ABSTRACT

Title of Dissertation: AFRICAN AMERICAN PATIENT PERCEPTIONS REGARDING PRE- AND POST-DIALYSIS EDUCATION AND TREATMENT

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Kidney disease is common in the United States. It occurs with more frequency and more complications among African Americans than in the general population. Patients with end stage renal disease (ESRD) are at that point in the progression of kidney disease where death is imminent if treatment is not performed to replace the limited kidney function. Hemodialysis is a replacement treatment for ESRD.

This study used ecological theory to examine pre-and post-dialysis education and treatment in a convenience sample of African American ESRD

patients. A pilot study of 29 patients and a final sample of 98 patients were used. Patient age, income, education and length of time on dialysis were the independent variables examined. Dependent variables included knowledge, satisfaction, treatment intervention, and quality of life. Oneway analyses of variance (ANOVA) were used to analyze the data. The following research questions were examined: 1) Are African American ESRD patient adequately educated about the disease, its causes, possible complications and range of treatments available? 2) Will African American ESRD patient with higher income and education levels score higher on the knowledge and pre-dialysis education subscale, when compared to patient with lower income and education levels? 3) Is the degree of satisfaction with pre-dialysis information and education positively related to age, level of education and income of African American ESRD patients? 4) Do African American ESRD patients with disparate income and education levels receive different treatment interventions? 5) What are the perceptions of African American dialysis patients regarding their quality of life?

When the data were analyzed, the research hypotheses related to questions one and three were not supported ($p > .05$). While the hypotheses for questions two and four were supported ($p < .05$). A significant relationship was found between patient satisfaction with pre-dialysis

education and treatment and level of education. Other significant relationships were also found when examining the quality of life subscales with income and education.

AFRICAN AMERICAN PATIENT PERCEPTIONS REGARDING PRE- AND POST-DIALYSIS EDUCATION AND TREATMENT

by

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DEDICATION

In memory of my mother, Mary P. Greene and my sister, Maretta Greene McKinley, two of the most magnificent, generous and loving individuals I have ever known.
You continue to inspire and uplift me.

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CHAPTER ONE

Introduction

Kidney disease is a disease which is a common clinical complication of disorders such as hypertension and diabetes. It has unique associated symptoms, and may cause other complications or diseases such as end stage renal disease (ESRD). Kidney disease is common in the United States. It is known to occur with more frequency and more devastating complications among African Americans than in the general population. Researchers do not have a definitive explanation for why African Americans have an increased risk of developing kidney disease, but they have identified many possible factors, including genetics, socioeconomic status, lifestyle, and differences in health perception (Struebing, 1999).

Patients diagnosed with ESRD are at that point in the progression of kidney disease where death is imminent if medical treatment is not undertaken to substitute for or replace the kidney function which has been severely limited by the disease. Kidney function is substituted for via dialysis, a modality which removes blood from the body, eliminates waste products from the blood, and returns it to the body, and it is replaced via kidney transplantation. It has been widely reported that there is a continuous and increasing shortage of viable organs, kidneys, for replacement, and that

African Americans in this country are less likely to receive kidney transplantation than others in the general population (Rozon- Solomon and Burrows, 1999). As a result, most African American patients with ESRD receive dialysis to perform the work of their diseased kidneys.

Background of the Problem

The National Institutes of Health Consensus Development Conference on Morbidity and Mortality of Dialysis (1993) brought together experts in general medicine, nephrology, biostatistics, nutrition, pediatrics, and the public to address: 1) whether early medical intervention in pre-dialysis patients influences morbidity and mortality; 2) how dialysis related complications can be reduced; and 3) future directions for research in dialysis. The conference findings included the following: 1) patients in the pre-dialysis phase of treatment should be referred to a renal team in an effort to reduce the morbidity and mortality incurred in the pre-dialysis and dialysis periods; 2) the social and psychological welfare and the quality of life of the dialysis patient are favorably influenced by the pre-dialysis period; and 3) the continued involvement of a multidisciplinary renal team is important throughout the course of the disease (NIH Consensus Statement, 1993).

Statement of the Problem

There are nearly 250,000 ESRD patients receiving hemodialysis in the

United States (NIDDK, 2001). Hemodialysis allows these patients to survive an otherwise fatal disease. The number of patients diagnosed with ESRD is increasing each year, with African Americans who have diabetes experiencing ESRD about four times more often than diabetic white Americans (NIDDK, September 1998). African Americans with hypertension (ages 25- 44*)* are 20 times more likely than whites in the same age group with hypertension to develop ESRD (NIDDK, 1999).

Purpose of the Study

The purpose and primary goals of this study were: 1) to identify the self reported level of satisfaction among Washington, DC African American ESRD patients regarding pre-dialysis information and health care to compare the care they received to the established standards of care for ESRD patients; 2) to determine what, if any, differences exist in the type and degree of pre-dialysis education and treatment; and 3) to discern whether the level of pre-dialysis information and health care provided is related to the environment of the patients (resources, access to health care). The results of this study may help health care providers be more cognizant of environmental factors when considering the causes, progression, and treatment of ESRD, and may help to ensure that future patients are provided with the information needed to make informed choices about dialysis treatment.

A questionnaire for African American dialysis patients was developed to determine what, if any, concerns and/or health complications they have encountered related to ESRD and the dialysis process; and their level of education and socioeconomic status. This study also sought to determine if patient satisfaction varies according to educational level and socioeconomic status; and if the pre and post dialysis process could be improved via a comprehensive patient education program prior to dialysis.

A chronic disease such as ESRD may have a negative impact on the quality of life of patients and their families. "Quality of life" is a term used to indicate aspects of health, happiness, life satisfaction, and well being. It is influenced by external factors, those areas outside the control of a patient, and internal factors (Wicks, et. al, 1997). Quality of life as a measure has become very important for health and social researchers, as a result of the way the U.S. health system is changing from an acute illness focus to one of chronic illness management and managed care. This type of system relies heavily on the assistance of skilled caregivers to treat the patient, and to maintain the patient in as functional a state as possible (Grzywacz and Fuqua, 2000).

A disease as severe and disabling as ESRD can be expected to negatively influence quality of life for both patients and family care givers. Quality of life is related to multiple factors, with the ability to enjoy family

interactions being a major contributor. Any examination of ESRD patients and their caregivers must include quality of life as a variable. Any disease or disorder, which has a negative effect on quality of life should be addressed from a multifaceted perspective, in order to identify and restore deficits in function and quality of life associated with the illness. The needs and perspectives of the patient, family, care givers and health care professionals must be considered.

Rationale for Research

When one considers the inherently devastating effects of chronic illness, and the lost productivity related to disease and disability in persons who may be in the prime of their lives, the tendency for healthy adults to misunderstand and/or misinterpret the needs of patients, while understandable, must be overcome. It is important that the needs of those affected by ESRD and its related complications be identified. Furthermore, it should be determined whether educational programs currently provided by health care institutions (such as hospitals and dialysis centers) meet those needs.

There are unique complications associated with a chronic disease such as ESRD, which is curable only through transplantation, but may be controlled or maintained through dialysis. The dialysis treatment is such a

physically limiting treatment procedure (the ESRD patient must be attached to the dialysis machine for hours at a time, several times a week) that there are attendant problems and complications associated specifically with the application of this modality. Once one understands the attendant problems, more attention can be paid by health professionals to the unique problems experienced by dialysis patients.

There has been a long history of lack of access to the health care system by underprivileged groups in this country. African Americans as a group are known to have less access to health care than the general population (Levinsky, 1999). The gap between the health status of African Americans and the general population continues to be vast, despite efforts by the established U.S. health care system (such as Healthy People 2000 and Healthy People 2010) to address the health care, psychological and educational needsof African Americans. Overall, the health status of all Americans is improving, but the gap between African Americans and the general population remains wide.

Educating all Americans about preventing kidney disease is important, as is identifying persons at risk (i.e. African Americans), so that prevention may occur, or treatment may be started early. Most research related to ESRD patients' type of treatment modality has been conducted by

researchers' asking questions and gathering data from the health care provider's perspective (Breckenridge, 1997). There is a great need to study the ESRD patient's dialysis treatment modality from his or her perspective. It is imperative that more effort is taken to ensure that the needs of patients are being met by individual health care providers and institutions.

Although there are several treatment options for ESRD, little is known about how treatment modalities are chosen by the primary care providers and the patients. A study conducted and reported by Badzek, Hines and Moss (1998) indicated that patients with little formal education were difficult to educate and often found medical explanations hard to understand. It is easy to suggest that consumers must assume more responsibility for their own care, and that they should become better informed about the range of providers and potential options for services. However, many ESRD patients and their families, who are members of under-represented and underserved populations, may place full faith in their health care providers, and may be unaware that they have rights or options to change or influence the care they receive to treat their disease. In this regard, it becomes the duty of health care providers and educators to ensure that patients, their families and care givers receive special interventions from the health care system, to ensure that they receive adequate education about their own or a family member's disease, and

the treatment modalities of choice associated with that disease.

Theoretical Framework

Biologic, behavioral and environmental factors each affect health status, but often the focus of interventions has been on individual lifestyle changes. This study used ecological theory to explore how the health status of African American dialysis patients was related to their environment, specifically, that the level of pre-dialysis education and the types of pre-dialysis medical treatment provided to African American ESRD patients by physicians and other medical personnel was varied, based upon the education and income levels of the patients. Specific environmental factors affecting the health status of African American dialysis patients include institutional racism, lack of access to health care, and comparatively lower educational and income levels among African American dialysis patients. Some of these factors were not under the immediate control of these patients.

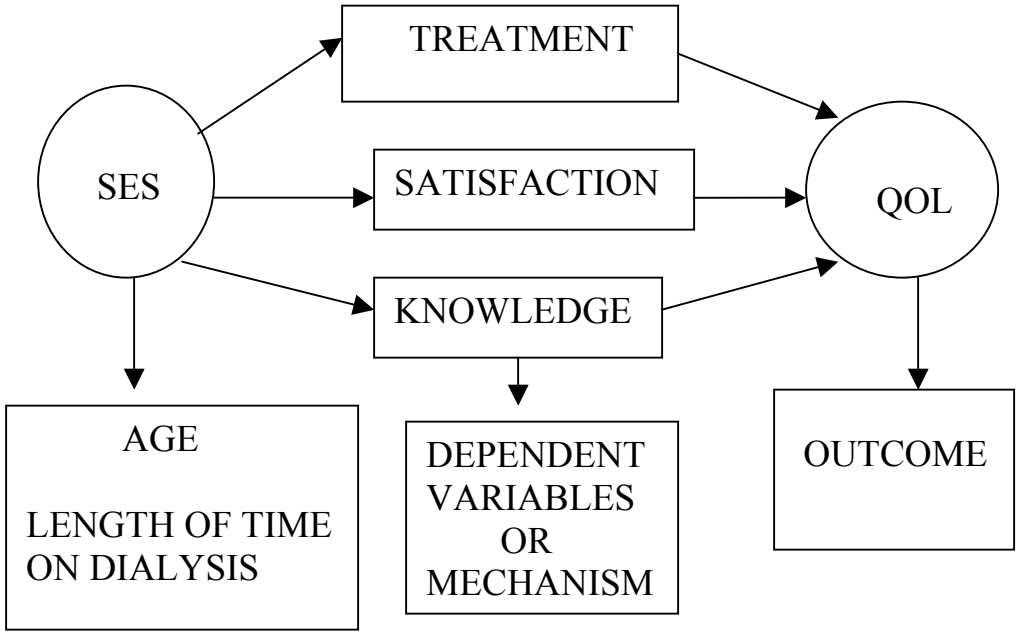
One of the core themes of social ecology is to highlight the dynamic relations between people and their surroundings. To fully understand health status, contextual and environmental issues must be considered. This study examined the treatment of ESRD, considering the education and income levels of the dialysis patient, their access to health care (different treatment options), and pre- and post-dialysis health education provided. Using

analyses of variance, the dependent variables of treatment, satisfaction, knowledge and quality of life were examined. It was anticipated that the dialysis patients' income and education would influence their quality of life and health status, via the mechanisms (or dependent variables) of treatment, satisfaction, and knowledge of disease (Figure 1).

There are disparities in the health status of African Americans compared to the health status of the general population in the United States for similar diseases and illnesses, including ESRD. The establishment and implementation of Medicare and Medicaid programs has increased access to care for poor, disabled, minority, and/or elderly Americans. However, these programs have not eliminated the differences in the quality of care received by minorities, particularly poor minorities (Watson, 2001). Health care institutions and individual providers continue to provide different care to their minority patients than they give to those who are white (Watson, 2001).

Institutional bias by physicians who do not always select the most aggressive medical interventions for African American patients may be one reason why African Americans continue to be more negatively affected by chronic illnesses when compared to the general population. African Americans' health status is generally worse than whites, and they have fewer doctor visits, receive less primary care and fewer preventive procedures even

Figure 1: Research Variables and Outcomes



SES = SOCIOECONOMIC STATUS

QOL = QUALITY OF LIFE

when they have the same insurance coverage as whites (Watson, 2001). Other possible explanations for disparities in health status include the under-representation of African American patients in research studies, a lack of trust in the medical care system by minority patients, and a general emphasis among some lower income African American patients on acute and emergency treatment for chronic illnesses instead of prevention (Watson, 2001).

It is commonly understood that African Americans are not a monolithic group, and that those African Americans with a higher education and income level may not be as disadvantaged when it comes to health status as those with a lower level of education and income. This point of view can be inferred from the ecological theory that the socioeconomic status of a minority group is inversely related to the group's level of segregation from the majority group (Darden, 2000). This study attempted to address this issue by examining health outcomes by varying income and educational levels.

Implications of the Study

In order to provide good health care, providers must strive to treat the whole person and not just symptoms of a disease. Studies have shown that patients who are educated about their disease and treatment are more satisfied and have less anxiety than those who are not. It is vital that the patient knows

the available treatments and information about the disease. Because knowledge about the disease can decrease anxiety related to injury and illness, providing good and relevant information to the patient will help in treating the "whole person" by paying attention to the emotional as well as the physical well being of the patient.

If this study determines that there is a perceived lack of pre-dialysis treatment and education for African American dialysis patients in the Washington, DC area, then the involved health care institutions will have the information needed to correct those deficiencies. In addition, if it can be inferred from the results that higher levels of socioeconomic status in African American dialysis patients is positively associated with the level of treatment provided and health outcomes for ESRD and dialysis patients, this would suggest that race alone is not the main factor influencing the disparate levels of treatment provided to African American ESRD patients.

Research Questions

1) Are African American ESRD patients adequately educated about the disease and dialysis treatment, as evidenced by their ability to describe the disease and its complications and the range of treatment options?

2) Will African American ESRD patients with a higher income and education level have higher knowledge scores than African American ESRD patients with a lower socioeconomic status?

3) Is the degree of satisfaction with dialysis education and treatment provided to African American ESRD patients positively related to age, level of education and income?

4) Do African American ESRD patients with disparate education and income levels receive different treatment interventions?

5) What are the perceptions of African American dialysis patients regarding their quality of life?

Definition of Terms

Circulatory system: the system which monitors the body's actions and adapts blood flow as needed in different parts of the body.

Continuous ambulatory peritoneal dialysis (CAPD): the type of dialysis where the peritoneal cavity is filled with dialyzing fluids and the patient's blood is purified as it passes through the peritoneal membrane. This process is continuous and the dialyzing fluid is replaced every few hours.

Diabetes mellitus: a disease characterized by high levels of blood glucose resulting from defects in insulin secretion, insulin action, or both.

Dialysis: a process whereby a person's blood is fed into a machine, which purifies the blood and returns it to the body.

End stage renal disease: that stage of kidney impairment which is irreversible and requires dialysis or kidney transplantation to maintain life.

Glucose: a sugar that is produced from foods.

Hemodialysis: a process whereby a person's blood is fed into a machine, which purifies the blood and returns it to the patient. The procedure may be performed at an inpatient or outpatient facility, and usually takes two to six hours to complete.

Hypertension: an abnormally high blood pressure, resulting from an increased resistance in the body's blood flow.

Homeostasis: a state of normalcy in the body.

Insulin: a substance (hormone) from the pancreas, which helps to convert sugar to energy for the body's cells.

Kidneys: fist sized organs located behind the abdomen and under the diaphragm, which produce and eliminate urine by separating the blood into waste products and nutrients.

Peritoneum: the membrane which lines the abdominal cavity.

Quality of life: a term used to indicate aspects of health, happiness, life satisfaction and well being.

Insulin dependent diabetes mellitus (IDDM): the type of diabetes which generally occurs before the age of 30; the pancreas stops making insulin, or makes only a small amount, so the glucose levels rise in the blood.

Non insulin dependent diabetes mellitus (NIDDM): the type of diabetes which can occur at almost any age, but is most common after the age of 40; the pancreas makes insulin, but in most cases, the body is unable to use that insulin. Type II diabetes is much more common than Type I.

