CHAPTER II

REVIEW OF LITERATURE

Literature review provides a base and enables the development of the study. It also helps to obtain information on the incidence, methodology adopted in different studies, the similarities, problems encountered and the areas of lacunae.

The review of literature for the current study is divided into literature on

2.1.1 Knowledge of epilepsy

2.1.2 Self-management in epilepsy

2.1.3 Quality of Life in epilepsy

2.1.4 Effect of an educational intervention on Knowledge, Self-management and Quality of Life in epilepsy

2.1.1 Knowledge of epilepsy

The literature review of studies on knowledge of epilepsy among PWE revealed the following:

Hassan, Alen, Wayne, Ahmadi, Anwar & Goh (2010) on questioning 1000 people about the understanding of attributes toward epilepsy among urban Chinese population in Malaysia, only 697 completed the questionnaire. More than 55.4% of the population would have talked about epilepsy only to people who were very close
to them, 83.4% responded that they would treat the person with epilepsy as they had before. 448 (64.3%) responded that people with epilepsy are not slow learners and did not have intellectual functioning below normal. There were positive responses with regards to prevention of isolation, performance of daily activities, education and that epileptics could become useful members of the society. The level of education had more positive responses.

Tu Luong, Tran, Quet, Odermatt, Preux & Chong (2007) in a systematic review of the knowledge, attitude and practice of people in Asia towards epilepsy reviewed 16 studies in the year 2000 with 1118 samples and found that 98.7% had heard about epilepsy, 27.3% thought that epilepsy is a mental illness, 45.6% thought that PWE would not be employed like the others, 89.2% of the respondents said that they would allow their child to play with an epileptic child, 71.3% would allow their child to marry a person with epilepsy. Among 120 references in the year 2003 the treatment gap was identified to range between 50-70%. In AED use in 105 studies, 20.8% received polytherapy, out of which 93% received phenytoin. The type of epilepsy identified in 16 studies in 2000 identified that 58.8% had generalized seizures and 30.6% had focal seizures. The researchers suggested for further studies on the psychosocial, cultural, economic, organisational, and political factors that influence epilepsy causation, management, and its outcome.

Barucha (2003) on comparison of several studies done in India identified that awareness of epilepsy in India was comparable with that of the western countries but negative attitudes had an effect on schooling, marriage, employment and other social activities. The PWE used both allopathic and traditional methods of healing. The
most troubling symptoms experienced by PWE were mood disturbances and somatic symptoms.

Adavi, Al-Salmy, Martin, Al-Naamani, Prabhakar, Deleu, Moosa & Dorvlo (2003) determined the patient’s perspective on epilepsy: self-knowledge among Omanis; although correctly endorsing issues related to their medication, the cross-cultural sample had limited knowledge about their condition. Most patients were unable to give accurate indications of epilepsy and were not able to give correct responses to the questions pertaining to safety and compliance. The researchers suggested the need for improving patient’s knowledge as with other chronic disorders, people with epilepsy should receive a systematic health education about how to manage the condition most effectively.

Doughty, Baker, Jacoby & Lavaud (2003) identified the cross-cultural differences in levels of knowledge about epilepsy among the selected 6516 people with epilepsy from 10 European countries using mailed self completion questionnaires. People who had epilepsy were asked to complete the questionnaire for themselves and hand on the carer questionnaire to a close relative or friend. The carers were asked to complete the carer questionnaire. The mean age of respondents were 37 years, more than 60% of the respondents said that they worried a lot about epilepsy, and only 13% said that they did not worry at all. The mean score on the impact scale was 23.38. More than half of the respondents did not feel stigmatized by their epilepsy. Only 17% reported of feeling very stigmatized. The mean score on the EKQ for PWE was 24.25 (range, 1–34). 52% had low score (<25) 41% had medium score (>25 to<30), 7% had high scores. Low scorers had lower education and more
frequent seizures. Those who had higher scorers had higher education, higher scores on psychosocial adjustment to epilepsy scale, and higher scores on stigma scale and a longer duration of epilepsy. PWE had lower rates of marriage (47%), and were less employed. More than half of PWE reported problems due to the limitations of epilepsy; 50% of the patients reported that because of epilepsy, they missed things they liked to do most and 49% of the patients reported their dependency on others than they would like to be. The mean score on the adjustment-to-illness scale for the whole study population was 24.71.

Long, Andrew, Reeves, Moore, Roach & Pickering (2000) assessed the epilepsy patients knowledge about their condition among 220 patients of whom 175 were included (28 were excluded due to non epileptic seizures and 17 were excluded due to a diagnosis other than epilepsy). The average age and number of years with epilepsy was 34.7 ± 13. There was no correlation between knowledge scores and age, number of years with epilepsy, nor years of education. 30% believed that epilepsy is a mental disorder or contagious, 41% believed that it is appropriate to place an object in a patient’s mouth during a seizure to prevent injury. Two of the lowest scores, 13.6% and 47.5%, pertained to the legal issues of driving and employment, respectively. A need for educational intervention was identified in this population, particularly related to injury prevention and the legalities of driving and employment.

Radhakrishnan, Pandian, Santhoshkumar, Thomas, Deetha, Sarma, Jayachandran & Mohamed (2000) identified the prevalence, Knowledge, Attitude, and Practice (KAP) of Epilepsy in Kerala, South India. In a door-to-door survey
covering the entire population of 238,102 people residing in 43,681 households in a semi urban area of central Kerala using a screening questionnaire administered by medical social workers with a sensitivity of 100% for identifying persons with epilepsy, following which the neurologists examined all the individuals who were suspected of having epilepsy. KAP toward epilepsy was assessed among 1,118 subjects (439 males and 679 females). In a three-phased survey 1,175 cases were ascertained (616 males and 559 females) with active epilepsy. The proportion of generalized and localization-related epilepsies was 58.8% and 30.6%, respectively. 99% of the KAP respondents had read or heard about epilepsy. 31% and 27% thought epilepsy was a hereditary disorder and a form of insanity, respectively. About 40% of the respondents felt that individuals with epilepsy could not be properly educated or employed. 11% would have objected to their children having contact with epileptic children.

