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The Relation of Compliance to Quality of Life in Dialysis Patients.

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The Relation of Compliance to Quality of Life
in Dialysis Patients

A Dissertation

Submitted to the Graduate Faculty of the
Louisiana State University
Agricultural and Mechanical College
in partial fulfillment of the requirements
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in

The Department of Psychology

by Linda S. Dietz

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M.A., Louisiana State University, 1985

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ABSTRACT

The goal of the current study was to gain knowledge of the impact that dietary compliance has on quality of life for end-stage renal disease patients receiving chronic in-center hemodialysis. As a result of this type of research, health care professionals may better understand the individual and collective influence that various aspects of dietary compliance have on quality of life. This knowledge may be helpful in making future recommendations about the necessity of the dietary regimen.

This study investigated the relation between three commonly employed physiological parameters of dietary compliance (blood urea nitrogen, potassium, and inter-session weight gain) and four measures of quality of life (Quality of Life Index, Personal Resource Questionnaire, Karnofsky Activity Scale, and Psychological General Well-Being Schedule). Also, the influence of relevant medical/demographic characteristics (age, age beginning dialysis, years on dialysis, and number of diagnoses) was examined. Subjects in the study included 67 hemodialysis patients from a university hospital dialysis center in a large southern city.

Correlational procedures, multiple regression analyses, and a canonical correlation were employed to investigate the association between dietary compliance, medical/demographic variables and quality of life. In general, the results

suggested that the dietary compliance variables have little impact on quality of life. This finding provided further support for the loosening of dietary restrictions. Medical/demographic variables, however, were modestly correlated with one quality of life variable, activity. Knowledge about relevant medical demographic characteristics suggest that high risk patient profiles may be developed for early identification of patients who may benefit from rehabilitation. One problem noted in this study is the difficulty in defining and measuring the construct of quality of life.

INTRODUCTION

End-Stage Renal Disease (ESRD) is a life-threatening, and costly health problem for a large number of individuals (Fisher, 1983). Until the early 60's, patients with ESRD had few treatment alternatives, and most died (Norton, 1982). Since that time, hemodialysis has become a standard treatment procedure, and the number of patients surviving and requiring long-term dialysis has increased (Stewart, 1983; Wauters, Hunziker, & Brunner, 1983). One factor that has contributed significantly to this increase has been the decision by the United States Congress in 1972 to pay for 80 percent (Fisher, 1983) of the cost of dialysis. For instance, in 1972, 11,000 persons were treated compared to 73,000 persons in 1982. Alternatives to dialysis are available (e.g., renal transplant and peritoneal dialysis), but are appropriate for only a minority of patients (Wauters, et al., 1983). Hemodialysis remains the most accepted and widely used method of treatment (Hirschman, Wolfson, Moseman, Clark, Dante, & Wineman, 1981). Although hemodialysis can prolong patient survival, it does not assure a high quality of life to the patient, particularly since dialysis treatment is followed by a number of physical and psychological sequelae as well as the necessity of living with a strict and complex regimen. This paper will

examine the relevant issues in renal failure, including medical and psychological complications, quality of life, and compliance. At the end of this paper, a study will be proposed to examine the relation between quality of life and compliance with the dietary regimen.

End Stage Renal Disease

Two types of renal failure exist: acute and chronic (Cameron, Russell, & Sale, 1976). Acute renal failure is distinguishable from chronic renal failure by its rapid onset and usually reversible nature (Stein, 1985; Schrier & Conger, 1980). Chronic renal failure results from a progressive and usually irreversible reduction in working nephrons (Kokko, 1985; Cameron et al., 1976; Alfrey, 1980). For the purposes of the present study, only chronic renal failure will be considered.

Chronic renal failure (CRF), a functional diagnosis, can result from any number of diseases that irreversibly destroy the nephrons and consequently cause glomerular filtration rate (GFR) to decline. GFR is a measure of the kidneys' ability to remove a substance (e.g., urea) from the bloodstream. In a study of 1049 patients on chronic hemodialysis, Hirschman et al. (1981) reported that roughly 30 percent of their patients required dialysis due to glomerulopathies, 19 percent to unknown causes, 13 percent to kidney disease, 7 percent to diabetes, 3 percent to vascular disorders, and 5 percent to miscellaneous causes.

Their findings are similar to those reported by other investigators (e.g. Kokko, 1985).

Many times there are no clinical manifestations of a renal problem until irreversible damage has occurred (Kokko, 1985; Wright, 1981; Cameron, et al., 1976). This is not surprising when one considers that most patients are asymptomatic until they have lost 90 to 95 percent of their renal function. A patient with progressive renal failure goes through four stages (Knochel & Seldin, 1981). In the first stage, the concentration of urea nitrogen and creatinine rises abnormally, however, the kidneys continue to excrete and regulate substances quite well with no symptoms noted by the patient. In the second stage of renal failure there is renal insufficiency, which is manifested by increased nitrogen in the bloodstream (azotemia), frequent urination at night, mild anemia, and impaired ability to concentrate urine. In the third stage of renal failure, a number of derangements are seen in the body's regulatory and excretory functions, including a worsening of the symptoms found in stage two. The final stage of renal failure is uremia or the "uremic syndrome".

Uremia. Uremia has been called "urine in the blood". This implies that substances that are normally filtered out of the blood are retained and that the body is poisoning itself with the toxins that should have been removed. Uremia disrupts every system in the body, and complications are

manifest in a number of ways (Kokko, 1985; Alfrey, 1981). Water and electrolyte abnormalities, including imbalances in potassium, sodium, calcium, chloride, magnesium, and phosphorus are present. Gastrointestinal complications of uremia (e.g., nausea, vomiting, and anorexia) are extremely common. Cardiovascular abnormalities are present. These include hypertension, hypertriglyceridemia (elevated triglyceride concentration in the blood), pericarditis (inflammation of the membrane around the heart), and increased mortality due to heart failure. The most common hematological abnormality is anemia. Skeletal changes associated with uremia include osteitis fibrosa (inflammation of the bone accompanied by replacement of bone tissue with fibrous tissue), Osteomalacia (softening and bending of bones), osteoporosis (reduction in the quantity of bone or atrophy of skeletal tissue), and osteosclerosis (abnormal hardening of the bone). Symptoms experienced by the patient include bone pain and fractures. Neuromuscular abnormalities are present and are associated with some of the earliest signs of CRF. Psychological and neurological problems include altered mental status, depression, psychosis, anxiety, headaches, and sleep disturbance. Peripheral neuropathies, including muscle weakness, muscle twitches and spasms, and parathesias may be present. Infections are common in uremic patients, probably due to a suppressed immune system. Carbohydrate metabolism is

altered; in particular, glucose tolerance is impaired. Finally, a common complication is generalized pruritus (itching). Although this list does not exhaust all the complications found in uremia, it provides a basic description of the extent to which uremia disrupts normal body function. For more detailed information, the reader is referred to Kokko (1985) and Alfrey (1980).

Treatment. Chronic renal failure can be managed in three ways: conservative management, transplantation, and dialysis (Norton, 1982; Wright, 1981). Conservative management is usually the step taken when nothing can be done to stop the progression of renal failure and before either dialysis or transplantation is initiated. The patient is observed and monitored closely. Dietary restrictions are initiated, including calorie, protein, sodium, potassium, fluid, and calcium restrictions. After conservative management is no longer effective, decisions are made about the next step in treatment. Transplantation of a kidney from either a relative or cadaveric donor is an effective treatment and results in a higher quality of life than dialysis (Kokko, 1985; Wolcott, & Nissenson, 1988; Johnson, McCauley, & Copley, 1982. Unfortunately, it is not feasible in many cases because of poor medical status or because a suitable donor is not available. Therefore the treatment of choice for most patients is dialysis (Kokko, 1985; O'Brien, 1980).

Two types of dialysis are available: peritoneal

dialysis and hemodialysis. In peritoneal dialysis, the peritoneal membrane in the abdomen is used as the semipermeable membrane through which substances are dialyzed. This procedure is simple and requires few specialized personnel and equipment; however, 24 to 48 hours are needed to remove toxins. Since the present study is restricted to patients receiving hemodialysis, the hemodialysis procedure will be described in greater detail.

The history of hemodialysis began in 1913 when three physicians used dialysis to experiment with a living animal (Longo, 1981). The method was primitive by today's standards, for example, leeches were ground to make the anticoagulant. Nevertheless, the point was made that certain unwanted substances could be removed from the bloodstream by passage through a semipermeable membrane. Hemodialysis refers to a procedure in which a machine removes from the bloodstream a variety of toxic substances that are normally removed by the kidneys and excreted in urine (Luke, 1985; Finn & Alcorn, 1986). Blood is routed out of the body via a vascular access (shunt, cannula, or fistula) and into an "artificial kidney". The artificial kidney is a machine comprised of channels bounded by membranes. The membranes are permeable to metabolic waste products from the blood while restoring water, electrolytes, and acid-base balance (Man and Jungers, 1982). Cleansed blood returns to the body via the vascular access (Norton,

1982). The dialysis procedure lasts a few hours and typically is performed on alternate days. The actual time required for dialysis depends upon the type of machine used and the physical status of the patient. The survival rate for dialysis patients has increased significantly since dialysis first was used as a treatment modality (Bradley, Evans, and Calne, 1987; Cameron et al., 1976). Research indicates that the three year survival rate is 85 percent for patients between the ages of 20 to 25 and 60 percent for those between the ages of 60 and 65 (Luke, 1985). Maker and Curtis (1987) reported that actuarial survival rates for 174 patients (aged less than 55 at the beginning of the study) were 69 percent, 52 percent, and 38 percent at 5, 10, and 15 years respectively. Rosensky and Eggers (1987) reported that despite the increase in older and sicker patients from the period of 1974 to 1979, survival rates remained stable and even improved for the older patients. This stability and improvement was thought to reflect improvements in care. Although patients on dialysis can survive, the artificial kidney does not completely substitute for the normal kidney and does not perform the excretory and regulatory functions as efficiently as the normal kidney does. These deficiencies lead to a variety of restrictions to lifestyle (Cameron et al., 1976; Kutner, Fair, & Kutner, 1985). Consequently, further discussion of these restrictions is warranted.

