

Chapter 1

Introduction

1.1 Background of the Study

“Bones can break, muscles can atrophy, glands can loaf, and even the brain can go to sleep without immediate danger to survival. But should the kidneys fail, neither bones, muscles, glands, nor could brain carry on”¹. Kidneys perform crucial functions that affect all parts of the body involving complex operations to keep the rest of the body in balance. And when the kidneys become damaged by disease, the other organs are affected as well¹. Kidney diseases can range from infections of the urinary tract to Chronic Kidney Disease (CKD). Urinary tract infections are localized and usually self-limiting with timely and proper treatment, but CKD requires lifelong management and care.

The Kidney Disease Outcome Quality Initiative (KDQOI) of the National Kidney Foundation (2002) defines chronic kidney disease as either damage to the kidney or a Glomerular Filtration Rate (GFR) of less than 60 mL/min/1.73m² for more than three months running².

Chronic Kidney Disease (CKD) is a worldwide public health problem, a social calamity, and an economic catastrophe. CKD is an important, chronic, non-communicable disease epidemic seen the world over, including India³. According to the National CKD registry, whose figures have been compiled from 166 kidney centers across India between 2006 and January 2010, there are 45,885 cases of CKD in India, out of which 14,331 cases are of diabetic nephropathy⁴. The approximate prevalence of CKD in India is about 800 per million population (pmp), and the incidence of End-Stage Renal Disease (ESRD) is about 150-200 pmp. India currently

has 820+ nephrologists, 710+ hemodialysis units with 2,500+ dialysis stations, and 4,800+ patients on CAPD. Approximately 2% to 3% undergo maintenance dialysis. There are more than 172 transplant centers, mostly privately run. Nearly 3,500 transplants are done annually, the total number of cadaver donors being approximately 700 up till now. Thus, taken together, nearly 18,000-20,000 patients (10% of new ESRD cases) in India get Renal Replacement Therapy (RRT)³. Data from the Mumbai Kidney Foundation shows 20,000 patients requiring RRT in India, out of which 12,500 are undergoing maintenance hemodialysis⁵.

Diabetes and high blood pressure are the leading causes in the development of CKD, followed by chronic glomerulonephritis, polycystic kidney diseases, infections, and calculi. In a study covering 48 hospitals distributed all over India, diabetes emerged as the most frequent cause (30–40%), followed by hypertension (14–22%), chronic glomerulonephritis (16–20%), chronic interstitial disease (5.4–12.7%), hereditary disease (8.4%), and obstruction including calculus (2.9%)⁶. National CKD registry of India, January 2010 estimates that 40% of CKD cases are due to diabetes⁴.

Bakris et al⁷, state that the kidney is both a cause and a victim of hypertension. High blood pressure is a key pathogenic factor that contributes to deterioration of kidney function. In a study conducted by national health and nutrition examination survey between 1999 and 2006, representing residents of United States aged 20 or older, 3.4 million out of 26 million adult participants had CKD stage 3. Those with diabetes and hypertension had far greater prevalence of CKD (37% and 26% respectively) compared to those without these conditions (11% and 8% respectively).

Chronic kidney disease is categorized from stage 1 to stage 5 depending on severity of damage. Stage 5 or end stage of CKD is diagnosed when GFR is less than 15 ml/min/1.73m² on dialysis⁷. Chronic kidney disease stage 5 is treated by renal

replacement therapy (RRT), which includes maintenance hemodialysis, peritoneal dialysis, or kidney transplantation. The number of patients needing RRT has increased from 426,000 in 1990 to 1.5 million in 2000, and is expected to rise to 2.5 million by 2010⁸

“Hemo” means blood. And dialysis is essentially a separation or filtration process. Metabolic wastes or toxins in the blood are filtered through a semi-permeable membrane and carried away by the dialysis fluid known as dialysate. Dialysis access is achieved by the creation of an arterio-venous fistula or arterio-venous graft, usually in the patient’s forearm. For temporary access, a venous catheter percutaneously inserted into the jugular vein, subclavian vein, or femoral vein, is used. The goal of hemodialysis is to manage the electrolyte imbalances, fluid overload, and uremia that occur as a result of chronic kidney disease. Hemodialysis treatment given to CKD patients as a long term therapy as prescribed by nephrologists is referred to as Maintenance Hemodialysis (MHD).

