

**Experiences of patients on haemodialysis
and continuous ambulatory peritoneal
dialysis in end stage renal disease: An
exploratory study at a tertiary hospital in
KwaZulu-Natal**

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DECLARATION

Submitted in partial fulfilment of the requirements for the degree of
...Masters..., in the Graduate Programme in ...
Social Work..... University of KwaZulu-Natal,
Durban, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree ofSocial Work..... in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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ABSTRACT

This study looked into patients' experiences of end stage renal disease (ESRD) and renal replacement therapy (RRT). A qualitative methodology was employed involving fifteen patients between the ages of 20 – 60 years that were interviewed on their experiences using the semi structured approach to interviewing. The knowledge gained was analysed thematically.

The study was explored within two theoretical frameworks, namely the biopsychosocial and the ecological models. Results of the study revealed that ESRD and RRT posed many psychosocial challenges at a micro and macro level, as patients attempted to reconcile these experiences with their lifestyles and lives.

Challenges were expressed in the areas of functional capacity, work and sexuality. Family life was seriously affected when patients had to make themselves available for life long treatment that depended on machines. Recommendations included mobilisation of positive support networks, religion/spirituality, and professional support playing an interrelational role in enabling patients to cope through the long term process so that they may emerge from it with a modicum of quality in their life. Thus a team approach was key to optimal living for the patient. From an ecological perspective, macrosystemic change was also considered important for government to introduce policies that ensure economically productive living for persons with kidney dysfunction.

ABBREVIATIONS

ESRD	End Stage Renal Disease
RRT	Renal Replacement Therapy
HD	Haemodialysis
CAPD	Continuous Ambulatory Peritoneal Dialysis

CHAPTER 1

ORIENTATION TO THE STUDY

1.1. Background and Outline of the Research

Chronic kidney disease as a major public health concern affects more than 19 million people in the United States, and its prevalence is expected to double within 10 years (Davidson 2007). According to Schlebusch (1990) ESRD, ranges from 40-60 to as high as 60-90 patients per million of the population per year, in South Africa and requires RRT. Such therapy contributes significantly to physiological and psychosocial stressors, both for patients and their families and renal unit staff as considerable responsibility is placed on the patient regarding satisfactory adjustment to treatment.

Social work intervention has a place in the treatment of such patients. Nephrology social work is a specialty practice within medical social work and the social workers are multidisciplinary team members in renal units. The primary goal of the nephrology social worker is to assist patients and their families in making the social and psychological adjustments necessary to cope with both a chronic illness and its treatment regime. In service to this goal, the social worker provides supportive counseling and education about the psychological impact of the illness and its various treatment options. Callahan's (1998) study showed that 91% of the patients believed that access to a nephrology social worker was important.

Thus in hospital settings, knowledge, skills and training in relevant specialized areas are needed but often overlooked despite the fact that social workers are expected to fulfill these roles; hence the need for this study.

The researcher is a Principal Social Worker at a state, training hospital in Durban. This hospital is a tertiary hospital and Nephrology is one of the

specialized services provided. The researcher currently works in the Renal Unit at the hospital and is one member of the multidisciplinary team serving the needs of the patient. Experience has shown that patients encounter critical challenges and constraints when they undertake RRT in ESRD. To date there have been no investigations conducted to ascertain how these patients cope and adjust to these treatment modalities in ESRD.

Limited data exists regarding the factors associated with patient adjustment to RRT. In particular psychosocial factors and their effects on patients treated with HD and CAPD are topics of research interest. It was a recommendation in a quantitative study undertaken by Shabalala (2004) that a qualitative study be considered into this area and it is thus the intention of the researcher to respond to this need via this study. Local literature is limited in context and the current study is envisaged to be the first of its kind for the dialysis population in South Africa.

Thus knowledge of the ways in which patients experience their disease and treatment options is important, since a better understanding of patients' situations can improve co-operation between social workers and patients. Increased knowledge about how patients with ESRD on HD and CAPD experience their physical, social and functional capacity will guide social workers in their intervention. To enable social workers and allied health professionals to achieve better understanding, knowledge is needed about what ESRD in relation to HD and CAPD really mean from patients' perspectives.

In South Africa, the National Health protocol has defined criteria for chronic dialysis in the public sector whilst the private sector has its own criteria. State facilities will offer RRT in the form of HD and CAPD only to patients who are eligible for a transplant. However there are no constraints of sex, race or social status.

Naicker (2003) reports that approximately 42% of patients receiving RRT in South Africa receive HD, 40% receive peritoneal dialysis and 18% per million of

the population receive kidney transplantation. For ESRD the ideal treatment would be the safe replacement of the patient's kidney, since it allows for a decrease in patient dependency on dialysis therapy and a general improvement in well-being. However HD which is accessible to only a few, is a popular therapy, although the cost of haemodialytic treatment, dependency on machines and various other problems remain constant considerations. CAPD with which many patients are treated, present with advantages of better nutritional status, freedom of mobility and better rehabilitation. This remains a useful therapy in Southern Africa, where a high percentage of patients would otherwise be denied treatment (Naicker 2003). Parsoo (1984) also highlighted advantages of CAPD, these being personal freedom, control of blood pressure and fluid balance and a recommendation of this study was that the value of CAPD be assessed further.

There is much debate around the impact on quality of life of patients on HD and CAPD. Several quantitative studies have been conducted eg Lok (1996) reported that CAPD patients were experiencing a higher quality of life than HD patients. As we note quality of life in patients with chronic renal failure has traditionally been measured by the use of different questionnaires, results are normally presented as scores, therefore do not provide information about the ways in which the treatment options are experienced. Pugh-Clarke cited in Heiwe, Clyne and Dahlgren (2003) argue that what is being measured through generic instruments may not represent the free choice of the individual whose quality of life is being assessed.

Of paramount importance in evaluating the psychosocial factors on outcomes in ESRD patients, is understanding the perceptions of such patients. The question that arises is what are the perceptions regarding the quality of life? This study endeavours to hear the voices of patients as they describe their experiences of RRT.

The study was undertaken under the auspices of a large, tertiary hospital that is state subsidized. It is a referral hospital that provides quaternary, specialized services. Nephrology is one of the specialized services offered and HD and CAPD are provided to patients. The sample of patients was selected from these groups as they attend their respective clinics.

1.2. Significance of the Study

Patients experience physical, psychosocial and economic constraints. According to White and Grenyer (1999) these challenges contribute to poor adherence to therapy, which affects them, as well as their friends, families, and communities. Given the above, this study is significant because there is limited knowledge about the impact of these treatment modalities from patients' perspectives. Knowledge gleaned in this area will inform and improve services not only in social work but also in the holistic management of the patient, in particular in nursing and medical care. This study would thus serve to update research on the psychosocial management of patients on renal replacement therapy.

Most of the research undertaken on the renal population has been done by doctors or nurses. Little has been written about the nephrology social worker, whose job is to assist patients in making an emotional adjustment to dialysis. Therefore, such a study can add to knowledge in nephrology social work practice. The results have served to contribute and advance social workers' skills in counseling and therapy to respond to the tremendous emotional impact that ESRD and treatment can have on patients in an era where it is possible to sustain life for years with the use of life support technology.

1.3. Assumptions

The major assumptions on which this study was based and which this study explored are the following:

- Based on the literature review, the researcher was of the assumption that the voices of ESRD patients have been unheard.
- The researcher also held the view that the quality of life for patients on HD is more compromised than on CAPD.
- A more specific assumption was that CAPD has better benefits than HD as the diet regime is less limiting and therefore there is flexibility in lifestyle for CAPD patients.
- HD patients are also likely to be non-compliant due to financial constraints, hence the need to explore macro influences on treatment.
- A further assumption was that patients may be seriously disadvantaged and discriminated in the area of employment and this study will explore this assumption by obtaining patient perspectives on the short and long term impacts of this.

1.4. Research Questions

The study sought to answer the following questions:

- What are the factors that support and prevent HD and CAPD treatment?
- What are the physiological and psychosocial stressors of these two groups of patients?
- What quality of life do patients on HD and CAPD experience?
- What coping strategies do they use?
- What are the patients' expectations and impressions of dialysis treatment?

- What are the perceived similarities and differences between HD and CAPD regarding the aforementioned?
- What services and support do patients perceive to be necessary?

1.5. Aim of the Study

This study aimed to explore and describe the biopsychosocial functioning of patients with ESRD undergoing HD and CAPD.

This general motivation was translated into specific objectives as follows:

1.6. Research Objectives

- To identify physiological and psychosocial stressors at various systemic levels associated with ESRD and its treatment.
- To describe the impact of these stressors on psychosocial functioning of HD and CAPD patients.
- To gain an understanding of what supports and prevents patients' compliance and non-compliance in HD and CAPD.
- To gain insight into the coping strategies of patients on HD and CAPD.
- To understand perceived similarities and differences regarding all of the above in HD and CAPD patients.
- To identify the impact of and perceived gaps in services and support available to these groups of patients.

1.7. Limitations

- The sample was selectively drawn from the local renal population at a specific hospital and was not representative of the wider population. Hence generalization will be limited. Racial and socio-economic representation was not always possible because of the tendency that people who are financially disadvantaged receive services from state hospitals. As this is a qualitative, exploratory study, the aim was to shed in depth information on an area that has not attracted empirical research.
- The findings are limited to public sector, tertiary hospitals and these may have limited value for the private sector.
- This study was exploratory in nature and a first in qualitative research in this area in KwaZulu-Natal. Thus there are no other local studies with which results could be compared.
- In using hospital records as part of data collection, it is possible that some data might contain institutional biases and facts that may have been distorted.
- The fact that the interviewer in this study was a social worker who works with the patients with chronic renal failure could be viewed both as an asset and obstacle in the interviews. It was an advantage that the interviewer was able to facilitate an open climate for patients to discuss their problems with insight into situations to which patients referred since they knew the interviewer. Possible disadvantages were that patients might have left out information which they assumed would be understood by the researcher since she worked with patients faced with kidney

failure. Another possible limitation was that the interviewer's experiences might have biased her probing into what patients were saying.

- The current study was limited in that the participants were predominantly from urban backgrounds. Although these participants' involvement provided rich insight, it would be interesting to have developed an understanding of the experiences of rural patients and draw comparisons accordingly.

As the study has many medical terms, these will be explained at the outset to facilitate understanding of the study.

1.8. Explanation of terms used in this Study

End stage renal disease (hereafter referred to as ESRD)

This is the final stage of chronic renal failure that is irreversible. During this stage the kidney has approximately 90% nephron loss and the glomerular filtration rate is decreased by 80%. The renal function is severely impaired. During this stage the patient can only be kept alive either by dialysis therapy or renal transplantation (Shabalala, 2004:9).

Haemodialysis (hereafter referred to as HD)

Dialysis means a filtering process. Haemodialysis means the process of filtering blood. It is a treatment that removes the waste products and the excess fluid that accumulates in the blood and body tissues as a result of kidney failure. The cleaning of the blood takes place outside the body in an artificial kidney termed a dialyzer. A doctor surgically creates a permanent access to the bloodstream so that blood can be diverted through the dialyzer and back into the body. This

access point is called a fistula. Haemodialysis usually requires that you need to have two to three treatment sessions per week and each session usually lasts between 3 – 5 hours (Baxter 2006).

Continuous Ambulatory Peritoneal Dialysis (hereafter referred to as CAPD)

This is the other form of dialysis. In this type of dialysis the patient's blood is cleaned inside of the body. A plastic tube called a catheter is surgically placed into the patient's abdomen. It acts as a permanent pathway into the peritoneal cavity. During the treatment, the abdominal area called the peritoneal cavity is filled with dialysate through the catheter. The difference is that the patients performs this type of dialysis at home or work and does it by exchanging the dialysis solution in the abdomen four times per day and these exchanges are spaced out throughout the day (<http://www.mayoclinic.com>).

For the purposes of this study we will refer to these two types of therapy as renal replacement therapy to be abbreviated as RRT.

CHAPTER 2

LITERATURE REVIEW

This chapter provides a general overview of literature within theoretical frameworks. The chapter leads into a discussion of the frameworks followed by the literature review.

2.1. Theoretical Frameworks

Both the biopsychosocial model and the ecological theory are combined to offer an overarching frame of reference to the study in question. These models provide complementary explanations and although the biopsychosocial model is assumed to be the most comprehensive model of health and disease, it fails to offer a broader perspective or macroscopic view in regards to the influence of macro systems and context of the patient. It is in view of this that the ecological model is incorporated into this study.

There are similarities between the biopsychosocial approach and person-environment fit in respect to the micro and mezzo systems and its link to the ecological theory.

Thus the structure of the literature that follows will explain the biopsychosocial impacts under the following, namely physiological, psychological and social impacts and the exosystem and macro systems would be explained under macro impacts.

The biopsychosocial model is based on a holistic systems perspective which focuses on the promotion and maintenance of health through socio-environmental and behavioural changes. Joyce cited in Ross and Deverell (2004:12) suggests that when the biological, psychological and sociological

approaches are presented as alternatives, it becomes obvious that they are all different aspects of the same problem. Engel cited in Schlebusch (1990:15) writes about the interaction of the biological, psychological and social factors in all disease.

According to this framework, people are not passive victims of disease, but can themselves participate in their recovery as well as promote their good health. The biopsychosocial model as stated by Ross and Devereil (2004:12) also encourages the caregiver to focus not only on the patient, but also on the family and significant others in the person's environment.

Consideration is given to stabilizing and destabilizing influences in the person's environment and the effects of the person's disease on others. The life span perspective adds an important dimension to this model by taking into consideration the role of the person's development and life stage in health and illness.

This model also considers the meanings which people attach to illness and health, and the cultural influences which shape a whole range of activities dealing with health and illness.

The holistic biopsychosocial view humans, to be referred to as patients in the study, as follows: Human beings are complex entities. This complexity allows them simultaneously to perform multiple functions. These functions can be classified into physical functions (related to structure and processes of the body, i.e. the biological sphere); mental functions (related to structure and processes of the mind, i.e. the psychological sphere) and social functions (related to the structure and processes of the society in which the person lives, i.e. the social sphere). The patient in context is therefore defined as a biopsychosocial being. The biological, psychological and social functions are closely interconnected. If one views human processes from one or two of these perspectives, one will not see the whole person (patient). Hence any understanding of the person's

problems will be limited and therefore needs to be viewed as a whole (Schlebusch 1990).

Hence to change dysfunctions (disease) the social worker needs to seek to identify the critical biopsychosocial factors. Critical factors are those biopsychosocial structures or processes which, if altered, change the dysfunction.

Treatment modalities, according to the biopsychosocial perspective, focus on the physical, psychological and socio-cultural aspects of the patient's life. The social worker that views the patient holistically sees the total environment as having great potential in improving the patient's well-being.

The aspects of functioning that are of importance with dialysis patients are summarized as per the figure below.

Figure 2.1. Quality of Life

(adapted from Henderson and Thuma, 1999:145)

<u>Physical</u>	<u>Psychological</u>	<u>Social</u>
physiological functioning	depression	psychosocial stress
disease stress	denial	social leisure activities
dialysis stress	anxiety	social support
sleep adequacy	social introversion	marital/family functioning
fatigue		vocational functioning

The concepts from the biological, psychological and social sciences are selected for their pertinence to the effective use of social work in direct services to people for the achievement of goals within the realm of psychosocial functioning. Within general systems theory, formulations concerning complex adaptive systems in

interaction with other systems are clearly useful. Its contribution to social work is the emphasis on interdependence, transactions, reciprocal roles, and communication.

Hence, because of the complexity of human systems, social workers need to draw upon the knowledge of various disciplines and adapt such knowledge for social work purposes and contribute to knowledge development.

The ecological model described by Germain cited in McKendrick (1991:141) views human development and functioning-including health and illness-as outcomes of continuous exchanges between the individual and the social environment, the physical setting and the cultural context. The ecological perspective moves away from linearity which is useful in the study of physical and biological entities. Instead the focus is on the wholeness, interdependence and complementarity of living organisms.

According to Apter cited in Kasiram (1993: 60) the ecological orientation is based on the assumption that the patient is a complete entity surrounded by a unique social system or ecosystem. When the various aspects of the system are functioning harmoniously together, then the ecosystem is congruent or balanced. When the different aspects of the system are not functioning optimally, the system is in a state of imbalance or the elements are said to be in conflict with each other.

Ecological theory is clearly relevant to health because the patient is in intimate interaction with his health. The social worker is placed at the interface of the patient and his health. The social worker also stands at the interface of the family, hospital-health care team, community and society. This suggests that a variety of interventions are needed to effect change and produce congruence within the patient's ecosystem.

The concepts that are pertinent to social work practice in health care will follow:

Adaptedness

Germain cited in McKendrick (1991:141) explain this concept as “when exchanges go well, a state of adaptedness, or person-environment fit, is said to exist between the individual’s rights, needs, goals, capacities and qualities of the environment”. Adaptation is viewed as a constant, continual process since people must adapt to all changes either they or their environment have induced. Clearly then the degree of adaptedness at any one time is the result of exchanges between the individual and the environment over time.

Stress

In contrast to adaptedness, stress represents a poor person-environment fit. Stress arises when the individual makes a conscious or unconscious appraisal of a discrepancy between a demand (stressor) and the personal and environmental resources for meeting the demand (Germain, cited in McKendrick, 1991:142). Reference is made to distinguishes between primary and secondary appraisal.

Primary appraisal involves the individual evaluating the significance of the demands made by the stressor, for example a disease, such as ESRD and its treatment HD, CAPD, and includes the search for meaning—the individual’s efforts to understand and define the experience and its implications; and social attribution—the individual’s ideas about the cause of the condition.