Dialysis Treatment Regimen

The medical regimen recommended for all dialysis patients is designed to avoid the complications associated with dialysis (Ginn & Teschin, 1983). Treatment requires frequent dialysis to remove metabolic waste products and to control fluid volume. Also, nutritional management is necessary to reduce metabolic by-products, electrolytes, minerals, and fluids that accumulate between dialysis sessions as well as supplement lost substances such as vitamins and minerals (Kluthe, 1983; Burton, 1974). Malnutrition and wasting are frequently seen in dialysis patients and can contribute to increased incidence of infection and increased morbidity. Although exact dietary requirements are dependent upon patient characteristics, such as age, weight, sex, occupation, and duration and frequency of dialysis, a number of general principles are known (Cameron, et al., 1976; Rodriguez & Hunter, 1981). First, protein intake must be limited in order to reduce the amount of blood urea nitrogen (BUN) that accumulates in the bloodstream, and thereby reduces the number of uremic symptoms (Kokko, 1985; Finn & Alcorn, 1986). BUN is a waste product that accumulates from the breakdown of protein. However, too little protein intake can lead to loss of strength, body weight, and muscle mass.

Sodium and potassium are restricted. Excessive sodium can lead to swelling and hypertension. The amount of sodium

allowed in the diet is dependent upon the patient's blood pressure (Rodriguez & Hunter, 1981; Cummings, Becker, Kirscht, & Levin, 1982). Usually sodium is restricted to 2 to 4 grams daily; however in a patient who has no symptoms of hypertension or fluid overload, sodium restriction may be liberalized. Potassium is an element that is not effectively dialyzed and has to be limited to 45 to 70 mg/kg per day. Hyperkalemia, a greater than normal concentration of potassium ions in the bloodstream, can lead to cardiac arrhythmias and death.

Phosphorus levels are controlled to prevent the development of osteodystrophy (Coburn and Llach, 1983). Phosphate binders are given to control the amount of phosphorus that is absorbed into the bloodstream from the intestinal tract. As renal function deteriorates, the quantity of phosphate binders required to control the phosphorus levels increases.

Fluid intake must be carefully monitored and controlled to keep pace with the kidney's ability to eliminate fluid (Cummings, Kirscht, Becker, & Levin, 1984). The consequences of fluid overload are serious and include edema, hypertension and heart failure. Also, inter-session fluid gain usually means that the patient will experience a distressing dialysis session with nausea, vomiting, and dizziness (Rostand & Rutsky, 1984). The need to limit fluids is probably the most difficult restriction (Rodriguez and

Hunter, 1981).

Although a variety of substances must be restricted, some lost as a result of dialysis (Luke, 1985; Finn & Alcorn, 1986). Water soluble vitamins are lost from the bloodstream during dialysis and must be replaced by routine administration of vitamin supplements. This supplementation is also necessary because many of the fruits and vegetables providing these vitamins are restricted. Vitamin K is given to the patient when taking antibiotics. Iron supplements required are since dialysis patients are frequently anemic. Another element that the dialysis procedure removes is zinc. Zinc deficiency leads to decreased taste sensitivity as and decreased appetite.

Medical Complications of Dialysis

Patients on maintenance dialysis require ongoing medical attention for a variety of iatrogenic complications, persistent uremia, and physical problems such as diseases of the cardiovascular system, hematologic system, skeletal system, gastrointestinal problems, infections, and neurological disorders (Luke, 1985; Wright, 1981). Many of the complications were mentioned in the section on uremia as complications of uremia. Generally, the problems are more severe during the uremic phase, then become chronic problems associated with repeated dialysis.

Iatrogenic Effects of Dialysis. The dialysis session may be complicated by episodes of hypotension, muscle cramps, and

by problems with anticoagulation. Hypotension refers to a drop in blood pressure and is experienced by the patient as dizziness, malaise, nausea and vomiting, and unexplained anxiety. Hypotension appears to be related to too rapid removal of fluid and/or excess fluid. Muscle cramps are common both during and between dialysis sessions. They are thought to result from too rapid removal of extracellular fluid which induces altered concentrations of sodium in the muscle cell. Anticoagulants are used to prevent clotting of the vascular access. A significant complication of this medication is spontaneous bleeding in the gastrointestinal tract, pericardium, pleura, joints, retroperitoneal space, and cerebrum (Butt, 1983).

Cardiovascular Complications. Cardiovascular problems are some of the leading causes of morbidity and death in dialysis patients (Wright, 1981). Comty and Shapiro (1983) reported that at the end of a 13 year study (with patients selected for their absence of vascular disease) 60 percent of deaths could be attributed to cardiovascular complications: hypertension, arteriosclerotic cardiovascular disease, congestive heart failure, and pericarditis.

Hypertension is the most common cardiovascular disorder in CRF, and its control is essential to longevity for dialysis patients as it is a predisposing factor in a number of cardiovascular disorders (White & Rubin, 1983; Wright, 1981). Approximately 80 percent of CRF patients have

hypertension when they begin a program of dialysis. It usually resolves after dialysis, but, is a recalcitrant problem for approximately 5 to 30 percent of patients. Treatment of this disorder in CRF patients is consistent with traditional hypertensive regimens and is done in a stepwise fashion. Salt and fluid intake is restricted. (Diuretics are not needed in patients with no renal output.) If this regimen is not sufficient to control blood pressure, Beta Blockers are prescribed to inhibit autonomic nervous system activity. Finally, for dialysis patients, a last alternative is a bilateral nephrectomy.

Evidence suggesting that dialysis accelerates the rate of vascular disease is equivocal; it does appear, however, that dialysis may hasten the process and increase mortality for patients who already have vascular disease (Burke, Francos, Moore, Cho, & Lasker, 1978). Vascular problems are most common in older patients. Typical clinical manifestations of vascular disease are angina, cerebrovascular accidents, and transient ischemic attacks. Treatment is similar to that prescribed for non-dialysis patients and does not preclude surgery if aggressive medical management does not succeed.

According to Comty and Shapiro (1983), congestive heart failure (CHF) frequently occurs in dialysis patients. Factors contributing to CHF in the nondialysis population contribute to the occurrence of heart failure in the

dialysis patient (Wright, 1981). Dialysis patients may suffer from congestive cardiomyopathy (disease of the middle layer of the heart muscle) caused by uremia and excessive accumulation of fluid. Treatment of CRF then consists of controlling hypertension, and fluid weight gain, conditions known to increase the cardiac workload. Treatment may also involve the use of vasodilator drugs and by-pass surgery. Pericarditis is a life-threatening complication of terminal uremia, and may continue to be a problem for long-term dialysis patients (Comty and Shapiro, 1983). Signs and symptoms of pericarditis are chest pain, fever, and compression of the venous return to the heart due to increased fluid volume in the pericardium (cardiac tamponade; Wright, 1981). Pericarditis is likely to occur during the first 2 months of dialysis treatment. Management consists of bedrest, maintenance of adequate nutrition, improving biochemical control of uremia through dialysis, restricting protein and fluid, preventing bleeding by decreasing the use of anticoagulants, and adding anti-inflammatory drugs to the regimen.

Hematologic Complications. Anemia develops in almost all CRF and dialysis patients (Eschbach, 1983). The kidneys reduce red blood cell mass by producing the hormone erythropoietin which stimulates the production of red blood cells in the bone marrow. Anemia can result from insufficient erythropoietin production. Another cause of

anemia is blood loss, ranging from 15-75 ml, which occurs with each dialysis session. Additional losses occur from blood samples required for various lab tests. Folic acid, a member of the vitamin B complex and necessary for red blood cell production is removed during dialysis. All those factors contribute to anemia in the dialysis patient. Treatment consists of either or both of two methods: iron supplementation and blood transfusion.

Renal Osteodystrophy. The term renal osteodystrophy is used in a generic sense to include all clinical syndromes of skeletal disease and altered calcium and phosphorus metabolism (Coburn & Llach, 1983). Vitamin D metabolism is altered due to the kidney's inability to produce the hormone needed to convert vitamin D into a biologically active form that facilitates the absorption of calcium and phosphorus. As a result, intestinal absorption of calcium is abnormally low. Parathyroid hormone is secreted in response to lowered levels of calcium. Elevated blood levels of parathyroid hormone cause bone changes that lead to skeletal abnormalities. Some of the signs and symptoms of renal osteodystrophy are skeletal pain, muscular weakness, itching, bone deformities and growth retardation in children, fractures, periarthrititis (acute pain, redness and swelling of joints), tendon rupture, ulceration of the skin, and altered biochemistry. Medical management consists of suppressing parathyroid hormone, and maintaining proper

blood concentrations of calcium, magnesium, and phosphorus, using dietary restrictions of phosphorus-containing foods, and dietary supplements of calcium, vitamin D therapy, and as a last resort, a partial parathyroidectomy.

Gastrointestinal Complication. Ten to fifteen percent of dialysis patients tend to have gastritis and duodenitis (without ulcers) causing gastric pain and "heartburn" (Wright, 1981). They do not generally experience the nausea and vomiting experienced by uremic patients, except occasionally during the dialysis procedure.

Infection. Frequent infections pose a major medical problem for dialysis patients (Keane & Raij, 1983; Mosely, Brantley, Jones, & Cocke, in press). The infections found are not rare or unusual, but dialysis patients are repetitively exposed to infection during the dialysis procedure. Contributing to infection in most patients is a compromised immune system and poor nutritional status.

Infection is a leading cause of death in dialysis patients with estimates ranging between 14-38 percent. The major infectious complications are access infections and thrombosis as a result of infections at the access site, pulmonary emboli caused by infection at the access site, bacterial endocarditis, osteomyelitis, bacteremia (the presence of viable bacteria in the bloodstream), septic arthritis, urinary tract infections, respiratory infections, and hepatitis (Palakoff, 1983; Butt, 1983).

Neurological Disorders. Neurological disorders are another frequent complication in dialysis patients (Jennekins, & Jennekins -Schinkel, 1983). Some of these complications result from the persistent slight uremia. Usually some encephalopathy is present. "Dialysis Dementia", a progressively fatal complication occurs in patients who have received dialysis for a number of years (Luke, 1985; Wright, 1981). It is a central nervous system disorder associated with speech and motor defects, dementia, and seizures. It is less common now than in years past, probably as a result of improved methods of dialysis. Intracerebral hemorrhage may occur as a complication of the anticoagulants used during dialysis. Multi-infarct dementia may be present, particularly in patients with hypertension. Peripheral neuropathies are some of the principal and most frequent neurological manifestations. The neuropathy of uremia is similar to that found in patients with diabetes. The most common complaint is an uncomfortable feeling in the legs that is relieved by movement, known as "restless leg syndrome". Burning and tingling in the extremities may also be present.

