#### Chapter 2

#### **Review of Literature**

"A research literature review is a written summary of the state of evidence on a research problem. Researchers undertake a thorough literature review to familiarize themselves with the knowledge base as studies are undertaken within the context of an existing base of knowledge"<sup>40</sup>.

The researcher has done an extensive review of literature to undertake this study. To start with, the concepts of the study topic were clarified by referring to nursing, medical, nutrition and research text books. Several studies done in the field, standardized instruments measuring HRQoL in chronic kidney disease and hemodialysis were also referred to prepare the tool.. The teaching manual was prepared by referring to text books and patient education materials. Several national and international journals were perused to find out the research studies already undertaken in maintenance hemodialysis patients and other chronically ill patients regarding HRQoL and the effect of education on their HRQoL. The literature reviewed has been presented under the following subheadings.

- Definition/Meaning of HRQoL
- Selected components of HRQoL of Maintenance Hemodialysis(MHD) Patients
- Studies related to selected components of HRQoL of MHD Patients
- Role of patient education in improving selected components of HRQoL of MHD patients
- Studies related to the effect of patient education in improving selected components of HRQoL of MHD patients
- Studies related to the effect of education in improving HRQoL in other chronic illnesses.

### 2.1 Definition/Meaning of HRQoL

"We should set the highest value, not in living, but in living well" - Socrates.

Living well is very important for every human being irrespective of age, socioeconomic or health status. It means being free from bodily and other discomforts and enjoying an optimum level of health. With health at an optimum level, his adaptation potentials are tapped to the maximum and his life becomes worthwhile. In short, he achieves quality of life.

Quality of life is defined by WHO as a composite measure of physical, mental, and social well being as perceived by each individual or by a group of individuals. That is to say happiness, satisfaction, and gratification as it is experienced in such life concerns as health, marriage, family, work, financial status, creativity, belongingness, and trust in others<sup>41</sup>. Quality of life per se is an important outcome representing a person's concerns. Quality of life is also an important indicator of other outcomes such as mortality and hospitalization and is being used increasingly as an important parameter of health and well being<sup>42</sup>.

HRQoL encompasses emotional, physical, social and subjective feelings of well being that reflect an individual's subjective evaluation and reaction to his/her illness. When the focus is on the impact of a disease or medical condition on functional health status and well being as perceived and reported by the patient, health- related quality of life (HRQoL) is considered the most appropriate aspect of quality of life<sup>43</sup>.

The physical, mental, social, and spiritual aspects of people on long term dialysis or maintenance dialysis are being affected by the impact of CKD, hemodialysis and other treatment regimens. The task of managing their life and disease and maintaining their quality of life becomes a complex task. Physiological functioning of the entire body is affected adversely. Maintaining an acceptable quality of life for persons on hemodialysis can be challenging due to thrice weekly dialysis sessions, frequent surgical revisions of arterio-venous accesses, increased symptom burden, dietary restrictions, and complicated medication regimens<sup>11</sup>.

The rigors of thrice-weekly dialysis, metabolic derangements that are common in those with ESRD/CKD stage 5, and psychosocial and vocational impact of dialysis dependence are likely to contribute to the many symptoms that are known to occur in patients who are on hemodialysis and to the decrements in HRQoL observed in this patient population. For example, fatigue that stems in part from the anemia of renal failure affects as many as 80% of hemodialysis patients and contributes to impaired HRQoL<sup>12</sup>.

Sathvik et al<sup>44</sup> observed that hemodialysis therapy is time-intensive, expensive, and requires fluid and dietary restrictions. Long-term dialysis therapy itself often results in a loss of freedom, dependence on caregivers, disruption of marital, family, and social life, and reduced or loss of financial income. Due to these reasons, the physical, psychological, socio-economic and environmental aspects of life are negatively affected leading to compromised QoL.

Due to cost constraints in India, patients often request for a reduction in the frequency of dialysis sessions, the use of less expensive dialyzers, dialyzer reuse, and do not even typically receive erythropoietin therapy. Hence, augmenting the QoL may perhaps be a challenge and an observable fact of specific interest for renal health care teams. According to them, the concepts of QoL and quality-adjusted life years in chronic diseases are still emerging concepts in India.

Although hemodialysis treatment effectively contributes to long-term survival, the morbidity and mortality of dialysis patients remain high, especially those due to cardiovascular diseases. Only 32% to 33% of patients on hemodialysis survive to the fifth year of treatment, whereas 70% of patients who have kidney transplants are alive after five years<sup>14</sup>. Maintenance Hemodialysis patients experience a host of

symptoms/problems. Their morbidity and mortality rates are high and consequently their HRQoL remains poor. These facts are supported by the observations of many researchers.

This calls for appropriate interventions: interventions which will reduce the frequency and intensity of the symptoms/problems of MHD patients which in turn would decrease the morbidity and mortality rate and improve HRQoL. To achieve this, the patients should be made aware of the causes as well as the remedial measures. This study was an attempt to do that. Out of the numerous symptoms/problems affecting MHD patients 12 symptoms/problems were selected for the study. Instruments measuring HRQoL, generic as well as kidney disease specific were referred to for ensuring that these 12 symptoms/problems did indeed reflect the HRQoL of MHD patients. The list of symptoms/ problems was finalized after obtaining validity from the experts and these symptoms/ problems are referred to as HRQoL in this study.

The researcher has developed the tool-a structured interview schedule on selected components of HRQoL to elicit the knowledge responses from the participants, before and after teaching regarding the causes as well as the management of these symptoms/problems and prepared an instruction manual containing this information.

## 2.2 Selected Components of HRQoL in Maintenance Hemodialysis Patients

The symptoms/problems of MHD patients are found in the subscales of generic and disease-specific instruments measuring HRQoL. Selected items from four generic instruments and two kidney disease specific instruments which capture the symptoms/problems of MHD patients were found congruent with the prevailing symptoms/problems of the MHD population .The same was validated by the content experts. Quality of Life researchers believe that both generic and disease specific instruments should be used to provide the most comprehensive assessment of HRQoL. As a result, it is possible to identify significant areas of patients' lives that have suffered and to help patients focus more accurately on their treatment and self-management efforts.<sup>43</sup>

Medical Outcomes Study 36 items Short Form (MOS SF-36), Quality of Well being Scale (QWB), World Health Organization Quality of Life-BREF (WHOQoL-BREF), and McGill Quality of Life Questionnaire (MQoL) are commonly used generic instruments. The MOS SF-36 was judged to be the most useful for descriptive purposes such as documenting differences between sick and healthy patients and for estimating the relative burden of different medical conditions. They include items depicting health status of people with kidney disease. The components of MOS SF-36 are Physical Health and Mental Health with eight scales consisting of 36 items of self reported health transitions. These eight scales are Physical Functioning, Role Physical, and Body pain, General Health, Vitality, Social Functioning, Role Emotional and Mental Health. WHOQoL-BREF deals with general health status. McGill Quality of Life Questionnaire comprises five sub-measures relating to physical symptoms and has been designed to measure subjective well being, that is, the patient's experienced quality of life<sup>45</sup>.