2.1.2 Self-management in Epilepsy

Walker, Bamps, Burdett, Rothkopf & DiLorio (2012) in an online study on the support systems, and how those individuals support people with epilepsy in their self-management efforts among 153 people with epilepsy, majority of the participants provided information about their supporters. The findings revealed that the number of support providers ranged from 0 to 6, with about 12% indicating no support. Parents and significant others were the most common supporters. Support providers offer emotional and instrumental support, reminders and aid for taking medication, and support for self-management strategies which could be encouraged.
Sweileh, Ihbesheh, Jarar, Abu Taha, Sawalha, Zyoud, Jamous & Morisky (2011) in a cross-sectional descriptive study of 75 patients on self-reported medication adherence and treatment satisfaction in patients with epilepsy identified that 11 patients (14.7%) had a low rate, 37 (49.3%) had a medium rate, and 27 (36%) had a high rate of adherence. Adherence was positively and significantly correlated with age and duration of illness. The mean satisfaction with respect to effectiveness, side effects, convenience, and global satisfaction were 73.6 ± 20.7, 82.4 ± 29.8, 69.5 ± 15.5, and 68.4 ± 18.3 respectively. Patients on monotherapy had significantly higher satisfaction in the effectiveness domain than patients on polytherapy. And those with well-controlled epilepsy scored significantly higher in the effectiveness and global satisfaction than those with poorly controlled epilepsy.

Fraser, Johnson, Miller, Temkin, Barber, Caylor, Ciechanowski & Chaytor (2011) investigated the perceived medical and psychosocial problems of adults with epilepsy, and preference for self-management program design and delivery format. Results indicated a more psychosocially challenged subgroup of individuals with significant depressive and cognitive complaints. The preferred Self-management program was face-to-face individual or group meetings led by an epilepsy professional and trained peer leader for 60 minutes weekly with 6 to 8 sessions focused on managing disability and medical care, socializing on a budget, and leading a healthy lifestyle and emotional coping strategies delivered on weeknights or saturday afternoons. The researchers concluded that emotional self-management and cognitive compensatory strategies require special emphasis given the challenges of a large subgroup.
Chen, Tsai, Lin, Shih & Chen (2010) investigated the relationships among medicine symptom distress, self-efficacy, patient–provider relationship, and medication compliance in 357 patients with epilepsy by convenience sampling from three medical centers in northern Taiwan. The logistic regression analysis indicated that comorbid chronic disease, self-driving, seizure after a missed dose, and self-efficacy were significantly associated with medication compliance. These data suggest that health care providers of patients with epilepsy pay more attention to treatment of comorbid chronic diseases, the safety issues of self-driving, seizures occurring after missed doses and awareness of self-efficacy.

Begley, Shegog, Iyagba, Chen, Talluri, Dubinsky, Newmark, Ojukwu & Friedman (2010), identified the impact of socioeconomic variables on Self-management and found that patients of low socioeconomic status (SES) reported higher scores on overall, information, safety management (\( P < 0.03 \)) and no differences on medication, seizure, and lifestyle management. Reported levels of self-efficacy, depression, social support, stigma, desire for control, and outcome expectations were higher for those of high SES (\( P < 0.01 \)). Knowledge of epilepsy and satisfaction with care were lower (\( P < 0.01 \)). People with higher levels of self-efficacy and social support also reported higher self-management (\( P < 0.01 \)) regardless of demographics, seizure frequency and SES (\( P < 0.05 \)).

Noreen, Shelley, Emily, Marie, Rusell & Arlene (2010) in a survey regarding the challenges that were faced by PWE in managing their condition among clinical, academic and human service professionals, among 101 respondents, identified that 30% of the respondents had personal experience with epilepsy. The two greatest
challenges reported most frequently for people with epilepsy were high quality health care and managing psychological and emotional effects. The two most important epilepsy outcomes were seizure control and Quality of Life. The two greatest challenges facing clinicians were too little time with patients and limited clinical focus. The two main weaknesses in the field were insufficient research and narrow approaches in addressing epilepsy. Few clinicians cited quality of care as a major challenge (p < 0.0001) compared to other professions. Few respondents with personal experience with epilepsy cited stigma as a challenge (p = 0.006).

Ross, Stefan, Schäuble, Day & Sander (2010) in an European survey of the level of satisfaction of patients and physicians in the management of epilepsy in general practice found that patients wanted greater involvement in discussions regarding treatment options though they were generally satisfied with their current medication, they wanted a balance between seizure control and AEDs. Physicians were less satisfied with current treatments, but were less concerned with AEDs. People with epilepsy wanted to be better educated about epilepsy and its management.

Wagner, Smith, Ferguson, Van Bakergem & Hrisko (2010) in a pilot study of an integrated cognitive-behavioral and self-management intervention for youth with epilepsy and caregivers: Coping Openly and Personally with Epilepsy (COPE) identified that among nine youth aged 10–15 and a parent who completed several self-report measures pre- and post-intervention, parents rated significant improvements in their children's coping skills following the COPE intervention. Compared with pre-assessment, children rated significant improvements in self-efficacy for seizure management. Knowledge of epilepsy also significantly improved
and two children reported mild suicidal ideation prior to the intervention, whereas no children reported ideation following the intervention.

DiIorio, Reisinger, Yeager & McCarty (2008) determined the feasibility of a telephone-based self-management program for people with epilepsy among 22 adults revealed that the intervention group received a five-session intervention with a nurse trained in Motivational Interviewing (MI) counseling. The first session was an in person interview and the remaining four sessions were conducted over phone. Ninety-five percent of the 55 planned MI sessions and the 44 planned courtesy calls for those in the control group were completed showing acceptance of the telephone based self-management program.

Sapna, Sheeba, John & Thomas (2008) determined the accidents and injuries in people with epilepsy attending a tertiary care center in India using a structured questionnaire, among PWE who had active epilepsy for one or more years. 255 patients completed the study. The diagnoses included localization-related epilepsy for 62.6% of the patients and generalized epilepsy for the remainder. During 12 months prior to the interview, 44.8% had at least one injury; 7.8% had sustained an accident. Road traffic accidents (3.1%), burns (2.5%), electric shocks (0.8%) and near drowning (0.4%) were the commonly reported accidents. Age, sex, type of epilepsy and type of medication had no significant association with the occurrence of injuries or accidents. A quarter of the people with epilepsy studied had experienced serious injuries.

