

**A STUDY OF COMPLIANCE BEHAVIOR  
OF HEMODIALYSIS PATIENTS**

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## ABSTRACT

### A STUDY OF COMPLIANCE BEHAVIOR OF HEMODIALYSIS PATIENTS

This research project was designed to identify variables within the dialysis patients' ecological field associated with compliance behaviors. The import of this study lies in the fact that dialysis patients' health and levels of social functioning are affected by the degree to which they are able to comply with their prescribed medical and dietary regimen.

Five measures of compliance were selected as the dependent measures for this study. Serum phosphorous, serum potassium, and between dialysis weight gains constituted three objective measures. An Overall Objective Compliance Index was created by standardizing and summing the patient's scores on the three objective measures. The fifth dependent measure was based upon the patients' self-reports of their compliance. We found this measure to be the least reliable and negatively correlated with the objective measures. Independent variables were grouped into five domains, demographic, intra-personal, inter-personal, health delivery system and environmental factors.

A random sample of 60 patients was selected from the 131 patient population at the Brooklyn Kidney Center for this cross-sectional descriptive study. Fifty-five patients were interviewed and five patients refused to be interviewed. The interviewed sample was predominantly male (66%), Black (73%), with less than a high school

education (52%), had a mean age of 46 and had been on dialysis an average of four years. A structured interview format was utilized to collect data; information was also abstracted from a review of the medical charts. Each patient was interviewed while they were being dialyzed.

Less educated, married, female patients new to dialysis reported experiencing the greatest impact from renal failure and dialysis treatments. However, when we correlated the overall degree of impact of the illness with the five dependent measures, there were no statistically significant associations. In other words, while these patients experienced the greatest impact, there was no relationship between their subjective experience and the compliance measures.

The findings between the demographic characteristics and compliance measures indicate that some patients are at higher risk of experiencing social role disruptions. A demographic profile of the patients most at risk in being non-compliant shows that they were older males, with less education, of lower socio-economic status, unemployed, born in the New York City area and new to dialysis.

The patients' coping activities and the availability of a neighbor were the only independent variables which emerged as being associated with all four objective measures of compliance. Patients who tended to reach out to others and did not solely rely on themselves and who continued to think about the current crisis were more compliant with respect to all four objective measures. Patients who had a neighbor to call upon

when in need of help were also more compliant. Families that lacked organization, internal support, or tended toward either of the extremes of overinvolvement or disengagement from the patient appeared to increase the likelihood that the patients would have problems with compliance.

Patients with lower objective knowledge scores and who experienced barriers to following their medical and dietary instructions such as the lack of cash to purchase medications when needed, feeling depressed, being too busy, etc., were less compliant. Contrary to expectations, patients who reported higher levels of satisfaction with the dialysis staff and quality of care were also less compliant. This was attributed to the patients' use of denial and fear of staff's criticisms.

A recommended program for increasing dialysis patients' compliance levels is presented in which more reliance is placed on a comprehensive psychosocial evaluation and the initiation of family and group services. Future research projects are discussed noting the importance of utilizing longitudinal type designs.

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CHAPTER I  
INTRODUCTION

Social work's primary goal is to maximize the social functioning of individuals in society.<sup>1</sup> Physical health affects both potential for social functioning and one's actual level of functioning. Health, as defined by Parsons, is "the state of optimum capacity of an individual for the effective performance of the roles and tasks for which he has been socialized."<sup>2</sup> Illness and injury affect a person's health altering role performance for a duration of time. For some, this disruption of life is rather temporary, while for others the illness is chronic. Renal failure is one type of illness which permanently influences the health of an individual.

The levels of health and functioning of renal patients is further affected by their ability to adjust to dialysis treatments and the medical and dietary regimen. The focus of this research project is to identify variables associated with patients' compliance with their medical and dietary regimen.

As illustrative of some of the issues and problems encountered

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<sup>1</sup>Harriet M. Bartlett, The Common Base of Social Work Practice (National Association of Social Workers, 1970).

<sup>2</sup>Talcott Parsons, "Definitions of Health and Illness in the Light of American Values and Social Structure," Patients, Physicians, and Illness, ed. E.G. Jaco, New York: Free Press, 1958, p. 117.



by dialysis patients, let's look at three case examples.

Mr. A. is a thirty-seven year old Black, single, male, college graduate who has been on dialysis for five years. He had no warning of his renal failure as he awakened in the hospital following "passing out" from a hypertensive episode. After being unemployed for a period of six months during the acute phase of the illness and initial adjustment to dialysis, he returned to full-time employment as a teller in a bank. He is dialyzed three evenings a week. A major area of concern for him is trying to meet women and possibly establish an ongoing relationship. He is often afraid that he will be rejected when the woman finds out that he is a dialysis patient. As is the case for many dialysis patients, he is also concerned about his ability to function adequately sexually. His relationship with his family is a source of support. He is generally a cooperative patient on the unit except for periodic "blow-ups" with the staff because he has to wait for the patient on the earlier shift to finish with his machine. While he did not actively seek social work services, he did develop a relationship with his social worker and currently seeks her out during crisis periods. Mr. A. purports to not follow any special diet, yet his potassium and phosphorous levels and between dialysis weight gains are generally considered to be within the compliant range. It is very likely that over the years he has learned to eliminate certain harmful foods from his diet. He has on occasion stated that he "cheats" intelligently which means he will only eat foods off his diet on selected occasions and/or only in small quantities. In general, Mr. A. has made an excellent adjustment medically, emotionally, and socially to his illness and dialysis treatments. Mr. A.'s ability to comply with his medical and dietary regimen appears to enhance his overall health.

