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A

**COPING AMONG HEMODIALYSIS PATIENTS**

by

**PATRICE J. NELSON**

A dissertation submitted to the Graduate Faculty in Psychology  
in partial fulfillment of the requirements for the degree of  
Doctor Of Philosophy, The City University of New York.

1995

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This manuscript has been read and accepted for the Graduate Faculty in Psychology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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## Abstract

### COPING AMONG HEMODIALYSIS PATIENTS

by

PATRICE JUDITH NELSON

Adviser: Professor Vera Paster

The objective of this study was to examine the coping patterns of inner-city hemodialysis patients in regard to the stressors presented by the chronic illness of End Stage Renal Disease necessitating treatment by hemodialysis. The hospitals that serve the subjects for this study are set in the most distressed areas of the city, where poverty is endemic, and where crime, alcoholism and narcotics addiction are rampant. Thus the rigors presented by the hemodialysis regimen is but one of the stresses of daily survival for these patients.

Adult patients who receive in-center hemodialysis treatment, and with no major medical or surgical events in the preceding three months were asked to participate in the study.

Within the context of physical illness, little attention has been paid to the mechanisms by which individual coping

efforts affect psychological well-being, and how increased psychological well-being can then contribute to resolving problems, preventing future difficulties, relieving emotional distress and promoting adjustment to a chronic illness. Far less attention has been paid to how these mechanisms apply to minority populations in inner city settings.

This study explored the types and severity of stressors associated with hemodialysis treatment, as perceived by the patient, using the Hemodialysis Stressor Scale. Coping was measured using the Ways of Coping Questionnaire. The role of social support in adjustment to the stressors of hemodialysis was evaluated using a Perceived Social Support Scale. Pearsons Correlation Coefficients were computed to determine the relationship between stressor scores and coping scores, and level of perceived social support.

The study yielded valuable information regarding both the stressors associated with hemodialysis and the coping strategies employed by patients to mitigate the stressfulness of the dialysis regimen.

## Acknowledgements

The spark for my interest in studying and working with individuals receiving hemodialysis came first hand from my own family's experience.

I dedicate this work to my brother for his courage in coping with the challenges of a life supported by maintenance hemodialysis.

I wish to thank Vera Paster, Ph.D., who served in the capacity as my dissertation chairperson. Far beyond that however, Dr. Paster gave me her support and mentorship (not to mention those 7:00 A.M. phonecalls!) Thank you Vera for your generosity!

A special thank you to all the individuals who served on my dissertation committee and gave freely of their time and expertise. A special thank you to Eli Friedman, M.D. and Peter Lundin, M.D., for the access they provided to their patients and treatment facilities. I would like to express my thanks to all those individuals along the way who guided me in the right direction, gave suggestions, suggested networks and conferences, and gave feedback on my dissertation.

Thank you to the Nursing and Professional staff at the facilities. A heartfelt thank you to the patients who so willingly gave their time and who spoke openly and candidly about their dialysis experience. Without their support and cooperation this study would not have been possible.

A special thank you to N. Mendie Cohn, Ph.D. for making my clinical work with dialysis patients a challenging, educational and rewarding experience. Thank you for your unwavering support and encouragement through some of the most discouraging times.

A special, sincere thank you is reserved for my husband, Andre. Thank you for making it possible for me to continue work on this dissertation when I needed to devote most of my time to it. Also, thanks for all the merging, copying and restoring of data files at times when the computer seemed to take on a mind of its own! Andre, thanks for the many years of support and patience!

To Andrea, my daughter, you too can accomplish your goals, and I know that you will. I love you very much!

Most of all I wish to thank my parents for believing in supporting and encouraging me. Thanks for giving me the educational and spiritual foundation that fortified and enabled me to pursue and attain my goals. Thanks for having faith in me. Without my family's love and support, none of this would be possible. All my love!

To all my relatives and friends - my Aunt Jean, Uncle Leroy, Aunt Faith, Dawn and Martin, my dear friend Esther, Liese, and everyone - too lengthy to mention individually, who lent support and encouragement - Thank You!

Finally, Merle, though you have entered another consciousness, I know that you are watching.

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CHAPTER I  
INTRODUCTION

The normal human body has two kidneys which perform several vital functions necessary for maintaining life. The kidneys maintain body fluid levels by excreting fluids when there is an excess, and by conserving fluids when they are low. A variety of chemicals are produced and released by the kidneys so that a balance is always maintained to keep the body healthy. The kidneys filter the entire blood supply every two minutes in order to perform their major function of removing waste from the blood and eliminating it in the urine.

There are many kinds of kidney disease, ranging from urinary tract infection, to kidney stones, to more serious disorders such as polycystic kidney disease, in which cysts form on the kidneys, and glomerulonephritis, an inflammation of the capillaries. If any kidney disease is left untreated future kidney damage can result, possibly leading to kidney failure. The majority of kidney diseases either improve spontaneously or can be treated in the early stages with medicine or surgery, and do not seriously impair patients' lives. However, approximately 33,000 people develop kidney failure or End Stage Renal Disease (ESRD) each year, defined as a 95% reduction in kidney function, where the kidneys are not functioning sufficiently to support life.

Until the early 1960's, end-stage renal disease (ESRD), that is, irreversible kidney failure was a fatal condition. With the development of hemodialysis as an artificial replacement therapy for the functional loss of kidneys, and with advances in renal transplantation, normal kidney function can be sufficiently replaced to prolong life. It had been recognized since the early years of this century that uremia, the accumulation of toxic substances in the blood as a result of lack of proper kidney function, could be controlled if it were possible to remove the accumulating chemical wastes from the patient's blood.

In 1914 a group of Johns Hopkins doctors reported that a process of dialysis permitted diffusible substances to be removed. Further work was hampered however, because the membranes, which separate the waste products from patients' blood, did not work well and blood clots formed.

The development and commercial manufacture of cellophane tubing and of heparin, an anti-clotting chemical preparation, provided the means to overcome these problems. The artificial kidney proved highly successful in the treatment of acute kidney trauma and disease such as battlefield injuries and tubular necrosis (the crush syndrome) which had been widely observed during the bombing of cities in World War II. Gradually, however, the physicians began to wonder whether patients in chronic renal failure might not benefit from the

procedure. Since then, two major forms of treatment, dialysis and transplantation have been developed.

The most common form of dialysis is called hemodialysis. Hemodialysis is derived from two words; hemo meaning blood, and dialysis, meaning to separate. Hemodialysis, the backbone of the modern treatment of irreversible kidney disease, is a blood purification technique wherein toxic metabolic substances are separated and removed from the patient's blood through a semipermeable membrane into a dialysis solution. In the United States over 150,000 people with ESRD are on dialysis. Hemodialysis treatments are required two to three times per week, and each session lasts from three to five hours. Patients receive treatment on a regular basis for the rest of their lives or until they receive a successful kidney transplant.

This research will focus on the nature of patient responses to stress associated with the hemodialysis regimen, coping strategies that patients employ to mitigate the stressfulness of life, and the role of social support in psychological adjustment to the demands of hemodialysis.

During hemodialysis treatment the patient's blood is circulated outside of the body through a shunt or fistula, a surgically implanted access to the patient's blood supply, and then into an artificial kidney machine, which acts as a link to the patient's circulatory system. The blood flows into the dialysis machine, is cleaned and then returns to the patient's

body. The dialysis process is continual, with new blood and dialysate constantly circulating into the machine and waste products and excess fluids constantly circulating out.

Treatment sessions alter body fluid composition efficiently and rapidly. These changes, coupled with rapid removal of fluid and salt from the body by manipulating the pressure gradient within the artificial kidney, may cause symptoms such as nausea, vomiting and cramps as well as sudden drops in blood pressure. In this form of treatment, patients must also take a variety of medications and adhere to stringent dietary and fluid restrictions.

Renal transplantation is the second major form of treatment for ESRD. Successful transplantation probably most closely approximates a return to pre-ESRD physical functioning and usually only requires the use of immunosuppressive medication. However, a suitable kidney for transplantation is limited to the availability of an immunologically matched donor, as well as other socioeconomic and political factors that influence access and outcome of transplantation. These factors will be elaborated later. It is also important to note that even in the case of successful transplantation, the recipient's body may immediately or ultimately reject the transplanted kidney, forcing the recipient to return to dialysis.

This description of what hemodialysis treatment and transplantation involve illustrates the dramatic advances in technology that make such treatment possible. What is also striking is the physically demanding, rigorous nature of the hemodialysis treatment regimen, and the psychologically stressful nature of the procedure.

Among the most commonly identifiable stressors in the lives of hemodialysis patients are uncertainty about survival, dependencies on medical technology, economic burdens, limited reproductive capacity, severe diet and fluid restrictions, reduced mobility, time requirements for the treatment, general feelings of malaise, and a variety of medication side effects. What is striking, however, is the great variation in how well individuals are able to cope with ESRD.

This study focuses on hemodialysis treatment and coping in an inner city. The hospitals that serve the subjects for this study are set in the most distressed area of the city, where oppressed people of color are concentrated, where poverty is endemic, and where crime, alcoholism and narcotics addiction are rampant. Thus, the rigors of hemodialysis is but one of the stresses of daily survival for these patients.

Within the context of physical illness, little attention has been paid to the mechanisms by which individual coping efforts affect psychological well-being, and how increased psychological well-being can then contribute to resolving

problems, preventing future difficulties, relieving emotional distress and promoting adjustment to a chronic illness. Far less attention has been paid to how these mechanisms apply to minority populations in inner city settings.

In New York City, the inner city can be characterized with such jarring statistics as unemployment as high as 60%, fatherless households as many as 75 %, and death in young adults often due to murder or the Acquired Immunodeficiency Syndrome (AIDS) (NYS J. of Medicine, 1991). The practice of medicine in the inner city forces compromises, and though many physicians throughout the history of medicine have accepted as part of their work attempts to maintain the health of their patients, often referred to as preventive medicine, in the inner city, social medicine seems more relevant. The task of medical care in the inner city is generally limited to attempts to "bind up the wounds", that is, crisis intervention. The wounds, metaphorically, refer to overarching poverty, high mortality rates for infants, or summary rates such as life expectancy at birth, morbidity rates, particularly for illnesses known to be preventable by measures such as immunization, safe water, adequate food supplies, appropriate education, and protection from environmental hazards.

Preventive medicine in the inner city, though recognized as important, becomes secondary to crisis intervention practices in overcrowded emergency rooms. Delays in admission force waits as long as five days for a hospital bed, even for the acutely ill. Nephrology in the inner city, has evolved into the practice of socioeconomic medicine. In a typical inner city hospital most renal complications are reflections of poverty and race. Diabetic, hypertensive and heroin associated nephropathy, alcohol induced acute and chronic renal failure, and AIDS associated nephropathy consume the time of the renal consultant (NYS J. of Medicine 1991).

