention.

4.3.3.5 PSE- Feeling of increased social isolation

While analyzing the impact of different socio-demographic and clinical variables in the area of PSE – Feeling of increased social isolation the reduction in average score was found more for the patients in the adult age group (-13.16) than elder patients (-4.23). The scores showed an increase (+8.44) for the adolescent group (<20). This implies that it is difficult to effect desirable changes in the adolescent age group with two psycho-educational group interventions. Among the gender the reduction in score due to psycho-educational group intervention was more for the females (-6.99) than the males (-4.23). Among the two educational groups the effect was more (-9.97) for the school-educated group. The college-educated group the change was slightly negative indicating change in this group was difficult with those who have higher education (Table 4.19).

Among the type of epilepsy it was found that reduction in score was more for LRE group of patients (-16.64). In the GE group the score was found to increase indicating a negative change (+10.04). Regarding the impact of the seizure frequency in this area of PSE it was found that reduction in score due to psycho-educational group intervention was more (-17.33) for those patients who have a high seizure frequency. It is interesting to note that the scores were found to increase in patients who have lesser seizure frequency (+10.74). This again proves the hypothesis that the effectiveness of the psycho-educational group session has no bearing on seizure frequency. Regarding the impact of age at onset of seizure on score in this area of PSE, it was found to be slightly more for those who have early onset of seizure. It was also noticed that the reduction in score due to the psycho-educational group session was more for patients who reported unhealthy family atmosphere (-10.87). The patients who reported healthy family atmosphere the changes were not showing a negative effect (4.28). In the area of PSE – Feeling of increased social isolation the reduction in average score was found more for the patients in the adult age group, female patients, school-educated group, LRE seizure type, patients with high seizure frequency and patients from unhealthy family atmosphere.

4.3.3.6 PSE- Lethargy / lack of energy

In this area PSE it was found that all age group except the adolescent group(<20) years showed improvement in KAP. Positive changes were also noticed among males, school-educated patients, patients with LRE seizure type , patients with shorter duration

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of epilepsy, high seizure frequency patients, patients with early onset of seizures, and patients coming from unhealthy family atmosphere. These results showed that patients who are likely to develop more psycho-social problems are largely benefited by psycho-educational group intervention.

4.3.3.7 WPSIQOL

While analyzing the effect of psycho-educational group sessions in different age group of patients it was found that scores of WPSIQOL were improving for patients above 30 years followed by 21-30 year age group and <20 age group. It was also found that for males the difference in the scores of WPSIQOL was more, while it was slightly negative for females. However for the two educational groups, the differences of scores were positive and it was higher for college-educated group. Among the seizure types LRE group was found an increase in scores (10.72) and there was reduction in score (Table 4.19) for the GE groups (-3.89).

Patients with AED side effect, patients with late age at onset, patients having shorter duration of epilepsy and patients from unhealthy family atmosphere patients were also found to have improvement in score of WPSIQOL after attending two psycho-educational group sessions at three-months post intervention assessment. The score were also found to improve more for patients with high seizure frequency (Engel's scores 6 indicating that group sections are effective irrespective of seizure frequency. WPSIQOL were improving for patients above 30 years followed by 21-30 year age group and <20 age group. Improvement in QOL was also noticed for male patients, LRE seizure types, patients with AED side effect, late onset of seizure, shorter duration of epilepsy and patients coming from unhealthy family situations.

The above results are supported by the study conducted by Snead et al., (2004) regarding the development and initial implementation of a 6-week structured psycho-educational group intervention for adolescents with epilepsy and their parents. In pre intervention, the QOLIE:AD-48, Childhood Depression Inventory, and Revised Children's Manifest Anxiety Scale were administered. Post-intervention outcome measurement indicated an overall positive trend for quality of life improvement in the adolescents. There remains, however, a paucity of research on psycho-social interventions for adolescents with epilepsy.

4.3.3.8 QOLIE:31

4.3.3.8.1 QOLIE:31 - Energy / Fatigue

In this study age, sex, education, type of seizure, duration of illness, seizure frequency AED side effect, age at onset of seizure and nature of family atmosphere of patients were not found to have noticeable impact on the change in the score of Energy / fatigue area of QOLIE:31 due to psycho-education. Among the seizure type increase in QOL score (1.78) was found to improve slightly for the LRE group whereas the GE group showed a slighted reduction in score (-0.48). In the duration of illness and score in QOL improvement was for the shorter duration of illness. Regarding seizure frequency and QOL score it was found that improvement in score (2.78) was more for patient with frequent seizures. Patients with AED side effect showed better improvement than the patients without side effects (Table 4.19).

In a related study by Dijibuti et al., (2003) among 115 adult patents with epilepsy to identify the clinical, demographic, and socio-economic factors that are associated with a poor quality of life in patients with epilepsy in Georgia The variables that most strongly predicted a lower QOLIE:31 total score were a low education level, high seizure frequency, and long duration of epilepsy. The QOLIE:31 all sub-component scores correlated strongly with seizure frequency. Advanced age was a significant predictor for a low overall quality of life, Energy / fatigue, and cognitive scores. Female sex was the factor that significantly predicted a low seizure worry score. Education level strongly correlated with overall quality of life, and cognitive and social functioning scores.

4.3.3.8.2 QOLIE: 31- Medication effect

The different age groups, sex, educational difference, type of seizure, duration of illness, seizure frequency AED side effect, age at onset of seizure and nature of family atmosphere did not show any obvious impact in the change in the score of medication effect area of QOLIE:31 due to psycho-education.

4.3.3.8.3 QOLIE: 31 - Overall Score

A negative and statistically significant reduction in score was (-8.73) noticed in the adolescent age group in overall QOL. This group was followed by 21-30 age group(12.94) and patients with above 30 age (9.68). The age group that showed maximum positive and statistically significant change was the adult age, school - educated group also found to have a significant increase in scores on overall QOL (16.97), but the higher educated patients was found to have a reduction in score (-2.02), showing a reverse impact of education. This result indicated that when compared to person with less education it was difficult to change the attitude of people with higher education (Table 4.19).

Among the seizure type the LRE group was found to have improved their score more (11.61), but its impact on the change in the overall score due to psycho-education was not significant. In those with high seizure frequency the QOL score improved well with a statistically significant impact (12.36).

Those with AED side effect also found to have improved their overall QOL score (9.92) than the patients without side effect through psycho-educational group sessions and the changes were statistically significant. Regarding the age at onset and overall QOL significant positive changes were noticed for those with <10 years onset. Again those with unhealthy family atmosphere were found to have improved their scores (7.94) better than those with healthy family atmosphere.

The age group that showed maximum positive and statistically significant change QOLIE:31 overall score is the adult age group. The school-educated group also been found to have a significant increase in scores on overall QOL. In short, the patients with LRE seizure type, high seizure frequency, patients with AED side effects, early age at onset and patients from unhealthy family situations also showed increase in QOL following psycho-educational group sessions. These changes can be attributed to the result of increasing interpesonal and intrapersonal communication and mutual empowerment occuring in the group sections among the members and therapist.

The results obtained in the present study are supported by the results of the following related studies. Gunter et al.,(2005) conducted a study to evaluate the impact of a comprehensive, multifaceted disease management program on self-reported quality of life (QOL) for adult patients with epilepsy. Pre-post analysis utilizing paired t-tests was conducted to identify any pre-post differences in QOL for both the intervention and comparison group patients, as measured by the seven specific domains of the epilepsy QOL instrument (QOLIE:31). The intervention group patients showed statistically significant positive changes in two QOL domains: Seizure Worry ($p < 0.001$) and Emotional Well-being ($p < 0.05$). One other domain, Overall Quality of Life, showed improvement in the intervention group that approached statistical significance ($p < 0.06$). Helde et al.,(2005) conducted another study titled 'A structured, nurse-led intervention program improves quality of life in patients with epilepsy: a randomized, controlled trial' The study tested the hypothesis that structured epilepsy nursing improves quality of life (QOL). All patients completed the QOLIE:89 before randomization and after 2 years. QOL was significantly improved from inclusion to completion of study in the intervention group ($P=0.019$), mainly in the sub items for Health discouragement ($P=0.01$), Medication effects ($P=0.035$), and Physical role limitations ($P=0.05$).

Table 4.19

Average difference of score at three month from the score at pre intervention of the variables exhibit significant change during intervention (ANOVA) in psycho-education group among different socio demographic and clinical variables

Patient Characteristics		KAP	Dep	St Ax	PSE - Dep	PSE-iso	PSE-lack	WPSI	QOL - enf	QOL - mee	QOL-Overall
Age	<20	-1.52	4.95*	-13.08	0.49	8.44	2.32	0.98	-1.09	-0.56	-8.73*
	21-30	1.75	-8.21	-2.65	-6.41	-13.16	-32.62	3.51	1.96	1.19	12.94*
	30+	0.29	-10.53	-6.79	-2.41	-4.23	-18.23	4.58	0.87	0.61	9.68*
Sex	Male	0.55	-6.54	-11.72	-5.42	-6.99	-20.10	5.96	0.71	0.55	6.47*
	Female	0.17	-5.44	-1.19	1.14	1.88	-16.02	-0.14	0.57	0.35	5.08*
Education	School	0.09	-13.40	-15.89	-0.90	-9.97	-20.89	2.20	1.71	1.12	16.97*
	College	1.30	-0.86	-1.22	-3.96	1.47	0.19	4.28	-0.11	-0.01	-2.02*
Type	GRE	0.08	5.41	1.03	0.96	10.05*	-14.83	-3.89	-0.48	0.53	0.17
	LRE	1.38	-17.57	-15.69	-6.33	-16.64*	-30.13	10.72	1.78	0.40	11.61
Duration of illness	1-15	0.41	-9.51	-7.51	-3.95	-6.83	-20.28	7.05	1.35	0.55	5.94*
	16	0.06	-1.29	-7.08	-0.92	1.65	-11.58	-1.67	-0.32	0.35	5.82*
Engel Score	5	-0.08	5.57*	5.69	-0.29	10.74*	-3.54	-3.56	-1.48	0.30	-0.58
	6	0.56	-17.74*	-20.35	-5.08	-17.33*	-27.27	10.38	2.78	0.63	12.36
AED effect	Yes	-0.91	-7.60	-14.37	5.76	5.39	-18.35	0.06	1.24	0.56	9.92*
	No	1.50	-5.58	-4.99	-5.50	-6.19	-16.41	4.53	0.45	0.43	4.55*
Age at onset	<10	0.97	-10.79	-3.12	-5.27	-6.99	-23.36	8.68	1.80	0.83	6.89*
	10+	-0.38	-4.51	-8.74	-1.82	-2.06	-11.40	1.66	0.27	0.34	5.56*
Family atmosphere	Healthy	-0.31	-1.59	-2.93	0.34	4.28	-9.64	-1.95	-0.50	-0.02	3.84
	Not healthy	0.90	-10.58	-11.74	-5.71	-10.87	-25.12	8.78	1.80	0.95	7.94

* p value < 0.050(significant at 5 percent level)

Dep= Depression, St Anx = State Anxiety, PSE- Dep = Psycho-Social Effect –Depression, PSE –iso,= Psycho-Social Effect –Increased Feeling of Social Isolation, WPSI= Washington Psycho-Social Seizure Inventory, QOL-enf = QOLIE:31- Energy/ fatigue, QOL-mee=QOLIE:31 – Medication Effect, QOL-Overall = QOLIE:31 – Overall Score, LRE- Localization Related Epilepsy, GE- Generalized Epilepsy

CHAPTER - 5

SUMMARY AND CONCLUSIONS

CHAPTER - 5

SUMMARY AND CONCLUSIONS

Epilepsy was identified in mysticism and superstition from the ancient period. Communities of developing countries continue to perpetuate many myths and misconceptions about epilepsy and consequently deprive patients of bonafide treatment. Epilepsy proved itself detrimental not only to the patients but also to their families and community. For patients with epilepsy, fear, misconceptions, social stigma and negative attitudes of the partially informed society are more disabling than the seizures.

Epilepsy is a chronic brain disorder characterized by recurrent unprovoked epileptic seizures, which affects people of all ages. A seizure is caused by a transient excessive and abnormal electrical discharge of nerve cells.

5.1 Need for study

Psycho-educational group sessions and Yoga-Meditation are important additional supportive methods practised in the Comprehensive Centre for Epilepsy Care, Department of Neurology, SCTIMST, Thiruvananthapuram. A scientific evaluation of the effect of psycho-education on patients with epilepsy still remains unaddressed in the field of research related to psycho-social aspects of epilepsy. Knowledge about the relationship of psychosocial and demographic characteristics on the effects of psycho-education group is another unexplored area in epilepsy research.

The present prospective, randomized study attempts to evaluate scientifically the psycho-social outcome of the psycho-educational group sessions and meditation on patients with epilepsy using an experimental research design with two experimental groups (Group Intervention and Meditation) and a control group. A detailed analysis was also conducted on the impact of psycho-social and demographic characteristics of the patients in the effect of psycho-education and yoga meditation.

5.2 Statement of the topic

The topic of the study is entitled : "Efficacy of group interventions in the psycho-social care of patients with epilepsy".

5.3 Objectives of the study

1. To translate and validate a Malayalam version of Epilepsy Psycho-Social Effect Scale (EPSES developed by Chaplin-1990) and to use the scale among patients who attend the group intervention programs.
2. To translate and validate a Malayalam version of Quality of Life in Epilepsy Inventory (QOLIE-31, Version 1.0), developed by Cramer (1993).
3. To prepare counseling / training module for conducting the group sessions for patients with epilepsy.
4. To find out the effectiveness of the group intervention among different types of patient groups with epilepsy.
5. To find out whether the effectiveness of the group sessions has got any impact, if the seizures are controlled with medicines or remain intractable.
6. To assess the quality of life of patients who are attending the group sessions
7. To evaluate the present method of conducting the group sessions and to explore possibility of improving its practice.

5.4 Hypothesis

1. Quality of life of the patients who are attending the group sessions are more when compared to those who are not attending the group sessions.
2. The more the number of times a patient attend group sessions the more will be the quality of life.
3. Intervention is effective irrespective of whether seizures are controlled or continue to be intractable.

5.5 Methodology

In the present study, the outcome of the psycho-education sessions for patients with epilepsy and their family members are evaluated using various psycho-social scales / inventories from a research design with two experimental groups (Psycho-education and Meditation) and a Control group.

The present study can be divided into two. The first part of the work is Malayalam translation and standardization of Epilepsy Psycho-Social Effect Scale and Quality of Life in Epilepsy Inventory (QOLIE:31) involving 440 patients (220 for each scale). The second part consists of evaluation of the efficacy of the two interventions (psycho-education and meditation) in the psycho-social status and quality of life of patients with epilepsy by a pre-post design using two experimental groups and a common control group. The experimental study was conducted on 36 subjects: 12 subject each in the psycho-education, meditation and control groups.

5.6 Pilot Study

A pilot study was conducted among 20 patients with an established diagnosis of epilepsy who attended the epilepsy clinic of SCTIMST. The interview schedule was then modified after analyzing the results of the pilot study.

The Epilepsy Counseling / Training Module developed by the investigator was used for comprehensively educating the patents and their family members of the psycho-educational group. The patients in the meditation and control group were not given any educational intervention .

5.7 Sample for the study

The sample of the study was selected from the epilepsy clinic of R Madhavan Nayar Centre for Comprehensive Epilepsy Care, SCTIMST,Thiruvanathapuram. The inclusion criteria were (1) Patients registered and diagnosed with epilepsy, (2) patients in the age group between 16 to 35, (3) patients belonging to Thiruvananthapuram District (4) patients with a minimum of two seizures during the past one year. The patients who have attended the psycho-educational group session or meditation earlier, patients with mental retardation, patients with other chronic physical illness and patients with major psychiatric illness were excluded from this study.

5.8 Tools used

The various psycho-social parameters of the three study groups namely, the psycho-education, the meditation and the control were assessed using the following scales / inventories.

KAP - Knowledge Attitude and Practice Questionnaire

(Radhakrishanan & Jayachandran 1995).

Depression Inventory (Kumar and Kumar 2002).

STAI - State -Trait Anxiety Inventory (Mohandas & Kumar, 1994).

Self - Esteem inventory (Thomas & Raj ,1990).

(IE) Scale - Locus of Control (Kumar & Immanuel, 1992).

EPSES - Epilepsy Psycho-Social Effect Scale (Chaplin 1990).

(Translated and standardized as part of this research).

WPSIQOL – Washington Psycho-Social Seizure Inventory, Dodrill, 1988.

(Malayalam adaptation Thomas, 1977).

QOLIE:31 - Quality of life in Epilepsy Inventory (Cramer 1993).

(Translated and standardized as part of this research).

Of the eight tools, six were developed / standardized by different authors. Two scales viz. The Epilepsy Psycho-Social Effect Scale (EPSES) and Quality of Life in Epilepsy Inventory (QOLIE: 31) were translated into Malayalam and standardized by the investigator. The reliability and validity these scales were found out using appropriate standardization procedures.

5.9 Variables

The social and demographic characteristics of the patients analyzed in this study include age, sex, religion, education, occupation, marital status, type of family, number of family members, place of residence and atmosphere in the family. Type of seizure, disabling effect of AED, age at onset of the first seizure, family history of seizure disorder, seizure type, time of occurrence of seizure, duration of illness, number of seizure during last one year are taken as the clinical characteristics of the patients. Knowledge Attitude Practice, Depression, State Anxiety, Trait anxiety, Total anxiety, Self- esteem, Locus of control, Quality of Life (7 Components) and Epilepsy Psycho-Social Effect (14 components) are taken as dependent variables.

5.10 Administration of tools

The respondents selected for the experimental study consisting of 36 patients were called for a meeting on a pre-scheduled day and were randomized into three groups of 12 patients each for psycho-education, meditation and control. The randomization was done using the Lottery Method of random sampling. Patients in the control group were informed that they were in the waiting list for both the intervention programs (psycho-education and meditation).

The pre-assessment (baseline) of all the patients was done on the day of the first gathering. The patients and their family members were interviewed by the investigator personally and collected relevant personal and family information with the help of a pre-tested structured interview schedule. The instructions for filling the scales and inventories were separately given to each patient. During the post-assessment after 3 months and 6 months the data collection was done separately for each group. The expiremental study was conducted during six months period from May 2004 to November 2004,

5.11 Consolidation of data

The relevant data from the subjects using the structured interview schedules and the eight scales / inventories were entered and processed with the help of a personal computer. The data was analysed using suitable statistical tools.

5.12 Statistical technique used

The important statistical techniques used in the present study were descriptive statistics, ANOVA, ANCOVA and Linear Multiple Regression Analysis.

5.13 Method of analysis

Changes in the scores of the scales/inventories were noted at three different times namely before the intervention (baseline), at three months and six months after intervention. One-way ANOVA was used for assessing the changes in the scores of scales/inventories of the three groups independently as a preliminary analysis. Since the sample size of the groups was not sufficiently large, the absolute change in the scores of the scales/inventories of psycho -education and meditation groups were studied by comparing with that of the control group at pre-assessment and at three months and six months using ANCOVA, ANCOVA which measures, the difference of scores at two different point of time after adjusting for the initial differences. Multiple Regression analysis was done to find out the impact of socio-demographic and clinical characteristics of the patients in the scores of psycho- social parameters, which showed significant change during (ANOVA) and due to (ANCOVA) intervention.

5.14. Objective-wise findings

The **first** objective of the study was to translate and validate a Malayalam version of Epilepsy Psycho-Social Effect Scale (developed by Chaplin-1990) and to use the scale among patients who attended the group intervention programs. The EPSES scale in English was translated it into Malayalam and cross-culturally validated by the investigator using appropriate standardization procedure. The Malayalam weightages of the forty-two items of the scale were found out following the method used while developing the original scale. Average overall reliability score for the whole questionnaire was found to be 0.85 and that of the original scale was 0.64. Malayalam version of the scale was validated against the original English version of EPSES where the original English version was taken as the 'Gold Standard'. This revealed an overall mean validity for the scale as 0.38, which was comparable to that of the original English version. The scale in Malayalam is now available for use for clinical and research purposes (Ref. Appendix). The scale with Malayalam weightages was used among the patients who attended the group intervention programs (Psycho-education and Meditation) in this research work to find out the efficacy of group intervention in psycho-social care of patients with epilepsy.