\* \* \* \* \*

Mr. M. did not make a good adjustment to his renal failure and dialysis regimen. He was a twenty-four year old white male who never married and had little contact with his family. Following graduation from high school, he had a sporadic history of employment and ceased working entirely after starting dialysis treatments. He was diagnosed as having

end stage renal disease, etiology unknown, possibly aggravated by heroin abuse. He had a history of drug and alcohol abuse which he continued after the onset of his illness and dialysis treatments. Mr. M. was angry and resentful at having renal failure, a quite common initial response, however, his anger continued unabated. Compliance with the medical and dietary regimen was an immediate problem for him although he denied being non-compliant. He frequently came to dialysis fluid overloaded with accompanying symptoms of shortness of breath and weakness. His blood chemistries indicated that he was not following his diet nor consistently taking prescribed medications. At times he would also miss his regularly scheduled dialysis treatments. While he interacted with some of the staff, he refused to cooperate with the social worker in completing an initial psycho-social evaluation and during subsequent contacts. He flatly refused to see a psychiatrist and denied any emotional or social problems. Due to his non-compliance, his medical condition worsened and he was hospitalized on several occasions. Eighteen months after starting dialysis he died.

\* \* \* \* \*

Ms. R. is a sixty-one year old Hispanic female who never graduated from high school and has been separated from her husband for a number of years. Her renal failure was a result of diabetes and she has been on dialysis for two and one-half years. She has a strong desire to live and is a very religious person. Her medical condition in general is not good. She has diabetes, hypertension, has had a stroke, is blind and must use a wheel chair. She has a strong supportive social network consisting of her three natural children and several foster children. Through her Church she is in contact with others and her religion is a source of emotional and spiritual support. While the patient's knowledge about her illness, dietary restrictions and medications is somewhat limited, she is a fairly compliant patient. When she is non-compliant it is usually with respect to her between dialysis weight gains and this seems to follow some type of personal crisis in her life. Her overall good compliance is probably a result of her wanting to be compliant coupled with the fact that her homemaker and family have an understanding of her medical and dietary regimen and usually prepare suitable meals for her. She has developed

excellent relationships with her social workers and utilizes them at difficult times. Parenthetically, one of the major problems in this specialized area of nephrology is the high turnover of staff, including social workers. Ms. R. has had four social workers in the past two years. In spite of Ms. R.'s serious medical problems, she has adjusted well to dialysis and is fairly compliant. Her good adjustment is probably a result of her motivation, strong religious beliefs, supportive social network, and the ability to rely upon and utilize the professional staff at the Center.

Chronic renal failure requires life adjustments in the areas of employment, family relationships, sexual behavior, income support, diet, self-image, and self-esteem.<sup>1-7</sup> While the degree of health is definitely altered by this on-going life health problem, the actual range of social functioning among patients is quite varied. Some patients function at very limited levels of social functioning, while others continue a fairly active life of employment, family

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<sup>1</sup>Sheila Joel and Susanne Wieder, "Factors Involved in Adaptation to the Stress of Hemodialysis," Smith College Studies in Social Work, 43:205, 1972-3.

<sup>2</sup>Diane Anger, "The Psychologic Stress of Chronic Renal Failure and Long Term Hemodialysis," Nursing Clinics of North America, Vol. 10, No. 3, September 1975;449-460.

<sup>3</sup>Franz Reichsman and Normal Levy, "Problems in Adaptation to Maintenance Hemodialysis," Archives of Internal Medicine, Vol. 130, December 1972,859-856.

<sup>4</sup>Irwin Greenberg et. al., "Factors of Adjustment in Chronic Hemodialysis Patients," Psychosomatics, Vol. 16, Oct./Nov., Dec. 1975;178-85.

<sup>5</sup>Elfi Friedman, et. al., "Psychosocial Adjustment to Maintenance Hemodialysis," New York State Journal of Medicine, March 1, 1970;629-637.

<sup>6</sup>Normal Levy, "Sexuality and the Hemodialysis Patient," Hospital Physician, October 1975, pp. 21-25.

<sup>7</sup>Denton Buchanan, et. al. "Psychological Adaptation to Hemodialysis," Dialysis and Transplantation, February/March 1976, pp. 36-42.

involvement, vacations, community work, participation in NAPHT (self-help group), physical activity, and so forth.

A patient's level of functioning is related to physical health, which in turn is influenced by the degree to which one is able to comply with the prescribed medical and dietary regimen. Compliance seems to be influenced by a variety of factors, e.g. patient's motivation, support from family, adequate medical advice, etc. While motivation or the "will power" to adjust to the medical and dietary regimen is difficult to measure, clinically the staff acknowledges its presence. Staff might comment that Mr. A. doesn't seem to want to live and that he will die prematurely but not for any specific medical reason. The staff will comment how the patient might have lived longer, but didn't seem to want to continue his existence on dialysis. Some studies have indicated that the rate of suicide (active and passive) for dialysis patients might be as high as 100 times that of the normal population.<sup>1</sup>

One needs a certain degree of motivation and energy to be able to make the multitude of required changes created by renal failure and the adjustment to the dialysis regimen. Not only is there the massive changes of diet and fluid restrictions but one needs to deal with the labyrinth of the medical system, the hospital, surgery, dialysis treatments, billing department, laboratory, transfer to another dialysis center, the medical team, and so forth.

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<sup>1</sup>H.S. Abram, G.L. Moore and F.R. Westervelt. "Suicidal Behavior in Chronic Dialysis Patients," American Journal of Psychiatry, 127:1199-1204, 1971.

Most patients want to survive and make a good adjustment to their medical and dietary regimen and continue to function socially, but they are often overwhelmed by all the changes in their lives. Social workers are a critical resource for dialysis patients helping them express their feelings about the multitude of changes being experienced, and assisting family members with their adjustments. A social worker can help the patient negotiate the medical system which can be overwhelming even when one is not very ill. Social workers can assist the staff in better understanding the psychological and social needs and emotional reactions of different patients. The role of the social worker on dialysis units is acknowledged and sanctioned by Federal Regulations which require at least one to be included as part of the renal patient's treatment team.<sup>1</sup>

Needless to say, the social work role is complex and difficult. Staff often initially see them exclusively as providers of concrete service as do many of the patients. When the social worker is fulfilling the legislated role of completing a psychosocial on every new patient, a few patients resist the process and sense it as an invasion of their privacy. They state that they have medical problems and should not be considered psychiatric cases. Gradually, the social worker is integrated into the health care team as a vital member whom patients and staff seek out for assistance with emotional problems and social concerns as well as concrete services.