Secondary appraisal makes reference to the individual’s assessment of his internal and external coping resources, options and constraints. Previous experiences, beliefs about self, the environment and the availability of resources all affect secondary appraisal.

Hence the individual experiences emotional stress as a consequence of an appraisal that the demand exceeds coping resources. Germain cited in McKendrick (1991:142) claim that what is experienced as stressful will depend on the interplay among personal and cultural factors, the nature of the demand,

and environmental features. In context to the study, the ESRD patient can represent perceived demands that exceed perceived resources for their resolution, and so forms a source of stress. This stress of disease in turn may lead to stress in other areas of life, especially in family, work, community roles, interfering with management of the health problem.

Hence the challenge that faces the social worker in health is to maintain a dual focus on the patient and the various components of his environment while individualizing the situation.

Coping

In regards to coping, its effectiveness will depend on both personal and environmental resources. Coping may be either effective which results in stress being reduced, eliminated or it can result be intensified stress which lead to emotional disturbance, social disruption in family, community life. Thus the clinical social worker needs to be aware of the efforts of the patient to cope by recognizing stress-provoking situations in the person-environment fit, assisting in problem solving and supporting positive adaptation behaviour.

Hence actions of social workers in nephrology care attempt to restore, maintain or enhance congruence between the individual and the environment and therefore, awareness of the person-fit relationship is required.

Whilst the ecological approach attends to the goodness of fit, between the patient and those of the environment, the ecological paradigm steers the social worker across methodological boundaries and invites intervention at micro, mezzo, exo and macrosystemic levels.

Pennekamp and Freeman cited in Kasiram (1993: 65) identify the key elements of the ecological paradigm in relation to the subsystems with which it is involved, as follows:

Microsystem. At the micro level of home and family networks that are explored, are the pervasive effects of the disease and treatment modalities on family relationships. The micro level of intervention has similarities to the biopsychosocial framework, as has been explained.

Mezsystem. At the mezzosystem of intervention, Pennekamp and Freeman cited in Kasiram (1993:66) states that attention to mezzosystems are “the glue needed to hold partnerships together”. The complexities within the microsystems make it essential for there to be a set of visible and publicized pathways. Within the context of the study, patients’ emotions may be aroused by their disease and inevitable dependency on treatment, complicated by conflicting emotions. Resources such as the renal staff comprising of the doctor, nurse and allied paramedical is identified so that there is some support given to the patient throughout difficult times. Relationship building between the patient, family and renal multidisciplinary team is seen as a method of working at the mezzosystem level.

Exosystem. The exosystem consists of neighbours, social agencies, businesses and community at large. The exosystem needs opportunities to reach out to the patient. Religious and cultural systems may be included in the exosystem as influencing and being influenced by the patient. What are the religious beliefs of the patient? Religion and culture play a pivotal role in the way patients, families deal with chronic disease.

In this study, the exosystem may also include the role of associations such as the KwaZulu-Natal Kidney Association that provides invaluable support to patients in the form of food and financial relief to assist with adherence in terms of diet and transport costs.

Macrosystems. The macrosystem includes national values, legislation, policies and funding patterns. These are not always seen as promoting the interests of patients.

Culture influences people's perception of illness and health and many Blacks still use traditional medicine, which impacts on their adherence to treatment. Legislative issues require collaborative teamwork with other systems and incorporating traditional healers into the national health care system, are essential.

Structural factors such as poverty and unemployment negatively impact on patients who are on treatment as they have limited access to proper nutrition as a result of their lower socio-economic status. Additionally transport costs impact further on patient compliance with therapeutic regimens.

Hence the subsystems outlined above, serve to guide the researcher in carefully identifying the areas in which deficit and dysfunction may occur in the care and management of patients with ESRD.

Barriers exist in the socioeconomic and biopsychosocial realms that impact on patient treatment. In terms of the relevance of these frameworks in social work research and practice, Callahan (1998: 636) reports that the identification of these barriers through a skilled biopsychosocial assessment is critical to ameliorate risk factors and maximize outcomes for the ESRD patient.

Looking at the study at hand there is recognition that while ESRD is a physiological process, as an illness associated with treatment, it is also a psychological and social process as it involves experiences such as depression, sexual dysfunction, impaired occupational functioning, thus only focusing on the physiological aspects would be inadequate. Justification for using the ecological model is also important as the patient is also part of a system such as the family and society which impacts on the experiences of patients.

2.2. Kidney Disease

2.2.1. Introduction

Naicker (2003) reports that renal disease, i.e. glomerular disease is more prevalent in Africa and is of a more severe form than that found in Western countries, with a higher frequency in Blacks, a lesser frequency in Indians and a lower frequency in Whites. She adds that the milieu of chronic parasitic, bacterial and viral infections predisposes one to an increased prevalence of glomerulonephritis. She maintains that the problems facing the African Continent and its people include poverty and overcrowding due to rapid urbanization with resultant lack of clean water and adequate sanitation. This may partially explain the high rate related to infectious diseases in Africa – 43% compared with rates of 1-2% in more developed continents. She adds these same people are not spared the ravages of chronic disease.

The National Kidney Foundation reports that 20 million Americans –1 in 9 United States adults have chronic kidney disease and another 20 million more are at risk (National Kidney Foundation: www.kidney.org).

Chronic kidney disease is emerging as a global threat to human health. Schippati and Giuseppe (2004) report that more than 1 million people worldwide are alive on renal dialysis or with a functioning graft. The incidence of renal failure has doubled during the past 15 years, a trend likely to continue into the next decade. The author further reports that it has been forecast that by 2010 in the United States, more than 600,000 patients will need renal replacement therapy; the costs estimated to grow to 28 billion dollars.

Baer (1998) agrees that worldwide chronic renal failure is increasing more than was anticipated. Bommer cited in Shabalala (2004) explains that in 1998 the prevalence of ESRD was higher in Japan at 1565 per million of the population when compared with the United States of America at approximately 256 per

million population. In Germany and other European countries such as Italy, Austria, Spain and France, the prevalence was lower than in Japan but higher than in the United States of America, ranging from 670 to 764 per million population.

According to Naicker (2003), the Statistics of the South African Dialysis and Transplant Registry (SADTR) reflect the patients selected for renal replacement therapy (RRT) and do not reflect the etiology of chronic renal failure.

The last reliable report of the SADTR in 1994 showed that 3399 patients (99 per million of the population) were alive on treatment for end-stage renal failure, with 754 new patients having commenced therapy in 1994, hospital HD in 1051 patients (30%), CAPD in 448 patients. This reveals that the saturation of haemodialysis units and the associated high costs of peritoneal dialysis fluids to undertake CAPD limits this option. She further states that there is not enough money for health care in the developing world, particularly for expensive and chronic treatment such as RRT.

Every end stage chronic renal failure patient should have access to dialysis. The reality as reported by (Naicker, 2003:121) is that there is not enough money for health care in the developing world, particularly for expensive and chronic treatment such as RRT. She maintains that CAPD is currently an expensive treatment modality in Africa. In low-income countries, facilities for dialysis are extremely scarce or non-existent. The obstacles in providing adequate health care to millions of people in poor countries are widely known. Poor infrastructure such as roads and sanitation, famine and malnutrition, cultural attitudes and practices, ignorance and inadequate public health systems are all-important factors in coping with chronic and infectious diseases.

2.3. Understanding Kidney failure

The kidneys play an important role in one's health. Most people are born with two kidneys-one on each side of the backbone just below the rib cage. Shaped like a kidney bean, each kidney is about the size of a small fist (12cm) and weighs about 150 grams (Baxter 2006).

Normal healthy kidneys perform the following functions:

- clean waste products from the blood and remove extra fluid to form urine
- keep minerals (sodium, calcium, potassium and phosphorus) in balance
- help control blood pressure
- help to make red blood cells
- produce vitamin D to keep bones healthy and strong

Kidney failure is a term that means that the kidneys are becoming less able than normal to perform their usual functions. When kidney disease starts, it is likely to get worse over time. However, this can take years and decades.

2.3.1. Types of Kidney failure

- Acute kidney failure occurs when there is a sudden loss of kidney function resulting from an injury or poison. It can be reversed if treated promptly.
- Chronic kidney failure is then a gradual loss of the kidney function that results from a long-term disease. This is the most common type of kidney failure and, although it cannot be reversed, it can be treated. It can range from mild dysfunction to severe kidney failure. Progression may continue to end stage renal disease.
- End stage kidney disease is a condition where the kidneys do not work or only very little function is left. Treatment on dialysis or transplant becomes essential.

Chronic renal failure usually occurs over a number of years as the internal structures of the kidney are slowly damaged. There may be no symptoms in the early stages and progression may be so gradual that symptoms do not occur until kidney function is less than one-tenth of normal.

It is reported that chronic renal failure and ESRD affect more than 2 out of 1,000 people in the United States. Diabetes and hypertension (high blood pressure) are the two most common causes and account for approximately two – thirds of the cases of chronic renal failure and ESRD. Other major causes include the following:

- Glomerulonephritis
- Polycystic kidney disease
- Alport syndrome
- Reflux nephropathy
- Obstructive uropathy
- Kidney stones and infection
- Analgesic nephropathy
- Toxins exposure (Chronic renal failure: www.nlm.nih.gov)

2.3.2. Symptoms

Kidney disease is often referred to as a ‘silent disease’ as some people may not even feel sick, or they may not notice their symptoms while others only become aware of their condition when their kidneys are no longer removing waste. As the kidney function slows down, the following symptoms of uraemia are experienced:

- Feeling tired and/or weak
- Swelling of the hands and feet
- Shortness of breath
- Appetite loss, vomiting, nausea

- Difficulty sleeping, itching, darkening of the skin

By the time end stage kidney disease develops, kidneys are functioning at less than 10 to 15% of capacity. At this point the kidneys are not able to keep up with waste and fluid clearance on their own, and dialysis or a transplant becomes the only option to support life.

Dialysis is a treatment that does some of the things done by healthy kidneys. It is needed when your own kidneys can no longer take care of your body's needs.

Dialysis is indicated when you develop end stage kidney failure; usually by the time you lose 85 to 90% of your kidney function (National Kidney Foundation:www.kidney.org).

Dialysis keeps your body in balance, like healthy kidneys and it serves the following functions:

- Removes wastes, salt and extra water to prevent them from building up in the body
- It keeps a safe level of certain chemicals in your blood, such as potassium, sodium and bicarbonate
- It helps control blood pressure

In chronic or end stage renal failure, the kidneys do not get better and dialysis is needed until a new kidney is obtained. Although dialysis and transplantation are serious undertakings that can be life-threatening, there however comes a time when their benefits outweigh their risks. There are different types of dialyses and this study will focus on two types known as HD and CAPD.

2.3.3. Types of Dialysis

Haemodialysis or HD is the most common form of dialysis. It essentially removes extra fluids, chemicals and wastes from the bloodstream by filtering the blood

through an artificial kidney (dialyzer). Blood is pumped out of the patient's body to the artificial vein through a vascular access that is created surgically, in the arm or leg. The patient's blood plasma moves across membranes inside the artificial kidney that filter out waste. Less than a cup of blood is outside the patient's body at any one time. Most patients require 12 hours of dialysis each week, usually divided into three sessions (Kidney failure, chronic: www.mayoclinic.com).

Continuous ambulatory peritoneal dialysis or CAPD is the other form of dialysis. In this type of dialysis the patient's blood is cleaned inside of the body. A plastic tube called a catheter is surgically placed into the patient's abdomen to make an access. During the treatment the abdominal area called the peritoneal cavity is filled with dialysate through the catheter. The difference is that the patient performs this type of dialysis at home, work and does it by exchanging the dialysis solution in the abdomen four times per day and these exchanges are spaced out throughout the day (Kidney failure, chronic: www.mayoclinic.com).

For the purposes of this study, the researcher will refer to the types of therapy as renal replacement therapy (RRT).

2.3.4. Advantages and Disadvantages of HD and CAPD

The advantages of HD are that the nursing staff performs the treatment for you in the hospital. It requires two to three treatments per week and no equipment or supplies are needed to be stored at home.

The disadvantages of this treatment are that the patient needs to travel to hospital two to three times a week on a fixed schedule. The patient may not be able to continue to work due to the dialysis treatment schedule. There is an insertion of needles at each treatment. A permanent access is created surgically and there might arise a need to insert a temporary catheter (Baxter 2006).

The advantages of CAPD treatment are:

It requires no equipment except the four, two litre bags of dialysate solution each day. The exchanges can be done anywhere, and patients can travel. Because CAPD reduces the disequilibrium syndrome, patients can walk about comfortably, without fear of falling. The patient's diet is more liberal and hypertensive control is improved.

The disadvantages of this treatment are: There is an increased risk of developing peritonitis (inflammation of the abdominal cavity), although peritonitis can be treated effectively in most cases. Catheter care requires strict adherence to sterile technique for routine cleansing, hence it requires storage space in the home for the supplies. Because of the risk of infection and damage to the catheter, patients would be restricted from physical activities and active sports (Baxter 2006).

Some patients are very self-conscious about the appearance of the catheter sticking out of the belly or about the pot-bellied appearance caused by carrying two litres of fluid around all day. So patients must be highly motivated to use CAPD treatment (Frazier-Fortner 1981).

People who have switched from HD to CAPD report feeling much better psychologically because of the physiological advantages and the freedom of movement. Even though patients feel better, the change to CAPD does require an emotional adjustment, and they need the same support systems as other patients (Baxter 2006).

Bare cited in Keser (1989:273), states that dialysis is a maintenance treatment and not a cure for renal failure. Dialysis will be necessary for the remainder of the person's life, unless the patient undergoes successful transplant surgery. The literature maintains that the patient faces a range of chronic and periodic medical

problems, including but not limited to weakness, fatigue, bone disease and sexual dysfunction arising from both physiological and psychological reasons (Keser 1989).

A survey was conducted by Lok (1996) on patients in two dialysis centers in Sydney; findings revealed that the quality of life was perceived as below average in both haemodialysis and continuous ambulatory peritoneal dialysis patients in regards to their level of physical and social activity and satisfaction with life. However, CAPD patients were experiencing a higher quality of life than HD patients.

2.4. Chronic Renal Failure in South Africa

The prevalence of Chronic Renal Failure in South Africa is unknown.

Data from the developed world is 200 new cases of chronic renal failure per million of the population (pmp) annually, 400 pmp for Afro-Americans and 2000 pmp for Australian Aborigines. Accurate data is required for South Africa, to facilitate service provision in view of the high cost of RRT. A nephrology group of professors and doctors have urged the Department of Health to make renal failure a notifiable condition (Nephrology Report: www.doh.gov.za).

Inaccurate statistics for treatment rates in South Africa creates problems for care. Moosa et al cited in (Nephrology Report: www.doh.gov.za) explain that the South African Dialysis and Transplant Registry (SADTR) have been in difficulties because of lack of financial support since 1994 which has hindered audit dialysis and transplant activity in South Africa.

Criteria for dialysis are based on eligibility for renal transplantation, according to a treatment protocol supported by the National Department of Health.

Due to the shortage of resources, government hospitals have come up with a set policy, which is a guideline, termed the National Health protocol that defines

criteria for chronic dialysis in the public sector. Naicker (2003) reports that because of financial constraints, the National Health Department, in consultation with nephrologists, has formalized a protocol for the management of end stage renal failure. The private sector adopts its own criteria.

Patients who suffer from acute renal failure that can be treated by renal dialysis are given automatic access to renal dialysis. However patients suffering from chronic renal failure which is not reversible are not automatically admitted to the chronic renal programme.

State facilities will offer RRT only to patients who are eligible for a transplant. There are no constraints of sex, race or social status dialysis is offered to transplantable patients who are able to attend for treatment. Naicker (2003) adds that with the low transplant rate in South Africa, HD units are saturated and it is becoming difficult to accommodate new patients unless they have a related donor or are able to undertake CAPD.

Another criterion for inclusion in the chronic renal programme is age (Assounga 2006). The age limit for a renal transplant is 60 years; hence the cut off age for chronic haemodialysis is 60 years. Adherence to therapy sessions and diet regime are aspects of compliance that are critical. Access to proper housing, water etc are other criteria for CAPD. Suffice to say that the poorest of the poor who live in a shack with no water cannot be admitted to the chronic renal programme. This is a concern.

Compliance with the medical and diet regimens, good socio-economic circumstances in regards to adequate housing, water and transport are amongst the high-ranking criteria that will qualify patients for RRT.

Patients should be accessing dialysis closer to home but the situation is challenging in the National Department of Health, as there are few state hospitals to cater for RRT due to inadequate resources and staff, compounded by financial

constraints in state hospitals. There is also a lack of expertise in more peripheral areas. RRT has to occur in conjunction with an active transplant programme to make it viable and more cost effective and currently there is a low transplant rate (Naicker 2003).

2.5. Quality of Life

The term 'quality of life' according to Lindsay, cited in Henderson and Thuma (1999) implies that each individual will define the quality of their own life in a unique way, with different priorities and different weights differentially assigned to the various aspects of personal existence. Lindsay in Henderson and Thuma (1999) adds that there is concern with patient quality of life as distinguished from the quality of life of the general population.

The concept of patient quality of life is derived from the World Health Organization's (WHO) definition of health as a "state of complete well-being and not merely the absence of disease or infirmity" (Henderson and Thuma, 1999:145). Henderson and Thuma add that when we consider the quality of life of a disease patient, by definition disease is present.

The central focus thus is the level of physical, mental and social functioning of the individual in life.

The dimensions of patient quality of life, as stipulated in the WHO definition of health, are physical functioning, social functioning and psychological functioning (Lindsay cited in Henderson and Thuma 1999).