DiIorio, Shafer, Letz, Henry & Schomer (2006) evaluated the extent to which selected behavioral, social, and affective factors contribute to self-reported epilepsy
self-efficacy, the participants completed three assessments 3 months apart. Only those completing both the first and second assessments were included for analysis that revealed self-management, depressive symptoms, and seizure severity which led to greater variance in self-efficacy; patient satisfaction and stigma were of less importance; and social support and regimen-specific support did not significantly predict self-efficacy.

Bebek, Baykan, Gürses, Emir & Gökyiğit (2006) identified the Self Induction (SI) behaviors in patients with Photosensitive (PSE) and Hot Water Epilepsy (HWE) in a comparative study from a tertiary epilepsy center in Turkey among 7609 consecutive patients, 129 were diagnosed as having PSE, and 34 HWE. Thirteen patients with PSE (10 females, 3 males, age at onset: 8.6; 3 with mental retardation) and 9 patients with HWE (all males, age at onset: 13.1) reported experiencing SI. A pleasurable feeling was described by all patients with HWE during seizures, but only by 3 patients with PSE. Patients with PSE induced their seizures by going very close to the TV screen or by waving their hands and blinking in front of the light sources. In the patients with HWE, seizures were precipitated by increasing the temperature of the water poured over the head or body. Self-management should include identification of trigger factors that vary between individuals.

Kobau & DiLorio (2003) described the self-efficacy beliefs and outcome expectancies towards medications, seizures, and lifestyle management behaviors with epilepsy among 108 adults. Modifiable behavioral risk factors such as confidence for following medication dosing schedule, planning for medication refills, coping with adverse effects of medication, getting sufficient sleep, avoiding alcohol, and obtaining
social support were identified. A larger proportion of persons reported higher self-efficacy for medication management behaviors than for healthful lifestyle behaviors. The individuals were adherent with medication therapy, but not with healthful lifestyle behaviors necessary for the prevention and treatment of chronic diseases. The authors conclude that individuals with low self-efficacy would get benefited from the interventions that increase self-efficacy beliefs to enhance their ability to adopt and maintain good self-management.

DiIorio, Shafer, Letz, Henry, Schomer & Yeager (2003) on examination of the perception of stigma among adults with epilepsy including its association with epilepsy self-management and perceptions of healthcare found that among 314 responses from PWE, the mean age of seizure onset was 22 years. 76% of the participants reported of having had a seizure within the past year. The levels of perceived stigma were similar for men, women, across ethnic groups and age groups. Participants who were not married or living with a partner, were not working for pay, and had limited income reported higher levels of stigma than did married participants, those working for pay and those in higher income brackets. Participants reporting higher levels of stigma included those who had their first seizure before the age of 50 and a seizure in the last year. Participants whose seizures interfered more with activities, who rated their seizures as under less control and who were not legally able to drive also reported higher levels of stigma.

2.1.3. Quality of Life in epilepsy

Mahrer-Imhof, Jaggi, Bonomo, Hediger, Eggenschwiler, Krämer & Oberholzer (2013) assessed the Quality of Life in adult patients with epilepsy and
their family members among 104 dyads of patient and family members. The subjective QoL in patients and family members differed significantly, as did satisfaction with care delivery. Family support contributed significantly to QoL. The Quality of Life of the family members was affected by the patient’s knowledge about the disease and the reason for their current hospitalization but patient QoL scores had no influence on the QoL of their family members. The patients’ QoL depended significantly on the QoL of the family members. Patient and family centered approach is therefore emphasized.

Melikyan, Guekht, Milchakova, Lebedeva, Bondareva & Gusev (2012) evaluated the socio-demographic and clinical factors influencing the health-related Quality of Life (HRQOL) of 208 adult PWE at Russia. They obtained lower mean QoLIE-31 scores. There was a negative correlation between duration of epilepsy with all QoLIE-31 subscores (p<0.05), except for emotional well-being (p=0.1). Depression score was the predictor of overall score and all QoLIE-31 domains, except for emotional well-being. Age was a predictor of cognitive and social functioning, medication effects and the total QoLIE -31 score. Seizure frequency was associated with all HRQoL domains, except medication effects and emotional well-being.

Shakir & Al-Asadi (2012) evaluated the Quality of Life and its determinants in People with Epilepsy in Basrah, Iraq on comparison of 116 PWE with healthy controls, the monthly family income among PWE showed that 43.1 % were medium income earners, while most of them in the control group 44.8 % were high income earners. Unemployment was the most frequent problem in 60.3% of PWE, 56 % were unmarried, while most of them in the control group were employed 53.4% and
71.6% were married. The mean total QoL score of epileptic patients was 47.9 ± 18.1 as compared to 71.7 ± 10.2 in the control group with a highly significant difference (P < 0.001). Most epileptic patients had poor to moderate QoL with a highly significant difference (P< 0.001). Older epileptic patients had lower mean QoL scores (39 ± 15.3) as compared with younger age groups (55.9 ± 18.3). Patients with low educational levels and low income also had lower QoL scores, with a significant association. Patients who have had epilepsy for less than five years as well as those who have had epilepsy for more than 10 years had lower QoL scores (43.9 ± 14.7, 47.9 ± 18.1). Factors that predicted QoL of epileptic patients were income, age, education, and frequency of seizures being responsible for 54.7% of the variability in QoL total scores. The excluded variables were sex, residency, marital status, employment, duration of the disease, and number of antiepileptic drugs. The main predictors of better QoL was younger age, higher levels of education and family income and the clinical predictor was seizure activity.

Viteva (2012) assessed the impact of perceived stigma on the Quality of Life of 70 Bulgarian patients with refractory epilepsy. The mean disease duration was 25.1±1.3 years. 40.0% of patients (±5.9) had symptomatic epilepsy. Seventeen patients (24.2%±5.1) had partial seizures, 16 (22.8%±5.0) had generalized seizures and 37 (52.9±6.0) had a mixture of partial and generalized seizures. Most participants had several seizures per week (45.7%) or month (30.0%) despite the fact that 90% were taking combination antiepileptic drug treatment. Perceived stigma was found among 43.6% of the patients with refractory epilepsy, and 28.7% of the patients self-reported of having experienced severe stigmatization. Only 4 (5.7%) patients with pharmacosensitive epilepsy reported stigmatization which was mild or moderate in all
cases. Perceived stigma had a negative impact on the overall score of the QoLIE-89 (T-score 47.8), as well as on all subscales of QoLIE-89, with the exception of "change in health" and "sexual relations". Patients with refractory epilepsy reporting stigmatization most commonly had very low scores on the subscales "health perceptions" (82.9%), "emotional well-being" (71.5%), "memory" (63.4%) and "health discouragement" (62.5%). Negative correlation was found between all QoLIE-89 subscales with perceived stigma severity.