CHAPTER TWO

Review of Literature

Those who work in and around the health related professions frequently interact with individuals (and their care givers) who suffer from chronic illness, disease and disability. The frequency of these interactions may often serve as an awakening for health professionals to the relatively unique barriers and problems faced by these individuals. People who do not have the privilege of these close interactions are often unaware of the damage caused by chronic illness and disability. End stage renal disease (ESRD) is one such chronic illness.

ESRD is a severely disabling and debilitating disease which affects hundreds of thousands of people in the United States each year. The disease involves that stage of kidney damage which is irreversible. ESRD cannot be controlled by conservative management alone, such as medications and non invasive procedures, but requires dialysis or kidney transplantation to maintain life (NIDDK, 1995).

Anatomy/Physiology of the Kidney

The normal human body has two kidneys. They are fist sized organs located behind the abdomen and under the diaphragm. The two kidneys are

essentially identical in structure and function. They comprise less than one percent of total body weight, and are essential for normal physiologic processes and for the continuation of life (NIDDK, April 1998). The kidneys are highly vascularized organs that are responsible for maintaining the body's internal environment. This activity sustains life (NIDDK, April1998). The kidneys are organs which control the amount and composition of body water by separating the blood into waste products and nutrients (NIDDK, April 1998). Normally, the kidneys clean the blood by filtering out extra water and wastes. They also produce hormones which strengthen the bones and keep the blood healthy (NIDDK, February 1998). The waste products leave the body as urine, and nutrients are returned to the body via the bloodstream (NIDDK, April 1998). By producing and eliminating urine, the kidneys help to maintain homeostasis, a state of equilibrium or normalcy in the body. The kidneys regulate the volume, electrolyte concentration and acid-base balance of body fluids, detoxify the blood, eliminate wastes, and regulate blood pressure. When both kidneys fail, the body retains fluid, blood pressure rises, the production of red blood cells decreases, and wastes build up in the body. If this occurs, intervention is required to replace the work of the failed kidneys (NIDDK, February 1998).

End Stage Renal Disease

Disorders of the kidney can occur for a variety of reasons, and at any age. The cause(s) may be congenital, or kidney disease may develop very quickly or over a long period of time. ESRD is usually the end result of a progressive loss of renal function. It is the final stage of a slow deterioration of the kidneys, a process known as nephropathy. The disease is fatal without treatment, but maintenance dialysis or a kidney transplant can prolong and/or sustain life (NIDDK, 1995).

In 1998, there were nearly 400,000 ESRD patients in the U.S. and more than 87,000 new people were treated for ESRD in that same year (NIDDK, 2001). The incidence of treated ESRD continues to rise at a rate of 7.8 percent per year (NIH Consensus Statement, 1993). More than fifty percent of all cases of ESRD are caused by diabetes or hypertension (NIDDK, 2001). In 1998, diabetes accounted for 33% of ESRD cases in the United States, and hypertension accounted for 21% (NIDDK, 2001).

African Americans contract ESRD at a disproportionate rate compared to the general population in the U.S. On average, African Americans and Native Americans are younger at the onset of treated ESRD and show dramatically higher incidence rates than whites or Asians (NIH Consensus Statement, 1993).

Prior to 1960, ESRD was fatal in all circumstances. However, as a result of biomedical research and medical technology, a treatment system was developed to allow repeated access to the vascular system, and dialysis is now performed in a chronic, intermittent manner to treat ESRD (NIH Consensus Statement, 1993). Dialysis had been used prior to this time, but to treat acute renal failure only. The development of dialysis treatment for ESRD, and the later federal legislation that allows Medicare coverage of ESRD treatment, regardless of the patient's age, made it possible for hundreds of thousands of patients with ESRD to receive life sustaining dialysis (NIH Consensus Statement, 1993).

ESRD is a particularly costly disease. The financial cost for care of patients with ESRD from all sources including federal, state and private funding was roughly $16.74 billion in 1998 (NIDDK, 2001). Not reflected in this figure are additional expenditures for outpatient drugs and supplies, the cost of lost productivity, and Social Security payments. As the U.S. population continues to age, the cost of kidney disease, including ESRD, is projected to continue to increase (NIH Consensus Statement, 1993).

The United States Congress enacted the United States Medicare End-Stage Renal Disease Program in 1973. This law extended financial coverage under Medicare to all U.S. citizens with renal disease who could

benefit from dialysis or kidney transplantation. The program guarantees dialysis to all who want ESRD replacement therapy. The number of patients with ESRD treated by dialysis has increased dramatically since the enactment of the ESRD Program. In 1969, 1000 ESRD patients were treated by dialysis in this country. In 1974 16,000 were treated. In 1996, more than 200,000 were treated by dialysis at a federal expenditure of more than $6 billion. The U.S. ESRD program is the only national catastrophic Medicare program that offers universal access, regardless of the patient's ability to pay (Breckenridge, 1997).

African Americans and ESRD

Because good function of the kidneys is mandatory for health and life, those persons who suffer from progressive, incurable renal failure require medical care to conserve kidney function, substitute for kidney function and eventually replace kidney function (NIDDK, 1997). Persons who have ESRD have two options: dialysis and/or transplantation. For those without a suitable donor kidney, long-term dialysis is the first -and most likely only - option (NIDDK, 1997).

End stage renal disease disproportionately affects African Americans in the United States. African Americans, while comprising approximately 12% of the United States population, account for approximately 33% of all

Americans on kidney dialysis due to ESRD (Urban Health Care, 2002). Explanations for this disparity are varied, and include a higher prevalence and severity of hypertension and diabetes, and a greater susceptibility of the kidney to injury in blacks (Perneger, et al., 1995). In addition, racial differences in health status related to ESRD may be partially caused by differences in socioeconomic status and limited access to the health care system (Perneger, et al., 1995). The incidence of treated ESRD in the United States is four times higher for blacks than for whites (Perneger, et al., 1995).

Blacks are also at a disadvantage compared to whites when one examines the rate of kidney transplants. Reports have shown that African Americans, and patients with low income have reduced access to kidney transplantation (Levinsky, 1999). It is therefore far more common for blacks with ESRD to be placed on dialysis. Because black patients can expect to wait almost twice as long for a kidney transplant as white patients, and most African Americans with ESRD receive dialysis, the importance of determining the psychological and educational needs of that population receiving dialysis to treat ESRD cannot be understated. Unfortunately, only 20-25% of patients are referred to a kidney specialist prior to the initiation of dialysis (NIH Consensus Statement, 1993).

Diabetes

Diabetes is the leading cause of ESRD, accounting for approximately 40 percent of new cases annually. In 1995 alone, approximately 28,000 persons with diabetes mellitus developed ESRD, and nearly 100,000 persons with diabetes underwent dialysis or kidney transplantation (NIDDK, August 1998). Diabetes mellitus is a group of diseases characterized by high levels of blood glucose resulting from defects in insulin secretion, insulin action, or both. It is estimated that nearly 16 million people (approximately 6% of the U.S. population) have diabetes, and approximately 800,000 new cases are diagnosed each year (NIDDK Publications, August 1998). Nearly half of these people do not know that they have the disease (Struebing, 1999). An approximately equal number of men and women have diabetes. Diabetes was the seventh leading cause of death in 1995, according to the Center for Disease Control's Center for Health Statistics.

Diabetes mellitus prevents the body's cells from using food properly. Many of the foods eaten are turned into sugar (glucose) by the body (Semple, 1996). Glucose provides energy (food) to the body's cells. The mechanism by which this occurs is via the hormone, insulin. Insulin is a hormone from the pancreas which helps to convert sugar to energy for the body's cells (Guthrie and Guthrie, 1997). Diabetes mellitus occurs when there is a relative or

absolute deficiency of insulin (NIDDK, 1995). The lack of insulin prevents the body's cells from converting food to energy. Without insulin, the food that one eats is converted to glucose and raises the blood sugar to higher than normal levels. Sugar essentially builds up in the blood.

Over 90% of diabetics have spontaneous diabetes mellitus, which can be divided into two types: Type I or insulin dependent diabetes mellitus (IDDM), and non insulin dependent diabetes mellitus (NIDDM) or Type II (NIDDK, 1995). Type I and Type II have different causes, but are both linked with insulin. Type I diabetes generally occurs before the age of 30. With Type I, the pancreas stops making insulin, or makes only a small amount, so the glucose levels rise in the blood (Semple, 1996). Type II can occur at almost any age, but is most common after the age of 40. The pancreas of a person with Type II makes insulin, but in most cases, the body is unable to use that insulin. Type II diabetes is much more common than Type I (approximately 13 million compared to approximately 1 million respectively (NIDDK, 1995)).

The kidneys of a person with diabetes must work harder to remove the excess glucose that builds up in the bloodstream that is not turned into energy. The kidneys may be stressed by this extra work, and blood vessel damage in the kidneys may occur. In this situation diabetes can cause damage to the

small blood vessels in the kidneys. If too many blood vessels are damaged, the kidneys will fail and poisons can build up in the body. The poisons must then be removed by dialysis or kidney transplantation (Semple, 1996).

Diabetes is an expensive disease for individuals and insurers. Glucose monitoring can cost more than four dollars per day. In addition, insulin and other diabetes medication may also be expensive. Unless one has insurance, it is difficult to monitor one's blood sugar daily and care for the disease. Direct medical costs of diabetes total about $44 billion each year, with nearly $54 billion more spent on disability payments, time lost from work and premature death from diabetes (Struebing, 1999).

Diabetes and African Americans

Diabetes mellitus is a major health problem in African Americans. Nearly three million African Americans have diabetes (NIDDK, 1995). Diabetes was relatively uncommon among African Americans at the beginning of this century, but it is now the fourth leading cause of death among black women and sixth among black men (NIDDK, 1998). The Task Force on Black and Minority Health, which was appointed by the Secretary of Health and Human Services in 1986, cited diabetes as one of six health problems responsible for excess mortality among U.S. minority populations.

A report issued by the National Center for Health Statistics in 1987

indicated that the prevalence of diabetes diagnosed in African Americans had increased fourfold over two decades. Approximately 228,000 African Americans were diagnosed with diabetes in 1963. This number increased to approximately 1 million in 1985. This was almost twice the rate of increase among white, non-Hispanic Americans. (NIDDK, 1998). National health surveys during the past three decades indicate that the percentage of the African American population diagnosed with diabetes is increasing dramatically. For example, in 1976-80, total diabetes prevalence in African Americans aged 40-74 years was 8.9 percent. In 1988-94, total prevalence increased to 18.2 percent. This was a doubling of the rate in just 12 years (NIDDK, 1998). Ninety to ninety-five percent of African Americans with diabetes have type II diabetes. African Americans have a prevalence of NIDDM which is 60% higher than in whites and they have higher rates of diabetes at all adult age levels (National Diabetes Information Clearinghouse, 1992).

Higher than normal levels of fasting insulin, hyperinsulinemia, are associated with an increased risk of developing type II diabetes. Hyperinsulinemia usually predates diabetes by several years. According to the most recent national health study, the NHANES III survey conducted in 1988-1994, among the people who did not have diabetes, insulin levels were

higher in African American adolescents and adults than in whites, indicating their greater predisposition for developing type II diabetes (NIDDK, 1998).

For type II diabetes, there appears to be diabetes genes which determine insulin secretion and insulin resistance. Some researchers believe that African Americans inherited a gene from their African ancestors that enabled Africans, during feast and famine cycles, to use food energy more efficiently when food was scarce. Today, the gene that developed for survival may instead make the African American who carries it more susceptible to developing type II diabetes (NIDDK, 1998).

Obesity is a major risk factor for type II diabetes. The NHANES surveys found that African American adults have significantly higher rates of obesity than white Americans. In addition to the overall level of obesity, the location of the excess weight is also a risk factor for type II diabetes. Excess weight carried above the waist is a stronger risk factor than excess weight carried below the waist. African Americans have a greater tendency to carry upper body obesity, which increases their risk of diabetes (NIDDK, 1998). Researchers do not believe that obesity alone is responsible for the higher prevalence of diabetes among African Americans, because even when compared with white Americans with the same levels of obesity, age and socioeconomic status, African Americans still have higher rates of diabetes.

Other factors, not yet identified, appear to be responsible (NIDDK, 1998).

Regular physical activity is a protective factor against type II diabetes; lack of physical activity is a risk factor for developing diabetes. Researchers suspect that a lack of exercise is one factor contributing to the high rates of diabetes in African Americans. In the NHANES III survey, 50 percent of African American men and 67 percent of African American women reported that they participated in little or no leisure time physical activity (NIDDK, 1998).

African Americans are more likely to develop complications from diabetes, and experience greater disability from the complications than white Americans with diabetes (NIDDK, 1998). African Americans experience higher rates of ESRD related to diabetes, as verified by studies in Michigan and Texas, which found that the rate of ESRD was at least four times higher in blacks with diabetes than in whites (NDIC,1992). As a result, ESRD related to diabetes is significantly higher in African Americans than in the general population. Not only is the incidence of diabetes greater in minority populations, but there is a more frequent occurrence of complications, which often have an earlier onset in minority populations than in the general population (Struebing, 1999).

A number of studies have reported the prevalence of type II diabetes

among African Americans, but it has not been indicated that the increased prevalence alone increases the onset and severity of complications. African Americans experience higher rates of diabetes complications such as eye disease, kidney failure, and amputations (NIDDK, 1998).

Diabetes is the leading cause of kidney failure, and accounted for 43 percent of the new cases of ESRD among African Americans during 1992-1996 (NIDDK, 1998). It is unclear whether this statistic represents a true increase in the prevalence of diabetes among African Americans in this country, or is an indicator of greater access to the U.S. health system for this minority group. In any case, African Americans in this country are developing diabetes, and are increasing their risk of renal disease, at a rate that has nearly quadrupled over the past three decades (NIDDK, August 1998).

Hypertension

Hypertension is defined as an abnormally high blood pressure. It is a disorder which affects the heart, circulatory and kidney systems (Dawson, 1995). Each time the heart beats, it pushes blood through blood vessels. The force of blood through the blood vessels is the blood pressure. The blood pressure is actually two pressures. It is determined by the rush of blood with each heart beat, and the smaller surge in between heart beats. The first number is the systolic pressure, and the second number is the diastolic

pressure. The National Institutes of Health's Joint National Committee on the Detection, Evaluation and Treatment of High Blood Pressure defines hypertension as a systolic blood pressure consistently greater than or equal to 140 mm/dl and a diastolic blood pressure consistently greater than or equal to 90 mm/dl (Bales, 1996). Some individuals have a blood pressure which is chronically high. Their blood pushes up against the walls of their arteries with higher than normal force. If left untreated, this can lead to serious medical problems (NIDDK, 1998). High blood pressure makes the heart work harder and over time can damage blood vessels throughout the body (NIDDK, 1998).

The heart is a fist sized muscle which beats daily about 100,000 times, and pumps approximately 40,000 gallons of blood along 60,000 miles of blood vessels, which make up the body's circulatory system (Bales, 1996). The circulatory system monitors the body's actions and adapts blood flow as needed in different parts of the body. This is called microcirculation (Bales, 1996). With hypertension, the microcirculation shuts down. The arteries become choked off, depriving organs like the heart, kidneys and brain of blood and thus oxygen (Bales, 1996).

The kidneys play an important role in keeping the blood pressure at the right level. Blood pressure is closely related to the health of the kidneys (NIDDK, 1998). Over a number of years, high blood pressure can narrow and

thicken the blood vessels of the kidneys. The kidneys then filter less fluid, and are unable to operate if their flow of blood is slowed or stopped (NIDDK, 1998). As a result, toxins and waste products build up in the blood and poison the entire body. All levels of hypertension (mild to severe) can decrease kidney function (Bales, 1996). The incidence of ESRD caused by hypertension has increased each year for the last decade. One fourth of all kidney dialysis patients in the U.S. lost their kidneys to the effects of hypertension (Bales, 1996). Anyone can develop high blood pressure, but some people are more likely to develop it than others. Most people with high blood pressure do not have any symptoms. The only way to determine if blood pressure is elevated is to have it measured (Bales, 1996). Hypertension is widespread among all Americans, but is epidemic among African Americans. Hypertension occurs twice as often in blacks than whites, develops earlier, and is more severe for African Americans than any other group of people (Bales, 1996).

African Americans and Hypertension

African Americans are more likely than whites to have high blood pressure and to develop kidney problems from hypertension, even when blood pressure is only mildly elevated. In fact African Americans aged 25 to 44 are 20 times more likely than their white counterparts to develop

hypertension related kidney failure. Kidney disease caused by hypertension is also a leading killer of African Americans, causing death in African Americans at six times the rate of white Americans. After diabetes, high blood pressure is the leading cause of ESRD. Each year, hypertension is responsible for 42 percent of new cases of ESRD among African Americans (NIDDK, 1998).