The second approach to measuring HRQoL involves the use of instruments that are specific to a disease (e.g. osteoporosis or chronic, a population (e.g., the elderly), or clinical problem (e.g., pain). Measures geared towards specific diseases or populations are likely to be more sensitive and therefore have greater relevance to practicing clinicians. The Arthritis Impact Measurement Scale and the Kidney Disease Quality of Life (KDQoL) instruments are examples<sup>43</sup>. KDQoL and the Dialysis Symptom Index are specifically used to assess the health outcome of patients with kidney diseases. Kidney Disease Quality of Life deals with items such as symptom, effects of kidney disease, burden of kidney disease, work status, cognitive function, and quality of social interaction, sexual function, sleep, social support, dialysis staff encouragement and patient satisfaction. Kidney Disease and Quality of Life, a revised version<sup>46</sup> (KDQoLTM-36) deals with health, general status, physical health status, emotional problems, pain, energy, depression, and social activities. Items related to kidney disease include the impact of kidney disease on one's life, time, the feeling of being a burden on one's family and frustration about the illness. The symptoms/problems specific to kidney disease which are included in the instrument are soreness in muscles, chest pain, cramps, itchy skin, dry skin, shortness of breath, fainting or dizziness, lack of appetite, feeling washed out or drained, numbness in hands or feet, nausea or upset stomach and problem with the access site. Items related to the effects of kidney disease on daily life include fluid restriction, dietary restriction, ability to work, travel, being dependent of doctors and other medical staff, stress or worries caused by kidney disease, sex life and personal appearance.

"Symptoms are highly correlated with the demand for medical services, expenditure on health care, and motivation to alter life styles"<sup>42</sup>. The researcher studied the effect of teaching on selected symptoms of the patients and the problems they faced due to the treatment. These symptoms/problems were conceptualized as selected components of HRQoL and consist of 12 symptoms/problems.

# 2.3 Studies Related to Selected Components of Health Related Quality of Life (HRQoL) of Maintenance Hemodialysis Patients (MHD)

The following research studies identified the symptoms/problems of MHD patients, and the most common ones were selected among those to teach the MHD patients. Several studies have been done to assess the HRQoL of maintenance hemodialysis patients.

Unruh<sup>17</sup> reported a study of a fifteen centre randomized sample of 1978 hemodialysis patients assessed using the KDQoL questionnaire in USA from March 1995 to December 2001. The most common symptoms affecting at least 60% of subjects were dry skin, itchy skin, lack of strength, excessive thirst, fatigue and weakness, feeling washed out or drained, dry mouth, muscle soreness, trouble sleeping, cramps during dialysis and sleepiness during the day.

Abdel-Khader et al<sup>15</sup> studied 90 patients with ESRD and 87 patients with CKD between April 2004 and November 2006. Between April 2004 and November 2006, patients with ESRD on maintenance dialysis and individuals with a history of stage 4 or 5 CKD receiving care at local dialysis units or outpatient nephrology clinics in Pittsburgh, PA, and/or the Thomas E. S. Transplantation Institute at the University of Pittsburgh were preliminarily screened. Exclusion criteria included age <18 year or >90 year, not residing at home, active malignancy, active infection (pneumonia), active coronary artery disease (e.g., unstable angina, myocardial infarction) within the last 6 months, advanced cirrhosis, advanced dementia, active alcohol abuse, active treatment for sleep apnea, refractory psychiatric disease, or an unsafe home environment. Patients' symptoms, depression and quality of life were assessed using Dialysis Symptom Index, Patient Health Questionnaire-9 and MOS SF-36 respectively. To complete the 30-item Dialysis Symptom Index (DSI), patients were asked to report which of 30 individual symptoms had been present over the past seven days. The symptoms noted were fatigue, pain, muscle cramps, difficulty with sleep, and sexual dysfunction affected half or more of the patients receiving chronic dialysis. The other symptoms noted were dry mouth, dizziness, bone or joint pain, headache, muscles soreness, chest pain, constipation, swelling in legs, decrease in appetite, nausea, shortness of breath, cough, numbness or tingling feet, vomiting, feeling sad, feeling nervous and feeling irritable.

Jablonsk<sup>47</sup> conducted a descriptive, cross-sectional research study on a convenience sample of patients on HD recruited from two in-center dialysis clinics located in the Midwest United States. Approximate census at the dialysis clinics during the data collection period was 281 patients .Symptoms were measured with a disease-specific, multidimensional tool designed for the study. The tool assessed the intensity, frequency, duration, and distress associated with 11 physical symptoms commonly experienced by HD patients, including tiredness, itching, headache, problems of sleeping,

joint pain, cramps, shortness of breath, chest pain, nausea/vomiting, abdominal pain, and muscle weakness. An "other" category encourages patients to report symptoms experienced in addition to those listed. The Ferrans and Powers Quality of Life Index-Dialysis Version (QLI) was used to measure QoL. The sample consisted of 130 patients, who represented 46% of the total census of the two dialysis clinics combined. Participants ranged in age from 22 to 88 years (M = 60.22, SD = 15.62). Male (51%) and female (49%) patients were equally represented. Average length of time on dialysis was 32.25 months (SD = 34.90), with a range of less than 1 month to 20 years. Patients reported a mean of four co morbid conditions. Hypertension (82%), peripheral neuropathy (49%), stomach ulcers/reflux (48%), arthritis (46%), and diabetes (46%) were among the top five co morbidities present in the sample. Symptoms description showed that the patients experienced an average of 5.67 symptoms. Tiredness, the most prevalent of the 11 physical symptoms assessed, was reported by 77% of the sample. Following close behind were problems of sleeping (63%). Least commonly occurring was chest pain (13%). In addition to symptoms listed, two symptoms frequently reported in the "other" category were numbness/tingling in the hands and feet (49%) and restless of legs (22%). Scores were computed for each symptom. Possible scores ranged from 0 to 20, with higher scores indicating higher symptom burden. The average symptom score was 13.41 (SD = 2.57). The lowest score was reported for nausea/vomiting (M = 11.49, SD = 3.52); the highest was reported for muscle weakness (M = 16.26, SD = 3.88). After muscle weakness, joint pain, problems of sleeping, and tiredness received the highest score