Noble, Goldstein, Seed, Glucksman & Ridsdale (2012) in a prospective study among 85 people with epilepsy attending emergency departments identified the characteristics of the mean age as 41; 53% were male, average number of ED attendances in the prior year (mean 3.2; median 2) exceeded that of other ED users and those with most chronic conditions. Some patients attended ED frequently. Compared to the general epilepsy population, ED attendees experienced more seizures, anxiety, had lower level of knowledge on epilepsy and its management and greater perceived epilepsy-related stigma. The investigators reported that in descending order, lower knowledge, higher perceived stigma, poorer self-medication management, and seizure frequency were associated with more emergency visits.

Quintas, Raggi, Giovannetti, Pagani, Sabariego, Cieza & Leonardi (2012) in a systematic review of literature from 2005 till 2010 to identify the Psychosocial Difficulties (PSD) in people with epilepsy found that the most frequent PSDs found in people with epilepsy were depressive symptoms, memory functions, Quality of Life, anxiety, stigma, locus of control, cognitive functions in general, and emotional
functions in general. The patients' life areas were affected by cognitive, emotional, and psychological problems.

Renato et al. (2012) in a study aimed at identifying Quality of Life issues and occupational performance of persons with epilepsy determined that the most affected domains of QoLIE-31 were seizure worry, 29.77 (±21.72), and effects of drugs, 49.75 (±28.58). For the Canadian Occupational Performance Measure, the average of performance and satisfaction were respectively 3.10 (±3.07) and 4.45 (±3.29), and performance limitations most frequently cited were maintenance of employment (18), left home alone (15) and courses (15). The correlation coefficient showed that the three main performance limitations posed by the COPM identified that a level of satisfaction influenced the perception of Quality of Life.

Li Yue, Pei-min Yu, De-hao Zhao, Dong-yan Wu, Guo-xing Zhu, Xun-yi Wu & Zhen Hong (2011) identified the determinants of Quality of Life in people with epilepsy and their gender differences. Perceived adverse effects of treatments and number of AEDs had a greater influence on QoL in women, whereas anxiety and seizure-related variables had a stronger impact on QoL among men. The researchers suggest that individualizing interventions to improve the QoL of people with epilepsy would improve QoL.

Nitin, Ray, Reshma, Shruthi, Herady, Kumar & Kiran (2011) assessed the Quality of Life, and stigma associated and self-management practices among patients suffering from epileptic seizures in a cross-sectional study at Mangalore, India among epileptic patients aged 7 or more by an interview among 56 patients, 55.4% patients had GTCS and 80.4% had multiple episodes of seizures. QoL and Self-
management practices were good in 44.6% and 71.4% patients. Self-management practices were found to significantly improve with age of patients \((P=0.012)\). Educational status of patients was found to significantly improve their QoL and self-management practices \((P=0.031)\). Stigmatization was reported by 66.1% of the patients and it was significantly more in patients in the age groups 30 to 50 years \((P=0.043)\). Self-management practices were good in most patients but this was not so with QoL or experience of stigma. The authors suggest that this could be improved by educating the people in order to generate greater social support for epileptic patients.

Lua & Selamat (2011) investigated the relation of Awareness Knowledge and Attitude to health-related Quality of Life within a Malaysian across all patients. Both Awareness, Knowledge and Attitude (AKA) levels: median: 80.0, range: 0–170 and overall HRQoL: median 51.5; range 15–97 were moderate. Awareness was significantly correlated with Seizure Worry \((rs = + 0.29, \ p < 0.05)\), whereas knowledge was not significantly linked to any domain. Attitudes was significantly correlated with all domains \((rs = + 0.35\) to + 0.47, \(p < 0.01)\) except Medication Effects and Seizure Worry. Patients with good AKA levels experienced significantly better Quality of Life and Cognitive Functioning \((p < 0.05)\). The researchers suggest that enhancing AKA through epilepsy awareness might help in improving health outcomes.

Pandey, Sahoo & Sayeed (2010) compared the Quality of Life (QoL) and marital adjustment in epilepsy with psychiatric illnesses among 30 PWE and 60 psychiatric patients. The findings revealed that 60 % of the PWE had better social
relationships as compared to 61.7% patients with psychiatric illness. 60% of patients diagnosed with epilepsy showed a good adjustment with their spouses as compared to 73.3% with psychiatric illness who had poor adjustment. Both the PWE and people with psychiatric illness had poor Quality of Life in 61.7% and 63.3% respectively. Both types of illnesses have similar impact on Quality of Life in the domains of psychological, physical and environmental QoL.

Sancho, Iváñez, Molins, López Gómez, Masramón & Pérez (2010) assessed the influence of changes in seizure severity on Quality of Life in patients with refractory partial epilepsy in a 6-month observational, prospective, multicenter study among 262 patients diagnosed with partial epilepsy and receiving two antiepileptic drugs. Reductions in seizure severity were detected from baseline to 3 months and 6 months (P < 0.0001). Improvements compared with baseline were found for Hamilton Anxiety and Depression scales (P < 0.0001), most Medical Outcomes Study—Sleep subscales (P < 0.05), and seven subscales of Quality of Life in Epilepsy Inventory-31 (QoLIE-31; P < 0.0005). Seizure severity correlated directly with anxiety (P < 0.0001) and inversely with QoLIE-31 measures (P < 0.0001).

