CHAPTER VII

SUMMARY, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

7.1 Summary:

Globally, approximately 10% of the population experiences a seizure at some point in their lives and most often it is during infancy and childhood (Hauser & Hesdeorffer, 1990). Epilepsy is one of the few diseases of childhood that plagues medical professionals more than any other disease and not because it is neurological in nature but due its detrimental psychosocial implications with respect to the individual’s emotional, educational, occupational and social development. In other words epilepsy although neurological in nature, has severe psychosocial implications which impact the over all quality of the individual’s life. Epilepsy is often seen synonymous with mental deterioration, insanity, and with a hopelessness of outlook that leads only to pessimism and despair (Bridge, 1949). Very few realise the magnitude of the public problem presented by epilepsy, which is caused largely by the stigma that has come to be associated with this disease. Behavioural changes both real and
imagined have formed a halo around epilepsy since ancient times. The myth of epilepsy as a curse has been largely vanished in modern cultures, but the disorder remains a social stigma for many.

Hence the goal of treating and helping individual’s with epilepsy should be to attain the best quality of life with the fewest seizures (hopefully none), the fewest number of medicines, and the fewest side effects. It is evident from most studies that the population suffering from epilepsy is achieving only a miniscule part of this goal where in the overall quality of life and the escape from side effects are still uphill battles.

The current study was carried out in the city of Mumbai and was one such step in that direction. The main objective of the study was to plan and implement a comprehensive intervention module evaluating different forms of therapeutic interventions which were need based and targeted psychological variables of epilepsy such as self esteem, depression, family relations and parental attitudes.
The module took into consideration the specific needs of the individual with epilepsy, based on the various psychological implications of the illness. Hence the study evaluated the effectiveness of the module using different psychotherapeutic interventions (namely Family Therapy, Cognitive Behaviour Therapy and Yoga) in light of the psychological variables (namely depression, self esteem and family relationships) affecting people living with epilepsy.

Western literature in the past few decades has provided an insight into the holistic management approach towards epilepsy which takes into account the psychosocial management of epilepsy and emphasises the importance of such comprehensive interventions. Studies done in the west provide for adequate evidence which indicates that majority of people with epilepsy can have their seizures managed successfully. Also Indian studies form a minute part of the vast research available internationally. Therefore the current research was also an attempt to study Epilepsy and its psychosocial implications in the Indian context.
The participant group of the study was representative of the larger population visiting epilepsy out patient clinics in government run and private hospitals in the city of Mumbai. The pre and post test assessments and the intervention programs were carried out at the Indian Epilepsy Association's Mumbai Chapter premises, popularly known as E-Cell.

The data was analysed using the statistical package for social sciences and the commonly used analysis was t test (independent and paired samples) and correlation analysis. The results of the study have been encouraging and have highlighted various psychological and social perspectives of epilepsy reiterating the need to develop programs and modules that can help people with chronic epilepsy to manage their life better. Not only did the results highlight the detrimental effects of epilepsy in terms of higher scores on psychological variables such as self esteem, family relations, depression and parental attitudes but also illustrated the influence of seizure related variables in terms of age of onset, number of years of epilepsy and number of years of anti-epileptic medication and their influence on
ones psychological well being. With regards to the main hypothesis of the study the results indicated the positive influence of planned therapeutic interventions. Yoga emerged as a form of therapy that had an overall beneficial impact followed by CBT in relation to the psychological variables which were under study. Family relations as a variable emerged as the most challenging variable to work upon and was benefiting only for the group that received family therapy.
7.2: Conclusions:

The most challenging task for any researcher is to document the outcome of the study in light of the existing literature and theories available. Initially with respect to the psychosocial aspect of epilepsy the literature available although scientific in nature was experiential and non-theoretical. As time progressed different aspects of epilepsy have been exposed, which are not necessarily neurological in natures and this has been the result of rigorous and methodologically sound studies conducted in different parts of the world. With respect to the Indian perspective the following conclusions can be made on the basis of the findings obtained of this current study. It is important to mention that the findings cannot be generalised as the participating sample was limited in size and localised.
Nevertheless the following inferences can be made:

a) Demographic variables studied clearly illustrated the impact of epilepsy on one's educational development where in majority of the participant group had not even cleared their basic education that is the SSC level in the state of Maharashtra (Mumbai). Also a large percentage of the participant group was unemployed and majority of them were unmarried. These statistics revealed the realistic picture of the social impact of epilepsy which is not uncommon to most medical and paramedical practitioners working in the field of epilepsy.

b) Seizure related variables such as age of onset, number of years of epilepsy and number of years of anti-epileptic medication also influenced the individual's psychosocial development where in higher scores on self esteem and depression were clearly related to increasing number of years of epilepsy and increasing number of years of antiepileptic medication. For majority of the participants i.e. 61.4% the age of onset was below
five years and the impact of developing epilepsy in one's formative years was clearly illustrated in the self esteem scores of this particular group. Also the longer the individual was on antiepileptic medication it resulted in higher scores on the specific variables of depression, parental attitudes and self esteem. Hence the findings of the study revealed that epilepsy not only affects the individual but also the immediate family and this is more due to the social stigmatisation and financial burden imposed by it.

c) The findings of the study have been immensely encouraging for the researcher and more importantly for the participant group as the scores on most psychological variables under study i.e. self esteem, family relations, depression and parental attitudes decreased significantly post intervention. This clearly indicates the positive impact of psychotherapy and reinforces the need for such planned interventions. More importantly the increased scores on these variables for the control group revealed the negative impact which can be caused on a continual basis when psychosocial aspects of epilepsy are neglected from the main stream line of
treatment. It is important to note at this stage that the researcher by no means is trying to undermine the significance of the contribution of neurologists and their treatment regimen. What the researcher is trying to emphasise is that a comprehensive module should be developed that can work as an adjunct to drug therapy which addresses the psycho social variables impacted by epilepsy.

d) The findings also reveal that Yoga had an overall beneficial impact when compared to the other study groups receiving CBT and FT respectively. The scores on the various variables under study are comparatively the lowest for the group receiving Yoga as a form of therapy. In the current study the second most effective therapy was that of Cognitive Behaviour Therapy and greatly impacted the variable of self esteem. Family Therapy was most beneficial for the variable of family relations which was difficult to change as that this variable could not be impacted by CBT and Yoga.
7.3 Limitations:

There were various limitations in the course of carrying out the study which gives insight into the methodological and practical problems that one can experience while conducting a research of this nature.

a) Adequate sample size which would be enough to conduct a research at the doctorate level was the biggest challenge. In spite of investing three months solely for this purpose, people with epilepsy and more so their family members were resistant to signing up for the intervention program. This was also a result of the ignorance with reference to importance of psychotherapeutic interventions in the effective management of epilepsy.

b) In a lot of cases where parents acknowledged that they needed psychotherapeutic interventions it was factors such as commuting to the place of the intervention and financial factors that were binding for the individual. Therefore lack of monetary support for the researcher was a major limitation. Like in the West if the study was funded, the researcher could have sponsored the travel for
the participants that needed financial assistance thereby making up for financial loss that would be endured by the family member.

c) The time period of three months of intervention and then again a one month gap for post test assessment was also a deterrent for many participants.

d) On a trial basis, a seizure log was requested for, but majority of the participants did not comply with this requirement and therefore this was excluded from the study as drawing inferences from this kind of data would be erroneous. The research would be more comprehensive had this variable been included as one could see the effectiveness of the therapeutic interventions directly on seizure frequency which is one of the main objectives of any practitioner working in the field of epilepsy.

e) The participant group was representative of the people with epilepsy at large but was urban and city based. One can only anticipate the ignorance that people with epilepsy and their
families experience in small towns and villages which is definitely a larger population and a tremendously neglected one.