Morais et al<sup>48</sup> conducted a prospective study among an outpatient group in the hemodialysis unit of Brazil aiming to correlate nutritional status with food ingestion. Stable patients undergoing chronic hemodialysis for at least 3 months (n = 44) were investigated by dietary recall and standard anthropometric, biochemical, and bio

impedance determinations, including subjective and objective global assessment. The mean age of the group was  $47.0 \pm 16.9$  years, and 63.6% were men. Body mass index was  $22.2 \pm 3.9$  kg/m<sup>2</sup> (mean  $\pm$  SD), calorie intake was  $1471 \pm 601$  kcal/day ( $20.7 \pm 6.7$  kcal/kg/day), and protein ingestion was  $74.3 \pm 16.6$  g protein/day (1.2 g/kg/day). Dietary and clinical findings were correlated with nutritional indices by linear regression analysis. Results revealed that malnutrition estimated by subjective global assessment was very common (> 90%), despite the fact that body mass index and serum albumin were within an acceptable range in the majority of the population. Objective global assessment yielded roughly comparable numerical findings, with 6.8% being well nourished, 61.4% at nutritional risk or lightly undernourished, 29.6% moderately malnourished, and 2.3% severely malnourished. Patients in end-stage renal disease often suffer from poor appetite, various co morbidities, and dietary restrictions. Despite regular hemodialysis, nutritional imbalances are frequently reported.

Murtagh et al<sup>16</sup> undertook a systematic review of literature aimed to describe prevalence of all symptoms, and to better understand the total symptom burden of ESRD patients. An extensive database, "gray literature," and hand searches were undertaken, by predefined protocol, for studies reporting symptom prevalence in ESRD populations on dialysis, discontinuing dialysis, or without dialysis. Prevalence data were extracted, study quality assessed by use of established criteria, and studies contrasted/combined to show weighted mean prevalence and range. Fifty-nine studies in dialysis patients, one in patients discontinuing dialysis, and none in patients without dialysis, met the inclusion criteria. For the following symptoms, weighted mean prevalence (and range) were fatigue/tiredness 71% (12% to 97%), pruritis 55% (10% to 77%), constipation 53% (8% to 57%), anorexia 49% (25% to 61%), pain 47% (8% to 82%), sleep disturbance 44% (20% to 83%), anxiety 38% (12% to 52%), dyspnea 35% (11% to 55%), nausea 33% (15% to 48%), restless legs 30% (8%to 52%), and depression 27% (5%to 58%). The

authors noted that greater recognition of and research into symptom prevalence and causes, and interventions was needed urgently to alleviate them.

Agarwal et al<sup>20</sup> identified hypertension among HD patients and undertook a randomized controlled trial to detect the effect of dry-weight reduction in hypertensive hemodialysis patients, as volume excess was thought to be important in the pathogenesis of hypertension among hemodialysis patients. The hypertensive patients were randomly divided into an additional filtration group (n=100) and a control group (n=50), and achieved reduction in dry weight by one kg and blood pressure –systolic 6.6 mm of Hg and diastolic by 3.3 mm of Hg at eight weeks.

Tarras et al<sup>49</sup> observed that hypertension was present in 70 to 90% of patients on hemodialysis (HD) and that it constituted one of the major risk factors contributing to cardiovascular disease in these patients.

This study by Weisbord et al<sup>12</sup> sought to assess symptoms and their relationship to quality of life and depression and conducted a cross-sectional, observational study of 162 long-term hemodialysis patients and their renal providers from February 2006 to July 2006. Study patients and providers were recruited from three dialysis units in Pittsburgh, PA, including one university-affiliated and two community-based units. The Dialysis Symptom Index was used to assess the presence and the severity of 30 symptoms. The Illness Effects Questionnaire and Beck Depression Inventory were used to evaluate quality of life and depression, respectively. Correlations among symptom burden, symptom severity, quality of life, and depression were assessed using Spearman correlation coefficient. Mean age was 62 years, 62% were men, and 48% had diabetes. The median number of symptoms was 9.0 .Dry skin, fatigue, itching, and bone/joint pain each were reported by  $\geq$ 50% of patients. Seven additional symptoms were reported by >33% of patients. Sixteen individual symptoms were described as being more than "somewhat bothersome". Overall symptom burden and severity each were correlated directly with impaired quality of life. Physical and emotional symptoms are prevalent, can be severe, and are correlated directly with impaired quality of life and depression in maintenance hemodialysis patients. The study suggests that incorporating a standard assessment of symptoms into the care provided to maintenance hemodialysis patients may provide a means to improve quality of life in this patient population.

Sabbatini, et al<sup>50</sup> studied 694 patients undergoing maintenance hemodialysis (384 males and 310 females) using Holley's questionnaire. Seven-hundred-and-thirty-seven HD out-patients, treated in 21 different hemodialysis units in Naples and its neighborhood, were enrolled in the study. All patients in each unit were surveyed by their nephrologists during routine treatment using a simple yes/no questionnaire. They were divided into insomnia group and control group. 156 male and 155 female patients who complained of insomnia defined either by delayed sleep onset and/or night time waking were in the insomnia group. There was a significantly higher risk of insomnia in patients with more than 12 months on dialysis, in patients dialyzed in the morning (p<0.003) and in patients with higher parathyroid hormone level (p<0.05). Neither body mass index, body weight gain and blood pressure, nor dialysis parameters differed between the groups. There was no difference in hemoglobin concentration or use of erythropoietin. The study demonstrated that the prevalence of insomnia is high and its solution would contribute towards improving the quality of life of HD patients and decreasing some complications linked to a poor sleep efficacy.