Eddy, Rizzo, Gulisano, Calì, Robertson & Cavanna (2010) on comparison of 50 young patients with controlled epilepsy and 102 healthy controls reported increased anxiety (P = 0.037) and more emotional and behavioral difficulties (P < 0.001) among the young patients with controlled epilepsy. Though there were no difference between the groups in Total QoL score, treatment-responsive epilepsy was associated with lower QoL within the Self domain (P = 0.016).
Babu, Satishchandra, Sinha & Subbakrishna (2009) identified the occurrence of co-morbidities in a prospective case-control study in resource-poor setting among 250 PWE attending neurology outpatient services in the age ranging from 16 to 60 years (29.66+/−11.31 years; M:F 116:134) compared with healthy matched controls (n=250; 30.35+/−11.05 years; M:F 114:136). The type of epilepsy revealed that 62.4% had generalized, 21.6% complex-partial, 8.8% simple-partial and 7.2% had unclassified seizures respectively. 69% were on monotherapy, and rest on polytherapy, with 90.8% on adequate dosages of anti-convulsants. 83.2% were compliant and 70.4% had satisfactory control of seizures. One co-morbid condition was noted in 152 (60.8%) cases and among them, 62 (24.8%) had ≥ 2 co-morbidities. Control population was also evaluated for the presence of same co-morbidities and compared with cases. The various significant co-morbidities included: migraine (cases: 25.6% vs. controls: 15.2%; p=0.02), anxiety (cases: 2.4% vs. controls: 0%; p=0.04), depression (case: 5.2% vs. controls: 0.4%; p=0.0009), sleep disturbances (case: 6.8% vs. controls: 0.4%; p=0.0002), neurocysticercosis (cases: 15.6% vs. controls: 0%; p=<0.001), pulmonary tuberculosis (cases: 3.6% vs. controls: 0%; p=0.002) and extra-pulmonary tuberculosis (cases: 2.8% vs. controls: 0.4%; p=0.03). Hypertension, diabetes, osteoarthritis, asthma, hypothyroidism, and acid-peptic disease were less common. The presence of comorbidities can also have an impact on the QoL.

Ohaeri, Awadalla & Farah (2009) assessed the Quality of Life in 276 Sudanese with grand-mal seizures and their caregivers, using the WHO 26-item QoL found that the QoL scores of patients were rather poor (50.6 -60.8%), and significantly lower than the control group. The scores being physical health domain
57.1%, psychological 60.1%, social relations 58.4%, environment 50.6% and general facet 60.8%. They had lower environmental domain scores than Sudanese diabetes patients. Caregivers had significantly higher scores (57.4 -73.7%) than patients and control group. There was a significant concordance between patient’s and caregiver’s rating. The higher QoL of the patients was associated with marriage, education, employment, no side effects and caregiver occupation.

Auriel, Landov, Blatt et al. (2009) identified that treatment side effects and unemployment (p<0.0001, p=0.037, respectively) were significant predictors for poor overall QoL, whereas age, gender, education, family status, co morbidity, seizure type, age of seizure onset, and epilepsy duration did not significantly affect the overall QoL among 103 patients. Ninety-four (92.2%) patients reported of experiencing at least one side effect of AEDs. The most common side effects involved the central nervous system. The most significant factor influencing the QoL in seizure-free patients on monotherapy was AED side effects. The researchers emphasized that physicians should take the time to ask specific questions on side effects of AEDs.

Sachin, Padma, Bhatia, Prasad, Kumar & Tripathi (2008) evaluated the psychosocial impact of epilepsy in women between 15 and 40 years of age with epilepsy, compared to those with migraine and healthy, pregnant women. Among three groups of women, 100 women with epilepsy, 50 with migraine and 100 healthy, over a two-year period of assessment using questionnaires for identifying the Quality of Life (QoL), coping strategies and caregiver burden, it was found that Quality of Life was least, and the burden experienced by the caregiver was significantly more in
patients with epilepsy ($p \geq 0.001$). Women with epilepsy relied more on religion/faith as a coping method ($p \geq 0.021$), and less on problem solving strategies ($p \geq 0.001$) when compared to those with migraine. When compared to healthy / pregnant women, they employed religious methods of coping and denial ($p \geq 0.001$), with significantly less use of problem solving techniques, acceptance, positive and negative distraction ($p \geq 0.001$). Less frequent seizures, better education and remission sustained for atleast six months, were associated with better QoL. Educational status, frequency of seizures and time elapsed since last seizure emerged as significant determinants of coping behaviour. Low educational status and monthly income of the family contributed significantly to caregivers burden. The researchers attribute the limited use of constructive coping strategies which contributed to their poor psychosocial status and adjustment within the family and society at large.

Day, Kenny, Morris & Paul (2008) revealed that a positive correlation between resilience and Quality of Life exists among 223 adults with intractable epilepsy. There was a positive correlation between resilience and Quality of Life. Multiple regression analysis indicated that a significant proportion of the variance in Quality of Life was accounted for by resilience. Seizure frequency did not account for a significant amount of the variance. Measures of anxiety and depression had a significant negative correlation with resilience.

Şenol, Soyuer, Arman & Öztürk (2007) identified the influence of fatigue, depression, clinical, demographic, and socio-economic factors on the Quality of Life of patients with epilepsy among 103 adult patients. The mean age of the patients was $34.3 \pm 12.6$, and mean duration of disease was $12.6 \pm 9.3$ years. Among these patients,
52.4% were men, 49.5% were married, 15.5% had a university education, 53.4% had low income, 45.6% had generalized seizures, and 35.0% had experienced one or more seizures per month during the preceding year. The most significant variables in the domain of overall Quality of Life was seizure frequency (P < 0.001), depression (P < 0.001), and fatigue (P < 0.001); the variables in the domain of Mental Health were seizure frequency (P < 0.001) and fatigue (P < 0.001); the variable in the Cognitive domain was fatigue (P < 0.001); the variables in the domain of Physical Health was social insurance coverage (P < 0.01), fatigue (P < 0.01), and age (P < 0.01); the variables in the Epilepsy Targeted domain were depression (P < 0.001), seizure frequency (P < 0.001), and fatigue (P < 0.01). One or more seizures per month, severe fatigue, and depression were associated with lower Quality of Life in some domains. Fatigue was a significant independent predictor of Quality of Life.

Raty & Wilde Larsson (2007) reported the highest QoL was in relation to the family domain, and the lowest, in relation to the psychological/spiritual domain among 102 young adults with uncomplicated epilepsy. They found that uncomplicated epilepsy did not significantly affect QoL in young adults and that the risk of social isolation due to uncomplicated epilepsy was not increased.

Pramuka, Hendrickson, Zinski & Van Cott (2007) examined effectiveness of a 6-week psychosocial intervention designed to improve self-efficacy and Quality of Life for 61 adults with diagnosed epilepsy in a randomized, controlled trial which revealed that there was a significant improvement in the QoLIE-89 role limitations-
emotional score in the treatment group at follow-up, but no significant differences were found in overall Quality of Life.