The **second** objective was to translate and validate a Malayalam version of Quality of Life in Epilepsy Inventory (QOLIE:31 Version 1.0) developed by Cramer (1993). The QOLIE:31 which contains 31 question was also translated and standardized in Malayalam language by the investigator. The reliability was found out by a test- retest procedure. The overall reliability was found to be 0.84. The translation and cross-cultural validation showed significant validity of 0.93 comparable to that of original English version of the Inventory. The Malayalam scale now containing 30 questions after standardization is available for clinical and research purposes (Ref. Appendix). This Malayalam version of QOLIE-31scale was used among the patients who attended the group intervention programs (Psycho-education and Meditation) in this experimental research work to find out the change in QOL.

To prepare Counseling / Training Module for conducting the group sessions for patients with epilepsy was the **third** objective of the study. The investigator prepared an

Epilepsy Counseling / Training Module in English and Malayalam languages for epilepsy education. The module consists of medical and psycho-social aspects of epilepsy. This module prepared in Malayalam and English, as part of this research is now available for epilepsy education / epilepsy training (Ref. Appendix).

The **fourth** objective of the study was to find out the effectiveness of the group intervention among different types of patient groups with epilepsy. In order to cover this objective, the analysis of the experimental study was mainly divided into two parts. The first part consists of identifying the psycho-social parameters of patients with epilepsy which exhibited significant change during (ANOVA) and due to (ANCOVA) intervention. The second part consists of studying the impact of socio-demographic and clinical characteristics of patients. The details of the changes observed due to and during psycho-educational group intervention amoung different types of patient groups are given here **(5.15 to 5.19).**

5.15 Change in scores of psycho-social parameters during intervention (ANOVA)

Changes in the scores of psycho-social parameters during intervention were found out through ANOVA. It was found that for psycho-education group, KAP of patients about their disorder and WPSI increased significantly during the period of study. A significant reduction in depression and state anxiety scale was also noticed. But no significant change was observed in meditation group and control groups. (Ref. Table 4.1, 4.2 & 4.3). The positive changes observed in the psycho-education group can be attributed as the desirable effect of the intervention.

In EPSES - Depression / emotional reaction, PSE Lethargy / lack of energy and PSE - Feeling of increased social isolation were found to reduce significantly over the study period.The reduction in scores observed in the above components of PSE was also the desirable effect of the intervention. Here also there was no statistically significant change in meditation group and control group probably because of the lack of additional cognitive inputs in these two groups (Ref. Table 4.6)

A significant increase in WPSIQOL score was found during the study period.(Ref 4.7). In QOLIE:31 - Overall QOL, Energy / fatigue, Medication effect and Overall total score increased significantly among psycho-education group (Ref. Table 4.8) The increase in scores observed in the psycho-education group probably are the desirable effect of the intervention. The increase in KAP, reduction in state anxiety and depression scores following psycho-educational group intervention can be attributed to the effect of mutal empowerment and social support following psycho-education. But in meditation group and control group there was no significant changes in any of the areas of QOLIE: 31 Scale or anyother variables tested.

5.16. Change in scores of psycho-social parameters due to intervention (ANCOVA)

Changes in the scores of psycho-social parameters due intervention were found out through ANCOVA. As compared to the control group, psycho-education group shows a significant increase in their KAP score from three months onwards. The intervention was found to have a stable and sustainable effect as the score of KAP was significantly higher at six months also (Ref. Table 4.9).

In the case of self-esteem, as compared to the control group the score was found to be significantly higher and stable change at three months, but the effect could not be sustained at six months. Similarly the score for IE scale also exhibited a significant increase and stable change at three months and failed to retain the effect at six months indicating that the effect was stable but not sustainable. Even though the scores of trait anxiety and total anxiety did not show any significant change at three months, they exhibited a significant and sustainable reduction at six months, when compared to the control group. In PSE, the score of Fear of stigma of employment and Lethargy / lack of energy were found to reduce significantly at six months. Similarly in QOLIE:31 the score of Medication effect was found to show significant increase at six months. The result indicated a sustainable effect in two areas of PSE and one area in QOLIE-31.

In the case of meditation group **trait anxiety** and **total anxiety** scores were significantly reduced by the meditation intervention. Trait anxiety reduced significantly from three months onwards, but total anxiety significantly reduced only at six months. The significant changes in trait anxiety was stable and total anxiety in meditation group was both stable and sustainable.

5.17 Impact of socio-demographic and clinical characteristics on psycho-social parameters

Effect of socio-demographic characteristics on the change in the selected variables was studied by Multiple Regression Analysis taking the difference in scores between three months after intervention and pre intervention (baseline). The independent variables selected for the analysis were : Age, Sex, Education Type of epilepsy, and Duration of illness, Engel's score (seizure frequency), AED effect and age at onset of seizure. In the case of psycho-education group 17 variables exhibited desirable changes in scores either in ANOVA or ANCOVA or in both and in meditation group two variables (Trait Anxiety and Total Anxiety) were found to exhibit change in a similar manner.

Knowledge Attitude Practice and PSE- lethargy / lack of energy were the variables which showed significant change both during and due to intervention among Psycho-education group.

The estimated difference in the scores of selected variables using Multiple Regression Analysis regarding Knowledge Attitude Practice and PSE- lethargy / lack of energy are presented here.

The age group 21-30 got the maximum positive changes in KAP scores. The score was higher among males than females. The positive changes were also noticed for the school-educated group, LRE patients, patients with controlled seizure frequency, those without AED side effects and patients whose epilepsy started early age at onset, easily changed with two psycho-educational groups sessions. As far as the gender of the patients was concerned, the KAP did not differ much among males and females and both the groups maintained a positive change. Among the different educational groups maximum positive change in KAP was noticed among the school-educated group. This indicated that the psycho-educational sessions were more effective among patients without higher education.

While analyzing the type of epilepsy and KAP changes among different seizure types, it was noticed that patients with LRE got the maximum benefit than the GE group. Regarding seizure frequency of the patients and KAP it was found that the controlled epilepsy and uncontrolled epilepsy group as per Engel's score did not differ much. Among those patients with or without disabling side effects of AED it was found that those patients with disabling side effects did not change their KAP with two psycho-educational group sessions. There was a positive change among those patients whose first epilepsy started before 10 years when compared to patients with relatively late onset of epilepsy. While analyzing the KAP changes in the type of family atmosphere those with unhealthy family atmosphere were found to make more positive changes after two group sessions than those with healthy family atmosphere.

Regression analysis in this area of PSE- Lack of energy/lethargy in different age groups showed that patients in the age group 21-30 got the maximum desirable effect followed by patients in the age group (30+). Patients in the age group of less than 20 found to have negative impact by psycho-education. Gender-wise analysis showed that Lack of energy/lethargy was considerably reduced among males than females. Among the different educational categories, patients with school-education showed maximum improvement in the score of PSE- Lack of energy / lethargy.

Among the two different seizure types patients with LRE was found to be more benefited from psycho education than patients with GE. Regarding the duration of illness and change in PSE it was found that those with less than 15 years history of epilepsy were more benefited than those with more than 15 years duration of epilepsy. In the case of seizure frequency patients with more frequent seizure (Engel's score 6) was more benefited by the group session in changing the scores of PSE. While analyzing the AED effect it was found that group sessions has reduced more Lack of energy/ lethargy in patients with AED side effects than patients without AED side effect. In the case of age at onset it was found that group sessions are more effective for patients who had early onset of seizures (<10years) than patients who had relatively late onset of epilepsy (>10). Regarding family atmosphere and benefit of group session on PSE it was found that those with unhealthy family atmosphere were more benefited than patients from healthy family atmosphere.

5.18 Variables found significant change in ANCOVA in psycho-education

Trait anxiety, Total anxiety, PSE- Fear of stigma of employment, and PSE Self - esteem and KAP are the variables of psycho-education group, which showed significant change due to intervention among psycho-education group.

Regression analysis showed that among the patients with different age groups, the maximum reduction of trait anxiety score was among the adolescent group (<20 years). In sex-wise analysis males showed more reduction in trait anxiety due to the effect of psycho-education. Where education is concerned, patients with school - education showed better improvement than patients with college - education. Regarding the seizure types it was found that there was more reduction of trait anxiety scores among the LRE group than the GE group. While analyzing the duration of epilepsy and change in the scores due to psycho-education it was observed that the change was more among the chronic illness group (>15 years) than less chronic group. The reduction of trait anxiety score was also more among patients with AED side effects, late age at onset of seizure (10+ years) and unhealthy family atmosphere (Table 4.17).

Regression analysis in total anxiety score which was the sum of state and trait anxiety scores, it was observed that there was considerable reduction in total anxiety among patients in the adolescent age group, among male gender, school educated patients, those who had LRE type, patients with chronic epilepsy, who had more frequent seizure (Engel score 6), with AED side effect, with late onset seizure and patients who had unhealthy family atmosphere. In short, it can be seen that patients who tend to have to have maximum psycho-social problems were benefited by the psycho-educational intervention in reducing trait and total anxiety scores.

While studying the effect of psycho-education in PSE- Fear of stigma of employment in EPSES it was found that the maximum reduction of score was for patients in the age group (21-30). The score was also higher among males and school educated. Patients with LRE type, patients with high seizure frequency and patients with early onset of seizure were also included in better-achieved groups. The changes in the scores with these characteristics of the patients were found to be statistically significant. It was also found that scores of patients from unhealthy family atmosphere changed more than that from healthy family atmosphere. The results revealed all the socio-demographic and clinical characteristics, which were prone to create more psycho-social problems, were positively gained by the effect of psycho-educational group interventions.

The relationship of the various demographic and clinical variables and self-esteem were analyzed using regression. It was found that the adolescent age group made a negative effect in the area of self-esteem (-9.81). The maximum positive change in self –esteem was made by the age group 21-30. The males made more improvement than the females. Improvements in self-esteem were also made by following groups of patients viz.school educated group (17.21), LRE seizure type (10.09), patients with shorter duration of epilepsy (1-15 years), more frequent epilepsy group(Engel score 6), those without AED side effects, early age at onset seizure group (<10 years) and patients with unhealthy family atmosphere (Table 4.17)

The regression analysis of IE scale revealed that all the patients irrespective of their age group showed improvement. Males made better improvement than females. Among the educational groups the school-educated group made better improvement than the college-educated group. Among the seizure types the GE group made better improvement than the LRE group, The different groups in the areas like duration of epilepsy, the seizure frequency, AED side effects, and age at onset of seizure did not make any significant difference in change in the locus of control, but all the group made uniform improvement irrespective of the differences in the groups. The change in locus of control towards internal was more among patients who reported unhealthy family atmosphere than those with healthy atmosphere and the changes were statistically significant.

In QOLIE:31-Medication effect, the different age groups, sex, educational difference, type of seizure, duration of illness, seizure frequency, AED side effect, age at onset of seizure and nature of family atmosphere were found not to make noticeable change in medication effect area of QOLIE:31.

In QOLIE:31- Overall Score, a negative and statistically significant effect was noticed in the adolescent age group. The age group which was benefited with maximum positive and statistically significant change (12.95) was the adult age group (21-30) followed by above 30 age group. The school-educated group again found to have a significant effect on overall QOL(16.97), but the higher education was found to have a negative effect which is also significant. Among the seizure type the LRE group was found to have benefited well (11.61). Those with high seizure frequency were benefited well with a statistically significant change (12.36). Those with AED side effect also found to have positively benefited by group sessions and the changes were statistically significant. Regarding the age at onset and overall QOL significant positive changes were noticed for those with <10 years onset. Again those with unhealthy family atmosphere were found to have benefited better than those with healthy family atmosphere (Ref.Table 4.17).

5.19 Variables found significant in ANOVA only in psycho-education (Regression Analysis)

The study could identify 9 areas of significant positive change during intervention (ANOVA). The areas are KAP, Depression, State anxiety, PSE- depression / emotional reaction, PSE - feeling of increased social isolation, PSE, lethargy / Lack of energy, WPSIQOL and QOLIE:31- Overall QOL, QOLIE-31 Energy / fatigue, QOLIE-31-Medication effect. The estimated difference in the scores of selected variables using multiple regression analysis is presented in Table 4.19.

5.20 Variable found significant in meditation (ANCOVA)

Trait anxiety and Total anxiety were the variables which showed significant change due to intervention among Meditation group. The regression analysis of the data of the meditation group revealed significant positive changes in trait and total anxiety in state trait anxiety scale. The reduction in strait anxiety scores were more evident in 21-30 age group (-9.73), male sex (-10.69), less seizure frequency (-15.27), patients with AED side effects (-6.89), patients with late seizure onset (-7.06) and patients who reported unhealthy family atmosphere (-8.22).

In the total anxiety the maximum reduction in scores was found in the age group 21-30 (-35.47), male patients (27.03), school-educated group(-11.78), GE,1-15 years history of epilepsy (-20.42), patients with less frequent seizures(-45.42), with AED side effect, late onset of epilepsy(-16.00) and patients with unhealthy family atmosphere. Here it is worth noting that people with less frequent seizures were more benefited than those more frequent seizures. This observation in meditation group was contradictory to the findings in psycho-educational group. The effect of meditation was more for person without AED side effects where as in psycho-educational group the improvement was for persons with AED side effects.

The **fifth** objective of the study was to find out whether the group sessions have got any impact, if the seizures are controlled with medicines or remain intractable -

From the the result of ANCOVA, it was evident that the average reduction of trait anxiety was found to be more (-11.91) for patients with difficult to control seizures than those with relatively controlled seizure patients (+3.42). Similar results were obtained in the case of all the other variables like trait anxiety, total anxiety, EPSES - Fear of stigma of employment and Lack of Energy / lethargy and self – esteem and internal - external locus of control (IE) and KAP which got significant reduction and stable change at three months in the ANCOVA. From ANOVA it was found that those with frequent seizures (Engel's score 6) showed maximum reduction in average score (-17.74). The patients with less frequent seizures (Engel's score 5) showed a negative impact in depression score (5.57). Similar results were obtained among other variables like state anxiety, EPSE (subscales): Depression / emotional reaction and social isolation, WPSI, and QOLIE:31 (subscales): Energy / fatigue and Medication effect were showed significant change among patients who attended psycho-educational sessions. (Table Nos 4.17 and 4.19).

In the YM Group, contrary to the observations in psycho-educational group sessions, the patients with lesser seizure frequency (-15.27) showed reduction in trait anxiety through YM whereas the change in score for patients with high seizure frequency was+ 2.62, showing a negative effect with an increase in trait anxiety scores. In total anxiety also changes in score obtained for patients with less frequent seizures were more (-45.42) and the score for persons with more frequent seizure was +12.58.(Table.No.4.18).

To assess the quality of life of patients who are attending the group sessions was the **sixth** objective of the study. Considering the growing importance in quality of life assessment in outcome evaluation studies two scales (WPSIQOL and QOLIE:31) were used in this research study. The assessment of QOL was done as baseline before intervention and after three months and Six months after initial intervention. The results obtained were compared with Meditation group and Control group during the same time intervals.

The **seventh** and the final objective was to evaluate the present method of conducting the group sessions and to explore possibility of improving its practice.

In both ANCOVA and ANOVA analysis there were 17 variables, which showed either stable and or sustainable positive effect following psycho-education. Among the rest of variables the changes were neither stable nor sustainable (Ref. Table. 4.14, 4.15, and 4.16). These results points to the need for the following changes in the present method of conducting the psycho-educational sessions.

1. Increasing the number of psycho-educational sessions for each patient with epilepsy and their family members.
2. Combining psycho-educational sessions with yoga-meditation as YM has proved to effect stable and sustainable reduction in trait and total anxiety and showed changing positive trend in many other areas assessed (Ref.Table 4.11 (Self esteem), Table 4.12 (IE scale) and Table. 4.13 (state and trait anxiety).
3. In addition to psycho-education and meditation, additional therapeutic inputs like individual counseling, psychotherapy, participation in self-help group programs, assertive training, and referral to appropriate centres are also suggested for patients with deeper psycho-social problems. Patients with deeper psycho-social problems can be easily identified during the psycho-educational sessions facilitating active intervention and appropriate reference. Separate groups for patients with identical or deeper psycho-social problems (Eg. Patients with intractable epilepsy, women with epilepsy, patients from unhealthy family atmosphere) can also be planned suitably targeting such vulnerable groups.

The **first** hypothesis of the study was that the Quality of Life of the patients who are attending the group sessions are more when compared to those who are not attending the group sessions. The Quality of life assessment using WPSIQOL and QOLIE:31of the psycho-education group patients showed better quality of life than the meditation and control group patients (who did not attend psycho-educational groups). The result showed that in all the areas which are not significant also showed improvement during assessment at three months and six months when compared to score of the baseline of the psycho-education groups of patients (Ref. Fig. 4.7, 4.8, 4.09, 4.16 and Tables. 4.7, 4.8, 4.15 and 4.16). These findings prove the hypothesis that quality of life of patients who are attending the group sessions are better when compared to those who are not attending the sessions

The **second** hypothesis was that the more the number of times a patient attend group sessions the more will be the quality of life. The assessment of Quality of life of the psycho-educational group with WPSIQOL and QOLIE:31 showed improvement from the baseline at three months(two psycho-educational sessions) and at six months (three psycho-educational sessions) indicating that the more the number times a patient attend sessions the more will be the quality of life (Ref. Fig . 4.7,4.8,4.09 and 4.16 and Table. 4.7, 4.8, 4.15 and 4.16) and thereby proving the hypothesis.

The **third** hypothesis was that the Intervention is effective irrespective of whether seizures are controlled or continue to be intractable. In the ANCOVA the average reduction of trait anxiety was found to be more (-11.91) for patients with difficult to control seizures than those with relatively controlled seizure patients (+3.42). Similar results were obtained in the case of all the other variables like total anxiety, psycho-social effect scale - fear of stigma of employment and lack of energy / lethargy and self – esteem and internal - external locus of control (IE) and KAP which got significant and stable changes at three months in the ANCOVA. In ANOVA while analyzing the seizure frequency and change in depression score among psycho education group, it was found that those with frequent seizures (Engel's score 6) showed maximum reduction in average score (-17.74). The patients with less frequent seizures (Engel's score 5) showed a negative impact in depression score (5.57). A similar results were obtained among other variables like state anxiety, EPSE (subscales) : Depression / emotional reaction and Feeling social isolation, WPSI, and QOLIE:31 (subscales):Energy fatigue and Medication effect were showed significant change among patients who attended psycho-educational sessions. (Ref. Table 4.17 and 4.19). The above results support and substantiate the hypothesis that psycho-educational interventions are effective even if the seizures continued to be uncontrolled or intractable. The results are in a reverse direction in the meditation group (Ref.Table.18), further validate the hypothesis.

5.21 Limitations of the study

The major limitation of the study is its small sample size. In an experimental group research design like this, The other limitation is that patients were selected only from a tertiary referral centre from Thiruvanathapuram district of Kerala State as the facilities and human resource for conducting both psycho-education sessions and meditation were available only in this centre at present.

5.22 Suggestions for further research

1. Further studies using larger sample are needed before broader, more conclusive generalizations can be made.
2. A long-term follow up of the sustainability of the effect of psycho-education and assessment of the cost effectiveness of the programs (both psycho-education and meditation) will be a matter of interest for Health Economists.
3. A medical treatment outcome evaluation regarding compliance with medication (with AED blood level) and seizure frequency following participation in psycho-educational program, preferably involving a Medical Neurologist / Psychiatrist.