The issue of patients' compliance with the medical and dietary

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<sup>1</sup>Federal Register, Vol. 43, No. 203, Thursday, October 19, 1978, p. 48591.

regimen is one which often initiates long and intense discussions among the health care team. Non-compliant patients are a constant concern for the staff as they worry about the effects of non-compliance on the patients' health and often feel inadequate in helping the patient become more compliant.

A goal of the health delivery system is to maximize the patient's level of compliance with the medical regimen, thus allowing for maximizing of social functioning. However, non-compliance with the medical regimen is a common phenomenon for numerous illnesses, e.g. hypertension,<sup>1</sup> streptococcal infections,<sup>2</sup> tuberculosis,<sup>3</sup> rheumatic fever,<sup>4</sup> myocardial infarction,<sup>5</sup> arthritis,<sup>6</sup> psychiatric disorders,<sup>7</sup> diabetes,<sup>8</sup>

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<sup>1</sup>David Sackett, et. al., "Randomized Clinical Trial of Strategies for Improving Medication Compliance in Primary Hypertension," The Lancet Saturday, May 31, 1975, pp. 1205-1208.

<sup>2</sup>J.A. Leistyna and J.C. Macaulay, "Therapy of Streptococcal Infections. Do Pediatric Patients Receive Prescribed Oral Medications," American Journal of Diseases of Children, 111:22-26, January 1966.

<sup>3</sup>M.J. Breite, "Urine Test for the Detection of PAS in Ambulatory Tuberculosis Patients," American Review Tuberculosis, 79:671, Nov. 1959.

<sup>4</sup>L. Gordis, et. al., "The Inaccuracy in Using Interviews to Estimate Patient Reliability in Taking Medications at Home," Medical Care. 7:49-54, January/February 1969.

<sup>5</sup>W.L. Johnson, "Conformity to Medical Recommendations in Coronary Heart Disease," Paper presented at American Sociological Association Chicago, Illinois September, 1965 (Mimeographed).

<sup>6</sup>C.R. Joyce, "Patient Cooperation and the Sensitivity of Clinical Trials," Journal of Chronic Diseases, 15:1025-1036. November 1962.

<sup>7</sup>R.S. Lipman, et. al. "Neurotics who Fail to Take Their Drugs," British Journal of Psychiatry, 111:1043-1049. November 1965.

<sup>8</sup>Julia Watkins, et. al., "Observation of Medication Errors Made by Diabetic Patients in Their Home," Diabetes, 16:229-230, March 1966.

ulcers,<sup>1</sup> and renal failure.<sup>2,3</sup> Davis<sup>4</sup> estimated that approximately 30 to 35 percent of patients fail to comply with the physicians' medical recommendations. It becomes apparent that the goal of maximum patient compliance is not being fully realized, and the patient is the one who ultimately suffers the consequences of non-compliant behavior. The question which arises and is apropos to this study is: Why are patients unable to comply with the medical regimen when that is what will benefit them most? While the question is not new, the answers have not been adequate, and non-compliance is still a frequent and not a well understood phenomenon. This research project is one of a number of studies which are attempting to develop a better understanding of renal patients' compliance and non-compliance with the prescribed medical and dietary regimen.

The author of this research project believes that in order to understand the complex phenomenon of compliance behavior, a comprehensive perspective, such as an ecological one, is needed. An ecological perspective helps us visualize the dialysis patient's

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<sup>1</sup>Harold Roth and David Berger, "Studies of Patient Cooperation in Ulcer Treatment," Gastroenterology, Vol. 38, No. 4, April 1960, pp. 630-634.

<sup>2</sup>Sue Blackburn, "Dietary Compliance of Chronic Hemodialysis Patients," Journal of the American Dietetic Association, Vol. 70, January 1977, pp. 31-37.

<sup>3</sup>A. Kaplan-DeNour and J.W. Czaczkes, "Personality Factors in Chronic Hemodialysis Patients Causing Noncompliance with Medical Regimen," Psychosomatic Medicine, Vol. 34, November 1972, pp.333-344.

<sup>4</sup>M.S. Davis, "Variations in Patients' Compliance with Doctors' Orders: Analysis of Congruence Between Survey Responses and Results of Empirical Investigations," Journal of Medical Education, 41:1037-1048, November 1966.

situation as influenced by a myriad of factors which are interdependent and related to compliance behavior. Because it is not a theory, an ecological perspective does not clarify how and why these parts are in interaction. Minahan<sup>1</sup> notes that "The perspective leads the social worker to identify and draw a map of such inter-connected parts as families, staff and the physical environment of societal institutions, community resources, workplaces, legislative bodies, housing conditions, and natural helping networks. The perspective forces a broad view." An ecological perspective served as a backdrop to our thinking by sensitizing us to the many areas which could contribute information regarding compliance behavior, and lead us to include less researched variables such as coping style and environmental factors among others.

Before presenting an overview of the Chapters, we want to explain that we generally organized them by the independent variables. The items and questions relating to the independent variables were categorized into five domains: demographic, intra-personal, inter-personal, health delivery system, and environmental factors. For this study five measures of patient compliance were selected. Phosphorous and potassium levels and between dialysis weight gains constituted three objective measures of compliance. We combined the patients' scores on these three variables in order to construct an overall objective measure of compliance which was the fourth dependent

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<sup>1</sup>Anne Minahan, "Theories and Perspective for Social Work," Social Work, Vol. 25, No. 6, November 1980, p. 435.



measure. The fifth compliance measure was the patients' self-reports of their compliance.

In Chapter Two we describe the history of dialysis, treatment options, and the different locations for dialysis treatments. The ecological perspective and the life model of social work practice are then discussed. The concept of compliance, the role of the social worker, and the significance of this study for social work is then presented. Chapter Three will review the literature on compliance and non-compliance, the psychosocial functioning of dialysis patients, and the relevant research studies on compliance behavior.