Pisoni et al<sup>51</sup> assessed the prevalence of pruritus using data collected from both DOPPS I (1996–2001) and DOPPS II (2002–2004). Adult hemodialysis patients were randomly selected for study participation from 308 dialysis facilities in DOPPS I (patients from seven countries: France, Germany, Italy, Japan, Spain, the UK and the US), and from 322 dialysis facilities in DOPPS II (patients from 12 countries: Australia, Belgium, Canada, France, Germany, Italy, Japan, New Zealand, Spain, Sweden, the UK and the

US). The total number of patients for whom pruritus data were available was 10,810 patients from 284 facilities in DOPPS I and 10,265 from 317 facilities in DOPPS II. The analysis was adjusted for age, gender, race Kt/V, hemoglobin, serum albumin, serum phosphorus, 13 co-morbidities, depression, and years on dialysis, country and facility. The patients were selected randomly for study participation. Pruritus was found to be less common in patients starting HD than in patients on dialysis for more than three months. Patients with moderate to extreme pruritus were more likely to feel drained (P < 0.0001) and to have poor sleep quality ( $p \le 0.004$ ) and QoL mental and physical composite scores lower (P < 0.0001) than patients with no/mild pruritis. Pruritis in HD patients was associated with 17% higher mortality risk (P < 0.0001). It was concluded that the pruritis/mortality relationship could be substantially attributed to poor sleep quality.

Akhyani, et al<sup>52</sup> also carried out a study on maintenance hemodialysis (HD) in Tehran, Iran, to evaluate the frequency of pruritus in hemodialysis patients and to correlate its presence with relevant clinical and laboratory parameters. All patients (n = 167) on maintenance HD attending three HD units at Emam Khomeini, Dr Shariati and Sina Medical Complexes in Tehran, Iran, from 1998–1999 were enrolled in a crosssectional study. Eighty-three patients were men and 84 were women. Their mean age was 47.95±16.73 years with a range of 10 –76 years. The routine of dialysis was 3 times per week for 4 hours. Itch intensity was scored as mild, moderate or severe. Age, sex, xerosis, presence of neuropathy, duration of dialysis, laboratory findings like hemoglobin, creatinine, calcium, phosphorous, parathyroid hormones were evaluated. Pruritis was found in 41.09% of patients. In 22 patients (31.4%), pruritis intensified during and after dialysis. Among the background variables only neuropathy was significantly more common in the pruritus group (63.8% versus 42.1%, (p < 0.006).

Eghbali et al<sup>53</sup> in a descriptive comparative study on 72 patients compared problems of patients with chronic renal failure undergoing hemodialysis and peritoneal

dialysis referring to medical university's hospitals. The samples included were two groups of hemodialysis (36 patients) and peritoneal dialysis (36 patients), referring to Al-Zahra and Noor hospitals in Isfahan .Data were collected using five questionnaires on sleeping disorders, depression, marital satisfaction, tiredness and readjustment with society. The mean scores of sleeping disorders and tiredness in the hemodialysis group was higher than in the peritoneal dialysis group, but there was no significant difference in the mean scores of depression, social readjustment, and marital satisfaction of the two groups. The results of this study showed that hemodialysis and peritoneal dialysis patients suffer sleep disorders and tiredness, but the severity of tiredness and sleep disorders is higher in hemodialysis patients. Therefore, nurses should pay more attention to these patients and provide them more support and care.

Sathvik et al<sup>44</sup> assessed the QoL in hemodialysis patients with reference to their physical, psychological, social, and environmental health dimensions, and to assess the effects of age, sex, income, level of education, duration of disease, co-morbidity, and treatment duration on the QoL of hemodialysis patients. Patients were recruited from dialysis centers of J.S.S Medical College Hospital and Basappa Memorial Hospital, Mysore in 2007. The criteria for inclusion were: ESRD patients who were aged 18 years and above of either sex; on regular twice a week hemodialysis for at least three months or more, or who had received renal transplant at least six months prior to enrollment into the study. To compare the QoL of ESRD patients with the QoL of patients suffering from another chronic ailment, asthma, patients of severity as per Global Initiative on Asthma grades II, III, and IV were enrolled in the study. Healthy individuals were selected from the general population. WHOQOL-BREF, was selected to quantify the health-related quality of life of ESRD patients and scores were analyzed with one-way ANOVA and Student's t-test .Quality of Life of hemodialysis patients was found to be

significantly (p < 0.05) impaired in comparison to the QoL of healthy individuals selected from the general population. In hemodialysis patients, the highest QoL score was observed in the environment domain ( $60.59 \pm 11.73$ ) followed by social relationships  $(53.93 \pm 16.91)$ , psychological health  $(40.92 \pm 18.66)$ , and physical domain QoL scores ( $38.81 \pm 18.36$ ). The study reported that duration of dialysis, education, annual family income, the number of co-morbidities, and the hemoglobin and serum albumin levels were significant (p < 0.05) positive predictors of one or more dimensions of the WHOOOL-BREF. Gender and employment status were significant negative predictors of psychological (p=0.036) and environmental dimensions (P=0.029). Employment status was observed to be a significant negative predictor (P=0.012) of the physical health dimension of WHOQOL-BREF. However, variables such as age, marital status, the type of co-morbidity and the primary cause of the kidney disease were not associated with any of the QoL dimensions of WHOQOL-BREF. The results of this study suggested that the QoL of hemodialysis patients was considerably impaired compared to that of the healthy subjects, especially with respect to the physical, psychological and social relationship domains. Renal transplant patients have better QoL in all the four dimensions of the WHOQOL-BREF compared to hemodialysis patients

### 2.4 Role of Patient Education in Improving HRQoL of MHD patients

"It's all about control. Take away a patient's sense of control over his life, and you have hurt him more than any injury or disease. Give him back that sense of control and you have helped him more than any drug therapy. He can make miracles happen". Gregory White Smith, brain cancer survivor.

A patient on hemodialysis is chronically ill whose life is restricted imposed by disease and treatment regimen. His daily routines like waking up, sleeping, choice of food, work, travel, leisure etc are decided at times by others including health care professionals. It happens when he is incapable of taking any decisions. Then he feels as though he is controlled which takes away his motivation and interest. However, if he is able to adapt to the prescribed life styles and able to take decisions in emergencies, integrating dialysis schedules and other treatment regimen into his daily routine he gets back a sense of freedom. Then he would become an active participant in his care with better compliance to the treatment regimen. This becomes possible by learning about the disease process, treatment options, food allowed and restricted, activities and exercises permitted, thorough knowledge about the medicines ,blood tests etc.. When he is capable of taking decisions for his daily activities, he achieves control over his illness and he becomes self-reliant. This is accomplished through patient education. Statistics reveal that patients on hemodialysis are living longer due to advances in the field; patient education will enhance the quality of their lives.