4. A follow-up outcome study with cross over design combining both psycho - education and meditation interventions.
5. Even though many results in both the experimental groups were not significant many variables showed a changing trend towards desirable effect, which need further evaluation involving more number of patients.
6. A similar study can be conducted among the family members attending the psycho-educational sessions regarding the changes in the family affect, support of autonomy to patients, parents KAP of epilepsy, parents Anxiety, depression and quality of life following participation attendance psycho-educational interventions.

The results of such studies will provide theoretical directions and empirical justification for group based and family based supportive treatment programs like psycho-education and yoga-meditation and need for incorporation of additional psychotherapeutic methods for efficiently handling the psycho-social problems thereby filling a critical treatment gap in the bio-psycho-social care of patients with epilepsy.

5.23 Conclusions

1. The study could validate and standardize two epilepsy specific scale/ inventories namely the Epilepsy Psycho-Social Effect Scale (EPSES) and Quality of Life in Epilepsy Inventory (QOLIE:31) in Malayalam language with significant reliability and validity comparable to that of the original English version.
2. The study has helped in preparing a Counseling / Training Module in Malayalam and English suitable for comprehensive epilepsy education / training.
3. The study could identify 8 areas which exhibited significant effect due to psycho-educational intervention (ANCOVA). The areas which showed significant positive

changes were KAP, Self – esteem, Internal Locus of control, Trait anxiety, Total anxiety, PSE- Fear of stigma of employment, PSE- Lack of energy/lethargy QOLIE:31- Medication effect.

6. The study could identify 9 areas of significant positive change during intervention (ANOVA). The areas are KAP, Depression, State anxiety, PSE Depression / emotional Increased PSE - Feeling of increased social isolotion, PSE - Lack of energy / lethargy, WPSIQOL and QOLIE:31- Overall QOL, QOLIE-31 Energy / fatigue, QOLIE-31- Medication effect.
7. The study could prove the hypothesis that quality of life of the patients who are attending the group sessions are better when compared to those who are not attending the group sessions.
8. The study also could prove the second hypothesis that the more the number of times a patient attend group sessions the better will be the quality of life.
9. The study proved with substantial evidence to support the third hypothesis that psycho-social Intervention is effective irrespective of whether seizures are controlled or continue to be intractable.
10. A major contribution of the study is the significant reduction found in Trait and Total anxiety of the patients participated in the Yoga - Meditation group. It is encouraging to note that the psycho-education group also recorded similar reduction in Trait and Total anxiety.

In short, The study revealed the efficacy of the both intervention techniques used - psycho-education and meditation in psycho-social care of Patients with epilepsy. However psycho-education is found to be more effective in dealing with these problems of patients with epilepsy. The meditation group recorded significant reduction both in trait anxiety and total anxiety, which also is a major finding of the study. The efficacy of psycho- educational and meditation technique will have wider application in epilepsy care and such interventions can be considered for other similar / chronic diseases, to reduce the increasing burden of such diseases to the individual, family and community.

5.24 Suggestions

Many patients and family have deficits in their knowledge, attitude and practice, and have psycho-social and emotional problems mainly because of stigma, misconceptions and restrictions due to their epilepsy. Psycho-education is an effective component of comprehensive epilepsy care in improving knowledge and active coping with epilepsy. The participants of the psycho-education and meditation programs evaluated the program positively and they proposed to extend such programs to more patients of other districts Considering the growing information needs of patients with epilepsy and their family members and prevailing psycho-social problems, psycho-education and meditation program should become standard service in all epilepsy clinics to tackle these problems efficiently, effectively and to bring them into the main stream of social life. The psycho-education and Yoga- Meditation methods can be extended for other areas of health care management especially among patients with chronic diseases.

Considering the increasing importance of group interventions globally as a **cost effective** and **developmental approach** and with proven efficacy in handling various psycho-social issues among patients with epilepsy, group interventions should become part of **Curriculum** in Social and Behavioural Sciences and related Health Sciences.

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APPENDICES

CONSENT FORM

We .... (Name and address of the patient and parent) understand that we will be participating in a study on the group intervention / yoga meditation program for epilepsy. We are at free will to continue or else leave the program at any time during the study. The investigator of the study has fully explained to us the nature and need for the study and its requirements. I am voluntarily participating in this study and express my willingness to cooperate with the requirements of the study

Signature	Signature
Name of the patient	Name of the parent / Guardian

Place :

Date :

<u>സമ്മതപത്രം</u>

ഗ്രൂപ്പ് തെറാപ്പി / യോഗാ മെഡിറ്റേഷൻ പഠനപരിപാടിയിൽ ഞങ്ങൾ .... (രോഗിയുടെയും ബന്ധുവിന്റേയും പേരും അഡ്രസ്സും) പങ്കെടുക്കുവാൻ താല്പര്യപ്പെടുന്നു. ഈ പരിപാടിയുടെ ഉദ്ദേശ്യവും ലക്ഷ്യവും മറ്റ് നിർദ്ദേശങ്ങളും ഞങ്ങളെ പറഞ്ഞ് ബോദ്ധ്യപ്പെടുത്തിയിട്ടുള്ളതാണ്. ഈ പരിപാടിയുടെ ഏതു ഘട്ടത്തിൽ നിന്നും പിന്മാറാനുള്ള സ്വാതന്ത്ര്യം ഞങ്ങൾക്കുണ്ടെന്ന് മനസ്സിലാക്കുന്നു. ഈ പരിപാടിയിൽ പൂർണ്ണ മനസ്സോടെ സ്വമേധയായാണ് ഞങ്ങൾ പങ്കെടുക്കുന്നത്.

ഒപ്പ്	ഒപ്പ്
രക്ഷകർത്താവിന്റെ പേര്	രോഗിയുടെ പേര്.

തീയതി :

സ്ഥലം :

EFFICACY OF GROUP INTERVENTION IN THE PSYCHO-SOCIAL CARE OF PATIENTS WITH EPILEPSY
INTERVIEW SCHEDULE

Name

Sl.No................................ Date...

Date of registration................. Income Category...........................

Diagnosis ....

SCTIMST Hospital No. ☐☐☐☐☐☐☐

Address

Phone Number ☐☐☐☐☐☐☐

Age (Years) ☐ Male ☐ Female ☐

Religion: Christian / Hindu / Muslim

Education: Illiterate/Primary / Secondary / Metric / Hg.Sec / College / PG / Professional / Technical

Profession: Student / Unemployed / Manual / Business / Office / Professional / Technical / Others

Physical Disability:	Totally Independent	Yes	No
	Requires some help	Yes	No
	Requires considerable help in activities of daily life	Yes	No
	Wheel chair bound	Yes	No

Marital Status: Married/Unmarried/Separated/Divorced

Type of family: Nuclear/Extended/Joint

Number of members in the family:...

Place of residence : Panchayat/ Corporation / Municipality

Education of father : Illiterate/ Primary/Secondary/ Metric/Hg.Sec/College/PG/Professional/ Technical

Occupation of father : Unemployed/Manual/Business/Office/Professional/Technical/Others

Education of mother : Illiterate/ Primary/Secondary/Metric/Hg.Sec/College/PG/Professional/ Technical

Occupation of mother : Unemployed/Manual/Business/Office/Professional/Technical/Others

Education of the caregiver: Iliterate/Primary/Secondary/Metric/Hg.Sec/College/PG/Professional/ Technical
(If it is other than father or mother)

Occupation of the caregiver : Unemployed/Manual/Business/Office/Professional/Technical/Others
(If it is other than father or mother)

Attitude of the care giver/ significant family members towards the patient:

Overprotected ○

Rejected ○

Hostile ○

Overcritical ○

Supportive ○

Attitude of the patient towards the caregiver / significant family member : Healthy / Unhealthy

Atmosphere in the family, (in terms of mutual co-operation and acceptance) : Healthy / Unhealthy

Disabling effects of AED (Disability) Yes No If yes give details ....

Family history of seizure disorder Yes No If yes give details ....

Family history of mental disorder Yes No If yes give details ....

Previous history of mental illness Yes No If yes give details ....

Duration of illness :................................

Age at first seizure :................................

Frequent time of occurrence of seizure :
During sleep / Early morning / Within 2 hours of walking / Only during night / Any time the day.

SEIZURE FREQUENCY

Number of seizure in the last 1- year..................
6 months...............
3 months...............
1 month................

SEIZURE TYPE

1.	Absence	Yes	☐	No	☐
2.	Myoclonic	Yes	☐	No	☐
3.	GTCS	Yes	☐	No	☐
4.	Simple Partial Seizure	Yes	☐	No	☐
5.	Complex Partial Seizure	Yes	☐	No	☐
6.	Secondary Generalization	Yes	☐	No	☐

7. Any other ....

PRECIPITATING FACTOR

1.	Sleep deprivation	Yes	No
2.	Emotional upsets	Yes	No
3.	Alcohol	Yes	No
4.	Menstruation	Yes	No
5.	Fever	Yes	No
6.	Poor AED compliance	Yes	No
7.	Physical exercise	Yes	No
8.	Recreational drugs	Yes	No
9.	Television	Yes	No
10.	Hot water	Yes	No
11.	Light Stimulation	Yes	No
12.	Loud sounds / music	Yes	No
13.	Reading	Yes	No

14. Eating	Yes	No
15. Fasting	Yes	No

16. Others ....

17. No known precipitating factor

TYPE OF THERAPY

Monotherapy ☐ Polytherapy ☐

Who administer the medicines ?
(a) Self (b) Parents (c) Siblings (d) Spouse (e) Any other
....

Do you miss medicine ?
(a) Never (b) Rarely (Once in a year)
(C) Occasionally (Once in a month) (d) Frequently

What is the reason for missing the medicine ?
(a) Financial difficulty, (b) Non availability of drug,
(c) Forgetfulness, (d) Side effect of drugs,
(e) Lack of awareness of compliance (e) others (Explain..)

<u>Family's level of satisfaction regarding the patient :</u>

Spouse: Very satisfied/Satisfied/Slightly satisfied/Very unsatisfied/ Unsatisfied/Slightly unsatisfied

Parents :Very satisfied/Satisfied/Slightly satisfied/Very unsatisfied/ Unsatisfied/Slightly unsatisfied

Siblings: Very satisfied/Satisfied/Slightly satisfied/Very unsatisfied/ Unsatisfied/Slightly unsatisfied

Relatives: Very satisfied/Satisfied/Slightly satisfied/Very unsatisfied/ Unsatisfied/Slightly unsatisfied

Friends: Very satisfied/Satisfied/Slightly satisfied/Very unsatisfied/ Unsatisfied/Slightly unsatisfied

Patient's level of satisfaction: Very satisfied/Satisfied/ Unsatisfied/Very unsatisfied

Patients level of participation in the family :

1 Visiting relatives : Often/Sometimes/Rarely/Never

2. Visiting friends : Often/Sometimes/Rarely/Never

3. Participating in
   family function : Often/Sometimes/Rarely/Never

4. Participating in festival/
   meeting neighbours: : Often/Sometimes/Rarely/Never

Patient's activities of each day:

Going to school/ college : Often/Sometimes/Rarely/Never

Going to market : Often/Sometimes/Rarely/Never

Going to work : Often/Sometimes/Rarely/Never

Household work : Often/Sometimes/Rarely/Never

Driving/travelling alone : Often/Sometimes/Rarely/Never

Any other (Specify) ....

How much epilepsy has affected patient's

Study : Not affected/Slight change/Moderate change/Severe changes
Memory: Not affected/Slight change/Moderate change/Severe changes

How much change has been there
in the patient's feeling of worthiness,
happiness,optimism : Not affected/Slight change/Moderate change/Severe changes

How much change has been there in the patient's negative feeling :

1. Stress : Not affected / Slight change / Moderate change / Moderately severe / Severe Changes

2. Anger : Not affected / Slight change / Moderate change / Moderately severe / Severe Changes

3. Self evaluation : Not affected / Slight change / Moderate change / Moderately severe / Severe Changes

4. Fear : Not affected / Slight change / Moderately severe / Severe Changes

5. Depression : Not affected / Slight change / Moderate change / Moderately severe / Severe Changes.

Patient's leisure activities

Going for walks / doing exercise : Often / Sometime / Rarely Never

Gardening : Often / Sometime / Rarely Never

Playing indoor / outdoor : Often / Sometime / Rarely Never

Others (Specify): Often / Sometime / Rarely Never

How much change has been there due to epilepsy to the patient's relation with

1. Spouse: Not affected / Slight change / Moderate change / Moderately severe / Severe changes
2. Parents: Not affected / Slight change / Moderate change / Moderately severe / Severe changes
3. Relatives: Not affected / Slight change / Moderate change / Moderately severe / Severe changes
4. Neighbours/ friends / collegues : Not affected / Slight change / Moderate change / Moderately severe / Severe changes

How much has the disease affected the patient's work life :

1. Job (if employed) : Not affected / Slight change / Moderate change / Moderately severe / Severe changes
2. Daily household work: Not affected / Slight change / Moderate change / Moderately severe / Severe changes
3. Looking after family member: Not affected / Slight change / Moderate change / Moderately severe / Severe changes

How much has the disease affected the following areas of patient's life ?

1. Family life : Not affected / Slight change / Moderate change / Moderately severe / Severe changes
2. Financial status of the patient: Not affected / Slight change / Moderate change / Moderately severe / Severe changes
3. Marriage life : Not affected / Slight change / Moderate change / Moderately severe / Severe changes
4. Personlity : Not affected / Slight change / Moderate change / Moderately severe / Severe changes
5. Any other significant findings ....

....

....

Appendix No I

KNOWLEDGE, ATTITUDE AND PRACTICE QUESTIONNAIRE (KAP)

Dr. K. Radhakrishnan & D. Jayachandran.
Department of Neurology,
Sree Chitra Tirunal Institute for Medical Science & Technology, Thiruvananthapuram

1995

Name ....

Age ....Sex................Education..

Occupation...

1. അപസ്മാരം എന്ന രോഗത്തെ കുറിച്ച് കേട്ടിട്ടുണ്ടോ ? ഉണ്ട്/ഇല്ല
2. ഇത് ശരീരത്തെ ബാധിക്കുന്ന രോഗമാണോ ? അതെ/അല്ല
3. ഇത് മാനസിക രോഗമാണോ ? അതെ/അല്ല
4. ഇത് തലച്ചോറിനെ ബാധിക്കുന്ന രോഗമാണോ ? അതെ/അല്ല
5. അപസ്മാരം പാരമ്പര്യ രോഗമാണോ ? അതെ/അല്ല
6. അപസ്മാര രോഗികൾക്ക് വിവാഹ ജീവിതം സാദ്ധ്യമാണോ ? അതെ/ഇല്ല
7. അപസ്മാരം സാധാരണ വിദ്യാഭ്യാസത്തിന് തടസ്സമാണോ ? അതെ/അല്ല
8. അപസ്മാര രോഗികൾ എല്ലാ ജോലികളിലും ഏർപ്പെടുമോ? അതെ/അല്ല
9. അപസ്മാരം സാധാരണ ലൈംഗിക ബന്ധത്തിന് തടസ്സമാണോ ? അതെ/അല്ല
10. അപസ്മാരത്തിന് അലോപ്പതി ചികിത്സ ഫലപ്രദമാണോ ? അതെ/അല്ല
11. അപസ്മാര രോഗത്തിന് ദീർഘനാൾ തുടർന്ന് ഉള്ള ചികിത്സ ആവശ്യമാണോ? അതെ/ഇല്ല
12. മരുന്ന് ഒന്നോ രണ്ടോ പ്രാവശ്യം ഇടയ്ക്ക് മുടങ്ങി പോയാൽ കുഴപ്പമുണ്ടോ? ഉണ്ട്/ഇല്ല
13. അപസ്മാര ചികിത്സയ്ക്കുപയോഗിക്കുന്ന മരുന്നുകൾ അധികവും പാർശ്വഫലങ്ങൾ ഉണ്ടാക്കുന്നുണ്ടോ ? അതെ/ഇല്ല
14. അപസ്മാര രോഗത്തിന് മന്ത്രവാദം നടത്തുന്നതു കൊണ്ട് പ്രയോജനമുണ്ടോ? ഉണ്ട്/ഇല്ല
15. അപസ്മാരത്തിന് നാട്ടുചികിത്സ ഫലപ്രദമാണോ ? അതെ/അല്ല
16. അപസ്മാരത്തിന് ആയുർവേദ ചികിത്സ ഫലപ്രദമാണോ ? അതെ/അല്ല
17. അപസ്മാരം ചികിത്സിക്കേണ്ട ആവശ്യം ഇല്ല എന്ന് കരുതുന്നുണ്ടോ? ഉണ്ട് / ഇല്ല
18. അപസ്മാര രോഗമുള്ളവർ പ്രത്യേക ദേവാലയങ്ങളിൽ പോയാൽ ശമനമുണ്ടാകുമോ ? ഉണ്ട്/ഇല്ല
19. അപസ്മാര രോഗികളോട് സമൂഹം അവഗണന കാണിക്കാറുണ്ടോ ? ഉണ്ട്/ഇല്ല
20. അപസ്മാരം ജീവിതം സന്തോഷകരമാക്കുന്നതിന് തടസ്സമാണോ? അതെ/അല്ല
21. അപസ്മാരം പകരുന്ന രോഗമാണോ? അതെ/അല്ല
22. അപസ്മാരം നമ്മുടെ മുൻഗാമികൾ ചെയ്ത പാപത്തിന്റെ ഫലമാണ് എന്ന് കരുതുന്നുണ്ടോ? ഉണ്ട്/ഇല്ല
23. നിങ്ങളുടെ കുട്ടി അപസ്മാര രോഗമുള്ള ഒരു കുട്ടിയോട് കളിക്കുന്നതിന് നിങ്ങൾക്ക് വിരോധമുണ്ടോ ? ഉണ്ട്/ഇല്ല
24. ഒരാൾക്ക് അപസ്മാര ബാധയുണ്ടാകുന്നത് നിങ്ങൾ കാണാനിടയായാൽ നിങ്ങൾ എന്ത് ചെയ്യും ? (ഉത്തരം ടിക് ചെയ്യുക)
    1. ഒരു താക്കോൽ കൂട്ടം കൊടുക്കും.
    2. വെള്ളം തളിക്കും
    3. ആശുപത്രിയിൽ കൊണ്ട് പോകാൻ സഹായിക്കും.

DEPRESSION INVENTORY

(Malayalam)

Dr. K. A. Kumar & Dr. S. Vinod Kumar

School of Behavioural Sciences
Mahatma Gandhi University, Kottayam
(2002)

ദൈനംദിന ജീവിതത്തിൽ സാധാരണയായി നിങ്ങൾക്ക് അനുഭവപ്പെടുന്ന കുറേകാര്യങ്ങൾ താഴെക്കൊടുത്തിരിക്കുന്നു. നിങ്ങളെ സംബന്ധിച്ചിടത്തോളം സാധാരണയായി ഇവ എത്രത്തോളം അനുഭവപ്പെടുന്നു എന്നത് ഒരു അടയാളത്തിലൂടെ രേഖപ്പെടുത്തുക.