2.5.1. Physical Functioning

In terms of the impact of ESRD on the life of the patient, disease related stress and dialysis related distress are important considerations in regards to the

incidence and severity of symptoms, the occurrence of physical problems and the level of discomfort during the dialysis procedure. Other aspects of treatment regimen stress as dietary and fluid restrictions present the physical domain of quality of life.

2.5.1.1. Diet and Fluid Restrictions

ESRD and its treatment cause major alterations in the life-style of most patients, who encounter frustration in all areas of life including dietary and fluid intake restrictions. Patients experiencing renal failure suffer marked weight loss, an increase in total body water, and an altered sense of taste. Patients are often unwilling to eat much when confronted with dietary restrictions. After the initial adjustment period, patients usually find that they can live comfortably with the diet.

Further to the researcher's communication with the Head of Department of Dietetics at Inkosi Albert Luthuli Central Hospital, Durban (2007) dietary treatment has three goals:

- To provide adequate intake of protein and calories
- To maintain and repair body structure
- To control the intake of fluids and salt to avoid fluid overload and hypertension

All three of these goals are confirmed by Mahan and Escott-Stump (2000).

Protein, sodium, potassium fluid, calories, calcium, and phosphorus are the main dietary factors that have to be controlled in patients with ESRD. The importance of dietary compliance cannot be overemphasized.

The most common problem with dialysis patients is unwillingness or inability to observe dietary regulations on the intake of food and drugs.

Many patients can stick to their diet for a while but then go on eating binges, which can often be correlated with a change in emotional state. Knowledge of drug therapy and its possible side-effects affects patients' emotional state. Some patients get anxious and it might be as a consequence of the effects of the drugs or an underlying social problem.

Patients who "make a game" about not following their diet and not taking their medication are often seeking attention or control over their situation.

The concept adherence is increasingly used instead of compliance as it stresses the active, knowledgeable co-operation of an individual with the treatment regime. Failure to adhere to the treatment regime constitutes non-adherence.

Tsay cited in Shabalala (2004:42) reports that many ESRD patients have difficulty in complying with fluid restrictions, adding that they need major lifestyle changes and self-efficacy to comply with the treatment regimen of their chronic illness. Hence a person with an increased perception of self efficacy is more likely to participate in self care activities and thus increase adherence to treatment regimen.

2.5.1.2. Activities

Activity is markedly restricted, especially those accustomed to swimming or active sports. An exercise programme approved by the doctor can increase strength and endurance, prevent fatigue, stress and depression and increase the overall quality of day-to-day living. Many patients with kidney failure report being unable to perform as much physical activity as before.

In a descriptive correlational study conducted by McCann and Boore (2000) to examine the fatigue in a group of adult haemodialysis patients, the findings indicated high levels of fatigue, with low vitality and reduced motivation. Reduced activity and mental fatigue were evident in the adult HD patients.

Lok's study (1996) which investigated the significant stressors and coping mechanisms that were related to quality of life among dialysis patients, revealed that the limitation of physical activity was the significant stressor, followed by

decrease in social life, uncertainty about the future, fatigue and muscle cramps. Other identified stressors included anxiety, depression, feelings of inadequacy, pain, discomfort, fluid and diet restrictions and weakness.

2.5.2. Psychological Functioning

Lindsay, cited in Henderson and Thuma (1999) explains that this domain reflects the individual's inner experience of the illness and treatment that will include the direct impact of the physical symptoms on subjective well-being, the meaning and significance to the person's self-concept and self-esteem of the losses entailed in a debilitating chronic disease, adjustments to the possibility of death, and the mobilization of defenses and coping mechanisms. Thus psychological functioning is influenced by, and exerts an influence over, physiological functioning and health.

2.5.2.1. Uncertainty

Many chronic conditions such as ESRD are surrounded by uncertainty at the time when the patient first notices that something is wrong and this may continue throughout the entire course of the illness. During this time patients are convinced that something is wrong, but often find their complaints dismissed by the attending practitioners as trivial. This can be a very difficult time for the patient and family. When a diagnosis is finally made it often comes as a relief as it legitimizes the person's complaints and experiences, and brings to an end conflicts with others over the reality of the symptoms. Regardless, confirmation of a diagnosis is a shattering experience for the persons concerned (Ross and Deverell, 2004:15)

2.5.2.2. Fear of the threat of death

Dialysis is a constant source of anxiety to ESRD patients because of possible complications such as infection in CAPD, possibility of bleeding to death if the

tubing comes out and the probability of clotting. The reminder of the threat of death is also rooted in the realization that a continuation of life is dependent on external variables beyond the control of the patient eg high technology medicine, the renal unit staff, available resources and society (Schlebusch 1990).

2.5.2.3. Body Image Disturbance and loss of Body Function

Some ESRD patients as alluded to by Schlebusch (1990: 149) unconsciously think of themselves as “semi-artificial”. He maintains body image does not necessarily refer to the actual body, since a dialysis machine or a phantom kidney can be experienced by the patient as an extension of the body.

Physical appearance is often modified. Changes in physical appearance due to chronic kidney disease vary from person to person. Sometimes the skin may become paler, dry and flaky and patients may want to use cosmetics to change their skin tones. Changes may occur in body weight, due to fluid loss or retention. Patients experience changed taste and different smell to their breath due to the build up in the body of waste materials that are normally removed by the kidneys. Although the fistula is placed under the skin, they remain obvious to the naked eye. According to Baxter (2006) the increased blood flow through the veins, cause them to be distended and raised on the back of the hand and forearm, and this is not cosmetically pleasing. Self-conscious patients are just as assiduous in their efforts to conceal their fistulas. Also, location of the fistula commonly placed in the forearm, may prohibit movement. If placed at the elbow, movement is impossible. When the fistula is placed in the upper arm, circulation to the hand and fingers is reduced, making it difficult or impossible to hold objects.

2.5.2.4. Dependence – Independence Issues

Another major psychosocial issue for the person on dialysis seems to be independence versus dependence. The person with kidney disease is faced with a two-sided problem: having to be independent and also to be able to return to

the tasks and activities that he was involved in before undergoing treatment. RRT requires patients to be dependent insofar as adhering to the medical regimen is concerned on the one hand, whereas they are expected to live a normal, productive life in which they must maintain a family, social and vocational relationships on the other. As Schlebusch (1990) states this leaves patients trapped with feelings of helplessness.

2.5.2.5. Use of Psychological Defense Mechanisms

Ross and Deverell (2004) state that all chronic disabling conditions pose a threat to a person's identity and self-concept. According to Williams cited in Ross and Deverell (2004:15) people with chronic illness must go through a process of "narrative reconstruction", in which the individual's biography is reorganized in order to account for the onset of illness. This identification of cause is part of the process of coming to terms with chronic illness and finding answers to the question "Why me?", and gives meaning and a sense of order to the individual's world. Hence chronically sick people like ESRD patients are involved in a constant struggle to lead valued lives and maintain definitions of self that are positive and worth-while. Interactions with others such as family, renal staff may constantly undermine the patient's self-worth. Loss of self can be a powerful form of suffering experienced by the chronically ill.

The dialysis literature states that the full range of psychological defense mechanisms has been used by patients to defend themselves from the stress of dialysis. According to Welch and Austin (2001) depression is very prevalent among patients with ESRD particularly those undergoing HD therapy. Kimmel (2000) stated that chronic dialysis patients sustain numerous losses, including the loss of kidney function, well-being, place in the family and workplace, time, financial resources and sexual function. It does not come as a surprise that most of these patients suffer from depression at one stage or another.

The primary defense used by people on dialysis is denial; simply understood as an adult advised to follow certain medical prescriptions agreed upon proceeds to just the opposite (Schlebusch 1990).

Depression occurs in the dialysis patient when denial breaks down. It often occurs when patients feel they can do nothing and yet are unable to ignore the demands. People on dialysis protect themselves against the stress they face by using whatever resources are available.

In spite of preparation, total renal failure is never accepted immediately as a reality. There is a definite reaction. Most patients enter a period of denial. They really are not convinced that their kidneys have failed.

Depression is another problem that is seen in patients with ESRD. In a study conducted by McCann and Boore (2000) on HD patients, depression was identified to be significantly associated with physical health status, sleep problems and anxiety.

The chronicity of the disease and the need for continued treatment causes patients to experience a feeling of helplessness leading to depression.

Displacement, isolation of feelings, projection and reaction formation are all defense mechanisms used by people on dialysis. Fear, anxiety, anger, withdrawal are common reactions displayed in adaptation to kidney disease. If anger and hostility is not expressed, feelings of guilt begin to surface. Withdrawal as another reaction occurs when anger was not expressed directly. Withdrawal from dialysis may be part of a 'giving up-given up' complex (Frazier-Fortner, 1981: 136).

Frazier-Fortner (1981) reports that the reactions of people on dialysis are situational and are seen as necessary reactions to profound stress. The patient's self-concept in dialysis changes, non-adaptive ways of functioning may develop. Hence the stresses, the psychological defenses, the varying reactions and the emotional drive reorganization form part of the picture of the struggle involved in

adapting to dialysis. The other part is psychosocial, involving patients' relations with others.

2.5.2.6. Treatment Nonadherence

ESRD patients must be able to manage their symptoms and manifestations during everyday life. The patient must be able to manage the medical regimens prescribed to control symptoms and these include drugs and diet. The treatment can be as bad as the disease, consuming time, energy and financial resources and requiring hard work such as a special diet (Ross and Deverell, 2004:15).

According to Schlebusch (1990:154), maladjustment to dialysis is an indication of treatment nonadherence, which is a decision by the patient to discontinue treatment. He further reports that deaths that result from treatment non-adherence to the chronic renal failure programme had been evaluated from a suicidal framework, if the patient decided unilaterally to terminate treatment. It has also been viewed as an attempt to reduce the anxiety that stems from the patient's considerable responsibility to the chronic renal programme or as a form of acting-out by expressing negative feelings towards dialysis.

In some instances patients refute their feelings of denial and dependency and this takes the form of treatment nonadherence by missing dialysis sessions and clinic appointments or by not adhering to dietary and fluid intake restrictions.

Treatment nonadherence has also been identified to be related to other extraneous factors such as the medical team, specialist-patient interaction and inter-staff relationships within a renal unit (Schlebusch 1990).

It is therefore evident that psychological factors play an important part in adjustment and noncompliance of treatment in renal patients.

2.5.3. Social Functioning

The pervasiveness of symptoms, the time and energy demanded by dialysis and other treatment considerations, means that every aspect of a patient's life-style changes after kidney failure. Continuing crises in the roles of partner and parent precipitates shifts in family responsibility and decision-making. Patients change jobs, work reduced hours or leave their employment altogether, thus placing greater burdens on spouse and family and causing changes to patterns of housework, diet, recreation and social activities.

2.5.3.1. Work

Dialysis patients are encouraged to return to work with their doctor's permission. At first, working in addition to following an involved medical programme can be tiring. Additional support and encouragement at home and from the health care team are important. Patients who are employed may want to consider taking sick leave or a brief leave of absence. Some patients tend to give up their jobs or are considered for medical boarding. Patients are encouraged to discuss openly with their employers the extent that their disease could affect their ability to work. Doctors in instances provide letters to employers indicating whether patients are able to work and limitations they may have. Special needs such as a change in work schedule are recommended. Dialysis units can be approached to schedule employed patients on a convenient shift

For the CAPD patient the employer must make provisions for a clean, private place to enable the patient to do CAPD.

People facing dialysis treatment, CAPD or HD worry that their treatment could cause them to lose their job. In America a law passed in 1990 (the Americans Disabilities Act) prohibits discrimination because of disabilities (National Kidney Foundation: www.kidney.org).

According to Kimmel and Levy cited in Daugirdas et al (2001: 415) about two-thirds of the patients on dialysis do not return to employment in which they had engaged prior to the onset of renal failure. The ability of individuals to return to

work depends on their socioeconomic circumstances and the severity of their illness at the time of initiation of ESRD therapy. It is much easier for a college professor or business executive on dialysis to work than for a patient qualified only for blue collar employment because of flexibility of work schedule and because less physical exertion is usually required in white-collar jobs.

2.5.3.2. Family and Adaptation

The dialysis patient, chronically anaemic, intermittently uremic, and prone to many medical complications, usually cannot assume previous emotional involvement with spouse and children. The stress of being ill makes most patients regress psychologically, draining the patient and leaving less energy available for family involvement.

Patients pass through a painful process of adaptation, relying on family for support. Even where family members are willing and able to provide help, the patient with ESRD on RRT may feel that he or she is a burden and may refuse the assistance that is needed. Also distressing symptoms such as swelling, feeling tired and weak may lead the patient to withdraw from family life altogether. In some instances, both the patient and family become isolated from the wider community. This lends to a situation with significant stress related consequences for the family unit, particularly when adaptation to the chronic renal programme is not satisfactory. Since the emotional trauma experienced by patients extends to significant others (eg. spouses and children), the quality and meaning of life for patients and their nuclear families is affected. The level of marital and family functioning, including cohesion, conflict, communication, affection, organization and control is both a primary resource for the patient and is vulnerable to disruption as a result of illness and treatment. Marital breakdown is not uncommon in these instances.

Another alteration of life-style includes the probable loss of financial security, resulting from lower productivity and income, and possible unemployment. There

is also role reversal with added responsibilities by the spouse and partner, thereby resulting in a loss of authority for the patient.

Hence, ESRD and the introduction of the treatment options can place intolerable strain on the family due to the need for levels of physical care and support, the emotional connotations of giving and receiving help, and changes in family roles and relationships eg when the wife is compelled to become the breadwinner.

A phenomenological study undertaken by White & Grenyer (1999) to investigate the biopsychosocial impact of ESRD on dialysis patients and their partners in Australia, revealed that both the patients and their partners viewed their relationships very positively, and both were overwhelmed by the impact of dialysis on their lives. Anger, depression and hopelessness were evident in the patients, whilst a pervasive sadness, resentment, guilt and loss were prevalent in the partners.

Given the above, whilst family support is important for satisfactory adjustment, dialysis families have to adjust to a narrower social world, re-organization in household tasks and concern with finances in order to diminish stress (Schlebusch, 1990:153).

2.5.3 3. Sexuality Issues

The desire for sexual activity, as with other chronic illnesses may change with the onset of kidney failure. Initially a lot of energy is needed for the physical and emotional adjustment to the illness. Sexual dysfunction and infertility further contribute to a decreased quality of life. Schlebusch (1990) and Galpin (1992) also emphasized the effect of change in body image on the patient's self esteem. This affects the patient's sexual function since the body image is interwoven with sexual identity and patterns of sexual functioning.

Kimmel and Levy cited in Daugirdas et al (2001: 414) maintain that dialysis of both genders frequently have sexual difficulties. They add that impotence eventually develops in men treated with dialysis and women on dialysis have a diminution in the frequency of orgasm during intercourse. Patients of both genders engage in sexual intercourse much less frequently than they did prior to becoming uremic. The cause of sexual dysfunction is related to psychological factors. In men, depression, reversal of family role due to loss of job, and the impact of cessation of urination (as the organ of urination is also the organ of sexuality) can all contribute to sexual dysfunction. In women cessation of menses, diminution of fertility and alteration in appearance may contribute to sexual dysfunction.

Galpin's study (1992) highlighted the effect of change in body image on the patient's self esteem and the consequent affect on sexual identity and patterns of sexual functioning.

2.5.3.4. Social Isolation

Social isolation is a problem faced by many patients. Patients who have undergone procedures in regards to HD and CAPD experience feelings of embarrassment. The social consequences of surgery can also lead to a restricted social life (Ross and Deverell, 2004:15).

Patients who require dialysis three times a week and who have to follow a strict diet and fluid restriction, experience isolation from their family and friends.

Social support from family and friends is one of the key resources that the dialysis patient can draw on for help in coping with the demands and disruptions of ESRD and its treatment.

In a study by Carl et al cited in Hardy et al (1991), conducted on the psychological and social adaptation of CAPD and HD patients, findings revealed that CAPD patients do not have significantly superior adaptation in comparison to HD patients. The data did suggest that haemodialysis patients, who experience

significant chronic distress from marked fatigue, weakness, restrictions on diet, fluid, and travel and the stress upon members of their social network, might find these problems less severe if they changed to CAPD. The evidence was mixed as to whether CAPD is associated with improved or poorer vocational status, as compared to HD patients.

The discussion that follows will explain the macro impacts.

2.6. Cultural Influences

Traditional beliefs and superstitions can have a major impact on intervention and on patients' attitudes towards ESRD treatment. There are cases where many non-westernized Black patients may turn to traditional healers for assistance, as they do not associate kidney function with urine formation but rather with sexual function. Because of their beliefs, they might consult the traditional healer. Tyler cited in Shabalala (2004) states that 80% of African people use traditional healers. There is also a risk of interaction between herbal products and conventional medications. Patients fail to adhere to the programme and often abscond from the treatment.

2.7. Health Education

The importance of health education can never be overstressed. It forms the basis of the whole therapy to be rendered. Cross cultural awareness of patient groups is critical as patients' knowledge is often scant and their vernacular lacks the equivalent terminology to explain concepts like loss of renal tissue, electrolyte imbalance.

In addition, patients often receive fragmented information from different sources during which their understanding of ESRD and the chronic renal failure programme which demands considerable learning and the acquisition of a new vocabulary can be adversely affected by their weakened condition and diminished learning ability.

Information is a significant resource for managing the lives of renal patients. It reduces uncertainty, helps the individual come to terms with the illness and allows for the development of strategies for managing the illness in every day life. Many ESRD patients and their families complain about the lack of information about the condition. Information on the Internet and World Wide Web has made significant strides in increasing the availability of information to those with access to the appropriate technology. It is possible that patients may misunderstand complex information available on the Web and may experience increased anxiety as a result, or may be instilled with false hope or a false sense of security. These problems would therefore be best managed by providing patients with as much information as they require gaining a sense of control over their illness.