Maintenance Hemodialysis (MHD) is the most common and practical technique for the treatment of patients with chronic renal failure. Treatment with MHD may be performed at dialysis units attached to a hospital or community dialysis centre, or at home. Community dialysis centers or satellite dialysis units typically offer only dialysis facilities with no admission facility.

Hemodialysis, or the “artificial kidney”, has come a long way since Dr. Willhem Kolff first introduced a rotating drum kidney dialyzer in 1943. Today, very successful novel renal replacement therapy devices, including wearable artificial kidneys, are available¹⁰. However, the complex functioning of a normal kidney cannot as yet be fully replicated through artificial devices. The general condition of the patient remains adversely affected. Maintaining an acceptable quality of life is

challenging for hemodialysis patients, with thrice weekly dialysis sessions, frequent surgical revisions of arterio-venous accesses, increased symptom burden, dietary restrictions, and complicated medication regimens¹¹.

The rigors of thrice-weekly dialysis, the metabolic derangements common in those with ESRD and the psycho-social and vocational impact of dialysis dependence likely contribute to the many symptoms that are known to occur in patients on hemodialysis and to the decrements in Health Related Quality of Life (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 HRQoL¹².

Although hemodialysis effectively contributes to long-term survival, morbidity and mortality rates remain high, especially morbidity and mortality resulting from cardiovascular diseases. Patient survival after renal transplantation is markedly better than that seen with either haemodialysis or peritoneal dialysis. Transplantation is also associated with a better quality of life and a higher degree of rehabilitation. One, five- and ten-year survival rates were 95.2%, 88.0% and 78.8% for Renal Transplantation Recipients (RTR) and 90.6%, 62.7% and 39.8% for Haemodialysis Patients (HDP). Renal transplantation recipients' survival was better than HDP survival in both diabetic and non-diabetic patients. In diabetic patients, 5-year survival was 89.3% for RTR and 34.7% for HDP ($P=0.0106$). In non-diabetic patients, 5-year survival was 87.9% for RTR and 68.6% for HDP ($P<0.0001$)¹³. According to Denhaerynck, about one third of patients on hemodialysis survive five years, whereas 70% of kidney transplants recipients are alive after 5 years¹⁴.

The hemodialysis regimen is built on two pillars: the restriction of certain nutrients, and removal of waste metabolites from the blood through regular dialysis.

Central to the effective management of patients with end-stage renal disease is adherence to this therapeutic regimen. Adherence refers to “the extent to which a person’s behavior - taking medication, following a diet, and/or executing lifestyle changes - corresponds to the agreed recommendations from a health care provider. Successful hemodialysis depends on four factors: fluid restriction, dietary guidelines, medication prescriptions, and attendance at hemodialysis sessions”¹⁴.

Several studies have been done to identify the symptoms/problems prevalent in MHD patients that affect HRQoL with an intention to modify treatment and lifestyle and thereby to improve general health.

Abdel Khader et al¹⁵ studied 90 patients with end-stage renal disease (stage 5 of CKD), and 87 with CKD. Patients’ symptoms, depression levels, and quality of life were assessed using the Dialysis Symptom Index, Patient Health Questionnaire-9, and Short Form 36, respectively. The symptoms noted were fatigue, pain, muscle cramps, difficulty with sleep, and sexual dysfunction, affecting half or more of patients receiving chronic (maintenance) dialysis. The other symptoms noted were dry mouth, dizziness, bone or joint pain, headache, muscle soreness, chest pain, constipation, swelling in the legs, decreased appetite, nausea, shortness of breath, cough, numbness or tingling feet, vomiting, and feeling sad, nervous, or irritable.

Murtagh¹⁶, in a systematic review of 59 studies which addressed symptoms experienced by persons on hemodialysis in London during the year 2006, the top-reported symptoms and their weighted mean prevalence were: fatigue (71%), pruritis (55%), constipation (53%), anorexia (49%), pain (47%), sleep disturbances (44%), anxiety (38%), dyspnea (35%), nausea (33%), restless legs (30%), and depression (27%).

Unruh et al¹⁷, reported a survey of fifteen centre randomized sample of 1978 hemodialysis patients to assess HRQoL using the Kidney Disease Quality of Life (KDQoL) questionnaire in the US, from March 1995 to December 2001. The most common symptoms affecting at least 60% of subjects were dry and itchy skin, lack of strength, excessive thirst, fatigue and weakness, feeling drained or washed out, dry mouth, muscle soreness, trouble sleeping, cramps during dialysis, and sleepiness during the day.