		ഒരിക്കലുമില്ല	വല്ലപ്പോഴും	മിക്കവാറും	എല്ലായിപ്പോഴും
1.	സ്വന്തം കുറവുകളെക്കുറിച്ച് ആലോചിട്ട് ഞാൻ വിഷമിച്ചിരിക്കാറുണ്ട്	1	2	3	4
2.	എനിക്ക് സാധാരണയായി അലസത തോന്നാറുണ്ട്	1	2	3	4
3.	എന്റെ ജോലികൾ ശരിയായ രീതിയിൽ ചെയ്യാൻ കഴിയാറുണ്ട്	1	2	3	4
4.	ഞാൻ മരിച്ചു പോയെങ്കിൽ എന്ന് ആഗ്രഹിച്ചിട്ടുണ്ട്	1	2	3	4
5.	ഞാൻ ഇതുവരെ ജീവിതത്തിൽ ഒന്നും നേടിയിട്ടില്ല എന്ന തോന്നൽ എന്നെ അലട്ടാറുണ്ട്	1	2	3	4
6.	ഞാനൊരു ഭാഗ്യദോഷിയാണെന്ന ചിന്ത എനിക്കുണ്ട്	1	2	3	4
7.	ഞാൻ ആലോചിക്കുന്നതെല്ലാം നടക്കാറുണ്ട്	1	2	3	4
8.	ജീവിതം ഒരു ഭാരമായി തോന്നാറുണ്ട്.	1	2	3	4
9.	എനിക്ക് സന്തോഷകരമായ ജീവിതം നയിക്കാനുള്ള കഴിവുണ്ട്.	1	2	3	4
10.	എന്റെ ജോലികൾ തൃപ്തികരമായി ഞാൻ ചെയ്യാറുണ്ട്.	1	2	3	4
11.	കഴിഞ്ഞുപോയ സംഭവങ്ങളെപ്പറ്റി ആലോചിച്ച് ഞാൻ തല പുണ്ണാക്കാറുണ്ട്.	1	2	3	4
12.	എനിക്ക് പരാജയ ബോധമുണ്ട്.	1	2	3	4
13.	കുറ്റബോധം എന്നെ അലട്ടാറുണ്ട്.	1	2	3	4
14.	എനിക്ക് സാധാരണയായി നിരാശ അനുഭവപ്പെടാറുണ്ട്.	1	2	3	4
15.	ജീവിതം ശൂന്യമാണെന്ന് തോന്നാറുണ്ട്.	1	2	3	4

Appendix No III

THE STATE-TRAIT ANXIETY INVENTORY

(Adaptation and Translation of Speilberger's State - Trait Anxiety Inventory)

by

Dr. S. Vinod Kumar & Dr. M. Mohandas
School of Behavioural Sciences
Mahatma Gandhi University, Kottayam

(1994)

നിർദ്ദേശങ്ങൾ

താഴെ കൊടുത്തിരിക്കുന്ന കാര്യങ്ങൾ ഇപ്പോൾ നിങ്ങൾ എത്രമാത്രം അനുഭവപ്പെട്ടുന്നുണ്ടെന്ന് ഓര ചോദ്യത്തിനും ഉചിതമായ ഉത്തരത്തിനു നേരെ അടയാളത്തിലൂടെ രേഖപ്പെടുത്തുക. മനോഭാവങ്ങളിലും താല്പര്യങ്ങളിലും ഓരോ വ്യക്തിയും വ്യത്യസ്ഥനായിരിക്കുന്നു എന്നതിനാൽ ശരിയോ തെറ്റോ ആയ ഉത്തരങ്ങളില്ല. ഓരോ ചോദ്യത്തിനും നാല് സാദ്ധ്യതകൾ ഉത്തരങ്ങളായി കൊടുത്തിട്ടുണ്ട്. അവയിൽ നിങ്ങൾ യോജിക്കുന്നത് ഏതാണെന്ന് അടയാളപ്പെടുത്തി സൂചിപ്പിക്കുക

ഇത് സമയപരിധിയില്ലാത്ത ഒരു ടെസ്റ്റ് ആണെങ്കിലും കഴിയുന്നതിലും വേഗത്തിൽ ചെയ്തു തീർക്കുവാൻ ശ്രമിക്കണം. ചോദ്യങ്ങളെക്കുറിച്ച് ചിന്തിച്ച് കൂടുതൽ സമയം കളയാതെ ഓരോ ചോദ്യവും വായിക്കുമ്പോൾ തോന്നുന്ന ആദ്യത്തെ പ്രതികരണം രേഖപ്പെടുത്തുക. എല്ലാ ചോദ്യങ്ങൾക്കും ഉത്തരം എഴുതുവാൻ പ്രത്യേകം ശ്രദ്ധിക്കുക. നിങ്ങളുടെ ഉത്തരങ്ങൾ പരമ രഹസ്യമായി സൂക്ഷിക്കുന്നതാണ്. ഈ ചോദ്യാവലയിൽ നിങ്ങളുടെ പേര് നല്കണമെന്നില്ല. എന്നാൽ ഗവേഷണത്തിന് താഴെ പറയുന്ന വിവരങ്ങൾ നൽകുക.

വയസ്സ് ....

സ്ത്രീ / പുരുഷൻ ....

വിദ്യാഭ്യാസ യോഗ്യത ....

കുടുംബാംഗങ്ങളുടെ എണ്ണം ....

വിവാഹിത(ൻ) / അവിവാഹിത (ൻ) ....

പ്രതിമാസ കുടുംബവരുമാനം...

No	പ്രസ്താവന	ഒരിക്കലുമില്ല Almost never	വല്ലപ്പോഴും Some time	മിക്കവാറും Often	എല്ലായ്പ്പോഴും Almost Always
1	എനിക്ക് ശാന്തത അനുഭവപ്പെടുന്നുണ്ട് I feel calm	1	2	3	4
2.	എനിക്ക് സുരക്ഷിതത്വം നോന്നുന്നുണ്ട് I feel secure	1	2	3	4
3.	എനിക്ക് മനോസമ്മർദം ഉണ്ടാകുന്നുണ്ട് I feel tense	1	2	3	4
4.	എനിക്ക് ആശ്വാസം തോന്നുന്നുണ്ട് I feel at ease	1	2	3	4
5.	എനിക്ക് അസ്വസ്ഥത അനുഭവപ്പെടുന്നുണ്ട് I feel upset	1	2	3	4

No	പ്രസ്താവന	ഒരിക്കലുമില്ല Almost never	വല്ലപ്പോഴും Some time	മിക്കവാറും Often	എല്ലായ്പ്പോഴും Almost Always
6.	വന്നു ചേരാവുന്ന നിർഭാഗ്യങ്ങളെക്കുറിച്ചുള്ള ആകുലചിന്ത എനിക്കിപ്പോൾ തോന്നുണ്ട് I am presently worrying over possible misfortunes	1	2	3	4
7.	എനിക്ക് വിശ്രമം ലഭിച്ചതായി അനുഭവപ്പെടുന്നുണ്ട് I feel rested				
8.	എനിക്ക് ഉത്കണ്ഠ അനുഭവപ്പെടുന്നുണ്ട് I feel anxious	1	2	3	4
9.	എനിക്ക് സുഖം തോന്നുന്നുണ്ട് I feel confortable	1	2	3	4
10	എനിക്ക് ആത്മവിശ്വാസം അനുഭവപ്പെടുന്നുണ്ട് I feel Self - Confident	1	2	3	4
11.	എനിക്ക് അധൈര്യം തോന്നുന്നുണ്ട് I feel nervous	1	2	3	4
12.	എനിക്ക് പിരിമുറുക്കം അനുഭവപ്പെടുന്നുണ്ട് I feel high -strung	1	2	3	4
13.	എനിക്ക് വിശ്രമം അനുഭവപ്പെടുന്നുണ്ട് I am relaxed	1	2	3	4
14.	എനിക്ക് സംതൃപ്തി തോന്നുന്നുണ്ട് I feel content	1	2	3	4
15.	എനിക്ക് നിരാശ തോന്നുന്നുണ്ട് I am worried	1	2	3	4
16.	ഞാൻ പെട്ടെന്ന് വികാരക്ഷോഭത്തിന് അടിമപ്പെടുന്നുണ്ട്. I feel over-excited and “rattled”	1	2	3	4
17.	എനിക്ക് ആനന്ദം തോന്നുന്നുണ്ട് I feel Joyful	1	2	3	4
18.	എനിക്ക് പ്രസന്നത തോന്നുന്നുണ്ട് I feel pleasent	1	2	3	4

എല്ലാ ചോദ്യത്തിനും ഉത്തരം എഴുതിയിട്ടുണ്ടോ എന്ന് ഒരിക്കൽകൂടി പരിശോധിക്കുക

നിർദ്ദേശങ്ങൾ

ദൈനംദിന ജീവിതത്തിൽ അനുഭവപ്പെടാറുള്ള ചില കാര്യങ്ങൾ താഴെ കൊടുത്തിരിക്കുന്നു. അവ സാധാരണയായി നിങ്ങൾക്ക് എത്രത്തോളം അനുഭവപ്പെടുന്നുവെന്നത് ഉചിതമായതിനും നേരെ 'X' അടയാളത്തിലൂടെ രേഖപ്പെടുത്തുക.

No	പ്രസ്താവന	ഒരിക്കലുമില്ല Almost never	വല്ലപ്പോഴും Some time	മിക്കവാറും Often	എല്ലായ്പ്പോഴും Almost Always
19	എനിക്ക് മനഃസുഖം തോന്നാറുണ്ട് I feel pleasant	1	2	3	4
20.	എനിക്ക് പെട്ടെന്ന് ക്ഷീണം അനുഭവപ്പെടാറുളണ്ട് I tire quickly	1	2	3	4
21.	എനിക്ക് കരയണമെന്ന് തോന്നാറുണ്ട് I feel like crying	1	2	3	4
22.	മറ്റുള്ളവരെപ്പോലെ സന്തോഷിരിക്കുവാനുള്ള ആഗ്രഹം എനിക്കുണ്ട്. I wish I could be as happy as others seems to be	1	2	3	4
23.	പെട്ടെന്ന് തീരുമാനങ്ങൾ എടുക്കുവാൻ സാധിക്കാത്തതു മൂലം പല നഷ്ടങ്ങളും എനിക്കുണ്ടാകാറുണ്ട് I am loosing out on things because I can't make up my mind soon enough	1	2	3	4
24.	എനിക്ക് വിശ്രമം അനുഭവപ്പെടാറുണ്ട് I feel rested	1	2	3	4
25.	എനിക്ക് സ്വസ്ഥതയും ശാന്തതയും അനുഭവപ്പെടാറുണ്ട് I am calm, cool and collected	1	2	3	4
26.	എനിക്ക് വിഷമതകൾ വർദ്ധിക്കുകയും അവയെ തരണം ചെയ്യുവാൻ കഴിയാതെയും വരാറുണ്ട് I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
27.	നിസ്സാരകാര്യങ്ങളെക്കുറിച്ച് ഞാൻ ചിന്താകുലനാകാറുണ്ട് I worry too much over something that really doesn't matter	1	2	3	4
28.	എനിക്ക് സന്തോഷമുണ്ട് I am happy	1	2	3	4
29.	സാധാരണ കാര്യങ്ങൾ കഠിനമായിട്ടെടുക്കുന്ന പ്രവണത എനിക്കുണ്ട്. I am inclined to take things hard	1	2	3	4

30.	എനിക്ക് സുരക്ഷിതത്വം തോന്നാറുണ്ട് I feel secure	1	2	3	4
31.	എനിക്ക് നിരാശ ഉണ്ടാകാറുണ്ട് I feel blue	1	2	3	4
32.	എനിക്ക് സംതൃപ്തി തോന്നാറുണ്ട് I am content	1	2	3	4
33.	അപ്രധാനമായ ചില ചിന്തകൾ എന്നെ വിഷമിപ്പിക്കാറുണ്ട് Some unimportant thoughts runs through my mind and bothers me	1	2	3	4
34.	ജീവിതനൈരാശ്യങ്ങൾ ഗൗരവപൂർവ്വമെടുക്കുന്നു മനസ്സിൽ നിന്ന് അവയെ മാറ്റുവാൻ കഴിയാറില്ല I take disappoinments so keenly that I can't put them out of my mind.	1 1	2 2	3 3	4 4
35.	സ്ഥിരചിത്തതയുള്ള വ്യക്തിയാണ് ഞാൻ I am a steady man	1	2	3	4
36.	അടുത്ത കാലത്തുള്ള എന്റെ സംരംഭങ്ങളെ കുറിച്ചും താല്പര്യങ്ങളെക്കുറിച്ചും ആലോചിക്കുമ്പോൾ എനിക്ക് മനോ സമ്മർദ്ദമുണ്ടാകുന്നു I get in a state of tension or turmoil as I think over my recent cocerns and interests	1	2	3	4

N.B. എല്ലാ ചോദ്യത്തിനും ഉത്തരം എഴുതിയിട്ടുണ്ടോ എന്ന് ഒരിക്കൽകൂടി പരിശോധിക്കുക.

Appendix No IV

SELF - ESTEEM INVENTORY

(REVISED)

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(1990)

Instructions:

Some statements are given below. Indicate how much you agree with each statements. There are five response categories, viz, A,B,C,D and E.

"A" denotes 'strongly agree', "B" denotes "agree", "C" denotes "undecided". "D" denotes "disagree", and "E" denotes "strongly disagree" .

After reading each statement, mark your answer with a "X" mark in the appropriate circle. Please note: select "C" only when you can't say clearly whether you either agree or disagree with a statement. Do not omit any statement. Your responses will be confidential.

നിർദ്ദേശങ്ങൾ

താഴെ ചില പ്രസ്താവനകൾ കൊടുത്തിരിക്കുന്നു. അവ ഓരോന്നിനോടും നിങ്ങൾ എത്ര മാത്രം യോജിക്കുന്നുവെന്ന് രേഖപ്പെടുത്തുക. ഓരോ പ്രസ്താവനയ്ക്കും A,B.C,D.E എന്നിങ്ങനെ അഞ്ച് ഉത്തരങ്ങൾ കൊടുത്തിട്ടുണ്ട്.

'A' ശക്തിയായി യോജിക്കുന്നു എന്നതിനെയും, 'B' യോജിക്കുന്നു എന്നതിനെയും 'C' വ്യക്തമായ ഉത്തരമില്ല എന്നതിനെയും 'D' വിയോജിക്കുന്നു എന്നതിനെയും 'E' ശക്തിയായി വിയോജിക്കുന്നു എന്നതിനെയും സൂചിപ്പിക്കുന്നു.

ഓരോ പ്രസ്താവനയും വായിച്ച ശേഷം A,B,C,D,E ഇവയിൽ ഏതെങ്കിലുമൊന്നിന്റെ താഴെയുള്ള വൃത്തത്തിൽ നിങ്ങളുടെ ഉത്തരം ഒരു 'X' അടയാളം കൊണ്ട് രേഖപ്പെടുത്തുക. യോജിക്കുകയോ, വിയോജിക്കുകയോ ചെയ്യുന്നതായി വ്യക്തമായിപ്പറയാൻ സാധിക്കാത്തപ്പോൾ മാത്രമേ 'C' എന്ന ഉത്തരം രേഖപ്പെടുത്താൻ പാടുള്ളൂ എന്ന കാര്യം പ്രത്യേകം ശ്രദ്ധിക്കുക. ദയവായി എല്ലാ പ്രസ്താവനകൾക്കും ഉത്തരമെഴുതുക. നിങ്ങളുടെ ഉത്തരങ്ങൾ രഹസ്യമായി സൂക്ഷിക്കുന്നതാണ്.

		A	B	C	D	E
1.	When I have made an embarassing mistake or have done something that makes me look foolish, I keep on worrying about it for long വിഡ്ഢിത്തം കാണിക്കുകയോ, അമളി പിണയുകയോ ചെയ്താൽ പിന്നെ ഞാൻ അതിനെക്കുറിച്ചു തന്നെ ഓർത്ത് വിഷമിച്ചിരിക്കാറുണ്ട്.	0	0	0	0	0
2.	I often feel ashamed of myself പലപ്പോഴും എന്നെക്കുറിച്ച് എനിക്ക് ലജ്ജ തോന്നാറുണ്ട്.	0	0	0	0	0

3. I am able to do things as well as
most other people
മറ്റുള്ളവരെപ്പോലെ തന്നെ
കാര്യങ്ങൾ ഭംഗിയായി ചെയ്യുവാൻ
എനിക്ക് കഴിയും. 0 0 0 0 0

4. When in a group of people I
often have trouble thinking
about the right things to talk about.
മറ്റാളുകളുടെ മുൻപിൽ എന്ത്
സംസാരിക്കണമെന്ന്
നിശ്ചയമില്ലാതെ ഞാൻ
പലപ്പോ◌ുവം വിഷമിക്കാറുണ്ട്. 0 0 0 0 0

5. On the whole, I am satisfied
with myself.
ആകെക്കൂടെ, എനിക്ക് എന്നെക്കുറിച്ച്
നല്ല തൃപ്തിയാണ്. 0 0 0 0 0

6. I often worry about whether
people like to be with me.
ഞാൻ കൂടെയുള്ളത് 0 0 0 0 0
മറ്റുള്ളവർക്കിഷ്ടമാവുന്നുണ്ടോ
എന്ന ചിന്ത മിക്കപ്പോഴും
എനിക്കുണ്ടാകാറുണ്ട്. 0 0 0 0 0

7. Most people are better
liked than I am.
എന്നെക്കാളധികം മറ്റുള്ളവരെയാണ്
കൂടുതൽ ആളുകളും ഇഷ്ടപ്പെടുന്നത്. 0 0 0 0 0

8. If I have something to say I usually
say it.
എനിക്ക് എന്തെങ്കിലും
പറയാനുള്ളപ്പോൾ
സാധാരണയായി ഞാൻ
അത് പറയാറുണ്ട്. 0 0 0 0 0

9. I often feel concerned and
worried about the
possibility that some of my
friends may not have
a good opinion of me.
ചില ആളുകൾക്കെങ്കിലും
എന്നെക്കുറിച്ച്
അത്ര നല്ല അഭിപ്രായം ഉണ്ടാകാനിടയില്ല
എന്ന തോന്നൽ എന്നെ പലപ്പോഴും
വിഷമിപ്പിക്കാറുണ്ട്. 0 0 0 0 0

10.	I prefer to do things that are novel and difficult. പുതുമയുള്ളതും പ്രയാസമേറിയതുമായ കാര്യങ്ങൾ ചെയ്യാനാണ് ഞാൻ കൂടുതൽ ഇഷ്ടപ്പെടുന്നത്.	0	0	0	0	0
11.	I often feel that my life is not very useful. എന്റെ ജീവിതം പ്രയോജനമില്ലാത്തതാണെന്ന് മിക്കപ്പോഴും എനിക്ക് തോന്നാറുണ്ട്.	0	0	0	0	0
12.	I find it is hard to make talk when I meet new people. ആളുകളെ പരിചയപ്പെടുമ്പോൾ അങ്ങോട്ടു സംസാരിക്കുവാനെനിക്ക് വിഷമം അനുഭവപ്പെടാറുണ്ട്.	0	0	0	0	0
13.	I am fully confident of my abilities. എന്റെ കഴിവുകളെക്കുറിച്ച് എനിക്ക് പൂർണ്ണമായ വിശ്വാസമുണ്ട്.	0	0	0	0	0
14.	I don't have much to be proud of. സ്വയം അഭിമാനിക്കത്തക്കതായി എനിക്ക് വളരെയൊന്നും ഇല്ല.	0	0	0	0	0
15.	I can make up my mind and stick to it. എനിക്ക് തീരുമാനങ്ങളെടുക്കുവാനും അവയിൽ തന്നെ ഉറച്ച് നില്ക്കുവാനുമുള്ള കഴിവുണ്ട്.	0	0	0	0	0
16.	I have good opinion of myself. എനിക്ക് എന്നെക്കുറിച്ച് നല്ല മതിപ്പാണ്.	0	0	0	0	0
17.	I often wish I were someone else. ഞാൻ വേറെ ആളായിരുന്നെങ്കിൽ എന്ന് പലപ്പോഴും ആഗ്രഹിക്കാറുണ്ട്.	0	0	0	0	0
18.	I am easy to like. എന്നെ എളുപ്പത്തിൽ എല്ലാവർക്കും ഇഷ്ടപ്പെടുവാൻ കഴിയും.	0	0	0	0	0
19.	I can usually take care of myself. എന്റെ കാര്യങ്ങൾ സ്വയം നോക്കാൻ സാധാരണ എനിക്ക് കഴിയാറുണ്ട്.	0	0	0	0	0
20.	I am doing the best work I can. കഴിയുന്നിടത്തോളം നന്നായി എല്ലാ പ്രവർത്തികളും ഞാൻ ചെയ്യും.	0	0	0	0	0

Appendix No V

INTERNAL - EXTERNAL LOCUS OF CONTROL (I E SCALE)

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University of Kerala, Thiruvananthapuram
1992

നിർദ്ദേശങ്ങൾ:

സാമൂഹ്യപ്രാധാന്യമുള്ള ചില കാര്യങ്ങളോട് വിവിധയാളുകൾ വച്ചുപുലർത്തുന്ന ചിന്താഗതികളും അഭിപ്രായങ്ങളുമടങ്ങുന്ന ഒരു ചോദ്യാവലിയാണിത്. ഇതിലെ ഓരോ ഇനവും (a) എന്നും (b) എന്നും രേഖപ്പെടുത്തിയിട്ടുള്ള രണ്ട് പ്രസ്താവനകളടങ്ങിയ ഓരോ ജോഡിയായിട്ടാണ് അവതരിപ്പിച്ചിരിക്കുന്നത്. ഈ രണ്ട് പ്രസ്താവനകളിൽ താങ്കളെ സംബന്ധിച്ചിടത്തോളം കൂടുതൽ യോജിക്കാൻ കഴിയുന്ന ഒരെണ്ണം (ഓർക്കുക ഒന്നുമാത്രം) തെരഞ്ഞെടുക്കുക. കൂടുതൽ ശരിയെന്ന് താങ്കൾ ശരിക്കും വിശ്വസിക്കുന്ന പ്രസ്താവനയാണ് തെരഞ്ഞെടുക്കേണ്ടത്. മറിച്ച് ഏതാണ് നല്ലതെന്നോ എന്താണ് നിങ്ങളുടെ ആഗ്രഹമെന്നോ അല്ല സൂചിപ്പിക്കേണ്ടത്. തികച്ചും വ്യക്തിപരമായ അഭിപ്രായഗതികൾ മാത്രമാണ് ഇതിലെ ഓരോയിനവും. അതുകൊണ്ട് തന്നെ ഇതിൽ പ്രത്യേകിച്ച് ശരിയോ, തെറ്റോ ഇല്ല.