Other neurological complications associated with the dialysis session result from severe azotemia (increased nitrogen in the bloodstream). Onset of symptoms usually occurs near the end of the session. This is called the Dialysis Disequilibrium Syndrome and is characterized by

headache, nausea and vomiting, blurred vision, disorientation, restlessness, and muscle cramps (Jennekins and Jennekins-Schinkel, 1983; Longo, 1981; Salmons, 1980). More severe manifestations of this syndrome include confusion and convulsions.

Psychological Complications of Dialysis

End-stage renal disease and concomitant dialysis therapy is a catastrophic and permanent change that significantly disrupts lifestyle and requires major life adjustments (Burton, Kline, Lindsay, & Heidenheim, 1986). As the patient gets sicker, progressing from a renal patient to a dialysis patient, more difficult restrictions, crises, and threats of personal loss occur. The patient must come to terms with disability and limitations created by the illness (Salmons, 1980; Ginn & Teschen, 1983).

Coping Styles. Many of the psychological stresses and problems that occur during dialysis are inherent in the situation. Some of the earliest work done by Kaplan De Nour and Czaczkes (1972) indicated that dialysis patients have high levels of aggression and an inability to openly express this aggression. Other factors that were identified were low frustration tolerance, the tendency to act out, denial of the sick role, secondary gain from the sick role, and self-destructive tendencies. Stewart (1983) discussed the prevalence of defense mechanisms, such as denial, displacement, isolation, projection and reaction formation.

In his analysis, denial is the most frequently used defense against the stress of chronic illness. Also, he emphasized patient dependency and regression with successful adaptation to dialysis. This does not mean that there is a "dialysis personality", but rather that the stress of dialysis brings out similar coping styles in patients. It would also be expected that some patients may have even more difficulty coping and may develop clear-cut psychological problems.

Depression. One problematic and common psychological presentation in dialysis patients is depression (Burton et al., 1986). Stewart (1983) estimated that at any one time at least a quarter of the patients on a dialysis unit will report signs and symptoms of major depression. Burton et al. (1986) reported that approximately 60 percent of patients in their sample were severely depressed. In general depression occurred more frequently and with greater severity in the dialysis population than in the non-dialysis population. Abram, Moore, and Westervelt (1971) reported that the suicide rate for dialysis patients was 100 times greater than that in the average population. If patients who had requested withdrawal from treatment were included in this estimate, the rate would increase to 400 times that of the non-dialysis population.

Anxiety. Anxiety is another common presentation of dialysis patients (Salmons, 1980). Nearly all dialysis patients experience anxiety at one time or another, since the threat

of imminent death is a real one. For some, anxiety may be episodic and short-lived and respond well to reassurance and support. For others, hemodialysis may lead to full-blown panic attacks (Salmons, 1980).

Sexual Dysfunction. Sexual dysfunction is another distressing problem for dialysis patients. This may be experienced as decreased libido, problems with erection, or problems with ejaculation. Stewart (1983) reported that prior to dialysis, 45 percent of male patients develop impotence secondary to uremia. After dialysis has been initiated, an additional 35 percent will develop impotence. Impotence appears to be correlated with psychological problems; organic factors, however, play an important part. Low blood zinc and testosterone levels, elevated parathyroid hormone, and neuropathies have been found to be related to impotence. Female dialysis patients also report sexual difficulties, but less is known about their problems. Sexual performance for both male and female dialysis patients may be impaired by poor physical health, anxiety, depression, the side -effects of medications, and organic factors.

Dementia and Psychosis. Organic and functional factors interact and can cause disruption in cognition and awareness (Salmons, 1980). Uremia, hypertension, anemia, cardiac complications, infection and metabolic abnormalities can effect cerebral function. Memory and abstract thought processes tend to deteriorate slowly. Other intellectual

abilities also tend to deteriorate slowly. In the past, it was not uncommon for patients maintained by dialysis to develop a progressive dementia accompanied by personality changes, such as apathy, irritability, and temper outbursts, frequent drowsiness, and fatigue. Improved methods of dialysis have brought about a significant decline in this "dialysis dementia". Psychotic states, accompanied by delusions and hallucinations, may be present in the dialysis patient. Most reported cases of psychosis are related to organic factors, such as a steroid psychosis or uremia, however, there are some reports in the literature of patients with a longstanding history of manic-depressive psychosis or schizophrenia prior to their beginning dialysis. These patients represent an especially difficult subpopulation of dialysis patients.

Noncompliance. Generally, compliance refers to the degree to which the patient's behavior coincides with prescribed medical or health advice (Haynes, 1982). Compliance with the medical regimen may involve relatively simple behaviors, such as keeping a physician's appointment or getting a chest x-ray or very complex behaviors, such as monitoring caloric intake and urine or blood glucose several times a day for a lifetime (Turk, Salovey, & Litt, 1986). An appropriate definition of compliance will obviously reflect the nature of the health problem for which treatment is being sought. Dialysis "patients are confronted with the

prospect that they cooperate continuously for an indefinite time, with treatment that is costly in terms of time, thought... [and] effort. Their regimen denies them many of the "normal means of coping ", such as eating, the use of tranquilizers and alcohol, sexual outlets, and physical exercise" (Ginn & Teschen, 1983). Also, their regimen is one of the most complex and demanding of all regimens, meaning that it is also one of the most difficult to follow (Nehemkis & Gerber, 1986; Eraker, Kirscht, & Becker, 1984; Masur, 1981; Stone, 1979). General compliance for the dialysis patient can be defined as: 1) compliance with nutritional management, including dietary and fluid restrictions, 2) general compliance with medical recommendations (i.e. taking medicine), and 3) the decision to continue dialysis rather than terminate treatment against medical advice (Kaplan De Nour & Czaczkes, 1979). Measurement of compliance with the dietary restrictions and with the prescribed medications has traditionally involved a combination of three methods. These are health care provider assessment, patient self-report, and biochemical measures. Of these three methods the biochemical measures are done routinely, systematically, and are the most objective (Luke, 1985; Cummings, Becker, Kirscht, & Levin, 1981; Kokko, 1985).

Health care provider assessment of compliance is the most frequently used clinical measure and has been used as a

supplemental measure in research (Roth, Caron, & Hsi, 1970). These ratings are usually based upon a review of the biochemical measures and can actually be considered a combination rating. Research has indicated that health care professionals tend to overestimate compliance and are able to predict compliance only at about chance levels (Becker, & Rosenstock, 1984). Therefore, sole reliance on this technique for research purposes has not been recommended.

Patient self-report measures usually involve a patient interview or self-monitoring or both. The interview is probably the most common method to obtain patient self-report (Kaplan, De-Nour and Czaczkes, 1972; Cummings et al., 1982; Cummings et al., 1984; Sherwood, 1983). Although this is a very easy and economical way to obtain data, research has indicated that self-report is not very accurate and, again, is not the technique of choice for research purposes (Park & Lipman, 1964).

Biochemical measures are those most used in dialysis research and are also considered the most objective for research purposes (Masur, 1981; Blackburn, 1977; Cummings et al., 1982; Sherwood, 1983; Finn & Alcorn, 1985; Streltzer & Hassell, 1988). A variety of physiological measures are routinely taken for dialysis: blood urea nitrogen (BUN), serum potassium levels (K), serum phosphate levels (SPHL), and inter-session weight gain (IWG). (For specific compliance criteria, please see Appendix C.)

Demographic factors found to be related to compliance in dialysis patients are age, educational background, SES, and race (Rostand, Kirk, Rutsky, & Pate, 1982; Relman, 1982). O'Brien (1980) found several variables associated with compliance: unskilled workers were less compliant than professionals, subjects who lived alone were the least compliant, and those living with other adults and children were the most compliant. Cummings et al. (1982), Ferraro, Dixon, and Kinlaw (1986) and Blackburn (1977) reported that those dialysis patients who had been undergoing dialysis for longer periods of time were less compliant.

Some other factors thought to be associated with compliance are knowledge and understanding of the regimen. Research has provided equivocal results, with some studies finding no relation (Eraker et al., 1984) and others finding a positive relation (Kaplan DeNour, & Czaczkes, 1972). Health beliefs have also been found to be inconsistently related to compliance. According to a review by Turk et al. (1986), some studies find that health beliefs do effect compliance while others find that health beliefs may be necessary but not sufficient conditions to improve compliance. Social support is another factor that has been found to be both positively and negatively related to compliance. Hartmen and Becker (1978) reported that dialysis patients with fewer family problems and more spouse assistance were more compliant. They also found that

married patients were more compliant than unmarried patients. A final variable to consider when discussing compliance in dialysis patients is the complexity of the treatment. This factor has been very consistently and positively related, the more complex the regimen the greater the noncompliance. As was discussed in the beginning of this section, the treatment regimen is quite complex, trying, and leads to considerable hardship for dialysis patients (Masur, 1981; Eraker et al., 1984; Nehemkis & Gerber, 1982; Stone, 1979).

QUALITY OF LIFE

Many of today's medical techniques can impressively halt and even reverse the progression of diseases that just a few years ago were fatal (Hollandsworth, 1988; Brennan, Davis, Bucholz, Kuhn, & Gray, 1987; Ganz, Haskell, Figlin, La Soto, Siaus, 1988). As a result, many very sick individuals have had years added to their lives. The traditional medical goal has been just that - to add years, or to increase survival. Frequently this has been done by using medical techniques that are invasive, intrusive, and have significant negative side-effects. There are numerous examples of this in the literature with a wide variety of patient populations represented, such as heart patients (Evans, Manninen, Maier, Garrison, & Hart, 1985; Raczynski, & Oberman, 19;), cancer patients (Dolgin, Katz, Doctors, & Siegal, 1986; Slevin, Plant, Lynch, Drinkwater, & Gregory, 1988) and end stage renal disease (ESRD) patients (Blagg, 1985; Wolcott & Nissenson, 1988; Evans, Manninen, Garrison, Hart, Blagg, Gutman, Hull, & Lowrie, 1985), to mention a few. The goal of survival has been attained, however, an important consideration is the price, in terms of quality of life (QL) that has been paid by patients because of the nature of the treatment. Consequently during the past 10 years, both researchers and health care professionals have been addressing the issue of quality of life in medical patients.