Harden, Maroof, Nikolov, Fowler, Sperling, Liporace, Pennell, Labar & Herzog (2007) evaluated the relationship between seizure severity and aspects of Quality of Life among 118 women. Two domains of the Quality of Life in Epilepsy-31 (QoLIE-31) correlated high significance with seizure severity: seizure worry \((r = -0.265, P = .004)\) and social functioning \((r = -0.280, P = 0.002)\). Two additional domains were significantly correlated: Overall Quality of Life \((r = -0.210, P = 0.023)\) and cognitive functioning \((r = -0.209, P = 0.024)\). Regression of QoLIE-31 was associated with seizure worry it was significant \((P = 0.006, R^2 = 0.153)\), along with social functioning \((P = 0.002, R^2 = 0.184)\) and the cognitive functioning \((P = 0.037, R^2 = 0.30)\). Severe and potentially injurious seizure behaviors were found to contribute to anxiety and socially avoidant behavior for persons with intractable epilepsy.

Alanis, Peña, Corona, López-Ayala, López-Meza & López-Gómez (2005) identified the most strong predictors for a lower QoLIE-31 total score after multiple regression among 401 patients with sleep disorders \((P < 0.001)\), socioeconomic status \((P < 0.001)\), female gender \((P = 0.002)\), and high seizure frequency \((P = 0.001)\). Depression and time of evolution of epilepsy did not have any significant influence on QoLIE-31 scores.

Schachter (2005) in an article on improving Quality of Life beyond seizure control states that these are other epilepsy related factors as medical and psychiatric comorbidities, side effects of therapy, stigma, parental anxiety, employment status,
seizure worry, self esteem and self mastery also have an impact on QoL. They may be amenable to education or therapeutic interventions.

Loring, Meador & Lee (2004) reported that symptoms of depression and seizure worry were the most important factors affecting QoL in patients with intractable epilepsy.

Djibuti & Shakarishvili (2003) identified the influence of clinical, demographic, and socioeconomic variables on Quality of Life in patients with epilepsy. Mean age of the patient population was 37.9 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 generalised seizures. A lower QoLIE-31 score was associated with low level of education, high seizure frequency, and long duration of epilepsy. The QoLIE-31 all subcomponent scores correlated strongly with seizure frequency. Advanced age was associated with a low overall quality of life, energy/fatigue, and cognitive scores. Female sex was significantly associated with a low seizure worry score. There was a strong correlation between level of education and the overall Quality of Life, cognitive and social functioning scores.

Bishop & Allen (2003) in a qualitative analysis on the impact of epilepsy on Quality of Life among 46 adults, it was found that epilepsy had both direct and an indirect impact on QoL.

Wiebe, Matijevic, Eliasziw & Derry (2002) determined the minimum important change in the different tools used to determine the QoL among 136 adults
with medically refractory epilepsy. Baseline HRQoL scores and the type of treatment (surgical or medical) had no impact on any of the estimates, and the results were replicated in the validation sample. The response rate for all instruments and global ratings ranged from 94% to 100%. There were no ceiling or floor effects in any of the HRQoL instruments. The summary global ratings showed that 85 patients (63%) rated themselves improved (> 1), 25 (18%) as unchanged (0 to 1), and 26 (19%) as worse (≤ 1); eight patients (6%) endorsed maximum change. The mean (SD) of the summary global rating score for the group was 1.9 (2.8). The MICs at nine months were 12.0 (95% CI, 8.6 to 15.5) for QoLIE-89, 11.1 (7.7 to 14.5) for QoLIE-31, 4.4 (1.5 to 7.4) for SF-36 MCS, 4.1 (2.4 to 5.9) for SF-36 PCS, and 0.13 (0.7 to 0.19) for HUI-III. All the instruments differentiated between no change and minimum important change with precision, and QoLIE-89 and QoLIE-31 also distinguished accurately between minimum important change and medium or large change.

Au, Li, Chan, Lui, Ng, Kwok & Leung (2002) on predicting the Quality of Life in Hong Kong Chinese adults with epilepsy showed that psychosocial variables contributed to the prediction of Quality of Life of the patients with epilepsy. Mood could act as a mediator between seizure characteristics and psychosocial factors, on the one hand, and Quality of Life, on the other. The statistical significance of the health locus of control and satisfaction with social support confirmed the importance of the influence of subjective sense of mastery of the condition on Quality of Life. The authors suggested the need for psychological interventions in increasing the self efficacy and resourcefullness of the patients.
Schachter (2000) in an article on Epilepsy: Quality of Life and Cost of Care stated that the primary goal of epilepsy management was to enable the patient to lead a lifestyle as free from the medical and psychosocial complications of seizures as possible. The indirect costs of epilepsy were related to the patient's ability to function. The medical and psychosocial aspects of the disease could be successfully managed resulting in decreased indirect costs.

Fisher, Vickrey, Gibson, Hermann, Penovich, Scherer & Walker (2000) in a mail survey among 1023 subjects determined the impact of epilepsy from the patient's perspective. 49% of the respondents had received less education, were less likely to be employed or married, and came from lower income households. 56% were on monotherapy, 68% were satisfied with their current AED’s, 20% of 920 respondents adjusted their own medication. Adverse events were an important concern. Complex partial seizures were the most prevalent seizures. 50% of the respondents reported incomplete control of their seizure disorder. Respondents listed uncertainty and fear of having a seizure as the worst thing about having epilepsy. Lifestyle, school, driving, and employment limits were also listed as major problems. Among the list of potential problems cognitive impairment ranked the highest.

Birgit, Margaret & Christof (1998) assessed the Quality of Life in 48 patients with Idiopathic Generalized Epilepsy (IGE). The recently diagnosed patients scored significantly lower QoL than controls and long-terms on the QoLIE subscales as work/driving/social function, health discouragement, seizure worry, medication effects, change in health, and overall health. The overall QoL score was significantly different among groups, with the controls scoring highest and the short-terms lowest.
QoL was significantly poorer in recently diagnosed patients than in patients with long-term epilepsy. Long-term patients did not differ significantly from normal controls on most indices of QoL. QoL in patients with IGE, changed throughout the course of the illness.