Dialysis

There are two types of dialysis, hemodialysis and peritoneal dialysis. Hemodialysis is used to clean and filter the blood, remove harmful wastes and extra salt and fluid, control blood pressure, and maintain the proper balance of chemicals such as potassium, sodium and chloride (NIDDK, February 1998). Hemodialysis uses a machine with a dialyzer. This is a special filter used to clean blood. Blood travels from the body through tubes, and into the dialyzer. After the blood is cleaned, it is returned to the body through another set of tubes (N1DDK, April 1998). Patients undergoing hemodialysis are attached to a machine for two to four hours, two or three times a week. Hemodialysis occurs most often in an outpatient center, but may also occur at home.

The second type of dialysis is peritoneal dialysis. The peritoneum is the membrane which lines the abdominal cavity. In peritoneal dialysis, the peritoneal cavity is filled with dialyzing fluids and the patient's blood is

purified as it passes through the peritoneal membrane. A cleaning solution, called a dialysate, travels through a catheter into the abdomen. Fluid, wastes, and chemicals pass from tiny blood vessels in the peritoneal membrane into the dialysate. After several hours, the dialysate is drained and the abdomen is re-filled with fresh dialysate to begin the cleaning process again (NIDDK, April 1998). This process is continuous and the dialyzing fluid is replaced every few hours.

There are three types of peritoneal dialysis: continuous ambulatory peritoneal dialysis (CAPD); continuous cyclic peritoneal dialysis (CCPD); and intermittent peritoneal dialysis (IPD). The most common type of peritoneal dialysis is CAPD. This process requires no machine, and may be performed in any well lit location. It is continuous. The dialysate passes through a plastic bag into the abdominal catheter, and then back into the plastic bag. The CCPD process is similar to CAPD, except a machine connects to the catheter and automatically fills and drains dialysate from the abdomen at night, usually while the patient is sleeping. During IPD, the same machine is used as with CCPD, but it is usually performed in the hospital and takes longer than CCPD (NIDDK, April 1998). Continuous ambulatory peritoneal dialysis (CAPD) is a self treatment, requiring 4-6 hours for each treatment, and the dialysate solution must be changed 3-4 times a day.

Continuous cyclic peritoneal dialysis (CCPD) requires a machine and the help of a partner. Treatment is performed for 10-12 hours each day. Intermittent peritoneal dialysis (IPD) requires a machine and the help of a partner. The treatment is performed several times a week for a total of 36-42 hours per week (NIDDK, April 1998).

Most African American patients undergo hemodialysis in an outpatient center, the far more restrictive type of dialysis. Of those patients surviving one year or more after ESRD diagnosis, less than 10 percent of black dialysis patients were undergoing peritoneal dialysis, compared to approximately 15 percent of white dialysis patients (Webster, 2000).

There are several possible reasons hemodialysis may be the modality of choice for African Americans with ESRD. One important issue is the higher risk of infection for African Americans receiving peritoneal dialysis. There appears to be a two fold increase in the rate of peritonitis, inflammation of the peritoneal membrane, for black persons compared with white persons who receive peritoneal dialysis. In addition, studies have found that the time to an initial episode of peritonitis for white persons was 50% longer than for black persons (Webster, 2000).

Another possible explanation for African Americans not using peritoneal dialysis is economic in nature. The living accommodations of

many African Americans may be inadequate to house the machinery and supplies needed for that modality; however, there may also be a bias on the part of health care providers who do not trust patients to properly administer the peritoneal dialysis, or who do not take the time to inform ESRD patients of their options for different types of dialysis (Watson, 2000).

Dialysis allows many ESRD patients to have effective and productive lives, but a variety of medical complications may occur as a direct result of the treatment. Problems with dialysis, including access, infections, atherosclerosis, cardiovascular disease, and acute symptoms related to the dialysis procedure itself, may limit a patient's health and quality of life (NIH Consensus Statement, 1993).

Hemodialysis is accessed via the forearm, upper arm, shoulder, neck or groin. The literature indicates that patients, dialysis nurses, technicians and physicians have concerns regarding the complications which may occur as a result of dialysis; however, the concerns that one group prioritizes are not always shared by the other groups. The main conflicts/disagreements in perceptions surrounded the issues of access and complications (Bay, Van Cleef, Owens, 1998).

Bay and associates surveyed 128 patients and 64 medical personnel (dialysis nurses and technicians, surgeons and nephrologists) about their

preferences and concerns with regard to hemodialysis and vascular access. The study participants were associated with the Ohio State University Hospital Dialysis program. One clinic was hospital based, and three were free standing Fresenius Medical Care Dialysis Centers. Thirty-three of the patients had received dialysis for less than one year; 71 patients for one to five years; and 24 patients for longer than five years. The individuals were asked which type of access they preferred for dialysis. Physicians preferred arterio-venous (A-V) fistula in the lower arm. The AV fistula is believed to be the best approach if the patient's veins are large enough and there is time to prepare it. A surgeon creates an AV fistula by connecting an artery directly to a vein, usually in the forearm. Connecting the artery to the vein causes more blood to flow into the vein. As a result, the vein grows larger and stronger, making repeated needle insertions easier (NIDDK, 2000). The nurses and technicians preferred polytetrafluoroethylene (PTFE) graft in the lower arm. If patients have small veins that won't develop properly into a fistula, vascular access can be achieved by the use of a synthetic tube implanted under the skin in the arm. The tube becomes an artificial vein that can be used repeatedly for needle placement. A graft does not need to develop as a fistula does, so it can be used sooner after placement, often within two or three weeks. Compared with fistulas, grafts tend to have more problems with infection or clotting, and need

replacement sooner, but a well cared for graft can last for several years (NIDDK, 2000). Patients preferred superficial access in the forearm, which was easy to use, and had minimal effect on their appearance, provided quick hemostasis after dialysis, and enabled arm comfort during access. The physicians' major concern regarding access was thrombosis (blood clots) and infection. The nurses and technicians' major concerns were insufficient blood flow, and difficult access, which prohibited dialysis access. The patients' main concern regarding access was pain during needle insertion.

Despite improvements in dialysis technology, morbidity and mortality in the ESRD population remains high for all patients. The average number of hospital days in a year for Medicare patients over the age of 65 who receive dialysis is more than five times the average days for Medicare patients over 65 who do not receive dialysis. In addition, the life expectancy for a 49 year old ESRD patient is seven years, compared with approximately 30 years for an individual of the same age from the general population (NIH Consensus Statement, 1993).

Quality of Life and ESRD

Many health care professionals are becoming increasingly concerned about the quality of life of their patients. However, it is not clear whether the health care provider's perceptions and concerns about quality of life are the

same as the perceptions and needs (educational and informational) identified by the patient(s) (Molzahn, Northcott, Doctor, 1997). Molzahn and colleagues (1997) of the University of Victoria in Victoria, BC, Canada conducted a study to describe the perceptions of physicians, nurses and patients regarding the quality of life of individuals with ESRD, in order to identify differences in ratings of quality of life and predictors of perceptions of quality of life for each group.

The sample consisted of 215 patients with ESRD, 42 primary care nurses and seven physicians who were responsible for the care of these patients. All of the patients received medical treatment at the ambulatory care clinic of a major teaching hospital in Western Canada. Of the sample group of patients, 96 were kidney transplant recipients, 52 received hemodialysis at a center, 37 received hemodialysis at home, and 30 received continuous ambulatory peritoneal dialysis (CAPD).

The patients, nurses and physicians were administered three instruments that measure quality of life. The Self Anchoring Striving Scale (SASS) consists of a ladder with 10 rungs that indicate the best to the worst possible life. A score of zero represents the worst possible life, and ten represents the best possible life. The Index of Well Being (IWB) consists of 11 items on a seven point differential scale (for example, boring vs.

interesting; or enjoyable vs. miserable). Finally, the Health State Utility Time Trade Off Technique (TTO) was utilized to measure an individual's preference for life in its present state of health versus death.

The differences in the mean scores of patients, nurses and physicians were small; however, some were statistically significant. There was only a moderate correlation between the physicians' and nurses' scores; though it was expected that the nurses' perceptions of the patients' quality of life would be closer to the patients' perceptions than to the physicians' perceptions (because nurses generally spend more time with the ESRD patients, and have greater opportunities to get to know them and understand their needs), this did not occur. The differences in the mean scores of physicians and nurses were larger than the differences in the mean scores between the patients and the nurses and the patients and the physicians. The variance between the mean scores of the comparison groups suggests that there may be ineffective communication among the health care professionals. In addition, the patients' sociodemographic characteristics appeared to predict the nurses and physicians' ratings of patient quality of life, but they did not appear to predict the patients' ratings of their own quality of life. The nurses and physicians predicted that those patients with a higher socioeconomic status had a higher quality of life. This may indicate some bias by the nurses and physicians

toward ESRD patients based upon socioeconomic status.

The study concluded that nurses, physicians, and patients rated the quality of life of individual patients differently. This study established that a health provider's perceptions may differ from those of his/her patients in a number of areas including pain, psychosocial needs, educational needs, quality of care and quality of life (Molzahn, et. al, 1997). It does not seem reasonable to expect that health care providers will interact with patients and family members in the manner which best addresses their health status and quality of life, if these providers do not know what aspects of quality of life are most important to the patients. It is important to develop a more effective way for health providers, patients and family members to communicate their needs and to ensure that treatment modalities provided have quality of life as a consideration - if this can be done without significant compromise to the patient's medical status.

Quality of life issues are very important before dialysis occurs, and should be given strong consideration during that time. ESRD patients need to realize that dialysis does not have to be the end of happiness and productivity in their lives. Maintenance of physical strength, appetite, and optimal physiologic and psychological functioning may facilitate acceptance of the dialysis, continuation of work activities and other interpersonal relationships,

and compliance in the patient's medical care, as outlined by his/her physician (NIH Consensus Statement, 1993). As the need for dialysis becomes more certain, preparation of the patient by introduction to 1) various aspects of the therapy; 2) members of the renal team; 3) the physical site of the therapy; 4) and other patients undergoing dialysis, will generally facilitate acceptance and compliance. Another potential benefit is the opportunity to discuss the characteristics of the various modes of dialysis therapy in order to involve the patient and his/her care givers in the selection (NIH Consensus Statement, 1993).

Importance of Health/Patient Education in ESRD

Good outcomes for patients on hemodialysis require that patients have the ability and motivation to engage in appropriate self care (Badzek, Hines, Moss, 1998). Many of the most common problems experienced by dialysis patients are directly related to the patients' failure to eat appropriate foods, restrict fluid intake, or take medications at prescribed intervals. The patients' failure to engage in self care practices increases their risk of complications and can be a major source of frustration for health care providers (Badzek, et al., 1998). Studies have shown that 25-50% of dialysis patients frequently fail to comply with recommended self care practices (Badzek, et al., 1998).

Providing anticipatory guidance and/or education for patients

experiencing changes in their lives because of the onset of disease and disability is extremely important in order to prevent unnecessary additional anxiety and misunderstanding. Anecdotal evidence suggests that there may be a dearth of culturally specific, meaningful, and appropriate ESRD and dialysis education materials or teaching tools in the Washington, DC metropolitan area, which can be accessed by African American dialysis patients and their families. For this study, an important area for consideration is if the patients have a good understanding of the causes, prevention of and possible treatments available for ESRD. When a patient is initially diagnosed with a possibly precipitating disease such as hypertension and diabetes, they should be made aware that ESRD is a possible/probable effect of these diseases, and that once kidney disease progresses to ESRD, it is irreversible. A comprehensive health education program may help to decrease the incidence and prevalence of ESRD. The responsibility for this education belongs to the patients' primary care providers (nurses, physicians, etc.) and the patient.

Research supports the immediate value of pre-dialysis education. One study revealed that patient education produced important benefits in ESRD patients. Devins, et al. (2000) evaluated ESRD patients before and after they began dialysis treatment. Those patients who received a specially designed pre-dialysis education program had a significant knowledge advantage over

those patients who received the usual standard of practice and were not exposed to a specific educational program (Devins, et al. 2000). One is mindful, however, that a greater degree of knowledge about the disease and treatment options alone may not evidence a change in behavior or improve health outcomes.

Some studies have shown that the medical treatment expectations for patients with a serious disease are higher for patients with education beyond high school (Myers, et al. 2000). This researcher suggests that those same patients would have been more likely to receive a thorough educational program because they would be more active in the desire to understand and seek the most comprehensive and appropriate treatment for their disease. Once a patient has been diagnosed with ESRD, it is also important that he/she be made aware of all possible treatment options, including transplantation. African Americans with ESRD receive kidney transplants at a much lower rate than the general population. It has been reported that the difference between blacks and whites in access to transplantation is not due to a difference in the preference of patients. African American patients were only slightly less likely than whites to want a transplant (Levinsky, 1999). The racial difference in access to kidney transplantation is part of a pattern in the United States, where African American patients have less access than white

patients to a number of effective clinical treatments (Levinsky, 1999). In addition, a study of Medicare dialysis patients conducted by Ayanian et al (1999) revealed that there may be racial differences in the quality of care provided African American ESRD patients, even when financial access to basic medical care is equal, because of Medicare coverage (Levinsky, 1999). All of the reasons for this disparity are not clear. However, one may infer that lack of information provided by the treating physicians, and cultural insensitivity may be contributing factors.

Much of the current literature on patient education focuses on the necessity of integrating cultural diversity in patient education (Bechtel and Davidhizar, 2000). Bechtel and Davidhizar (2000) focus on the need for nurses and other health care providers, educators and supervisors to incorporate cultural research and health beliefs in patient and staff education. The ability to effectively provide health education to different cultures and population groups is termed "cultural competence" by Garrity (2000).

Once a patient begins dialysis, there is another educational process which must occur, including the nutritional and physical requirements for dialysis patients, and an explanation of the complications of this life saving treatment. Borden et al (2000) investigated the short period of training provided to peritoneal dialysis patients, and found that educational methods

such as group meetings and the influence of the media helped to improve knowledge on nutrition for patients and family members. It is not certain if patients who receive dialysis are aware of the complications related to hemodialysis. If they are not sufficiently aware, then they may benefit from a more comprehensive education program prior to the start of their dialysis, in order to prepare them for these potential complications.

It is anticipated that those patients with a higher level of formal education may receive a more comprehensive health education program because they may be more actively involved in the treatment of their kidney disease. The basis for this determination will be the amount and types of pre-dialysis information provided to the patients, and the reported level of satisfaction by study participants regarding the pre-dialysis information and education they received. It is hoped that findings of a disparity between the amount and degree of pre-dialysis health education provided to ESRD patients based upon income, socioeconomic status, and educational level would facilitate a more specific, need based and comprehensive educational program for all ESRD patients before dialysis becomes necessary.

Ecological Perspective/Ecological Theory and Health

The ecological perspective and ecological theory are concepts which have been outlined by Bronfenbrenner and colleagues in order to describe

how ecological concepts influence health, and may be used by health professionals in order to promote health and prevent or better treat disease (Grzywacz and Fuqua, 2000). In "The Ecology of Human Development," Urie Bronfenbrenner (1979) combined aspects of sociology and developmental psychology to place child development in an ecological perspective. He presented a model of the ecological environment using interconnecting systems (Sloan, 1990). Bronfenbrenner's ecological perspective emphasized an individual's relationship within his/her social context. He theorized that human development occurs in a set of overlapping ecological systems, and that all of these systems operate together to influence what a person becomes as he/she develops (Bronfenbrenner, 1979).

Bronfenbrenner's model consists of four interlocking systems that shape individual development: microsystem, mesosystem, exosystem, and macrosystem (Sloan, 1990). The microsystem is defined as a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting. The mesosystem is the interrelations among two or more settings in which the developing person actively participates (family, work, social life). The exosystem refers to one or more settings that do not involve the developing person as an active participant, but in which events occur that affect or are affected by what happens in the setting containing the

person, for example, neighborhood or community structures that affect the functioning of smaller systems. The macrosystem refers to the broad ideological belief systems and organizational patterns within which the meso and exo systems exist (health policies). Macrosystems are not static, but change through evolution and revolution (Sloan, 1990). A distinguishing feature of Bronfenbrenner's model and other ecological models is an equal focus on both the person and the environment. These models have been expanded to include phenomenon other than child development. Ecological theory has been used to influence the treatment and prevention of poor health by drawing the health practitioner's attention to habits and resources, as well as characteristics of the individual that influence health (Grzywacz and Fuqua, 2000).

Social ecology as a theory provides a conceptual framework for understanding the cause(s) of health problems, and for designing broad based educational, therapeutic and policy interventions. The ecological theory asserts that health care providers must understand that a person's resources (such as education, income, etc.) contribute to health problems, and are likely to influence treatment or intervention strategies (Grzywacz and Fuqua, 2000). Myers et al (2000) assessed the intention of African American men to have the recommended follow-up in the event of an abnormal prostate cancer early

detection examination. They found that African American men who have a high school education or less may be less inclined to adhere to recommended follow-up treatment.