Hult et al<sup>54</sup> stated that "Society is undergoing great changes that affect healthcare and medical services in many ways. For example, people live longer and an increasing number live with multiple diseases. They travel more and thus come into contact with unusual illnesses. New technology has become increasingly more integrated into medical care, making it into a high-tech field, and the time patients spend in hospitals is becoming shorter"<sup>54</sup>. This is again emphasizing the need for patient education for self-management of illnesses.

Wengstrom et al <sup>55</sup> are of the view that to manage CKD efficiently, it is necessary to have related knowledge, capability, autonomy, and self-efficacy, as well as have better control of their life situations. In summary, it is a question of supporting and increasing patient involvement and self-care ability. Involvement means understanding and having knowledge about one's health-related situation, and being able to take part in plans and decisions concerning one's own care. In this context, self-care can be described as the activities required for an optimal daily life with a disease. Self-care ability can be briefly described as knowledge, competence, and activities related to health (Orem, 1985). The specific components of self-care applicable to people with Stage 4 and Stage 5 CKD (such as those with GFR less than 30 ml/min) are having control over nutritional and fluid intake, physical activity, and weight, as well as monitoring bodily signs and symptoms (such as shortness of breath, edema, nausea, pruritus, dizziness, and signs of infection). It may involve tasks including maintaining a diet, blood pressure measurements, managing medication and dialysis access care.

Chronically ill patients like those who are on MHD require a lot of adjustments in daily life and they should make those decisions themselves. It is not feasible for a patient to visit a hospital whenever he develops symptoms that are very frequent. Even if he manages to visit a health facility, neither the patient nor the healthcare professionals would be able to achieve much. Firstly, MHD patients when sick are invariably impaired physically and cognitively. Secondly, the priorities of the heath professional would be different due to the emergency nature of the symptoms. The solution would be a planned education program. If a patient is educated about his illness related to his disease and management of his symptoms/problems, it would help him to prevent many of these symptoms/problems. "Care and education have much in common, and work in the healthcare sector is closely associated with learning and teaching"<sup>54</sup>.

Thomas Hawkins et al<sup>56</sup> "strongly believed that in a world in which those with chronic illnesses spend about one hour a year in face-to-face conversations with healthcare providers, patients shoulder the responsibility for a day to day management of chronic illness".

Wengstrlam et al<sup>55</sup> stated that chronic kidney disease infringes on life and often leads to significant functional impairment. One goal for nursing care is to improve the patient's quality of life during every stage of the disease. In Sweden, the care of people with chronic kidney disease is based to a large extent on patient participation and is carried out mainly at home, either by the patient or relatives. Patient education is therefore an important part of the treatment. Several studies on the impact of early education for patients with chronic kidney disease show positive effects, such as a delayed initiation of renal replacement therapy, and better quality of life.

Thomas Hawkins et al<sup>56</sup> opined that the number of people with chronic illnesses is increasing at an alarming rate and the population of CKD requiring MHD is one major category. Self management of these people is no simple task. For example, the goals of treatment for people with chronic kidney disease stage 5 include identifying and managing co-morbidities and complications besides undergoing renal replacement therapy like hemodialysis. People in their final stage of chronic kidney disease often simultaneously manage other chronic conditions such as diabetes or hypertension, which are the most common causes of chronic kidney disease.

Curtin et al<sup>57</sup> noted that investigators have long studied the methods people use to live with illness and what "self-management" means to those with chronic illnesses, They examined patients on long term dialysis and defined self-management as the "patients' positive efforts to oversee and participate in their healthcare in order to optimize health, prevent complication, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred life style".

According to Richard<sup>38</sup> self-care management encompasses compliance and adherence and advocates clients being partners in their treatment, having the knowledge and skills to care for themselves, making decisions about their care, identifying problems, setting goals, and monitoring and managing symptoms.

Lan et al<sup>58</sup> observed that four trends are currently present globally in relation to health care management:

• A shift from professional care to self care

- A shift from "one pill, one ill" to multiple options
- A shift to the home as health care centre
- A shift to health care as information flow

Dialysis patients must make frequent daily decision about fluid intake, nutrition, physical activity management of symptoms, and coping with stress. Managing these factors is therefore an important aspect of self care. However, patient compliance is difficult to achieve. The role of the healthcare professional is therefore to improve patient awareness that consequently improve compliance. "An empowerment program is a valuable intervention for improving self-management by patients: it can both improve quality of life and assist in rehabilitation<sup>34</sup>" Lan et al also observed that patients with chronic diseases are increasingly demanding additional professional opinions and clearer explanations and are reserving final decisions about diagnosis and treatment for themselves.

Legg<sup>59</sup> was of the view that early assessment and intervention help patients cope with the effects of kidney disease and its complications on the quality of their lives. For assessment of people with chronic kidney disease one of the most commonly used tools is the Kidney Disease Quality of Life (KDQoL) Short form validated 36 items self administered questionnaire originally designed in 1994 for use by patients on dialysis.

Mapes et al<sup>60</sup> found in their study of hemodialysis patients that low scores in the health-related portion of the KDQoL were associated with higher risks of hospitalization and death, regardless of ages, race or co-morbidities. Early and frequent education helps patients to better understand and participate in their care by tracking indicators such as weight, blood pressure and laboratory results they also see the results of their actions such as lowering potassium intake and following medication regimen diligently. Lorig et al<sup>61</sup> reviewed trials involving chronic disease self management programs, concluding that "significantly improved behaviors" were demonstrated, including increased time spent exercising, improved communication between patients and physician and reduction in pain, fatigue, distress, worry and health case use. "Effective management of chronic kidney disease and hemodialysis depended on recognizing that the patient was the principal manager and that proficiency in specific skills and tasks was required to master this role for which nursing support was vital .In later stage of chronic kidney disease, medical management and self management would become more complicated. Adherence to the treatment regimen was important and patient needed information and support for the same".

Maureen<sup>62</sup> commented that the number of cases of peritonitis in patients on peritoneal dialysis (P. D.) could be greatly reduced through adherence to patient training along with other stiff protocols. A team based approach was the best defense against infection and the most important members were P.D. nurses who were effective educators knowledgeable about P.D., flexible, committed to ensuring good outcome.