ഓരോ പ്രസ്താവനയും ശ്രദ്ധാപൂർവ്വം വായിച്ച് നിങ്ങളുടെ അഭിപ്രായം രേഖപ്പെടുത്തുക. അതേസമയം ആവശ്യത്തിലേറെ സമയം ഒന്നിലും ചെലവഴിക്കേണ്ടതില്ല എന്നും ഓർക്കുക. എല്ലാ ജോഡികളിൽ നിന്നും ഓരോന്ന് തെരഞ്ഞെടുക്കണം എന്ന കാര്യവും ഓർത്തിരിക്കേണ്ടതാണ്. നിങ്ങൾക്ക് കൂടുതൽ യോജിക്കാൻ കഴിയുന്ന പ്രസ്താവനയെ സൂചിപ്പിക്കുന്ന ഇംഗ്ലീഷ് അക്ഷരത്തിന് (“a” അല്ലെങ്കിൽ “b”) നേർക്ക് ഒരു അടയാളം ഇട്ടാണ് ഉത്തരം രേഖപ്പെടുത്തേണ്ടത്.

ചില അവസരങ്ങളിൽ ജോഡിയായി തന്നിട്ടുള്ള രണ്ടഭിപ്രായത്തോടും നിങ്ങൾ യോജിക്കുന്നുവോ അല്ലെങ്കിൽ രണ്ടിനോടും വിയോജിക്കുന്നു എന്നോ വന്നേയ്ക്കാം. അങ്ങനെ വരുമ്പോൾ രണ്ടിലും വച്ച് കൂടുതൽ ശരിയായി നിങ്ങൾക്ക് തോന്നുന്ന ഒന്നാണ് തിരഞ്ഞെടുക്കേണ്ടത്. ചോദ്യാവലിയിലെ ഓരോ അഭിപ്രായങ്ങളും വ്യത്യസ്തങ്ങളായി പരിഗണിക്കേണ്ടതാണ്. ചോദ്യാവലിയിൽ നിങ്ങൾ നേരത്തെ പ്രകടിപ്പിച്ചിട്ടുള്ള അഭിപ്രായങ്ങളുമായി പിന്നീടുള്ളവ ബന്ധപ്പെടുത്താൻ ശ്രമിക്കേണ്ടതില്ല.

വയസ്സ്   ആൺ/പെൺ   വിദ്യാഭ്യാസം

ജോലി   വരുമാനം   വിവാഹിതർ/അവിവാഹിതർ

മതം

1. a.നമ്മുടെ നിലനില്പ് ദൈവകരുണയെ ആശ്രയിച്ചിരിക്കുന്നു.
   b.നമ്മുടെ നിലനില്പ് കഴിവിനേയും പരിശ്രമത്തെയും ആശ്രയിച്ചിരിക്കുന്നു.

2. a.വിജയം നേടുന്നത് ഭാഗ്യം കൊണ്ടല്ല, കഠിനാദ്ധ്വാനം കൊണ്ടാണ്.
   b.നല്ല ജോലി കിട്ടുക എന്നത് ഒരാളുടെ നല്ല സമയത്തേയും കാലത്തേയും ആശ്രയിച്ചിരിക്കുന്നു.

3. a.മനുഷ്യൻ ഒന്നുദ്ദേശിക്കുന്നു. ദൈവം മറ്റൊന്നു നടത്തുന്നു.
   b.തന്നത്താൻ സഹായിക്കുന്നവരെ ദൈവവും സഹായിക്കുന്നു.

4. a.ഒരുവന്റെ വിജയം അവന്റെ പ്രയത്നത്തെ ആശ്രയിച്ചിരിക്കുന്നു.
   b.ഒരുവന്റെ വിജയം അവന്റെ ദൈവവിശ്വാസത്തെ ആശ്രയിച്ചിരിക്കുന്നു.

5. a.വെല്ലുവിളികളെ സ്വീകരിക്കുകയും അവസാനശ്വാസം വരെ ശക്തമായി നേരിടുകയും ചെയ്യുന്നയാൾ വിജയം നെടും.
   b.ഉന്നത വിജയം നേടുന്നതിന് പരിശ്രമത്തിലുപരി ഭാഗ്യവും ആവശ്യമാണ്.

6. a.ജീവിതത്തിലെ കഷ്ടപാടുകളൊക്കെ ഒരു പരിധി വരെ ദുർഭാഗ്യം കൊണ്ട് ഉണ്ടാകുന്നവയാണ്.
   b.കഷ്ടപ്പാടുകൾ സ്വന്തം തെറ്റുകളിൽ നിന്നുമാണ് ഉണ്ടാകുന്നത്.

7. a.പോക്കറ്റടിക്കപ്പെടുന്നത് ഒരാളുടെ നിർഭാഗ്യം കൊണ്ട് തന്നെയാണ്.
   b.വേണ്ടത്ര സൂക്ഷിച്ചാൽ പോക്കറ്റടി തടയാവുന്നതാണ്.

8. a.അപകടങ്ങൾ നമ്മുടെ നിയന്ത്രണങ്ങൾക്ക് ഉപരിയായ ഒരു കാര്യമാണ്.
   b.രക്ഷാ നിയമങ്ങൾ പാലിക്കുകയും മുൻകരുതലുകൾ എടുക്കുകയും ചെയ്താൽ അപകടങ്ങൾ ഒഴിവാക്കാം.

9. a.ഒരുവന്റെ ഭാവിയുടെ താക്കോൽ വിധിയുടെ കരങ്ങളിലാണ്.
   b മനുഷ്യൻ തന്നെയാണ് അവന്റെ ഭാവിയുടെ ശില്പി.

10. a.ജന്മനാഭാഗ്യഹീനമായ ചില ആൾക്കാരുണ്ട്. അവരെത്രയൊക്കെ ശ്രമിച്ചാലും ജീവിതത്തിൽ വിജയം കൈവരിക്കുകയില്ല.
    b. പ്രസിദ്ധിയും സ്വപ്രയത്നവും ഒരു വ്യക്തിയെ വിജയത്തിലെത്തിക്കുന്നു.

11. a.മനുഷ്യൻ കഠിനമായി യത്നിക്കുകയാണെങ്കിൽ അവന് ഭൂമിയിൽ സ്വർഗ്ഗം നിർമ്മിക്കാം.
    b.കഷ്ടതയനുഭവിക്കുക എന്നത് മനുഷ്യന്റെ വിധിയാണ്.

12. a.കാര്യങ്ങൾ മുൻകൂട്ടി നിശ്ചയിക്കുകയും അത് വേണ്ട രീതിയിൽ നടപ്പാക്കുകയും ചെയ്താൽ വിജയം സുനിശ്ചിതമാണ്.

b.സംഭവിക്കാനുള്ളത് എങ്ങനെയായാലും സംഭവിക്കും.

13. a.എന്റെ തെറ്റു കൊണ്ടല്ല പലപ്പോഴും കാര്യങ്ങൾ വിപരീതമാകുന്നതെന്ന് എനിയ്ക്ക് തോന്നിയിട്ടുണ്ട്.

b.വേണ്ടത്ര ശ്രദ്ധയോടും അർപ്പണബോധത്തോടും ചെയ്യുകയാണെങ്കിൽ ഒരു കാര്യവും നടക്കാതെ വരികയില്ല.

14. a.ഒരു ജോലിക്ക് വേണ്ടതായ പ്രത്യേക യോഗ്യത നേടിയാൽ മാത്രമേ ഒരാൾക്ക് ആ ജോലി ലഭിക്കുകയുള്ളു.

b.ഭാഗ്യമുള്ള ഒരുവന് ജോലികിട്ടും.

15. a.എനിയ്ക്ക് എന്തു സംഭവിക്കുന്നു എന്നത് എന്റെ പ്രവൃത്തിയുടെ ഫലമാണ്.

b.എന്റെ ജീവിതത്തിന്റെ ഗതി ഞാനല്ല പൂർണ്ണമായും നിയന്ത്രിക്കുന്നത് എന്ന് ചിലപ്പോഴൊക്കെ തോന്നാറുണ്ട്.

EPILEPSY PSYCHO-SOCIAL EFFECT SCALE

Developed by : (Chaplin J E, 1990)
Translation and Standardization : **D. Jayachandran, Dr. K.A. Kumar**
School of Behavioural Sciences
Mahatma Gandhi University, Kottayam

ദയവായി എല്ലാ പ്രസ്താവനകൾക്കും ഉത്തരം നല്കുക
താഴെ കൊടുത്തിരിക്കുന്ന സൂചിക പ്രകാരം ഉത്തരം നല്കുക

0 - ഒരിക്കലുമില്ല
1 - അപൂർവ്വമായി
2 - വല്ലപ്പോഴും
3 - മിക്കപ്പോഴും
4 - മിക്കവാറും/എല്ലായ്പ്പോഴും/തീർച്ചയായും

1. എന്റെ ജന്നി അംഗീകരിക്കുവാൻ എനിക്ക് ബുദ്ധിമുട്ടുണ്ട് 0-1-2-3-4

2. എനിക്ക് അസുഖം വരാം എന്നതിനാൽ ഒറ്റയ്ക്കിരിക്കാൻ പ്രയാസമുണ്ട്. 0-1-2-3-4

3. എനിക്ക് ഈ അസുഖം ഉണ്ട് എന്ന് തൊഴിലുടമയോട്/മറ്റുള്ളവരോട് പറയുവാൻ വിഷമമുണ്ട്. 0-1-2-3-4

4. എനിക്ക് അപസ്മാരം ഉള്ളതിനാൽ പുതിയൊരു ജോലി കിട്ടാൻ പ്രയാസമുണ്ട് 0-1-2-3-4

5. എനിക്ക് ജന്നി ഉണ്ടാകും എന്നതിനാൽ പൊതുവാഹനങ്ങൾ ഉപയോഗിക്കുവാൻ താല്പര്യമില്ല. 0-1-2-3-4

6. ഈ അസുഖം കാരണം വളരെക്കുറച്ച് മാത്രം പുറത്ത് പോകുന്നതാണ് എനിക്കിഷ്ടം. 0-1-2-3-4

7. എനിക്ക് അസുഖം ഉണ്ടാകുന്നത് കാരണം എന്റെ ഒഴിവുസമയപ്രവർത്തികളുടെ രീതി മാറിയിട്ടുണ്ട്. 0-1-2-3-4

8. അസുഖം കാരണം എന്റെ ജീവിതത്തോടുള്ള കാഴ്ചപ്പാട് മോശമായിട്ടുണ്ട്. 0-1-2-3-4

9. എന്റെ അസുഖത്തെക്കുറിച്ച് കുടുംബാംഗങ്ങളോട് തുറന്നു പറയാൻ പ്രയാസം അനുഭവപ്പെടാറുണ്ട്. 0-1-2-3-4

10. എനിക്ക് മരുന്നു കഴിക്കാൻ തോന്നാറില്ല. 0-1-2-3-4

11. എന്റെ അവസ്ഥയിൽ ഡോക്ടർമാർക്ക് താല്പര്യക്കുറവുള്ളതായി എനിക്ക് തോന്നുന്നു. 0-1-2-3-4

12. അപസ്മാരം കാരണം ജീവിതം അർത്ഥശൂന്യമായതായി എനിക്ക് തോന്നുന്നു. 0-1-2-3-4

13. എന്റെ അസുഖം കാരണം ആരോടും അടുപ്പം തോന്നാറില്ല. 0-1-2-3-4

14. അസുഖമുള്ളത് കൊണ്ട് എപ്പോഴും എനിക്കൊരു ക്ഷീണമാണ്. 0-1-2-3-4

15. ഈ അസുഖം എന്റെ ജീവിതം നശിപ്പിച്ചതായി എനിയ്ക്ക് തോന്നുന്നു. 0-1-2-3-4

16. ജന്നി എന്ന ചിന്ത തന്നെ എനിയ്ക്ക് വെറുപ്പാണ്. 0-1-2-3-4

17. ജോലി സ്ഥലത്തു വച്ച് ജന്നി ഉണ്ടായാൽ അവരെ പിരിച്ചു വിടുമെന്നുള്ളത് തീർച്ചയാണ്. 0-1-2-3-4

18. ഈ അസുഖം ഉള്ളവർ വിവാഹം കഴിക്കാൻ പാടില്ല എന്ന് എനിക്ക് തോന്നുന്നു. 0-1-2-3-4

19. അസുഖം കാരണം എനിക്ക് ഒഴിവു ദിവസം കാര്യമായി ക്രമീകരിക്കുവാൻ സാധിക്കുന്നില്ല. 0-1-2-3-4

20. എനിക്ക് മനസ്സ് തുറന്ന് സന്തോഷിക്കുവാൻ ഈ അസുഖം മൂലം സാധിക്കുന്നില്ല. 0-1-2-3-4

21. ഈ രോഗം മൂലം വ്യായാമം ചെയ്യാൻ എനിക്ക് കുറച്ചെ സാധിക്കുന്നുള്ളൂ. 0-1-2-3-4

22. ഈ അസുഖം തുടങ്ങിയതു മുതൽ മറ്റുള്ളവരിൽ നിന്നും വ്യത്യസ്തനായി എനിക്ക് തോന്നുന്നു. 0-1-2-3-4

23. ഈ രോഗം കാരണം എന്റെ കുടുംബം എന്നെ വ്യത്യസ്തനായാണ് കണക്കാക്കുന്നത്. 0-1-2-3-4

24. എന്റെ അസുഖത്തിന് തന്ന മരുന്നുകൾ കൊണ്ട് ഒരു പ്രയോജനവും ഉളതായി തോന്നുന്നില്ല. 0-1-2-3-4

25. എന്റെ കുഴപ്പം എന്തെന്ന് ഡോക്ടർമാർക്ക് മനസ്സിലായതായി തോന്നുന്നില്ല. 0-1-2-3-4

26. എന്റെ അസുഖം തുടങ്ങിയതു മുതൽ കാര്യങ്ങളെല്ലാം തകരാറിലായി എന്ന് തോന്നുന്നു. 0-1-2-3-4

27. എന്റെ അസുഖം കാരണം ഞാൻ മറ്റുള്ളവർക്ക് ഒരു ഭാരമായെന്ന് തോന്നുന്നു. 0-1-2-3-4

28. അസുഖം തുടങ്ങിയതു മുതൽ എല്ലാക്കാര്യങ്ങളും ക്ലേശകരമായി തോന്നുന്നു. 0-1-2-3-4

29. എന്റെ അസുഖം കാരണം ഞാൻ മറ്റുള്ളവരിൽ നിന്നും വ്യത്യസ്തനാണെന്ന് തോന്നുന്നു. 0-1-2-3-4

30. ജന്നി വരുമെന്നതിനാൽ പുറത്തു പോകുന്നത് അസുഖകരമായി തോന്നുന്നു. 0-1-2-3-4

31. ജോലി സ്ഥലത്തോ/പൊതു സ്ഥലത്തോ വെച്ച് അസുഖമുണ്ടായാൽ എനിക്ക് അതൊരു കുറച്ചിലാകും. 0-1-2-3-4

32. ഈ അസുഖം ഉള്ളവർക്ക് കുട്ടികൾ ഉണ്ടാകുന്നത് ശരിയല്ല എന്ന് എനിക്ക് തോന്നുന്നു. 0-1-2-3-4

33. ജന്നി ഉണ്ടാകുന്നത് കാരണം ഞാൻ യാത്ര ചെയ്യാൻ പ്രത്യേക സജ്ജീകരണങ്ങൾ നടത്താറുണ്ട്. 0-1-2-3-4

34. അസുഖം കാരണം എന്റെ സാമൂഹ്യ ജീവിതം കുറഞ്ഞിട്ടുണ്ട്. 0-1-2-3-4

35. എന്റെ വിനോദ പരിപാടികൾ ഈ അസുഖം നിമിത്തം കുറഞ്ഞതായി തോന്നുന്നു. 0-1-2-3-4

36. എന്റെ അസുഖം നിമിത്തം എനിക്ക് എന്റെ ഭാവിയെക്കുറിച്ച് അത്ര ഉറപ്പില്ല. 0-1-2-3-4

37. എനിക്ക് അസുഖമുള്ളതു കൊണ്ട് എന്റെ കുടുംബം എന്നെ കുറ്റപ്പെടുത്തുന്നതായി തോന്നുന്നു. 0-1-2-3-4

38. എന്റെ അസുഖത്തിന് മരുന്ന് കഴിക്കാൻ എനിക്ക് വൈമുഖ്യമാണ്. 0-1-2-3-4

39. എനിക്ക് തോന്നുന്നത് എന്റെ ചികിത്സ തൃപ്തികരമല്ലെന്നാണ്. 0-1-2-3-4

40. അപസ്മാരം കാരണം എന്റെ ജീവിതം അവതാളത്തിലായെന്ന് എനിക്ക് തോന്നുന്നു. 0-1-2-3-4

41. അസുഖമുള്ളത് കാരണം മറ്റുള്ളവരുമായി ഒത്തുപോകാൻ വിഷമമാണ്. 0-1-2-3-4

42. അസുഖം കാരണം ഞാൻ പെട്ടെന്ന് ക്ഷീണിതനാകുന്നു. 0-1-2-3-4

WASHINGTON PSYCHO-SOCIAL SEIZURE INVENTORY QUALITY OF LIFE (WPSIQOL)

(Developed by Carl. B. Dordill, 1995)

Malayalam Adaptation : **Dr. Sanjeev V. Thomas.**
Department of Neurology, SCTIMST, Trivandrum - 695 011
(1997)