Cooper, et al¹⁸ identified several problems affecting hemodialysis patients' mortality and morbidity, such as infections, cardiovascular disease, malnutrition, dialysis complications, access complications, significant fluid and electrolyte disorders, and the requirement for temporary dialysis access catheters, which necessitates frequent hospitalizations and the consequent increase in medical expenses.

Stacey et al¹⁹ collected data on Sleep Quality (SQ) from 11,351 patients in 308 dialysis units and assessed the prevalence of pruritis by a self-reported questionnaire. The patients' self-reported SQ scale showed that nearly half (49%) of the patients experienced poor SQ. Pruritis was associated with poor outcomes and a higher mortality risk, probably attributed to poor sleep quality.

Agarwal²⁰ and Tarrass et al²¹ have identified hypertension among MHD patients, and volume excess was thought to be important in the pathogenesis of hypertension among hemodialysis patients. Culleton et al²² have reported cardiovascular complications and anemia causing mortality among HD patients.

The studies quoted above highlight the general health status vis-a-vis symptoms/problems and complications generally experienced by MHD patients. A high symptom burden impacts negatively on patients' HRQoL. Identification of

patients' symptom perceptions can assist patients in selecting appropriate strategies for the self-management of their symptom burden. Self-management refers to the health promotion and patient education programs developed to encourage behavioral changes and assist in the adjustment for a chronic illness. Patients' perceptions of symptoms should be routinely assessed as part of clinical care to improve self management strategies²³. The ability to predict future morbidity and mortality is key factor to reducing the burden of CKD. To this end, monitoring a patient's functional and subjective status of well-being, collectively known as HRQoL, is of particular importance in CKD patients²⁴.

Reducing these symptoms/problems is necessary to improving HRQoL. Knowledge of symptoms/problems and their remedial measures would help patients to reduce the incidence and intensity of symptoms/problems, which will eventually improve their HRQoL. The researcher assessed the knowledge of MHD patients regarding symptoms/problems commonly/frequently experienced by them, and the way they managed them, and compared the effects on the same after teaching. The researcher has conceptualized the items for the assessment tool by observing and interviewing MHD patients, consulting experts in the field, and reviewing literature. The selected sub-scales of standardized HRQoL instruments measuring symptoms and burden of the disease, such as the SF-36 MOS, KDQoL, Dialysis Symptom Index, and WHO-QOL BREF have also inspired the researcher in creating the tool. These symptoms/problems experienced by MHD patients are referred to as the "selected components of HRQoL" in this study.

Health Related Quality of Life (HRQoL) is a composite of measures of the patients' physical, social role functioning, mental health, emotional well being, and perception of general health. According to the revised Wilson and Cleary's (1995)

model of HRQoL, there are five types of measures of patient outcomes. First, biological functioning which is assessed through such indicators as laboratory tests, physical examination, and medical diagnosis and second, symptoms (originally symptom status) refers to physical, emotional, and cognitive symptoms perceived by a patient. Functional status, the third component, is composed of physical, psychological, social, and role functions. The fourth is general health perceptions, which refers to a subjective rating that includes all of the health concepts that precede it. Fifth, overall quality of life is described as subjective well-being, which means how happy or satisfied someone is with life as a whole²⁵. In this study the main emphasis is on symptoms experienced by the patients' consequent to CKD and hemodialysis treatment regimen.

The physical status of most dialysis patients is seriously compromised. Thong²³, led a study of 1,553 hemodialysis (HD) and Peritoneal Dialysis (PD) patients between January 1997 and January 2007, who were recruited to participate in the Netherlands Cooperative Study on the adequacy of dialysis and completed the KDQoL Short Form symptom/problem list three months after the start of dialysis. These symptoms were found strongly associated with poor quality of life and suggested that to reduce patients' symptom burden and to improve quality of life, patients' cognitions and beliefs should be routinely assessed to ensure that their self-management strategies can be appropriately supported.

Mental health or emotional well being is also another dimension of health related quality of life in hemodialysis patients. Depression is a frequent by-product of chronic disease. Diminished self worth, loneliness, isolation, sense of loss, and lack of motivation are some of the problems dialysis patients face. This component is not included in the present study.