Chapter Four describes the methodology utilized in this study including the overall design, data sources, the structured interview questionnaire and main independent variables, sampling procedure, obstacles encountered and patient refusals. In Chapter Five, we operationally define the dependent measures of phosphorous and potassium levels, between dialysis weight gains, and the Overall Compliance Index. The utilization of the patients' self-reports of compliance as a dependent measure is also discussed. We also present our findings on the extent of non-compliance among the patients in this study.

Chapter Six presents the demographic characteristics of the patients interviewed for this study. Demographic variables constitute the first major group of independent variables that we analyzed in relation to compliance behavior. In Chapter Seven, we explore the extent of the impact of the illness on the patients' lives. Eleven specific aspects affected by the illness were categorized into

behavioral, affective, and relational areas. In the last section of this Chapter, we discuss the relationship between the impact of the illness and compliance.

The relationship between intra-personal variables and compliance behavior is presented in Chapter Eight. We discuss life crises and coping responses, patients' attitudes toward illness, cognitive understanding of the medical regimen, affective states and patient's self-esteem as these variables relate to compliance behavior. In Chapter Nine, we examine the domain of inter-personal variables focusing on the role of the family, friends and neighbors vis-à-vis patient compliance behavior. Chapter Ten combines the last two domains of the health delivery system and environmental factors. We discuss the patients' relationships with the staff, the degree of patient satisfaction, and the staff's provision of information. The association between environmental factors such as availability of proper dietary resources, status of neighborhood, housing, etc., and compliance behavior are presented.

In Chapter Eleven we seek to further understand the influence of selected variables on compliance behavior by the utilization of multiple regression analyses. We identify those variables which seem to explain the most variance with respect to each of the five dependent measures. In the concluding Chapter, we will discuss the overall implications for social work in a health setting as it relates to dialysis patients' compliance behavior. Ideas for future research projects on compliance will also be presented.

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CHAPTER II  
SOCIAL WORK AND DIALYSIS

In this Chapter, we describe the history of dialysis, the various options for treatment, and the different locations available for dialysis treatments. The ecological perspective and the life model of social work practice are also discussed. The role of the social worker and the significance of this study for social work will then follow.

History of Dialysis

The technical development of an artificial kidney began as early as 1914. However, it was not until the early 1940s that Dr. William Kolff built an artificial kidney which could be used for human beings.<sup>1</sup> During the 1950s patients could be treated on a short term intermittent basis for acute and temporary loss of kidney functioning. Cannulas (tubes) had to be surgically implanted into an artery and vein for each dialysis, and each cannula could only be used once, thus limiting the number of possible dialyses. In 1960, Dr. Belding Scribner and his colleagues at the University of Washington's School of Medicine in Seattle developed a semi-permanent apparatus which could be used as the cannula site. This apparatus was called an external shunt. Patients could now be maintained on dialysis on a continuing basis.

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<sup>1</sup>Renee Fox and Judith P. Swazey, The Courage to Fail (Chicago: University of Chicago Press, 1975).

The next major concern which arose was the decision about selecting patients for treatment. The number of individuals requiring treatment far outnumbered the number of artificial kidney machines available. Patient selection committees were developed and both medical and psychosocial input was utilized in the decision making process. Dr. Scribner<sup>1</sup> felt that the medical procedures would be relatively stabilized within a couple of years and that psychosocial factors would be the area that would need more attention and understanding if the patients were to effectively cope, adjust, and survive.

#### Treatment Options

There are various options for treatment available for individuals suffering from end stage renal disease. The first option available to the patient, albeit a controversial one, is no treatment at all. At the point where the kidneys no longer remove a sufficient portion of the toxins from the patient's system, the patient dies. The most common option chosen is hemodialysis. In this procedure, a fistula or external shunt (surgical connection of an artery and vein) is implanted usually in the arm. The individual then goes for dialysis treatments either two or three times a week for four or five hours per visit. Another option for treatment is peritoneal dialysis. In this procedure, an access (catheter) is surgically placed in the abdominal cavity so the dialysate (fluid) can be pumped into this area. The peritoneal sac then filters the impurities and toxins from the blood. A separate tube removes the dialysate and toxins from the body cavity. A fourth option

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<sup>1</sup>Ibid.

for treatment is a kidney transplant. A kidney from a blood related donor or from a cadaver is transplanted into the recipient. If the patient's body does not reject the kidney, the person resumes normal kidney functioning and a more normal way of life.

#### Location of Treatment

Along with determining the best medically feasible option for treatment, a decision for location of treatment is also made. The options include home dialysis, satellite centers, hospital located facilities, or inpatient medical settings. Home dialysis is a procedure where by a patient and usually a family member are trained to perform the dialysis treatment without professional assistance. After a training period of six to eight weeks, the patients perform the treatment at home with the assistance of their partners. This arrangement allows the most autonomy for the patients because they can select the dialysis time most convenient for them. Individuals who are not medically stable, or without an adequate family or living situation, are usually not considered for home dialysis. Because the patient does not have weekly contact with professional staff, there have been some problems with a lack of social services and other professional interventions and support for this group of patients.

Another location for treatment is a satellite center which is separate from a medical setting (hospital). Patients come to the center two or three times a week for treatment. They may be placed on self-care where they actively participate in the treatment process setting up their machines, taking their own blood pressure, and monitoring their own runs. Self-care allows the patients to maintain

more autonomy and control over their lives. The dialysis technicians and nurses are available to assist the patient, if needed. Other patients in the satellite center may be on a limited-care procedure whereby all the dialysis procedures are performed by the staff. These patients are medically, physically, or emotionally unable to be on self-care. The medical director's own biases are an important variable affecting the actual number of patients being placed on self-care.

Another location for treatment is a center within a hospital setting, with a ward or some other area being utilized. While there are often options for self-care or limited care, the hospital based units frequently handle a more medically unstable population. The number of patients on limited-care is usually greater than the number on self-care at hospital based units. One distinct advantage of a hospital based unit is that it has immediate access to the hospital's wide range of personnel and services. A major disadvantage is that it may encourage the patients to maintain more of a "patient role". Because many dialysis patients are medically stable, the multiple trips to a hospital based center may reinforce their self-perception of "sick", instead of a self-perception of a functioning individual with a medical problem.