In examining the prevalence and incidence of ESRD among minorities, it should be noted that in the United States, the relative risk of ESRD is about fourfold higher for Black persons than for White. Black persons, approximately 12 percent of the U.S. population, accounted for 27 percent of the patients with ESRD in 1987 (US Renal Data Systems, 1989; The National Institutes of Health, National Institute of Diabetes and Kidney Diseases, 1989). The higher relative risk of ESRD among people of African ancestry is geographically widespread, has been found at all ages over 15 years and has, generally been found among both men and women (NEJ of Medicine, 1991). Although Black people have an increased prevalence of hypertension and diabetes, the increased incidence of ESRD among this group cannot be attributed to any one cause. The Council on Ethical and Judicial Affairs of the

American Medical Association has recently chronicled the "persistent, and sometimes substantial, differences in both need and access" to health care experienced by American Blacks who live largely in inner city ghettos (JAMA, 1990). Black and Hispanic uremic patients are less likely to receive kidney transplants, open heart surgery, and first class obstetrical or internal medical care. The stresses of the ghetto translate into a higher rate of hypertension, kidney disease, psychiatric morbidity and other health problems (Johnson, 1989). Once renal failure develops, often as a result of poverty and other issues, this population has been found to be less likely to adhere to a dietary regimen prescribed during maintenance hemodialysis (Berg, 1989), or to the drug regimen established for renal transplant recipients (Schweizer et al. 1990). On the other hand, and as yet unexplained, Black persons have higher survival rates than do Whites when both are treated for renal failure by maintenance hemodialysis or peritoneal dialysis (Wolfe et al. 1990).

Given these dimensions of differences in incidence, prevalence, and severity of renal disease among inner city populations, and given also the backdrop of the paucity of research in the area of how minority, inner city populations cope with the combined stressors of illness and poverty, it seems not only worthwhile but imperative to explore these mechanisms.

While it is well known that kidney failure, necessitating hemodialysis, is a major stress among those afflicted, what is not well known are the mechanisms developed by individuals and groups for coping with this assault on their daily living. The nature of the chronic hemodialysis regimen at inner city hospital settings provide an arena for such an endeavor. The psychological stressfulness of chronic hemodialysis has been well documented in the literature, (Abrams, 1971; Binik, 1983; Cummings et al. 1982; Czaczkes and De-Nour, 1978; Devins, 1981; Friedman, 1991; Levy, 1978, 1981, 1983, 1984). Devins (1981) has suggested that ESRD patients may be viewed as a "living stress laboratory" for the study of coping with a chronic illness. People who receive dialysis treatment typically are faced with stressors that impact on several levels. In order to anchor the discussion, a review of the literature identifying and discussing the stressors associated with ESRD and renal dialysis is warranted.

CHAPTER II  
REVIEW OF THE LITERATURE

Contemporary research on psychological stress emerged more than a quarter of a century ago, stimulated by the desire to understand breakdowns in adaptive behavior observed in extreme situations. Situations that were of immediate concern at that time included military combat (Grinker & Spiegel, 1945), the concentration camp (Bettelheim, 1943), bereavement (Lindemann, 1944), and traumatic injury (Hamburg, Hamburg, & deGoza, 1953). The disturbances in functioning that had been observed were often as dramatic as the extreme situations themselves and included psychotic behavior, severe anxiety, bleeding ulcers (Paster, 1948; Swank, 1949), and hypertension (Graham, 1945). By conceptualizing these phenomena as consequences of stress, investigators could formulate general principles that transcended the particular situation in which their observations were made. Hypotheses about the sources of stress, mechanisms of stress production, and factors that increase or decrease the psychological and somatic costs of stress could be developed.

In subsequent decades the scope of stress research expanded from field studies of the casualties of extreme situations to laboratory analogue studies examining the conditions under which skilled performance deteriorates, as well as the impairment of morale, overall functioning and

somatic health in a wide variety of naturalistic settings (Lazarus, 1981; Lazarus & Folkman, 1982).

The study of psychological stress and its effects on psychological and physical functioning has mushroomed over the last decade. Efforts to develop and evaluate techniques for preventing or managing stress and its effects have accelerated as well. Until the advent of the hemodialysis machine and kidney transplantation, irreversible kidney failure had been fatal. As these methods of treatment became increasingly successful, survival depended more and more on coping with the lifestyle that the treatment regimen imposed. Given that individuals today may live with a chronic condition for 15 years or longer, coping with chronic illness is an area of immediate and rapidly growing importance.

The study of stress from a psychological perspective is a relatively recent development. However, the concept itself has a long history. The word stress has its origins in the Latin words *strictus*, meaning tight or narrow, and *stringere*, the verb, meaning to tighten. These root words reflect the internal tightness and constriction of the muscles and breathing reported by many under stress. The term stress began to be used in engineering in the 1800s, and in medicine by the late 19th century, to denote the entire range of pressures and challenges to health undergone by the body.

The literature on stress has offered essentially three different approaches to the study of the topic:

the stimulus-based or engineering approach, the response-based or medico-physiological approach, and a more psychological approach exemplified by 'interactional' and 'appraisal' theories of stress. (Cox, 1978, 1990; Cox and Mackay 1991).

The engineering approach regards stress as a stimulus characteristic of the person's environment. The stimulus is often defined as the level of demand or load placed on the person or some adverse or noxious element of the environment. Stress, as defined in the engineering approach, produces a strain reaction. This approach essentially states that each individual has an innate capacity to withstand environmental stressors. When the cumulative stress experienced is greater than the individual's capacity to withstand them, the individual begins to undergo a deterioration in function; the reaction is stress. Models based on this reasoning focus measurement efforts on the characteristics of the individual's environment, for example, life events and time demands.

In the 1930's, Hans Selye began his landmark studies of stress that provided much of the impetus for current psychological investigation. Selye's pioneering work gave rise to what is known as the response-based or medico-physiological approach. Selye noticed that many medical conditions had common elements. That is, while each disorder had unique, distinctive symptoms, there was also a pool of symptoms held in common with most other disorders.

Whereas the primary thrust of the science of medicine had been to identify the unique symptoms, Selye turned in the opposite direction and began studying the commonalities in illness. Selye (1936) defined stress as a 'generalized and non-specific' response to aversive or noxious environmental stimuli.

Despite a certain popularity, both the engineering and response based approaches to stress have been judged to be inadequate in terms of their ability to account for the available data, and in terms of their limited theoretical sophistication. The shortcomings of these approaches lie in their failure to consider individual differences in relation to perceptions of stimuli as stressful, tolerance levels, and the perceptual and cognitive processes which underlie such differences.

It is this vacuum that the more psychological approach has attempted to fill. The question of individual differences in relation to the experience and effects of stress and in relation to coping with the effects of such stress is virtually the defining characteristic of the more psychological approach.

The psychological approach, also categorized as 'interactionist' or 'transactional' in nature, holds that stressful circumstances cannot be understood merely in terms of the stressful event. This framework holds that stress is neither an external situation nor an internal state - but

rather proceeds entirely from a complex interaction between environmental demands, perceptions of these demands, and the perceived ability to meet or alter them (Lazarus 1984; Lazarus and Folkman 1966). In other words the transactional approach to understanding stress is one of process and evaluation. Stress is viewed as a psychological state - a relationship or process which involves an ongoing sequence of person-environment transactions. (Cox, 1978, 1985,1990; Lazarus and Folkman, 1984).

Further, according to Lazarus and his colleagues, stressors must first be perceived and evaluated before they can elicit a stress response. This judgement, and the individual's efforts to manage and shape the stress experience are conceptualized in terms of two interacting processes: appraisal and coping.

Appraisal is the evaluative process that imbues stress transactions with meaning. (Holroyd and Lazarus, 1982). The term refers to our sense that something of importance is jeopardized or at stake, as well as to the ways opposing demands and options, constraints and resources moderate this sense of jeopardy. Appraisal is said to be comprised of primary and secondary processes. When involved in primary appraisal, the person asks: 'Is this particular encounter relevant to my wellbeing, and in what way? Is the implication of the transaction that of a challenge, threat, harm/loss or benefit?' (Lazarus and Folkman, 1984).

Secondary appraisal is concerned with the question: 'What can be done about the situation?' This evaluation of coping options and constraints is influenced by previous experience in similar situations, generalized beliefs about the self and the environment and availability of personal (e.g. physical strength and problem-solving skills) and environmental (e.g. social support or money) resources (Wrubel, Brenner & Lazarus, 1981). As such, it is a decision making process (Cox, 1987), which must take into account the coping resources and options available to the person, their preferred style(s) of coping, and the nature of the stressful situation.

The chronically ill must face such problematic issues as coping with anxiety and depression, and managing restrictions on work and social life, dealing with threats to self-esteem and self-concept. Individuals receiving hemodialysis are faced with both physiological and psychological stressors. Hemodialysis, a chronic, potentially debilitating, life-sustaining regimen, leads to increased demands for adaptation, at the same time as it diminishes the individual's capacity to act. The loss of body function, the rigors of hemodialysis itself, the limitations it imposes on the individual, both physically, economically and socially, and the emotional distress, presents an opportunity for the application of the interactional model of stress.

The combined physiological and psychological demands of hemodialysis, the very nature of this chronic illness, offers

an interplay between environmental and psychological stressors. Other theoretical perspectives, namely stimulus-based and response-based approaches, limit the scope of examination of the topic, and are too unidimensional for the complex, multifaceted, dynamic investigation posed by the study of the stressors of hemodialysis. Add to this the stressors of urban living - poverty, overcrowding, poor health care and social services that are stretched to capacity, and the stage is set for a "stress laboratory" for the study of coping with external stress. Attempts to examine moderators of stress among hemodialysis patients have barely scratched the surface of what coping strategies patients employ. Furthermore, research has not at all addressed the coping efforts of inner city, minority populations receiving hemodialysis.

Stressors Associated With End Stage Renal Disease (ESRD)  
And Renal Dialysis

In order to avoid death, the dialysis patient must cope with a less than normal existence. People who receive dialysis treatment are typically faced with stressors that impact on several levels. Binik (1983) classified the substantial number of stressors associated with ESRD and dialysis treatment into the following categories.

Uncertainty About Survival

Perhaps the most important stressor is uncertainty about life expectancy (Beard, 1969; Binik, 1969; Levy, 1979; Sand et al. 1966). Patients interviewed rarely revealed ideas or plans for their future and were more willing to talk about their past. This observation was supported by Poznanski, Miller, Salguero & Kelsh (1978) who found that ESRD patients did not project themselves into the future. In many cases patient uncertainty about survival is realistic. Hutchinson, Thomas and MacGibbon (1982) found an average survival of approximately seven years for all ESRD patients. The increase in relative risk with every ten years of age is approximately the same for ESRD patients as for the general population but the baseline risk is approximately six times higher for the ESRD population.

### Machine Dependence

Survival for dialysis patients depends on a machine as a substitute for a vital organ. This necessary dependence on a "machine" for life is in conflict with the independence needed to maintain a "normal" life. The patient's dependence extends to others who assist with dialysis: the professional renal staff in the case of in-center dialysis and to a key support person for home dialysis treatment. Changes in the professional staff or fluctuations in the relationship with the support person further accentuates the power of this stressor.

### Treatment Related Restrictions - Restrictions in Diet and Mobility

The many restrictions in the life of the patient can be divided into at least two groups. One consists of the dietary or treatment related restrictions which are very real, very immediate and continuous. The other consists of restrictions on travelling and in planning daily activities. (Goldstein and Reznikoff 1971, Levy 1974, 1976; Wright et al. 1966). Dietary restrictions bring repeated frustrations of drives - deviations from the regimen quickly result in discomfort and sometimes severe pain to the patient. The regimen provides a constant reminder that choices, once available, cannot be made without risking survival.