Arnold<sup>63</sup> under took a cross sectional study of 129 patients on hemodialysis of age 18 years or older from several hemodialysis centers in western U.S. The study was aimed to find out their fluid adherence using the Illness Perception Questionnaire. Of the 116 patients responded 42 (36.2%) participants were adherent and 74(63.8%) were non-adherent to fluid restrictions. He emphasized the need for patient counseling and education.

Thomas Hawkins et al<sup>56</sup> reported a qualitative study of elderly persons on hemodialysis. The content analysis of the data revealed that before dialysis began many participants didn't interpret symptoms of loss of appetite and weight loss as stemming from kidney disease. Instead they construed symptoms as gastro intestinal in origin and chose to "tough it out" until the symptoms went away, highlighting the need for regular patient education programs.

The observations and comments of the experts and researchers stress the role of patient education in the management of chronic patients including hemodialysis patients.

# 2.5 Studies Related to the Effect of Patient Education in Improving Selected Components of HRQoL of MHD Patients

The literature review helped to identify several studies done showing the effect of patient education on the HRQoL of MHD patients. These studies support that patient education helped improving knowledge of MHD patients and consequently HRQoL.

Barnett et al<sup>30</sup> examined the effectiveness of a patient education program on fluid compliance as assessed by interdialytic weight gain, mean pre-dialysis blood pressure and rate of fluid adherence. An exploratory study was conducted in 2004-05 using a quasiexperimental, single group design in a dialysis centre located in a major teaching hospital in Kuala Lumpur, Malaysia. Twenty-six patients with an interdialytic weight gain of greater than 2.5 kg were identified as non-compliant and recruited to the study. The intervention was carried out over a two month period and included teaching and weekly reinforcement about diet, fluids and control of weight gain. Patients' mean interdialytic weight gain decreased following the educational intervention from 2.64 kg to 2.21 kg (p <0.05) and adherence to fluid restrictions increased from 47% to 71% following the intervention. Pre dialysis mean blood pressure did not improve following the intervention, although the maximum recording for pre dialysis systolic pressure dropped from 220 mmHg to 161 mmHg. Whilst no statistically significant associations were detected between inter dialytic weight gain and age, educational level, marital status or employment status, women demonstrated a greater decrease in mean interdialytic weight gain than men. The study concluded that nephrology nurses often have long-term relationships with their patients and are ideally placed to provide ongoing education and

encouragement, especially for those experiencing difficulties in adhering to fluid and dietary restrictions.

Ching, et al<sup>64</sup> did a study to find out the effect of group intervention to quality of life in hemodialysis patients. The study applied an experimental design. Out of 60 patients randomly assigned into experimental or control group, 48 completed the study. Twenty patients in the experimental group received group psychosocial intervention. The therapy ran for two hours per week for two months. Twenty eight patients in the comparison group received routine unit care and self-care booklet. Instruments included. The Strategies Used by People to Promote Health, the Beck Depression Inventory and the Short Form-36. The data were collected at pretest and one month following therapy. The findings demonstrated that self-care, self-efficiency depression and quality of life significantly improved statistically for patients in the therapy group compared with patients in the comparison group. The study indicated that group psychosocial intervention significantly reduced depression, improved self-care, self-efficiency and quality of life in hemodialysis patients.

According to Sathvik et al.<sup>65</sup> ESRD patients who are on hemodialysis have complex drug regimen and often they receive on an average of 10-12 medications daily, many of which requires multiple doses/day. Due to polypharmacy, frequent medication adjustments on dialysis versus non-dialysis days, medically unstable nature of the disease and restricted life styles, these patients are at high risk for developing drug related problems and non adherence. Male and female hemodialysis patients aged from 18 to 80 years, undergoing regular hemodialysis on outpatient basis, and receiving their scheduled medications at least for the past one month were approached for consent to participate in the study. Patients were excluded if they had multiple organ system failure, malignancies, memory impairment, were unconscious, severely disabled, if they were on short-term/irregular dialysis, were unable to speak/understand the local language, Kannada or English or if they were unwilling to participate in the study. In this prospective randomized study of 90 hemodialysis patients, baseline medication knowledge was assessed using medical knowledge assessment questionnaire developed for the study. During the interview, five parameters like ability of each patient to recall the names of his/her medications, the purpose of use (indication), dose/strength, the number of doses to be taken each time and side effects of the medications were assessed. Number of medications assessed and counseled was restricted to five most common classes of medications received by hemodialysis patients: 1) anti hypertensive, 2) calcium and phosphate binders, 3) vitamin D<sub>3</sub> analogues, 4) folic acid, 5) iron preparations. During the first phase of the study, Group I patient received the education provided by a trained clinical pharmacist regarding their medications for eight weeks and Group II was deprived of clinical pharmacist provided education, but received usual services. The same questionnaire was once again administered to both the groups and statistically significant improvement were found in the scores of medication knowledge assessment questionnaire (p>0.05). The study confirmed that medication knowledge of the hemodialysis patients was extremely poor regarding the name, indication and dosage regimen of their medications. The study emphasized the need for the continued education to the hemodialysis patients for better understanding of the medications they use. A trained clinical pharmacist could play a vital role in educating hemodialysis patients, which has obvious benefits on therapeutic outcome.

A prospective comparative study by Ramani et al.<sup>66</sup> on dialysis patients (n=53) on the effect of patient education on their HRQoL found statistically significant improvement. Patients were kept under observation for a period of one month and were assessed for HRQoL before and after providing patient education. Education was provided regarding the disease, medication, storage of medication, over the counter drugs, diet, exercise, dressing, emotion sharing, and problems occurring during and after dialysis. The HRQoL of the patients were assessed using SF-36 Questionnaire. At the end of study patients had significantly (P<0.05) higher HRQoL score as compared to their scores before receiving patient education. The conclusion was that patient education can play an important role in the improving the HRQoL of patients on dialysis.