Hence one can conclude that the limitations of the study were more related to infrastructural issues as opposed to methodological issues.
7.4: Recommendations:

a) Although there are various studies which illustrate the psychosocial impact of epilepsy there are very few which study the effectiveness of psychotherapeutic interventions which can be used to alleviate them. Therefore more studies need to be conducted which study the impact of psychotherapeutic interventions by means of methodologically sound studies.

b) It is evident from the vast literature available that people with epilepsy live with various issues on a day to day basis which negatively impacts their overall quality of life. Therefore a life skills training programme can be conducted for people with chronic epilepsy consequently helping them manage their epilepsy better. Strategies based on the premise of cognitive behaviour therapy can be extremely effective for such training sessions. Also these programmes, if funded adequately can be conducted at local municipal hospitals, after the out patient clinic timings so as to ensure convenience with reference to commuting and other related issues mostly financial in nature.
c) Family members of people with epilepsy also need to be involved in the therapeutic programs. It is evident from the findings of the current study that family relations was the most challenging variable to influence and therefore family therapy is essential for family members of people with epilepsy. Therapy ideally would not only deal with psychological issues but would also ensure educating the family about epilepsy consequently helping alleviate the perceived social stigma associated with it.

d) Yoga asanas and pranayam can form an essential component of a psycho therapeutic program for people with epilepsy, as a significant percentage of seizures experienced by people with epilepsy are stress precipitated and therefore deep breathing and being aware of ones physical state can be an extremely valuable skill for the person with epilepsy.

e) Out reach programs can be conducted by local epilepsy chapters of the Indian Epilepsy Association with the objective of reaching out to small towns and villages. These programs can be
intensive and of a shorter duration consequently targeting the surface level issues experienced by the person with epilepsy

f) Educating masses is the most important factor as it will control the unintentional traumatisation of the person with epilepsy. The public education message for epilepsy should include and clarify common myths and misconceptions i.e.

- epilepsy is a common disorder
- epilepsy is not contagious, it is a physical condition not a disease
- epilepsy is not caused by supernatural forces, often no cause is identifiable
- for many people the attitude of the public can be harder to live with than the seizures
7.5 Managing epilepsy- The Way Forward:

People all over the world grapple with the stigmatisation associated with epilepsy. Whether it is the person with epilepsy, their family, medical and paramedical practitioners, social workers, teachers...any body even distantly related to epilepsy experiences the stigma attached to it. This stigma not only impacts their individual personality but sows the seeds for emotional, psychological and social deterioration. Psychological variables such as the individual’s self esteem, feelings of depression, and relationships within the family and how the family views the individual with epilepsy are all impacted by this social stigma attached to the illness. Therefore public education for epilepsy is most critical to stall this deterioration as it is a consequence of the unintentional traumatisation caused by people ignorant about epilepsy.

Secondly systematic and focussed programs need to be developed and implemented which deal with issues experienced by people with epilepsy and their families consequently providing therapy and handling the psychological implications of the illness.
Hopefully these planned psychotherapeutic and educational intervention programs with educate people in general and help people with epilepsy and their families; which will eventually help form an aware and empathising society consequently alleviating the stigma associated with epilepsy.

With respect to the Indian perspective it is important to note that in a country like India; taking into considerations its population and the fact that the majority of its population lives below the poverty line, it is unlikely that treatment options go beyond medication. For some people living with epilepsy; there is no timely medical management. Therefore intervention with the family or psychotherapeutic interventions of any kind that would benefit the individual and which provides for a skill set to manage epilepsy better is only a prerogative of a few who live in cities. But if the health care system takes initiatives at the primary and tertiary level small changes can be made where in adequate information and knowledge about epilepsy and its treatment can be made available to all.
Commendable work is being done by a lot of institutions and organisations such as the Indian Epilepsy Association, NIMHANS, Sri Chitra Tirunal Institute of Medical Sciences and Technology. These efforts may be tiny drops in the ocean but are accomplishing huge milestones in bringing epilepsy out of the shadows...