Treatment related stressors are both psychological and physiological. In a survey of 35 patients, fluid restriction was rated as one of the highest psychosocial stressors, and muscle cramps and post treatment fatigue were the top physiological stressors (Baldree et al 1982). Other major stress factors reported by 174 patients include needle anxiety, decreased social life and limitations on their activities, loss of body function, including decreased sex drive, changes in family responsibilities, uncertainty about the future and dependency on the staff and doctors (Murphy et al, 1985).

The second set of restrictions, actually means loss of freedom or of the sense of being master of one's daily routine. Few patients are able to be mobile and active as they were before ESRD. One reason is reduced physical strength. Another is the necessity of remaining close to a dialysis treatment facility. Though arrangements can be made for treatment in other centers, this requires special advance planning and dealing with an unknown dialysis staff and environment. When asked what changed most in their lives or what they miss most, patients frequently mention being "tied down" and unable to participate in formerly satisfying activity (Binik 1983).

### Other Stressors

Binik (1983) identified several additional stressors in the lives of ESRD patients. These include income or job loss, loss of financial status and possessions as well as loss of membership in groups. General feelings of malaise, medication side effects, difficulty in finding stable mates, and disrupted family life and friendships are all additional stressors.

An additional stressor that should also be mentioned is one termed by Kjellstrand, Rosa, Shidman, Rodrigo, Davin and Lynch (1978) as unphysiology.

Unphysiology refers to the oscillations in blood chemistries and fluid volumes associated with intermittent dialysis. These oscillations may be seen as stressors because they are accompanied by oscillations in subjective feelings of psychological and physical well-being. Feelings of fatigue, mood changes and anxiety likewise oscillate with the treatment regimen. Numerous investigators have identified and described the variety of psychological concerns that are tied to the stressors described above. These psychological complications include depression, suicide, sexual dysfunction, problems in rehabilitation and "uncooperativeness". Depression as an affect, mood and/or syndrome, is the most common complication, not only of patients undergoing hemodialysis, but of all suffering from chronic medical illness. (Cramdon et al. 1967; Lefebvre et al. 1972).

While several investigators have identified depression as a primary complication associated with dialysis treatment (Cardenas and Kutner, 1982; Cardenas, Kutner and de Andrade, 1984; Levy, 1979, 1981), others see depression as a normal step on the path to adaptation, resolving with stable health and longer time on hemodialysis (House, 1987; Kunter et al. 1985). In some patients depression did not begin with renal failure but was part of a premorbid history (Craven et al. 1987), treatable with psychotherapy or antidepressants (Kennedy et al. 1989). Depression may also have a physiological basis in patients who are persistently uraemic due to underdialysis (Locsex et al. 1987), and may have a psychological basis for patients on units where staff attitudes about the restorative potential of dialytic therapy are negative.

A second negative mood state related to ESRD is high anxiety (Gulledge et al. 1985; Kunter and Gray, 1981; Levy, 1979; Malmquist, 1973). Kutner (1983) also found that anxiety decreases with time on dialysis treatment, suggesting a positive adjustment over time. Suicide has been identified as a major psychiatric complication associated with the stressfulness of the dialysis regimen. Abram, Moore and Westervelt (1971) reported that suicide among hemodialysis patients is greater than for the general population. In this study it was reported that suicide was committed by 0.66% of center and 0.26% of home dialysis patients, that it was

attempted by another 0.6% of center and 0.13% of home dialysis patients, and that 3.5% of center and 2.7% of home dialysis patients had life-threatening accidents. A more recent study (Haenel, Brunner and Battegay, 1980) confirms the findings of the earlier study, but reports a smaller difference compared to the general population. The shortcomings of these studies, as pointed out by Binik (1983) is that neither of these studies controlled for other factors that are known correlates of suicide (age, gender, etc.), suggesting that the high suicide rates are more complexly related to renal failure and dialysis treatment. In considering suicide among dialysis patients, however, the distinction should be made among suicide, attempted suicide and also suicidal ideation, which is, of course, more difficult to assess than the first two phenomena.

Foster et al. (1973) reported that 43% of his patients had suicidal thoughts and that 19% of the patients attempted suicide. Holcomb and Macdonald (1973) found that 35% of their patients had suicidal thoughts and Shulman et al. (1974) reported that 46% of the patients had suicidal thoughts. This rate of suicidal ideation is indicative of the quality of life of dialysis patients and is easily understood especially in terms of the high frequency of depression in these patients. It is important to note, however, that dialysis patients have ready access to methods of death. Non-compliance in the form

of a dietary binge or failing to return to treatment is always available as an effective, though painful means of suicide.

Another psychological concern tied to the stressors described above is the rate of sexual dysfunction (impotency for men and decrease in frequency of orgasm for women) which is higher than that for the general population. (Levy, 1979, 1981; Gullede et al. 1983; and Cardenas et al. 1984) Among other groups of patients with chronic illness, namely those suffering from rheumatoid arthritis, findings have been that sexual dysfunction or inhibition of sexual function generally exist (Buckwalter, Wernimont and Buckwalter, 1982; Chesson, 1984).

#### Coping With the Stress of Chronic Illness

Having identified the major stressors associated with hemodialysis, the focus will now shift to the means by which individuals cope with the stresses raised by chronic illness in general, and by the rigors of hemodialysis in particular.

Coping consists of "efforts, both action-oriented and intrapsychic, to manage (that is, master, tolerate, reduce, minimize) environmental and internal demands and conflicts among them" (Lazarus and Launier, 1978).

The literature distinguishes between two types of coping efforts: problem-solving efforts and efforts at emotional regulation (Lazarus and Folkman, 1984).

Problem-solving efforts are defined as efforts that attempt to do something active about the stressful condition; emotion-focused coping involves efforts to regulate environmental consequences. Generally, however, research has gone beyond the problem-focused / emotion-focused dichotomy, and has attempted to identify specific coping strategies adopted by individuals to manage stressful events.

Among chronically ill populations, investigations into coping strategies have included hemodialysis patients, cancer patients and patients with diabetes, hypertension and rheumatoid arthritis.

Among hemodialysis patients, a study by Baldree, Murphy and Powers (1982), found that patients experienced psychological and physiological stressors equally, and used problem-oriented coping methods more often than affective coping methods. A replication of this study by Gurklis and Menke (1988), resulted in similar findings. With an N of 68, the five most frequently identified stressors by hemodialysis patients were: feeling tired, limitations of fluid, limitations of food, limitations of physical activities, and frequent hospital admissions. The five most frequently used coping methods, divided into affective or emotion-oriented and problem-oriented coping were listed as: prayer and trust in

God, and trying to maintain a sense of hopefulness (affective-oriented); trying to maintain control over the situation, accepting the situation as it is, and looking at the problem more objectively (problem-oriented). Least frequently used coping methods included drinking alcohol, taking drugs and blaming others. Eichel (1986) proposed that social desirability response sets may influence the low ratings of these coping methods. Moreover, it is not feasible for hemodialysis patients to cope by using drugs and alcohol because of the kidney's decreased ability to remove fluids and to excrete drug metabolites. Physiological stressors were significantly related to affective coping, however, psychological stressors were significantly related with both affective and problem-oriented coping.

Consistent with the findings of Baldree, Murphy and Powers (1982), hemodialysis patients in the Gurklis and Menke study (1988), used problem-oriented coping methods significantly more than affective-oriented methods. These findings do not support the assertion by Shanan, De-Nour and Garty, (1976) that the prolonged stress of hemodialysis decreased the patient's tendency to actively cope with problems.

Another important factor that has been investigated is length of time on dialysis. In the Gurklis and Menke study, (1988), the length of time on hemodialysis was found to be significantly related to problem-oriented coping. As time

passed, patients may evaluate the effectiveness of specific problem-oriented strategies and develop a repertoire of useful coping methods.

Other studies of chronically ill patient groups point the way to a better understanding of how individuals cope. In a study by Dunkel-Schetter, Feinstein, Taylor and Falke (1992), cancer patients specified their most troublesome cancer-related problem and then completed a sixty-eight item version to the Ways of Coping Inventory developed by Folkman and Lazarus (1988). Factor analysis of the items yielded five strategies. Though in no way implying the way in which all chronically ill individuals or all cancer patients cope with the stresses of their illness, five strategies were identified:

1). Social support/direct problem-solving, which included items indicating the seeking out and use of social support, as well as other direct-problem solving actions (e.g., "I talk to someone to find out more about the situation.")

2). Distancing, which involves efforts to detach oneself from the stressful situation (e.g., "I didn't let it get to me. I refused to think about it too much.")

3). Positive focus, characterized by efforts to find meaning in the experience by focusing on personal growth (e.g., "I came out of the experience better than I went in.")

4). Cognitive escape/avoidance, which involves such efforts as wishful thinking (e.g., "I wished that the situation would go away.")

5). Behavioral escape/avoidance, such as efforts to avoid the situation by eating, drinking, smoking, using drugs or taking medication.

The cancer patients in the Dunkel-Schetter et al.(1992) study rated their coping efforts concerning the aspects of cancer they found to be most stressful, with results as follows: fear and uncertainty about the future (41%); limitations in physical abilities, appearance and lifestyle (24%); and pain management (12%).

Another aspect of chronic illness that may have an influence on how well individuals cope is prognosis.

Felton et al. (1984) found that terminally ill cancer patients were less likely than patients with hypertension, diabetes or rheumatoid arthritis, to use cognitive restructuring or to hold the belief that something good could come out of their

diagnosis. For patients diagnosed with ESRD, the prognosis is of a disease that is irreversible and incurable. The options are dialysis, transplantation, or death.

### Determinants of Successful Coping

Having investigated and identified the range of coping strategies used by chronically ill patients, the direction most often pursued in the literature is that of identifying which strategies facilitate psychological adjustment. Though this question still lacks a definitive answer, there is evidence that particular coping strategies are associated with increased psychological distress, while others are associated with psychological adjustment.

The discussion will now proceed to identify those strategies that are associated with adjustment among chronically ill populations in general, and then more specifically among hemodialysis patients.

Investigations by Cronkite and Moos (1984) and Halahan and Moos (1986, 1987) found that the use of avoidant coping is associated with increased psychological distress and may therefore constitute a psychological risk factor for adverse

responses to stress. Consistent with this position, Felton et al.(1984) found that cognitive restructuring was associated with good emotional adjustment in patients with hypertension, diabetes or rheumatoid arthritis, whereas coping by fantasizing, expressing emotion, or blaming oneself was associated with poor adjustment. Similarly, Weisman and Worden (1976, 1977) found poor adjustment among cancer patients was associated with efforts to forget the cancer, fatalistic views of cancer, passive acceptance, withdrawal from others, blaming of others and self-blame.