2.8. Socio-economic Factors

Socio-economic concerns are amongst those factors that have an impact on outcomes of treatment in ESRD patients. The therapeutic regimen causes patients to curtail their role in business. It may mean changing the occupation or giving up employment or at best working on a part-time basis. The adjustments that have to be made may cause both economic and social changes for family members, especially if the patient has been the main source of income. Special dietary requirements and transport means incur problematic additional expense.

Unemployment is a major stressor among chronic ESRD patients. A study conducted by Kimmel (2000) revealed that a large percentage of the ESRD population is unemployed or unable to work, due partly to old age, medical illness and social disincentive.

Patients from low socio economic backgrounds may fail to meet the financial demands of haemodialysis therapy. They might fail to attend therapy sessions because they live far from the hospital and cannot afford transport fare or might fail to adhere to dietary restrictions because they do not have enough money to buy food. The patient might be working fewer hours or be unemployed because of his/her debilitating condition (Kimmel 2000). This holds true for CAPD patients

as well who experience difficulty with employers that are reluctant to recruit them due to risks associated with the regime.

Hence most of the patients on HD and CAPD are unemployed and this impacts on their compliancy.

2.9. Religious Factors

Religious factors are among several factors that give meaning and order to cultural groups and influence the care and health status of individuals, families, groups and institutions (Martsolf and Mickey cited in Shabalala, 2004:33).

Andrew and Boyle cited in Shabalala (2004:33) indicate that health care workers should ask patients about their religious beliefs and practices as it can promote mutual goals and priorities between the health worker and the patient. According to Shabalala (2004) in Africa, medicine cannot be separated from religion because the patient's body, soul and spirit form an integrated whole.

Studies in the dialysis population seem to indicate that religion may be associated with increased patient satisfaction with life and increased levels of social support.

A study was conducted by Berman et al. (2004) on the religiosity in an HD population and its relationship to satisfaction with medical care, satisfaction with life and adherence. The findings revealed that religious beliefs are related strongly to measures of satisfaction with life, whereas religious behaviours are related to satisfaction with medical care. Age was identified as the single most important demographic factor associated with adherence, showing that older age individuals reported increased satisfaction with medical care and increased adherence.

Thus these associations reinforce the idea that religion has a role in patients with chronic illness, therefore it is important for health care providers to understand patients' beliefs about illness and care.

2.10. Education

According to Adler, cited in Shabalala (2004:20), individuals that have progressed academically are said to have a better understanding of the nature of the illness and how to deal with its demands and thus adhere to therapy.

Barsoum cited in Kjellstrand & Dosseter (1992) highlight the importance of education and knowledge in chronic renal failure, reporting that on the African continent, a patient diagnosed with chronic renal failure starts a long, tough struggle of survival frustrated about the discrepancy between how much they expect from and how much they get out of medical and social support. Their expectations depend on their knowledge about modern treatment of chronic renal failure. Their knowledge depends on their culture, educational level and public information available. Unfortunately, there is poor dissemination of information and treatment among the poor and uneducated.

2.11. Poverty

Poverty in South Africa is basically a general form of deprivation, which arose from an unequal distribution of resources. Overcrowding, illiteracy, unemployment and lack of access to energy sources and water are conditions associated with poverty and important factors in determining the failure of patients to cope with ESRD.

This thus completes discussion on the macro impacts.

2.12. Role of the Nephrology Social Worker

Ross and Deverell (2004:15) highlight the importance of the professional caregiver-patient relationship, stating that there has been a shift of emphasis from repairing damage caused by disease to a focus on education and understanding about living with chronic illness. In this regard, information, advice

and support are among the most important interventions social workers and allied health care professionals have to offer, their goal being to help the patient live as normal and satisfying a life as possible within family and community. Such help needs to be approached with care, sensitivity, information and support provided within the context of a professional relationship.

Hence the discussion that follows will focus on the role of the social worker in nephrology.

The WHO definition of health as defined earlier highlights the contribution of social work to the field of health in the following ways:

- It notes the central role of social well-being for the attainment of a state of health
- It implies the notion of a holistic approach to health
- It de-emphasizes the bio-medical perspective of health as the absence of disease

Schlesinger cited in McKendrick (1991:123) proposed an alternative definition of health in view that social workers promote healthy functioning despite the presence of disease and symptoms, as follows:

Health involves not the absence of disease but the capacity to cope in physical or psychological terms. Health is related to the quality of social relationships and the capacity to carry out a variety of activities consonant with age, interests, physical and mental capacities.

Suffice to say that with the gradual shift in medicine to a more holistic approach to health care, social work is being challenged to re-assess its contribution to the health field. Hence health care social work practice attempts to address more appropriately the interplay of the economic, environmental, social, psychological, cultural and biological factors affecting the health status on the individual.

The nephrology social worker provides a broad range of services and these encompass concrete (information and referral) and psychosocial, therapeutic type services. Examples of concrete services are those centered around financial considerations, transportation, employment and housing. Therapy would encompass issues such as depression and anxiety, fear of death and dying, family concerns and sexual dysfunction.

A total, comprehensive therapeutic effort from the entire multidisciplinary team is required to minimize the emotional impairment that occurs with dialysis patients. Patients with chronic renal failure feel shock, disbelief and anger upon learning that they are in renal failure. Family members often feel the same thing, and experience guilt or self blame.

The social worker's role is to assist the patient in redefining his life goals in light of the limitations imposed by dialysis. In working with patients, the target areas would involve intra personal subsystems as well as interaction with the social and physical environment, such as the dialysis unit, and the hospital. Goals also include changes in cognitive thinking, such as helping the patient understand the reasons for noncompliance and reframing compliance so that it is consistent with the patient's understanding of illness, altering emotional thinking, helping the patient to feel less depressed about changes in life caused by renal disease; and helping the patient to make behaviour changes such as reducing the patient's demand for analgesics.

After addressing emotional needs arising from the diagnosis of renal disease, it is important to ensure that the patient is educated in all treatment alternatives. Thus the task of the social worker would be to help patients understand the risks and complications that accompany treatment alternatives of HD, CAPD and transplantation.

An important goal is to help the patient adjust to life on dialysis. A patient once reported to the social worker that "although dialysis was keeping him alive, it was

a mixed blessing". Dialysis does impose very stringent limitations on the patient's lifestyle because it involves time commitments: travel restrictions; and frustration of basic drives such as food, water and sex. Most patients resent the restrictions and impositions that dialysis entails. Specifically it is critical for the patient on dialysis to comply with medical and dietary regimens and this requires that the patient assumes an active role in treatment and rehabilitation. However denial of illness and dependence on the machine results in behaviour that is maladaptive and interferes with treatment. The social worker helps the patient recognize the reasons for noncompliance and need for control into a more positive direction, including employment.

Callahan (1998:632) reports that skilled social work interventions directed at treating depression are critical to quality patient care. Therefore psychosocial interventions are driven by skilled biopsychosocial assessment that focuses on predictors of adaptation such as previous coping styles, support systems, developmental strengths, social role functioning, pre-morbid norms for well-being and socioeconomic supports. Research by Callahan (1998:632) also reports that 76% of depressed patients would prefer to seek counseling from the nephrology social worker on the treatment team. Thus the nephrology social worker must provide skilled assessments because patients' health status, needs, goals and environment continually change, and adequate assessment and treatment can lead to improved outcomes.

Intervention with the family is also identified as the therapeutic unit. The objective of family intervention by the social worker is to alter the influences that contribute to the dysfunction of one or more family members.

Fortner-Frazier (1981) reports that the onset of ESRD, markedly changes family relationships. In the dialysis setting, the social worker finds herself doing family casework when the patient's problems are affecting family relationships or when problems at home affect adjustment to medical treatment.

Areas of intervention with the family are as follows:

- Financial hardships due to job loss and medical expenses that often cause role reversal among spouses
- Changes in self-image, in terms of physical appearance and personality expression
- Conflicting feelings of dependence-independence on the machine or on the spouse
- Changes in the marital and family relationship, such as lack of interest in sex or impotence, curtailment of social activities, and the loss of involvement with children
- The unpredictability of the disease, the threat of death are anxiety producing for families as well as for the patients

Thus the social worker's role is to help the family members identify their problems, become aware of their coping patterns and how they express internal conflicts through attitudes and behaviour. The intention is to identify dysfunctional interactional patterns to be replaced with more facilitative ways of relating to one another as a family. It is prudent to establish a relationship with the patient's support system as this keeps the family informed about the patient's progress, which in turn may offer suggestions about effective ways to interact with the patient. The family also provides valuable information about how the patient functions at home.

Hence individual and family intervention has been highlighted because it is seldom in the dialysis population that the patient is treated by the social worker without some involvement with the family or support system. This intervention with the family is often referred to as "family therapy".

Callahan (1998:633) reports that social support from the family influences morbidity, mortality and the course of illness, adding that ESRD impacts the

marital role and marital adjustment and causes changes in other relationships, by impacting the functioning of the family system. It is further reported that family psycho-education is an effective type of intervention used in working with families who have a member with chronic illness, stressing that family education and family therapy improve patient compliance and assist the patient and family in coping with and adapting to changes brought about by illness and hospitalization. This supports the patient in improved functional status.

Crisis intervention is a frequently used treatment modality as patients tend to experience many crises during the course of the illness causing disequilibrium and interference with emotional functioning. Hence the goals of social work crisis intervention include relief of symptoms and restoration to pre-crisis functioning. The social worker assists in foreseeing future crises and plans effective coping strategies based on problem-solving skills. Another modality of treatment is education. Often information imparted at the outset of treatment is not successfully integrated because the patient is generally overwhelmed physically and emotionally by the disease leading to denial of the long-term need for treatment. This implies that the education process with the patient must continue throughout.

Patient compliance depends on patients' understanding, patient perceived value of health outcome, and perception of vulnerability. Coping with chronic illness requires cognitive-behavioural skills that help the patient control the adverse of the disease by adhering to the demands of the treatment regimen. Thus cognitive behavioural interventions are also implemented which can increase dietary adherence, decrease depression and increase life satisfaction in ESRD patients as well increase rehabilitation potential. Suffice to say social workers are showing positive outcomes from cognitive-behavioural interventions with ESRD patients in the areas of patient compliance and adaptation to illness.

Callahan's article (1998:630) titled "The Role of the Nephrology Social Worker in optimizing treatment outcomes for End-Stage Renal Disease Patients" also maintains that group therapy also increases social support and quality of life, and physical health for patients. Group work focuses on education, communication issues, health behaviours, increasing coping capacities and psychosocial adjustment. Group work outcomes would include reductions in mood disturbance and can improve overall rehabilitation potential of young persons with ESRD.

Literature suggests that ESRD patients are capable of working than actually do work. The literature identifies barriers to vocational rehabilitation and associates vocational rehabilitation with medical, psychological and social adaptation. The research also supports the impact of psychosocial factors in the maintenance of employment among HD patients (Callahan, 1998:632). Hence early intervention, education and psychosocial support have a positive effect on maintaining employment as well as on reducing hospitalizations to support employment.

Hence individual, family and group work interventions are aimed at increasing social support which has a direct impact on the psychosocial adjustment and functioning of the patient with ESRD.

2.13. Role of the Multidisciplinary team

The Renal Multidisciplinary team essentially consists of the following members: renal nurse, dietitian, social worker, clinical psychologist and nephrologist.

The activities and responsibilities of the social worker within the renal multidisciplinary team are as follows:

- Sharing responsibility and stimulating appropriate planning for patient and family care
- Communicating significant social, emotional, economic and cultural factors which may affect illness, treatment
- Maintaining liaison and encouraging continuity of care
- Identifying and facilitating the development of resources
- Educating team members on social services
- Participating in and facilitating relevant social action

The challenge herein lies in the contributions of various professionals in health care settings and rests on the extent to which the interplay of psychological, social and biological factors in the course and outcome of disease is recognized and accepted.

The social worker serves as an intermediary. The social worker provides the interdisciplinary team with a biopsychosocial view of the patient's strengths and needs through use of the person-in-environment model of assessment.

In Callahan's study (1998) research was conducted with HD patients and showed that a social work intervention aimed at including the patient in setting rehabilitation goals increased interdisciplinary team care planning interventions to support rehabilitation goals.

The emphasis in medical social work is on the mutual interaction of the patient and the patient's context such that the nephrology social worker's ongoing biopsychosocial assessment which provides the basis for collaborative team interventions to ameliorate psychosocial problems that have a direct impact on treatment outcome.

ESRD patients experience multiple losses and psychosocial risks associated with their diagnosis and treatment. They require comprehensive psychosocial interventions at various stages throughout the course of their illness. The lifetime course of the ESRD patient's treatment may include infections, family dysfunction, changes in functional status, depression and issues of death and

dying. Barriers exist in the socioeconomic and biopsychosocial realms that negatively impact patient treatment outcomes. Callahan (1998:636) states that the identification of these barriers through a skilled biopsychosocial assessment is critical to maximizing patient outcomes, adding that that these skilled psychosocial interventions can alleviate psychosocial risk factors , thus improving outcomes for the ESRD patient. Callahan (1998:636) mentions a study in which it was reported that patients ranked the services provided by the nephrology social worker in the top four of 25 aspects of care, and another study showed that 91% of the patients believed that access to a nephrology social worker were important.

2.14. Conclusion

There is a considerable amount of literature on understanding what kidney disease is, its trends, prevalence, as well as understanding it as a biological phenomenon and the challenges it imposes on psychological and social functioning. From the literature presented, it is thus evident that patients with ESRD on dialysis therapy face a wide variety of challenges across different spheres of the lived experiences. This study aimed at obtaining thick descriptions of the experiences of patients with regards to the psychosocial effects of dialysis therapy and in so doing assists and informs the health professionals in intervening at the social, psychological and macro levels of functioning to facilitate a holistic and client centred approach towards interventions.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. Introduction

Babbie and Mouton (2001: 74) refer to a research design as a “plan or blueprint of how you intend conducting the research”. There is much confusion between research design and research methodology. Research designs attempt to answer different types of research problems or questions, and different combination of methods and procedures are employed. Methodology focuses on the research process and allows the researcher to follow certain procedures. Methodology includes research design, methods of data collection, sampling techniques, data analysis and reporting. Clearly methodology is important as it provides the researcher with the acceptable standards of conducting the research. Validity and reliability of the research findings tend to depend on the methodology used in the research.

What follows is a discussion of the research design and data collection methods. In addition the limitations of the design and methodology are examined and this is followed by a discussion of issues of reliability and validity.

3.2. Research Design

A qualitative research approach is considered appropriate for this study as the primary emphasis in such an approach is placed on the subjective meaning of an experience communicated by subjects to the researcher. Qualitative research aims at understanding and interpreting the meanings and impact of given phenomena. In this study, patients’ experience and meanings attached to these experiences will be explored. Insights gained through such processes then may

be used to enhance nephrology social work practice, not by establishing causality but by changing and enhancing comprehension of the phenomena as a whole.

The use of qualitative research methodology enables the researcher to obtain a rich holistic understanding from the data that is available in the form of words, pictures, quotes and descriptions.

This study was concerned with gaining an understanding of the experiences of patients on HD and CAPD in ESRD. In its broadest sense, the qualitative research paradigm refers to research that elicits accounts of meaning, experience and behaviour (De Vos et al 2002). Rich descriptions of individuals' perceptions, beliefs and feelings provide insights into the meanings and interpretations given to various events and behaviours.

The researcher used a combination of exploratory and descriptive research designs within the qualitative research paradigm.

The study used an exploratory research design because De Vos et al (2002) maintain that exploratory research is conducted to gain insight into a situation, phenomenon, community or individual. This study focused on RRT options in ESRD as perceived by the patients. It explored phenomena without any manipulation and control of human behaviour. Hence, the researcher was able to obtain a greater understanding of the patient's knowledge and views of RRT as they experience it. As limited local updated literature is available on the reflections of patients on RRT in ESRD in South Africa, an exploratory design was used for the purpose of asking questions and seeking out new insights. Babbie and Mouton (2001) point out that the less developed an area, the more likely exploration should be the design used to build a foundation of general ideas and tentative theories, as in the case of nephrology social work and therefore in this study.

Babbie and Mouton (2001) further report that description is a more intensive examination of phenomena and their deeper meanings, thus leading to a thicker description. This study also accommodated a descriptive research design because it described the psychosocial factors that impact on treatment of ESRD patients. From the descriptive details, the study attempts to generate common themes.

De Vos et al (2002) indicated that descriptive and exploratory research may blend in practice; descriptive research presents a picture of the specific details of a situation whereas exploratory studies aim to become conversant with basic facts and create a general picture of conditions. The researcher was able to do both, as there were no previous qualitative studies that have been done on experiences of patients on HD and CAPD in ESRD in South Africa, hence the exploratory nature; and patients' accounts of their experiences will add to the richness of a thick description, hence the descriptive nature.

3.3. Sampling

According to Brink (2006: 124) sampling refers to the researcher's process of selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest. Selection of participants was done using the non-probability sampling method, often used in qualitative studies. According to Babbie and Mouton (2001) when non-probability sampling is used; the researcher is able to handpick the sample, selecting those elements that are information rich according to the nature of the research problem and the phenomenon under study.

As this was an explorative, descriptive study, non-probability sampling was used for the purpose of identifying, exploring and understanding the experiences and challenges of patients on HD and CAPD in ESRD.

Patton as cited in Marlow (1998) identifies different types of sampling methods:

In this study criterion sampling was used. Criterion sampling involves the selection of participants according to some eligibility criteria.