The leading causes of death and disability during the past century have shifted from infectious diseases to chronic conditions, such as ESRD. A variety of behavioral, social and psychological factors influence this disease (Grzywacz and Fuqua, 2000). One such factor is socioeconomic status. Individuals with lower SES consistently have a lowerhealth status than those with a higher SES (Grzywacz and Fuqua, 2000). Socioeconomic status may be assessed using indicators such as educational attainment, income and occupation. Low socioeconomic status (SES) is consistently linked to decreased health status and mortality across races and cultures, and is specifically associated with kidney failure among African Americans (Perneger, et al, 1995).

Ecological models are generally very complex, which is a limitation of the theory and its application. The ecological perspective for health is characterized by several principles, which include the following: individual and community well-being are contingent upon multiple aspects of the person/population, as well as multiple dimensions of the environment; health is an outcome of the quality of the person-environment fit; certain individual

or environmental conditions exert a disproportionate amount of influence on health and well being; and, the physical and social environments are interdependent (Grzywacz and Fuqua, 2000). The models may be simplified by focusing on individual and environmental factors that are most important for a given health outcome (Grzywacz and Fuqua, 2000).

This study was guided by the ecological theory's joint and equal focus on both the person and the environment. This focus is directed to the dispositions, resources and characteristics of the individual ESRD patient which influence his/her health (Grzywacz and Fuqua, 2000). The researcher sought to determine if the dispositions, resources and characteristics of the African American patient influenced the care they received from health care practitioners. The characteristics examined in this study were age, gender, and length of time on dialysis. The resources examined included income, education, and access to care. Income and education were descriptive variables of the sample, but for the purposes of this study, they were also considered proxy measures of the dialysis patients' environment. The resource "access to care" included the variables of pre- and post-dialysis education and treatment, knowledge of disease, family support, and patient satisfaction. The disposition variables examined were quality of life and the patients' beliefs regarding health status.

CHAPTER THREE

This chapter will describe the samples, instrumentation, procedures and data analyses that were conducted for this study, including a description of the research design, selection of research sites, participant recruitment, data collection instruments and methods. Operational definitions for statistical analyses and the procedures used to analyze the data collected will also be discussed.

Sample

The study participants were drawn from a convenience sample of hemodialysis patients in the Washington, DC metropolitan area. Initially, the researcher approached two dialysis centers, and asked for permission to collect data (Gambro Medical Center and Fresenius Medical Center), and this approval was obtained. There were two research samples, the pilot study group and the final sample. It was not possible to obtain a random sample of participants, given the voluntary nature of the study. To meet the assumption of a normal distribution of cases, 30 respondents were needed for the pilot study sample and a goal of at least 100 respondents was set for the final sample. It was anticipated there would be at least a 50% non-response rate, given that participants were dialysis recipients, and not likely to be feeling well. Therefore, over-sampling by at least 50% was necessary. The samples

were comprised of African American patients who received dialysis at designated outpatient hemodialysis centers. Any patient 18 years of age or older, was eligible for participation. Patient participation was contingent upon his/her consent (Appendix A), and approval from the University of Maryland at College Park Institutional Review Board (Appendix B).

Instrumentation

This researcher developed a 113 item questionnaire measuring the following constructs: demographic characteristics of the sample, knowledge of kidney function and disease, dialysis education and treatment received, and quality of life (Appendix C). The constructs and related questionnaire items are highlighted in Table 1. Questions designed to elicit responses on quality of life were taken from the 68 item Ferrans and Powers Quality of Life Index of Dialysis, Version III 1984 and 1988. The final two questions were open ended. They were designed to elicit qualitative information from patients to determine how they were affected personally by dialysis, and what information they were provided prior to beginning the process. It was expected that the answers to these questions would help health care providers and health educators provide more relevant and comprehensive care to ESRD patients.

The background and demographic items were designed to determine

the length of time the participant had been on dialysis, his/her understanding of the cause of ESRD, family history of diabetes and hypertension, and dialysis treatment history. The thirteen item knowledge subscale consisted of an eight item knowledge test on kidney disease, and a five item list of pre-dialysis education interventions, which could have been provided to patients. For the pre-dialysis education and treatment subscales, participants were asked about the pre-dialysis education information and resources they received, including provision of information on the disease, access to a nutritionist, kidney specialist, or other health care professionals, and whether they received other treatment options besides hemodialysis (i.e. transplantation, medication, peritoneal dialysis).

The satisfaction subscale items measured the participant's degree of satisfaction with the pre-dialysis treatment they received, and their perceptions regarding how prepared they were for the dialysis process itself, by health care professionals. Quality of life was measured using the 68 item Ferrans and Powers Quality of Life Index Dialysis Version III. The final two questionnaire items were open ended, and elicited participants' opinions on the impact of dialysis on their lives, and their suggestions regarding the treatment and education which should be provided to pre-dialysis patients.

Procedures

The following study protocol and patient data collection procedures were reviewed with the dialysis center staff at the participating institutions:

1) Each patient who agreed to complete the questionnaire was to sign a consent form. If a patient agreed to participate and signed the form, he/she would be provided a questionnaire.

2) A cover letter explaining the purpose of the survey and emphasizing the importance of strictly following the directions for the questionnaire was attached to the questionnaire (Appendix D). The patient's name was not included on the questionnaire.

3) All participating patients were asked to complete the questionnaire prior to leaving the facility.

4) The questionnaire was to be placed in a sealed envelope, and left in a clearly marked box located in the reception area of the clinic.

5) In order to collect the data, the clinic receptionist was to ask all patients who came to their facility during a 30 day period if they wanted to complete the questionnaire. The pilot study data were collected between September 2002 and October 2002.

Because of a number of difficulties encountered by the researcher, the proposed procedures were changed during the course of data collection. The

pilot study surveys initially were provided to the dialysis center receptionist, with envelopes for each survey, in order to ensure confidentiality. After one week, the researcher returned to the clinic and was informed that the receptionist had forgotten to ask the patients to complete the surveys. The researcher returned the following week, and one survey had been completed and returned. At that time, the researcher asked the clinical director if it would be possible for the researcher to personally ask the patients to complete the survey. Permission was provided to do that. The researcher agreed that patients who were sleeping would not be disturbed, and patients who declined to participate would not be cajoled or badgered to change their mind.

Over a period of one month, approximately 13 surveys were completed. The researcher was asked by seven of the first ten participants for assistance with completing the survey. On three occasions the patient stated that the dialysis equipment prevented him/her from writing and completing the survey. When the patient was asked if he/she could complete the survey with assistance, each responded "yes." On other occasions, the researcher was asked to read aspects of the questionnaire, or to explain the meaning of a specific question or word. The researcher assisted the participants by reading specific questions and responses, and circling the answer(s) provided by the participant.

Privacy (in terms of being overheard by other patients) was maintained because of the positioning of chairs and equipment in the dialysis center. Each chair was located at least six feet from the other, and the noise of the dialysis machinery made it difficult for another patient to overhear questions or answers being read and answered. Other patients could not see the responses which were circled by the researcher. The researcher sat next to the patient and read each questionnaire in a normal to low tone of voice.

It was determined that the researcher needed to be on site when questionnaires were completed. Further, the researcher needed to read each survey aloud to participants. The researcher was granted permission from Gambro Medical Care, Inc. to conduct research for the final study at five additional dialysis centers in the Washington, DC metropolitan area (Appendix E).

Data Analysis

The dependent variables examined were pre- and post-dialysis treatment provided to ESRD patients, patient satisfaction with dialysis treatment, knowledge of ESRD and related treatments, and quality of life. The independent variables were income and educational level of the ESRD patients. In addition, age, gender, and length of time on dialysis were examined as possible confounding variables to determine if they had an

impact upon the dependent variables.

Research question one asked: “Are African American ESRD patients adequately educated about the disease, its causes, possible complications, and range of treatments available?” Research question two asked: “Will African American ESRD patients with higher income and educational levels score higher on the knowledge and pre-dialysis education subscales when compared to patients with lower income and education levels?”

Responses from questionnaire items 10 through15 and 18 were used to answer these questions. Items 10 through15 made up the knowledge test. The answers were checked for correct responses, and the sum of correct answers was tabulated. The highest possible score was eight. Each correct or best answer received one point. Incorrect responses received zero points. Item 18 listed five types of educational material the participant may have received prior to beginning dialysis. The participant was asked to indicate the material(s) he/she was provided, pre-dialysis. For each item selected, one point was assigned. The maximum score which could be awarded for that area was five. The possible range of scores for the knowledge subscale was 0 through13. A higher score indicated a higher level of knowledge and pre-dialysis education. The mean scores for each income and education group were compared, using analyses of variance (ANOVA), in order to

determine if the differences between the groups' responses were significant.

Research question three asked: "Is the degree of satisfaction with pre-dialysis information and education positively related to the age, level of education and income of African American ESRD patients?" Items 19 and 25 through 28 were used to comprise the satisfaction subscale. The scores in this subscale ranged from minus two (-2) to six. In question 19, participants were asked how satisfied they were with the pre-dialysis educational materials provided to them. The listed answers and respective scores included: very satisfied (2), satisfied (1), not satisfied (-1) and very unsatisfied (-2). For items 25 through 28, participants were asked if they believed their physician and other medical professionals spent enough time with them in their pre-dialysis appointments, and if the physician completely answered all of the questions they had about why they needed dialysis, prior to beginning treatment. The responses were "yes," "no," and "I do not remember." For each "yes" response, a score of one was given. For all other answers, a score of zero was given. The satisfaction subscale item scores were summed. A higher score indicated a greater degree of satisfaction with pre-dialysis education and treatment. Analyses of variance were performed for each age, education and income group, in order to determine if there were significant differences between the scores for each category.

Research question four asked: "Do African American ESRD patients with disparate income and education levels receive different treatment interventions?" Questionnaire items 23 and 29 were used to answer research question 3. Item 23 listed treatment interventions which may have been provided prior to receiving dialysis. The list was based on the NIH recommended pre-dialysis treatment interventions. Item 29 listed treatment interventions which may have been provided after dialysis began. Each participant was asked to indicate which of the treatment interventions he/she had received. Each response in items 23 and 29 was assigned a value of one point. The responses were summed, with a possible range of scores from zero to ten for each participant. The scores for each income and education group were calculated and compared, using analyses of variance, in order to determine if the differences between the groups' scores were significant.

Item17 was used to determine what treatment options were provided prior to dialysis and items 21 and 22 were used to determine if the participant had ever received a different type of dialysis. These responses were tabulated and reported in the descriptive statistics section.

Research question five asked: What are the perceptions of African American dialysis patients regarding their quality of life? Quality of Life scores were calculated according to instructions provided by the authors of

the Ferrans and Powers Quality of Life Index. Five scores were calculated: 1) Total Quality of Life Score, which reflects overall quality of life, 2) Health and functioning subscale score, 3) Social and economic subscale score, 4) Psychological/spiritual subscale score, and 5) Family subscale score. The Quality of Life Index was made up of two 34 item questionnaires. Part 1 included "satisfaction" items. Part 2 included "importance" items. Specific items from each questionnaire were used to calculate the subscale scores.

Study Limitations

This study used a convenience sample of African American dialysis patients in the greater Washington, DC area, which presented limitations related to external validity. Because this study's sample was drawn from a narrow, specific geographic area, many of the dialysis patients may have had the same physicians and health care providers. This potential lack of variability may have influenced the results of the study, in that the pre-dialysis treatment options and patient education may have been similar for the entire group. Also, because this was a convenience sample, findings can not be generalized to other groups.

A potential for investigator bias may also have existed. The researcher conducted each interview, and the study participants were aware the research was being conducted for a dissertation. A halo effect could exist, with

participants attempting to provide answers they thought the researcher wanted to hear, instead of revealing their true feelings.

A threat to internal validity also exists, history. Because there was no limit on the participants' length of time on dialysis, there was the potential that some answers related to participants' satisfaction with pre-dialysis educational and medical intervention may have been influenced by the recency of the initiation of dialysis. Conversely, they may have found it difficult to remember back to their pre-dialysis treatment.

Table 1 Questionnaire Constructs

Variable/Construct Measured	**Questionnaire Item #**
Demographic and Background Information	1-9, 20-22, 24, 30-31, 39-43
Knowledge Subscale	10-15
Pre-dialysis Education Scale	16-18
Satisfaction Subscale (Education, Treatment)	19, 25-28
Pre-dialysis Treatment Scale	23
Post-dialysis Treatment Scale	29
Effects of Dialysis on Family; Family Interactions	32-34
Quality of Life Scale	35-38, 44-111
Open Ended Questions	112-113

CHAPTER FOUR

Analysis

This chapter includes the results of the pilot study and findings from the final questionnaire. A description of the sample, response rates, item analyses, baseline comparisons, and analyses of the research questions are provided. The study procedures and questionnaire were reviewed by the institutional review board (IRB) of the University of Maryland at College Park, to ensure that subjects' rights were protected. Institutional review board approval of the questionnaire was received from the University of Maryland.

Pilot Study Results

To develop the final questionnaire, a pilot study was conducted, and an expert panel was used. The pilot study sample consisted of 29 dialysis patients from two dialysis clinics. The five person expert panel consisted of a nephrologist, a physiologist, a health educator, an expert in ecological theory, and another in research design. The experts included the medical director for the Howard University Dialysis center, a retired professor of health education, a research design consultant for the National Institutes of Health, and a former member of the researcher's dissertation committee, who was an expert in ecological theory. These experts were asked to provide their opinion

regarding the content validity, acceptability and comprehensibility of the items (Table 2). After changes to the questionnaire suggested by the experts were made, the revised instrument was then pilot tested with a sample of dialysis patients (n= 29) to establish reliability of the knowledge subscale. These respondents also provided feedback regarding readability, understandability, and acceptability of the questionnaire (Appendix F).

Over a period of two months, between the two dialysis centers, ninety patients were approached to participate, 29 dialysis patients agreed (32% response rate.) (Table 3) Thirteen participants were male; 16 were female. Twenty-five of the participants were African American; four were white. The ages of the participants ranged from 33 to 81. The median age was 59, and the mean was 56.8 years (SD=11.6). The majority of pilot study respondents had an income of $0-$10,000 (55%), and had a high school degree or less (93%).

The purpose of the pilot study was to determine if the knowledge scale was reliable, and to elicit opinions from respondents regarding the appropriateness of the questionnaire. Cronbach's reliability of the knowledge test was .70. The knowledge test was included as part of the knowledge subscale.

Respondents were also asked about the readability of the questionnaire.

Table 2 Summary of Expert Panel Review

Panel Member Expert in:	Understandability and readability of directions and questions	Comments on the questionnaire format	Recommendations
Nephrology	No problems identified	No problems identified	The survey should ask if the participant had seen a physician at least six months prior to dialysis
Physiology	Some words appear sophisticated, and the patients may not be able to understand them, i.e. "ethnicity," "physician," "gender."	No problems identified	It is important to ensure that the language used is age, education level appropriate
Education	None	The questionnaire feels long when starting; however it is not long when reading through	Edit for grammar
Ecological Theory	None	None	Edit the education categories: 1) 0-8th grade, 2) 9^{th} -12^{th}, etc. The income classes should have specific meaning
Research Design	None	Operationalize "satisfaction" questions so that they can be fully assessed.	The research design should include ANOVA or multiple regression analysis to answer the research questions.

Table 3 Demographic Characteristics of Pilot Study Participants

Characteristic	N	(%)
Gender		
Male	13	(44.8)
Female	16	(55.2)
Age (years)		
33-49	8	(27.6)
50-64	14	(48.3)
65-81	6	(20.7)
Missing	1	(3.4)
Ethnicity		
African American	25	(86.2)
White	4	(13.8)
Education		
Up to High School	12	(41.4)
At least High School Graduate	15	(51.7)
College Graduate and Above	1	(3.4)
Missing	1	(3.5)
Income		
$0 - $10,000	16	(55.2)
>$10,000 - $30,000	9	(31.0)
>$30,000	2	(6.9)
Missing	2	(6.9)

N = 29

Three participants (10%) stated the questionnaire was too long. Ten percent also (n=3) stated that the questions were too personal. Three percent (n=1) stated the questions were redundant. The overwhelming majority of pilot study participants (76%, n=22) indicated the questions were clear and easy to understand, and they had no negative comments about the survey. As a result of these findings, the questionnaire was not changed prior to distribution to the final study participants. In conclusion, the sample for the pilot study consisted of 29 patients who received hemodialysis treatment at one of two clinics.

Results

Description of the Final Sample

Power analysis indicated at least one hundred respondents would be needed in the final sample. One hundred eighty four patients were approached by the researcher and asked to participate in the study. One hundred and eight dialysis patients completed the interview, resulting in a 59% response rate. To ensure that the final sample was comprised of only African American dialysis patients, surveys where the respondent was not identified as African American were excluded. Participants in the final study consisted of 98 African American hemodialysis patients between the ages of 26 and 85; the median age was 56 years. The majority of participants were

male (58%), high school graduates (65%), unemployed (85%), and in the $10,000 or less income category (51%) (Table 4). Respondents were asked to identify the cause(s) of their ESRD. Eighty-one percent identified hypertension and or diabetes as the cause of ESRD/dialysis (Table 4). Approximately one third of the sample (28%, n=28) reported they were unaware they had ESRD prior to being informed that they needed dialysis. Twenty-four percent (n=23) of the participants had been receiving dialysis less than one year while thirty-six percent of the sample (n=35) had been receiving dialysis for the past two to five years.