Correspondingly, research has found lower psychosocial morbidity to be associated with confrontative responses to stress, with optimism (Scheier, Weintraub and Carver, 1986), with high internal locus of control (Burgess, Morris and Pettingale, 1988), and with beliefs that one can personally exert control over an illness (Fifield, 1987; Taylor, Lichtman and Wood, 1984). Similarly, low helplessness has been associated with superior psychological and behavioral functioning and reduced symptom severity in patients with rheumatoid arthritis (Stein, Wallston, Nicassio and Castner, 1988).

In summary, individuals faced with the stresses of chronic illness engage in a variety of coping strategies. These strategies include direct problem solving (as in seeking social support), distancing, using a positive focus, cognitive escape and behavioral escape. Further, particular coping

strategies have been found to be associated with psychological adjustment, while others are associated with psychological distress.

### The Role of Denial and Social Support in Facilitating Adjustment Among Hemodialysis Patients.

The discussion will now shift to examining two strategies that have been found to have a role in coping and adjusting to chronic illness, and more specifically, to coping with the stresses of hemodialysis. These two strategies or resources are denial and social support.

Researchers have known for decades that intermittent denial may be useful in enabling people to come to terms gradually with the threatening aspects of stressful events (Lazarus, 1983; Meyerowitz, 1980). Denial can be defined as a conscious effort to remove from awareness certain fear-arousing elements and characteristics of an event or situation in order to minimize emotional distress.

Beard, (1969) saw dialysis patients in the complex position of fearing to live an unsatisfactory life, while at the same time having to deny the seriousness of their illness in order to avoid fears of impending death.

Kaplan De-Nour (1982) concluded that denial can be usefully adaptive when one refuses to accept that the problems associated with ESRD and hemodialysis must necessarily have a detrimental outcome, at the same time, not ignoring the severity of the illness by rejecting needed treatments and assistance.

### Defensive Denial

ESRD patients may cope with the stresses imposed by their life-threatening illness by isolating and excluding illness-related events from their overall experience of life, by minimizing their impact and maintaining a non-depressed emotional status as a result. This coping strategy has been labelled defensive denial. It has been suggested that the psychological situation faced by ESRD patients - especially those on maintenance hemodialysis - may simply be too threatening to maintain in conscious awareness (Czacakes and De-Nour, 1978; Short and Wilson, 1969; Yanagida, Streltzer, and Siemsen, 1981).

The findings concerning denial also imply that coping strategies may be most effective when they are matched to the particular problem or points in time when they may be most useful (i.e., a matching hypothesis). There is evidence that people spontaneously match coping strategies to aspects of a stressful event. For example, people are more likely to use

problem-solving strategies for aspects of a stressor that are amenable to direct control and to employ emotion-focused coping for aspects of a stressful event that remain uncontrollable (e.g. Folkman and Lazarus, 1980; Scheier, Weintaub and Carver, 1986). Also consistent with a matching hypothesis, some research suggests that multiple coping strategies may be most effective in managing stressful events. (Collins, Taylor, Skokan, 1990; Perlin and Schooler, 1978). The same may hold true for the use of denial as it is invoked for coping with certain aspects of the dialysis regimen.

#### Social Support

Social support appears to be an important coping resource for those suffering from chronic disease. The influence of good social relationships on positive adjustment to chronic disease can be found in the literature on a range of chronic illnesses. Social support has been associated with better recoveries from kidney disease (Dimond, 1979), and end-stage renal disease (Siegal et al., 1987). Positive adjustment has also been reported among cancer patients, (Fitzpatrick et al., 1988; Siegal, Calsyn and Cuddihee, 1987; Taylor et al., 1987), among diabetic patients, (Schwartz, Springer, Flaherty and Kiani, 1986), and among patients with myocardial infarctions, where the likelihood of mortality was reduced (Wiklund et al., 1988).

Fewer illness-related problems among chronically ill or elderly populations have been documented for those with higher levels of social support (Wallston et al., 1983). Social support also appears to affect health habits and, in particular, promotes adherence to medical regimens. People with higher levels of social support are usually more compliant with their medication requirements and they are more likely to use health services (Wallston et al., 1983).

The influence of family and friends on psychological adjustment of ESRD patients is well supported in the literature. (Burton et al., 1983; Siegal et al., 1987). The prolonged stress associated with the hemodialysis regimen often reduces the ability to cope, while at the same time producing feelings of alienation and estrangement from family members and friends. Factors found to be predictive of coping with the limitations and difficulties of dialysis were good family relationships and supports and pre-dialysis functioning. The literature on the psychological stressors associated with ESRD suggests that support systems can decidedly affect the experience, course and outcome of the renal regimen. There is consensus in the literature of a positive association between supportive family attitudes and successful adaptation (Sand, Livingston and Wright, 1966). There is evidence of a significant association between morale and social support and between self-esteem and family cohesion (Dimond, 1979). Diminished depression in the presence of

social support has been reported in studies by Aneshersel and Frericks (1982) Burton et al., (1983) and Husaini et al., (1982).

Social support may be most effective when it provides coping assistance. Different stressors create different needs that elicit different coping efforts. Social support efforts may be viewed as assisting these coping efforts and should be more effective when they match the person's needs. Consistent with the view that social support represents coping assistance, Dunkel-Schetter, Folkman and Lazarus (1987) found that individual ways of coping were strongly associated with the types of support received.

#### Hypotheses

The following hypotheses are considered tenable:

1. Subject's level of stress will be constant regardless of perceived social support from family and friends.
2. Subject's level of stress will vary directly with length of experience on hemodialysis.
3. Subject's level of coping will vary directly with level of social support from family and friends.
4. Subject's level of coping will vary directly with length of experience on hemodialysis.

## CHAPTER III

### METHOD

#### Description of the Sample

The sample of hemodialysis patients consisted of 25 males and 25 females. The respondents ranged in age from 20 to 71, with a mean of 45.3 years (SD = 13.4).

Table 1 presents frequency distributions on categorical scale demographic and background characteristics. The data in the Table indicates that the majority of the respondents were self-identified as Black (84%). Most were born outside the United States (66%). The highest religious group was Protestant (44%), followed by Catholic (24%) and no religious affiliation (8%).

**Table 1**  
**Respondent Demographic and Background Characteristics**

VARIABLE	VALUE	N	%
GENDER	Male	25	50.0
	Female	25	50.0
ETHNIC GROUP	Black	42	84.0
	White	3	6.0
	Hispanic	3	6.0
	Asian	2	4.0
PLACE OF BIRTH	U.S.	17	34.0
	Outside U.S.	33	66.0
RELIGION	Protestant	22	44.0
	Catholic	12	24.0
	Other	12	24.0
	None	4	8.0

(Table continues)

Table 1 (continued)

VARIABLE	VALUE	N	%
MARITAL STATUS	Single	17	34.0
	Married	21	42.0
	Separated	3	6.0
	Widowed	4	8.0
	Divorced	2	4.0
HAVE CHILDREN?	Yes	39	78.0
	No	11	22.0
EDUCATIONAL LEVEL	Less than 8th grade	6	12.0
	Eighth grade	10	20.0
	Some high school	4	8.0
	High school grad.	19	38.0
	Some college	10	20.0
	College graduate	0	0.0
	Advanced degree	1	2.0
EDUCATED IN U.S.	No	33	66.0
	Yes	17	34.0

(Table continues)

Table 1 (continued)

VARIABLE	VALUE	N	%
EMPLOYMENT STATUS	Full-time	13	26.0
	Part-time	2	4.0
	Homemaker	2	4.0
	Retired	3	6.0
	Student	1	2.0
	Unemployed	29	58.0
SMOKE?	Not at all	30	60.0
	Former smoker	18	36.0
	1 pack or less	2	4.0
DRINK ALCOHOL	Not at all	24	48.0
	Occasionally	26	52.0

The largest group of respondents were married (42.0%), but more than one-third reported that they were single (34.0%). More than three quarters of the sample indicated that they had children (78%). With respect to educational level, the modal category was high school graduate (38%), followed by "some college" (20.0%). More than one-third of the sample had not completed high school (40.0%). The majority indicated that they were educated outside the United States (66.0%).

The majority of respondents indicated that they were unemployed (58.0%). About one-fourth of the sample was employed full-time (26.0%), and a small group were employed part-time (4%).

The majority of the respondents indicated that they had never smoked (60.0%), and a substantial number indicated that they were former smokers (36%). Only two respondents were current smokers, and these two both indicated that they smoked one pack or less a day. Forty-eight percent of the respondents indicated that they did not drink alcohol at all, and 52% indicated that they drank alcohol occasionally.

Table 2 presents the data provided by respondents on their disease histories, and Table 3 presents data on the respondents' treatment histories. The data in Table 2 indicate that 37 respondents reported having high blood pressure, 23 has visual problems, 11 had diabetes, and 9 had heart disease. Other diseases were reported by fewer respondents.

Table 2  
Respondent Disease History Data

Disease	Had Disease?	
	Yes	No
Epilepsy	2	48
Bronchitis, Lung disease	3	47
Thyroid disease	4	46
Jaundice	0	50
Psychiatric disorder	2	48
Tuberculosis	0	50
Heart disease	9	41
High blood pressure	39	11
Bladder problems	3	47
Bowel problems	2	48
Hearing problems	3	47
Visual problems	23	27
Stroke	2	48
Diabetes	11	39
Ulcers	5	45
Skin rash	6	44
Joint disease	8	42
Allergy	8	42
Other diseases	14	36

**Table 3**  
**Respondent Treatment Histories**

VARIABLE	VALUE	N	%
Hospitalizations for problems other than kidney disease?	Never	17	34.0
	Once	12	24.0
	Twice	6	12.0
	Three times	4	8.0
	Four or more	11	22.0
Had psychiatric treatment?	Yes	6	12.0
	No	44	88.0
Had outpatient therapy?	Yes	6	12.0
	No	44	88.0
Had psychiatric hospitalization?	Yes	2	4.0
	No	48	96.0
Had family treatment?	Yes	0	0.0
	No	50	100.0
Had counseling?	Yes	0	0.0
	No	50	100.0

(Table continues)

Table 3 (continued)

## Respondent Treatment Histories

VARIABLES	VALUE	N	%
What is it like for you to keep dietary restrictions?	Impossible	2	4.1
	Very difficult	17	34.7
	Somewhat difficult	28	28.6
	Relatively easy	12	24.5
	Very easy	4	8.2
Do you keep to restrictions?	Never	3	6.0
	Mostly no	4	8.0
	Half of the time	22	44.0
	Mostly yes	17	34.0
	Always	4	8.0
How long have you been receiving dialysis?	Under 6 months	9	18.0
	6-11 months	6	12.0
	1-5 years	22	44.0
	6-11 years	7	14.0
	12 or more years	6	12.0
How many times did you miss dialysis last month?	None	39	18.0
	Once	8	16.0
	Twice	1	2.0
	Five Times	2	4.0

Table 3 (continued)

VARIABLE	VALUE	N	%
How many times do you miss dialysis in an average month?	None	6	54.5
	Once	1	9.1
	Twice	2	18.2
	Three times	2	18.2
Have you received other forms of dialysis?	Yes	4	8.0
	No	46	92.0
Have you received a kidney transplant?	Yes	1	2.0
	No	49	48.0

The data in Table 3 indicate that 68 percent of the sample had been hospitalized at least once for problems other than kidney disease. The majority of the respondents (67.0%) reported having at least some difficulty in keeping the dietary and fluid restrictions of dialysis. Forty-two percent of the respondents indicated that they did keep to the restrictions most or all of the time. The largest number of respondents (44%) indicated that they had been receiving dialysis from one to five years. The majority of respondents (78%) indicated that they had not missed any dialysis appointments during the previous month, and a majority (54.5%) indicated that they typically missed no appointments. Four respondents had received another form of dialysis, and one had received a kidney transplant.