The researcher was guided by the following criteria in the study:

- Patients who were accepted onto the chronic renal programme between 2005-2007, and would have to be on chronic HD and CAPD for a minimum of four months as the researcher was of the opinion that this would be sufficient time to have experienced both treatment modalities
- All population groups and both genders, who are willing, were admitted in the study
- Patients between the ages of 20-60 years were chosen
- Proficiency in English was not a requirement and a social worker was available to serve as an assistant interpreter, which was not required
- No previous kidney transplantation was performed on the patient

The sample that was chosen for the study explored the patient's perspective of the respective treatment modalities and in so doing, served to identify and provide understanding of their experiences and challenges in end stage renal disease.

The setting was the renal unit at one tertiary hospital in the Durban Metropolitan region.

The chosen hospital is a teaching hospital where the researcher is employed as a social worker in the Renal Unit. Thus, knowledge of patients and procedures did not pose a problem.

The sample of participants chosen for the study was drawn from the population of patients as outpatients attending the respective clinics i.e. HD and CAPD at the hospital. This type of sample is indicative of availability sampling. As Babbie and Mouton (2001) point out, this type of sampling takes the cases at hand, that is, those that are linked to the topic under study, available to the researcher and convenient to access. Access to the sample involved prior consultation with the

attending specialist followed by direct contact with the participant to discuss availability to participate in the study, followed by a scheduled appointment.

The number of participants was eight for the CAPD option and seven for the HD option. Thus fifteen interviews were conducted with patients altogether.

3.4. Data Collection

In this study two methods of data collection were used, namely records and interviews. The researcher was particularly fortunate in the amount and quality of data that was available to her via hospital records. These records of patients constitute rich data sources and are available electronically, with the permission of the hospital administration.

Hospital records pertaining to patients' personal information helped to obtain the research sample. In addition, these records provided data on patient diagnosis, treatment and progress. These notes are recorded by members of the multidisciplinary team and provided invaluable information on the topic. They are generally readily accessible, provided they are used with discrimination and in the patient's interest. The hospital's ethical committee reviewed the researcher's request to use these records. Thus hospital ethical procedures were respected.

According to de Vos et al (2002: 292): "qualitative interviews are attempts to understand the world from the participant's point of view, to unfold the meaning of people's experiences and to uncover their lived world prior to scientific explanations".

Wilkinson, Joffe and Yardley as cited in Sutton et al (2004) report that the most widely used and familiar means of eliciting qualitative data is the semi-structured or depth interview. Data collection interviews are generally classified as either "structured" or "unstructured" and interviews between these two classifications are referred to as "semi-structured" (Brink, 2006:151).

This study used the semi-structured interview as its main tool. The participants were the patients and the interview was guided by themes.

The use of an interpreter i.e. another social worker within the hospital was not utilized as no assistance with translation was required. An audio tape recorder was used with the permission of the participants. The interviews were transcribed.

According to de Vos et al (2002), interviews are conducted because the interviewer is interested in the interviewee's stories and interviewing the participant not only involves description of the experience but also involves reflection on the description.

This study included themes on the concrete life world of the interviewee (Sutton 2004). Probing each theme enabled the patients to talk in detail and to give extended personal accounts of their views and experiences of HD and CAPD in ESRD, allowing the researcher to understand their perceptions and experiences.

The advantages of the research interview is that it allowed natural responses, spontaneity, as well as taking into consideration any additional information not anticipated by the interviewer. Some areas of concern mentioned by the participants were further explored if necessary. In this regard, since the researcher in the study was also a social worker, concerns that warranted the intervention of allied professionals, was easily facilitated through appropriate referrals. Interviews allowed for flexibility as both verbal and non-verbal communication was recorded to cater for literate and illiterate patients.

It was important to be aware that qualitative research is extremely time consuming in comparison with survey methods and that sufficient time needed to be allocated for carrying out the in-depth interviews. This was respected.

Hence, as this study involved exploration and description, in depth data collection was utilized, involving multiple sources of information, highlighted above, that were rich in content.

3.5. Data Analysis

The primary mission in the analysis of qualitative data is to look for patterns in the data, noting similarities and differences. As qualitative data tends to be inductive rather than deductive, the technique that was used involved the identification of patterns, themes and categories that emerged from the data. Marlow (1998: 213) terms this data analysis as constructing categories. What was to be ensured in this study was that the data was considered in context rather than rigidly imposing categories.

In this study, the semi-structured in depth interview with patients did lend itself to content analysis. De Vos et al (2002) recommend that the content of interviews be analyzed while they are still fresh and preliminary coding which is characteristic of content analysis may be useful. Reference was also made to the manifest content which is the visible, surface content and latent content which is the underlying meaning (Babbie and Mouton 2001). Latent meaning was explored using interview skills, corroborating non-verbal with verbal communication and responding to cues that lend themselves to further exploration.

The tape-recorded interviews were transcribed. Codes were given to field notes drawn from interviews. The data was sorted out in order to establish similar phases, patterns, themes etc. These patterns, commonalities and differences were noted.

Marlow (1998) maintains that one central purpose of interpretive research and qualitative data analysis is that the data are understood in context as this provides for a great deal of assurance that the findings are not distorted. The researcher was mindful of context, the ecological framework was applied to appreciate context-rich impacts.

3.6. Reliability, Validity and Trustworthiness

De Vos et al (2002) indicate that reliability is primarily concerned not with what is being measured but with how well it is being measured. It is further stated that the more reliable the instruments, the more consistent and dependable the results. In this regard the research instrument was constructed after a careful analysis of literature, consultations with experts in the field and patient records. Multi-source reliability was thus assured as two different data sources were used.

Qualitative validity should rest upon knowing and understanding the phenomenon as fully as possible rather than measuring the results. Validity according to Brink (2006) is concerned with the accuracy and truthfulness of scientific findings. Qualitative researchers tend to reject the terms “reliability” and “validity” in favour of ‘credibility,’ ‘transferability,’ ‘dependability’ and ‘confirmability’ found in the notion of trustworthiness of data (Babbie and Mouton: 2001:276).

Guba and Lincoln cited in Babbie and Mouton (2001) put forth aspects relevant to ensure trustworthiness during the research process. In this study these were:

Truth-value: which asks whether the researcher has established confidence in the truth of the findings for the participants and the context in which the research was undertaken?

In this study social work skills of the researcher and debriefing of participants was used to facilitate honest responses. The researcher also viewed transcribed notes and engaged in peer debriefing, adding to the “truth” value.

Transferability: refers to whether the findings can be applied to other contexts and settings. Babbie and Mouton (2001) identify strategies for transferability. One such strategy that was given focus in the study was thick descriptions to obtain rich and valuable information to add to knowledge and experience about

ESRD. This detail will assist other professionals and motivate for further research in this field.

Dependability: notes whether the findings would be consistent if the enquiry were replicated with the same subject or in a similar context. The semi-structured interviews allow for replication in similar contexts because the data collection tools were painstakingly constructed, using literature, experience, expert consultation and patient records. This is also referred to as triangulation of data sources.

Neutrality: refers to the degree to which the findings are a function of the informants and conditions of the research and not of other biases, motivations and perspectives. Every effort was made to be open and transparent with the participants about the role of the researcher, using neutrality during interviews.

3.6. Ethical Considerations

The following ethical considerations were respected:

- The purpose of the research and the use of material were explicitly stated to the participants.
- Informed consent was obtained from the participants.
- Participation in the research was voluntary and the participant incurred no penalty for refusal to participate.
- The researcher ensured that confidentiality was maintained during and after the research process.

- The participants were not subject to any physical, mental distress or harm in the research process.
- The researcher respected the code of ethics governing the Hospital and the university in the research process.
- The participant's dignity and privacy was maintained and respected throughout the research process.
- The researcher acknowledged all participants in the research. All sources for the research were acknowledged whether consulted directly or indirectly.
- Engagement and disengagement techniques were employed by the researcher prior to and after the research was completed.
- The patients in this study sometimes became emotional during the interviews. These concerns were dealt by the researcher as she is a qualified social worker. Appropriate referral services were enlisted. The participant was at liberty to withdraw at any point during the research process without penalty.
- The researcher ensured that the time of the interviews did not coincide with the participant's treatment and aspects of saturation and fatigue were considered when interviewing.
- Finally, ethical clearance for the study was secured from the University of KwaZulu-Natal, under whose auspices this research was conducted.

CHAPTER 4

ANALYSIS AND DISCUSSION

4.1. Introduction

In this chapter data analysis is presented and the findings discussed. The reader is reminded of the research methodology to enable understanding of the research sample and process. The study was qualitative using individual interviews with 15 participants.

This chapter introduces the 15 participants in the study and begins by giving a profile of each participant. Thereafter, a detailed analysis and discussion on the identified themes will follow. These themes synchronized with the research aims and objectives and where appropriate and applicable, themes are conflated to present a more holistic picture.

Names of participants have not been provided to ensure confidentiality and anonymity of participants.

What follows is a presentation of the demographic information on the patients.

Table 4.1: Demographic details of the patients

Participant	Race	Age	Gender	Marital Status	Education	Religion	No of dependents	Employment	Treatment Modality
A	Black	40	M	Married	Secondary	Christian	4	Self employed	CAPD
B	Black	23	M	Single	Secondary	Christian	None	Casual worker	CAPD
C	Indian	37	F	Single	Secondary	Hindu	None	Unemployed	CAPD
D	Indian	58	M	Divorced	Secondary	Hindu	None	Employed	CAPD
E	Colored	20	M	Single	Secondary	Christian	None	Unemployed	CAPD
F	Indian	46	F	Married	Secondary	Christian	1	Medically boarded	CAPD
G	Black	40	M	Married by common law	Secondary	Christian	3	Unemployed	CAPD
H	Black	38	M	Married	Tertiary	Christian	2	Teacher	CAPD
I	Indian	49	M	Married	Secondary	Christian	3	Unemployed	HD
J	Indian	60	F	Married	Primary	Hindu	2	Unemployed	HD
K	Indian	47	F	Single	Secondary	Hindu	None	Medically boarded	HD
L	Indian	27	M	Single	Secondary	Christian	None	Unemployed	HD
M	Black	47	F	Single	Secondary	Christian	2	Unemployed	HD
N	White	46	F	Divorced	Tertiary	Christian	2	Unemployed	HD
O	Indian	50	F	Married	Secondary	Hindu	3	Unemployed	HD

As per the above table, details pertaining to each participant provide a backdrop of data against which findings may be understood. 15 participants who are patients were studied. All of the participants live in Durban and its surrounding areas with the exception of one participant who resides a little further on the South coast of Durban. The participants were between the ages of 20 and 60 years old, with the majority, in the age range of 40 to 50 years. Most of the participants acquired some secondary education whilst 2 participants acquired tertiary education. Since most participants had a fairly good education, their understanding of instructions and adherence in respect of their condition and medical management could have been superior, thus promoting better management.

Majority of the participants were unemployed implying that this was probably due to the illness and dialysis therapy.

Details were obtained from case records, these representing a valuable data source as discussed in chapter 3.

A focus on discussing the themes that emerged from thematic analysis of the data obtained from the interviews held with the participants, as outlined in chapter 3, follows:

4.2. Physical Factors

4.2.1. Symptoms

Participants undergoing HD and CAPD were asked if they were affected by the side effects/symptoms of these treatments. The majority of the participants were affected by a range of symptoms as indicated in the table below. Table 2 presents and identifies the symptoms experienced by the HD and CAPD participants:

Table 4.2: Symptoms experienced

HD	CAPD
Headaches	Sores in mouth
Nausea	Weight gain
Pains (back, knees)	Swollen legs
Cramps	Numb legs
Sleeping problems	Itching

From the above it is evident that all of the participants undertaking renal replacement therapy had generally experienced symptoms which differed across the different treatment modalities.

Participants were then asked what impact these symptoms had on them, physically.

Table 4.3: Physical Impacts

HD	CAPD
Weak	Have a lot of energy
You get tired	Feel much stronger
Can't do things for yourself	Some tiredness
Don't have the strength	Have strength
Appearance changes	
Loss of weight	
Loss of sight	

Tiredness and a general lack of energy was the most significant symptom associated with HD. Other common symptoms that participants experienced were headaches, pains, nausea, cramps, loss of weight and sight.

On analysis of the accounts of the CAPD participants, it was clear that they suffered to a lesser degree with symptoms of tiredness; they described themselves as having more strength, energy. However other symptoms experienced were sores in the mouth, weight gain and itching.

In studies done by Faber, Lindqvist et al cited in Polaschek (2003) it was noted that variability existed in well-being following dialysis for renal clients. According to the dominant discourse of Polaschek (2003), dialysis is an efficacious therapy, generally removing the symptoms of ESRD. But the experience of the participants in this study suggests that symptoms persist despite renal replacement and also occur as a consequence of the therapy, whether HD or CAPD itself.

For the participants undertaking HD and CAPD in the study, the researcher infers that the symptoms felt were significant to patients. However Challinor and Sedgwick cited in Polaschek (2003) view symptoms from the effects of ESRD or RRT as a marginal issue. Participants in the current study reported being anxious about the side effects, as is explained further in the sections that follows.

4.3. Physical Impacts

4.3.1. Fatigue

HD participants experienced fatigue, which appeared often and varied in degree. Some HD participants described being so tired that they were having difficulty in fully concentrating on what was being said, or on what they were doing, as expressed in the extract below:

I get headaches... I would feel very tired... sometimes nausea... and you can't concentrate on what you are doing

HD participants also reported that they were sometimes so tired that they could fall asleep at any moment if there was no activity around them. The feeling of fatigue was described as different from a normal feeling of fatigue – an unpleasant, “sickly” and heavy feeling, which HD participants experienced as something that they really had to deal with as evidenced in the following:

I don't know how to say it because it really gets to you at times... because of the headaches you feel so uncomfortable... there are days where you always get pains, your head, knee or your back... there's not a day that goes where you just feel like I'm fine today, you must have like a pain or something bothering you

Participants undergoing HD also felt more tired on the days they underwent treatment and had to rest on the day of their treatment, thus making it difficult for them to perform any activities. It was common not to feel like doing anything more than was absolutely necessary, eg:

When I come out of HD majority of the times I am very, very weak... its a kind of tiredness when you can't read, you're too tired to talk or to do anything... you can't manage...

Hence a fundamental description amongst the HD participants was a persistent lack of energy. This feeling of physical weariness dominated living especially when they would start to perform physical activity, and would vary from day to day. On days of HD treatment participants felt “**lots of exhaustion**”, whereas participants undergoing CAPD did not experience this same shift in degree of tiredness and fatigue.

HD participants also felt that they had no power and strength, this created a fear of not being able to walk and that the physical fatigue would cause them to fall.

With HD I can't walk a distance... it takes a lot of effort... I lie down a lot... if haemoglobin is low I don't have the strength and fear I may fall

Physical fatigue for the HD participant was a common experience that could be overcome only with great difficulty.

Suffice to say that the HD participants experienced a great degree of mental and physical fatigue in their treatment therapy as compared with the CAPD participants who did not experience it to such a degree. This also provides the researcher with insight, deducing that the experience of fatigue is related to a patient's physical and functional difficulties, and this influences their everyday activities (biopsychosocial perspective). Physical and mental fatigue are thus to be seen as core aspects in dialysis literature.

4.3.2. Functional Capacity

Participants were also affected in their ability to carry out everyday chores because their functional capacity was reduced. Performance and endurance were aspects that were challenging for them.

HD participants experienced difficulty in walking and were prone to using assistive devices eg wheelchairs. They also reported difficulties in performing everyday chores such as managing their personal hygiene, lifting things, as expressed in the extract below:

There's days where you have no strength and you can't even stand and take a bath, he (spouse) helps me to give me a bath, he cleans up the house and does the cooking... I do have difficulty walking as I get tired that's why I'm on a wheelchair when I go shopping to the malls.

In regards to CAPD participants they coped well and were better able to undertake their activities and were not limited in their performance as were the HD participants.

Interestingly, however, both HD and CAPD participants reported difficulties in performing physical activities over a prolonged period, for instance cooking without having to take a rest several times, which they did not have to do before their chronic renal failure. It was also reported that they experienced difficulties in performing activities at the same pace as they did before the reduction in their renal function. They felt that their endurance was lower as compared to before, as evidenced from the following quotes of both participants:

I cant walk a distance... it takes alot of effort... I have to lie down and rest... I wish I could go for the entire day without having to sit down and rest so often because I don't have the energy... (HD participant).

I can manage most activities but I can't do them as fast as before I had this illness, because I don't have the energy (CAPD participant).

The results from the current study revealed that participants inherently experienced fatigue and physical restraints in relation to the RRT experience. Findings highlighting the presence of fatigue and physical limitations were consistent with observations made by several authors. Mc Cann and Boore cited in Shabalala (2004) reported high levels of fatigue, together with low vitality, reduced motivation, reduced activity and mental fatigue that were experienced by adult haemodialysis patients.

In another study by Lok (1996), the common stressors highly ranked for both HD and CAPD group were 'limitation of physical activities' and 'fatigue'.

In regards to this study, findings were compatible and consistent with the above-mentioned studies for the HD participants but were inconsistent for the CAPD participants in that this group generally coped well physically and did not experience fatigue to the same degree, felt by the HD participants.

Kouidi (2004) maintains that documented evidence show that exercise training in dialysis patients results in significant increase of functional capacity, improvement of psychological well being and enhancement of social function. Goldberg et al cited in Kouidi (2004) further added that exercise training can return certain HD patients to a near normal life-style by improving their psychosocial functioning and increasing their energy. Hence the intervention of the physiotherapist as a core member of the health multi disciplinary team can compliment to maximize patients functional status to an adjusted quality of life.