Wingard et al<sup>28</sup> report on the Right Start Program (RSP), which provided prompt medical management and self-management education to hemodialysis patients. A matched cohort analysis was conducted to validate the expanded program's continued effectiveness. Death risk was reduced in RS patients (n = 4308) versus matched controls by 34% and 22% at 1 year. RS patients had lower hospitalization during the first year (RS \_ 15.5 days per patient year versus C \_ 16.9, At 120 days, more RS patients achieved hemoglobin 11 to 12 g/dl (RS \_ 22.4% versus C \_ 19.7%, Kt/V > 1.2 (RS \_ 66% versus C \_ 53.5%, , albumin > 4.0 g/dl (RS \_ 26% versus C \_ 22%, and phosphorus 3.5 to 5.5 mg/dl (RS \_ 52.4% versus C \_ 45.4%). At 120 day, RS patients had a greater reduction in catheter use (RS \_ 32% versus C \_ 25%), and more vitamin D use (RS \_ 60% versus C \_ 55%,) Expansion of RS to a larger incident patient population results in significant reduction of morbidity and mortality associated with improvement of intermediate outcomes.

Conn et al<sup>67</sup> reported a meta analysis highlighting the effect of education on CKD and other chronic illnesses. A total of 213 samples including 22557 subjects from 163 reports were eligible for the Meta analysis. Studies represented samples with diverse chronic illness: mixed medically and surgically managed cardiac diseases, hypertension, peripheral vascular disease, myocardial infarction, coronary artery disease, arthritis, renal disease and so on. It was documented that moderate physical activity behavior effects following diverse patient educational intervention. Physical activity is especially important for adults with chronic illness because it may delay progression of some chronic illness and manage symptoms of other. The researcher emphasized the importance of increasing physical activity among many chronically ill adults and justified in continuing to develop diverse education efforts.

Tsay et al<sup>34</sup> investigated the effectiveness of an empowerment program on empowerment level, self-care, self-efficacy and depression in patients with end-stage renal disease. The study was a randomized controlled trial. Qualified patients in two dialysis centers of major hospitals in southern Taiwan were randomly assigned to an empowerment group (n=25) and a control group (n=25). The empowerment program included identification of problem areas for self-management; exploration of emotions associated with these problems; development of a set of goals and strategies to overcome these problems to achieve these goals; creation and implementation of behavioral change plans; and stress management. The outcomes measured were the Empowerment Scale, the Strategies Used by People to Promote Health and the Beck Depression Inventory. Data were collected at baseline and six weeks following intervention. Primary statistical analysis was by means of *t*-test and analysis of covariance. The results indicated that scores of the empowerment (P<0.001), self-care self-efficacy (P=0.002) and depression (P=0.03) in the empowerment group have a significantly greater improvement than the control group.

Fathima<sup>68</sup> carried out an evaluative research with one group pre-test post-test design at Vijaya Hospital, Chennai on care givers of hemodialysis patients with samples selected through non-probability convenient sampling technique. The caregivers of hemodialysis patients were given the information booklet on dietary management, fluid management, care of vascular access site, worsening signs of kidney failure and activities of daily living. The data collected after one week showed that the overall knowledge score increased from 50.35 in pre-test to 86.25 in post-test. The 't' value was highly significant proving the effect of education in improving care related knowledge.

Schlatter et al<sup>69</sup> undertook a study to determine the effect of a patient education intervention on decreasing serum phosphorus levels, increasing calcium levels, and increasing knowledge in hemodialysis patients with abnormally high phosphorus levels (n = 29). Study subjects were (a) on hemodialysis at least 3 months, (b) English speaking, (c) mentally alert, (d) not under constant nursing care, and (e) hyperphosphatemic. The study was conducted at two suburban dialysis units in the Chicago Metropolitan area. This study had a one group, pretest-posttest design, using subjects as their own controls. The intervention was a one-on-one education session performed by a nephrology nurse using a teaching booklet, an osteodystrophy tool and a medication diary. Results showed that the mean change score for phosphorus did not reach significance (p = .50). The change in mean phosphorus levels was not related to gender, education, or dialysis unit. There was a weak relationship between a decrease in phosphorus and an increase in knowledge about phosphorus (r = 0.21). However, calcium levels improved significantly after the teaching intervention (P = 0.003). Mean overall scores for knowledge about phosphorus control increased significantly ( $P = \langle 0.01 \rangle$ ). The findings of this study demonstrated that an education session can have an effect on patients' knowledge and compliance.

Tomasello et al<sup>70</sup> and colleagues investigated compliance with regimen of phosphate binders among 188 patients at a dialysis facility. The average pill burden was 8.3 phosphate binders per day; 37.8% of patients reported taking less than 80% of their phosphate binders. Only 10% of the patients met the National Kidney Foundation (NKF)'s calcium supplementation and parathyroid hormone level. A combination of strategies including reinforcement, counseling and education showed success in improving adherence.

# 2.6 Studies related to the Effect of Patient Education on HRQoL in other Chronically III Patients

Patient education is the key to successful rehabilitation in all chronic illnesses. Researches conducted on the effect of education on different types of chronic patients reveal similar results: patient education improved compliance and adherence to the treatment regimen and improved HRQoL.

Kroff et al <sup>71</sup> defined chronic conditions as illnesses that last longer than three months and are not self limiting. Patients and their families are the primary care givers in chronic illness. Self care refers to: Engaging in activities that promote health, build physiologic reserve and prevent adverse sequelae; interacting with health care providers and adhering to recommended treatment protocols; monitoring physical and emotional status and making appropriate management decisions on the basis of the results of self monitoring; and managing the effects of illness on the patient's ability to function in important roles and on emotions, self-esteem and relationship with others. Self care and medical care are enhanced by effective collaboration by health care providers. In many chronic conditions interventions have shown improvement in medical, emotional and functional outcomes and the authors have reported several studies to support this.

Maintenance Hemodialysis patients are chronically ill. Their management is similar in principle like any other chronic patients. Studies showing effect of patient education in different chronic illnesses are quoted below.

Mazzuca et al<sup>72</sup> carried out the Diabetes Education Study (DIABEDS) which was a randomized, controlled trial of systematic education program for diabetes patients and its effects on patient knowledge, skills, self-care behaviors, and relevant physiologic outcomes. The original sample consisted of 532 diabetes patients from the general medicine clinic at an urban medical center in U.S.A. Patients were predominantly elderly, black women with non-insulin-dependent diabetes mellitus of long duration. Patients randomly assigned to experimental groups (N = 263) were offered up to seven modules of patient education. Each content area module contained didactic instruction (lecture,

50

discussion, audio-visual presentation), skill exercises (demonstration, practice, feedback), and behavioral modification techniques (goal setting, contracting, regular follow-up). Two hundred seventy-five patients remained in the study throughout baseline, intervention, and post intervention periods (August 1978 to July 1982). Despite the requirement that patients demonstrate mastery of educational objectives for each module, post intervention assessment 11-14 months after instruction showed only rare differences between experimental and control patients in diabetes knowledge. However, statistically significant group differences in self-care skills and compliance behaviors were relatively more numerous. Experimental group patients experienced significantly greater reductions in fasting blood glucose (-27.5 mg/dl versus -2.8 mg/dl(P < 0.05) and glycosylated hemoglobin (-0.43% versus + 0.35%(P< 0.05) as compared with control subjects. Patient education also had similar effects on body weight, blood pressure, and serum creatinine.