### Instruments

A total of four questionnaires were used for this study. The first was a subject demographic questionnaire that provided a profile of subjects along several dimensions (e.g. age, marital status, length of time on hemodialysis), and was used to assess premorbid level of functioning, for example, educational level, steadiness of prior employment.

The second instrument, the Hemodialysis Stressor Scale developed by Baldree, Murphy, Powers, (1982), is a 29-item

rating scale constructed to evaluate the incidence and severity of stressors associated with the treatment of End Stage Renal Disease (ESRD) by hemodialysis, as perceived by the patient. Stressors are classified as primarily physiological or psychosocial. Murphy et al.(1985), reported reliability coefficients of .89 for the total stressor scale, .69 for the physiological subscale and .88 for the psychosocial subscale.

The third item administered was the Ways of Coping Questionnaire developed by Lazarus and Folkman (1985). This instrument is designed to identify the thoughts, actions and coping processes an individual uses in stressful encounters. The items in the questionnaire yield eight coping subscales. Alpha coefficients are as follows: Confrontive Coping .70; Distancing .61; Self-Controlling .70; Seeking Social Support .76; Accepting Responsibility .66; Escape-Avoidance .72; Planful Problem Solving .72; Positive Reappraisal .79.

The fourth item, Measures of Perceived Social Support from Friends and Family, developed by Procidano and Heller (1978) is a measure of the extent to which an individual believes that his/her needs for support, information and feedback are fulfilled from friends and from family. Cronbach's alpha coefficients for Perceived Social Support from Friends (PSS-Fr) = .88 ; Perceived Social Support from Family (PSS-Fa) = .90.

## Procedures

Subjects who met the study participation criteria were approached on the hemodialysis unit while awaiting their scheduled appointments or while being treated. A verbal and written description of the study was provided, the purpose of the study was explained including the estimated length of time involved in completing the questionnaire. Confidentiality of responses was emphasised and participants given the assurance that only code numbers would be used, and all reports would be in group form. Those who agreed to participate were asked to read and sign the consent form attached to the questionnaire. Some patients agreed to be interviewed immediately. Others gave consent and agreed to be interviewed at a later date. Subjects were informed that they could withdraw from the study at any time without penalty of any sort. Where necessary the experimenter assisted in providing clarification or further explanation of questions.

## CHAPTER IV

### RESULTS

The relationship among stress, coping styles and social support was assessed using bivariate correlations and multiple regression analysis. These inferential statistics were appropriate, since all the variables constitute interval scale data. In this chapter the results of the study are presented. This chapter will report the tests of research hypotheses and additional analyses of the data.

Hypothesis 1 was tested by obtaining the Pearson Product Moment Correlation between the stress scale, (which is subdivided into physiological stress and psychological stress) and each of the two social support scales (support from family and support from friends). Each correlation was evaluated for significance using a two-tailed test at the .05 level of significance.

Hypothesis 2 was tested by obtaining the Pearsons correlations between number of months on dialysis and the stress scale. These correlations were evaluated as indicated above. Hypothesis 3 was tested by obtaining the Pearson correlations between each of the two social support scales (family and friends) and coping scales of the Ways of Coping Questionnaire. These correlations were evaluated in two-tailed test at the .05 level.

Hypothesis 4 was tested by means of Pearson correlations between the coping scale and the number of months on dialysis, evaluated as specified above.

In addition, two multiple regression analyses were be carried out, one for physiological stress and one for psychological stress. In each analysis, the predictors were the number of months on dialysis, social support from family and friends, and coping.

A stepwise analysis was used, with the probability-to-enter set at .95, in order to maximize the number of predictors included. At each step, in each analysis, F-tests were used to evaluate the significance of the entire regression and each individual predictor. Beta weights were used to assess the relative importance of the several predictors at the last step in each regression.

#### Tests of Hypotheses

The four research hypotheses all concerned the correlations between the stress and coping measures, on the one hand, and the social support measures and the amount of time the patient has been receiving dialysis, on the other. Table 5 presents these correlations.

Hypothesis 1 stated that the stress experienced by subjects would be unrelated to social support received from family and friends. This hypothesis was confirmed only in

part. Support from family and was related significantly to physiological stress ( $r=.37$ ,  $p < .01$ ). Those patients who reported experiencing relatively much physiological stress also reported receiving relatively much support from family.

Psychological stress was not related significantly to support from family ( $r=.19$ ,  $p > .05$ ). Support received from friends was not related significantly to either physiological ( $r=.15$ ,  $p > .05$ ) or psychological stress ( $r=.09$ ,  $p > .05$ ).

Hypothesis 2 stated that the subject's level of stress would vary directly with the length of time the patient was on dialysis. This hypothesis was not confirmed. Time on dialysis was not related significantly to physiological stress ( $r=.20$ ,  $p > .05$ ), or to psychological stress ( $r = -.01$ ,  $p > .05$ ).

Hypothesis 3 stated that the subject's level of coping would vary directly with support received from family and friends. This hypothesis was also confirmed in part. Support from family was not related significantly to any of the coping subscales. Support from friends was related significantly and in the expected direction to seeking social support ( $r=.38$ ,  $P < .01$ ) and was significantly positively related to the positive reappraisal subscale ( $r=.38$ ,  $p, .01$ ).

Hypothesis 4 stated that coping would vary directly with the amount of time the patient was on dialysis. This hypothesis was not supported. Time on dialysis was not related significantly to any of the coping subscales.

Table 4 presents descriptive statistics on the interval scale variables of the study including physiological and psychological stress, social support received from friends and from family, and scores on the eight coping scales of the Ways of Coping Questionnaire.

**Table 4**  
**Descriptive Statistics on Stress Scales,**  
**Social Support Scales, and Coping Scales.**

VARIABLE	N	MINIMUM	MAXIMUM	MEAN	SD
Physiological stress	50	0.0	18.0	7.7	4.7
Psychological stress	50	5.3	53.1	29.5	16.3
Social support from friends	50	23.0	59.0	45.5	9.1
Social support from family	50	26.0	56.0	47.3	8.8
<b>Coping:</b>					
Confrontative	50	2.0	15.0	7.5	3.4
Distancing	48	3.0	18.0	11.5	3.8
Self-control	46	4.0	21.0	12.8	3.9
Seeking social support	50	1.0	18.0	10.1	4.8

Table 4 (continued)

Descriptive Statistics on Stress Scales,  
Social Support Scales, and Coping Scales.

VARIABLE	N	MINIMUM	MAXIMUM	MEAN	SD
Accepting responsibility	48	0.0	12.0	4.4	3.2
Escape avoidance	48	0.0	21.0	11.0	4.2
Planfulproblem solving	48	2.0	15.0	9.3	3.9
Positive reappraisal	47	1.0	21.0	12.8	4.5

Norms were available for the coping scales in the Manual of the Ways of Coping Questionnaire (Lazarus and Folkman, 1988). Independent sample t-tests were carried out to compare the present sample of dialysis patients to the test norming sample on each of the eight coping scales. These tests were all significant. The dialysis patients had higher scores than the norming sample on all eight coping style scores.

Table 5  
Correlations between Stress and Coping Measures and  
Measures of Social Support and Time on Dialysis.

VARIABLE	CORRELATION WITH					
	Support from family		Support from friends		Time on dialysis	
	N	r	N	r	N	r
STRESS:						
Physiological stress	50	.37**	50	.15	50	.20
Psychological stress	50	.19	50	.09	50	-.01
COPING:						
Confrontative	50	-.02	50	.15	50	.10
Distancing	48	-.11	48	.15	48	-.02
Self-Control	46	.05	46	.03	46	-.02
Seeking social support	50	.00	50	.38 **	50	.22
Accepting responsibility	48	-.16	48	.07	48	-.15
Escape avoidance	48	-.09	48	.02	48	-.23
Planful problem solving	48	.19	48	.06	48	-.12
Positive reappraisal	47	.10	47	.38**	47	.10

\*\* p < .01

### Additional Analyses

Additional analyses included stepwise multiple regression analyses predicting experience of physiological stress and psychological stress from perception of social support, the coping scale scores and length of time on dialysis. Stepwise multiple regression shows the increment added by each predictor. The best predictor is selected in Step 1 and a one-predictor regression equation provided. Each successive step selects the variable that would contribute the most additional variance until all variables have been partialled out. The results of these analyses are presented in Tables 6 (Physiological stress) and Table 7 (Psychological stress).

The data presented in Table 6 indicate that three variables contributed significantly to the explanation of variance in physiological stress. These variables were social support from family ( $t=3.71$ ,  $p,.001$ ), distancing ( $t=-2.46$ ,  $p <.05$ ), and length of time on dialysis ( $t=2.48$ ,  $p <.05$ ). Together these variables explained 47 percent of the variability in physiological stress. Perception of family support and length of time on dialysis were related positively to physiological stress. That is to say, when a regression analysis was computed, for patients reporting experiences of high physiological stress, perception of family support was also reported as high. As time on dialysis increased, so too were reported experiences of physiological stress. Distancing,

the coping strategy defined as the cognitive efforts individuals make to detach themselves from, and minimize stressful situations, was found to be negatively related to physiological stress. This is to say, patients who employed high levels of the this particular coping strategy, tended to report lower experienced levels of physiological stress. Patients unable or ineffectively employing this particular coping mechanism tended to report higher experienced levels of physiological stress.

Table 6  
 Regression of Perceived Social Support,  
 Coping Scales, and Length of Time on Dialysis on  
 Physiological Stress (N=38)

Step	Variable	R	R <sup>2</sup>	t (A)	beta (B)
1	Family support	.52	.27	3.71***	.51
2	Distancing	.61	.38	-2.46*	-.31
3	Length of time on dialysis	.69	.47	2.48*	.31

(A) At entry

(B) In final regression

\*\*\*p<.001

The data in Table 7 show that only one variable met the criterion for entry into the regression equation: Social support from family ( $t=2.27$ ,  $p < .05$ ). This variable explained approximately 12 percent of the variance in psychological stress. After support from family, none of the other predictors explained significant additional variability in psychological stress. This is to say, support from family would best predict levels of reported psychological stress in this population.

Table 7  
Regression of Psychological Stress on  
Social Support, Coping Scales, and Length  
of Time on Dialysis (N=38)

Step	Variable	R	R2	t	beta
1	Family support	.35	.12	2.99**	.35

\*\*p <.01

Where there were a sufficient number of study participants reporting a particular health problem to permit a valid statistical comparison, an independent sample t-test was run to compare those who did and did not report that problem on the variables representing perceived support received from friends and family. These t-tests are presented in Table A. The data in Table A indicate no significant differences between those with and without these specific health problems on support perceived as received from either friends or family.