Bruce, Barbara, Ron, Joyce, Orrin, Kimford, Kenneth, Lawrence & George (1996) on comparison of Health Related Quality of Life in patients with epilepsy (N = 271) to multiple sclerosis (N = 85) and diabetes (N = 555) using a generic measure of HRQoL (RAND 36-Item Health Survey 1.0 (SF-36)), and the eight SF-36 scale scores found that the patients with multiple sclerosis had significantly lower HRQoL than patients with diabetes and epilepsy but patients with epilepsy had lower scores on emotional well-being and role limitations compared to patients with diabetes. The patients with epilepsy had better health perceptions than the other two groups.

2.1.4. Effectiveness of an educational intervention on Knowledge, Self-management and Quality of Life in epilepsy

Frizzell, Connolly, Beavis, Lawson & Bye (2011) determined the effect of personalised epilepsy education intervention for adolescents and its impact on knowledge acquisition and psychosocial function among thirty adolescents with epilepsy (female: 24, male: 6; median age: 16 years; partial symptomatic epilepsy: 15, generalised idiopathic epilepsy: 15). Self-knowledge of syndrome (p < 0.0001), general knowledge of epilepsy (p < 0.0001), attitudes towards epilepsy (p= 0.008) and seizure self-efficacy (p = 0.049) were improved. The intervention significantly improved self-knowledge and general knowledge of epilepsy, attitude towards
epilepsy and seizure self-efficacy. There was a positive impact on psychosocial outcomes following an educational intervention without a psychological component.

Bautista, Glen, Shetty & Wludyka (2009) determined the association between health literacy and outcomes of care among epilepsy patients and found that those who had problems learning about their medical condition due to difficulties in understanding written information had poorer scores on the QoLIE-10, increased seizure frequency, and lower educational levels.

Sureka & Sureka (2007) assessed the Knowledge, Attitude, and Practices with regard to epilepsy in rural north-west India. Generalized seizures were the most common (84%) type of seizure, followed by partial seizures (9.4%). The most common antiepileptic drug used was phenytoin, followed by phenobarbitone. The most common alternative therapy used was ayurvedic treatment. Evil spirits were believed to be the cause of the disease by 26.4% of the patients in the year 2000, but it was decreased to 11.2% in the year 2004. Faith in the curative power of drugs was increased from 18% in the year 2000 to 59% in the year 2004. Polytherapy was being resorted to by 60% of the patients in the year 2000; this was reduced to 45.6% in the year 2004. Positive attitudinal changes over four years from 2000 to 2004 had confirmed the need for effective health education that could remove misconceptions regarding the disease.

Shaw, Stokes, Camosso-Stefinovic, Baker, Baker & Jacoby (2007) in a meta analysis of self-management education for adults with epilepsy identified 1744 trials (including duplicates), 1712 were assessed as not relevant. From the 32 full text papers, 16 were primarily about adults. Further examination led to exclusion of 13
papers. The exclusion was based on the study design and intervention not meeting the definition of self-management. This left three papers describing two trials for inclusion in the review. The Helgeson trial did not report how withdrawals or dropouts were accounted for (Helgeson 1990), and the May trial (May 2002) reported results for completers only. At four months (Helgeson 1990), significant improvements were seen in the SEE fears of death and brain damage subscale (intervention mean 2.25 standard deviation (SD) 1.41 to mean 0.85 SD 1.27, control mean 2.94 SD 3.52 to mean 3.17 SD 2.78, P<0.04, WMD -1.63, 95% CI -3.23 to -0.03, becoming non-significant using the 0.3 imputed coefficient), hazardous medical self-management practices subscale (intervention mean 6.85 SD 2.56 to mean 3.2 SD 1.61, control mean 6.67 SD 2.61 to mean 7.67 SD 1.97, P<0.001, WMD -4.65, 95% CI -6.12 to -3.18 remaining significant using the 0.3 imputed coefficient), and the extent of overall misinformation and misconceptions (intervention mean 14.05 SD 4.08 to mean 7.05 SD 2.76, control mean 15.39 SD 4.95 to mean 14.33 SD 5.83, P<0.002, WMD -5.94, 95% CI -8.91 to -2.97 remaining significant using the 0.3 imputed coefficient). Seizure frequency (average monthly seizure frequency during previous four months) decreased in both groups, but the differences between groups were not significant (intervention mean 2.47 SD 3.98 to mean 2.32 SD 4.01, control mean 2.14 SD 4.72 to mean 2.05 SD 4.73, WMD -4.88, 95% CI -7.68 to -2.08 remaining significant using the 0.3 imputed coefficient).

At six months (May 2002), significant improvements were seen in the intervention group for the primary outcomes of epilepsy Knowledge (intervention mean 43.03 SD 17.10 to mean 54.62 SD 17.08, control mean 46.44 SD 16.09 to mean 48.50 SD 19.39, P<0.001, WMD 9.53, 95% CI 5.11 to 13.95 remaining significant
using the 0.3 imputed coefficient), coping with epilepsy (intervention mean 59.70 SD 16.41 to mean 65.60 SD 16.64, control mean 58.29 SD 15.31 to mean 59.92 SD 14.58, P<0.01, WMD 4.27, 95% CI 0.28 to 8.26, becoming non-significant using the 0.3 imputed coefficient), ability to express emotions (intervention mean 58.50 SD 21.17 to mean 64.46 SD 22.11, control mean 56.97 SD 21.33 to mean 58.27 SD 18.89, P<0.05, WMD 4.66, 95% CI -0.64 to 9.96 remaining non-significant using the 0.3 imputed coefficient), and information seeking (intervention mean 68.32 SD 16.84 to mean 75.69 SD 17.23 control mean 68.09 SD 16.65 to mean 69.42 SD 16.15, P<0.001, WMD 6.04, 95% CI 1.81 to 10.27 remaining significant using the 0.3 imputed coefficient). Also, improvements were seen in the secondary outcome of the tolerability of AED treatment (intervention mean 2.20 SD 0.86 to mean 2.05 SD 0.88, control mean 2.03 SD 0.85 to mean 2.10 SD 0.82, P<0.05, WMD -0.22, 95% CI -0.44 to 0.00 remaining non-significant using the 0.3 imputed coefficient). Outcomes showing no significant difference were measures of active coping versus resignation, restriction in daily living, mobility and leisure behaviour, epilepsy-related fear, stigma, SF-36 mental or physical component, self-esteem, efficacy of AED treatment, and depression.