Virtually all of the dialysis patients (99%, n=97) received dialysis three times a week. Even though eighty-five percent of the sample (n=83) reported they had seen a physician in the six to twelve months prior to beginning dialysis, twenty-eight percent (n=27) reported they were informed they had kidney disease at the same time they found out they needed dialysis (Table 4). Respondents were also asked to report the ethnicity of their kidney doctor. Fifteen percent (n=15) indicated that their physician was African American; 34% (n=33) identified their physician was White; 27%,n=26) indicated their physician was "a foreigner."

Research Questions One and Two

Research question one asked: "Are African American ESRD patients

adequately educated about the disease, its causes, possible complications, and range of treatments available?" Research question two asked: "Will African American ESRD patients with higher income and education levels score higher on the knowledge and pre-dialysis education subscale, when compared to patients with lower income and education levels?" Responses from questionnaire items 10 through 15 and 18 were used to answer these questions. Items 10 through15 made up the knowledge test, and the sum of correct answers was tabulated. The highest possible score was eight. All 98 participants answered the knowledge test items. Forty percent of the sample (n=39) answered all of the knowledge questions correctly. Approximately 87% of the sample (n=85) scored six or higher on the knowledge test. The minimum score participants received on the knowledge test was 38% (three correct responses); the maximum score was 100% (eight correct responses). The mean score on the knowledge test was 6.8 (SD=1.3); on average respondents scored an 85% on the test.

Item 18 listed the types of educational material participants received about dialysis before beginning treatment. For each educational resource received, one point was assigned, for a maximum score of five. The pre-dialysis education sum was combined with the knowledge test score to develop the knowledge subscale, resulting in a possible range of scores from

Table 4 Demographic and Background Characteristics of Respondents

Characteristics	N	(%)
Demographic Variables		
Gender		
Male	57	(58.2)
Female	41	(41.8)
Age (years)		
26-45	23	(23.5)
46-55	23	(23.5)
56-65	28	(28.5)
65-85	24	(24.5)
Education		
Up to High School	22	(22.4)
At least High School Graduate	64	(65.3)
College Graduate and Above	12	(12.2)
Income		
$0 - $10,000	50	(51.0)
>$10,000 - $30,000	27	(27.6)
>$30,000	16	(16.3)
Employment Status		
Unemployed	83	(85.0)
Employed	15	(15.0)
Background Variables		
Cause of ESRD/Dialysis		
Diabetes	14	(14.3)
Hypertension	39	(39.8)
Hypertension and Diabetes	26	(26.5)
Congenital Kidney Disease	4	(4.1)
Other	15	(15.3)

Table 4 Demographic and Background Characteristics of Respondents (cont.)

Characteristics	N	(%)
Background Variables		
When told of ESRD diagnosis		
When dialysis began	27	(27.6)
Six months before	25	(25.5)
One year before	24	(24.5)
Up to five years before	20	(20.4)
I do not remember	1	(1.0)
Length of time on dialysis		
Less than one year	23	(23.5)
Between 1 to 2 years	21	(21.4)
Between 2 to 5 years	35	(35.7)
More than 5 years	19	(19.4)
Seen by physician 6 to 12 months pre-dialysis		
Yes	83	(84.7)
No	14	(14.3)
I do not remember	1	(1.0)
Ethnicity of kidney physician		
African American	15	(15.3)
White	33	(33.7)
Latino/Hispanic	7	(7.1)
Asian	11	(11.2)
Other/"Foreigner"	26	(26.5)
I do not know	6	(6.1)

N = 98

zero to thirteen. A higher score indicated a higher level of knowledge and pre-dialysis education. Respondents' actual scores ranged from four to twelve.

Respondents were divided into categories based upon income and education. A total of 93 respondents answered the income item, and data were collapsed into the following categories, $0 - $10,000 (n=50), >$10,000 - $30,000 (n=27), and >$30,000 (n=16). Ninety-eight respondents answered the education item, and again, data were collapsed into three categories, up to high school (n=22), at least high school graduate (n=64), and college graduate and above (n=12).

These research questions referenced "higher" income and education levels. However, the majority of the sample had a low to moderate income and education. Twelve percent of the sample had a college degree and 16% had an annual income >$30,000. While the term "higher" is used in the context of the sample characteristics, one must be mindful that the sample for this dissertation was less educated and had a lower income level than the general population. Oneway analyses of variance (ANOVA) were used to determine if there were significant differences between income level and knowledge, and educational level and knowledge. The overall mean knowledge score, among all respondents who completed the income item was 9.1 (SD=1.75). Knowledge subscale scores ranged between 8.8 (SD=1.85)

for those who earned $10,000 or less and 9.6 (SD=1.50) for those who earned $30,000 or more (Table 5). The knowledge subscale scores increased as income increased, however, the differences between the means were not significant (F=1.72, p=.19).

The mean subscale scores for the education groups ranged from 8.4 (SD=1.76) for those who had up to a high school educational level, to 9.50 (SD=1.57) for those who were at least college graduates (Table 5). The mean scores increased with each educational category, but again the differences between the means were not significant (F=2.43, p=.09). Based on these results, the hypotheses for research questions one and two were not supported.

Research Question Three

Research question three asked, "Is the degree of satisfaction with pre-dialysis information and education positively related to age, level of education and income of African American ESRD patients?" Items 19 and 25 through 28 were used to comprise the satisfaction subscale. Scores on this subscale ranged from minus two to six, with a higher score indicating a greater degree of satisfaction with pre-dialysis education and treatment. Age was divided into four categories, 26-45 years (n=22), 46-55 years (n=22), 56-65 years (n=28), and 66 years and above (n=22). Ninety-four (94) of the respondents answered the age item. Education and income were categorized

Table 5 Mean Knowledge Scores by Income and Education

Variable	**Knowledge Score**		
	N	$\overline{X}$	SD
Income Group			
$0 - $10,000	50	8.8	1.85
>$10,000 - $30,000	27	9.3	1.64
>$30,000	16	9.6	1.50
Total	93	9.1	1.75
Educational Level			
Up to High School	22	8.4	1.76
At Least High School Graduate	64	9.3	1.71
College Graduate and Above	12	9.5	1.57
Total	98	9.1	1.73

as indicated in the previous discussion of research question one. Eighty-nine of the respondents answered both the income and pre-dialysis education items ($0-$10,000 [n=47], >$10,000 - $30,000 [n =27], >$30,000 [n=15]), while ninety-four of the respondents answered both the education and pre-dialysis and education subscale items (up to high school [n =20], at least high school graduate [n=63], college graduate and above [n=11]).

Oneway ANOVAs were used to compare satisfaction subscale scores by age, income, and education. There were no statistically significant differences in pre-dialysis satisfaction scores when examining age ($F = 1.32$, $p = .27$) or income ($F = 1.69$, $p = .19$). The highest income category appeared to be the least satisfied with the pre-dialysis education and treatment provided (Table 6). The mean satisfaction subscale scores ranged from 3.64 (SD=2.11) for the 46-55 years old category to 4.78 (SD=1.38) for the 66 years and above category (Table 6). The mean scores on the satisfaction subscale by income level ranged from 3.5 (SD=2.17) for the >$30,000 category to 4.6 (SD=1.22) for the $10,000 - $30,000 category. The mean satisfaction score for the entire group was 4.04 (SD=2.04).

When examining educational level, there was a statistically significant difference in satisfaction scores based on educational level ($F= 3.50$, $p=.03$). The mean satisfaction subscale scores ranged from 2.72 (SD=2.37) for the

college graduate and above category to 4.70 (SD=1.22) for the up to high school category (Table 6).

The mean subscale scores decreased with each education category, indicating the degree of satisfaction with pre-dialysis education and treatment decreased as the level of education increased. Tukey post hoc tests revealed that the mean scores for the up to high school and college graduate and above groups significantly differed from one another 4.70 (SD=1.22) vs 2.72 (SD=2.04) (Table 7). The hypothesis for research question three was supported in that education level was negatively related to satisfaction with pre-dialysis information received, but this did not hold true when examining satisfaction levels based on age and income groups.

Research Question Four

Research question four asked, "Do African American ESRD patients with disparate income and education levels receive different treatment interventions?" Items 23 and 29 of the questionnaire detailed five pre- and post-dialysis treatments or interventions, and asked the participant if he/she performed any of the listed activities. For each yes response, one point was assigned. Pre- and post-dialysis treatment interventions were considered separately and combined. For each scale, there was a possible range of scores from zero to five. For the combined scale, there was a possible range of scores

Table 6 Mean Satisfaction Scores by Age, Income and Education

Variable	Satisfaction Score		
	N	$\overline{X}$	SD
Age of Respondent			
26 to 45 Years	22	3.9	2.52
46 to 55 Years	22	3.6	2.11
56 to 65 Years	28	3.9	1.97
66 Years and Above	22	4.8	1.38
Total	94	4.0	2.04
Income Level			
$0 -$10,000	47	4.0	2.20
>$10,000 - $30,000	27	4.6	1.22
>$30,000	15	3.5	2.17
Total	89	4.1	1.96
Educational Level			
Up to High School	20	4.7	1.22
At Least High School Graduate	63	4.1	2.11
College Graduate and Above	11	2.7	2.37
Total	94	4.0	2.04

Table 7
Post Hoc Tests - Tukey HSD (Mean Satisfaction Scores by Education)

Education	Comparison	Mean Difference	Std. Error	Sig.
Up to High School	At Least High School Graduate	.64	.51	.43
	College Graduate and Above	1.97	.75	.03
At Least High School Graduate	Up to High School	-.64	.51	.43
	College Graduate and Above	1.34	.65	.11
College Graduate and Above	Up to High School	-1.97	.75	.03
	At Least High School Graduate	-1.34	.65	.11

from zero to ten.

Oneway analyses of variance (ANOVA) were used to determine if there were significant differences between the treatment interventions provided, using income and education as independent variables. As previously mentioned, income was divided into three categories. The mean scores for pre-dialysis treatment interventions ranged from 1.6 (SD=1.54) for the >$30,000 group, to 1.9 (SD=1.55) for the >$10,000 - $30,000 group (Table 8). There were no statistically significant differences in pre-dialysis treatment intervention mean scores when considering income (F=.51, p=.60).

The mean scores for post-dialysis treatment by income ranged from 3.8 (SD=.73) for the $0 - $10,000 income group, to 4.0 (SD=.38) for the >$30,000 income group (Table 8). While the number of treatment interventions increased after dialysis began, and the mean scores for post-dialysis treatment interventions increased as income increased, there were no significant differences based on income (F=.97, p=.38).

The mean scores for pre-dialysis treatment interventions based on education ranged from 1.6 (SD=1.25) for the up to high school and college graduate and above groups to 1.8 (SD=1.28) for the at least high school graduate group (Table 8). The differences between the means were not statistically significant (F=.19, p=.83).

Table 8 Mean Treatment Intervention Scores by Income and Education

Variable	**Satisfaction Score**		
	N	$\overline{X}$	SD
Pre-Dialysis			
Income Level			
$0 -$10,000	49	1.7	1.14
>$10,000 - $30,000	27	1.9	1.55
>$30,000	15	1.6	1.55
Total	91	1.7	1.33
Educational Level			
Up to High School	22	1.6	1.25
At Least High School Graduate	63	1.8	1.28
College Graduate and Above	11	1.6	1.62
Total	96	1.7	1.30
Post-Dialysis			
Income Level			
$0 -$10,000	50	3.8	.73
>$10,000 - $30,000	27	3.9	.44
>$30,000	15	4.0	.38
Total	92	3.9	.61
Educational Level			
Up to High School	22	3.7	.78
At Least High School Graduate	64	3.9	.53
College Graduate and Above	11	4.0	.63
Total	97	3.8	.61

The mean scores for post-dialysis treatment interventions based on education ranged from 3.7 (SD=.78) for the up to high school group to 4.0 SD=.63) for the college graduate and above group. The mean scores for post-dialysis treatment interventions increased as level of education increased, however, the differences between the means were not statistically significant (F=1.67, p=.19). Overall, patients with disparate income and education levels did not receive significantly different treatment interventions either pre - or post-dialysis, therefore the hypothesis for research question four was not supported.

Research Question Five

Research question five asked: What are the perceptions of African American dialysis patients regarding their quality of life? Items 44 through 111 of the questionnaire comprised the 68 item Ferrans and Powers Quality of Life Index, which was divided into two parts (34 items each). The first part included "satisfaction" items. The second part included "importance" items. The first section asked the participants how satisfied they were with certain aspects of their lives. Possible responses were very dissatisfied (1), moderately dissatisfied (2), slightly dissatisfied (3), slightly satisfied (4), moderately satisfied (5), and very satisfied (6). The second section asked how important these aspects were to them. Responses on this section could range

from very unimportant (1) to very important (6). Quality of Life subscale scores were calculated according to instructions provided by the authors of the Ferrans and Powers Quality of Life Index (QLI). A total quality of life score, and four separate subscale scores were calculated. The subscales included: 1) total quality of life, 2) health and functioning quality of life, 3) social and economic quality of life, 4) psychological/spiritual quality of life, and 5) family quality of life. The index and subscales were scored based upon the following formula which was provided by the QLI authors.

1) Recode satisfaction scores by centering the scale on zero. This was accomplished by subtracting 3.5 from the satisfaction response for each item, in order to produce responses of -2.5,-1.5, -.5, +.5, +1.5, and +2.5.
2) Weigh satisfaction responses with the paired importance responses. This was accomplished by multiplying the recoded satisfaction response by the raw importance response for each pair of satisfaction and importance scores.
3) Obtain preliminary score for the total score. This was accomplished by adding together the weighted responses obtained in step 2 for all of the items.
4) Obtain the final total QLI score. This was accomplished by dividing each sum obtained in step three by the number of items answered by each individual. To eliminate negative numbers, "15" was added to every score. This produced the total QLI score. The possible range for the final scores was zero to thirty (0 to 30).

The same steps were used to calculate subscale scores; items from Part 1 (Satisfaction) and Part 2 (Importance) were used to make up the subscales (Table 9). As indicated above, the participants chose a number (one through six) which identified how satisfied they were with certain aspects of their lives, and how important those aspects were to them.

Oneway analyses of variance (ANOVA) were used to determine if there were significant differences on total quality of life, and on each subscale by age, income, length of time on dialysis and education. When examining total quality of life scores by age, the mean score ranged from 20.9 (SD=4.87) in the 26 to 45 years category to 23.1 (SD=3.11) in the 66 years and above category. The total mean quality of life score for the entire sample was 22.5 (SD=3.92); the possible score range was 0 to 30, and the actual range was 6 to 30. Individual subscale scores could also range from 0 to 30. There were no significant differences on total quality of life scores among the various age groups (n=98) ($F = 1.68$, $p = .176$), however the scores did increase as age of respondents increased (Table 10).

The mean scores for the health and functioning subscale ranged from 20.2 (SD=5.73) in the 26 to 45 years category to 21.8 (SD=4.49) in the 46 to 55 years category (Table 10). The total mean health and functioning quality of life score was 21.2 (SD=4.53). There were no significant differences by

Table 9 Ferrans and Powers Quality of Life Subscale Items

Subscale	N	Items
Total Quality of Life Score	68	1 to 68
Health and Functioning Subscale	14	1, 2, 3, 4, 5, 6, 7, 8, 12, 17, 18, 19, 26, 27
Social and Economic Subscale	8	15, 16, 20, 21, 22/23, 24, 25
Psychological/Spiritual Subscale	7	28, 29, 30, 31, 32, 33, 34
Family Subscale	5	9, 10, 11, 13, 14

Table 10 Mean Total and Subscale Quality of Life Scores by Age

Quality Of Life Subscale	Variable	N	$\overline{X}$	SD
Total Quality of Life	26 to 45 Years	23	20.9	4.87
	46 to 55 Years	23	22.9	3.83
	56 to 65 Years	28	22.9	3.58
	66 Years and Above	24	23.1	3.11
	Total	98	22.5	3.92
Health and Functioning Quality of Life	26 to 45 Years	23	20.2	5.73
	46 to 55 Years	23	21.8	4.50
	56 to 65 Years	28	21.0	4.34
	66 Years and Above	24	21.6	3.49
	Total	98	21.2	4.53
Social and Economic Quality of Life	26 to 45 Years	23	19.0	5.73
	46 to 55 Years	23	22.0	5.05
	56 to 65 Years	28	22.7	4.47
	66 Years and Above	24	22.6	3.18
	Total	98	21.6	4.83
Psychological/Spiritual Quality of Life	26 to 45 Years	23	22.2	5.29
	46 to 55 Years	23	24.9	4.63
	56 to 65 Years	28	25.0	4.36
	66 Years and Above	24	25.0	3.54
	Total	98	24.4	4.57
Family Quality of Life	26 to 45 Years	23	23.9	4.67
	46 to 55 Years	23	24.4	4.55
	56 to 65 Years	28	25.9	2.92
	66 Years and Above	22	25.7	3.74
	Total	96	25.0	4.01

age (F = .57, p = .63).