Correlations were run between support perceived as received from friends and family and compliance with the dietary restrictions expected of hemodialysis patients. These correlations are presented in Table B. The data in Table B indicate no significant relationship between the support of friends and family and the measures of compliance.

Finally, a series of independent sample t-tests were calculated to compare male and female respondents on the measures of social support and compliance with the prescribed medical restrictions. The results are presented in Table C.

The data in Table C indicate no significant gender differences.

Table A  
 Perceived Support from Friends and Family  
 Among Respondents With and Without Selected  
 Health Problems.

PROBLEM AREA	SUPPORT FROM	WITH PROBLEM			WITHOUT PROBLEM			t
		N	Mean	SD	N	Mean	SD	
High blood pressure	Friends	39	45.4	9.4	11	45.8	8.2	-0.15
	Family	39	46.2	9.5	11	51.4	4.4	-1.76
Visual problems	Friends	23	45.1	8.5	27	45.7	9.7	-0.23
	Family	23	49.6	5.5	27	45.4	10.6	1.73
Diabetes	Friends	11	44.8	10.0	39	45.6	8.9	-0.26
	Family	11	50.4	5.0	39	46.5	9.5	1.30
Joint diseases	Friends	8	45.5	8.3	42	45.5	9.3	0.01
	Family	8	49.5	6.4	42	46.9	9.2	0.76
Allergies	Friends	8	43.8	10.5	42	45.8	8.9	-0.58
	Family	8	48.0	5.5	42	47.2	9.4	0.24

**Table B**  
**Correlations Between Support From Friends**  
**and Family and Compliance Measures**

COMPLIANCE MEASURE	SUPPORT OF FRIENDS	SUPPORT OF FAMILY
How difficult is it to keep restrictions	.08 (49)	-.19 (49)
Extent to which you do keep restrictions	.09 (50)	.09 (50)

(No significant relationships)

Table C  
Social Support and Compliance Measures  
by Gender

MEASURE	MALES (N=25)		FEMALES (N=25)		t
	MEAN	SD	MEAN	SD	
Support from friends	44.8	9.7	46.1	8.5	-0.51
Support from family	48.7	7.7	45.9	9.8	1.12
How difficult is it to keep restrictions	3.25	1.03	2.72	1.02	1.81
Extent to which you do keep restrictions	3.48	0.82	3.12	1.05	1.35

(No significant differences)

Table D presents the mean ratings of the stress associated with each of the physiological and psychological stressors in the Hemodialysis Stress Scale. The data in Table D indicate that the five most stressful aspects of dialysis were cramps (mean=1.92), limiting fluids (mean=1.86), uncertainty (mean=1.76), limits on vacations (mean=1.58) and limiting foods (mean=1.52).

Table D  
 Mean Stress Ratings of Physiological and  
 Psychological Stressors Associated With  
 Dialysis

STRESSOR	MEAN	RANK	*	STRESSOR	MEAN	RANK
Cramps	1.92	1	*	Diminished sex	1.26	11
Limit fluids	1.86	2	*	Cost	1.24	12
Uncertainty	1.76	3	*	Job interrupt.	1.22	14
No vacations	1.58	4	*	Boredom	1.22	14
Limit foods	1.52	5	*	Able kids	1.22	14
Length of treatment	1.46	7	*	Diminished social life	1.20	16
Limit on activities	1.46	7	*	Tiredness	1.16	17
Transportation	1.46	7	*	Hospital	1.14	18
Family responsibility	1.36	9	*	Itching	1.12	19
Changes/body	1.30	10	*	Feeling cold	1.00	20
				Nausea	.94	21.5

(Table continues)

Table D (continued)

STRESSOR	MEAN	RANK
Equipment	.94	21.5
Sleep deprivation	.92	23.5
Loss of functions	.92	23.5
Needle stick	.90	25
Role reversal	.71	26
Stiffness	.70	27
Dependence on nurses	.68	28
Dependence on physicians	.52	29
Being alone	.20	30

## CHAPTER V

### DISCUSSION

The study was designed to investigate factors associated with the stress experienced by hemodialysis patients. Among the variables investigated were reported events of physical and psychological stress, length of time on dialysis, perception of social support received from family and friends and characteristic coping strategies. Patients were interviewed using various scales of stress and coping. Correlations were then computed among the different variables.

The social context for this study, and from which the sample population was derived, is the inner-city. In patients receiving hemodialysis at inner-city health care facilities or hospitals, end-stage renal disease can often be directly linked to diabetic nephropathy, hypertensive nephropathy, heroin associated nephropathy, alcohol induced acute and chronic renal failure and AIDS associated nephropathy. The overarching link however is poverty - the stresses of the inner-city translating into higher rates of hypertension, kidney disease, psychiatric morbidity and other health problems.

Although this study does not directly address the effects of these variables, the results of this study can be used as a baseline for the study of stress and coping in this

particular hemodialysis population. Future research might investigate the effects of variables such as, socioeconomic status, race and ethnicity, in identifying stressors and coping efforts of hemodialysis patients. It is therefore important not to make broad generalizations of the findings of this study to other hemodialysis populations without controlling for the above mentioned variables.

The research hypotheses posited a correlation between stress and coping as one dimension of the study, and between social support measures and the amount of time a patient had been receiving dialysis as another. Using the Hemodialysis Stressor Scale, (Powers,1984) patients identified both physiological and psychological stressors. These stressors were ranked and later correlated and analyzed in relation to the subjects' responses to the measures of perceived social support, coping scale scores and length of time on dialysis.

Patients in this study reported experiences of psychological stress at a rate approximately four times higher than physiological stress. Findings in the literature are that patients experience physiological and psychological stress equally. The elevated rate of reported psychological stressors in this patient population might be due to the possible interactive effects of the stressors associated with poverty, as well as the fact that patients were interviewed

while on the dialysis unit. The reaction to being interviewed on the dialysis unit - some while being dialysed, while experiencing discomfort, or having difficulty attending to the questions being asked - may have intensified the psychological distress of the experience. Interviewing patients while not receiving treatment, or while not on the dialysis unit may have reduced the degree of reported distress.

Another explanation for the elevated level of reported psychological stressors might be the effect of length of time on dialysis. Approximately 44% of the respondents indicated that they had been receiving hemodialysis for 1 to 5 years. Given this relatively small window of time, the patients may be viewed as still in the early adjustment phases to the regimen of dialysis. Psychologically, patients may still be occupied with adjusting to some of the drastic limitations imposed on their lives, including, loss of ability to maintain regular work schedules, cuts in income, social life becoming circumscribed, limitations on food, restrictions on travel, changes in family responsibilities, changes in body appearance. The sense of their distress resulting from these factors is greater than their distress when they focus on the actual physiological aspects of their illness.

Those subjects who are receiving dialysis for a longer period reported an increased level of physiological stress. Therefore this results in less of a discrepancy between physiological

and psychological distress for those subjects receiving dialysis for a period of greater than five years.

Results indicated that there were differences in the sources of support received, that is, support from family versus support from friends.

Support from family was strongly correlated with reported levels of physiological stressors as well as length of time on dialysis. This means that the higher the reported level of physiological stress, the higher the perceived support from family. Thus, regardless of support from family, patients continue to report high levels of physiological stress. Patients might also perceive family mobilization around their illness and therefore perceive more family support.

Two subscales of the Lazarus and Folkman Coping Questionnaire - seeking social support, and positive reappraisal - were found to be significantly related to perceived support from friends. In responding to the items on each subscale, subjects were asked to recall a particularly stressful situation experienced over the past week and to give responses on a scale ranging from 0,1,2 or 3 from (0) - Does Not Apply, to (3) - Used a Great Deal. Examples of items on the Positive Reappraisal subscale are: 'Changed or grew as a person in a good way', 'I came out of the experience better than I went in', 'I rediscovered what is important in life.' Responses on this scale would indicate a more optimistic view

of life and in turn lead to the perception that friends were helpful.

Examples on the subscale, Seeking Social Support, are 'Talked to someone to find out more about the situation', talked to someone who could do something concrete about the problem', 'talked to someone about how I was feeling.' Seeking social support and perceived social support from friends are significantly correlated. Since both these items measure somewhat similar variables, a correlation between them is not entirely unexpected.

For this population in particular, identified as overwhelmingly immigrant, with 66% born outside the United States, the source of perceived social support, in terms of their ability to cope with the stress of dialysis, may come, not from family, who may not be immediately accessible because of geographic factors, but instead may be provided by friends. Another explanation for the results obtained, may be that patients may have less ambivalent feelings toward friends versus family. For some patients, family involvement may be seen as 'overinvolvement' and perhaps even as intrusive, as family members take on a more care-giving role. Patients may therefore seek out friends in efforts to gain informational and tangible support (the coping strategy of seeking social support) as well as to make attempts at creating more positive meaning out of their experiences (the coping strategy of

positive reappraisal), and/or to help mitigate feeling of overwhelming dependency on family members.

In summary, Hypothesis 1, which stated that the stress experienced by subjects would be unrelated to social support received from friends and family, was only partly sustained. Physiological stress did not vary with perceived support from either family or friends. The more the experience of physiological stress and distress of the dialysis regimen, the more the subjects seemed to turn to family members for support. Level of perceived support did not mitigate physiological stress.

Hypothesis 2, which stated that the subjects' level of stress would vary with the length of time on dialysis, was not confirmed. Although time on dialysis was not related significantly to either physiological or psychological stress, patients, the majority of whom had been receiving dialysis for between 1 to 5 years, reported four times higher psychological stress than physiological stress.

Hypothesis 3 stated that the subject's level of coping would vary directly with support received from family and friends. Perceived support from family was not related significantly to any of the coping subscales. However, support from friends was related significantly to seeking support and positive reappraisal. This finding may be seen as an index of validation for the measures used and supports a more optimistic outlook in terms of coping. Hypothesis 4, stated

that coping would vary directly with time on dialysis. This was not supported, as scores on the coping measures did not vary with time on dialysis. With this dialysis population, their illness remains at a problematic level. This may also be an effect of the general social situation experienced by many of these poor, largely minority subjects.

#### SUMMARY AND CONCLUSION

End stage renal disease necessitating treatment by hemodialysis is a stressful life event that impacts on the physiological, psychological and social levels. Stressors of the urban environment further complicate the diagnosis, course and prognosis for individuals experiencing compromised renal function and subsequent treatment.

The central focus of this study was on the nature of patient responses to the stress associated with the hemodialysis regimen, coping strategies that patients employed and the role of social support in adjustment to the demands of hemodialysis.

Subjects were 50 hemodialysis patients who were receiving treatment for end-stage renal disease in a hospital site hemodialysis unit. Patients were asked to respond to

questions on the following measures: Demographic Questionnaire, Hemodialysis Stressor Scale, Ways of Coping Questionnaire, Perceived Social Support From Family and Friends Questionnaire.

The following conclusions are considered tenable:

These subjects tended to report greater distress concerning the psychological concomitants of their illness.

Length of time on dialysis did not mitigate the stressfulness of the hemodialysis regimen.

Those who were more optimistic tended to report greater support from friends, while those who were more focused on psychological distress tended to report more support from family. Thus, regardless of support from family and friends, subjects continued to report high levels of physiological and psychological distress. The stress of dialysis was not reduced in any systematic way by perceived support from family and friends.