1. നിങ്ങൾക്ക് പതിവായി ക്ഷീണം തോന്നാറുണ്ടോ ? ഉണ്ട്/ഇല്ല
2. നിങ്ങളുടെ മാനസികനില തെറ്റുന്നുണ്ടെന്ന് തോന്നാറുണ്ടോ ? ഉണ്ട്/ഇല്ല
3. വ്യക്തമായി ചിന്തിക്കുന്നതിന് നിങ്ങൾക്ക് കഴിയുന്നുണ്ടോ ? ഉണ്ട്/ഇല്ല
4. മനസ്സ് ഏകാഗ്രമാക്കുന്നതിന് നിങ്ങൾക്ക് ബുദ്ധിമുട്ടുണ്ടോ ? ഉണ്ട്/ഇല്ല
5. നിങ്ങൾ ചീത്ത ദിവസങ്ങളെക്കാൾ നല്ല ദിവസങ്ങളാണോ അനുഭവിച്ചിട്ടുള്ളത് ? അതെ/അല്ല
6. ഭാവിയെക്കുറിച്ച് നിങ്ങൾക്ക് അകാരണമായി ഭയം തോന്നാറുണ്ടോ ? ഉണ്ട്/ഇല്ല
7. നിങ്ങൾ സമൂഹത്തിന് പ്രയോജനമുള്ള വ്യക്തിയാണെന്ന് ബോദ്ധ്യമായിട്ടുണ്ടോ ? അതെ/അല്ല
8. നിങ്ങൾ ഉറക്കത്തിൽ നിന്ന് എഴുന്നേൽക്കുമ്പോൾ വിശ്രമിച്ചതിന്റെ ഉന്മേഷം തോന്നാറുണ്ടോ ? ഉണ്ട്/ഇല്ല
9. നിങ്ങളുടെ ഇപ്പോഴത്തെ ജീവിതത്തിൽ നിങ്ങൾ സംതൃപ്തനാണോ ? അതെ/അല്ല
10. സാധാരണ ആധിയിൽ നിന്നും പിരിമുറുക്കത്തിൽ നിന്നും നിങ്ങൾ മുക്തനാണോ ? അതെ/അല്ല
11. അപസ്മാരം നിങ്ങൾ ചെയ്യുന്ന ജോലിയിൽ പരമാവധി സന്തോഷം നേടുന്നതിൽ നിങ്ങളെ തടയുന്നുണ്ടോ ? ഉണ്ട്/ഇല്ല
12. വ്യക്തമായി ചിന്തിക്കുന്നതിനുള്ള കഴിവ് നിങ്ങൾക്ക് നഷ്ടപ്പെടുന്നുണ്ടോ ? ഉണ്ട്/ഇല്ല
13. ഏത് സാഹചര്യവും ഭംഗിയായി കൈകാര്യം ചെയ്യാനുള്ള കഴിവ് നിങ്ങൾക്ക് നഷ്ടപ്പെടുന്നുണ്ടോ ? ഉണ്ട്/ഇല്ല
14. നിങ്ങൾക്ക് താൽപര്യമുള്ള പ്രവർത്തികൾ കൊണ്ട് നിറഞ്ഞതാണോ നിങ്ങളുടെ ജീവിതം ? അതെ/അല്ല
15. നിങ്ങൾ എപ്പോഴും സന്തോഷവാനാണോ ? അതെ/അല്ല
16. നിങ്ങൾ മരുന്നു കഴിക്കുന്നതിനാൽ നിങ്ങളുടെ പ്രവർത്തനക്ഷമത കുറഞ്ഞിട്ടുണ്ടോ ? ഉണ്ട്/ഇല്ല
17. നിങ്ങൾക്ക് എപ്പോഴും പരിഭ്രമവും ആകാംക്ഷയും തോന്നാറുണ്ടോ ? ഉണ്ട്/ഇല്ല
18. നിങ്ങൾക്ക് ആവശ്യത്തിനുള്ള ആത്മവിശ്വാസമുണ്ടോ ? ഉണ്ട്/ഇല്ല
19 അപസ്മാരബാധ മൂലം നിങ്ങൾ മറ്റുള്ളവരിൽ നിന്ന് വ്യത്യസ്തനാണെന്ന് തോന്നിയിട്ടുണ്ടോ ? ഉണ്ട്/ഇല്ല
20. സന്നി വരുമോ എന്ന് എപ്പോഴും നിങ്ങൾ ഭയപ്പെടുന്നുണ്ടോ ? ഉണ്ട്/ഇല്ല
21. നിങ്ങളുടെ ചിലവുകൾക്ക് ആവശ്യമായ പണമുണ്ടോ ? ഉണ്ട്/ഇല്ല

Appendix No VIII

QUALITY OF LIFE IN EPILEPSY

(QOLIE : 31, VERSION:1.0)

(Developed by : **Cramer J.A, 1993**)

Malayalam Translation & Standardization : **D. Jayachandran, Dr. K.A. Kumar.**
Department of Behavioural Sciences
Mahatma Gandhi University, Kottayam

PATIENT INVENTORY

NAME:

HOSP. NO:

AGE: MALE / FEMALE

ഈ ചോദ്യാവലി നിങ്ങളുടെ ആരോഗ്യത്തെയും ദിനചര്യയേയും സംബന്ധിച്ചുള്ളതാണ്. ഒരു ചോദ്യത്തിന്റെ തക്കതായ ഉത്തരം രേഖപ്പെടുത്തുവാൻ അറിയില്ലെങ്കിൽ ഏറ്റവും യോജിച്ച ഉത്തരം രേഖപ്പെടുത്തിയിട്ട് ഒരു വിശദീകരണം അടിക്കുറിപ്പായി നല്കാവുന്നതാണ്. ഈ ചോദ്യാവലി വായിച്ചു തരുന്നതിനും, പൂരിപ്പിക്കുന്നതിനും ഒരു സഹായിയെ ഉപയോഗിക്കാവുന്നതാണ്.

1. നിങ്ങളുടെ ജീവിതത്തിന്റെ പൊതുവായ മേന്മ എത്രമാത്രമുണ്ട് എന്ന് ഈ സൂചികയിൽ അടയാളപ്പെടുത്തുക.

10	9	8	7	6	5	4	3	2	1
ഏറ്റവും മെച്ചമാണ്									വളരെ കഷ്ടമാണ് (മരിക്കുന്നതാണ് ഇതിലും ഭേദം)

കഴിഞ്ഞ ഒരു മാസം ജീവിതം നിങ്ങൾക്കെങ്ങിനെ ഉണ്ടായിരുന്നു എന്നതിനെ സംബന്ധിച്ച കാര്യങ്ങളാണ് താഴെയുള്ള ചോദ്യങ്ങൾ.

2. എത്ര സമയം നിങ്ങൾ ഉന്മേഷവാനായിരുന്നു ?
   1. എല്ലായ്പ്പോഴും
   2. മിക്കപ്പോഴും
   3. കൂടെക്കൂടെ
   4. ചിലപ്പോഴൊക്കെ
   5. വല്ലപ്പോഴും
   6. ഒരിക്കലും ഇല്ല

3. നിങ്ങളുടെ കാര്യങ്ങളിൽ നിങ്ങൾ വളരെ ആകാംക്ഷാഭരിതനാണോ ?
   1. എല്ലായ്പ്പോഴും
   2. മിക്കപ്പോഴും
   3. കൂടെക്കൂടെ
   4. ചിലപ്പോഴൊക്കെ
   5. വല്ലപ്പോഴും
   6. ഒരിക്കലും ഇല്ല

4. നിങ്ങൾ നിരാശയുടെ പടുകുഴിയിൽ ആണെന്നും, ഒന്നിനും നിങ്ങളെ പ്രസന്നനാക്കാൻ കഴിയില്ലെന്നും ഉള്ള തോന്നൽ ഉണ്ടോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

5. നിങ്ങൾക്ക് സ്വച്ഛതയും സമാധാനവും തോന്നുന്നുണ്ടോ .

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

6. നിങ്ങൾക്ക് വളരെ ഉത്സാഹമുണ്ടായിരുന്നോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

7. നിങ്ങൾക്ക് വളരെ നിരാശയും ദു:ഖവും തോന്നിയിരുന്നോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

8. നിങ്ങൾക്ക് വളരെ തളർച്ച തോന്നിയിരുന്നോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

9. നിങ്ങൾ വളരെ സന്തോഷവാനായിരുന്നോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

10. നിങ്ങൾക്ക് ക്ഷീണമുണ്ടായിരുന്നോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

11. ഇനിയും ഒരു സന്നിയുണ്ടാകും എന്ന ചിന്ത നിങ്ങളെ അലട്ടിയിരുന്നോ ? 1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

12. പ്രശ്നങ്ങൾ അപഗ്രഥിച്ച് അനുയോജ്യമായ തീരുമാനങ്ങൾ എടുക്കുന്നതിന് നിങ്ങൾക്ക് പ്രയാസമുണ്ടോ ?
(അതായത് പുതിയ കാര്യങ്ങൾ മനസ്സിലാക്കുക, തീരുമാനങ്ങൾ എടുക്കുക, രൂപരേഖയുണ്ടാക്കുക എന്നിങ്ങനെ)

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

13. നിങ്ങളുടെ ആരോഗ്യം നിങ്ങളുടെ സാമൂഹിക ബന്ധങ്ങളെ ബാധിച്ചിട്ടുണ്ടോ?
(ബന്ധുക്കളെ സന്ദർശിക്കുക, വിവാഹങ്ങളിലും മറ്റും പങ്കെടുക്കുക.)

1.എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4.ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

14. കഴിഞ്ഞ ഒരു മാസം നിങ്ങളുടെ ജീവിതം എത്രമാത്രം കേമമായിരുന്നു?
(അതായത് പൊതുവേ കാര്യങ്ങൾ എങ്ങനെയുണ്ടായിരുന്നു)

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

താഴെയുള്ള ചോദ്യങ്ങൾ ഓർമ്മയെ സംബന്ധിച്ചുള്ളതാണ്.

15. കഴിഞ്ഞ നാലാഴ്ച നിങ്ങൾക്ക് ഓർമ്മക്കുറവ് കൊണ്ട്
എന്തെങ്കിലും പ്രശ്നങ്ങളുണ്ടായോ ?

1. ഉവ്വ്, വളരെ
പ്രശ്നങ്ങളുണ്ടായി
2. ഉവ്വ്, കുറെയൊക്കെ
3. അല്പമൊക്കെ
4. ഇല്ല, അശേഷം ഇല്ല

കഴിഞ്ഞ നാലാഴ്ചകളിൽ എത്ര പ്രാവശ്യം നിങ്ങൾക്ക് ഓർമ്മക്കുറവ് ഉണ്ടായി അഥവാ ഓർമ്മക്കുറവ് നിങ്ങളുടെ സാധാരണ ജീവിതത്തെ എങ്ങനെ ബാധിച്ചു എന്ന് താഴെകൊടുത്തിരിക്കുന്ന സൂചികയിൽ അടയാളപ്പെടുത്തുക.

16. മറ്റുള്ളവർ പറയുന്ന കാര്യങ്ങൾ ഓർമ്മയിൽ വയ്ക്കുന്നതിന് പ്രയാസമുണ്ടോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

17. ശ്രദ്ധകേന്ദ്രീകരിച്ച് വായിക്കുന്നതിന് തടസ്സമുണ്ടോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

18. കാര്യങ്ങൾ ഏകാഗ്രതയോടെ ചെയ്യുന്നതിന് തടസ്സമുണ്ടോ ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

ചില പ്രവൃത്തികൾ ഏർപ്പെടുന്നതിന് അപസ്മാരവും അതിനുള്ള മരുന്നുകളും മൂലം നിങ്ങൾക്കുണ്ടായിട്ടുള്ള തടസ്സങ്ങളെ സംബന്ധിച്ചുള്ള ചോദ്യങ്ങളാണ് താഴെ കൊടത്തിരിക്കുന്നത്.

19. ഉല്ലാസ പ്രവൃത്തികളിൽ ഏർപ്പെടുന്നതിന് എത്രത്തോളം വിഘാതം ഉണ്ടാക്കിയിട്ടുണ്ട് ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

20. ഡ്രൈവിംഗ് അഥവ ഒറ്റയ്ക്ക് യാത്ര ചെയ്യുന്നതിന് ?

1. എല്ലായ്പ്പോഴും
2. മിക്കപ്പോഴും
3. കൂടെക്കൂടെ
4. ചിലപ്പോഴൊക്കെ
5. വല്ലപ്പോഴും
6. ഒരിക്കലും ഇല്ല

താഴെയുള്ള ചോദ്യങ്ങൾ നിങ്ങളുടെ സന്നി നിങ്ങളെ എങ്ങനെ ബാധിക്കുന്നു എന്നതിനെക്കുറിച്ചാണ്:

21. അടുത്ത ഒരു മാസത്തിനുള്ളിൽ തന്നെ വീണ്ടും സന്നിയുണ്ടാകും എന്ന ഭയം നിങ്ങളെ എത്രത്തോളം അലട്ടുന്നുണ്ട് ?

1. വളരെയധികം ഭയമുണ്ട്
2. കുറെയൊക്കെ ഭയമുണ്ട്
3. അല്പം ഭയമുണ്ട്
4. തെല്ലും ഭയമില്ല

22. സന്നിയുണ്ടാകുമ്പോൾ നിങ്ങൾക്ക് ശരീരഹാനി സംഭവിയ്ക്കും എന്ന് ഭയമുണ്ടോ?

1. വളരെ ഭയമുണ്ട്
2. ചിലപ്പോഴൊക്കെ ഭയമുണ്ട്
3. തെല്ലും ഭയമില്ല

23. അടുത്തുതന്നെ (ഒരു മാസത്തിനുള്ളിൽ) ഒരു സന്നിയുണ്ടായിട്ട് എന്തെങ്കിലും സാമൂഹിക പ്രശ്നങ്ങളോ അതുമൂലമുള്ള മറ്റ് ബുദ്ധിമുട്ടുകൾ ഉണ്ടാകാം എന്ന ഭയമുണ്ടോ ?

1. വളരെയധികം ഭയമുണ്ട്
2. കുറെയൊക്കെ ഭയമുണ്ട്
3. അത്രയ്ക്ക് ഭയമില്ല
4. അശേഷം ഭയമില്ല

24. നിങ്ങളുടെ മരുന്നുകൾ, ദീർഘകാലം ഉപയോഗിക്കുമ്പോൾ ശരീരത്തിന് ഹാനികരമാകുമെന്ന് ഭയമുണ്ടോ ?

1. വളരെയധികം ഭയമുണ്ട്
2. കുറെയൊക്കെ ഭയമുണ്ട്
3. അത്രയ്ക്ക് ഭയമില്ല
4. അശേഷം ഭയമില്ല

താഴെക്കൊടുത്തിരിക്കുന്ന പ്രശ്നങ്ങൾ നിങ്ങളെ എത്രമാത്രം അലട്ടുന്നു എന്ന് താഴെക്കൊടുത്തിരിക്കുന്ന സൂചികയിൽ അടയാളപ്പെടുത്തുക.

		അശേഷം അലട്ടുന്നില്ല			വളരെയധികം അലട്ടുന്നുണ്ട്	
25.	സന്നി	1	2	3	4	5
26.	ഓർമ്മക്കുറവ്	1	2	3	4	5
27.	ജോലിക്കുള്ള തടസ്സം	1	2	3	4	5
28.	സാമൂഹിക തടസ്സം	1	2	3	4	5
29.	മരുന്നിന്റെ ശാരീരിക പാർശ്വഫലം	1	2	3	4	5
30.	മരുന്നിന്റെ മാനസിക പാർശ്വഫലം	1	2	3	4	5

Appendix No IX

അപസ്മാരം

കൗൺസിലിംഗ് / പരിശീലന മാർഗരേഖ

(വൈദ്യശാസ്ത്ര - സാമൂഹികവശങ്ങൾ)

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School of Behavioural Sciences
Mahatma Gandhi University, Kottayam

- അപസ്മാരം ദീർഘനാൾ നീണ്ടുനിൽക്കുന്നതും സമൂഹത്തിൽ അവജ്ഞയുളവാക്കുന്നതും ഗുരുതരമായ - സാമൂഹ്യ - മാനസിക പ്രത്യാഖ്യാതങ്ങൾ ഉള്ളതുമായ ഒരു രോഗമാണ്.
- ലോകത്തിലെ ഏതൊരു രാജ്യത്തും കൂടുതൽ ആൾക്കാരിൽ കണ്ടുവരുന്ന മസ്തിഷ്ക സംബന്ധമായ ഒരു രോഗമാണ് അപസ്മാരം
- ഏകദ്ദേശം അഞ്ച് ശതമാനത്തോളം ആൾക്കാരുടെ ജീവിതത്തിൽ എപ്പോഴെങ്കിലും ഒന്നോ അതിലധികമോ പ്രവശ്യം ജന്നി ഉണ്ടാകുന്നതായി കണ്ടുവരുന്നു.
- ലോകത്തിലാകമാനം ഏതൊരു സമയം എടുത്താലും ഏകദ്ദേശം 40-50 ദശലക്ഷം ആൾക്കാർക്ക് അപസ്മാര രോഗമുള്ളതായി കാണുന്നു.
- അപസ്മാര രോഗം ലോകത്തിൽ സാർവ്വത്രികമാണ്. അപസ്മാരത്തിന് പ്രായ-ലിംഗഭേദമനുസരിച്ചോ, വംശീയമായോ, ഭൂമിശാസ്ത്രപരമായോ, പ്രാദേശികമായോ അതിർവരമ്പുകൾ ഇല്ല.
- അപസ്മാരം പ്രധാനപ്പെട്ട ഒരു പൊതുജനാരോഗ്യപ്രശ്നവും എടുത്തുപറത്തക്ക സാമ്പത്തിക ബാദ്ധ്യതയുള്ളതുമായ ഒരു രോഗമാണ്.
- ആരംഭത്തിൽതന്നെ രോഗ നിർണ്ണയവും, ചികിത്സയും തുടങ്ങിയാൽ മുക്കാൽഭാഗം രോഗമുള്ളവരിലും രോഗനിയന്ത്രണം സാധ്യമാണ്.
- അപസ്മാരം എടുത്തപറയത്തക്ക ഒരു സാമ്പത്തിക ബാദ്ധ്യതയാണ്.

വൈദ്യശാസ്ത്രവശങ്ങൾ

എന്താണ് അപസ്മാരം?

- അടിക്കടി ജന്നിയുണ്ടാകുന്നതിനുള്ള പ്രവണതയാണ് അപസ്മാരം.
- തലച്ചോറിലെ ന്യൂറോൺസ് കോശങ്ങളിൽ പെട്ടെന്നുണ്ടാകുന്നതും, അനിയന്ത്രിതവുമായ വൈദ്യുത ഡിസ്ചാർജ്ജ് മൂലമാണ് ജന്നിയുണ്ടാകുന്നത്.
- ജന്നിയുടെ പ്രകടമായ ലക്ഷണങ്ങളിൽ കൂടുതലായി കണ്ടുവരുന്നത് ബോധം നഷ്ടപ്പെടുക, പരിസരബോധം ഇല്ലാതാവുക, ശരീരഭാഗങ്ങളുടെ ചലനത്തിലുണ്ടാകുന്ന മാറ്റങ്ങൾ, ഇവ കൂടാതെ കാഴ്ച, കേൾവി, രുചി ഇവയിലുണ്ടാകുന്ന വ്യത്യാസങ്ങൾ എന്നിവയാണ്.
- സാധാരണയായി അപസ്മാരം പ്രത്യക്ഷപ്പെടുന്നത് : ഏറ്റവും ചുരുങ്ങിയ സമയത്തേക്ക് അനുഭവപ്പെടുന്ന ശ്രദ്ധക്കുറവ് മുതൽ പേശികളിൽ ഉണ്ടാകുന്ന കോച്ചൽ തുടങ്ങി ദീർഘവും, ശക്തവുമായ ജന്നിവരെയാണ്.

വിവിധതരം അപസ്മാരം

അപസ്മാരത്തെ പൊതുവെ രണ്ടായി തരം തരിക്കാം.

- പൂർണ്ണ അപസ്മാരവും 2. ഭാഗിക അപസ്മാരവും

പൂർണ്ണ അപസ്മാരം : ഇതിൽ രോഗിക്ക് പൂർണ്ണമായും ബോധം നഷ്ടപ്പെടുകയും, വീഴുകയും, കൈകാലിട്ടടിക്കുകയും ചെയ്യുന്നു. എന്നാൽ ഈ ലക്ഷണങ്ങൾ ആബ്സന്റ്സ് ജന്നിയിൽ കാണുന്നില്ല.