Unfortunately, the issue of QL is difficult to address since it is a multidimensional phenomenon which defies easy definition (Greenwald, 1987). Both researchers and clinicians have had difficulty agreeing on its definition and measurement. Efforts to define it began with President Eisenhower's Commission on National Goals, which published its report in 1960 (Flanagan, 1982). For the general population, a variety of issues have been considered including: social and environmental factors, economic growth, health and welfare, psychologic disturbance, physical problems and overall happiness of the individual (Gurin, G., Verhoff, J., Feld, S., 1960). Researchers have attempted to define more specifically what they mean by QL (Binik & Devins, 1987; De Haes & Knippenberg, 1985). Some have stated that QL refers to the degree of need satisfaction within the physical, psychological, social, material and structural areas (Binik & Devins, 1987; De Haes & Knippenberg, 1985). Others have defined QL as a product of the patient's natural endowment and the efforts made on his/her behalf by the family and society (Andrews & Withey, 1976). Some define QL as a global evaluation of the good or satisfactory character of people's lives (Campbell, Converse, & Rodgers, 1976). Quality of Life has also been defined as the totality of those goods, services situations, and state of affairs which constitute the basic nature of human life (Flanagan, 1982). This list of definitions

reflects the difficulty with defining quality of life.

Measurement of quality of life has not been easy either, but researchers have been able to differentiate measurement approaches into two categories: objective and subjective (Hollandsworth, 1988). The medical literature has focused on objective measures as these are thought to more closely approximate "hard" measures and to be more scientific. Examples of objective measures include survival, health status, exercise tolerance, employment status, and medical complications (see Hollandsworth, 1988 for an extensive list of both objective and subjective measures). One characteristic of the objective measures is that they are determined by a health care professional and do not simply reflect the patients' opinion.

Most recently, both the medical and the psychological literature have begun to emphasize the importance of the patients' subjective assessment of their QL. Subjective measures include a wide variety of self-report measures (e.g., Profile of Mood States, Sickness Impact Profile, Eysenck Personality Inventory, MMPI, Social Dependency Scale, etc.,...) that reflect researchers' conceptualizations or definitions of QL. Numerous instruments have been developed to assess many of the attributes listed previously, and frequently include such specifics as psychological state, social support, stress, and life satisfaction. The essence of the subjective

measures is that they are supposed to reflect the patients' experiences as appraised by the patients.

In sum, many definitions and measures exist due to the lack of agreement about the meaning of QL. Despite the disagreement, researchers have attempted to answer relevant questions about the impact of medical treatment on QL. The typical approach to doing this has been for the researcher or clinician to judge which measures are appropriate for his or her purposes and to find those measures having adequate reliability and validity (Binik & Devins, 1987; Greenwald, 1987).

Despite the uncertainty about which dimensions are most suitable, there is good agreement about which diseases affect QL. End stage renal disease was the second most represented disorder in the quality of life literature (Hollandsworth, 1988). It is a disease with a treatment modality that is technologically advanced and effectively increases survival. Yet in many cases the treatment is accompanied by significant morbidity and disability that many researchers believe diminishes QL (Evans et al., 1985; Blagg, 1985; Evans, Mannien, Maier, Garrison, & Hart, 1985). Wolcott, Nissenson, & Landsverk, (1988) addressed the dilemma of defining QL by conceptualizing it in terms of three dimensions: medical, psychological, and social. They have been used by other dialysis researchers (Evans et al, 1985; Ferrans & Powers, 1985; Binik & Devins, 1987) and by

those studying other chronic illnesses (Raczynski & Oberman, 198; Dolgin et al., 1986; Slevin et al., 1988). However much of the quality of life literature relating to ESRD patients compared maintenance dialysis patients with renal transplant patients or peritoneal dialysis patients, since the general population is not the proper comparison group and, these represent the alternative treatment regimens (Freeman, 1986; Poznanski, Miller, Salquero, & Kelsh, 1978; Ginn & Teschen, 1983). Therefore, a discussion of the various dimensions of QL thought to be relevant to dialysis patients is included in this report, comparing chronic hemodialysis patients with other ESRD patients.

Medical. Medical measures of QL are almost always objective and are usually assessed by physicians and other medical staff. These measures include health status, functional status, and employment status. One commonly used objective measure that reflects functional status is the Karnofsky Activity Scale (Freeman, 1986; Poznanski, et al., 1978; Ginn & Teschen, 1983; Carlson, Johnson, and Kjellstrand, 1987; Karnofsky and Burchenal, 1949). The Karnofsky scale is a 100 point scale developed to rate the functional status of patients at the beginning of treatment and every six months afterwards. Numerical scores corresponding to behavioral descriptors occur at each 10 point gradation of the scale and range from 0 (dead) to 100 (normal, no complaints, no evidence of disease). Carlson et al. (1987)

found that patients who received a renal transplant had initial rehabilitation scores that were higher than rehabilitation scores of dialysis patients. Patients undergoing dialysis for a two-year period showed improvement in rehabilitation status, however they never reached the level of rehabilitation of the transplant patients. The best predictor of rehabilitation status at two years for both groups was rehabilitation status at the initiation of dialysis.

In Evans et al. (1985) renal transplant patients and dialysis patients were compared using the Karnofsky Scale and by asking patients how able they were to work for pay ("Are you now able to work for pay full-time, part-time, or not at all?). They found that 79.1 percent of the transplant patients were able to function at near normal levels (as measured by the Karnofsky) compared to 47.5 percent of the patients treated with hemodialysis. Almost 75 percent of transplant patients were reported being able to work compared to 24.7 percent of hemodialysis patients.

Wolcott and Nissenson (1988) compared hemodialysis patients with home dialysis patients and found no significant differences between the groups on medical status variables (primary diagnosis, presence of diabetes, and the Karnofsky); however, their selection criteria were quite strict and patients in very poor health were excluded. Despite the restriction of range, home dialysis patients

were more likely to be working than were hemodialysis patients. The authors concluded that dialysis modality exerts a small effect on QL.

Health status is another objective measure frequently used in the literature. Some overlap exist between health status and rehabilitation status; health status, however, more specifically reflects the nature and degree of organic pathology and those behaviors thought to be associated with the presence of illness such as symptom reporting, medical utilization, and perceptions of physical well-being. Health status is usually assessed through physician assessment (e.g., medical examination, diagnosis). Physician rating scales are considered the most objective, and they vary in their format from, global ratings to highly structured interviews. Patient self-ratings of health status are considered subjective measures and are highly correlated with life satisfaction (Palmore & Luikart, 1972; Kaplan and Camacho, 1983).

In general, successful transplant patients report better health status than hemodialysis patients. Renal transplant patients report being less tired, feel that their lives are easier, and feel less inconvenienced by medical treatment than did dialysis patients (Johnson, et al., 1982).

In sum, medical status measures are more objective and are typically based on an observation by a trained health care professional. Also the variables, employment status

and number of diagnoses, are more objective. Research consistently shows that in terms of medical status variables, dialysis patients have a poorer QL than other ESRD patients.

Psychological Measures. Many studies (e.g., Eiseman, 1981; Boulding, 1981; Poznanski et al., 1978) have supported the efficacy of examining psychological aspects of QL.

Psychological measures are subjective measures and are almost always based on patient self-report. Evans et al. (1985) used the Index of Psychological Affect, the Index of Overall Life Satisfaction, and the Index of Well-being, all developed by Campbell and colleagues (Campbell, et al., 1976; Campbell, & Converse, 1980). These measures were designed to examine the QL of the United States population. On three subjective measures (Life Satisfaction, Well-being, and Psychological Affect) transplant patients reported a higher QL than patients on hemodialysis. Furthermore, home dialysis patients also reported better QL than patients receiving hemodialysis did. These differences persisted even after significant medical/demographic variables (i.e., age, disease severity) were controlled statistically.

Poznanski et al. (1978) used an interview to assess subjective well-being focusing on life areas such as job/school performance, body image, social activities, and plans for the future. They found that QL between dialysis patients and renal transplant patients was strikingly

different in almost every area assessed, with renal transplant patients having the best adjustment.

Wolcott and Nissenon (1988) used the Simmons Self-Esteem Scale, the Profile of Mood States, self-ratings, The Multidimensional Health Locus of Control, The Dialysis Modality Specific Stresses Scale, the General Treatment Stresses Scale, the Global Illness Stresses on Self and Others scale, and the Global Adjustment to Illness scales to compare home dialysis patients. They concluded that home dialysis patients have a modestly better level of psychological adaptation than hemodialysis patients.

Johnson, et al (1978) developed their own measures of QL based on Campbell's work. Their measures included three items that assessed satisfaction with marriage, satisfaction with children, and overall life satisfaction, and five items assessing negative feelings. Subjective QL was not different for the groups. The authors hypothesized that denial and accommodation mechanisms may have accounted for the lack of differences between the patient groups.

Binik and Devins (1987), in a series of three studies compared successful transplant patients, transplant failure patients, and dialysis patients, using a variety of psychological measures. These were: the McGill Pain Questionnaire (Melzack, 1975), Beck Depression Inventory (Beck, 1967), Self-esteem Inventory (Coopersmith, Wallston, Kaplan, and Maides, 1976), Internal-External Locus of

Control Scale (Rotter, 1966), Health Locus of Control Scale (Wallston, Wallston, Kaplan, and Maides, 1976), Affect Balance Scale (Bradburn, 1969), Profile of Mood States (McNair, Forr, & Droppelman, 1971), Hamilton Rating Scale (Hamilton, 1967), a self-rating of helplessness (Devins, Binik, Hollonby, Barre, and Guttman, 1981), and a checklist of somatic symptoms of distress (Devins, Binik, Hutchinson, Hollonby, Barre, and Guttman, 1983). They found no significant differences in levels of pain, depression, normal mood states, perceived intrusiveness or perceived locus of control among hemodialysis as compared to transplant or transplant failure patients.

To summarize, research examining psychological status variables includes a wide variety of measures. Results comparing hemodialysis patients with other ESRD patients have been inconsistent, with some studies finding poorer QL for hemodialysis patients and others reporting no significant differences in QL.