#### Recommendations for Future Research

The study participants were selected from affiliated hospitals serving the inner-city. The sample thus reflected inner-city demographics and responses. The value and implications of the study's findings based on this population, in this setting, cannot be underestimated. Future research

might however seek to repeat this study with a middle class and non-minority sample and to examine the extent to which socio-economic and cultural factors determine the results.

The possible effects of interviewing patients on the dialysis unit needs further investigation. Future research might involve using treatment setting as a variable; hospital facility, versus satellite clinic, versus home dialysis. Patients interviewed on the hemodialysis treatment unit may have reported elevated levels of psychological stress. Further research could explore shifts in reported stress levels depending on activity and treatment setting.

Overall there needs to be a continued commitment to research in all areas of renal disease. In particular, research into the psychological factors involved for patients receiving hemodialysis will promote better understanding of stressors experienced, coping processes and adjustment, and promote satisfying new levels of organization for hemodialysis patients.

**APPENDIX    A**

**CONSENT FORMS AND QUESTIONNAIRES**

Dear Hemodialysis Patient:

I am trying to find out how you are reacting to hemodialysis. It is hoped that this study will lead to a better understanding of the issues experienced by hemodialysis patients.

I will ask you to answer some questionnaires. They will take about one hour to complete. There are no right or wrong answers.

Your name will not be used. Only group results will be reported. Whether or not you participate in this study will have no effect whatsoever on your treatment. You may also withdraw from the study at any time.

I think you will find the questionnaires interesting.

I would be most grateful for your help. Please participate.

Sincerely,

Patrice J. Nelson, M.A.

-----  
PLEASE RETURN THIS SECTION

Check:

I am interested in participating in the hemodialysis study.

Print Name: \_\_\_\_\_ Date: \_\_\_\_\_

## CONSENT FORM

This research is part of my doctoral dissertation concerning patients who are on dialysis. You are asked to complete questionnaires about your experience on dialysis. In addition, your medical practitioner will be asked about your health.

The completion of the questionnaire will take approximately one hour. The information that you provide will be kept confidential. You will be asked to choose a code number to be written on the materials that you complete. Your particular responses will not be singled out in any way. All responses will be reported only in group form. It will not be possible to identify any individuals.

There are no right or wrong answers. Feel free to give whatever responses that convey your reactions. You are free to stop at any time without penalty of any sort, but I hope that you will answer all the questions.

I will be happy to answer any questions you may have regarding procedures or any aspect of the study.

Your participation in the study is very much appreciated.

Patrice J. Nelson, M.A.

Doctoral Candidate (718) 983-1962

PLEASE SIGN THE ATTACHED CONSENT FORM

## CONSENT AUTHORIZATION

I agree to participate in the dialysis study as described above.

-----  
Name - Please Print

-----  
Signature

-----  
Date

1. First, choose any combination of 4 letters and numbers.  
for example: 4 8 3 B or C X 2 L  
This is your code number and should be written on the top right corner of every page of the questionnaires.
2. Please respond to each item of the questionnaires.
3. Don't hesitate to ask if there is anything that is confusing or raises a question.

Again, thank you for your cooperation.

Your Code Number \_\_\_\_\_

## Questionnaire 1

1. Today's Date (month)\_\_\_\_\_ (day)\_\_\_\_\_ (year)\_\_\_\_\_
  
2. Date Of Birth (month)\_\_\_\_\_ (day)\_\_\_\_\_ (year)\_\_\_\_\_  
Age \_\_\_\_\_
  
3. 1  Male                      2  Female
  
4. How do you describe yourself? Check all that apply.
  - 1  African descent
  - 2  White, Non-Hispanic
  - 3  Hispanic
  - 4  Asian
  - 5  Other:(specify)\_\_\_\_\_
  
5. Place of Birth \_\_\_\_\_
  - 1  U.S.
  - 2  Other

CODE # \_\_\_\_\_

## 6. Religion

- 1 [ ] Protestant Type: \_\_\_\_\_
- 2 [ ] Catholic
- 3 [ ] Jewish
- 4 [ ] Muslim
- 5 [ ] Other (specify) \_\_\_\_\_
- 6 [ ] None

Are you observant? \_\_\_\_\_

## 7. Marital Status

- 1 [ ] Single (Never Married)
- 2 [ ] Married....How many years, this marriage? \_\_\_\_\_  
 Previous marriages? Yes [ ] No [ ]  
 How many? \_\_\_\_\_ Years for each: \_\_\_\_\_; \_\_\_\_\_
- 3 [ ] Living together..How many years? \_\_\_\_\_  
 Previous living together arrangements? Yes [ ] No [ ]  
 How many? \_\_\_\_\_ Years for each: \_\_\_\_\_; \_\_\_\_\_
- 4 [ ] Separated.....How many years? \_\_\_\_\_
- 5 [ ] Widowed.....How many years? \_\_\_\_\_
- 6 [ ] Divorced.....How many years? \_\_\_\_\_

CODE # \_\_\_\_\_

8. Do you have any children ? 1  Yes      2  No

If yes, please check the following. For those who do not live with you give their age when they stopped living with you:

Age	Sex	Live with You?	Age when no longer living with you
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

9. With whom do you live? (Please check all that apply)

- 1  Alone
- 2  Husband/Wife/Spouse Equivalent
- 3  Parent(s)
- 4  Others.....Who? \_\_\_\_\_

CODE # \_\_\_\_\_

## 10. Education (please check highest grade/degree completed)

- 1 [ ] Less than 8th grade
- 2 [ ] Completed 8th grade
- 3 [ ] Some high school
- 4 [ ] High school graduate
- 5 [ ] Some college
- 6 [ ] College graduate
- 7 [ ] Post college courses
- 8 [ ] Advanced degree.....What degree?\_\_\_\_\_

If educated other than in the U.S., please specify:

Country\_\_\_\_\_

CODE # \_\_\_\_\_

## 11. Current employment status (Please check only one)

- 1 [ ] Employed full-time
- 2 [ ] Employed part-time
- 3 [ ] Homemaker
- 4 [ ] Retired
- 5 [ ] Student
- 6 [ ] Unemployed

## 12. Current occupation?                      When last employed?

\_\_\_\_\_

## 13. Do you enjoy this work (please check one)

- 1 [ ] All the time
- 2 [ ] Most of the time
- 3 [ ] Some of the time
- 4 [ ] Not at all

CODE # \_\_\_\_\_

## 14. Do you smoke?

- 1 [ ] Not at all  
2 [ ] Former smoker..Last smoked/number of years  
ago: \_\_\_\_\_

If now smoking:

- 3 [ ] Less than 1/2 - 1 pack of cigarettes per day  
4 [ ] 2 or more packs per day  
5 [ ] Cigar  
6 [ ] Pipe

How many years have you been smoking? \_\_\_\_\_

## 15. Do you drink alcohol?

- 1 [ ] Not at all  
2 [ ] Occasional social drink  
3 [ ] On weekends only  
4 [ ] Regularly....1-3 drinks per day  
5 [ ] Regularly....4 plus drinks per day

Years used \_\_\_\_\_

Type of alcohol \_\_\_\_\_

Last drink/number of days ago: \_\_\_\_\_

CODE # \_\_\_\_\_

16. Do you, or have you used any of the following drugs?

Indicate the extent by writing in the numbers 1, 2 or 3.

1 = Not at all

2 = Occasional

3 = Regularly

\_\_\_\_ Cocaine/Crack    \_\_\_\_ Heroin    \_\_\_\_ Marijuana

\_\_\_\_ Uppers    \_\_\_\_ Downers

Years used/number of years: \_\_\_\_\_

Last use/number of years since: \_\_\_\_\_

CODE # \_\_\_\_\_

## 17. Have you had any of the following conditions?

	YES		NO	
Epilepsy, seizures	1	[ ]	2	[ ]
Bronchitis, other lung disease	1	[ ]	2	[ ]
Thyroid Disease	1	[ ]	2	[ ]
Jaundice or Liver Disease	1	[ ]	2	[ ]
Psychiatric Disorder	1	[ ]	2	[ ]
Tuberculosis	1	[ ]	2	[ ]
Heart Disease	1	[ ]	2	[ ]
High Blood Pressure	1	[ ]	2	[ ]
Bladder Problems	1	[ ]	2	[ ]
Bowel Problems	1	[ ]	2	[ ]
Hearing Problems	1	[ ]	2	[ ]
Visual Problems	1	[ ]	2	[ ]
Stroke	1	[ ]	2	[ ]
Diabetes	1	[ ]	2	[ ]
Ulcers, Other stomach problems	1	[ ]	2	[ ]
Skin rash	1	[ ]	2	[ ]
Joint Disease, Arthritis	1	[ ]	2	[ ]
Drug Allergies	1	[ ]	2	[ ]
Other _____	1	[ ]	2	[ ]

CODE # \_\_\_\_\_

18. Have you ever been hospitalized for medical problems other than kidney related problems?

- 1 [ ] Never  
 2 [ ] Once  
 3 [ ] Twice  
 4 [ ] Three times  
 5 [ ] Four or more times

For what condition(s) \_\_\_\_\_

19. Have you ever had psychological or psychiatric treatment? 1 [ ] Yes 2 [ ] No

If so, what type? For how long? Most recent date

__ Outpatient therapy	_____	_____
__ Hospitalization	_____	_____
__ Marital/family therapy	_____	_____
__ Counseling	_____	_____

20. Do you have close family members with chronic (longterm) illness? Please check.

- 1 [ ] No  
 2 [ ] Yes - Husband/Wife/Spouse Equivalent  
 3 [ ] Yes - Sister/Brother  
 4 [ ] Yes - Father/Mother  
 5 [ ] Yes - Son/Daughter

CODE # \_\_\_\_\_

21. What is it like to keep the dietary and fluid restrictions of dialysis ?

- 1 [ ] Impossible
- 2 [ ] Very difficult
- 3 [ ] Somewhat difficult
- 4 [ ] Relatively easy
- 5 [ ] Very easy

22. Do you keep to the dietary restrictions ?

- 1 [ ] Never
- 2 [ ] Mostly no
- 3 [ ] Half and half
- 4 [ ] Mostly yes
- 5 [ ] Always

23. How long have you been receiving hemodialysis?

- 1 [ ] less than 6 months
- 2 [ ] 6 to 11 months
- 3 [ ] 1 to 5 years
- 4 [ ] 6 to 11 years
- 5 [ ] 12 or more years

CODE # \_\_\_\_\_

24. How many times in the last month have you missed your dialysis appointment ?

\_\_\_\_\_ times in the last month.

Is this typical? 1  Yes 2  No

If no, how many times a month do you typically miss?

\_\_\_\_\_ times a month.

25. Have you ever received any other form(s) of dialysis?

1  Yes 2  No

If so, what form(s)? \_\_\_\_\_

26. Have you ever received a kidney transplant?

1  Yes 2  No

How many? \_\_\_\_\_

If yes, for how long were they successful?