The mean scores on the psychological/spiritual subscale ranged from 22.2 (SD=5.29) for the 26 to 45 years category to 25.0 (SD=3.54) for the 66 years and above category. Respondents did not differ in their psychological/spiritual quality of life subscale scores based on age (F = 2.25, p = 0.87). However, psychological/spiritual mean scores increased as age increased. Ninety six participants answered both the age and family quality of life subscale items (26 to 45 years [n=23], 46 to 55 years [n=23], 56-65 years [n=28] and 65 years and above [n=22]).

The mean scores on the family quality of life subscale ranged from 23.9 (SD= 4.69) for the 26 to 45 years group to 25.9 (SD=2.92) for the 56 to 65 years group. There were no significant differences on family quality of life subscale scores based on age (F = 1.42, p = .241). Mean scores on the social and economic quality of life subscale ranged from 19.04 (SD=5.76) for the 26 to 45 years category to 22.7 (SD=4.48) for the 56 to 65 years category. There were significant differences in social and economic quality of life scores by age (Table 10) (F = 3.21, p = .03).

Tukey HSD post hoc tests revealed significant differences in the scores for the participants who were aged 26 to 45 years and those between 56 to 65 years of age. There were also differences between the 26 to 45 years age

group and those aged 66 years and above.

The mean scores on the social and economic quality of life subscale ranged from 19.9 (SD=5.05) for the $0 - $10,000 group to 25.0 (SD=3.31) for the >$30,000 income group (Table 11). The differences between mean scores on the social and economic quality of life subscale, based on income, were significant (F = 8.47, p = .00). Tukey HSD post hoc tests revealed the differences between the $0 - $10,000 and >$30,000 income groups were significant (Table 12). There was a positive relationship between perceived social and economic quality of life and income (Table 11).

The mean scores on the psychological/spiritual quality of life subscale ranged from 22.9 (SD=4.78) for the $0 - $10,000 group to 26.8 (SD=3.28) for the >$30,000 income group (Table 11). Again, differences between the means on this subscale differed significantly by income group (F = 5.44, p = .01). Tukey HSD post hoc tests indicated the significant differences were between $0 - $10,000 and >$30,000 income groups. There was a positive relationship between income and psychological/spiritual quality of life scores (Table 12).

The mean scores on the health and functioning quality of life subscale ranged from 20.49 (SD=4.30) for the >$10,000 - $30,000 group to 23.1 (SD=3.68) for the >$30,000 income group. The differences between the

Table 11 Mean Quality of Life Total and Subscale Scores by Income

Quality Of Life Subscale	Variable	N	$\overline{X}$	SD
Total Quality of Life	$0 - $10,000	50	21.6	4.16
	>$10,000 - $30,000	27	22.5	3.43
	>$30,000	16	24.6	3.34
	Total	93	22.4	3.94
Health and Functioning Quality of Life	$0 - $10,000	50	20.7	4.84
	>$10,000 - $30,000	27	20.5	4.31
	>$30,000	16	23.2	3.68
	Total	93	21.0	4.57
Social and Economic Quality of Life	$0 - $10,000	50	19.9	5.05
	>$10,000 - $30,000	27	22.0	3.78
	>$30,000	16	25.0	3.31
	Total	93	21.4	4.81
Psychological/Spiritual Quality of Life	$0 - $10,000	50	22.8	4.78
	>$10,000 - $30,000	27	24.9	4.07
	>$30,000	16	26.7	3.28
	Total	93	24.1	4.57
Family Quality of Life	$0 - $10,000	50	24.9	3.97
	>$10,000 - $30,000	26	25.6	3.23
	>$30,000	15	24.2	5.68
	Total	91	25.0	4.08

Table 12

Post hoc tests - Tukey HSD (Quality of Life Scores by Age and Income)

Age by Social and Economic Quality of Life	**Comparison**	**Mean Difference**	**Std. Error**	**Sig.**
26 to 45 Years	46 to 55 Years	-2.96	1.37	.14
	56 to 65 Years	-3.65	1.31	.03
	66 Years and Above	-3.54	1.36	.05
46 to 55 Years	26 to 45 Years	2.96	1.37	.14
	56 to 65 Years	-.68	1.31	.95
	66 Years and Above	-.58	1.36	.97
56 to 65 Years	26 to 45 Years	3.65	1.31	.03
	46 to 55 Years	.68	1.31	.95
	66 Years and Above	.10	1.30	1.00
66 Years and Above	26 to 45 Years	3.54	1.36	.05
	46 to 55 Years	.58	1.36	.97
	56 to 65 Years	-.10	1.30	1.00
Income by Total Quality of Life				
$0-$10,000	>$10,000 - $30,000	-.86	.91	.61
	>$30,000	-2.99	1.10	.02
>$30,000	$0-$10,000	2.99	1.10	.02
	>$10,000-$30,000	2.12	1.21	.19
Income by Social and Economic Quality of Life				
$0 - $10,000	>$10,000 - $30,000	-2.11	1.06	.12
	>$30,000	-5.16	1.28	.00
>$30,000	$0-$10,000	5.16	1.28	.00
	>$10,000 - $30,000	3.04	1.40	.08
Income by Psychological/Spiritual Quality of Life				
$0 - $10,000	>$10,000 - $30,000	-2.05	1.04	.12
	>$30,000	-3.88	1.25	.01
	$0-$10,000	3.88	1.25	.01
>$30,000	>$10,000 - $30,000	1.83	1.04	.38

means were not significant (F=2.17, p =.12).

Ninety-one participants answered both the income and family quality of life items. The mean scores on the family quality of life subscale ranged from 24.3 (SD=5.68) for the >$30,000 income group, to 25.6 (SD=3.23) for the >$10,000 - $30,000 income group. The differences between the scores for the various income groups were not significant (F = .56, p = .58).

The hypothesis for research question five was supported when examining total quality of life, social and economic quality of life, and psychological/spiritual quality of life, based on income. The other quality of life mean subscale scores (health and functioning and family quality of life) did not vary significantly based upon income.

Quality of life was also analyzed using length of time on dialysis as the independent variable. Length of time on dialysis was divided into four groups, less than one year, between one to two years, between two to five years, and more than five years. All respondents answered the total quality of life, health and functioning, social and economic, and psychological/spiritual subscales items, and the length of time on dialysis item.

Ninety-six participants answered the family quality of life questions and length of time on dialysis item. The mean scores for total quality of life subscale ranged from 21.7 (SD=3.87) for participants who had

been on dialysis for more than five years to 23.3 (SD=3.79) for those on dialysis between one to two years (Table 13). The differences between the groups were not significant (F=.51, p=.68) (Table 14). The mean scores did not differ significantly on any of the quality of life subscales by length of time on dialysis (Table 13, Table 14). The hypothesis for research question five was not supported when examining quality of life subscales based on length of time on dialysis. Although participants who had been on dialysis more than five years consistently had the lowest quality of life scores, and those on dialysis between one to five years consistently had the highest quality of life scores, these differences were not significant.

As indicated previously, education was divided into three categories, and all participants answered the education item and total quality of life subscale, health and functioning subscale, social and economic subscale and psychological/spiritual subscale items. The mean scores ranged from 21.9 (SD=3.78) for the up to high school group to 23.6 (SD=3.31) for the college graduate and above group (Table 15). Differences between the means for quality of life based on educational level were not statistically significant (F = .70, p = .49).

Ninety-five participants answered the education and family quality of life items. The mean scores for the subscale ranged from 25.0 (SD=3.55) for

Table 13: Mean Quality of Life Total and Subscale Scores by Length of Time on Dialysis

Quality of Life Subscale	Variable	N	$\overline{X}$	SD
Total Quality of Life	Less Than One Year	23	22.3	3.92
	Between 1-2 Years	21	23.1	3.80
	Between 2-5 Years	35	22.7	4.10
	More than 5 Years	19	21.2	3.87
	Total	98	22.5	3.92
Health and Functioning Quality of Life	Less Than One Year	23	20.5	4.18
	Between 1-2 Years	21	21.9	5.06
	Between 2-5 Years	35	21.8	4.51
	More than 5 Years	19	20.1	4.39
	Total	98	21.2	4.53
Social and Economic Quality of Life	Less Than One Year	23	21.8	4.77
	Between 1-2 Years	21	22.0	5.53
	Between 2-5 Years	35	21.6	4.84
	More than 5 Years	19	21.2	4.41
	Total	98	21.6	4.84
Psychological/Spiritual Quality of Life	Less Than One Year	23	23.9	5.21
	Between 1-2 Years	21	25.0	4.12
	Between 2-5 Years	35	24.3	4.62
	More than 5 Years	19	24.1	4.41
	Total	98	24.4	4.57
Family Quality of Life	Less Than One Year	23	25.6	4.10
	Between 1-2 Years	21	25.9.	2.93
	Between 2-5 Years	34	24.7	4.58
	More than 5 Years	18	23.7	3.74
	Total	96	25.0	4.02

Table 14 ANOVAs: Quality of Life by Length of Time on Dialysis

Quality of Life Score	N	F	p
Health and Functioning	98	0.91	.44
Social and Economic	98	0.11	.95
Psychological/Spiritual	98	0.21	.89
Family	96	1.26	.30
Total	98	0.51	.68

Table 15 Mean Quality of Life Total and Subscale Scores by Education

Quality of Life Subscale	Variable	N	$\overline{X}$	SD
Total Quality of Life	Up to High School	22	21.8	3.78
	At Least HS Graduate	64	22.5	4.07
	College Grad and Above	12	23.5	3.31
	Total	98	22.5	3.92
Health and Functioning Quality of Life	Up to High School	22	21.2	4.17
	At Least HS Graduate	64	21.2	4.67
	College Grad and Above	12	20.8	4.80
	Total	98	21.2	4.53
Social and Economic Quality of Life	Up to High School	22	19.0	5.19
	At Least HS Graduate	64	22.2	4.46
	College Grad and Above	12	23.0	4.70
	Total	98	21.6	4.84
Psychological/Spiritual Quality of Life	Up to High School	22	24.1	4.11
	At Least HS Graduate	64	23.8	4.82
	College Grad and Above	12	27.3	2.66
	Total	98	24.3	4.57
Family Quality of Life	Up to High School	22	24.6	4.82
	At Least HS Graduate	63	25.0	3.55
	College Grad and Above	11	26.0	4.93
	Total	96	25.0	4.01

the at least high school graduate group to 26.0 (SD=4.93) for the participants who were college graduates. The differences between the mean scores were not statistically significant (F=.45, p=.64).

The mean scores on the health and functioning quality of life subscale ranged from 20.8 (SD=4.80) for the college graduate and above group, to 21.4 (SD=4.67) for the up to high school group (Table 15). The differences between the groups for the health and functioning quality of life subscale, based on the participants' educational level, were not significant (F = .04, p = .96).

The mean scores on the social and economic quality of life subscale ranged from 19.0 (SD=5.19) for the at least high school group to 23.0 (SD=4.70) for the college graduate and above group. Differences between the education groups on the social and economic quality of life subscale by the educational groups were statistically significant (F = 4.70, p = .01). Post hoc tests (Tukey HSD) revealed the significant differences were between the up to high school and at least high school graduate group, as well as the up to high school and college graduate and above groups.

The mean scores for the psychological/spiritual quality of life subscale ranged from 23.8 (SD=4.82) for the at least high school graduate group to 27.3 (SD=2.66) for the college graduate and above group. The differences

between the means for the psychological/spiritual quality of life subscale by education were statistically significant (F = 3.14, p = .04). Post hoc tests (Tukey HSD) revealed the significant differences were between the at least high school graduate and college graduate and above groups.

Research question five was supported when examining social and economic quality of life and psychological/spiritual quality of life based on education. The other mean quality of life subscale scores did not vary significantly, however the mean scores for quality of life increased as level of education increased.

Open-ended Questions

The final two items on the questionnaire were open ended. Item112 asked each respondent to describe in his/her own words how dialysis affected his/her daily life. When the answers were examined and tallied, several trends emerged.

1) One fourth of respondents (26%, n=25) indicated they had less freedom because they had to schedule their lives around dialysis treatment.
2) Twenty-four percent (n=24) reported the dialysis process was limiting and difficult, however, they also stated that the positive aspects of dialysis (i.e. the treatment keeps them alive) overrode any of the negative aspects of treatment.
3) Sixteen percent (n=16) reported they were unable to perform leisure activities or travel like they wanted.

4) Twelve percent (n=12) reported dialysis was inconvenient, “a hassle.”
5) Eight percent (n=8) reported being depressed by having to be on dialysis.
6) Eight percent (n=8) reported dialysis had caused them to lose their job.

Item 113 asked respondents to indicate the most important advice or information they believed dialysis patients and their families should receive before beginning dialysis. Again, several trends emerged.

1) A majority of respondents (53%, n=52) stated that the patients should get as much information as possible about the disease (ESRD) and dialysis treatment **before** beginning dialysis.
2) Nineteen percent (n=19) advised patients to go to every treatment, follow physician’s orders, be positive about dialysis, and follow diet restrictions.
3) Fourteen percent (n=14) advised the patients be certain they need dialysis and know why, before they begin treatment.
4) Seven percent (n=7) suggested patients get other medical opinions and treatment options before beginning hemodialysis.

CHAPTER FIVE

Discussion, Recommendations and Implications

The purpose of this study was to examine the pre- and post-dialysis education and treatment of African American ESRD patients in the Washington, DC metropolitan area. This chapter presents a discussion of the findings, recommendations, and implications for further research.

Discussion

Research questions one and two sought to determine if African American ESRD patients were adequately educated about the disease, its causes, possible complications and range of treatments. Many of the participants in this survey appeared to suggest they were not adequately educated about ESRD pre-dialysis. When asked what advice they would provide to other ESRD patients, 53% (n=52) recommended that ESRD patients get as much information as possible about the disease and dialysis treatment **before** beginning dialysis. Another 14% (n=14) advised that patients fully understand why they need dialysis before beginning treatment. The mean knowledge subscale scores were not statistically significant by income or education level. However, as respondent's income and education increased, the knowledge subscale scores also increased. This was expected, as patients with a higher educational level should demonstrate a more

comprehensive knowledge regarding ESRD and dialysis. This trend suggests that statistically significant differences in knowledge scores by income and education may have been found with a larger sample size. However, there was not a great deal of variability in income levels for this sample. The majority of respondents (51%) fell into the $0-$10,000 income group, and only 16% had an income >$30,000.

The majority of participants scored an 85% on the knowledge test, but several demonstrated a lack of practical knowledge about the ESRD and its range of treatments. When provided the options of "hemodialysis," "continuous ambulatory peritoneal dialysis," "other," and "I don't know," twenty-five percent of the sample (n=25) could not correctly identify the type of dialysis they received (hemodialysis). This may suggest that those patients were unaware of the different treatment options available to ESRD patients. While 85% of the sample (n=83) reported they had been seen by a physician six to twelve months pre- dialysis, 28% (n=27) learned they had end stage kidney disease at the same time they were informed they needed dialysis, and 26% (n=25) learned about their diagnosis only six months prior to beginning dialysis. This suggests that survey participants may have received inadequate pre-dialysis education and treatment. End stage renal disease is a terminal disorder, which occurs primarily in patients diagnosed with diabetes and/or

hypertension, both of which are chronic diseases. One would expect that physicians who had diagnosed either of those diseases in a patient would have informed him/her of the possibility of ESRD. Furthermore, symptoms of ESRD should have been apparent to an observant physician long before dialysis was required.

Criticism of pre-dialysis education and treatment received by the sample was tempered by well documented evidence that while African American patients see physicians regularly, they are less likely to have a primary care physician, and tend to use emergency rooms as primary care. These tendencies may limit a physician's ability to provide consistent and comprehensive care. In addition, the participants may have been informed of their diagnosis, but may not have understood the serious health ramifications of ignoring the disease.

Research question three was designed to determine if the degree of satisfaction with pre-dialysis information and education was positively related to the age, level of education and income of African American ESRD patients. There were no significant differences based on age or income. However, the satisfaction mean scores significantly differed between participants with less than a high school diploma, and participants who were college graduates. The dialysis patients with a college degree were the least

satisfied with pre-dialysis education and treatment, while patients with less than a high school diploma were the most satisfied. Because this sample had a small number of patients with a college degree (12%, n=12), one may infer that the satisfaction results are not valid. However, the results do support findings from other studies, which have shown that the medical treatment expectations for patients with a serious disease are higher for patients with education beyond high school (Myers, et al. 2000).