Social Support Measures. Although most studies of QL in dialysis patients acknowledge that social support is very important (Hartmen & Becker, 1978; Cummings et al., 1982; O'Brien, 1980; Kossaris, 1970; Pentecost, Zwerenz, & Manuel, 1976; Steidl, Finkelstein, Wexler, Fergenbaum, Kutson, Kluger & Quinton, 1980; Sherwood, 1983), it is a variable that is frequently omitted. Few standardized measures for assessing social support are available, particularly for

illness populations. For example, Johnson et al. (1982) assessed social support by asking hemodialysis and transplant patients to list the number of relatives and friends they had talked to during the previous month. No significant difference was noted between the two groups. Binik and Devins (1987) assessed social support via self-rating measures of perceived control over eight life areas (Devins, et al, 1981), one of which was the family dimension. They found no differences in social support based on treatment modality or failed transplant.

Wolcott and Nissenon (1988) included current marital status, participation in social and leisure activities, patient ratings of quality of relationships with other dialysis patients, dialysis physicians, and dialysis nurses, and patient ratings of satisfaction with five categories of social support they had received in the previous three months. They compared home dialysis patients with hemodialysis patients and reported no differences between the groups on marital status, participation in social and leisure activities, or satisfaction with social support. They found that home dialysis patients had more positive relationships with other dialysis patients and dialysis staff. They concluded that greater independence and autonomy for the home dialysis patients may have resulted in better relationships.

These studies suggest that researchers have used many

different measures to assess social support. Social support does not appear to differ greatly for ESRD patients regardless of their prescribed treatment modality.

In summary, QL is a multidimensional concept not easily defined or measured. The previous review of the QL literature for dialysis patients has focused on three aspects: medical, psychological, and social. A number of different measures have been used to assess each of the different aspects. It can be concluded that as of now, there are no definitive measures for assessing QL for dialysis patients. Research suggests that, in general, hemodialysis patients have a poorer QL than other ESRD patients whose dialysis regimen is less restrictive and intrusive.

PROPOSED STUDY

Although hemodialysis removes toxins and metabolic by-products from the body, it does this less effectively than the kidneys (Cummings et al., 1982). To compensate for this ineffectiveness, dietary management has been prescribed to reduce the amounts of toxins and metabolic by-products (e.g., urea, creatinine, sodium, and potassium) that must be removed from the body. A prescription for regular hemodialysis sessions combined with dietary management comprises an intrusive and difficult treatment regimen for patients with ESRD. Noncompliance with the regular dialysis sessions, will surely result in death. Noncompliance with the dietary restrictions may result in relatively mild complications (e.g., nausea, weakness) or at worst, more severe complications (e.g., cardiovascular problems, and death).

Most patients comply with dialyzing, but are notoriously noncompliant with the dietary restrictions, despite the consequences (Hartmen & Becker, 1978). Considerable effort has been devoted to helping dialysis patients improve their compliance, and the literature is replete with studies designed to identify factors which contribute to noncompliance with the dietary regimen. For example, demographic variables are related to compliance, but relatively little can be done to alter them (Cummings et al., 1982; Mosely, et al., in press). Other factors found

to affect compliance include knowledge of the regimen, health beliefs, available social support and regimen complexity. Regimen complexity, in particular, is one of the most powerful contributors to noncompliance. Most professionals believe that compliance with the dialysis regimen will prevent or at least abate short-term and long-term medical complications (Acchiardo, Moore, & Cocherell, 1984; Barsotti, Giannoni, Morelli, Fozzeri, Vlames, Baldi, & Giovannetti, 1984). However, recent research has suggested that compliance may have little impact on long-term medical complications, such as medical utilization, health status, or survival (Bruce, Brantley, Cocke, & McKnight, 1987; Ruggiero, 1988). While it may be premature to make changes in the prescribed dietary regimen at this stage in the research, it is appropriate to continue to examine the impact that the regimen has on relevant patient outcome variables, one of these being QL. Given the complexity and restrictiveness of the regimen, it would appear logical to question the impact of the regimen on patients' QL. Similarly, this leads to speculation on how restrictive the regimen needs to be to prevent short-term complications while allowing the highest QL. It is agreed that hemodialysis patients suffer a poorer quality of life than the general population, and to a large extent, other ESRD patients who have had renal transplants or have less restrictive dialysis regimens (Hutchinson, 1979; Blagg,

1985; Evans, Manninen, Marer, Garrison, and Hart, 1985; Simmons, Anderson, Kamstra, and Ames, 1985). However as was stated earlier, hemodialysis is the treatment of choice for most ESRD patients. While little can be done to alter medical and demographic variables which effect QL, alterations could be made in the dietary regimen if there were evidence to support the utility of this. The purpose of the present study was to examine the relation between dietary regimen (as it is presently being prescribed by professionals in renal medicine) and QL in hemodialysis patients. It was reasoned that if a positive relation was found between compliance and QL then support would be provided for treatment efforts to improve compliance. If there was a negative relation or no relation found between compliance and QL, then research should focus on ways to relax the regimen while preventing short-term complications and promoting QL. This study also examined the relation between significant medical/demographic characteristics in predicting QL.

The following questions were addressed.

Question 1. What are the relations between compliance with the regimen (as measured by physiological parameters) and quality of life?

Question 2. What are the relations between demographic/medical variables and quality of life?

Question 3. What parameters of compliance predicted quality

of life?

Question 4. Did demographic/medical attributes predict quality of life?

Question 5. Which patient attributes (physiological parameters of compliance, or demographic/medical variables) are the better predictors of quality of life?

Predictions based on Question 1. If compliance as measured by BUN, IWG, and K is important to quality of life, which measures are related to criterion variables reflecting quality of life. It was expected that compliance would be significantly but modestly correlated with overall quality of life. It was predicted that measures of compliance (BUN, IWG, SP) would be differentially related to the quality of life variables.

Predictions based on Question 2. It was predicted that there would be a significant relation between medical/demographic variables and quality of life measures.

Predictions based on Question 3. Given that measures of compliance are important to quality of life, these measures were hypothesized to add to prediction of QL. Compliance should predict overall quality of life at a modest level.

Predictions based on Question 4. Given that the patient's demographic/medical characteristics are important to his or her quality of life, it was hypothesized that these measures would predict quality of life at better than chance levels.

Predictions based on Question 5. Even though both

compliance variables and demographic/medical variables were hypothesized to be important in quality of life, it was predicted that demographic/medical variables would be better predictors than compliance measures since medical/demographic characteristics are better predictors of other aspects of dialysis (e.g., survival, medical utilization).

METHOD

Subjects

A list of 127 eligible patients from the University of Alabama Hospital dialysis unit in Birmingham, Alabama was obtained based on the following inclusion criteria: a) those who had been receiving dialysis treatments for a minimum of 15 months (prior to November 1, 1987), b) a renal diet with recommendations for limiting sodium, potassium, protein, and fluid intake, and c) negligible or no remaining urinary output. Of the 127 eligible patients, 67 completed the study. See Appendix A for the Informed Consent form.

Sixty of the 127 subjects were not included in the study for the following reasons: a) refused to participate, b) received kidney transplants before they could be interviewed, c) died before they could be interviewed, d) transferred to another dialysis center, e) insufficient biochemical data, or f) were unable to either read the questionnaires or comprehend the questionnaires when read to them (see Table 1). Subjects were allowed to choose whether they wanted to complete the questionnaires by themselves or if they wanted to have the questionnaires read to them (due to poor eyesight, vascular access in dominant hand, etc.). Those who wished to read the questionnaires were required to have at least an 8th grade reading level as measured by the Wide Range Achievement Test - Revised (Jastak, & Jastak; 1978). Those who wished to have the questionnaires read to

them were administered the Comprehension section of the WAIS-R (Wechsler, 1981) to assure adequate comprehension ability. Subjects were required to obtain a standard score of at least 7. The criterion on the Comprehension section was lowered to a standard score of 6 for two subjects who appeared to understand the questions, had difficulty expressing their answers clearly, and had at least a 10th grade education. One subject was not screened with either instrument, but was high-school educated (see Table 2 for scores and education level characteristics).

At the time of the study, the subjects ranged in age from 19.6 years to 77.7 years, with a mean age of 50.9. This sample was 61.2 percent female, 38.8 percent male, 83.6 percent black, and 14.9 percent white (see Tables 2 and 3).

Predictor Variables

Certain medical and demographic variables have been found to predict health status, medical utilization and survival. Therefore, some of them were used as predictor variables in this study: 1) age at onset of dialysis (the patient's age in years at the time of their first chronic dialysis treatment), 2) years on dialysis (total number of years from the patient's first chronic dialysis treatment until the time period from which the data were collected for the proposed study), and 3) the total number of morbid conditions coexisting with ESRD (diagnoses included were based on review of the literature: diabetes mellitus,

hypertension, congestive heart failure, chronic obstructive pulmonary disease, systemic lupus erythematosus, liver disease, malignancy, and arteriosclerotic cardiovascular disease (See appendix B for medical/demographic form). Age of onset of dialysis ranged from 18.1 years to 75.5 years, with a mean of 45.5. Number of years on dialysis ranged from 1.2 years to 22.7 years, with a mean of 5.4 years. The number of diagnoses per subject ranged from 0 to 4 with a mean of 1.5. (see Tables 2 and 3).

Other predictor variables were the biochemical measures blood urea nitrogen (BUN), serum potassium level (K), and inter-session weight gain (IWG; see Appendix C for compliance criteria). Those measures were chosen because they are the most commonly used measures of dietary compliance reported in the literature (e.g. Blackburn, 1977; Finn et. al., 1986; Ferraro et. al., 1986; Cummings et. al., 1984). Also, they are taken routinely by the dialysis staff, and they provide convenient and practical measures for research purposes. To ensure reliability and validity, a mean was computed on at least 6 repeated measures for BUN and K (Ruggiero, 1988). These biochemical measures were abstracted from patient medical records for the 15 month period prior to the assessment of QL. BUN and K are typically measured every two months at the University of Alabama at Birmingham dialysis center. Compliance with fluid restrictions was assessed by weighing the patient prior to

each dialysis session and then weighing the patient again after dialysis. The difference between the pre and post dialysis weights is the intersession weight gain (IWG). IWG was abstracted from the medical records for the three months prior to the assessment of QL (see Table 4 for the ranges, means, and standard deviations of the compliance measures).