\_\_\_\_\_ ; \_\_\_\_\_

27. How would you describe your sexual orientation?

1  Homosexual

2  Heterosexual

3  Bisexual

Questionnaire 2 CODE # \_\_\_\_\_

People view the dialysis treatment in many ways. Some people find parts of the treatment difficult, others do not.

To what extent are you affected by the following things. In the spaces provided, please circle the appropriate number.

Example: If the room temperature troubles you a great deal, then circle number 3. If the room temperature troubles you moderately, you would circle number 2, etc.

In the space provided at the end of the list, please include additional items not on the list, and to what extent you are troubled by these.

NOT AT ALL      SLIGHTLY      MODERATELY      A GREAT DEAL

I am troubled by:

1. ARTERIAL &

VENOUS STICK	0	1	2	3
--------------	---	---	---	---

---

2. NAUSEA &

VOMITING	0	1	2	3
----------	---	---	---	---

---

3. MUSCLE CRAMPS/

SORENESS	0	1	2	3
----------	---	---	---	---

---

CODE # \_\_\_\_\_

	NOT AT ALL	SLIGHTLY	MODERATELY	A GREAT DEAL
I am troubled by:				
4. ITCHING	0	1	2	3
<hr/>				
5. LENGTH OF TREATMENT	0	1	2	3
<hr/>				
6. STIFFENING OF JOINTS	0	1	2	3
<hr/>				
7. FEELING TIRED	0	1	2	3
<hr/>				
8. LOSS OF BODY FUNCTION	0	1	2	3
<hr/>				
9. DECREASE IN SOCIAL LIFE	0	1	2	3
<hr/>				
10. LIMITATION OF FOOD	0	1	2	3
<hr/>				
11. LIMITATION OF FLUID	0	1	2	3

CODE # \_\_\_\_\_

NOT AT ALL      SLIGHTLY      MODERATELY      A GREAT DEAL

I am troubled by:

## 12. INTERFERENCE

WITH JOB      0                      1                      2                      3

---

## 13. DECREASE IN

SEXUAL DRIVE 0                      1                      2                      3

---

## 14. LIMITATION OF PHYSICAL

ACTIVITY      0                      1                      2                      3

---

## 15. SLEEP DISTURBANCE

0                      1                      2                      3

---

## 16. CHANGES IN FAMILY RESPONSIBILITIES

0                      1                      2                      3

---

## 17. REVERSAL IN FAMILY ROLE

WITH SPOUSE 0                      1                      2                      3

---

## 18. REVERSAL IN FAMILY ROLE

WITH CHILDREN 0                      1                      2                      3

---

CODE # \_\_\_\_\_

	NOT AT ALL	SLIGHTLY	MODERATELY	A GREAT DEAL
19. UNCERTAINTY ABOUT				
FUTURE	0	1	2	3
<hr/>				
20. CHANGES IN BODY				
APPEARANCE	0	1	2	3
<hr/>				
21. LIMITED IN STYLES				
OF CLOTHING	0	1	2	3
<hr/>				
22. COST OF TREATMENT/TRANSPORTATION/OR				
OTHER COST FACTORS	0	1	2	3
<hr/>				
23. TRANSPORTATION TO AND FROM				
THE UNIT	0	1	2	3
<hr/>				
24. LIMITS ON TIME AND PLACE				
FOR VACATION	0	1	2	3
<hr/>				
25. FREQUENT HOSPITAL				
ADMISSIONS	0	1	2	3
<hr/>				
26. DIALYSIS MACHINE AND/OR				
EQUIPMENT	0	1	2	3

CODE # \_\_\_\_\_

NOT AT ALL      SLIGHTLY      MODERATELY      A GREAT DEAL

I am troubled by:

## 27. DEPENDENCY ON NURSES AND

TECHNICIANS	0	1	2	3
-------------	---	---	---	---

---

## 28. DEPENDENCY ON

PHYSICIANS	0	1	2	3
------------	---	---	---	---

---

## 29. FEAR OF BEING

ALONE	0	1	2	3
-------	---	---	---	---

---

## 30. FEELINGS RELATED TO TREATMENT

(example: FEELING COLD)

	0	1	2	3
--	---	---	---	---

---

## 31. BOREDOM

	0	1	2	3
--	---	---	---	---

---

## 32. DECREASED ABILITY TO

HAVE CHILDREN	0	1	2	3
---------------	---	---	---	---

---

OTHER _____	0	1	2	3
-------------	---	---	---	---

---

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## Questionnaire 3 A CODE # \_\_\_\_\_

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with friends. For each statement there are three possible answers: Yes, No, Don't know. Please circle the answers you choose for each item.

- |     |    |            |  |
|-----|----|------------|--|
| Yes | No | Don't know | 1. My friends give me the moral support I need.  |
| Yes | No | Don't know | 2. Most other people are closer to their friends than I am.                            |
| Yes | No | Don't know | 3. My friends enjoy hearing about what I think.  |
| Yes | No | Don't know | 4. Certain friends come to me when they have problems or need advice.                  |
| Yes | No | Don't know | 5. I rely on my friends for emotional support.   |
| Yes | No | Don't know | 6. If I felt that one or more of my friends were upset with me, I'd keep it to myself. |

CODE # \_\_\_\_\_

- |     |    |            |   |
|-----|----|------------|---|
| Yes | No | Don't know | 7. I feel that I 'm on the fringe in my circle of friends.                                      |
| Yes | No | Don't know | 8. There is a friend I could go to if I were just feeling down, without feeling funny about it. |
| Yes | No | Don't know | 9. My friends and I are very open about what we think about things.                             |
| Yes | No | Don't know | 10. My friends are sensitive to my personal needs.  |
| Yes | No | Don't know | 11. My friends come to me for emotional support.  |
| Yes | No | Don't know | 12. My friends are good at helping me solve problems.   |
| Yes | No | Don't know | 13. I have a deep sharing relationship with a number of friends.                                |
| Yes | No | Don't know | 14. My friends get good ideas about how to do things or make things from me.                    |

CODE # \_\_\_\_\_

- |     |    |            |     |   |
|-----|----|------------|-----|---|
| Yes | No | Don't know | 15. | When I confide in friends it makes me feel uncomfortable.   |
| Yes | No | Don't know | 16. | My friends seek me out for companionship.   |
| Yes | No | Don't know | 17. | I think that my friends feel that I'm good at helping them solve problems.                                  |
| Yes | No | Don't know | 18. | I don't have a relationship with a friend that is as intimate as other people's relationships with friends. |
| Yes | No | Don't know | 19. | I've recently gotten a good idea about how to do something from a friend.                                   |
| Yes | No | Don't know | 20. | I wish my friends were much different.  |

## Questionnaire 3 B CODE # \_\_\_\_\_

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with family. For each statement there are three possible answers: Yes, No, Don't know. Please circle the answer you choose for each item.

- |     |    |            |  |
|-----|----|------------|--|
| Yes | No | Don't know | 1. My family gives me the moral support I need.  |
| Yes | No | Don't know | 2. I get good ideas about how to do things or make things from my family.  |
| Yes | No | Don't know | 3. Most other people are closer to their family than I am.   |
| Yes | No | Don't know | 4. When I confide in the members of my family who are closest to me, I get the idea that it makes them feel uncomfortable. |
| Yes | No | Don't know | 5. My family enjoys hearing about what I think.  |

- |     |    |            |  |
|-----|----|------------|--|
| Yes | No | Don't know | 6. Members of my family share many of my interests.  |
| Yes | No | Don't know | 7. Certain members of my family come to me when they have problems or need advice.                                 |
| Yes | No | Don't know | 8. I rely on my family for emotional support.  |
| Yes | No | Don't know | 9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later. |
| Yes | No | Don't know | 10. My family and I are very open about what we think about things.  |
| Yes | No | Don't know | 11. My family is sensitive to my personal needs.   |
| Yes | No | Don't know | 12. Members of my family come to me for emotional support.   |
| Yes | No | Don't know | 13. Members of my family are good at helping me solve problems.  |

- | Yes | No | Don't know |  |
|-----|----|------------|--|
|     |    |            | 14. I have a deep sharing relationship with a number of members of my family.  |
|     |    |            | 15. Members of my family get good ideas about how to do things or make things from me.   |
|     |    |            | 16. When I confide in members of my family, it makes me feel uncomfortable.  |
|     |    |            | 17. Members of my family seek me out for companionship.  |
|     |    |            | 18. I think that my family feel that I'm good at helping them solve problems.  |
|     |    |            | 19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members. |
|     |    |            | 20. I wish my family were much different.  |



Does not apply or not used Used somewhat Used quite a bit Used a great deal	<b>WAYS OF COPING QUESTIONNAIRE</b>
11. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I hoped for a miracle.
12. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I went along with fate; sometimes I just have bad luck.
13. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I went on as if nothing had happened.
14. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I tried to keep my feelings to myself.
15. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I looked for the silver lining, so to speak; I tried to look on the bright side of things.
16. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I slept more than usual.
17. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I expressed anger to the person(s) who caused the problem.
18. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I accepted sympathy and understanding from someone.
19. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I told myself things that helped me feel better.
20. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I was inspired to do something creative about the problem.
21. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I tried to forget the whole thing.
22. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I got professional help.
23. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I changed or grew as a person.
24. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I waited to see what would happen before doing anything.
25. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I apologized or did something to make up.
26. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I made a plan of action and followed it.
27. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I accepted the next best thing to what I wanted.
28. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I let my feelings out somehow.
29. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I realized that I had brought the problem on myself.
30. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I came out of the experience better than when I went in.
31. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I talked to someone who could do something concrete about the problem.
32. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I tried to get away from it for a while by resting or taking a vacation.
33. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I tried to make myself feel better by eating, drinking, smoking, using drugs, or medications, etc.
34. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I took a big chance or did something very risky to solve the problem.
35. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I tried not to act too hastily or follow my first hunch.
36. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I found new faith.
37. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I maintained my pride and kept a stiff upper lip.
38. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I rediscovered what is important in life.
39. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I changed something so things would turn out all right.
40. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I generally avoided being with people.
41. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I didn't let it get to me; I refused to think too much about it.
42. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I asked advice from a relative or friend I respected.
43. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I kept others from knowing how bad things were.
44. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I made light of the situation; I refused to get too serious about it.
45. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I talked to someone about how I was feeling.
46. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I stood my ground and fought for what I wanted.
47. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I took it out on other people.
48. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I drew on my past experiences; I was in a similar situation before.
49. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I knew what had to be done, so I doubled my efforts to make things work.
50. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I refused to believe that it had happened.
51. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I promised myself that things would be different next time.
52. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I came up with a couple of different solutions to the problem.
53. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I accepted the situation, since nothing could be done.
54. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I tried to keep my feelings about the problem from interfering with other things.
55. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I wished that I could change what had happened or how I felt.
56. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I changed something about myself.
57. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I daydreamed or imagined a better time or place than the one I was in.
58. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I wished that the situation would go away or somehow be over with.
59. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I had fantasies or wishes about how things might turn out.
60. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I prayed.
61. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I prepared myself for the worst.
62. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I went over in my mind what I would say or do.
63. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I thought about how a person I admire would handle this situation and used that as a model.
64. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I tried to see things from the other person's point of view.
65. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I reminded myself how much worse things could be.
66. <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	I jogged or exercised.

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