It can be inferred that participants with a lower level of education were more satisfied with pre-dialysis education and treatment, and may have been less likely to object to or question the medical treatment provided to them. Their reported satisfaction may be related to intimidation when interacting with health care professionals, who have a higher level of education. Those participants with a college education may have more pre-conceived expectations of medical care, and may demonstrate a greater degree of advocacy related to the treatment of their disease. Regardless of the mean satisfaction scores, it was apparent by responses to the open ended questions that the majority of survey participants placed a high value on pre-dialysis treatment and education.

While ESRD patients without a high school diploma may have reported a higher degree of satisfaction because of lower expectations of pre-dialysis

education and medical treatment, it is equally plausible that college educated ESRD patients reported low satisfaction with treatment because of unreasonable and unrealistic expectations of care. Reported satisfaction with treatment may vary based on any number of variables.

However, health care professionals can improve satisfaction by providing treatment that is competent and consistent, regardless of the income or education of the patient.

The purpose of research question four was to determine if African American ESRD patients with disparate income and education levels received different pre- and post- dialysis treatment interventions. The mean score differences for this question were not significant. The range of scores for pre-dialysis and post-dialysis treatment interventions was zero to five. The participants were asked if they received any of the treatment interventions recommended for ESRD patients by the National Institutes of Health (NIH Consensus Statement, 1993). These interventions included educating the patient about different aspects of ESRD treatment, meeting with a kidney specialist and other members of the renal team (i.e. nutritionist, nurse), a tour of a dialysis center, and introduction to other dialysis patients.

It is notable that the pre-dialysis treatment/intervention mean scores by income ranged from 1.6 (SD=1.14) to 1.96 (SD=1.55) and the pre-dialysis

treatment intervention mean scores by education ranged from 1.6 (SD=1.62) to 1.8 (SD=1.28). The scores indicated that pre-dialysis patients in this study were provided an average of less than two of the five recommended treatments. Conversely, the post-dialysis mean scores by income ranged from 3.8 (SD=.73) to 4.0 (SD=.38) and the post-dialysis mean scores by education ranged from 3.7 (SD=.78) to 4.0 (SD=.63). The participants consistently received four of the five recommended treatments post-dialysis. While it is commendable that the patients appeared to receive standard care post-dialysis, it is regrettable they did not receive the same types of services pre-dialysis. Reasons for this disparity may include lack of consistent primary medical care and decreased access to health care (secondary to limited finances, no insurances, etc.) pre-dialysis. Those limitations are no longer apparent once a patient begins dialysis, probably because dialysis patients are guaranteed health insurance via the Medicare program. The disparity between pre- and post-dialysis medical treatment/interventions supports ecological theory in that dialysis patients' resources (education, income, access to care) appeared to influence the type of treatment provided to them.

Research question five involved asking patients about their perceptions of quality of life. The Ferrans and Powers Quality of Life Index was used to

answer this question. Several of the findings were statistically significant. Quality of life scores steadily increased with age for all quality of life indices except psychological/spiritual and family quality of life. In those areas, quality of life scores increased until the 65 years and above group, when the scores decreased slightly. These results suggest that the youngest ESRD dialysis patients consistently perceived their quality of life lower than those in the other age groups. There may be depression associated with having such a debilitating, limiting disease at a young age. The findings may also suggest that patients become more comfortable with and or accepting of their health status and station in life as they age.

Perceived quality of life scores increased as income increased for all categories, except health and functioning quality of life, and family quality of life. The differences between the group scores were not significant, but followed certain trends. For health and functioning quality of life the $0 - $10,000 and >$10,000 - $30,000 income groups had nearly identical quality of life scores. For family quality of life, the >$30,000 income group had the lowest quality of life scores. This may be the result of the patients with relatively more money being able to continue a certain standard of life, even after having to receive dialysis. A number of patients reported that one of the negative effects of dialysis was no longer being able to work.

The dialysis patients' perceptions of health and functioning quality of life and family quality of life, based on income, were similar to the findings in a 1997 study conducted by Molzahn and colleagues at the University of Victoria in Victoria, British Columbia (Canada). In that study, the ESRD patients' sociodemographic characteristics did not appear to predict their quality of life ratings. The Canadian ESRD patients with higher income and education levels did not consistently rate their quality of life more favorably than the patients with relatively lower income and education levels.

The mean scores for the total quality of life, social and economic quality of life and psychological/spiritual quality of life categories differed from the Molzahn et al (1997) study. The dialysis patients in this survey with a relatively higher income perceived their quality of life as better than those living in poverty or near poverty. Another similarity between the Molzahn (1997) study and this one is that the differences between the mean scores in that study were also small, and the findings were not always significant.

A non significant trend in the current study was that each of the quality of life category scores increased as level of education increased. While not statistically significant, this trend indicates perceived quality of life may be positively associated with the educational level of ESRD patients in this sample.

Recommendations

While several statistically significant differences were found when examining quality of life scores and education and income levels, analyses in other areas (including knowledge and pre-and post-dialysis education and treatment) revealed trends, but no significant differences. The small sample size and minimal variability in the income and education groups in this sample is obviously a study limitation. It is recommended that a larger sample size with more individuals in each income and education category be used in future studies.

Earlier discussion of potential reasons for health status differences between African Americans and the general population identified environmental factors, including institutional racism, lack of access to health care, and lower educational and income levels among African American dialysis patients. This study analyzed different education and income levels among African American ESRD patients, and access to health care (treatment interventions provided to the patients). Health care professionals can help to improve satisfaction with health care by providing treatment that is of high quality and consistent, regardless of patient education or income. It is recommended that health care practitioners provide services to pre-dialysis ESRD patients, based on the standards of care established by the National

Institutes of Health. It is further recommended that future studies examine additional environmental factors in more depth, to determine if they impact significantly on the health status of African American ESRD patients.

Implications

As a result of this study, there are implications for health care providers, educators, and social service workers. Health care providers and health educators, who could ensure that African American ESRD patients receive proper education pre-and post-dialysis, should pay attention to the suggestions made by the ESRD patients in this study. They indicated the importance of receiving specific types of pre-dialysis education, including the cause(s) of ESRD, types of treatments available (other than hemodialysis), and diet restrictions. If health care providers and educators addressed these concerns, the ESRD patients would probably be more knowledgeable about the disease and its treatments, and more satisfied with the pre- and post-dialysis education and treatment provided.

Consideration also should be given to the area of job training and employment. There was a high level of unemployment among the dialysis patients in this study. Eighty-five percent (n=83) were unemployed. Dialysis did not appear to be the sole cause of each instance of unemployment, given that 37 % (n=36) reported they had not worked in more than five years, and

19% (n=19) had been on dialysis more than five years. Twenty-nine percent (n=24) of the participants had been unemployed for less than two years. Special efforts should be made for vocational training for these patients who are relatively young, so that they can remain productive.

Conclusions

This study used social ecology and ecological theory as a framework to examine pre-and post-dialysis education and treatment of a convenience sample of African American ESRD patients (n=98). Patient age, income, education and length of time on dialysis were the independent variables. Dependent variables included knowledge, satisfaction, treatment intervention, and quality of life. While income and education were demographic characteristics of the study participants, in keeping with social ecology and ecological theory, they were also considered as part of the environment (resources) of the dialysis patients.

Multiple oneway analyses of variance (ANOVA) were used to analyze the data. When the data were analyzed, the research hypotheses for questions one, two, and four were not supported. Research hypotheses for questions three and five were partially supported. A statistically significant difference was found between patient satisfaction and level of education. Several other significant differences were also found between the quality of life subscales

and the income and education variables.

The results may not be generalizable because of the nature of the study (convenience sample, lack of variability in the income and education levels among the participants, and relatively small sample size) however, they may serve to inform the medical and health education communities of the disparities in pre-dialysis education and treatment provided to African American dialysis patients in the Washington, DC metropolitan area. In addition, the results may help those who provide education and medical services to this population to develop a more comprehensive program, which adheres to established standards of care, in order to ensure that those patients with less education and income than the general population are not marginalized.

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Appendix A

INFORMED CONSENT FORM

TITLE	Patient Perceptions Regarding Pre- and Post-Dialysis Education and Treatment Options
STATEMENT OF AGE OF SUBJECT	I state that I am over 18 years of age, and wish to participate in a program of research being conducted by Dr. Sharon Desmond in the Department of Public and Community Health at the University of Maryland, College Park
PURPOSE	The purpose of this study is threefold: 1) to identify the self reported satisfaction regarding pre and post dialysis education and health care among African American ESRD patients; 2) to determine what, if any, differences exist in the pre and post dialysis education and treatment provided to those patients; and 3) to discern whether the treatment and education provided are related to the income and educational levels of the patients.
PROCEDURES	The procedures involve the completion of a questionnaire. I will be asked to complete this questionnaire.
CONFIDENTIALITY	All information collected in this study is confidential, and my name will not be identified at any time. My completed questionnaire will be placed in a sealed envelope and stored by the researcher. The data I provide will be grouped with data others provide for reporting and presentation purposes.
RISKS	There are no known risks associated with this study.
BENEFITS, FREEDOM TO WITHDRAW, AND ABILITY TO ASK QUESTIONS	The study is not designed to benefit me personally. However, the results of the study may help health care providers develop more effective dialysis education programs. Participants may withdraw at any time and without penalty. Dialysis services will not be affected by participation.
CONTACT INFORMATION OF INVESTIGATORS	Please contact either of the persons listed below may be contacted if you have any questions or concerns regarding your participation in this study. Sharon Desmond, Ph.D. (301) 405-2526 Department of Public and Community Health sd47@umail.umd.edu Revenda Greene Doctoral Candidate revenda@msn.com

Name of Participant _____

Signature of Participant _____

Date _____

Appendix B Institutional Review Board Approval

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

2100 Lee Building
College Park, Maryland 20742-5121
301.405.4212 TEL 301.314.9305 FAX

Reference: IRB HSR Identification Number 02-0010

August 14, 2002

MEMORANDUM

Notice of Results of Final Review by IRB on HSR Application

TO: Sharon M. Desmond
Revenda A.Greene
Department of Public and Community Health

FROM: Dr. Marc A. Rogers, Co-Chairperson
Dr. Joan A. Lieber, Co-Chairperson
Institutional Review Board

PROJECT ENTITLED:
"Patient Perceptions Regarding Pre and Postdialysis Education and Treatment Options"

The Institutional Review Board (IRB) concurs with the departmental Human Subjects Review Committee's preliminary review of the application concerning the above referenced project. The IRB has approved the application and the research involving human subjects described therein. We ask that any future communications with our office regarding this research reference the IRB HSR identification number indicated above.

Please note that, should there be any deviations from the approved protocol, you are required to submit the modifications to your departmental Human Subjects Review Committee.

If you have any questions or concerns, please do not hesitate to contact either of us at irb@deans.umd.edu. Thank you.

Enclosures (where appropriate), will include:
stamped copy of informed consent forms included in application and any copies of the application not needed by the IRB, and
copies of this memorandum and any consent forms to be sent to the Chairperson of the Human Subjects Review Committee.

IRB APPROVED
VALID UNTIL
AUG 3 1 2005
UNIVERSITY OF MARYLAND
COLLEGE PARK

INFORMED CONSENT FORM

TITLE	Patient Perceptions Regarding Pre and Postdialysis Education and Treatment Options
STATEMENT OF AGE OF SUBJECT	I state that I am over 18 years of age, and wish to participate in a program of research being conducted by Dr. Sharon Desmond in the Department of Public and Community Health at the University of Maryland, College Park
PURPOSE	The purpose of this study is threefold: 1) to identify the self reported satisfaction regarding pre and post dialysis education and health care among African American ESRD patients; 2) to determine what, if any, differences exist in the pre and post dialysis education and treatment provided to those patietns; and 3) to discern whetner the treatment and education provided are related to the income and educational levels of the patients.
PROCEDURES	The procedures involve the completion of a questionnaire. I will be asked to complete this questionnaire.
CONFIDENTIALITY	All information collected in this study is ocnfidential, and my name will not be identified at any time. My completed questionnaire will be placed in a sealed envelope and stored by the researcher. The data I provide will be grouped with data others provide for reporting and presentation purposes.
RISKS	There are no known risks associated with this study.
BENEFITS, FREEDOM TO WITHDRAW, AND ABILITY TO ASK QUESTIONS	The study is not designed to benefit me personally. However, the results of the study may help health care providers develop more effective dialysis education programs. Participants may withdraw at any time and without penalty. Dialysis services will not be affected by participation.
CONTACT INFORMATION OF INVESTIGATORS	Please contact either of the persons listed below may be contacted if you have any questions or concerns regarding your participation in this study. Sharon Desmond, Ph.D. (301) 405-2526 Department of Public and Community Health sd47@umail.umd.edu Revenda Greene Doctoral Candidate (301) 390-3949 revenda@msn.com

Name of Subject _____

Signature of Subject _____

Date _____

Appendix C Dialysis Patient Questionnaire

Please circle the best response to each question.

1. When did you first find out you had kidney disease?
    1. When I began dialysis
    2. About six months before I began dialysis
    3. About one year before I began dialysis
    4. Up to 5 years before I began dialysis
    5. I do not remember

1. Did you see a doctor in the 6-12 months before you began dialysis?
    1. Yes
    2. No
    3. I do not remember

3. What is the race/ethnicity of your kidney doctor?
    1. African American
    2. White
    3. Hispanic/Latino
    4. Asian
    5. Other _____
    6. I do not know

4. How long have you been receiving dialysis?
    1. Less than one year
    2. Between 1-2 years
    3. Between 2-5 years
    4. More than 5 years

5. How often do you receive dialysis?
    1. Two days a week
    2. Three days a week
    3. Other _____

6. Why do you receive dialysis? (Medical diagnosis or condition which caused the ESRD). Circle all that apply.
    1. Diabetes
    2. High blood pressure
    3. Kidney disease from birth
    4. Other _____

7. Has any other family member been diagnosed with high blood pressure or diabetes?
    1. Yes
    2. No
    3. Not sure

8. If yes, what relation is that family member to you?

    _____

9. Who explained the cause(s) of kidney disease to you?
    1. My doctor
    2. A nurse
    3. Another health care professional explained it to me
    4. I read books/pamphlets and studied on my own
    5. No one did
    6. Other _____

10. What have you learned is the main cause(s) of kidney disease?
    1. High blood pressure
    2. Diabetes
    3. Both “1" and “2"
    4. None of the above

11. The body organ which separates blood into waste products and nutrients is:
    1. The heart
    2. The kidney
    3. The bladder
    4 The brain

12. Insulin is used to help the body change what substance into energy
    1. Salt
    2. Protein
    3. Sugar
    4. Fat

13. Dialysis becomes necessary when:
    1. The heart is not functioning well
    2. The kidneys shut down
    3. The patient has a stroke
    4. None of the above

14. Dialysis takes blood from the body for what purpose?
    1. To filter out waste products and extra fluid
    2. To add white blood cells
    3. To add protein
    4. None of the above

15. Dialysis can be performed
    1. In the hospital or outpatient facility
    2. In the home
    3. Both “1" and “2"
    4. None of the above

16. Who explained the dialysis process to you?
    1. My doctor
    2. A nurse
    3. A technician
    4. No one did
    5. Other _____

17. What treatment options for ESRD were discussed prior to you beginning dialysis? Check all that apply.
    1. Medication
    2. Dialysis in the hospital or outpatient facility
    3. Dialysis in the home
    4. Kidney transplant
    5. Other _____

18. What type of information, if any, did you receive about the dialysis process before you began dialysis? Check all that apply.
    1. Explanation of the procedure by your doctor or another health care provider
    2. Audiotape or videotape
    3. Pamphlet/booklet
    4. Tour of facility
    5. Other

19. How satisfied were you with the educational materials provided?
    1. Very satisfied
    2. Satisfied
    3. Not satisfied
    4. Very unsatisfied

20. What type of dialysis do you currently receive?
    1. Hemodialysis
    2. Continuous Ambulatory Peritoneal Dialysis
    3. Other _____
    4. I don't know

21. Have you ever received another type of dialysis?
    1. Yes
    2. No
    3. I am not sure

22. If yes, what type of dialysis treatment did you receive?

    _____

23. Did you do any of these activities **before** beginning dialysis? Please respond to each item.

1.	See a nutritionist?	YES	NO
2.	See a kidney specialist?	YES	NO
3.	Visit a dialysis center?	YES	NO
4.	Speak with other dialysis patients?	YES	NO
5.	Attend a support group for dialysis patients?	YES	NO

24. If you did any of those activities before beginning dialysis, who attended at least one of those appointments with you? **Please circle all that apply.**

    A. When you saw a nutritionist, who was with you?
    A family member A friend Went alone Did not do

    B. When you saw a kidney specialist, who was with you?
    A family member A friend Went alone Did not do

    C. When you visited a dialysis center, who was with you?
    A family member A friend Went alone Did not do

    D. When you spoke with other dialysis patients, who was with you?
    A family member A friend Went alone Did not do

    E. When you attended a support group for dialysis patients, who was with you?
    A family member A friend Went alone Did not do

25. During your medical appointments before you began dialysis, did your doctor spend enough time with you to answer all of your questions and concerns?
    1. Yes
    2. No
    3. I do not remember

26. During your medical appointments before you began dialysis, did other medical professionals (such as the nurse or technician) spend enough time with you to answer all of your questions and concerns?
    1. Yes
    2. No
    3. I do not remember

27. Do you feel that your doctor completely answered all of the questions you had about your kidney disease before you began dialysis treatment?
    1. Yes
    2. No
    3. I do not remember

28. Do you feel that your doctor completely answered all of the questions you had about why you needed dialysis, before you began treatment?
    1. Yes
    2. No
    3. I do not remember

29. Which of these activities have you done **since you began dialysis**? Please respond to each item.

1.	Seen a nutritionist?	YES	NO
2.	Seen a kidney specialist?	YES	NO
3.	Visited a dialysis center?	YES	NO
4.	Spoken with other dialysis patients?	YES	NO
5.	Attended a support group for dialysis patients?	YES	NO

30. If you have done any of those activities since you began dialysis, who attended at least one of those appointments with you? **Please circle all that apply**.