ഭാഗിക അപസ്മാരം : ഇതിൽ കുടുതലായി കണ്ടുവരുന്നത് സങ്കീർണ്ണ അപസ്മാരമാണ്.

അപസ്മാരത്തിന്റെ കാരണങ്ങൾ

- ജനനസമയത്തുണ്ടാകുന്ന ക്ഷതങ്ങൾ / തലയ്ക്കുണ്ടാകുന്ന മുറിവുകൾ
- കേന്ദ്രനാഡീവ്യൂഹത്തിനുണ്ടാകുന്ന പഴുപ്പുകൾ (മെനിഞ്ചൈറ്റിസ്, എൻസഫലൈറ്റിസ്)
- പാരസൈറ്റ് ഇൻഫെക്ഷൻ (ന്യൂറോസിസ്റ്റി സർക്കോസിസ്)
- തലച്ചോറനെ ബാധിക്കുന്ന ക്ഷയരോഗം
- തലച്ചോറിലെ മുഴകൾ
- പക്ഷാഘാതം എന്നിവയാണ്.
- എന്നാൽ മുപ്പത് മുതൽ അമ്പത് ശതമാനം വരെ കേസുകളിൽ മാത്രമേ അപസ്മാരത്തിന്റെ ശരിയായ കാരണം കണ്ടെത്തുവാൻ കഴിയുകയുള്ളൂ. അപസ്മാരം ഉണ്ടാകുന്നതിന് ജനിതകമായ കാരണങ്ങളും ഉള്ളതായി മനസ്സിലാക്കുന്നു.

രോഗനിർണ്ണയം

- വളരെ കൃത്യമായ രോഗചിത്രമാണ് രോഗനിർണ്ണയത്തിന്റെ മൂലക്കല്ല്. ഏറ്റവും ആശ്രയിക്കാവുന്നത് ഒരു ദൃക്സാക്ഷിയിൽ നിന്നും ലഭിക്കുന്ന കൃത്യമായ രോഗവിവരണമാണ്.
- വൈദ്യശാസ്തപരിശോധനകൾ : ഇലക്ട്രോ എൻസഫലോഗ്രാം, വീഡിയോ ഇ. ഇ. ജി. കൂടാതെ എം. ആർ. ഐ. സ്കാൻ എന്നിവയും രോഗനിർണ്ണയത്തെ സഹായിക്കും.

അപസ്മാരത്തിന് പ്രഥമ ശുശ്രൂഷ

- ഒരു തുറന്ന സ്ഥലത്ത് ജന്നി ഉണ്ടാകുന്ന വ്യക്തിയെ കിടക്കാൻ അനുവദിക്കുക.
- ജന്നി ഉണ്ടാകുന്ന വ്യക്തിക്ക് മുറിവോ ക്ഷതമോ ഏൽപ്പിക്കാൻ സാധ്യതയുള്ള വസ്തുക്കൾ പരിസരത്ത് ഉണ്ടെങ്കിൽ അത് മാറ്റുക.
- മുറികിയ വസ്ത്രങ്ങൾ അയച്ചുകൊടുക്കുകയും കണ്ണടകൾ ഉണ്ടെങ്കിൽ അതു മാറ്റുക
- നാക്ക് കടിച്ചുമുറിക്കുന്നത് ഒഴിവാക്കാനായി രോഗം വരുന്ന വ്യക്തിയുടെ വായിൽ ഒന്നും തിരുകി കയറ്റാതിരിക്കുക.
- ജന്നി വന്നു കൊണ്ടിരിക്കുമ്പോൾ ആ വ്യക്തിക്ക് ഒന്നും കുടിക്കാൻ കൊടുക്കരുത്. ജന്നി വന്നു കൊണ്ടിരിക്കുന്ന ആളിന്റെ വായിൽ നിന്നുള്ള സ്രവങ്ങൾ സുഗമമായി പുറത്തുപോകത്തക്ക രീതിയിൽ ഒരു വശത്തേക്ക് ചരിച്ച് കിടത്തുക

ചികിത്സ

- ചികിത്സയുടെ അത്യന്തികമായ ലക്ഷ്യം ജീവിതമേന്മയാണ്. ഇത് സാദ്ധ്യമാകുന്നത് അടിക്കടിയുണ്ടാകുണ്ടാകുന്ന ജന്നിയിൽ നിന്നുള്ള രോഗിയുടെ മോചനം. മരുന്നിന്റെ കുറഞ്ഞ പാർശ്വഫലങ്ങൾ, സാധാരണ സാമൂഹ്യജീവിതം, രോഗിയുടെ സാമ്പത്തിക ഭദ്രത എന്നിവയിലൂടെയാണ്.
- മരുന്നു ചികിത്സ കൊണ്ട് 75 ശതമാനം രോഗബാധിതരിലും രോഗമുക്തി സാദ്ധ്യമാണ്.
- 3/2 ഭാഗം രോഗികൾക്ക് മരുന്നുകൊണ്ട് തന്നെ രോഗശമനം സാധ്യമാണ്.

ലഭ്യമായ ചികിത്സാരീതി

- മരുന്നുകൾ കൊണ്ടുള്ള ചികിത്സ
- അപസ്മാര ശസ്ത്രക്രീയ
- മാനസിക - സാമൂഹിക ചികിത്സാക്രമങ്ങൾ

ചികിത്സാ തത്വങ്ങൾ

- ഒരുതരം / ഒരിനം മരുന്ന് നൽകികൊണ്ടുള്ള ചികിത്സാ രീതി
- മരുന്നും ചികിത്സാ നിർദ്ദേശങ്ങളും കൃത്യമായി പാലിക്കുക
- മരുന്നു ചികിത്സ കൊണ്ട് ഭേദമാകാത്തവരെ അനുയോജ്യമായ വിശദപരിശോധനകൾ നടത്തുക.
- മാനസിക സാമൂഹിക ചികിത്സാ രീതികളുടെ പ്രയോഗം എന്നിവയാണ്.

ചികിത്സയുടെ കാലയളവ്.

- ചികിത്സയുടെ കാലയളവ് അപസ്മാരം ഏത് തരത്തിലുള്ളതാണെന്ന് ആശ്രയിച്ചിരിക്കും.
- ചിലതരം അപസ്മാരത്തിന് ഒന്നോ രണ്ടോ വർഷത്തെ ചികിത്സ മതിയാകും
  ഉദാ. കുട്ടികളിൽ കണ്ടുവരുന്ന ബെനെയിൻ എപ്പിലെപ്സി
- ചിലയിനം അപസ്മാരത്തിന് ദീർഘനാൾ തുടർന്നുള്ള ചികിത്സ ആവശ്യമാണ്.
  ഉദാ. ടെമ്പർലോബ് എപ്പിലെപ്സി.
- മറ്റ് ചിലയിനം അപസ്മാരത്തിന് കാലാവധി നിശ്ചയിക്കാൻ കഴിയാത്തവിധം ചികിത്സ ആവശ്യമാണ്.
  ഉദാ. ജുവനൈൽ മയോക്ലോണിക് എപ്പിലെപ്സി

സാമൂഹിക വശങ്ങൾ

- അപസ്മാരമുള്ള വ്യക്തികൾക്ക് സാമൂഹികവും മാനസികവും ആയ ബുദ്ധിമുട്ടുകൾ അനുഭവപ്പെടാം.
- അപസ്മാരമുള്ള ഓരോ വ്യക്തിയും അപസ്മാരത്തെ വ്യത്യസ്ഥ രീതിയിലാണ് അനുഭവിക്കുന്നത്.
- അപസ്മാരത്തെക്കാൾ കൂടുതൽ അവശത ഉണ്ടാത്തുന്നത് സാമൂഹിക മാനസിക പ്രശ്നങ്ങളാണ്.

അപസ്മാരവും വിദ്യാഭ്യാസവും

- അപസ്മാരമുള്ള കുട്ടികളെ, സാധരണ കുട്ടികളെപ്പോലെ കണക്കാക്കുകയും അമിത ലാളനയും അവഗണനയും ഒഴിവാക്കുകയും വേണം.
- ഭൂരിഭാഗം അപസ്മാരമുള്ളവർക്കും സ്കൂളിൽ പോയി പഠിക്കാനും, ഉന്നതവിദ്യാഭ്യാസത്തിനും സാധിക്കും.
- അപൂർവമായി ഉണ്ടാകുന്ന ജന്നി കാരണം കുട്ടികൾ സ്കൂളിൽ പോകുന്നത് നിർത്തരുത്.
- അപസ്മാരമുള്ള കുട്ടികളെ കായിക പരിപാടികൾ ഉൾപ്പെടെയുള്ള പ്രവർത്തനങ്ങളിൽ പങ്കെടുപ്പിക്കേണ്ടതാണ്.
- അപസ്മാരമുള്ള കുട്ടികളിൽ ചിലർക്ക് പഠിക്കുവാനുള്ള ബുദ്ധിമുട്ട്, ശ്രദ്ധിച്ചിരിക്കുവാനുള്ള ബുദ്ധിമുട്ട് അല്ലെങ്കിൽ ഓർമ്മക്കുറവ് ഇവ അനുഭവപ്പെടാം.
- പരീക്ഷാസമയങ്ങളിൽ അപസ്മാരമുള്ള കുട്ടികൾ, ശീലമില്ലാത്ത ഉറക്കമൊഴിയൽ ഒഴിവാക്കേണ്ടതാണ്, കാരണം ഉറക്കമൊഴിച്ചിൽ അപസ്മാരം ഉണ്ടാകാനുള്ള സാധ്യത വർദ്ധിപ്പിക്കും.
- ഗുരുതരമായ പഠന വൈകലമുള്ള കുട്ടികൾക്ക് വിദഗ്ധ സഹായമോ, പ്രത്യേക സ്കൂൾ പഠനമോ ആവശ്യമായി വന്നേക്കാം.

അപസ്മാരവും ജോലിയും

- അപസ്മാരമുള്ളവർ വിലമതിക്കത്തക്ക തരത്തിൽ ജോലികൾ ചെയ്യാൻ കഴിവുള്ളവരാണ്. അതിനായി അവർക്ക് അനുയോജ്യമായ ജോലി നൽകുകയും വേണ്ടിവന്നാൽ അവരെക്കൂടി ഉൾക്കൊള്ളാൻ ആവശ്യമായ അധിക സൗകര്യങ്ങൾകൂടി ചെയ്തുകൊടുക്കുകയും വേണം
- അപസ്മാരം നിയന്ത്രണത്തിലാണെങ്കിൽ, അപസ്മാരമുള്ള വ്യക്തികൾക്ക് മിക്കവാറും എല്ലാ ജോലികളും ചെയ്യാവുന്നതാണ് എന്നാൽ താഴെപ്പറയുന്ന ജോലികൾ അനുയോജ്യമല്ല.
  1. ബസ് ഓടിക്കുക / തിരക്കുള്ള നിരത്തുകളിൽ വണ്ടിയോടിക്കുക.
  2. ഭാരിച്ചതും, അപകടസാധ്യതയുള്ളതുമായ യന്ത്രങ്ങളുമായുള്ള ജോലികൾ
  3. ഉയരങ്ങളിൽ ഉള്ള ജോലി

അപസ്മാരവും വിവാഹവും

- അപസ്മാരമുള്ള വ്യക്തികൾക്ക് സാധാരണ വിവാഹ ജീവിതം നയിക്കുവാനും ആരോഗ്യമുള്ള കുട്ടികൾക്ക് ജന്മം നൽകുവാനും കഴിയും.

- സാമൂഹ്യമായിട്ടുള്ള വിലക്കുകൾ / അബദ്ധധാരണകൾ അപസ്മാരമുള്ള വ്യക്തികളുടെ വിവാഹത്തിന് തടസ്സമാകാറുണ്ട്. ഇത്തരം വിലക്കുകൾ കൂടുതലായി ബാധിക്കുന്നത് സ്ത്രീകളെയാണ്.

- അസുഖം ഉള്ള കാര്യം വിവാഹം കഴിക്കാൻ പോകുന്ന ആളിനെ മുൻകൂട്ടി അറിയിക്കുന്നത് ഭാവിയിൽ ഇതുമൂലം ഉണ്ടാകാവുന്ന തെറ്റിദ്ധാരണകൾ ഒഴിവാക്കുവാൻ സഹായിക്കും.

- അപസ്മാരമുള്ള വ്യക്തികൾ വിവാഹം, ഗർഭധാരണം എന്നീ അവസരങ്ങളിൽ വിദഗ്ധ ഉപദേശം തേടേണ്ടതാണ്.

ജീവിത ഗുണമേന്മ (ക്വാളിറ്റി ഓഫ് ലൈഫ്)

- ജീവിത ഗുണമേന്മ എന്നത് ഒരു വ്യക്തിയുടെ ഭൗതിക, മാനസിക, സാമൂഹ്യ ആരോഗ്യതലങ്ങളിൽ തന്റെ സ്ഥാനത്തെക്കുറിച്ചുള്ള അവബോധമാണ്.
- ഒരു വ്യക്തിയുടെ ജീവിതഗുണമേന്മയും അവന്റെ സാമൂഹിക-മാനസിക പ്രവർത്തനക്ഷമയുടം തമ്മിൽ വളരെ അടുത്ത ബന്ധമുണ്ട്.
- അപസ്മാരരോഗമുള്ള 60% ആൾക്കാർ സാധാരണ ജീവിതം നയിക്കുമ്പോൾ, ബാക്കി 40% ആൾക്കാർക്ക് വിവിധതരം പ്രശ്നങ്ങൾ അഭിമുഖീകരിക്കേണ്ടിവരുന്നു.
- ജീവിതഗുണമേന്മയെ ബാധിക്കുന്ന സാമൂഹിക-മാനസിക പ്രശ്നങ്ങൾ അപസ്മരമുള്ള ആൾക്കാരിൽ സർവ്വസാധാരണമാണ്.
- സാമൂഹികമായ അവജ്ഞ, അപസ്മാരത്തെക്കുറിച്ചുള്ള തെറ്റിദ്ധാരണകൾ തന്നെക്കുറിച്ചുള്ള മോശമായ വിലയിരുത്തലുകൾ, ആത്മാഭിമാനക്കുറവ് ഇവ അപസ്മാരമുള്ളവരുടെ ജീവിത ഗുണമേന്മയെ ബാധിക്കാറുണ്ട്.
- അപസ്മാരമുള്ളവരുടെ ജീവിത ഗുണമേന്മ വർദ്ധിപ്പിക്കുന്നതിനായി അവർക്ക് കുടുംബാംഗങ്ങളിൽ നിന്നും സുഹൃത്തുക്കളിൽ നിന്നും ആവശ്യമായ പിൻബലം നൽകേണ്ടതാണ്.
- തന്നെ ബാധിക്കുന്ന കാര്യങ്ങളിൽ സ്വയം തീരുമാനമെടുക്കാനുള്ള പ്രാപ്തി ജീവിത ഗുണമേന്മ വർദ്ധിപ്പിക്കുന്നതിനും സഹായിക്കും

അപസ്മാരമുള്ളവർ ചെയ്യേണ്ടവ.

- അപസ്മാര രോഗത്തെക്കുറച്ച് കഴിയുന്നത്ര അറിവ് നേടുക.
- ഡോക്ടർ നിർദ്ദേശിക്കുന്നപ്രകാരം മരുന്നുകൾ കൃത്യനിഷ്ഠയോടെ കഴിക്കുക.
- നിങ്ങളുടെ അപസ്മാര പ്രേരകങ്ങളെ കണ്ടെത്തുക.
- ജന്നിയുടെ വിശദാംശങ്ങൾ രേഖപ്പെടുത്തി സൂക്ഷിക്കുക.
- ചിട്ടയായ ഉറക്കം ശീലിക്കുക
- സമീകൃതാഹാരം കഴിക്കുകയും, ആഹാര സമയത്തിന് ചിട്ട പാലിക്കുകയും ചെയ്യുക.
- കഴിയുന്നത്ര സജീവമായി പ്രവർത്തികളിൽ ഏർപ്പെടുകയും സന്തോഷമായിരിക്കുകയും ചെയ്യുക.

അപസ്മാരമുള്ളവർ ചെയ്യരുതാത്തവ.

- സ്വയം മരുന്നുകൾ നിർത്തുകയോ, മരുന്നിന്റെ ബ്രാന്റുകൾ മാറി കഴിക്കുകയോ ചെയ്യരുത്.
- നിരാഹാരം ഒഴിവാക്കുക.
- ഉറക്കം നഷ്ടപ്പെടുത്തരുത്.
- അമിതമായ മാനസിക സംഘർഷങ്ങൾ ഒഴിവാക്കുക.
- മദ്യപാനം, പുകവലി എന്നിവ ഒഴിവാക്കുക.
- അമിതമായി വണ്ണം വയ്ക്കാതിരിക്കുക.

ഓർമ്മിക്കുക.

- അപസ്മാരം ഒരു ശാപമല്ല.
- അപസ്മാരം പകരുന്ന രോഗമല്ല.
- അപസ്മാരം ഉണ്ടെങ്കിലും നിങ്ങൾക്ക് എല്ലാ കഴിവുകളും പ്രയോജനപ്പെടുത്തി ജീവിത വിജയം കൈവരിക്കുവാൻ സാധിക്കും.

Appendix No X

KNOWLEDGE, ATTITUDE AND PRACTICE (KAP)

Dr. K. Radhakrishnan & D. Jayachandran.
Department of Neurology,
Sree Chitra Tirunal Institute for Medical Science & Technology,
Thiruvananthapuram

1995

1. Have you ever heard of a disease called epilepsy? Yes/No
2. Is epilepsy a bodily disease? Yes/No
3. Is epilepsy a mental illness? Yes/No
4. Is epilepsy a disease affecting the brain? Yes/No
5. Is epilepsy a hereditary disease? Yes/No
6. Is it possible for epilepsy patients to lead a married life ? Yes/No
7. Do you think epilepsy affects the education of affected persons? Yes/No
8. Do you think that epilepsy patients can be employed? Yes/No
9. Can epilepsy patients lead a normal sexual life? Yes/No

10 Do you think allopathic treatment is beneficial for epilepsy? Yes/No

11 Do you think epilepsy need prolonged treatment? Yes/No

12 Is there any problem by missing one or two dozes of medicine Yes/No

13 Do you think the most of the medicines used for epilepsy have side effects Yes/No

14 Do you think witchcraft is effective for epilepsy? Yes/No

15 Do you think indigenous drugs are effective for epilepsy? Yes/No

16 Do you think ayurvedic treatment is beneficial for epilepsy? Yes/No

17 Do think that there is no need for treating epilepsy Yes/No

18 Do you think visiting special temples are beneficial for epilepsy Patients Yes/No

19 Do you think society discriminates against person with epilepsy? Yes/No

20 Do you think that epilepsy is a hindrance to happy life? Yes/No

Appendix No XI

DEPRESSION INVENTORY

(English Translation)

Dr. K. A. Kumar & Dr. S. Vinod Kumar

School of Behavioural Sciences
Mahatma Gandhi University, Kottayam

(2002)

Directions : A Number of statements that people have used to describe themselves are given below. Read each statement and then blacken the appropriate space on the answer sheet to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

1. I worry about my own limitations
2. I usually feel lazy
3. I am able to do my work correctly.
4. I wish whether I were dead.
5. My feeling that, I haven't gained anything in my life, often irritates me.
6. I have the feeling that I am an unlucky person.
7. whatever I think happens accurately
8. I feel life as a burden
9. I have the ability to lead a happy life
10. I do my work satisfactorily
11. I often worry myself about past happenings.
12. I am failure conscious.
13. Guilt feeling irritates me.
14. I usually have the feeling of disappointment
15. I feel that life is a flop

Appendix No XII

EPILEPSY PSYCHO-SOCIAL EFFECT SCALE

Developed by : Chaplin J.E. (1990)
ENGLISH

Please indicate how much you feel you are affected by the epilepsy in the following areas.