The only other location for treatment is an inpatient unit of a hospital. The inpatient unit is the location where patients are usually first dialyzed when their kidneys cease to function adequately. After the patients are stabilized (after several dialyses), they are moved to either a satellite or hospital based center. Some patients are re-admitted to the inpatient unit for fistula revisions or other required medical operations.

### Ecological Perspective

Historically, social work has been aware of the influences of the environment on the patient, as well as the patient's reactions and responses to external and internal stimuli. Richmond,<sup>1</sup> in her book Social Diagnosis, outlined the many areas of the client's environment. She highlighted the importance of an exhaustive collection of data and information from areas such as school, employment, neighborhood, family, etc. However, her goal for intervention was to change the client's personality.

As social work models of practice (psychosocial, functional, etc.) developed, they tended to adopt a rather narrow, linear perspective. One such model is that of psychosocial therapy. While the overall perspective purports to encompass both the person and the environment, the vantage point is usually the person and how the person handles the environment. The genesis of problems are often attributed to early childhood experiences, thus the interventions need to be with the person and of a reconstructive therapeutic nature. This approach is linear in the sense it begins with focusing on the individual and then follows certain logical steps. For example, if a person meets a novel situation which he or she was unable to cope with, the focus of intervention would probably be the individual.

Historically, aside from group work, social work practice models had a tendency to view situations from a cause and effect perspective, i.e., a childhood experience or a personality conflict was perceived as the cause of the client's presenting problem. In these practice

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<sup>1</sup>Mary E. Richmond, Social Diagnosis (New York: Free Press, 1917).

models there tended to be a lack of mutuality in the client/worker relationship, as the worker assumed the role of expert. Assessment was a process of the client providing data in response to the worker's queries. Interventions were usually focused only on the individual.

In the 1950s and 1960s social work was influenced by burgeoning sources of new information and theories. Crisis intervention theory, family theory, systems theory, research into ecology, etc. were sources which impacted upon social work models of practice. Social work's viewpoints and perspectives were changing. Gordon<sup>1</sup> suggested that social work increase its attention at the interface between the person and the environment. Social work's focus of attention would then include the person, the environment, and the quantity and quality of the transactions and interactions between the person and the environment.

Ecology is the science concerned with the adaptive fit of organisms and their environments and with the means by which they achieve a dynamic equilibrium and mutuality.<sup>2</sup> Germain<sup>3</sup> utilized the concept of ecology as a metaphor in order to increase social work's awareness to the multifaceted aspects of the patient's ecological field, and the interactions within that system. An ecological perspective includes the entire situation which effects and is affected by the client system. For example, this perspective might include assessing the impact of the following variables on each other: client's psychic functioning,

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<sup>1</sup>William Gordon, "Basic Constructs for an Integrative and Generative Conception of Social Work," in The General Systems Approach: Contributions Toward an Holistic Conception of Social Work, ed. Gordon Hearn (New York: Council on Social Work Education, 1969), pp. 5-11.

<sup>2</sup>Carel Germain, "An Ecological Perspective on Social Casework," Social Casework, (June 1973), p. 325.

<sup>3</sup>Ibid.



physiological information, income, housing, the family, the extended family, significant others, neighborhood, employer, the agency, community, cultural background, etc. The ecological perspective is one which looks at these various components and how they interact with each other.<sup>1</sup>

A central component of an ecological perspective is the use of systems theory. Systems theory views a situation as comprised of various parts which interact to create a whole. Janchill notes that "all living organisms are open systems, which are characterized by an active exchange of energy with the environment."<sup>2</sup> Some basic concepts of systems theory are the ideas of energy, thruput, output, cycle of events, negative entropy, information, feedback, dynamic equilibrium, differentiation, boundaries and equifinality.<sup>3</sup> A problem, such as non-compliance, could be viewed as the product (output) of the interactions of a number of sub-systems (patient, staff, family, etc.), which is maintained in a state of dynamic equilibrium. Energy (e.g., new information) is required in order to affect this equilibrium and when one sub-system (e.g., the patient) is affected, there is some subsequent effect on the other sub-systems. Equifinality refers to the idea that one can introduce change at a number of different points within the system and this can have salutary results. Theoretically, increasing patient compliance could be a result of changes with the patient, a different approach from the staff, an increased involvement of the family and so forth.

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<sup>1</sup>Ibid.

<sup>2</sup>Mary P. (Sister) Janchill, "Systems Concepts in Casework Theory and Practice," Social Casework (February 1969), pp. 74-82.

<sup>3</sup>Ibid.

Drawing upon systems theory, an ecological perspective contains the concept of an adaptive "fit" between the person and their environment. Adaptation is an on-going process which includes behaviors, actions, and modifications in the various sub-systems (e.g., patient, family, staff) and their transactions which attempt to maintain an equilibrium. These components are dynamically intertwined into a functional system, so that as one aspect of the system changes, other components are also affected. The individual is equipped with defense mechanism, cognitive skills, reflexes, coping skills and abilities, which are some of the means by which he/she continues to adapt. Components of the environment are also capable of changing or being changed which allows for their adaptation. The interactions are the avenues by which the individual and environment are connected, relay information and reciprocally effectuate change.

Theoretically, the ecological perspective incorporates evaluating the strengths and weaknesses of the client, the environment, and their interactions. For this study, we found the ecological perspective helpful in sensitizing us to the multitude of variables which may influence compliance behavior. This perspective also assisted in highlighting certain variables for inclusion, e.g., coping activities, patients' perceptions and so forth. This perspective assumes the majority of the elements in the system have the capacity to be modified, i.e., be responsive to changes in other parts of the system. When the system is operating to the detriment of the components, modifications or interventions are necessary. A social worker who represents new information and energy for the system, could intervene at any number

of points within the ecological field. Hopefully, subsequent changes in the entire system would result.