4.4. Psychological Impacts

4.4.1. Depressed Mood

There were reports of depressed mood amongst the HD participants. The common features of this were feelings of sadness, helplessness as well as the question, “why me?” When one looks at the Diagnostic and Statistical Manual of Mental Disorders, the above-mentioned features form part of the signs and symptoms of depressed mood (APA-2000).

The reasons for feeling depressed varied across the participants and this variation clearly demonstrated the role that the uniqueness of each individual’s context and situation plays in influencing their illness. The patient faced with the burden of disease does not only experience physical pain but psychological, social, financial and spiritual pain too, in accord with the biopsychosocial model.

For one participant the severity of the symptoms namely tiredness, fatigue, and the emergence of physical problems in terms of the loss of sight, discomfort during the dialysis procedure had profound emotional impact. Not being able to fulfill his role as father, husband, pastor as a result of the dialysis treatment served to exacerbate feelings of helplessness and hopelessness in this

participant when faced with the reality that he could not be strong as expected, as evidenced in the extract below:

Apart from the symptoms, when I come out from HD I am very weak... the greatest problem that I have is with sight... my sight is only 10%... I no longer drive because of my sight... I cannot read anymore and its actually handicapping the work that I do as a pastor... majority of the times frustration builds in and you get frustrated with the family, you get frustrated with the people that are assisting you... its not deliberate but its something that just stirs up, it comes up all of a sudden... And you are always depressed, always... when I'm on dialysis for the 4 hours I don't speak to anybody because of depression, thinking that what am I doing here, I'm not supposed to be in this bed... I don't belong here and it really brings me down when you are told by somebody and they say hey your face is swelling, you looking very sick today, it brings me down more in many ways (HD participant).

Another young HD participant was angry at his situation and loss which resulted from dialysis, in particular the imposed physical limitation. This participant reported feeling particularly distressed about not being able to actively take care of himself and his family. A quotation illustrating the participant's experience follows:

I felt that I was worthless, I could not do things for myself....at times it gets very depressing and you become angry when you see your friends, or family doing things and you want to make that living for yourself...it is like so impossible after having this sickness and treatment (HD participant).

Being faced with HD therapy and the fact that it imposed on participants' ability to provide for their family and disrupted their plans for life in general, made participants see themselves as weak and vulnerable, sinking them into a deep, depressed mood as evidenced above. Results from the current study revealed

that participants experienced sadness, depressed mood and worthlessness in relation to dialysis therapy. These findings were consistent with an observation made by White & Grenyer (1999) of anger, depression and hopelessness commonly reported amongst participants.

4.4.2. Thoughts about death

Accounts from some of the HD participants also illustrated that there had been experiences of depressed states due to HD. According to Schlebusch (1990) the fear of death is a major stressor since HD is a reminder of the struggle to survive. For the HD participants, their quality of life was already depleted and the fear was intolerable as in the realization that the continuation of life was dependent on external variables beyond their control i.e. high technology medicine. Suffice to say that at times HD participants expressed some anxiety about potential problems that could arise or prospect of premature death.

Examples of HD participants' accounts of their experience are outlined in the extracts below.

- *With HD you really don't know what's going to happen the next day... today you can be fine, you can be laughing and the next minute you can just fall down and die... I guess that's my main fear of dying because you just don't know when it's going to happen*

- *It is quite scary, the four hours is quite a long time to be on the machine and like when your pressure drops... you don't know what is going to happen to you*

- *When you are on the machine... when my B.P.(blood pressure) drops I'm scared because I feel terribly sick... you think to yourself sometimes are you going to make it or not... and how long is it going to carry on for... how long do you have to live with this (HD)... you scared of the unknown*

4.4.3. Anxiety

For both CAPD and HD participants' dialysis is a constant source of anxiety because of the awareness of possible complications such as peritonitis in CAPD or a clotted dialyzer in HD which can result in injury or death. There is justification in this as Kouidi (2004) reports that dialysis patients still face many acute and chronic stressors, maintaining that their survival depends entirely on technology and artificial means.

Majority of the CAPD participants expressed that the risk to infection, peritonitis was their worst fear. This concurs with Juergensen et al as cited in Kouidi (2004) in which it was reported that higher depression and anxiety scores in CAPD patients were associated with higher complications rates in terms of hospitalization, peritonitis and exit-site infections.

One CAPD participant in the study admitted that he had cheated on his routine and the impact for him was overwhelming physiologically and psychologically:

I wasn't doing 4 bag changes, I was doing 3 bag changes, I cheated... then landed in hospital out of breath, weak and body started accumulating fluid... it affected me adversely... I almost thought I was going to die... and this was once and only once that I defaulted... and I've learnt my lesson

By comparison CAPD participants reported some psychological effects but these were not as debilitating as those experienced by the HD participants.

Participants who had the experience of HD and were then put on CAPD shared the following experiences and especially regarding the differences between them.

The CAPD participants described HD as a treatment that removed them from one's 'normal' functioning to a condition that had made them 'abnormal' compared to other healthy individuals. Artinan, Morgan, Gerhardt, Lindqvist et al cited in Polaschek (2003) discussed a 'struggle for normality' to be an important

aspect of the renal patient experience, in that participants comments indicating the abnormality in their lives created by the treatment regime, implied a realization over time of the ongoingness of life on dialysis for them. Suffice to state that not only did affected CAPD participants experience loss of physical function but psychological loss was also experienced regarding one's identity associated with changes in roles as well as changes in broader areas of their lives (marital, family, social responsibilities). This study's findings were similar to Lok's (1996) findings which revealed that both HD and CAPD patients perceived that their level of physical activity, social activity and satisfaction with life were generally below average. Of note, however is that the ability to do normal tasks was significantly higher in CAPD patients when compared with HD patients. In essence, this indicates that the CAPD patients are perceived to have a better quality of life than HD patients. Below are quotations illustrating CAPD participants' experiences accordingly:

- *I do not have a problem with the bag treatment... I feel alive, good... ever since I have been on the bag I have been a normal person, active and with my work situation it makes me go forward, what I could not do I can do it with the bag... .before the people used to ask me what is wrong with me*
- *Before I got sick with renal failure, I was a very active person... now I feel much stronger, much stronger... I feel like normal, much normal... it means that I've got strength, energy... being on HD it takes away everything and you are not the same. Going onto the bags makes you the kind of person before you got sick, a person full of energy and life. To me CAPD was a very good thing from HD I feel good on it...now I have more time for myself, friends, family*

- *At least it brings back your normal life... I'm now able to pass urine, can eat as have an appetite... as opposed to the time on HD it was very difficult*

In light of the above, participants had no regrets and were grateful that CAPD gave them another chance to live and notably the view that was predominant is that CAPD is by far a better treatment.

- *I think it's a good thing (CAPD) especially for me because it has given me a second chance in life and also given me a second chance to see my kids growing, if I don't tell people that I am on CAPD or I am sick, they will not tell, sometimes when on HD they can see that I am tired, in that aspect I think it is a better treatment and has given me a chance to see my daughters and son growing, I think it is the best (CAPD participant).*
- *I feel great, I'm no more feeling that I'm a renal patient, this 'thing' (CAPD) has changed my lifestyle, and I'm a normal person. Nobody knows that I'm a renal patient unless I tell them (CAPD participant).*

According to the discourses above, participants in the current study, living on CAPD were enabled by living a nearly normal life and managing their treatment enhanced autonomy. This was congruent with findings by Merkus et al and Simmons et al, cited in Kouidi (2004) that CAPD patients have better health-adjusted quality of life compared to HD patients. In another study by Wolcott and Nissenson, cited in Kouidi (2004), CAPD patients had significantly better life and therapy satisfactions, lower illness, lower modality related stress, lower mood disturbances and superior psychosocial adaptation compared to HD patients.

4.4.4. Stress

4.4.4.1. Diet / Fluid Regime

Participants reported increased stress levels as a result of needing to adhere to a treatment regimen on their lives. The treatment regimen at times proved to be beyond their normal coping resources. The main areas in which stress levels manifested were diet and social activities.

In ESRD, the treatments of HD and CAPD respectively include adherence to a special diet and fluid limitations. To be diet and fluid adherent in HD, participants are expected to limit the intake of sodium, potassium and protein. To be adherent to fluid intake, a prescribed limitation of 2 cups per day is required, as cited in Mahan and Escott-Stump (2000). HD participants clearly admitted that they did not fully comply and cheated on the regimen notably reporting that the fluid intake was the most difficult to adhere to.

Their experiences were relayed as follows in the extracts below:

- *Sometimes I cheated, my potassium would rise... it just happens that you cheat. I found the fluid difficult to comply with because you feel very thirsty (HD participant).*
- *I do cheat on the diet sometimes but the fluid I try to be as strict as possible... although on a hot day you tend to drink a little more because 500ml is not enough for the day (HD participant).*
- *I am following the diet to an extent... as foods need to be boiled, soaked... is difficult for me to do that... its so strict especially with the liquid intake, I do go overboard... 2 cups for me is impossible, so that's why I cant comply (HD participant).*

- *I must be honest and say that it is not easy to have fluid control ...I admit that the fluid intake is bad and I go overboard with it (HD participant).*
- *At the moment I am guilty I step over... I've just come to the conclusion... everything in moderation... in terms of fluid, I know I drink more than I should, you get extremely thirsty (HD participant).*

Herselman (2008) too complains that despite attempts to use theoretical approaches to explain the importance of diet and compliance to patients, non-adherence to dietary prescription remains a common problem in patients with chronic kidney disease. Tsay, cited in Shabalala (2004) reported that many ESRD patients have difficulty in complying with fluid restrictions and need major lifestyle changes and self-efficacy to comply with the treatment regimen of their chronic illness.

As per the study in question, CAPD respondents did not experience the same degree of stress that was apparent with the HD participants and generally reported to have adjusted well with the diet and fluid regime. This might also be attributed to the point, reflected by participants that the diet regime is modified for CAPD as compared to HD.

Below is a reflection of the views of CAPD participants:

- *It is comfortable because with CAPD, the things you can't eat when you are on HD you can eat them but not indulge in them*
- *Yes there is a big difference, the experience on HD limited one to certain diets... on CAPD no limitations... can eat whatever you like... this is a positive aspect towards managing CAPD more comfortably*
- *Another CAPD participant indicated that after being trained on HD when you get into CAPD you still kind of on your diet even with your fluids*

As with several other reported findings in this study, CAPD participants reported less stress and degree of debilitation as compared to HD patients, suggesting that CAPD should be the healthy choice for improvement in quality of life.

4.4.5. Body Image

In responding to a question that focussed on participants' body image perceptions, it did however pose a concern for at least three of the participants. One CAPD participant who was the youngest in the study was self conscious of his swelling and how he was judged by his friends and the community.

I was conscious... walking and people looking at you and everyday you got a different excuse, I tell them I don't know why I'm swelling up... my friends would ask me everyday what's going on with you, I felt ashamed of the sickness and told them the truth (CAPD participant).

It was however interesting to note that with the other CAPD participant, who was a single female who had experienced a change in her appearance "... *regained my complexion in a way feel much better*" was positive and motivating for her self image and confidence.

An HD participant who was divorced, prior to the diagnosis and since the onset of treatment, experienced continuous swelling and had a distinct distended abdomen. She perceived herself as unattractive and undeserving of attention. People were of the view that she was pregnant; it was not possible for her to wear revealing or tight clothing. Hence choice of clothing as well as social activities proved challenging to her as she felt that these were central to her feeling acceptable as well as attractive as a women.

Below is an extract capturing the participant's feelings in this regard:

Also my appearance changed drastically... I had a flat stomach and as time has gone the stomach has gone bigger and bigger and everyone thinks I'm pregnant... people sort of comment like when is baby due... so that has affected me. In the beginning you are embarrassed and then you get angry and now I just make light out of it... because you know they don't understand. Because my stomach is sticking out... you have to go for loose, elasticated dresses... My Manager wasn't happy to have the likes of my appearance in the front office (HD participant).

Majority of the above participants were within the age group of 21-50 and during this stage of their development individuals are faced with tasks related to affirming their identity, finding out what matters relating to affirming their identity, establishing a career, developing intimate partner relationships and establishing a family (Sutton 2004). These tasks need to be mastered without necessarily impairing one's ability to love or to work. Hence understanding individuals in relation to the developmental tasks that they are confronted with highlighted difficulties that participants experienced in view of physical changes resulting from RRT.

For participants in the study, physical appearance was modified and some developed discomfort with their bodies as well as the perception that they were no longer attractive.

The RRT experience may therefore add to already existing dissatisfaction with one's body image as it affects swelling, weight gain.

Schlebusch (1990) maintains that body image problems can contribute to stress in all chronically diseased patients, particularly patients on a chronic renal failure programme and such problems can be external disfigurement, changes which

occur in internal body parts and organs, and changes in the physiology or somatic functioning of ESRD patients.

Galpin (1992) also emphasized the effect of change in body image on the patient's self esteem. This also affects the patient's sexual function since body image is interwoven with sexual identity and sexual functioning which will be looked at in a later section.

One might also assume that participants' discomfort with their body image was aggravated by ignorance about ESRD and RRT.

4.4.6. Social Activities

Issues related to social activities also proved stressful for participants in the current study.

Participants reported feeling that their dialysis regime limited them from social activities such as holidays, travel, sport, hobbies. Both HD and CAPD participants could not continue with some of the sport and hobbies that they were undertaking prior to their renal failure and since the onset of treatments. Participants across both the modalities experienced this decreased range of social activities due to physical symptoms, impact of procedures and possible complications. Several reported that they could not have a 'real' holiday while living on dialysis as aspects of a holiday such as relaxation and freedom from a regular schedule of HD or CAPD was not always manageable and practically possible. Polaschek's study (2003) also mentioned difficulties with travel and holidays as an obvious limitation. Many of the respondents felt that social activities were contradicted by the dialysis regime, as evidenced in the following quotes:

- *Used to play a lot of volley ball... is very difficult as now you don't have the energy that's the most important thing... can't go on holidays due to the dialysis schedule (HD participant).*
- *I was like an outgoing person, helping people, going to functions, doing things for others like cooking... I can't do all that now (HD participant).*

CAPD Participants said,

- *Before we used to go camping and to the beach to swim with the kids, but that does not happen anymore because I have to do my bag changes*
- *I used to play for a soccer team... it makes me feel very bad, hurt inside that I cant play soccer anymore... if I try to run a little bit, I get tired... so it makes me feel really bad inside*
- *I'm not able to function the way I used to... like before I was functioning well, I was a soccer player now I cant play anymore... its even limiting me in visiting friends, normally I'm a person who is always participating in community events like sport and any community upliftment project... now I can't*

However two CAPD participants indicated that they had changed their interests by taking up a new sport, hobby and in so doing integrated the regime into their lifestyle. This is illustrated in the excerpt below.

I was playing soccer, was an athlete as well... renal problem didn't really impact on my life significantly... I now read, go fishing

That some participants could make this shift is indicative of the possibility that this is a feasible option to pursue in better managing the patient and has implications for health advisers and social workers.

4.5. Social Impacts

4.5.1. Relationship

Both CAPD and HD respondents, that were married, made positive statements about their relationships with their partners. Overall no negative comments were made. Some participants were married for many years. HD and CAPD participants spoke about their life partners with admiration, respect and kindness. Participants described what their partners were like. For example, that partners were loving and caring, kind and warm. They appeared grateful and appreciative of the support and caring of their partners.

An HD participant, reported as follows:

“He (husband)... takes good care of me, there’s days that I feel very sick, I can’t have a bath, he helps me to give me a bath. He cleans up the house, he does everything for me... ”

A CAPD participant alluded as follows:

“He (husband) always tells me that he does not want to hurt me and feels sorry for me... he is a man with compassion... ”

One HD participant involved in a relationship with his girlfriend for 8 years reported that the physical debilitation and fatigue had impacted on his relationship and attributes their continued relationship to his partner’s understanding and acceptance of his condition, saying:

I can't do things with her like the way I used to like going to the malls, supper, dance... where she wants to do things... because I'm very tired all the time, I just want to lie down... she understands this is how it is for me

Another CAPD participant did not have the support of her partner and was in fact rejected in the relationship because of her illness. Her relationship did indeed fail to handle the strain.

When I got sick he was supportive... when I started HD he said I was useless... I'm not wanting to look after his kids and be around because I'm always tired, I don't have the strength to do anything... it got worse as he started womanizing ... when I was put on CAPD and thinking it will get better but it did not... it was already far gone

All of the HD participants that were married reported that their condition of ESRD and its associated treatment of HD did not have any adverse impact on their marital relationships and notably that spouses had acknowledged and accepted their partners' condition unconditionally. In general this study revealed that dialysis did not affect the strength of the patient and partner relationship. This finding concurs with that of White & Grenyer (1990) who reported that a positive aspect of dialysis (HD and CAPD) was related to the patient's and partner's relationship. Their study highlighted the importance of the partner being able to maintain their health.

Participants' accounts also reported a "we" experience suggesting that activities such as going to hospital together for HD in a way brought couples closer to each other. It came across that relationships were seemingly cohesive prior to the commencement of dialysis and hence such experiences did not lead to relationship disintegration, with the exception of one CAPD participant.

4.5.2. Sexuality

There were notably revelations/reports by both the HD and CAPD participants of a disruption in the sexual relationship. This disruption is said to have been due to factors such as tiredness, fatigue and complications brought about by treatment side effects such as loss of libido, impotency.

One HD participant was no longer enjoying their marriage because of his chronic condition. Further adding to the participant's stress was his decreased sexual involvement in the marital relationship, which had consequences for his ability to maintain his role as a sexual partner. The participant also expressed concern with how he was being perceived by his spouse, doubtful of his spouse's sense of fulfilment in their marriage. Associated with this fear was a sense of guilt at being responsible for their changed sexual relationship.