Criterion Variables/Instruments

Four instruments were used to assess quality of life (QL). The first measure, the Karnofsky Activity scale (KAS), represented the patient's performance of activity (See Appendix D). It was completed by the two hemodialysis social workers who have consistent contact with the subjects; their two ratings were averaged for the statistical analyses. The KAS has been found to be both reliable and valid when employed by trained health care professionals who are familiar with the subjects and who use behaviorally based guidelines (Shag, Heinrick, & Ganz, 1984). Specifically, Hutchinson et al. (1985) reported that inter-rater reliability was poor in the absence of operational criteria to define the gradations of the scale. Shag et al. (1984) used a series of interview questions to serve as guidelines for helping the health care professional determine the activity status of the individual. Using them, Shag et al. (1986) obtained an inter-rater reliability coefficient of .89. Those questions were included as part of a brief interview in this study (see Appendix E), and an inter-rater

reliability of .85 was obtained using the Spearman-Brown Prophecy formula (see Table 5 for ranges, means, and standard deviations of all the QL measures).

The second measure used was the Personal Resource Questionnaire (PRQ), a 25-item measure of perceived social support (Brandt & Weinert, (1981; see Appendix F). Evaluation of the instrument supported its internal consistency (Chronbach's alpha ranged from .85 to .93 with 3 different age groups - young adults, middle-aged, and elderly). There was also evidence to substantiate content, construct, and criterion-related validity. This instrument was chosen as the measure of social support because it was developed using spouses of a chronic illness population, and thus more appropriate than other social support instruments for this population.

The third measure used was the Psychological General Well-Being Schedule (PGWBS) which provides a brief, but broad-ranging indicator of subjective feelings of psychological well-being and distress. This scale reflects both positive and negative feelings, including anxiety, depression, general health, positive well-being, self-control, and vitality. Its internal consistency is high (.91 for males and .95 for females). Test-retest reliability as well as validity have been found to be quite adequate (McDowell & Newell, 1987; see Appendix G).

The fourth, and final measure was the Quality of Life

Index (QLI) for dialysis patients developed by Ferrans and Power (1985). It is a comprehensive measure of subjective well-being and quality of life (See Appendix H). It is a 70- item questionnaire that has adequate reliability (Chronbach's alpha of .90) and validity.

Procedure

All subjects completed an interview scheduled during their routine dialysis treatment which lasted an average of 45-75 minutes. A consent form was signed by both the subject and the experimenter at the beginning of the interview. Subjects were told that the objective of the study was to examine QL in hemodialysis patients. After the consent form was signed, subjects completed either the WRAT-R or the Comprehension subtest of the WAIS-R.

Subjects were allowed to complete the questionnaires on their own if they were able to read at or above an 8th grade level as measured by the WRAT-R. An experimenter was available to them during this time in case a problem were to arise. If the subject choose to have the questionnaires read to him or her, the measures were administered orally by the examiner. Demographic and medical information were obtained from each subject's medical records. Also, biochemical analyses of BUN, SP, and IWG were obtained from the medical records.

Staff ratings of activity (KAS) were completed independently by two staff social workers within the 1-week

period the quality of life measures were administered to the subject.

RESULTS

Preliminary Analyses

In order to control for the large number of correlations calculated, probability was set at $p < .01$ for all analyses in order for the coefficient to be significant. A preliminary analysis was done to determine if any significant differences existed between the subjects who completed the WRAT-R (because they read and answered the questionnaires on their own) and the subjects who completed the Comprehension section of the WAIS-R (because they had the questionnaires read to them and their answers were recorded by the interviewer). If the subjects' data were significantly different because of their group, error would be introduced into the analyses. For example, subjects who had the questionnaires read to them may have responded in a more socially acceptable manner, making their results different from the subjects who completed the measures on their own and who may have felt free to respond more honestly.

Fifty-one subjects completed the Comprehension subtest, and 15 subjects completed the WRAT-R. T-tests yielded no significant differences between the two groups on age, age beginning dialysis, years on dialysis, number of diagnoses, biochemical measures, or the quality of life measures. The only significant difference noted between the groups was

that subjects who completed the WRAT-R were better educated ($t = -3.68$ (23.9), $p < .0007$). Given that this was the only difference, separate analyses did not appear to be warranted.

Another question that warranted investigation before the hypotheses were tested was whether or not the quality of life (QL) measures (criterion variables) were intercorrelated. Correlational analysis revealed correlations between scores on the social support measure, the Personal Resource Questionnaire (PRQ) and the psychological well-being measure, the Psychological General Well-being Schedule (PGWBS; $r = .33$, $p < .007$), the PRQ and the overall QL measure, the Quality of Life Index (QLI; $r = .44$, $p < .0002$), and the PGWBS and the QLI ($r = .51$, $p < .0001$). Thus the PRQ, PGWBS, and the QLI were modestly correlated with each other. The activity measure, the Karnofsky Activity Schedule (KAS) was unrelated to other measures of QL (see Table 6).

Also, the intercorrelations between the compliance measures were examined. Analysis revealed correlations between blood urea nitrogen (BUN) and potassium (K; $r = .48$, $p < .0001$) and between K and intersession weight gain (IWG; $r = .34$, $p < .004$). This also indicated a modest correlation between the compliance measures (see Table 7).

Prediction 1

According to Prediction 1, compliance measures should

be moderately and significantly correlated with QL measures. Furthermore, the compliance measures should be differentially correlated with the quality of life measures. The results of the analyses indicated that IWG was significantly correlated with activity (KAS; $r = .33$, $p < .008$; see Table 8). No other measures of compliance correlated with QL measures (see Table 8). These results are somewhat paradoxical since higher levels of activity were associated with poorer compliance.

Prediction 2

According to Prediction 2, demographic/medical variables are significantly correlated with QL variables. The results of this analysis revealed significant correlations between age and activity (KAS; $r = -.59$, $p < .0001$), between age when beginning dialysis and activity (KAS; $r = -.61$, $p < .0001$), between number of diagnoses and activity (KAS; $r = -.44$, $p < .007$) and between age beginning dialysis and social support (PRQ; $r = .33$, $p < .007$). Therefore Prediction 2 was supported in part (see Table 9), indicating that activity is related to certain medical/demographic characteristics. Also, social support was related to age beginning dialysis.

Prediction 3

According to Prediction 3, measures of compliance should add to the prediction of QL. This was tested using a stepwise multiple regression procedure. Four multiple

regressions were done. The three compliance variables (BUN, K, and IWG) were entered into the equation to predict social support (PRQ). Results again were nonsignificant, R-squared (3,61) = .06. Compliance measures were entered into another equation to predict psychological well-being (PGWBS). Regressions were nonsignificant, R-squared (3,61) = .041. Compliance measures were entered into another equation to predict overall quality of life (QLI). Results were nonsignificant, R-squared (3,61) = .05. Finally, compliance measures were entered into the last analysis to predict activity (KAS). Results again were nonsignificant, R-squared (3,61) = .14. Therefore, Prediction 3 was not supported: compliance measures did not add to the prediction of QL (see Table 10).

Prediction 4

According to Prediction 4, medical/demographic variables significantly should predict QL. This was tested using a stepwise multiple regression procedure. Four analyses were done, entering the demographic/medical information into the equation to predict each of the four QL variables. Results of the analysis predicting social support (PRQ) were nonsignificant, R-squared (3,61) = .11. Results of the analysis predicting psychological well-being (PGWBS) were nonsignificant, R-squared (3,61) = .06. Results of the analysis predicting overall quality of life (QLI) were nonsignificant, R-squared (3,61) = .09. Results of the

analysis predicting activity (KAS) were significant, R-squared (3,61) = .48, $p < .0001$. Therefore, Prediction 4 was supported in part, indicating that in this study, medical demographic variables were related to activity (see Table 11).

Prediction 5

According to Prediction 5, medical/demographic variables combined with compliance variables should significantly predict QL. This was tested using a standard multiple regression procedure. Four analyses were done, entering the demographic/medical and compliance information into the equation to predict each of the four QL variables. Results of these analyses revealed that the combination of medical/demographic and compliance variables significantly predicted activity (KAS), R-squared (6,58) = .50, $p < .0001$. Results of the analysis predicting social support (PRQ) were nonsignificant, R-squared (6,58) = .18. Results of the analysis predicting psychological well-being (PGWBS) were nonsignificant, R squared (6,58) = .09. Results of the analysis predicting overall quality of life (QLI) were nonsignificant, R-squared (6,58) = .14 (see Table 12). Upon examination of the beta weights, the medical demographic variables add to the prediction with no significant contribution made by the compliance variables. Results suggest that activity is related to medical/demographic variables such as age beginning dialysis and number of

diagnoses.

Further Analyses

In addition to the above analyses, a canonical correlation was performed on the data in hopes that this type of analysis may be a more effective technique to examine the patterns of interrelationships between the sets of variables. This type of analysis seemed particularly relevant when one considers that both QL and compliance are multidimensional phenomenon. In this analysis, maximal linear combinations of the compliance and QL variables were formed and correlated. Thus, the compliance measures were combined in such a way as to be maximally correlated with the QL variables. The canonical analysis of the relationship between the compliance variables and the QL variables yielded a significant canonical correlation of .51, Eigenvalue=.35, approx $F(12, 153.75) = 2.43$, $p < .006$. Successive canonical roots were nonsignificant (see Table 13).

In order to interpret the canonical correlation, the canonical weights and canonical loadings were examined. The canonical weights are standardized canonical correlation coefficients that indicate how much the variable relates independently of the other variables to the extracted factor. The canonical loadings are correlation coefficients indicating the relation of the canonical variate to the extracted factor. Weights and loadings for compliance and QL

variables are presented in Table 14. Data suggest that the compliance variables provide a single factor representing compliance. The QL weights and loadings do not provide evidence that a single factor contributes to QL. However, the measures that appear to be contributing most to the extracted factor are activity (KAS) and overall quality of life (QLI). The activity measure is positively correlated with the extracted compliance factor; the overall quality of life measure is negatively correlated with the extracted compliance factor. Furthermore, a redundancy analysis, which indicates to what extent all the variables in a given set are contributing, indicated that the canonical variables of both sets accounted for little of the variance and are poor predictors of the opposite set of variables (see Table 15). Therefore, results of the canonical correlation suggest that the extracted compliance factor is weakly, although positively related to activity (KAS). Accordingly, poor compliance is associated with better activity levels. Also, the extracted QL factor is weakly, although negatively related to the compliance factor. This indicates that poor compliance is associated with poor subjective QL.