### Life Model of Social Work Practice

Utilizing an ecological perspective Germain and Gitterman,<sup>1</sup> Maluccio,<sup>2</sup> and others are developing a life model approach to social work practice. Meyer<sup>3</sup> notes that a model of practice is like a roadmap, which helps guide and direct specific worker actions. We will briefly discuss the following aspects of a life model approach to practice: assessment, client/worker relationship, and the intervention process.

Assessment is the process of the client and worker focusing on and evaluating the client's ecological field. They attempt to determine what salient and relevant aspects are associated with the presenting problem. Salient aspects of the ecological field are those which thrust themselves forward with respect to the presenting problem.<sup>4</sup> For example, when a renal patient who does not comply with certain dietary requirements states that his wife prepares food in accordance with cultural customs, the role of the family and culture become salient areas for further exploration. Hamilton<sup>5</sup> introduced the concept of relevance, and suggested that certain areas be tapped selectively with respect to the presenting problem. Relevant issues are those which are akin to the

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<sup>1</sup>Carel Germain and Alex Gitterman, The Life Model of Social Work Practice (New York: Columbia University Press, 1980).

<sup>2</sup>Anthony Maluccio, "Action as a Tool in Casework Practice," Social Casework (January, 1974), pp. 30-36.

<sup>3</sup>Carol Meyer, "Practice Models--The New Ideology," Smith College Studies in Social Work, (February, 1973), pp. 85-98.

<sup>4</sup>Morris Schwartz and Charlotte Schwartz, Social Approaches to Mental Patient Care (New York: Columbia University Press, 1964).

<sup>5</sup>Gordon Hamilton, Theory and Practice of Social Case Work (2nd. ed. rev.) (New York: Columbia University Press, 1951).

presenting problem, but do not immediately thrust themselves forward. A relevant issue, in the above example, might be the availability of income in order to prepare two separate meals.

The assessment process is one which evaluates the client's ecological field for areas of strengths, as well as difficulties. The salient and relevant factors in respect to the individual, environment, and their interactions are explored in order to ascertain how the system is functioning. Coping skills and abilities are an important area of exploration because of their function in the individual's adaptation. Aspects of the environment are evaluated for their roles in maintaining the problem, as well as strengths and capacities for assisting in changing the problem. Areas of support and assistance are identified in the client's natural networks in order to decrease the client's dependency on professional networks, and to include the network in resolving the problem. How the person and environment interact are also assessed. Communication lines need to be open so that information is clearly and accurately relayed to the various components of the system. The degree of "fit" between the patient's coping patterns and the environment is also evaluated.

In a life model of practice the assessment procedure encourages the client to be actively involved in the process. The client/worker relationship is characterized by feelings of mutuality and reciprocity, thus each is viewed as having their own abilities and expertise. The worker does not assume a role of expert who has the solution to the problem. The client is viewed as an individual with resources who is seeking to adapt to a difficult situation or problem. The client/worker

relationship usually includes the idea of contracting. Contracting involves an overt statement of a mutually agreed upon purpose and specific achievable goals.<sup>1</sup> The contract incorporates the assignment of tasks for both the worker and the client. Tasks in this sense are the actions which need to be accomplished in order to begin to alleviate the presenting problem.<sup>2</sup> The assignment of appropriate tasks is based on an assessment of the individual's coping patterns, the present environmental conditions, and their transactions so that it is possible for the task to be successfully accomplished. Completion of a task would effectuate some change in the individual, environment, and/or transactional patterns.

The person, environment, and their interactions all have a role in the maintenance of dysfunction within the system resulting in the presenting problem. An ecological perspective and a life model approach allows for multiple points for intervention, as problems are viewed as having multiple causative factors. Interventions may be directed at the individual, environment, or their interactions, or any combination of these.

The individual might be assisted in increasing his coping skills in certain areas where the environmental demands are excessive. Components of the environment might be modified or assisted in changing. For example, a family's expectation of a renal patient may need to be

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<sup>1</sup>Brett Seabury, "The Contract: Uses, Abuses, and Limitations," in Social Work, Vol. 21, No. 1 (January 1976), pp. 16-23.

<sup>2</sup>Elliot Studt, "Social Work Theory and Implications for the Practice of Methods," Social Work Education Reporter, 16:22-24 (June 1968).

adjusted in order to better fit the patient's coping skills. The medical staff may have to change their usual procedure for assigning medications to certain elderly patients, because of the patients' memory lapses. Interventions can also be focused upon the interactions between components of the patient's ecological system. Modification of the doctor/patient or patient/family interactional patterns may be necessary. The manner in which the doctor informs the patient about certain medical restrictions may not "fit" the patient's coping style. For example, a lack of "fit" may be experienced between a very autonomous patient and an overly directive doctor.

#### Role of the Social Worker

Social workers are directly involved with the vast majority of patients receiving dialysis treatments. Federal legislation (HR-1, July 1, 1973) mandated that social workers become a formal component of the dialysis treatment team. The Federal Register states that the focus of social services in the dialysis center is "to provide services to patients and their families and to support and maximize the social functioning and adjustment of the patient."<sup>1</sup> The specific areas of social work responsibilities are also outlined. "The qualified social worker is responsible for conducting psychosocial evaluations, participating in team review of patient progress and recommending changes in treatment based on the patient's current psychosocial needs, providing casework and group work services to patients and their families in dealing with the special problems associated with ESRD (End Stage Renal

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<sup>1</sup>Federal Register, Vol. 41, No. 108, Thursday, June 3, 1976, p.22520.

Disease), and identifying community social agencies and other resources and assisting patients and families to utilize them."<sup>1</sup> While these goals and responsibilities for social workers are congruent with social work's philosophy, the task is monumental due to the magnitude of problems of each dialysis patient. In order to deal effectively with this challenging task, social workers need to develop a sound knowledge base about this client population and the clients' responses to their illness.