The researcher has identified the prevalence of several of these problems/symptoms in MHD patients through her observations and has validated them by consultations with nephrologists, dialysis unit nurses, technicians, maintenance hemodialysis patients, and also through literature review. Symptoms/problems experienced by the majority of MHD patients in varying degrees and studied by the researcher include breathing difficulty or shortness of breath, excessive thirst and dry mouth, loss of taste and appetite, constipation, body pain, cramps during and after dialysis, weakness after dialysis, disturbed sleep, dry and itchy skin, restricted mobility, clotting or problem with the access site, sexual dysfunction, and stress related to illness or treatment. The researcher prepared a teaching manual listing these symptoms/problems, explained their causes and suggested remedial measures, and gave each of the patients a copy of the manual after having taught them on a one-to-one basis.

Recurrent symptom episodes, repeated hospitalizations, and the need for medical procedures greatly interfere with patients' lives: reducing such events by enhancing and maintaining a hemodialysis patient's wellness goes a long way in improving the health status¹¹. Preserving dialysis patients' ability to care for themselves and to be able to perform productive activities are important long-term outcomes of care. All these can be achieved through patient education.

“Patient education/information is defined as the planned activity initiated by a health professional, whose aim is to impart knowledge, attitudes, and skills with the specific goal of changing behavior, increasing compliance with therapy, and thereby improving health²⁶. ”

According to Lewis²⁷, ongoing changes in healthcare are placing increasing attention on patient education. Patient education has emerged as an important component in many health promotion and disease management programs.

Numerous studies report the beneficial effects of education on chronically ill patients, including MHD patients, with respect to changes in knowledge, medical characteristics, symptom/problem burden, morbidity, and mortality. These findings reflect the effect of education on HRQoL of the study population.

Wingard, et al²⁸ 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 rate and hospitalization were lower and biochemical values were better in RS patients.

A semi-experimental survey was carried out by Dagdeviren, et al²⁹ aiming to assess how knowledgeable adolescents undergoing haemodialysis treatment were regarding hyperkalemia, and determining how effective an education program in preventing hyperkalemia would be. A month after the education program the knowledge scores had increased, and blood potassium levels had significantly decreased ($P < 0.02$).

Barnet³⁰, examined the effectiveness of patient education on fluid compliance as assessed by interdialytic weight gain, mean pre-dialysis blood pressure and rate of fluid adherence of non-compliant patients in a dialysis centre located in Kuala Lumpur, Malaysia (n=26). Patients' mean interdialytic weight gain decreased following the educational intervention, and the conclusion drawn was that nephrology nurses 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.

Tanner et al³¹ assessed the effectiveness of a self-monitoring tool on perceptions of self-efficacy, health beliefs, and adherence in patients receiving hemodialysis by a monthly intervention using a pretest, posttest design over a six month period. Knowledge scores and the findings in the treatment group significantly improved as compared to the control group.

Sharp et al³² reported a randomized, controlled trial of a group-based cognitive behavioral intervention aimed at improving fluid-restriction adherence in patients receiving hemodialysis. (n=56). Difference in mean Inter Dialytic Weight Gain (IDWG) between the groups was found during longitudinal analysis, and there was a significant effect in mean IDWG. The study provides evidence for the feasibility and effectiveness of applying group-based cognitive behavior therapy to enhance adherence to hemodialysis fluid restrictions.

Heidarnia et al³³ carried out a study to evaluate the ability of the health education program to improve patient's health-related quality of life with coronary artery bypass graft surgery. Seventy Iranian patients in pre-operation were randomized into the controlled study. Repeat test after one month showed statistically significant improvements in most of the components of the Nottingham Health Profile, thus demonstrating the effect of health education.

Tsay³⁴ investigated the effectiveness of an empowerment program on empowerment level, self-care, self-efficacy, and depression in patients with end-stage renal disease using a randomized controlled trial. At six weeks following, the intervention empowerment group showed a significantly greater improvement than the control group in relation to the empowerment variables.

These studies point to one important fact: patient education can improve compliance to the treatment regimen and consequently better outcomes. That is, improved HRQoL.

The real life experiences of MHD patients revealed through discussions with patients and their family members regarding their experiences/responses with the treatment regimen, the researcher's own observations from her past clinical experience and during supervisory rounds of the dialysis unit helped her to understand the problems of hemodialysis patients. It also brought to light their ignorance about the causes and management of many of the symptoms/problems. It was noted that some patients were unaware of the action of the drugs or the need for fluid restriction, and had even developed complications such as pulmonary edema in the past. Upon reflecting on the state of affairs, the researcher felt the need for a program to educate MHD patients about their health maintenance. A Senior Professor of the researcher with very close experience of maintenance hemodialysis also emphasized the need for educating hemodialysis patients in order to minimize the symptoms/problems and thereby improve their independence and ability to work.