Please respond to all statements

Judge each statements on the following scale :

0 = Never
1 = Rarely
2 = Often
4 = Almost always or always

1. I have trouble accepting my always 0-1-2-3-4

2 I am uncomfortable being alone because - of possible attacks 0-1-2-3-4

3 It would be difficult to tell an employer that I have attacks 0-1-2-3-4

4. It would be difficult getting a new job because of my attacks 0-1-2-3-4

5. I do not want to use public transport because I might have an attack 0-1-2-3-4

6. I want to go out less because of my attacks 0-1-2-3-4

7. I feel my spare time activities have changed because of my attacks

8. I feel my outlook on life is negative because of my attacks 0-1-2-3-4

9. I feels difficult to talk to my family about my attacks 0-1-2-3-4

10. I dont feel like taking medication. 0-1-2-3-4

11. I feel that the doctors are not interested in my attacks 0-1-2-3-4

12. I feel that life is not worth living because of my attacks 0-1-2-3-4

13. I feel there is no one I am close to because of my attacks 0-1-2-3-4

14. I feel tired all the time because of my attacks 0-1-2-3-4

15. I feel that the attacks have ruined my life 0-1-2-3-4

16. I hate the idea of an attack 0-1-2-3-4

17. I feel that an attack at work would mean dismissal 0-1-2-3-4

18. I would / do feel that I should not get married because of my attacks 0-1-2-3-4

19. I feel I cannot plan holidays because of my attacks 0-1-2-3-4

20. I feel I enjoy myself less because of my attacks 0-1-2-3-4

21. I feel less able to exercise because of my attacks 0-1-2-3-4

22. I feel odd since my attacks started. 0-1-2-3-4

23. My family treats me differently because of my attacks 0-1-2-3-4

24. I feel that the medication given for my attacks is usless. 0-1-2-3-4

25. I feel that the doctors do not know what is wrong with me 0-1-2-3-4

26. I feel that things are getting me down since the start of my attacks 0-1-2-3-4

27. I feel a burden to people because of my attacks 0-1-2-3-4

28. I feel that everying is an effort since the attacks started 0-1-2-3-4

29. I feel different from others because of my attacks 0-1-2-3-4

30. I would feel uncomfortable going out because of possible attacks 0-1-2-3-4

31. I would feel embarrased if I had an attack at work / in public 0-1-2-3-4

32. I feel it would be wrong for me to have children because of my attacks 0-1-2-3-4

33. I make special travel arrangements because of my attacks 0-1-2-3-4

34. I feel I have less social life because of my attacks 0-1-2-3-4

35. I feel my leisure activities are limited by my attacks. 0-1-2-3-4

36. I feel that leisure activities are limited by my attacks. 0-1-2-3-4

37. I feel that my family 'blames' me for my attacks 0-1-2-3-4

38. I do / would resent having to take medication - for my attacks 0-1-2-3-4

39. I feel that my medical treatment is unsatisfactory 0-1-2-3-4

40. I feel on edge because of my attacks. 0-1-2-3-4

41. I find it hard to get on with people because of my attacks 0-1-2-3-4

42. I feel easily tired because of my attacks 0-1-2-3-4

Appendix No. XIII

WASHINGTON PSYCHO-SOCIAL SEIZURE INVENTORY QUALITY OF LIFE (WPSIQOL)

Developed by : **Carl. B. Dordill (1995)**

ENGLISH

The development of the WPSIQOL Scale was presented at the 21st International Epilepsy Congress in Sydney, September 1995. It was based on the total score for the Quality of Life in Epilepsy Inventory - 31, and the items which are listed below are those which correlated 40 or greater with the QOLIE - 31 total score. The items used in the scale are given below along with the direction of scoring for each. For 203 adults referred for neuropsychological evaluations, the average score was 10.83 on the scale (SD=5, 42), The sum of the 21 items correlates 0.83 with the QOLIE-31 total score using the same 203 subjects. For more information, contact Carl B. Dodrill, Ph.D or Lawrence W. Batzel MSW (Regional Epilepsy Center, Harborview Medical Center, Box 359745, 325 Ninth Ave, Seattle WA 98104 ; Fax (206) 223-4409).

1.	Do you usually feel tired ?	No.
2.	Do you feel you are losing your mind ?	No
3.	Are you usually able to think clearly ?	Yes
4.	Do you have inability to concentrate a problem ?	No.
5.	Do you have more good days than bad ?	Yes
6.	Do you feel uneasy about the future?	No.
7.	Do you feel useful atleast most of the time	Yes
8.	Do you usually feel rested when you awake	Yes
9.	Are you satisfied with your life as it is now?	Yes
10.	Are you usually free from tension and worry?	Yes
11.	Does epilepsy keep you from experiencing satifaction in the area of work or employment?	No.
12.	Are you losing your ability to think clearly?	No.
13.	Are you entirely capable of handling every situation	Yes
14.	Is your life filled with activities that keep you interested	Yes
15.	Are your usually happy?	Yes
16.	Do your medications make you less able to function?	No.
17	Do your have enough self-condfidence?	Yes.
18	Are you often tense and anxious?	No.
19.	Do you feel different or strange due to your seizures?	No.
20.	Do you continually dred the possibility of a seizure?	No.
21.	Do you have enough money to pay your bills	Yes

Appendix No XIV

QUALITY OF LIFE IN EPILEPSY

(QOLIE : 31, VERSION:1.0)

Developed by : **Cramer J.A, 1993**

ENGLISH

PATIENT INVENTORY

NAME:

HOSP. NO:

AGE: MALE/FEMALE

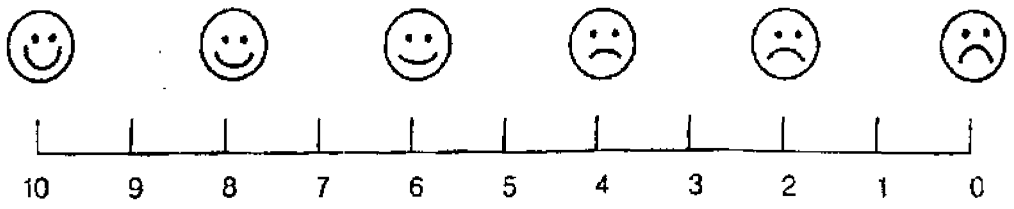
INSTRUCTIONS

This survey asks about your health and daily activities. **Answer every question** by circling the appropriate number (1,2,3...)

If you are unsure about how to anwer a question, please give the best answer you can and write a comment or explanation in the margin.

Please feel free to ask someone to assist you if you need help reading or marking the form.

1. Overall, how would you rate your quality of life ?
(Circle one number on the scale below)



Best possible
Quality of life

Worst Possible
Quality of Life

(as bad as or worse
than being dead)

These questions are about how you **FEEL** are how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling.

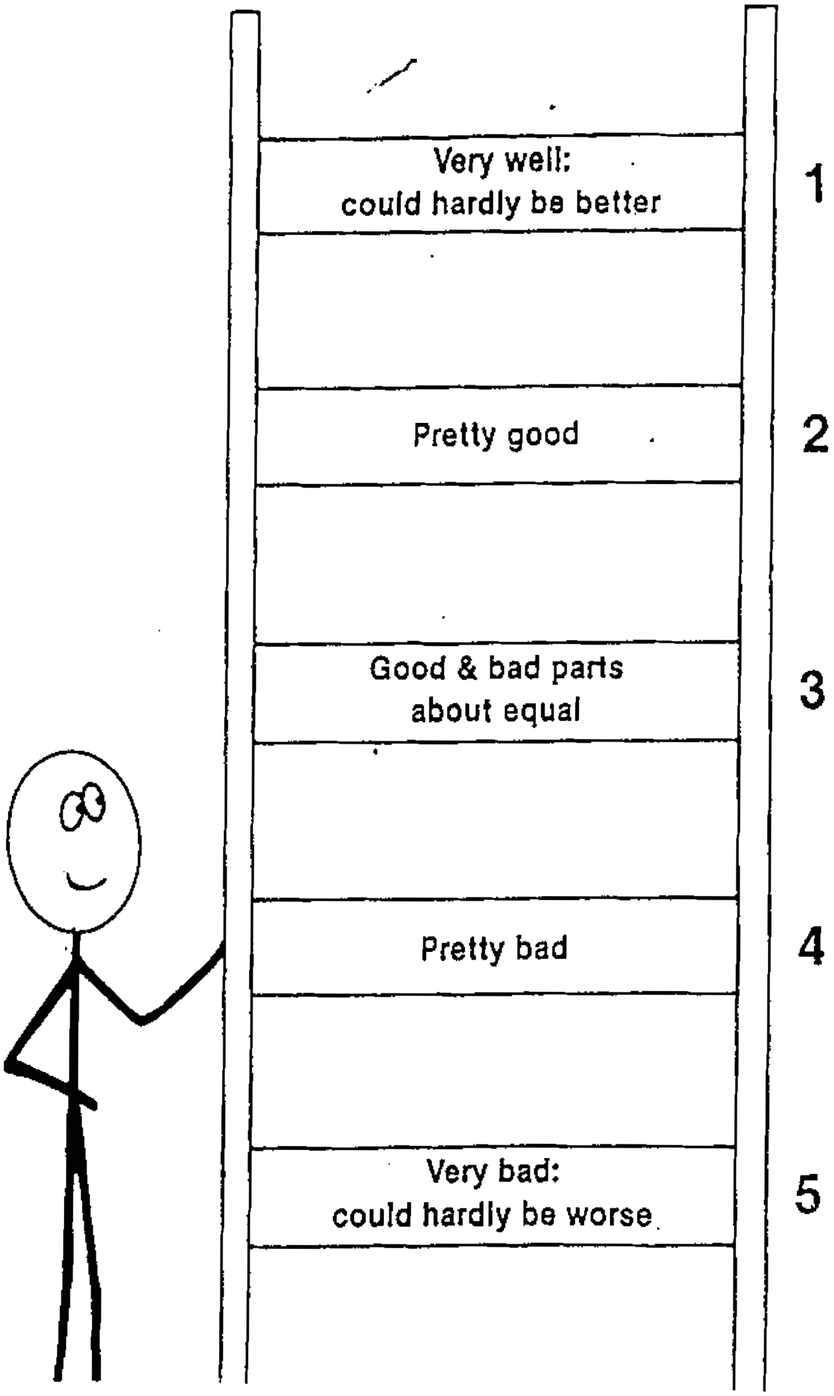
How much of the time during the past **4 weeks** .....

(Circle one number of each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
2.	Did you feel full of pep?	1	2	3	4	5	6
3.	Have you been a very nervous peson	1	2	3	4	5	6
4.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
5.	Have you felt calm and peaceful?	1	2	3	4	5	6
6.	Did you have a lot of energey	1	2	3	4	5	6
7.	Have you felt downhearted and blue	1	2	3	4	5	6
8.	Did you feel worn out ?	1	2	3	4	5	6
9.	Have you been a happy person?	1	2	3	4	5	6
10.	Did you feel tired	1	2	3	4	5	6
11	Have you worried about having another seizure	1	2	3	4	5	6
12.	Did you have difficult reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
13.	Has your health limited your social activities (such as visiting with friends or close relatives)?		1	2	3	4	56

14. How has the **QUALITY OF YOUR LIFE** been during the **past 4 weeks** (that is, how have things been going for you)?

(Circle one number)



The following question is about MEMORY.

(Circle one number)

		Yes a great deal	Yes somewhat	Only a little	No, not at all
15.	In the past 4 weeks, have you had any trouble with your memory	1	2	3	4

Circle one number for how often in the past 4 weeks you have had trouble remembering or how often this memory problem has interfered with your normal work or living.

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
16.	Trouble remembering things people tell you	1	2	3	4	5	6

The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the past **4 weeks** you had trouble concentrating or **how often** these problems interfered with your normal work or living

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
17.	Trouble concentrating on reading	1	2	3	4	5	6
18.	Trouble concentrating on doing one thing at a time	1	2	3	4	5	6

The following questions are about problems you may have with certain ACTIVITIES. Circle one number for **how much** during the **past 4 weeks** your epilepsy or antiepileptic medication has caused trouble with ......

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time
19.	Leisure time (such as hobbies, going out)	1	2	3	4	5
20	Driving	1	2	3	4	5

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The following questions relate to the way you **FEEL** about your **seizures**.
(Circle one number on each line)

		Yes a great deal	Yes somewhat	Only a little	No, not at all
21.	How fearful are you of having a seizure during the next month	1	2	3	4

		Worrry a lot	Occasionally worry	Don't worry at all
22.	Do your worry about hurting yourself during a seizure	1	2	3

		Very worried	Somewhat worried	Not very Worried	No, not at all
23.	How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4
24.	How worried are you that medication you are taking will be bad for you if taken for a long time	1	2	3	4

For each of these Problems circle one number for how much they bother you on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome.

		Not at all bothersome				Extremely bothersome
25.	Seizures	1	2	3	4	5
26.	Memory difficulties	1	2	3	4	5
27.	Work limitations	1	2	3	4	5
28.	Social limitations	1	2	3	4	5
29.	Physical effects of antiepileptic medication	1	2	3	4	5
30.	Mental effects of antiepileptic medication	1	2	3	4	5

21 Do you think epilepsy is contagious? Yes/No

22 Do you think epilepsy is caused by ancestor's sin? Yes/No

23 Would you allow your child to play with a child with epilepsy? Yes/No

24 What would you do if you happened to see a person getting epileptic attacks? (Tick your Answer)

1. Make him hold a bunch of keys

2. Sprinkle water over his face

3. Take him to a hospital

EPILEPSY COUNSELING / TRAINING MODULE

(Medical and Social Aspects)

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- Epilepsy is a chronic and stigmatized illness with serious psycho-social implications
- Epilepsy is the commonest brain disorder in every country in the world
- Upto 5% of people would develop one or more seizure during their lifetime.
- At any one time, 40 million people worldwide may have epilepsy, but 2-3 quarters are untreated.
- Epilepsy is universal – there is no age, sex, racial, national, or geographical boundaries.
- With early diagnosis and treatment three-quarter of those affected can be controlled.
- Epilepsy is a major public health problem with significant global health economic burden.

MEDICAL ASPECTS

WHAT IS EPILEPSY ?

- Epilepsy is a tendency to get recurrent seizures
- Seizures are the result of sudden, usually brief, excessive electrical discharges in a group of brain cells called neurons.
- Commonest manifestations of seizure include : Loss of consciousness/ awareness, disturbance of movements, unusual sensation (Visual, hearing, taste, etc).
- Seizures may vary from briefest lapse of attention or muscle jerks to severe and prolonged convulsions.

TYPE OF SEIZURE

- Seizures can be broadly classified into two:

GENERALIZED SEIZURE:

- Generalized seizures are characterized with complete loss of consciousness, falling down and convulsions. (except for absent seizures.)

LOCALISATION RELATED EPILEPSY / PARTIAL

- In partial seizures, the commonest and important type is complex partial seizure.
- It is characterized by disturbance in awareness, confused behavior and automatisms.

CAUSES OF EPILEPSY

There are several causes for epilepsy:

- Birth injuries / head injuries
- CNS infections (Meningitis/Encephalitis)
- Parasitic infection/Neurocysticercosis
- Brain tuberculosis
- Brain tumors
- Stroke

FIRST AID FOR EPILEPSY

- Keep the person in lying position in an open place.
- Remove any object in the surrounding area that may hurt the patient.
- Loosen tight clothing and remove spectacles.
- Do not force any objects into the patient's mouth to prevent tongue bites.
- Do not give anything to drink during the seizure.
- Make the person lie down on oneside so that any secretion from the mouth can flow out freely.
- Do not hold or restrain the patients and allow a seizure to happen
- Do not overreact to a seizure event, but give assurance as he/she regains consciousness.

DIAGNOSIS

- The cornerstone of diagnosis is precise history. The most reliable history is from an eyewitness.
- Medical examination – Electroencephalogram (EEG), Video – EEG and MRI may assist in the diagnosis.

TREATMENT

- The ultimate goal of treatment is to improve the quality of life, which depends on seizure freedom with least side effects, normal social life and economic productivity.
- Seventy five percent of people with epilepsy can achieve seizure freedom with medical treatment.
- Nearly two – thirds of people with epilepsy need only one antiepilpetic drug.

TYPE OF TRATMENT AVAILABLE

- Medical treatment
- Psycho-social Intervention
- Surgery for intractable epilepsy

PRINCIPLES OF TREATMENT

- Monotherapy as far as possible
- Adherence to compliance behavior
- Appropriate evaluation of intractable epilepsy
- Incorporation of psycho-social inputs.

DURATION OF TREATMENT

- Duration of the treatment depends on the type of epileptic syndrome . (some type may need only one or two years of treatment, eg. Benign childhood epilepsy).

- Some may need longer treatment eg.Temporal lobe epilepsy.

- There are few other types of epilepsy like Juvenile myoclonic epilepsy which requires treatment for an indefinite period.

SOCIAL ASPECTS

- People with epilepsy may experience social, emotional or psychological stress.
- Each person who has epileptic seizures experiences them in a different way.
- Psycho-social issues are more debilitating than the seizures themselves.

EPILEPSY & EDUCATION

- Child with epilepsy should be treated like any other child and should avoid overprotection or rejection.

- Most people with epilepsy can have normal schooling and higher/professional education.

- Children should not discontinue schooling because of occassioanl seizures.

- Children with epilepsy should be allowed to take part in all regular school activities, sports and arts.

- Some children with epilepsy may experience learning/concentration or memory problems.

- Children with severe learning disability may require professional help or special schooling.

- Students should avoid unaccustomed latenight studies before final examinations, as lack of sleep could increase the possibility of a seizure.

EPILEPSY & EMPLOYMENT

- People with epilepsy can be valuable employees, when placed in the right job or when suitable adjustments are made.

- Almost all jobs should be open to people with well controlled seizures, but

the folowing jobs are not suitable:
Driving a bus/driving in heavy traffic.
Working with heavy and dangerous machine/accident –prone jobs.
Working at heights.
Swimming unassisted.

EPILEPSY AND MARRIAGE

- People with epilepsy can have normal married life and have healthy babies.
- Social taboos can cause hindrance in the way of marriage of a patient.
- It is preferable to inform the prospective spouse about epilepsy to avoid future misunderstanding.
- Should seek appropriate medical/perofessional help regarding marriage, pregnancy and related problems,if any

QUALITY OF LIFE

- Quality of life is the individul's perspective of his position in the physical, psychological and social domains of health / well – being.
- Quality of life is closely related to psycho-social functioning of the individual.
- Psycho-social problems affecting quality of life are common among people with epilepsy.
- When 60% of people with epilepsy lead a normal life, the remaining 40% face problems of varying degrees.
- Social stigma, misconceptions about epilepsy, low self-concept and self-esteem often interfere with quality of life in people with epilepsy.
- People with epilepsy should get social support from family members, friends and significant others to improve their quality of life.
- An internal locus of control facilitates better compliance and quality of life.

DO'S AND DONT'S IN EPILEPSY

DO'S IN EPILEPSY

- Should learn as much as you can about your epilepsy.
- Take your medication *regularly* as instructed by your physician.
- Should identify your seizure triggers.

- Should keep a written record of your seizures.
- Should follow regular sleep pattern and avoid sleep deprivation.
- Should maintain regular food habits and eat a nutritionally balanced diet.
- Try to be as active and happy as possible.

DO NOT'S IN EPILEPSY

- Do not stop your medicines yourself or change the brand.
- Avoid fasting.
- Avoid undue stress.
- Avoid smoking and alcoholism.
- Avoid overweight.

REMEMBER

- Epilepsy is not the "Curse".
- Epilepsy not contagious
- You can lead a normal and achieve life's full potential in spite of epilepsy.

Photographs showing patients and family members attending psycho-educational group session in SCTIMST