The onset of renal disease requires massive adjustments in numerous aspects of the patient's life. The social worker's primary objective is to assist patients in their adjustment to the illness, and to help maximize their levels of psychosocial functioning. The social worker's role includes providing direct assistance in the areas of finances, transportation, housing, education, rehabilitation, as well as addressing the emotional concerns of the patients and family members. Because the patient's condition is not static, the social worker needs to remain available to all patients on an on-going basis. The social worker in a dialysis center completes a psychosocial evaluation on every patient and attends staff meetings where patient treatment plans are discussed and developed. The Federal guidelines specify that short-term care plans be developed on a monthly basis by the multidisciplinary team which includes the social worker. A long-term care plan is formulated yearly by the multidisciplinary team in conjunction with the patient and the family.

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<sup>1</sup>Ibid, p. 22519.

In addition to providing direct casework and group work services to the patients and their families, the social worker has certain other functions within the dialysis center. The social worker assists the patient and family in their negotiating and maneuvering within the complex health delivery system and other bureaucratic structures. This assistance may consist of helping the patient to understand the various agency regulations, requests by the doctors, etc. Because patients are under a great deal of stress, they can become volatile and verbally abusive to staff members. The critical function of assisting staff members in their relationships with patients is another frequent task of the social worker. The social worker may also acquire the role of staff mediator. Ideally, when conflict occurs among disciplines and/or staff members, the social worker can help in clearly identifying the conflict and seeking possible resolutions.

The social worker in a dialysis center has the challenging task of providing direct and indirect services to large numbers of patients with multiple problems, lending professional expertise to other staff members, and dealing with their own emotional responses to a stressful situation. The social worker's situation is considerably complicated by size of caseload. The National Association of Patients on Hemodialysis and Transplantation (NAPHT), ..cited. statistics on professional caseloads. The average number of patients per social worker in a dialysis center is 42. If home patients are included in the patient load, then the number increases to 43 per professional.<sup>1</sup> At the

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<sup>1</sup>National Association of Patients on Hemodialysis and Transplantation News, ed. June Crowley, Great Neck, New York (February 1978), p. 21.



Brooklyn Kidney Center, site of this study, the ratio is a staggering 66 patients per social worker.

For social workers with large caseloads just assisting cooperative patients with their finances, housing, transportation, and emotional concerns is a time consuming task. At the same time the dialysis staff frequently relies on the social worker to help deal with patients who are not complying with their medical/dietary regimen. In any setting, patients labelled non-compliant are often the ones who occupy a sizeable proportion of professional staff time, sometimes with minimal changes in their non-compliant behavior. Because of the realistic time constraints imposed upon the social workers, they need as much information as possible about non-compliant behavior. More comprehensive information is the first step toward identifying optimum loci for interventions. If some of the more consistent contributory factors of non-compliance can be identified, then the social workers can initially begin exploration with the patient in those areas. With increased knowledge, hopefully, more effective and relevant social work interventions can be delivered to patients labelled non-compliant.

The issue of non-compliance is critical for social workers for several reasons. Non-compliance can result in a significant decrease in the patient's level of social functioning or even result in a patient's death. A patient's continuing non-compliance creates stress for a staff which can affect the staff's morale, and the staff often depends on the social worker to help the patient become more compliant.

The amount of knowledge and information about dialysis patients is rapidly increasing. Medical technology is continuously improving

the medical equipment and procedures for treating dialysis patients. The improved equipment allows for more rapid and efficient dialyses. However, no matter the level of technical sophistication, if the patient is not able to comply with the medical/dietary requirements, all can be for naught. The contributing factors of non-compliance are very complex and multifaceted, and not very well understood. The social work profession has a responsibility to respond to this situation by researching the issue of patient non-compliance, and by contributing to the knowledge base around compliance behavior. Research into patient non-compliance, from an ecological perspective, may assist practitioners by identifying common salient and relevant issues that are associated with non-compliant behavior.

#### Significance for Social Work

As previously noted social workers dealing with dialysis patients are confronted with a monumental task. If all aspects of the patient's ecological field were operating in synchrony, the social worker would still be extremely active in just providing the necessary services. However, the patient's ecological field is frequently not in equilibrium, in terms of the maximization of the patient's adjustment and social functioning. The disequilibrium is often manifested by the patient exhibiting non-compliant behavior. The non-compliance becomes a signal which usually evokes an increase in professional interventions. The professional staff and social worker intervene with the patient in order to decrease the non-compliant behavior. Frequently, the social worker and other staff do not have an adequate understanding of the

factors contributing to non-compliant behavior, thus their primary focus for intervention becomes the patient. If the non-compliance is a result of a combination of factors, then intervening with the patient only may not produce salutary results.

This research project is significant for social work because if salient and relevant factors related to non-compliance can be identified, this will increase our knowledge base. Secondly, with increased information, hopefully, more effective and relevant social work interventions could be implemented. Finally, there is an ever increasing population of chronic patients whose level of functioning will be affected by their response to illness. The number of hemodialysis patients is rapidly increasing. In 1979 there were 45,565 Americans on dialysis, an increase of 25 percent from 1978, and the cost was \$850.5 millions.<sup>1</sup> Chronic illness is currently the leading health problem in this country.<sup>2</sup> Research into the area of chronic renal disease is important to social work, because a better understanding of these patients' compliance behavior and adjustment will contribute relevant information about other chronic health problems.

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<sup>1</sup>End-Stage Renal Disease Second Annual Report to Congress,  
Department of Health and Human Services (FY 1980), p. 1.

<sup>2</sup>P. M. MacElveen, "Patient Outcome Success Related to Cooperation Among Patient, Partner, and Physician," Journal of the American Association of Nurses and Nephology Technicians, Vol. 2, No. 4, 1975, pp. 148-156.

CHAPTER III  
THEORETICAL CONSIDERATIONS AND  
RELATED LITERATURE

In this chapter, we discuss the theoretical concepts of health, illness behavior, adaptation, stress, coping, adjustment, the "sick role", and the "patient role". These are the concepts which provide a framework from which to understand and assess the phenomenon of compliance. We then discuss the psychosocial functioning of dialysis patients. Finally, we focus upon the concept of compliance, studies of compliance and non-compliance with the medical regimen, and the findings of relevant research projects of dialysis patients' compliance behavior.