DISCUSSION

The purpose of this study was to determine the association between compliance with the dietary regimen and quality of life (QL) in patients receiving chronic in-center hemodialysis. This was done by examining the relation between three physiological parameters of dietary compliance (blood urea nitrogen, potassium, and intersession weight gain) and four measures of QL (The Karnofsky Activity Scale, Psychological General Well-Being Schedule, Personal Resource Questionnaire, and the Quality of Life Index). Furthermore, the relation between medical/demographic characteristics (age, years on dialysis, age beginning dialysis, and number of diagnoses) and QL was examined. In general, the results of this investigation failed to demonstrate a strong relation between compliance with the dietary regimen and QL. Medical/demographic characteristics were modestly associated with QL.

The first hypothesis of this study proposed that compliance would be associated with QL. In general, little relation was found between them. Traditionally, compliance with the diet has been a very important part of the dialysis regimen. For instance, professionals in renal medicine have proposed that compliance with the dietary regimen would decrease morbidity, mortality, hospitalizations, and medical utilization. However, recent research has found that compliance is not related to these relevant outcome

variables (Bruce et al., 1987; Ruggiero, 1988). Another relevant outcome variable, QL, also does not appear to be related to compliance. The present findings call into question the emphasis that traditionally has been placed on compliance. If compliance is not related to relevant outcome variables, then recommendations about revising and possibly loosening the restrictions of the dietary regimen may be in order. However, before specific treatment recommendations could be made, replication of this study, as well as more systematic investigation, would be warranted.

The second hypothesis of this study was that medical/demographic characteristics would be associated with QL. In general, a relation between medical/demographic characteristics and quality of life was found. Specifically, older patients who were older when they began dialysis, and who were rated sicker were less active. Also, the older the patients when they began dialysis, the better they rated their social support. The association between age, age beginning dialysis, number of diagnoses and activity makes intuitive sense. The older and sicker the patients, the less likely they are to carry on activities associated with younger people in good health, such as having a job or participating in a wide variety of activities.

The implication that those who began dialysis at a later age are more satisfied with their social support is

more difficult to explain. One would wonder if those who started dialysis at a younger age lost their social support as a result of their illness. Perhaps patients beginning dialysis later in life, during a time when family and friends expect their loved ones to develop health problems, are better incorporated into the social network as a result of this expectation. Younger people may not be expected to develop chronic illnesses that require such intensive care and support. This, however, is speculative and would warrant further investigation.

Although little can be done to improve medical/demographic variables, there could be benefits associated with knowing that these variables may be related to quality of life. Health care professionals could identify, in advance, those patients who are likely to suffer from poorer quality of life (i.e., a "high risk" profile). Once identified, these patients may benefit from a referral for additional rehabilitation aimed at improving their QL. Furthermore, the results of this study confirm the need to provide conscientious and swift medical assessment and treatment for other medical problems associated with chronic renal failure. Also, recent research has indicated that the relationships between dialysis staff and patients are important (e.g., Steidl et al., 1980; Cummings et al., 1981). For patients within the high risk group, additional staff support and involvement

may help improve QL.

Another hypothesis of this study was that compliance would predict QL. The results indicated that compliance does not predict quality of life, further supporting the results of the correlational analysis. Therefore, knowing that patients are compliant with their diet does not necessarily assure that they will experience a better quality of life. As has been mentioned previously, this finding has been paralleled in studies investigating other relevant medical outcomes. One would wonder why compliance does not predict quality of life. Probably, there are no simple answers to this question. It may be that the dietary regimen really is not as important as has been thought. Before this statement can be made with any assurance, replication of studies should be done as well as more specific research regarding the role of compliance for dialysis patients. An example of this would be to study groups receiving different dietary regimens, i.e., a control group that receives the regimen as it is presently being prescribed, another group receiving a slightly less restrictive regimen, and perhaps another group receiving a very strict regimen. Another possibility for the lack of prediction may be due to the difficulties and possible error in the measurement of the constructs of compliance and QL. These issues will be discussed in a later section.

This study also hypothesized that medical/demographic

characteristics would predict QL. They predicted one aspect of QL - activity. It seems sensible that medical/demographic characteristics such as age and number of diagnoses would predict activity levels. It is expected that individuals who are older or sicker may be less active. In contrast, other, more subjective aspects of QL, such as social support, psychological well-being, or overall quality of life, were not predicted by medical/demographic characteristics. This finding is consistent with past research (e.g., Evans et al., 1985; Johnson et al., 1982) that found little relation between medical/demographic characteristics and subjective measures of quality of life. For example, hemodialysis patients in both studies had poorer medical status than transplant patients, yet reported subjective quality of life to be very similar to the transplant patients and to the general population. It is not clear how dialysis patients can protect themselves psychologically from the losses associated with their illness and treatment, but it seems that human beings have the ability to adapt to unfortunate circumstances and to "make the best" of it. Future research focusing on how individuals interpret and evaluate this type of negative experience may be useful in facilitating adjustment to chronic illnesses, like end stage renal disease.

This study also attempted to answer the question of which variables would be better predictors of QL: compliance

variables or medical/demographic characteristics.

Compliance added little to prediction, and as hypothesized, medical demographic variables provided the best prediction of QL. These results were not surprising given the results of the separate analyses.

A canonical correlation was done since this analysis is thought to be particularly helpful in studying multidimensional concepts such as QL and compliance. The result of that analysis addressing the relation between the dietary variables and QL only weakly supported the association between compliance and QL. The extracted compliance variate modestly predicted activity, revealing that poorer compliance was associated with better ratings of activity, a contradictory finding. The compliance variate was not able to predict any other aspects of QL. The extracted QL variate indicated that lower levels of overall QL were associated with poorer compliance.

The results of the canonical correlation are difficult to explain. A relation between compliance and quality of life is suggested, specifically poor compliance is associated with poor subjective QL. However, this same poor compliance is associated with higher activity levels, as measured by health care professionals. One possible explanation for this is that dialysis patients who were attempting to be as active as they could and lead as normal a life as possible were rated more functional. Their

continued efforts to lead a normal life were done at the expense of their diet and their subjective QL. Patients who were struggling to continue working or to take care of their homes and families may have perceived that that they had fewer resources to care for themselves and may have felt less satisfied with their lives. A variant of this explanation is that those who were attempting to be more active and functional may have been denying the reality of their illness. As a result of this denial, they may also have been less compliant. These explanations are quite speculative and would require further research. However, each of the above explanations have treatment implications. For example, if patients were trying to function at previous levels of ability or denying their illness, treatment should help patients adjust their expectations to levels consistent with their current functional deficits. Osberg, McGinnis, De Jong, & Seward (1987), indicated that this is a primary task for patients experiencing life changes as a result of chronic illness.

One finding of this study that warrants further explanation is the low correlations among the QL measures: The Quality of Life Index (QLI), The Personal Resources Questionnaire (PRQ), The Psychological General Well-being Schedule (PGWBS), and the Karnofsky Activity Scale (KAS). The first three measures are subjective measures and represent overall quality of life, satisfaction with social

support, and psychological well-being. These three measures were modestly correlated. However, the KAS, a medical status variable, was not correlated with the other measures of QL. Although some may think it is appropriate to discard this measure as a QL variable due to its poor association with other measures of QL, it remains one of the more objective measures traditionally used in research. Discrepancies between objective and subjective measures are not uncommon (e.g., Slevin et al., 1988).

The lack of correlation between the KAS and other measures of QL may have been due to the KAS measuring a different aspect of QL. To some extent, all of the variables used in this study (social support, psychological well-being, and overall quality of life) appeared to measure different aspects of QL. This finding is consistent with Wolcott et al.'s (1988) investigation of quality of life that medical, psychological, and social support variables were only weakly correlated.

The low inter-correlations among the quality of life variables point to an important question not directly addressed by this study. What constitutes quality of life? As reviewed in another section of this paper, quality of life is a complex phenomenon which defies easy definition or measurement. Little agreement has been reached among researchers or clinicians about what constitutes it or how it is measured. Quality of life is a multidimensional

phenomenon. Adequately determining what dimensions comprise QL and designing appropriate measures is a task for future research. Although conscientious attempts were made to assess quality of life in this study, one problem may have been that the measures did not sufficiently represent the construct of quality of life for these subjects. Quality of life is an important topic, and perhaps more effort should be placed in defining and measuring it rather than designing studies using inadequate measures.

Another finding that warrants explanation is the significant and modest correlations among the compliance variables. Other studies (e.g., Bruce, et al., 1987) have suggested that compliance with one aspect of the regimen is correlated with compliance with other aspects of the regimen. This finding was supported in this study. Measures of BUN were significantly correlated with K; IWG was significantly correlated with K. Although IWG was not significantly correlated with BUN, the relation was suggestive. The canonical analysis provided further evidence that the compliance variables were correlated and together formed a factor that measured compliance.

A concern in interpreting the results of this study was whether or not compliance was adequately measured. As discussed earlier, compliance is a difficult construct to define and measure. Also, defining and measuring compliance will depend upon the type of illness the individual has.

The measures included in this study - BUN, K and IWG, are the most frequently used ones in dialysis research. Previous research (e.g., Ruggiero, 1988) has demonstrated the appropriateness of using multiple data points to obtain a more representative sample. Also, the measures when statistically combined provided a reasonable factor representing compliance. Without straying too far from the data, it does appear that compliance as it is defined for dialysis patients was measured adequately. Whether or not the construct of compliance was sufficiently represented is uncertain. Limitations in measurement techniques continue to be a problem in compliance research that should be addressed in future research.

The methodology of the current study may suffer from certain shortcomings. Specifically, sampling and selection criteria were done in an effort to get as many of the eligible patients to participate as possible. Of the original 127, only 67 participated in the study. This indicates that this sample may not be highly representative of the dialysis patients at large. Furthermore, this study was conducted in a dialysis center in a southern city in which the dietary habits, racial, ethnic, and cultural subsamples may not be representative of a national sample. This makes the generalizability of this study more restricted, and conservative interpretation warranted.

In summary, the regimen may have little impact on QL.

Other studies have found that compliance has little impact on other relevant medical goals, making the necessity for the restrictive regimen questionable. Future research may emphasize loosening of the dietary restrictions while educating patients about the aspects of their diet that can cause acute complications and uncomfortable dialysis sessions. Medical/demographic variables such as age, age beginning dialysis, and number of diagnoses predict activity, one aspect of QL. While little can be done to alter medical/demographic variables, knowledge of their impact may help provide a high risk profile of patients who may experience poor health, increased morbidity and mortality, and poor quality of life. However, the current findings should be replicated using a broader sample and giving further consideration to measuring the construct of quality of life.