Following the opinion of guides and experts including nephrologists, and after taking into consideration the feasibility of the study, the researcher decided to study 12 symptoms/problems from the list of the most common symptoms/problems prevalent in hemodialysis patients in Mumbai/Navi Mumbai. The consulting psychologist's opinion was to limit the study to physical symptoms and some major problems faced by MHD patients as assessment of stress and intervention would not be feasible in this study. Hence the 12 most commonly occurring symptoms/problems from the many components of HRQoL affecting MHD patients were selected and studied.

1.2 Need for the Study

Patient education is an integral and essential part of nursing practice. One of the goals of nursing is to help people become as independent as possible in caring for themselves. Nursing care includes providing health counseling and health education. It is a mandate for nursing. “At times, the patient may not be able to perform self-care, but families or support resources can provide the needed assistance if they have the required information. Teaching the patient and/or family provides the basis for independent functioning. In the process of receiving care, to encourage proper and safe use of medication, supplies, or equipment, it is often necessary to teach patients or families about treatments they are receiving. In today’s sophisticated, technologically advanced health care environment, information needs to be presented and frequently reinforced to ensure equipment is being used properly. Difficulties arise when medications are not taken as scheduled, or are taken with foods or other medications that cause negative effects, or are avoided because the side effects are uncomfortable. Understanding the medication and equipment will promote their safe and effective use”³⁵.

Goper³⁵ observed that “majority of patients with chronic renal insufficiency have only limited knowledge of their condition. Various studies on the benefits of patient education programs have shown that educated patients have a reduced incidence of emergency dialysis compared with control patients. Additionally, more educated patients are able to start dialysis as an outpatient rather than in hospital. An education program also allowed a greater number of blue-collar workers to remain employed after starting dialysis”.

Nurses are responsible for the direct care of patients undergoing dialysis. Patient and family education, and ongoing reinforcement and support for self-care are

the other services provided by the nurse³⁶. Nurses teach patients about their health maintenance during the dialysis process or during outpatient attendance, thereby modifying their practices and preventing many complications. Patients undergoing maintenance hemodialysis suffer many symptoms/problems which get worsened mainly due to an ignorance of the need for regular and adequate dialyses, and adherence to fluid and food restrictions. The consequences could be fatal, leading to hyperkalemia and pulmonary edema. Richard³⁷ states that dietary management between HD treatments is an important aspect of self-care management to maintain nutritional status and electrolyte balance. HD patients at times develop shortness of breath due to a fluid overload after consuming extra fluid in the form of ice or salty food items without knowing its effects. Non-adherence to fluid restrictions can cause shortness of breath, muscle cramping, dizziness, anxiety, panic, lung edema, and hypertension. Non-adherence to dietary and medication regimens can result in chronically elevated serum levels of phosphate, which play an important role in the development of secondary hyperparathyroidism and renal osteodystrophy. Elevated levels of phosphate can increase coronary artery disease even in young dialysis patients¹³.

The researcher has observed active and independent patients and very weak malnourished patients being brought by relatives for hemodialysis. The major difference noted in these two categories of patients was lack of knowledge related to self-management of the illness and treatment regimen. The researcher felt that educating these patients would help to increase personal independence and thereby improved health related quality of life and longevity, these being the essential purposes of nursing. "Patient education will empower people to be in control of their own health"²⁷.

Dialysis Nurses can contribute to their health maintenance and prevent frequent hospitalizations and subsequent suffering by empowering the patient through educative supportive services.

Several studies have been done to explore various symptoms like insomnia, pruritis, fatigue, anorexia and stress in MHD patients. Reports are also available about the relationship between the various aspects of HRQoL in MHD patients. The effect of providing information to the caregivers of MHD patients regarding their management has also been reported. Studies have been done on depression in dialysis patients. There are also reports of studies on the effect of education on quality of life and reduction in serum levels of potassium and phosphorous. However, no data are available about any study conducted to find out the effect of education on the knowledge and practices of MHD patients in relation to the symptoms/problems affecting the components of HRQoL as conceptualized by the researcher. Awareness of these symptoms/problems, including their causes and prevention, are important to improve HRQoL. Mumbai and Navi Mumbai have many dialysis centers. Some are attached to hospitals and others are free-standing units. The researcher has surveyed these dialysis units and found that there are nearly ten thousand patients undergoing hemodialysis for their survival. A regular program of patient education is not conducted in the majority of these centers. The majority of them have no access to any kind of patient education except the advice received at nephrologists' consultations. Such advice is usually inadequate due to time constraints. Therefore, the researcher decided to teach MHD patients using an instruction manual covering these symptoms/problems and to assess the effects of the teaching by administering a structured interview schedule. The researcher has planned to carry out the study in

hemodialysis patients of Mumbai and Navi Mumbai as the researcher is working in Navi Mumbai.