HD participant: *The truth in the matter is that I'm not sure whether dialysis people can be sexually intimate... I'm not sure about it. But I realized that ever since I'm on HD it has affected us very very badly. We have discussed it, my wife and I, and she's got no problem with that. It affects me... its really causing concerns because I can't really explain it but its more of impotency, it just started when I just started H.D... there's not a problem at all as far as this is concerned because her concern is me. She says your health means more to me and I don't want you to be in problem... don't worry about all of this. My wife is very very supportive... some nights when I cannot fall of to sleep, she will sit with me in the lounge till I fall asleep... I feel it doest affect our relationship, our marriage... on my side it affects me because I feel for my wife, I trouble about that.*

These findings are in agreement with author, Schlebusch (1990) who reveals that sexual dysfunction and infertility contribute to a decreased quality of life and an impoverished life for the patient. He adds that several studies point to marked deterioration in the sexual functioning of patients, especially males, undergoing dialysis.

The female HD participants were somewhat uncomfortable to express how H.D had impacted on their sexual relationships and this seemed not to appear to be a significant concern for them. Perhaps their discomfort at discussing their sexual relationship precluded honest sharing regarding this issue.

Some of the participants in the study related their declining sexual activity to age.

For those HD and CAPD participants who were single during the time of the study, but had previous relationships prior to their diagnosis, a new set of anxieties were experienced around how new partners might react after hearing about the diagnosis and the treatment modalities and therefore avoided relationships.

Several of the CAPD participants reported decreased sexual interest and 'ejaculation' difficulties:

... I never had a problem with libido, sexual life was fine, now with CAPD, sometimes I am alright, sometimes I am down, sometimes I can go on with a stretch without having an interest...

Another CAPD participant reported as follows:

... She asks me what the problem is, she thinks that I am fooling around. I told her that if a person has renal failure, they will have this problem (early ejaculation)

Performance anxiety seemed to permeate the sexual relationship and despite the impact of the effects that dialysis therapy had on the sexual relationship, at no point did this trigger any disintegration in participants' relationships with their partners.

Consistent with the current study's findings, Kimmel (2000) maintains that dialysis of both genders frequently produces sexual difficulties. Kimmel informs

that impotence eventually develops in men treated with dialysis and women on dialysis who will have a diminution in the frequency of orgasm during intercourse. Patients of both genders engaged in sexual intercourse much less frequently than they did prior to becoming uremic.

4.5.3. Family Adaptation

Participants were asked about the impact of the different treatments in regards to their roles and responsibilities. This study revealed that the CAPD respondents managed their roles and responsibilities, independently. With reference to the HD respondents, 2 patients were challenged by sight difficulties due to the effects of the treatment, which resulted in re-assignment of tasks and responsibilities within the home. Families had to take on responsibilities which had not been previously theirs, such as maintaining some control over running of the household, making decisions and performing practical tasks. For two single female HD participants who lived on their own, it meant that they had to return to live with their families as they could not cope to do tasks, exacerbated further by financial strain as they were unemployed at that time. Hence HD participants were fraught with challenges that extended to the family.

As one HD participant reported:

I was the head of the house... I was the person that provided the food, paying the bills... now I'm inactive... my son was staying out... when he found out I was very ill... he moved in and has taken on most of the responsibilities and which it concerns me....he takes care of all...

White & Grenyer (1999) confirm that indeed ESRD is a progressive, debilitating, chronic illness and as the disease progresses, constant adaptations are required, adding that the family and most relationships that existed prior to the illness are progressively changed by the presence and the responsibility of caring for a dialysed person.

Comments raised by HD participants indicated that it is not easy to relinquish independence and to rely on others, one's spouse, or sibling to compensate for loss of optimal functioning in the patient, a finding supported by Schlebusch (1990).

For both HD and CAPD participants, the treatments placed considerable strain on families as many of their usual activities needed to 'be on hold' in order for the participants to attend to hospital for HD treatments, schedule of bag changes, have blood tests. They felt that they could not do things spontaneously since their medical care governed their time in addition to daily routines being changed by the presence of symptoms:

"... to go wherever I want to go is limited... I always have to keep an eye on the time... how long can I be away?"

Patients that were parents reported that time as a family was challenging as available time was either taken up for therapy or rest. Beder (2006) too maintains that family issues included a struggle for parents because they could not spend as much time in family activities as they desired, were not as available as they would have wanted to be in activities of nurturing and parenting, and worried about the direct effect of illness on their children. It is realistic to conclude that chronic disease and ESRD affect more than the parent; the entire family system is affected in accord with the ecological theory.

Further impacting on the family experience of ESRD and its treatments of HD and CAPD, is the financial distress participants across both HD and CAPD reported. Participants who had reported this worry, expressed concerns relating to inadequate medical aid, loss of jobs and not being convinced that their families could afford payments towards their therapy in the long term. Some participants received disability grants which alleviated the financial distress, however this was not guaranteed. Shabalala (2004) reported similar findings.

Hence through this portrayal of the impact that the illness experience and dialysis had in families, the study's findings are also in line with Kimmel's (2000) assertion that patients obviously do not exist as discrete treatment units. He adds that psychosocial issues consider the patient within the framework of an intimate dyad, within a family and as a member of the dialysis units. In addition, outcomes may be affected by issues grounded in neighborhoods or states (ecological model).

4.6. Work

Beder (2006) states that ESRD affects people in many ways. It is the basis of major modifications in lifestyle, life goals, vocational choices, opportunities, recreational activities, interpersonal relationships, family roles, and family position. The author adds that beyond the necessity of daily or three times per week dialysis, the patient must adhere to dietary restrictions and medications. They experience changes in body image and function, including loss of physical energy, loss or change in sexual functioning, and other signs of physical deterioration, and it is because of the physical demands of the disease; many people are unable to work.

In light of the above and looking at the study in question, RRT predictably had both direct and indirect effects on respondents' occupational functioning and performance.

The HD participants seemed to experience direct effects of the physical symptoms that resulted in decreased occupational performance and drive. The execution of some work activities was made difficult by pain, tiredness and weakness. The chronicity of these symptoms reduced HD participants' capacity to pursue employment and career goals, aggravated by the need to attend scheduled dialysis thus limiting their scope of finding alternate, suitable jobs.

These are some of the reported frustrations of the HD participants:

- *I was a dressmaker and 2 years now I can't do sewing*
- *Before I went on HD, I was employed permanently... I got boarded off because of my illness... now I do a temporary job as a driver, I take passengers and get a few 'bucks' just to keep me going for my private use...being a kidney patient, to find employment is absolutely difficult because nobody wants to take you because you take time off and get absent*
- *I worked in car sales from 1990, I did buying and selling of cars, motor repairs, I was very motor - minded. I also got into the Ministry to work as a pastor. After I lost my sight, I cannot read anymore, being a pastor requires a lot of reading and that has handicapped me in many ways... I stepped down on most of the things because I cannot function... now I just help out in the Church and I get a small contribution*
- *About 2 years now I'm not employed... they made life very difficult, the boss, manager wasn't happy to have the likes of my appearance in the front office... I was a secretary, it was a small company that I worked for and I worked with them for 10 years, he just sort of felt that front view should be more interesting... yes, I was terminated of my job... no I was not offered another job within the company... the minute people hear you have chronic renal failure and my appearance... limits me from job opportunities... I'm not going to go through that embarrassing stage, its too embarrassing... why put yourself through that...*

Suffice to state, the therapeutic regimen curtails HD participants in business (biopsychosocial effects). It may mean changing the occupation or giving up

employment. What clearly emerged with the HD participants was the need to be employed and continue employment versus frustration in not being able to uphold a job due to limitations in functioning that resulted in participants' jobs having to be terminated or medically boarded. The ability to cope with work also appeared to be influenced by the type of occupation that the participant had.

According to Kimmel and Kurtner, Brogan & Fielding cited in Shabalala (2004) unemployment is one of the stressors among chronic ESRD patients, revealing that a large percentage of ESRD population is unemployed or unable to work, because of old age, medical illness and social discentives.

On the contrary many of the CAPD participants returned to being productive, were employed and able to integrate their CAPD regime into their work schedules but this was conditional on education and advocacy with the employer. One of the CAPD participants returned to his teaching career, another was employed as supervisor, another was employed as a casual worker at a clothing store.

One CAPD participant that was self-employed expressed frustration that he could not effectively attend to his job as he was bound by the schedule of CAPD exchanges which he would return home to do timeously.

These differences in job security and leading productive lives where there is active financial contribution to the family, in both sets of patients have strong and far reaching consequences for service providers, policy makers and government so that ultimately all patients may be supported to be productive citizens.

4.7. Coping

ESRD and its associated treatments of HD and CAPD had impacted on participants' coping as they reported experiencing some degree of emotional/psychological breakdown. Participants experienced a range of emotions and symptoms including tiredness, fatigue, frustration, sadness and mild depression. Having to undertake HD at the hospital for either two or three times per week, CAPD four times a day resulted in much frustration, distress and a sense of detachment and isolation from family, friends and activities.

Various coping mechanisms were used by participants and these drew on various aspects, namely biological, psychological, social and spiritual. In terms of biological aspects to coping, HD and CAPD participants reported that taking their medication and complying with the schedules for HD and CAPD were their first line of coping. Other measures that was useful in increasing energy and encouraging well being was adherence to the diet and fluid intake which HD and CAPD participants reported as challenging in that they were not always compliant.

Psychologically, the participants tended to adopt approaches as individuals to cope with the continuum of care through dialysis. This involved acceptance of their medical problems and having a positive mind set in managing their condition. For some it was sheer determination and endurance that facilitated their coping, psychologically.

Some participants felt that certain cognitive shifts were necessary in order to cope. Rather than being overwhelmed by the negative aspects of the treatment modality, the fact that they could have a second chance to life mattered. According to Cares, Buker and Owens cited in Shabalala (2004) participants who regard renal failure as a challenge do well and take an active part in their treatment. Those who regard renal failure as punitive are bitter, angry and

confused by their situation and tend to do badly. CAPD participants took a proactive stance as individuals in coping with their treatment therapy but this was not the case with HD participants. HD participants tended to use avoidance in their coping and relied on religion to cope. Implications for service users are again obvious, as clearly the biopsychosocial impacts need acknowledgement in order that better medico-physical care may produce functional emotional-psychological coping.

The quotes below illustrate coping by CAPD respondents:

- *I think I'm a bit stronger... I'm able to view things positively... I will sit down and say if this is the situation... what are the challenges and opportunities for me to live a better life. The first challenge is that I must stick to my treatment... that is very important as well as visits to the clinics for reviews (CAPD participant).*
- *It is necessary for you to accept your situation and remain positive (CAPD participant).*
- *You got no other alternatives. You've just got to follow the instructions... its for your own good and being positive... in that I want to carry on in life, no matter what happens... I want to live (CAPD participant).*

The study done by Lok (1996) which highlighted the most highly ranked coping methods for both the HD and CAPD group, were noted as follows:

- 'try to maintain control over situation'
- 'look at problem objectively'

There were associations in the current study with Lok's (1996) findings for specifically the CAPD participants. For the HD participants, religion was presented as the mode of coping with the demands of treatment therapy. Kasiram (2006) too discusses this dimension of coping as a core necessity, especially for persons who are chronically ill or who are confronted by impending death.

The nurse patient relationship also played a significant role in mediating the effects of dialysis for both groups of participants. CAPD and HD participants appreciated information and acknowledged a 'compassionate' and 'caring' attitude that nurses showed them. The study findings supports literature by Ward-Collins cited in Shabalala (2004) who emphasized the importance of communication, essential in health education. The study findings also acknowledged the recommendations of Martens cited in Shabalala (2004) that a combination of oral and written information is seen as ideal. Participants raised the importance and benefits of being informed regarding their condition and were appreciative of being given information brochures. However none of the participants actively sought out literature/information to understand their experience themselves. Obstacles to being informed were identified as access to resources such as internet facilities that were not readily accessible. Martens cited in Shabalala (2004) reports that there is little documented research about patient education, despite it being accepted as important, suggesting the need for research on how best to communicate and educate patients about their condition. Kasiram and Naidoo (2006) suggest "edutainment" as a helpful means to educate although, given the financial constraints in medicine, one wonders whether this important function will not be sidelined for more direct medically oriented services.

HD and CAPD participants made the following revelations about information and education on their condition in this regard:

- *Nurses spoke to us and they give you information leaflets (HD participant).*
- *The nurses were a good source of information, were given pamphlets ..before I started dialyzing (HD participant).*
- *I get a lot of support from the nurses, they make you happy... I go visit them whenever in the hospital, they ask me how my 'bags' are going, they are like family to me (CAPD participant).*

Apart from information which was useful, both HD and CAPD participants appreciated situations where they were able to exchange their personal experiences. HD participants reported that being with other patients whilst dialyzing and whom they described as their 'extended' family was beneficial. The scope for formalizing group support here is abundantly clear from this finding.

- *We meet at HD and together we sit and talk, is helpful (HD participant).*
- *We are like a family there, we talk, laugh, greet each other and share our difficulties (HD participant).*

One CAPD participant alluded that being with other CAPD patients in a group enabled him to tell his story with other affected CAPD participants, which seemed to have had a supportive and validating effect on one's personal experience, without patients having to feel guilt and to think that their health and related problems as unimportant and not worthy of discussion.

Yes, I attended a support group....when we sit together, we talk about ourselves and speak about our problems and I used to tell them about my experiences, I would tell them about my appetite...then you could see how the entire group would talk and respond...so we created a platform to talk. (CAPD participant)

Thus for the HD and CAPD participants having a context in which to hear other participants' stories enabled them to re-evaluate their own situations and gain renewed perspectives on their condition. Having rich access to empathetic support enabled a sense of containment, without having to minimize their concerns.

According to Shabalala (2004) the dialysis patient needs support to establish that his efforts are indeed meaningful to family and friends. She adds that non profit organizations like the Natal Kidney Association organize social functions at which patients and their families can meet other people with similar problems (Natal Kidney Association 2002).

Another important aspect of social coping with the treatments was the support given by partners and family. Participants benefited from practical interventions provided by their partners or family members such as driving, assisting with household duties eg cooking. This was identified as useful in helping them cope. Some participants reported that the mere emotional availability of their partners or family members was recognized as invaluable to the coping process. The value of partner attendance at HD sessions and support group meetings was considered beneficial to the participants.

These were some of the reflections by the HD and CAPD participants:

- *My children, husband are very supportive, relatives are always willing to help as well (HD participant).*
- *I have very good support from my family... husband and children... they do everything as much as they can to keep me comfortable. I have a lot of friends and they come to visit me (HD participant).*

- *It's the love of my family, my girlfriend, they are the ones who keep me going every single day, if it wasn't for them... I have no reason to live they are supportive (HD participant).*
- *It is the love between my wife and myself... the support from my family is great... I think that's what keeps me going (CAPD participant).*
- *Supportive family... I've never had a better family than them (CAPD participant).*
- *I've got a very supporting wife and kids... they understand me and almost all of the diet (CAPD participant).*

The findings in this study do support the literature by Pang et al cited in Shabalala (2004) as well as White and Grenyer (1999) who assert that a partner's support could reduce the negative experience of dialysis. Thus, from a biopsychosocial perspective, it is clear that individual physical effects could greatly impact social health and relations.

Participants in the current study reported having utilized their religious orientation as a source of coping. Being Christian or Hindu, participants in the study reported having asked God for better health and expressed their gratitude for health and life when going through the dialysis experience. Thus prayer, whether alone or with others marked an integral part of the experience. The importance of religion in this study did not only have to do with communication with the omnipotent but also involved fellow members eg church as a source of support, thus helping participants find communal strength during their time of ill health as discussed by Kasiram and Partab (2002) in their work on communal grieving.

Findings of the current study with regards to religion were in agreement with Aukst-Margeti & Margeti (2005) and Kasiram (2006) that religion can impact health in the following ways:

- By providing an avenue for coping with and reducing stress brought about by difficult situations in life
- By opening up channels for social support
- By receiving unconditional support and strength from a Higher Power
- By promoting responsibility to practice healthier living

This then highlights that for religiously oriented patients, practices and beliefs associated with their religion can be potentially health enhancing, having the potential to impact on physical as well as psychological health outcomes through the restoration of hope (biopsychosocial theory).

It did emerge in the current study that the HD participants particularly tended to use religion to cope as a source of strength and hope in their experience. The quotes below are some of their reflections:

- *My faith in God and attending service has helped me through (HD participant).*
- *Just prayer gives me strength (HD participant).*
- *I've been a lot into my religion... reading the bible, attending church since my illness, it gives you a lot of piece of mind and boosts your spirit...my religion helps me to cope (HD participant).*

Clearly “hope” as a key element is crucial for ongoing living and is discussed by Kasiram (2006) to generate productivity for those affected by ill health (renal impairment).

4.8. Conclusion

This chapter has shown that ESRD and its associated treatments of HD and CAPD posed many psychosocial challenges. Patients on dialysis were vulnerable to physical, social and psychological impacts. Long-term dialysis increased patient dependence, reduced work capacity and physical abilities and caused family role reversals. Stress caused by reduced physical energy, loss or change in sexual function had significant impact on patients' coping strategies. Various coping mechanisms were used by participants and these drew on various aspects, namely biological, psychological, social and spiritual.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1. Introduction

The aim of the study was to explore and describe the biopsychosocial functioning of patients with ESRD undergoing HD or CAPD. In so doing the intention was to gain insight into the experiences of patients on HD and CAPD. Altogether 15 patients participated in the study, which comprised of 7 HD participants and 8 CAPD participants. To achieve the study aims, a semi structured interview schedule was designed in line with the themes that the review of literature revealed. In order to develop an understanding of the factors contributing to the study's findings, the theoretical framework grounding the study utilized biopsychosocial as well as ecological theory. These two theories proved relevant for the study through consideration of the interplay of a range of biopsychosocial factors in influencing life experiences for chronic kidney disease patients.