Gasllefoss et al<sup>73</sup> studied the effect of patient education in patients with asthma and Chronic Obstructive Pulmonary Disease (COPD) on HRQoL using the St. George's Respiratory Questionnaire (SGRQ) on 78 asthmatics and 62 patients with COPD. In this randomized control study, following two – 2 hours group sessions each by a nurse and a physiotherapist, baseline quality of life assessment showed statistically better scores (P<0.05) for the educated asthma group after 12 months compared with the control group. This aligned with the 12 months SGRQ assessment, which revealed better symptoms activity impact and total scores by 11 (P<0.02), 15 (P<0.01), 19 (P<0.001) and 16 (P<0.001) respectively. Patient education among asthmatics increased the FEV by a mean value of 6.1% compare with the control group (P<0.05). Education among patients with COPD did not indicate a significant increase in HRQoL as measured by the SGRQ or increase in FEV<sub>1</sub>.

Thomson-Hawkins et al<sup>56</sup> referred to a pilot study of a tailored educational intervention designed to reshape cancer patient/s misinterpretations of cancer pain and its

treatment. 83% of those who participated revealed that the intervention changed the way they thought about pain.

Kreuter et al<sup>74</sup> explored the potential priming effect of physician advice on patient responses to behavior change interventions in adult patients (n = 915). In a randomized controlled trial with a three month follow up of four community based group of family medicine clinics, adult patients received printed educational materials designed to encourage patients to quit smoking, eat less fat and increase physical activity. Patients who received physician advice prior to receiving intervention material on the same topic were more likely to remember the materials, show them to others and perceive materials as applying to them specifically. They were also more likely to report trying to quit smoking Odds Ratio (OR) 1.54; 95% confidence interval (CI) = 0.95 - 2.40, quitting smoking at least 24 hours OR = 1.85; 95% CI = 0.2 - 3.34 and physical activities OR = 1.51; 95% CI = 0.95 - 2.40. The findings support an integrated model of prevention in which physician advice is a catalyst for change and is supported by coordinated system of information and activities.

Rana et al<sup>75</sup> studied the impact of health education on health related quality of life among elderly persons in a randomized controlled community based study in Bangladesh. A total of 1135 elderly persons were selected for the study. The analysis include 839 participants (Intervention n = 425; Control n = 414) who participated in both baseline and post intervention surveys. Participants were in the intervention were further stratified into compliant (n = 315) and non-compliant (n = 110) group based on the reported compliance to intervention activities. The intervention includes health education on physical activity, advice on healthy food intake, and other aspects of management. The HRQoL was assessed using multi-dimensional generic instrument designed for elderly person. Multivariate analysis revealed in non compliant group the probabilities of increased scores were less likely – overall HRQoL (OR – 0.52; 95% CI – 0.32 – 0.82).

Among the control group, overall HRQoL was (OR- 0.44; 95% CI- 0.32 - 0.59 (adjusted for age, sex, literacy, material status and economic status). This study concludes that provision of community based health education intervention might be a potential public health initiative.

Abell et al<sup>76</sup> assessed the association between physical activities and HRQoL among person with arthritis or chronic joint symptoms. A cross sectional telephone survey estimated HRQoL using the number of physically or mentally unhealthy days during the past 30 days in community dwellings adults of United States of America residing in all 50 cities. Inactive men and women mere 1.2 to 2.4 times more likely to report impaired HRQoL compare with those who met physical activity recommendations. It shows that those who followed health advice received informally or imbibed from every day life through mass media or contact with people enjoyed better quality of life.

Mannise et al<sup>77</sup> evaluated the effect of a headache education program in a work place setting. A 45 minute standardized educational program was delivered to 492 participants at eight companies. Participants completed questionnaire regarding their head aches and head ache management techniques. Short Form (SF)–36 and the Headache Disability Inventory before and one month after the presentation. The intervention significantly improved heath related quality of life before decreased headache related disability and promoted the use of self management technique.

Schnerder et al<sup>78</sup> reported a study done to assess the effect of a multimedia computer based headache program in New York City. A total of 185 participants completed a baseline information about the types, severity and frequency of their headaches; and lost workdays as a result of headache. They received personalized reports about their headaches and were given access to an on-site neurologist and additional educational information. A follow up assessment after three months showed that out of 177 participants, 19% saw a physician for headache, 56% reported over all improvement

in headache symptoms (P<0.01) with a decreased headache frequency and better understanding of headache most often selected as reason for management. The numbers of lost work days were also less. The results of this study indicate that headache program improved out come. Educational material or education played a role in the improvements observed and the study warrant further study in larger, controlled trials.

The researcher in her study planned to conduct pre-test, to teach the patients one-on-one basis in the dialysis unit and to give the instruction manual to reinforce the learning and to carry out a post-test after 21 to 28 days to study the effect of planned teaching on knowledge and practices related to selected components of HRQoL.

#### Conclusion

These studies conducted in different parts of the world using different research approaches revealed the kind of symptoms/problems, the complications and morbidities faced by the MHD population and also showed the effect of patient education in reducing symptoms and improving even bio-chemical values like serum albumin and hemoglobin, and eventually improving the HRQoL. There were also studies done to find out the effect of education in improving HRQoL in various other chronic conditions. Most of these studies have been done in countries outside India. The number of researches conducted and reported from India and other developing countries are low.

The researcher has planned to carry out a study on hemodialysis patients of Mumbai and Navi Mumbai as the researcher is working in Navi Mumbai. This study is an attempt to assess the awareness of MHD patients about their health related quality of life and to teach them about symptoms/problems and related facts so as to enable them to achieve a better HRQoL through self-care management. It is also hoped to reduce the incidence of hospitalization and the additional burden of medical expenditure.