1.3 Problem Statement

Effect of Planned Teaching on knowledge and practices related to Selected Components of Health- Related Quality of Life (HRQoL) among hemodialysis patients of selected dialysis units in Mumbai and Navi Mumbai.

1.4 Objectives

1. To assess the knowledge of hemodialysis patients before and after planned teaching in relation to the selected components of Health Related Quality of Life. (HRQoL).
2. To assess the HRQoL related to selected components of Health- Related Quality of Life before and after the planned teaching.
3. To assess the practices of hemodialysis patients before and after planned teaching in relation to the selected components of HRQoL.
4. To evaluate the effect of planned teaching on knowledge, selected components of Health-Related Quality of Life (HRQoL) and practices in relation to the selected components of HRQoL.
5. To find out the relationship between selected background variables and knowledge.

1.5 Operational Definitions

1. Hemodialysis.

It is a process of cleansing the blood of accumulated waste products using the principles of diffusion, osmosis, and ultra filtration: a process by which blood is artificially cleansed in the absence of normal kidney function. During the process, blood is diverted from the body through an arterio-venous access, pumped

through an extra corporeal circuit where waste products and excess fluid diffuse through a semi-permeable membrane for disposal, and the cleansed blood is returned to the body. All persons attending the dialysis units and connected to the hemodialysis machine via an arterio-venous access are considered to be undergoing hemodialysis¹¹.

2. Hemodialysis patients.

Adult patients undergoing chronic or maintenance hemodialysis (MHD) in a dialysis unit of a hospital or dialysis centre for the treatment of chronic kidney disease, as a long term renal replacement therapy prescribed by nephrologists.

3. Planned teaching.

Teaching imparted to hemodialysis patients by the researcher about selected components affecting the health related quality of life using a teaching plan. It also involves reinforcing the learning by giving clarifications at planned intervals and providing a manual in the language of the patient's choice (i.e., in English, Hindi or Marathi).

4. Effect.

Changes that take place in hemodialysis patients after planned teaching in relation to knowledge, HRQoL, and self expressed practices related to selected components as assessed using a structured interview schedule.

5. Selected Components of HRQoL.

HRQoL has physical, psychosocial and spiritual components. The selected components are the symptoms/problems prevalent in MHD patients which affect their HRQoL. The researcher has identified 12 most commonly occurring symptoms/problems and are referred to as selected components of HRQoL, as listed below:

1. *Breathing difficulty.*

Shortness of breath affecting speaking, eating, and other activities.

2. *Excessive thirst and dry mouth.*

Uncontrollable desire for water or other fluid, associated with dryness of lips, mouth, or throat.

3. *Loss of taste and appetite.*

Do not feel like eating, and do not enjoy the taste of the usual food any more.

4. *Constipation.*

Difficulty in passing stool or an incomplete or infrequent evacuation of dry hardened feces from the bowels, which is different from the usual pattern.

5. *Body pain.*

Sensation of pain involving head, body, limbs, joints, muscles, back, or any other part of the body affecting comfort and daily activities.

6. *Disturbed sleep.*

Disruption of the hours of sleep, difficulty in falling asleep, awakening earlier than usual, interruption of night's sleep by periods of wakefulness or not feeling rested after sleep, and/or sleepiness during the day.

7. *Cramps during and after dialysis.*

Spasmodic and, often painful contraction of one or more muscles occurring during or after dialysis or at any time resulting in severe pain.

8. *Weakness after dialysis.*

Feeling of extreme tiredness or being “drained out” soon after the hemodialysis process, forcing the person to lie down ,affecting activities.

9. *Dryness and itching of skin.*

Dryness of the skin on any part of the body characterized by a pattern of fine lines ,scaling and itching sensation.

10. *Restricted mobility.*

Inability to achieve a functional level of mobility in the environment, a reluctance to move or abnormal or impaired ability to coordinate movements or unable to move around freely due to tiredness, pain, swelling, or dizziness, affecting physical and social functioning.