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Table 1

Frequency of Subjects Excluded From the Study (N=60)

REASONS	FREQUENCY
Refused	16
Transplanted	2
Died	4
Transferred	1
Incomplete Data	4
Comprehension Deficits	33

Table 2**Sample Characteristics**

Characteristics	N	Mean	SD	Range
Age	67	50.9	11.9	19.6-77.4
Years on Dialysis	67	5.4	4.0	1.2-22.7
Age began Dialysis	67	5.5	12.3	18.1-75.5
# Diagnoses	67	1.5	0.9	0-4
Comprehension	51	7.9	1.6	6-14
WRAT-R	15	95.7	13.6	71-125
Education	67	11.5	3.3	3-20

Table 3**Further Demographic Characteristics**

Characteristics	N	Percent
Sex		
Male	26	38.8
Female	41	61.2
Race		
Black	56	83.6
White	11	16.4

Table 4

Means, Standard Deviations, Ranges of Compliance Measures

<u>Characteristic</u>	<u>N</u>	<u>Mean</u>	<u>SD</u>	<u>Range</u>
BUN	67	73.67mg/ml	15.8	37.6-112.0
K	67	5.0mEq	.62	3.7-6.3
IWG	67	2.8kg	.89	1.6-5.1

Table 5

Means, Standard Deviations, Ranges of Quality of Life Measures

QL Measures	N	Mean	SD	Range
KAS	66	75.5	10.9	50-100
PRQ	66	146	22.9	72-175
PGWBS	67	78.9	18.5	34-110
QLI	67	23.2	4.4	12-30

Table 6

Correlations Among Quality of Life Measures (N=67)

	ACT	PRQ	PGWSB	QLI
ACT		.04	.16	.05
PRQ			.33*	.44**
PGWSB				.51***
QLI				

* $p < .01$

** $p < .001$

*** $p < .0001$

Table 7

Correlations Among Compliance Measures (N=67)

	BUN	K	IWG
BUN		.49**	.20
K			.34*
IWG			

* $p < .01$

** $p < .0001$

Table 8

**Correlations Between Compliance Measures and Quality of Life
(N=67)**

	BUN	K	IWG
PRQ	.124	-.112	.031
PGWBS	.167	.019	-.107
QLI	-.152	-.113	-.175
KAS	.236	.273	.33*

* $p < .01$

Table 9

Correlations Among Medical/Demographic Variables and Quality of Life (N=67)

	KAS	PRQ	PGWBS	QLI
Sex	.21	.07	-.05	.08
Age	-.59***	.30	.13	.24
Age Began	-.61***	.33*	.09	.26
Years On	.10	-.11	.14	-.08
# Diagnoses	-.45**	.06	-.11	-.10

* $p < .01$

** $p < .001$

*** $p < .0001$

Table 10

Compliance Variables Predicting Quality of Life Variables

Quality of Life

<u>Variable</u>	<u>Regression Results</u>
QLI	R-squared (3,61) = .05, <u>ns</u>

PGWBS	R-squared (3,61) = .04, <u>ns</u>

PRQ	R-Squared (3,61) = .06, <u>ns</u>

KAS	R-squared (3,61) = .14, <u>ns</u>

Table 11

Medical Demographic Variables Predicting Quality of Life Variables

Quality of Life

<u>Variable</u>	<u>Regression Results</u>		
QLI	R-squared (3,61) = .09, <u>ns</u>		

PGWBS	R-squared (3,61) = .06, <u>ns</u>		

PRQ	R-squared (3,61) = .11, <u>ns</u>		

KAS	R-squared (3,61) = .48, <u>p</u> , < .0001		

	<u>Predictors</u>	<u>Beta</u>	<u>p <</u>

	Age dialysis began	-.53	.0001
	Years on dialysis	.01	<u>ns</u>
	Concurrent diagnoses	-.34	.001

Table 12

**Medical/Demographic and Compliance Variables Predicting
Quality of Life**

Quality of Life

<u>Variable</u>	<u>Regression Results</u>		
QLI	R-squared (6,58) = .14, <u>ns</u>		

PGWBS	R-squared (6,58) = .09, <u>ns</u>		

PRQ	R-squared (6,58) = .18, <u>ns</u>		

KAS	R-squared (6,58) = .50, <u>p <.0001</u>		

	<u>Predictors</u>	<u>Beta</u>	<u>p <</u>

	Age dialysis began	-.49	.0001
	Years on dialysis	.01	<u>ns</u>
	Concurrent diagnoses	-.31	.01
	BUN	.08	<u>ns</u>
	K	.05	<u>ns</u>
	IWG	.10	<u>ns</u>

Table 13

Canonical Correlation: Compliance and Quality of Life

No.	Canonical R	Eigenvalue	Approx F	Df	p
1	.51	.36	2.43	12,153.7	.006
2	.32	.12	1.57	6,118	.16
3	.20	.04	1.30	2,60	.28

Table 14**Canonical Correlation Weights and Loadings for Compliance
and Quality of Life**

Variables	Canonical Weights	Canonical Loadings (First Factor)

COMPLIANCE		
BUN	.82	.88
K	-.13	.44
IWG	.50	.66

QUALITY OF LIFE		
ACT	.66	.64
PRQ	.55	.24
PGWBS	.31	.15
QLI	.89	-.44

Table 15

Canonical Redundancy Analysis

Canonical Variate	Squared Multiple Correlation

Quality of Life	Compliance Factor
ACT	.1076
PRQ	.0156
PGWBS	.0056
QLI	.0526

Compliance	Quality of Life Factor
BUN	.2082
K	.0521
IWG	.1151

APPENDIX A

Informed Consent

I, _____, freely and willingly consent to be a participate in a research project investigating Quality of Life in hemodialysis patients. As a research subject, I agree to complete 4 paper and pencil questionnaires that deal with my feelings about my health and well-being and quality of life. Additionally, I agree to allow the researchers, Linda S. Dietz, M.A. and Charlotte Jenkins, R.N., to review any of my pertinent medical records. I understand that there are no risks involved by participating in this project.

I understand that I may withdraw from participation in this study at any time with no adverse consequences. In addition, any information I provide during this project will be kept in strict confidence, and if this information is presented publicly (i.e., conferences, journal articles), no information will be identified with me personally.

I realize that I have the right to ask questions at any time and to have these questions answered to my satisfaction. I have read and thoroughly understand this consent form.

APPENDIX B

Demographic/Medical Data

Patient's Name _____

Age _____ Sex _____ Race _____

Current job status _____ Occupation _____

Source of Income _____ Education _____

Living Arrangements _____

Primary Medical Diagnosis

(Renal)

(Other medical Dx)

Current Dialysis:

Relevant Treatment History (e.g. renal transplant failure,
etc.,) _____

APPENDIX C

Compliance Criteria

1. Excellent. Weight gain between dialysis is never above 500g. Predialysis serum potassium levels are never above 6 mEq/liter and most of the time less. Predialysis BUN levels are steady.
2. Good. Weight gain between dialysis is from 500 to 1000 g. Predialysis potassium levels are usually 6 mEq/liter. Predialysis BUN levels are usually steady but may show occasional jumps.
3. Fair. Weight gain between dialysis is mostly 1000 to 1500 g rarely going up to 2000 g. Predialysis potassium levels are from 6.0 to 6.8 mEq/liter.
4. Some abuse. Weight gain between dialysis is always above 2000 g or most of the time above 2500 g. Predialysis potassium levels are frequently above 7.0 mEq/liter.
5. Great abuse. Weight gain between dialysis is always above 2000 g or most of the time above 2500 g. Predialysis potassium levels are frequently above 7.0 mEq/liter.

Taken from Kaplan De-Nour, A., & Czaczkes, J.W. (1972).

Personality factors in chronic hemodialysis patients causing noncompliance with the medical regimen. Psychosomatic Medicine, 34, 333-344.

APPENDIX D

Karnofsky Activity Scale

Please rate _____'s functional status on the following scale:

Able to carry on normal activity; No special care needed:

100% Normal; con complaints; no evidence of disease

90% Able to carry on normal activity; minor signs or symptoms of disease

80% Normal activity with effort; some signs or symptoms of disease

Unable to work; able to live at home; care for most personal needs; a varying amount of assistance:

70% Cares for self; unable to carry on normal activity or to do active work

60% Requires occasional assistance but is able to care for most of his needs

50% Requires considerable assistance and frequent medical care

APPENDIX D (cont.)

Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly:

40% Disabled; requires special care and assistance

30% Severely disabled; hospitalization is indicated though death not imminent

20% Very sick; hospitalization necessary; active supportive treatment is necessary

APPENDIX E

Interview Questions for the Karnofsky

INSTRUCTIONS

Please ask the patient the following questions before completing the Karnofsky Activity Scale.

1. Have you had any weight loss or weight gain?
2. Have you had any decrease in energy or increase in fatigue?
3. Have you had any difficulty grooming or bathing?
4. Have you had any difficulty driving?
5. Have you had any difficulty in walking or moving about?
6. Have you had any difficulty working full or part-time?

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These consist of pages:

- | | |
|----------|---|
| 105-106, | Personal Resources Questionnaire |
| 107-110, | Psychological General Well-being Schedule |
| 111-116, | Quality of Life Index |

U·M·I

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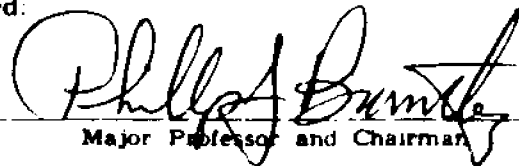
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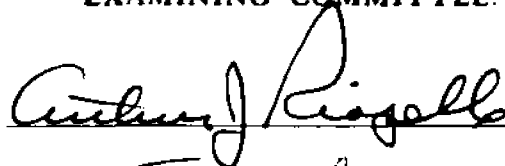
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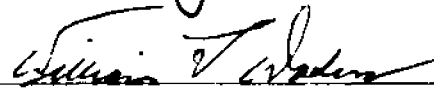
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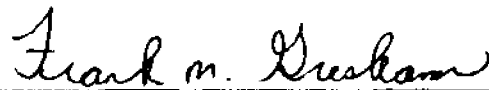

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