The chapter is presented in accord with the study's key aims and objectives followed by recommendations suggested both by participants and by the researcher.

5.2. Conclusions

The main assumption of the biopsychosocial model is that ill health and well being are aspects of not only physical but of social as well as psychological concern. This theory thus presents that social and psychological factors play an influential role in affecting the experience of illness and treatment.

Drawing from the biopsychosocial model, the current study therefore looked at how ESRD and treatment modalities impacted on patients' psychological and social worlds, seeking also to understand how the impact imposed by RRT – on psychosocial well being may have in turn influenced their experience of the illness. The range of factors discussed in the findings suggests the need for adoption of the ecological framework, especially regarding the interplay of factors at various systemic levels of influence.

Physical Impacts

The researcher found that majority of the participants on RRT was affected by a range of symptoms and of note, these differed across the different treatment modalities. Tiredness and a general lack of energy presented as the most frequent and significant symptoms amongst other symptoms namely headaches, pains, nausea, cramps, loss of weight and loss of sight experienced by participants undertaking HD. The CAPD participants also acknowledged that they were affected by tiredness but not to the degree experienced by the HD participants. Comparatively they had more energy, strength and vitality. Other symptoms experienced by CAPD patients were weight gain, sores in the mouth and itching.

In light of the above, the experience of fatigue in this study was related to participants' physical and functional difficulties, and this also had an influence on their daily activities. The experience of HD placed participants in a negative spiral, where as the experience of physical and mental fatigue increased, functional capacity decreased. CAPD participants did not experience this degree of mental and physical weariness.

There was a clear interrelational link between fatigue and functional capacity. From a functional capacity outlook, aspects of performance and endurance were challenging for the participants in the study. As a consequence of extreme physical fatigue, HD participants experienced limitations in their performance and

encountered difficulties in undertaking their activities of daily living. The CAPD participants were not challenged by limitations in performance and seemed to cope comfortably with activities of daily living.

Interestingly in terms of endurance, both HD and CAPD participants felt that their endurance was lower as compared to before the reduction in their renal function. Although the study was qualitative, the relationship across these factors was abundantly clear. One can conclude that there is an interrelation between limited performance and low endurance. Reduced endurance results in impaired performance capacity but impaired performance capacity also causes endurance to be reduced still further, since patients stop performing certain physical activities that require endurance they do not have, thus lowering their physical activity level.

Hence the introduction of rehabilitation might have a positive effect on physical fatigue and improves both endurance and performance capacity. It would therefore be important for these patients to be referred to the physiotherapist at an early stage so that they receive information and are assisted with physical exercise training. In so doing, this could contribute to a patient's increase in personal resources, which can then be used to improve their level of participation. It is also important that physiotherapists consider patients' views when reflecting upon and interpreting how they can support and strengthen them in their effort to be able to perform physical and functional activities as well as social activities. Knowledge of the various ways in which patients experience functional incapacity is important for the rehabilitation process, since a better understanding of a patient's situation can only serve to improve the co-operation between patients and physiotherapists.

The results of this study have thus provided us with a greater understanding of the relationship between physiological aspects and the importance of rehabilitation in the lives of patients on RRT.

Psychological Impacts

Beyond the physical level, the impact of RRT continued to be felt on other levels. Not only did participants experience loss of physiological functioning but psychological impact was also experienced. As can be seen in the discussion (see Chapter 4 for a detailed discussion), indeed RRT as a treatment posed a challenge to participants' psychological functioning. HD brought on perceptions of vulnerability and uncertainty thus evoking feelings of depression. HD participants demonstrated strong emotional reactions to dialysis including anger, sadness and an inability to face up to the limitations in their lives imposed by their disease. Both HD and CAPD was a constant source of anxiety for participants because of the realization that their continuity of life was dependent on external variables i.e. high technology medicine which was beyond their control. Hence anxiety was associated with possible complications, infections that could arise and the prospect of death that permeated participants' fears.

The chronicity of the illness and its treatment for both HD and CAPD patients also called for immediate adjustments in health and lifestyle functioning, while simultaneously demanding more time and energy than participants could afford. This made patients feel overwhelmed and unable to cope. Despite the availability of support from partners and families, the therapies did evoke stress. The respective treatments of HD and CAPD demanded dietary regimes, adjustments and adherence and this adjustment process proved incalculably difficult for the HD participants. Whilst this was so for HD, CAPD participants did not experience this same degree of stress, generally adjusting better to the dietary regime. The researcher attributes this adjustment to the fact that the diet is modified when you move from HD to CAPD and provides for some flexibility which facilitates adherence.

With regards to social activities, the study highlighted that participants had been challenged by integrating the requirements of the dialysis regime into daily

schedules, and this process of adjustment had resulted in some limitations in lifestyle pertaining to sport and holidays. CAPD participants were already accustomed to making shifts in their social lifestyle and adjusted better compared to the HD participants who felt limited physiologically and psychologically.

Further adding to the participants' stress was the physical changes resulting from the long term effects of HD and CAPD. This called for an adjustment in participants' perceptions of their bodies, including that of perceived attractiveness. This adjustment proved challenging for some of the participants and had repercussions for relationships with their partners (microsystemic influence).

Despite RRT having brought about challenges into all of the participants' lives, there were however, participants that reported that it gave them some hope and motivated their appreciation of life. The CAPD participants in particular reported that with the previous experience of HD, came a realization that their lives on CAPD was worth more than they had realized or predicted and thus they needed to appreciate and value their health. Such participants started to view themselves in a better light, looked forward to achieving, than they had done before, as the treatment experience gave them yet another chance in life.

Social Impacts

Looking into the social aspects and their impact on partner relationships, it emerged that solid, marital and partner relationships existed amongst both the HD and CAPD participants, despite the effects of the treatments on their lives. These relationships appeared to be functioning optimally prior to the onset of treatment and hence such experiences did not lead to marital breakdown or relationship disintegration with the exception of one CAPD participant.

The effect of HD and CAPD did evoke stress for both HD and CAPD participants with regards to sexual activity and intimacy. The physical and emotional effects

brought about by treatment side effects as well as a changed body image were challenges that impacted negatively on the perceptions of sexual desirability and profoundly affected sexual activity.

The illness and dialysis therapy also called for immediate adjustments in routine functioning, roles and responsibilities in patients' lives.

Tasks relating to family time, parenting, nurturing was also important for the patients. All these activities were evidently negatively impacted upon and disrupted to differing extents for both sets of participants as medical care governed their time. Clearly caregivers and family members need to be cared for and supported as they tend to the needs of a person with ESRD.

Socioeconomic Impacts

The ability to work and lead productive lives presented as a significant impact on the lives of the participants. For the HD participants, the demands of the treatment regime proved beyond their coping and precipitated feelings of distress as the challenges of employment were crucial to their survival. The CAPD participants returned to being productive and with support from the health advisers, effectively facilitated the regime in their occupational settings. It is the researcher's suggestion that nocturnal dialysis could be a solution for patients who are employed, a proposal for government, as it can serve to improve the number of working hours, alleviate financial distress and enhance the quality of life of citizens compromised by chronic diseases, in a society faced with poverty and unemployment. Results also have implications for the role of occupational therapy in facilitating to create adjustment in occupational roles and tasks. The occupational therapist can provide assessments and guidance with alternative work placements as well as self employment opportunities for patients.

There is also scope for collaboration with employee assistance practitioners for those patients that are employed.

Results also revealed that patients were not adequately informed about their rights as workers and the social worker can play an advocacy role to avoid unfair

discrimination against workers who become incapacitated for particular work roles.

Coping

Participants in the study related how they had continued to draw strength from fellow patients and family. They also reported on the remarkable strength received from their religious affiliation as well as from church members, indicating that psychosocial interventions for patients should also focus on the broader context in which ESRD occurs.

Thus the findings clearly highlighted the nature of the relationship between the physiological / biological, social and psychological factors in influencing health outcomes. This affirms the WHO's definition of health as not only referring to the absence of disease but also to a state where there is complete physical, mental and social well-being (Henderson and Thuma 1999). In addition to the impact that RRT experience had on families, social networks and work, the findings are also in line with Germain and Gitterman's (1980) ecological theory which is based on the assumption that the patient is a complete entity surrounded by a unique social system or ecosystem. Hence what affects these patients also has implications for the broader systems within which they exist and in the case of the study, influence of partners, family and social networks.

Having gained some insight into the lived experiences participants faced with ESRD on renal replacement therapy, some "in roads" for intervention strategies for affected participants and families are hereunder presented as recommendations.

5.3. Recommendations

- Quality of life is experienced in various aspects of one's physiological, psychological and social being. The effects of RRT in ESRD permeated

into various aspects of participants' lives. Thus intervention at each of these levels is indicated. At the physical level, best practice must prevail as should best practice for attending to the psychological concerns that these patients experience. A team approach that facilitates team discussions to tailor plans for individual patients is important and should involve members from disciplines representing each of the systemic influence areas.

- The implications for social work practice are that social workers need to recognize and respond to the tremendous emotional impact that chronic illness and its treatment can have on patients as well as families especially in an era when technology advances are sustaining life. A clear recommendation is thus for life partners and families to be included in the treatment process, so that psycho education and support form an inherent part of the treatment regime. This may be accomplished by individual and family oriented work, although family therapy may be the modality of choice to problem solve around grave concerns that affect both individual and family. The invaluable role of group work with the patients can also contribute towards empowering patients through their illness and treatment experience.

- As we note in the study, patients' coping resources need to be mobilized and strengthened and attempts must be made to support supportive relationships such as support groups which are not available to patients, presently.

- The ability to maintain the role as a 'working husband', father was very important in sustaining participants' sense of self. The multiple roles expected could not always be met by the participants or their families, specifically with HD participants. The need is for the team to extend beyond the hospital interdisciplinary team into the workforce and liaise

with employee assistance practitioner networks. From an ecological perspective, exosystemic influence of business and community is important and is recommended to plan a successful financial future for patients.

- The fatigue and physical restraints caused by RRT magnified role conflict inherent in maintaining one's role as husband, father and carer. The need is for engagement with partners and patients to open this discussion for creative joint problem solving. This may be accomplished at both individual and marital level as well as at a group level, especially while patients are receiving therapy.
- In view of the multiple ways in which HD and CAPD impacts on sexuality, requires intervention directed to both partners. This is crucial as marital and relationship support plays a major role in providing psychological support to patients. Thus partners' and spouses' involvement in specialized therapeutic intervention eg sex therapy could function as a tool to decrease marital and relationship distress.
- Peer counseling is thought to be one of the most effective methods by which people are taught to help others. The health care team is able to deal with specific aspects of a patient's care, but are not usually able to share the common experiences of living with a chronic illness like kidney disease and its different treatment modalities. People can more easily discuss a concern or problem with someone of their own age, social circumstances, with similar health problems, with the understanding of having 'been there' too. Such volunteers can come to better terms with their own illness and in so doing improve their own well-being, while helping others. A challenge for health care professionals is to promote peer counseling education and training as an intervention strategy for health promotion in the support of kidney disease. These preventative

strategies can be joint initiatives between government, Natal Kidney Association and National Kidney Foundation.

- Unemployment is one of the stressors amongst haemodialysis patients, the demographic information in this study confirmed that a majority of the HD participants and to some extent the CAPD participants were unemployed. The study also reveals that there appears to be a lack of advice from health care practitioners for employers and the workplace that could be helpful for patients. There is thus a need for a more integrated approach to support extending beyond just the physician to include inclusive support from health care practitioners as well as workplace management. Greater awareness and psycho education in the workplace, and the establishment of forums are proposals, to advocate in the best interest of health.

- In as much as psycho education material was made available to some patients, it needs to also be extended to families, social networks and community organizations. Social networks such as friends and colleagues play an important supportive role in patients' lives during the treatment regime. Hence the value of psycho education can never be overemphasized and can therefore prove useful for raising awareness and providing information and education on the treatment and its potential health outcomes.

- Looking into the beneficial effects of exercise and rehabilitation on physical fatigue and functional capacity, it is important for physiotherapists to consider patients' views when reflecting upon and interpreting how they can support and strengthen them in their effort to function optimally. Acknowledging patients' subjective information makes them more active and empowered in decisions about their healthcare hence research about

how patients experience their health situation is valuable for all health care professionals.

Education and Training

Institutions of teaching and learning should ensure sufficient attention to holistic health care in kidney care. The team should also be emphasized as crucial to such holistic care. Ongoing continuing professional development could also take the form of workshops and short courses to update health care workers on current treatment options and on emerging needs of patients. Hospitals and care centres could focus on such updates with regularity.

Policy

Over the years there has been a plethora of legislation and policies eg HIV/AIDS to ensure the best health, welfare and rights of people faced with HIV/AIDS.

Other chronic illness programmes include T.B. Similarly efforts need to be made to solicit the commitment of government in the implementation of policies for Kidney Disease.

Patients faced with advanced kidney disease need the support of the department of social welfare and non governmental organizations to provide them with services such as sheltered employment, yet there are no programmes that target such a vulnerable group.

The government's home based programme needs to be strengthened to reach out to patients with kidney disease in the community. Currently the government cannot deliver this service on its own; partnerships with civil society is critical for effective service delivery. Capacity building programmes and other means of support need to be put in place to enable both government and civil society to provide quality and yet affordable home based care services.

Future Research

This study was qualitative involving a small sample of HD and CAPD patients. To better isolate relationships, a quantitative study involving a larger sample is suggested. Also, the study could extend to other hospitals. A further recommendation is for comparative research to be conducted across state hospitals and private hospitals to establish differences across patients in different socio-economic settings. The rural-urban bias is also an area for possible future research.

The role of spirituality in association with successful health outcomes of patients faced with ESRD on dialysis therapy is also an open area for further research for health advisors.

It is noted with interest the different coping styles of HD and CAPD participants and this aspect warrants further exploration.

There is also scope for research on family resilience in patients on HD and CAPD in ESRD.

5.4. Concluding Remarks

This biopsychosocial and ecological inquiry into patients' lived experience and quality of life drew on narratives from patients living with ESRD on dialysis therapy and illustrated the dynamics of interrelational factors that emerge from patients' biological, psychological and social worlds. While these findings cannot be generalized to a wider population, it provides rich stories and insights and identifies opportunities for further research which would benefit the practice of multidisciplinary and holistic health care in South Africa.

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**UNIVERSITY OF
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6 AUGUST 2007

MS. B HARILALL (891158049)
SOCIAL WORK & COMMUNITY DEVELOPMENT

Dear Ms. Harilall

ETHICAL CLEARANCE APPROVAL NUMBER: HSS/0477/07M

I wish to confirm that ethical clearance has been granted for the following project:

“Experiences of patients on haemodialysis and continuous ambulatory peritoneal dialysis in end stage renal disease: An exploratory study at a tertiary hospital in KwaZulu-Natal”

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Yours faithfully


.....
MS. PHUMELELE XIMBA
RESEARCH OFFICE

- cc. Post-Graduate Office (Lyn Marriott)
- cc. Supervisor (Prof. Ml Kasiram)

CONSENT

Private Bag XO3
MAYVILLE
DURBAN
4058

Mr/Mrs/Ms/Miss _____

27 May 2007

Dear Sir/Madam

I am pursuing the master's course in social work at the University of KwaZulu - Natal. I shall be conducting research on the following topic:

Experiences of patients on haemodialysis and continuous ambulatory peritoneal dialysis in end stage renal disease: an exploratory study at a tertiary hospital in KwaZulu-Natal.

The study is envisaged to be worthwhile and necessary in understanding patient's experiences of haemodialysis and continuous ambulatory peritoneal dialysis in end stage renal disease as it will serve to contribute to the knowledge and practice of nephrology social work, update research on the psychosocial management and provide recommendations for further research and practice in nephrology social work, nursing and medical care.

The sample in this study will comprise of patients who were accepted onto the chronic renal programme between 2005 and 2007, and would have to be on chronic haemodialysis and continuous ambulatory peritoneal dialysis for a minimum of four months.

Your participation in this study is essential and shall be valued. The study will be undertaken under the auspices of the School of Social Work and Community Development at the University of KwaZulu-Natal (Howard College). The researcher will not at any point in the study or the report identify any participant. All ethical considerations in working with patients will be taken onto account.

There will be no payment for participation in the study and you have a right to withdraw from the study at any stage and for any reason with no penalty.

Should you wish to add any further comments or clarify any of the above information, kindly contact me?

Kindly complete the consent paragraph below and posted it to the above address or alternatively it can be collected as per arrangements.

Thanking you for your co-operation

Yours faithfully

Bharita Harilall (Miss)
Tel No: 031 240 1638 (work)
Cell No: 083 790 8410

Research Supervisor: Prof M I Kasiram
Tel: 031-2607443

Informed Consent:

I, _____ the undersigned understand the contents and conditions of the study and further understand that my rights will be protected at all times. I hereby agree / do not agree to participate in the study under the conditions mentioned above.

Signature of participant

Date

Kindly note that the letter was translated into Zulu as well.

SEMI - STRUCTURED INTERVIEW SCHEDULE

- Biographical information
- Understandings of ESRD and dialysis treatments
- Understandings of the perceived impact of dialysis therapy on quality of life
- Impact of dialysis on the following areas of functioning:
 - Physical
 - Psychological
 - Occupational
 - Sexual
 - Family
- Impact on gender identity, role and responsibilities
- Socio-cultural factors
- Perceptions of medical support
- The effect of, and role played by, social support
- Coping skills and strategies
- Challenges, services and recommendations