11. *Problem or clotting of dialysis access.*

Obstruction of the dialysis fistula, catheter or any other vascular access, leading to interruption or complete stopping of the dialysis process.

12. *Sexual dysfunction.*

A reported inability to achieve sexual satisfaction ,an alteration in the sexual relationship with the partner and a change in interest

in the self or lack of desire or inability to perform the sexual act in a married male or female living with spouse.

1.6 Assumptions

1. Chronic hemodialysis patients suffer from symptoms/problems related to chronic kidney disease, co-morbidities, and the treatment.
2. Chronic hemodialysis patients may not have adequate knowledge about the symptoms/problems nor the measures to manage the problems. The majority of them do not have access to detailed information about these symptoms/problems.
3. Symptoms/problems in hemodialysis patients and the knowledge about the symptoms are affected by age, co-morbid conditions, socio-economic status, food practices, length of time on dialysis, compliance to treatment, and other factors.
4. Hemodialysis patients are under continuous supervision of nephrologists and their medicines, and dietary prescriptions are revised periodically.
5. The education of patients help to change their health related behavior and hence compliance to the treatment regimen.
6. Nurses working in hemodialysis units are in a unique position to educate and motivate the patient to follow the treatment regimen to minimize symptoms/problems.
7. Patients while on hemodialysis sessions lasting for four hours, lying awake most of the time welcome any type of patient nurse interaction and nurses could utilize the opportunity to teach them.

1.7 Research Hypotheses

Ho1: The planned teaching has no significant effect on knowledge in relation to selected components of HRQoL among hemodialysis patients.

Ho2: The planned teaching has no significant effect on HRQoL in relation to selected components among hemodialysis patients.

Ho3: The planned teaching has no significant effect on practices in relation to selected components of HRQoL among hemodialysis patients.

1.8 Delimitations of the study

1. Hemodialysis patients are affected physically, psychosocially, and spiritually, but only selected components are included in the instruction manual and in the teaching.
2. Practices related to symptoms existing for one week prior to pre/post test of patients are only elicited.
3. Responses to knowledge item on causes of sexual dysfunction are not elicited from single and unmarried subjects.
4. Hemodialysis can cause dramatic swings in blood pressure and electrolytes. In addition, intra-dialytic cognitive changes, including decreased concentration and memory may be present in some patients. Thus, they may not feel at their best while answering questions related to their symptoms and related practices.

1.9 Theoretical Framework

This study is based on Dorothea Orem's Theory³⁸. According to the theorist the goal of nursing is to render the patient or members of the family capable of meeting the patient's self care needs. D Orem's theory of nursing has three related parts: theory of self care, theory of self care deficit, and theory of nursing systems. Theory

of self care includes practice of activities that individual initiates and perform on their own behalf in maintaining life, health and well being. Self care agency is a human ability which is “the ability for engaging in self care”, conditioned by developmental state, life experience, socio-cultural orientation, health, and available resources. The three categories of self care requisites are universal self care requisites, developmental self care requisites and health deviation self care requisites.

Universal self care requisites are those associated with life processes and the maintenance of the integrity of human structure and functioning. Developmental self care requisites are derived from a condition or associated with an event. Health deviation self care requisites are requirements arising in conditions of illness, injury, or disease such as

- Seeking and securing appropriate medical assistance
- Being aware of and attending to the effects and results of pathologic conditions
- Effectively carrying out medically prescribed measures
- Modifying self concepts in accepting oneself as being in a particular state of health and specific form of health care.
- Learning to live with effects of pathologic conditions

Theory of self care deficit explains that nursing is required when an adult (or in the case of a dependent, the parent) is incapable or limited in the provision of continuous effective self care.

Theory of nursing systems describes how the patient’s self care needs will be met by the nurse, the patient or both. It identifies three classifications of nursing systems to meet the self care requisites of the patient which are wholly compensatory, partially compensatory and supportive-educative.

In this study a part of Orem's theory is being applied. Maintenance hemodialysis patients have to manage the burden of chronic kidney disease, co morbidities and the rigorous treatment regimen which may adversely affect their HRQoL. Their morbidity and mortality rates may also be increased. HRQoL is also influenced by the demographic and medical characteristics of the patients. Demographic characteristics may be considered as 'universal self care requisites' and medical characteristics along with other factors affecting selected components of HRQoL are to be considered as 'health deviation self care requisites'. These patients do not have the abilities to meet their requisites which mean they have a 'self-care deficit'.