    A. When you saw a nutritionist, who was with you?
    A family member A friend Went alone Did not do

    B. When you saw a kidney specialist, who was with you?
    A family member A friend Went alone Did not do

    C. When you visited a dialysis center, who was with you?
    A family member A friend Went alone Did not do

D. When you spoke with other dialysis patients, who was with you?

A family member A friend Went alone Did not do

E. When you attended a support group for dialysis patients, who was with you?

A family member A friend Went alone Did not do

31. Were you prepared for any of the physical side effects you experienced from dialysis treatment?
    1. Yes
    2. No
    3. I have not had any side effects

32. Since beginning dialysis, has it been more or less difficult to interact with family members?
    1. More difficult
    2. No change in family interactions
    3. Less difficult

33. What effect do you believe your dialysis had on your family relations?
    1. It has made my family closer
    2. It has had no effect on my family relations
    3. It has made interactions with my family more difficult

34. How supportive do you feel your family has been to you since you began receiving dialysis?
    1. Very Supportive
    2. Supportive
    3. Unsupportive

35. In comparison to others my age and sex, I would rate my health as:
    1. Excellent
    2. Good
    3. Average
    4. Poor
    5. Very Poor

36. Compared to others my age and sex, I would rate my quality of life as:
    1. Excellent
    2. Good
    3. Average
    4. Poor
    5. Very Poor

37. How many hours do you work each week?
    1. Less than 10 hours
    2. 10-20 hours
    3. 20-40 hours
    4. 40 or more hours
    5. I do not work

38. If you are not working, how long has it been since you were employed?
    1. Less than one year
    2. 1-2 years
    3. 2-5 years
    4. Greater than 5 years
    5. I am currently working

39. What is your yearly income?
    1. $0-$10,000
    2. $11,000-$20,000
    3. $21,000-$30,000
    4. $31,000-$40,000
    5. $41,000-$50,000
    6. Greater than $50,000

40. What is your education?
    1. Up to the eighth grade
    2. Attended high school
    3. Completed high school
    4. Attended college
    5. College graduate
    6. Attended graduate school
    7. Completed a graduate program

41. What is your date of birth? (Month/Year) _____

42. What is your race/ethnicity
    1. African American
    2. Asian
    3. Hispanic/Latino
    4. White
    5. Other _____

43. What is your sex?
    1. Male
    2. Female

For each of the following, please choose the answer that best describes how **satisfied** you are with that area of your life. **Please mark your answer by circling the number**. There are no right or wrong answers.

Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1	2	3	4	5	6

How satisfied are you with:		Very Dissatisfied					Very Satisfied
44.	Your health?	1	2	3	4	5	6
45.	Your health care?	1	2	3	4	5	6
46.	The amount of energy you have for everyday activities?	1	2	3	4	5	6
47.	Your ability to take of yourself without help?	1	2	3	4	5	6
48.	The likelihood you will get a kidney transplant?	1	2	3	4	5	6
49.	The changes you have had to make in your life because of kidney failure (such as diet and need for dialysis)?	1	2	3	4	5	6
50.	The amount of control you have over your life?	1	2	3	4	5	6
51.	Your chances of living as long as you would like?	1	2	3	4	5	6
52.	Your family's health?	1	2	3	4	5	6
53.	Your children?	1	2	3	4	5	6
54.	Your family's happiness?	1	2	3	4	5	6
55.	Your sex life?	1	2	3	4	5	6

Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1	2	3	4	5	6

How satisfied are you with:		Very Dissatisfied					Very Satisfied
56.	Your spouse, lover, or partner?	1	2	3	4	5	6
57.	The emotional support you get from your family?	1	2	3	4	5	6
58.	Your friends?	1	2	3	4	5	6
59.	The emotional support you get from people other than your family?	1	2	3	4	5	6
60.	Your ability to take care of family responsibilities?	1	2	3	4	5	6
61.	How useful you are to others?	1	2	3	4	5	6
62.	The amount of worries in your life?	1	2	3	4	5	6
63.	Your neighborhood?	1	2	3	4	5	6
64.	Your home, apartment, or place where you live?	1	2	3	4	5	6
65.	Your job (if employed)?	1	2	3	4	5	6
66.	Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
67.	Your education?	1	2	3	4	5	6
68.	How well you can take care of your financial needs?	1	2	3	4	5	6
69.	The things you do for fun?	1	2	3	4	5	6

Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1	2	3	4	5	6

How satisfied are you with:		Very Dissatisfied					Very Satisfied
70.	Your chances for a happy future?	1	2	3	4	5	6
71.	Your peace of mind?	1	2	3	4	5	6
72.	Your faith in God?	1	2	3	4	5	6
73.	Your achievement of personal goals?	1	2	3	4	5	6
74.	Your happiness in general?	1	2	3	4	5	6
75.	Your life in general?	1	2	3	4	5	6
76.	Your personal appearance?	1	2	3	4	5	6
77.	Yourself in general?	1	2	3	4	5	6

For each of the following, please choose the answer that best describes how **important** that area of your life is to you. **Please mark your answer by circling the number**. There are no right or wrong answers.

Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1	2	3	4	5	6

How important to you is/are:		Very Unimportant					Very Important
78.	Your health?	1	2	3	4	5	6
79.	Your health care?	1	2	3	4	5	6
80.	Having enough energy for everyday activities?	1	2	3	4	5	6
81.	Taking care of yourself without help?	1	2	3	4	5	6
82.	Getting a kidney transplant?	1	2	3	4	5	6
83.	The changes you have had to make in your life because of kidney failure (such as diet and need for dialysis)?	1	2	3	4	5	6
84.	Having control over your life?	1	2	3	4	5	6
85.	Living as long as you would like?	1	2	3	4	5	6
86.	Your family's health?	1	2	3	4	5	6
87.	Your children?	1	2	3	4	5	6
88.	Your family's happiness?	1	2	3	4	5	6
89.	Your sex life?	1	2	3	4	5	6
90.	Your spouse, lover or partner?	1	2	3	4	5	6
91.	The emotional support you get from your family?	1	2	3	4	5	6

Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1	2	3	4	5	6

How important to you is/are:		Very Unimportant					Very Important
92.	Your friends?	1	2	3	4	5	6
93.	The emotional support you get from people other than your family?	1	2	3	4	5	6
94.	Taking care of family responsibilities?	1	2	3	4	5	6
95.	Being useful to others?	1	2	3	4	5	6
96.	Having no worries?	1	2	3	4	5	6
97.	Your neighborhood?	1	2	3	4	5	6
98.	Your home, apartment or place where you live?	1	2	3	4	5	6
99.	Your job (if employed)?	1	2	3	4	5	6
100.	Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
101.	Your education?	1	2	3	4	5	6
102.	Being able to take care of your financial needs?	1	2	3	4	5	6
103.	Doing things for fun?	1	2	3	4	5	6
104.	Having a happy future?	1	2	3	4	5	6
105.	Peace of mind?	1	2	3	4	5	6
106.	Your faith in God?	1	2	3	4	5	6

Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1	2	3	4	5	6

How important to you is/are:		Very Unimportant					Very Important
107.	Achieving your personal goals?	1	2	3	4	5	6
108.	Your happiness in general?	1	2	3	4	5	6
109.	Being satisfied with life?	1	2	3	4	5	6
110.	Your personal appearance?	1	2	3	4	5	6
111.	You to yourself?	1	2	3	4	5	6

112. In your own words, please describe how dialysis affects your every day life.

113. What is the most important advice or information you believe dialysis patients and their families should receive before dialysis begins?

Thank you for your participation

Appendix D Questionnaire Cover Letter

Dear Dialysis Patient:

I am a doctoral student in Public and Community Health at the University of Maryland, College Park. I am studying the opinions of dialysis patients regarding end stage renal disease (ESRD), and the education and treatment they received before and after beginning the dialysis process.

Please take the time to complete the following questionnaire. I know this survey may appear to be really long, but it does not take as long to complete as it may seem. It will take only about 20-30 minutes of your time. Your responses will be used to gather valuable information so that better educational programs for ESRD patients can be developed. There are no right or wrong answers. Your opinion is what is important. Do not write your name on the questionnaire. After you finish the questionnaire, please place it in the envelope provided, seal it, and put it in the basket at the receptionist's desk.

Thank you for your time and participation. It is my desire to help future dialysis patients, and I could not do this without your help. I really appreciate it.

Sincerely,

Revenda A. Greene, MHSA

Appendix E Gambro Dialysis Center Sites

Clinton	10401 Hospital Drive, Ste 202	(301) 856-6550
Cottage City	3804 Bladensburg Rd Cottage City, MD	(301) 277-6130
Landover	1877 Brightseat Road, Building D	(301) 322-6423
Southern Maryland	9211 Stuart Lane 4th Floor	(301) 856-6602
District of Columbia	4907 Georgia Avenue Washington, DC 20011	(202) 829-6295
GW-SE	3857 A Pennsylvania Ave, SE Washington, DC 20020	(202) 543-9105

Appendix F **Review Sheet for Pilot Study**

Thank you for completing the "Patient Perceptions Regarding Pre- and Post-dialysis Education and Treatment Options" questionnaire. I would like your comments about the questionnaire. Please answer the questions below.

1. Were the directions clear and easy to understand?
   A. Yes
   B. No
   If no, comment below.

44. Did you have trouble understanding any of the questions?
   A. Yes
   B. No
   If no, comment below.

44. Do you have any other comments about the questionnaire?

Appendix G Review Sheet for Ecological Theory Expert

Thank you for agreeing to review this "Patient Perceptions Regarding Pre- and Post-Dialysis Education and Treatment Options" questionnaire. Please examine the questionnaire items, and answer the following questions. If any question is not applicable to you, please indicate n/a in the space provided. Please use the back of this form, or additional sheets of paper, if more space is needed.

1. Were the questions clear and easy to understand?
   A. Yes
   B. No
   If no, please comment.

2. Did you have trouble understanding any of the questions?
   A. Yes
   B. No
   If yes, please comment below, and give the number of the question you had trouble understanding.

3. Do the questions adequately assess the internal and external environments of the ESRD patient prior to the dialysis process?
   A. Yes
   B. No
   If no, please comment below

4. Do the questions allow the researcher to assess the impact the patient's environment may have on the pre-dialysis patient education and treatment received?
   A. Yes
   B. No
   If no, please comment below.

5. Do you have any other comments about the questionnaire?

Appendix H

Review Sheet for Renal Disease (Nephrology) Medical Expert

Thank you for agreeing to review this "Patient Perceptions Regarding Pre- and Post-Dialysis Education and Treatment Options" questionnaire. Please examine the questionnaire items, and answer the following questions. If any question is not applicable to you, please indicate n/a in the space provided. Please use the back of this form, or additional sheets of paper, if more space is needed.

1. Were the questions clear and easy to understand?
   - A. Yes
   - B. No

   If no, please comment.

2. Did you have trouble understanding any of the questions?
   - A. Yes
   - B. No

   If yes, please comment below, and give the number of the question you had trouble understanding.

3. Do you believe that the dialysis patients you generally treat will have trouble understanding any of the questions?
   - A. Yes
   - B. No

   If no, please comment below

4. Do the questions appropriately reflect the general standards of practice/treatment provided to ESRD patients?
   - A. Yes
   - B. No

   If no, please comment below.

5. Do the questions adequately cover the basic knowledge ESRD patients should have regarding their disease?
   - A. Yes
   - B. No

   If no, please comment.

6. Is the questionnaire format appropriate?
   - A. Yes
   - B. No

   If no, please comment.

7. Do you have any other comments/concerns about any aspect of the questionnaire?

Appendix I Review Sheet for Physiology Expert

Thank you for agreeing to review this "Patient Perceptions Regarding Pre- and Post-Dialysis Education and Treatment Options" questionnaire. Please examine the questionnaire items, and answer the following questions. If any question is not applicable to you, please indicate n/a in the space provided. Please use the back of this form, or additional sheets of paper, if more space is needed.

1. Were the questions clear and easy to understand?
   A. Yes
   B. No
   If no, please comment.

2. Did you have trouble understanding any of the questions?
   A. Yes
   B. No
   If yes, please comment below, and give the number of the question you had trouble understanding.

3. Is the questionnaire format appropriate?
   A. Yes
   B. No
   If no, please comment below

4. Do the questions allow the researcher to assess the patient's level of knowledge regarding the function of the kidney, cause(s) of ESRD, and dialysis intervention?
   A. Yes
   B. No
   If no, please comment below.

5. Do you have any other comments/concerns about any aspect of the questionnaire?

Appendix J Review Sheet for Health Education Expert

Thank you for agreeing to review this "Patient Perceptions Regarding Pre- and Post-Dialysis Education and Treatment Options" questionnaire. Please examine the questionnaire items, and answer the following questions. If any question is not applicable to you, please indicate n/a in the space provided. Please use the back of this form, or additional sheets of paper, if more space is needed.

1. Were the questions clear and easy to understand?
   A. Yes
   B. No
   If no, please comment.

2. Did you have trouble understanding any of the questions?
   A. Yes
   B. No
   If yes, please comment below, and give the number of the question you had trouble understanding.

3. Do the questions adequately cover the basic knowledge ESRD patients should have regarding their disease?
   A. Yes
   B. No
   If no, please comment below

4. Do the questions adequately assess the amount and types/kinds of patient education that could be received by the pre-dialysis ESRD patient?
   A. Yes
   B. No
   If no, please comment below.

5. Do the questions adequately assess the degree of satisfaction that ESRD patients have, related to the pre-dialysis education that they received?
   A. Yes
   B. No
   If no, please comment.

6. Is the questionnaire format appropriate?

7. Do you have any other comments/concerns about any aspect of the questionnaire?

Appendix K Review Sheet for Research Design Expert

Thank you for agreeing to review this "Patient Perceptions Regarding Pre- and Post-Dialysis Education and Treatment Options" questionnaire. Please examine the questionnaire items, and answer the following questions. If any question is not applicable to you, please indicate n/a in the space provided. Please use the back of this form, or additional sheets of paper, if more space is needed.

1. Were the questions clear and easy to understand?
   A. Yes
   B. No
   If no, please comment.

2. Did you have trouble understanding any of the questions?
   A. Yes
   B. No
   If yes, please comment below, and give the number of the question you had trouble understanding.

3. Are the questions appropriate, given the research design outlined in the proposal?
   A. Yes
   B. No
   If no, please comment below

4. Does the questionnaire solicit the information required to answer the research questions?
   A. Yes
   B. No
   If no, please comment below.

5. Is the research design for this study appropriate?
   A. Yes
   B. No
   If no, please comment.

6. Do you have any other comments/concerns about any aspect of the questionnaire or the research design?

Appendix L Letter to Gambro Dialysis Centers Regional Manager

September 18, 2002

Gambro Dialysis Centers Regional Manager

To whom it may concern:

I, Revenda A. Greene, am a doctoral student at the University of Maryland, College Park. The major part of my dissertation project involves the completion of a questionnaire, "Patient Perceptions Regarding Pre- and Post-Dialysis Education and Treatment Options," by dialysis patients.

I have spoken with Ms. Gayle Franks in the risk management office at your company, and I have received permission to distribute the questionnaire to patients at Gambro clinics. I have been instructed that I need permission from each individual clinic before the patients can be asked to complete the questionnaire. I have contacted your office to get a list of the dialysis clinics in the Washington, DC metropolitan area (Washington and Maryland). Per your request, I am enclosing the informed consent form and the questionnaire, which have been approved by the University of Maryland Institutional Review Board.

Please contact me at (301) 390-3949 h; (301) 868-3600 x 32 w; or revenda@msn.com if you have any other questions.

Respectfully,

Revenda A. Greene
Doctoral Candidate
Department of Public and Community Health
University of Maryland, College Park