Seizure frequency as measured on a scale of 0 (no seizures in past six months) to 5 (one or more seizure per day) improved significantly in the intervention group (intervention mean 3.23 SD 1.64 to mean 2.77 SD 1.64, control mean 2.90 SD 1.48 to mean 2.74 SD 1.62, P<0.05, WMD -0.30, 95% CI -0.70 to 0.10 remaining non-significant using the 0.3 imputed coefficient). Nineteen per cent of the MOSES group improved two or more points on the seizure frequency scale compared to 7.2% of the control group. 4.8% of the control group deteriorated (two or more points on the
scale) in seizure frequency compared with 1.8% of the MOSES group. The percentage of people without seizures or with only few seizures (one to two seizures) in the past six months increased in the MOSES group from 35.4% to 50.4% (+15.0%); the control group 38.7 to 45.8%, (+7.1%). The percentage of people with a high seizure frequency (weekly or daily seizures in the past six months) decreased in the MOSES group from 24.7 to 18.6% (-6.1%) and in the control group from 17.9 to 15.6% (-2.3%). The researchers suggested that the implications for practice as the use of self-management education to improve health and other outcomes for adults with epilepsy, but based on the evidence reviewed, were unable to determine how effective it was, or what the key components of the programme should be. The recommendations of the authors were to determine:

(1) the effect of different theoretical models underpinning the intervention.

(2) the effectiveness of delivering the intervention to groups or individuals.

(3) whether self-management education to improve outcomes for adults with learning disabilities.

(4) the cost effectiveness of delivering self-management education to adults with epilepsy.

(5) the effect of self-management education in adults with different types and severity of epilepsy.

(6) the effectiveness of peer (or lay) educators in delivering self-management education.
Helde, Bovim, Bråthen & Brodtko (2005) in a randomized, controlled trial to assess the impact of a structured, nurse-led intervention program on the Quality of Life in patients with epilepsy found that QoL was significantly improved from inclusion to completion of study in the intervention group (P = 0.019), mainly the subitems for Health Discouragement (P = 0.01), Medication Effects (P = 0.035), and Physical Role Limitations (P = 0.05).

Ridsdale, Kwan & Cryer (2000) in a randomized controlled trial of ninety people with new epilepsy identified that at baseline, fewer than half the patients reported of having been given enough advice on epilepsy, and there were important differences in patient’s knowledge of epilepsy. Lack of a U.K. school-leaving examination pass (General Certificate School Examination) was associated with lower knowledge of epilepsy (p = 0.03). At follow-up, the patients randomized to see the nurse specialist reported that enough advice had been provided on most epilepsy-related topics compared with the control group. There were no significant differences in knowledge of epilepsy scores. However, there were significant differences in the group who, at baseline, had knowledge scores in the lowest quartile; those randomized to the nurse had higher knowledge scores (42.7 vs. 37.2; p < 0.01). The nurse was highly rated for providing clear explanations. Patients who had less general education had less knowledge of epilepsy. The intervention had helped those with the least knowledge of epilepsy to improve their Knowledge scores.

2.2 CONCEPTUAL FRAMEWORK

The conceptual framework for the current study is based on the Wilson and Cleary model of patient outcomes in health related Quality of Life (1995).
The CHARACTERISTICS OF THE INDIVIDUAL includes the concept of being. This encompasses the biological and physiological factors, symptom status, functional pattern, general health perception. The characteristics of the individual is determined by identifying the existing knowledge, self-management skills and the overall Quality of Life in epilepsy at pretest and any variations thereof at posttest I and II.

a. Biological and physiological factors

An individual with epilepsy comes from a background and is in turn affected by the background from which he / she has come. The background variables that affect him and his health status are demographic variables such as age, gender, education, occupation, family income, residence, marital status and type of family.

b. Social factors

This includes the support system available as the caregivers. The primary caregiver may either be the parent or the spouse. The relationship of the caregiver and the ability to support the PWE has an impact on the adherence and coping capacity of the individual. The PWE may be dependent or independent in meeting their medical expenditure which may in turn affect or be affected by the social and economic well-being.

c. Symptom Status

Patients with epilepsy vary in terms of the type of epilepsy which may either be focal or generalized. The age at onset may be from early childhood, during
adolescence/adulthood or later. The duration of epilepsy and the duration of medication intake which in turn affects the tolerability and adaptation. The time of occurrence of epilepsy may either be during the day time, during the nights or at anytime. The effect of epilepsy on the performance of activities of daily living, job performance and socialization, is affected by the severity and frequency of seizures.

d. Functional status

This includes the ability of the individual to carry out the activities of daily living, physical, psychological, social and spiritual domains, including time for leisure and activities that one likes to do which in turn determines the Quality of Life.

e. General health perception

The existing awareness or Knowledge about epilepsy and Self-management strategies as information, medication, safety, seizures and lifestyle management carried out by the person.

f. Characteristics of the environment

The environment is the place that can initiate, promote and help maintain a change. This encompasses the characteristics of belonging in terms of physical, social and community belonging. Lifestyle modification can be enhanced by external factors this includes the nurse executed epilepsy education program with explanation clarification and discussion about the nature of epilepsy using an epilepsy information booklet with periodic reinforcement for a group of 3-5 patients.
g. Overall Quality of Life

Quality of Life is the degree to which a person enjoys the possibilities of life. The QoL is the subjective well-being of an individual and this integrates the illness and its management. The overall Quality of Life is the well-being of the individual on aspects as seizure worry, Quality of Life, emotional well-being, energy/fatigue, cognitive functioning, medication effects and social functioning. These domains are specific to patients with epilepsy and include the way in which the individual manages his/her day-to-day activities. This involves the practical becoming, leisure becoming and growth becoming, seeing to domestic activities, activities that promote relaxation and stress reduction, improvement of knowledge and skills fostering adaptation to the condition.

The conceptual framework shows the being, belonging and later movement to the becoming stage as an adaptation of PWE to the demands imposed on them by the condition. This is enhanced by the use of the different support systems to enhance the well-being. This is applicable to the current study in that the being is assessed by the pretest on Knowledge, Self-management and Quality of Life followed by the educational intervention and reinforcement and the becoming as determined by the posttest on Knowledge, Self-management and the Quality of Life among patients with epilepsy. These patient outcomes are intertwined and important for any intervention.
Figure 1. Conceptual framework based on Wilson and Cleary’s Patient outcomes in Health related Quality of Life Model