Nursing agencies meet the self-care needs or requisites through three types of services: wholly compensatory, partially compensatory or educative supportive services. They may not have adequate knowledge about the causes or management of the symptoms/problems. In this study educative supportive service of nursing agency is being selected as MHD patients require educative supportive services to manage the 12 symptoms/problems. The gain in knowledge and consequent change in practices would lead to a reduction in factors affecting selected components of HRQoL and eventually lead to an improvement in HRQoL and a reduction in morbidity and mortality. The patient eventually would develop optimum abilities and would become self-care efficient. The theoretical framework based on Dorothea Orem's self -care theory is illustrated as Figure 1.

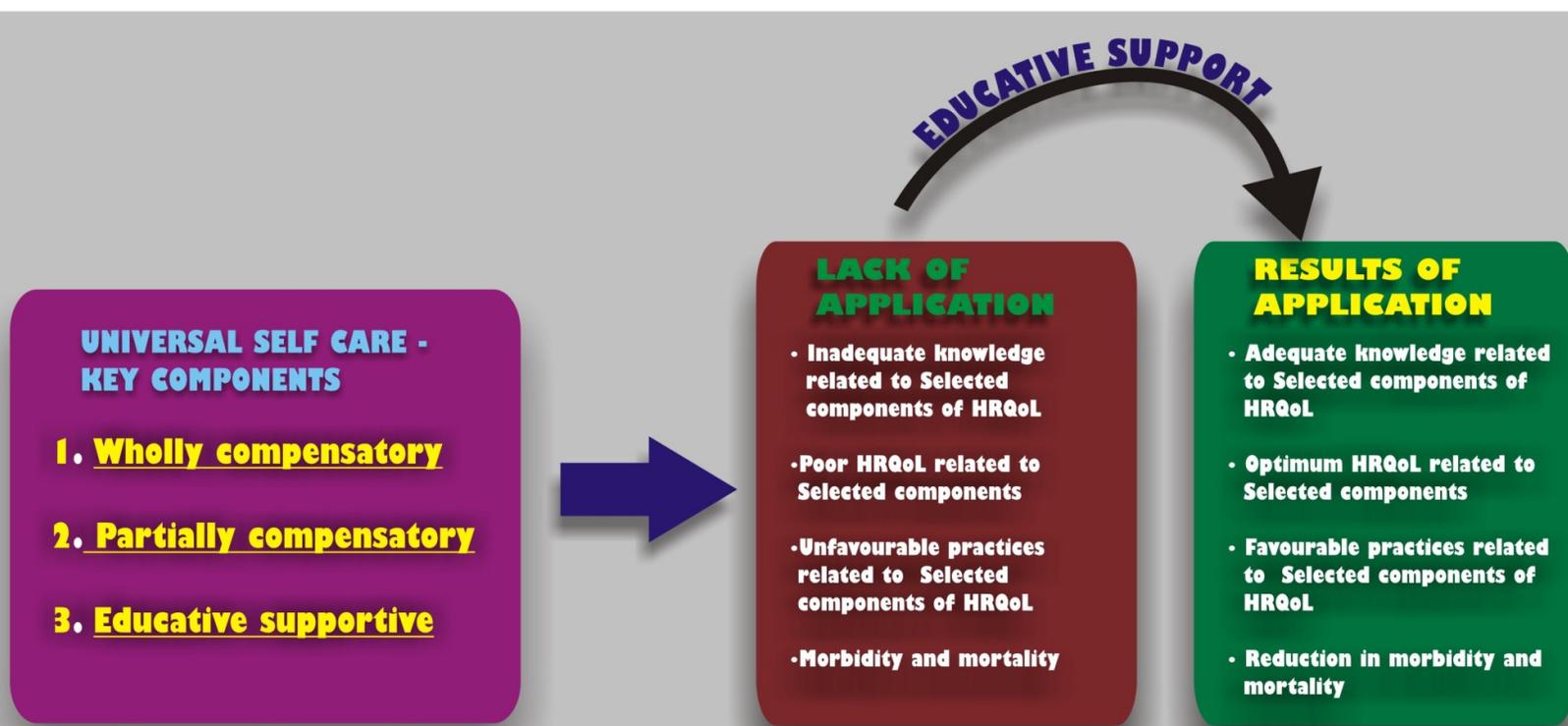


Fig.1
Theoretical Framework
 based on
Dorothea Orem's Self Care Deficit Theory