Foundation Concepts

Parsons states that "somatic health is sociologically defined, as the state of optimum capacity for the effective performance of valued tasks."<sup>1</sup> End stage renal disease alters the health of the individual and affects role performance in many areas, e.g., employment, family, recreation, sexual functioning, etc. Each individual responds to these changes in different ways. Illness behavior is a term used by

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<sup>1</sup>Talcott Parsons, Patients, Physicians, and Illness, p. 110.

Mechanic to describe the study of attentiveness to pain and symptomatology, and the broader constellation of the person's responses and behavior vis-à-vis illness. He defines illness behavior as the "secondary psychological and social processes associated with the illness, as contrasted with the primary biological ones."<sup>1</sup> The specific responses to illness are influenced by the person's age, sex, race, religion, socio-economic status, and cultural variables. For example, Koos<sup>2</sup> found that members of the upper class were more likely than lower class persons to view themselves as sick and seek medical advice. Zborowski<sup>3</sup> noted ethnic differences in response to pain. Jewish and Italian patients tended to respond to pain in an emotional way, while Irish individuals used more denial and "Old Americans" were more stoical. Women report many more subjective symptoms than men and frequent hospitals and clinics more often. Mechanic<sup>4</sup> cautions us to be more critical of the apparent vast differences in illness behavior by sex. If type of illness is controlled, and objective measures of health versus subjective symptoms are introduced, then the vast differences between sexes are greatly diminished.

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<sup>1</sup>David Mechanic, "Response Factors in Illness: The Study of Illness Behavior, in E.G. Jaco, Patients, Physicians, and Illness, p. 129.

<sup>2</sup>E. Koos., The Health of Regionville: What the People Thought and Did About It (New York: Columbia University Press, 1954).

<sup>3</sup>M. Zborowski, "Cultural Components in Response to Pain," J. of Social Issues, 8:16-30, 1952.

<sup>4</sup>David Mechanic, "Sex, Illness, Illness Behavior, and the Use of Health Services," Journal of Human Stress (December 1976), pp. 29-40.

Illness can also be examined in terms of the individual's adaptation to the changes created by becoming ill. White<sup>1</sup> sees adaptation as the overall concept which includes mastery, coping, and defense. We see adaptation as an on-going process which includes any behaviors or actions which facilitate the mutual "fit" between the individual and the environment. Stress affects the degree of mutual "fit" between the individual and the environment, and illness is one type of stress. Mechanic defines stress as "a complex set of changing conditions that have a history and a future, and not as a short-term stimulus."<sup>2</sup> The vast repertoire of behavior which is evoked by the stressful situation of illness can be viewed as an attempt by the individual to cope with the situation. Coping is the individual's attempts to deal with a difficult situation which cannot be handled by reflexes or organized skills alone.<sup>3</sup> The individual is striving to arrive at an optimal level of adjustment which is seen as the "goodness of fit between the person and the environment."<sup>4</sup> The range of adjustment is from no adjustment (death in the case of renal patients), to maximum adjustment with renal patients fulfilling their normal roles and tasks within the boundaries imposed by their physiological condition.

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<sup>1</sup>Robert White, "Strategies of Adaptation: An Attempt to Systematic Description," in G.V. Coelho (ed.) Coping and Adaptation (New York: Basic Books, 1947), p. 47.

<sup>2</sup>David Mechanic, "Social Structure and Personal Adaptation: Some Neglected Dimensions," in Coelho, Coping and Adaptation, p. 35.

<sup>3</sup>Lois Murphy, "Coping, Vulnerability, and Resilience in Childhood," in Coelho, Coping and Adaptation, p. 71.

<sup>4</sup>John French, "Adjustment as Person-Environment Fit," in Coelho, Coping and Adaptation, p. 316.

End stage renal disease is a stressful illness which requires patients to cope with many changes. The on-going adaptation to the illness includes attempts to maximize adjustment and levels of social functioning. In an effort to help the patient cope and adjust with illness, social roles which facilitate the adaptational process have evolved. The "sick role" is a socially institutionalized role which has several characteristics. Parsons<sup>1</sup> outlines these characteristics as: 1) the person cannot be held responsible for the illness; 2) the illness is a legitimate exemption from regular role and task obligations; 3) the person is obligated to "get well" and cooperate with others to this end; 4) the person and family are obligated to seek competent help and assistance in dealing with the illness. The idea of the "sick role" is to facilitate reciprocity between the individual and society's health networks, thus maximizing the adjustment and rehabilitation process.

Mechanic<sup>2</sup> states that the person adopts the "patient role" which is an extension of the "sick role". The "patient role" is a further clarification of the expectations associated with the institutionalized "sick role". Specific expectations are apparent for different illnesses. For example, a pregnant woman is expected to have periodic obstetric visits, not use certain drugs, etc. A patient with schizophrenia is

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<sup>1</sup>Parsons, Patients, Physicians, and Illness, p. 117.

<sup>2</sup>Mechanic, Patients, Physicians, and Illness, p. 134.

expected to participate in therapy, take prescribed medications, etc. A renal patient is expected to be dialyzed several times a week, adhere to a strict diet, follow the medical regimen, and so forth.

The "sick role" and "patient role" are terms originally developed by Parsons in his work on acute illnesses. Kassenbaum<sup>1</sup> notes that the definitions need some modifications in order to be applicable to chronic illness. The "sick role" as it applies to chronic illness has three characteristics: 1) it is not a temporary condition, but a permanent one; 2) the incapacity to perform roles is more often partial than a total incapacitation; 3) in temporary illnesses the "sick role" is dominant for the duration of the illness, but this is less so with the chronic patient. End stage renal patients are a good example of the last point. Patients are reminded of their "patient role" numerous times each week, e.g., whenever they want to eat or drink; while they are receiving dialysis; when they feel fatigued, etc. However, there are also numerous times when they are not in the "patient role", e.g., when at work, school, involved in recreation, socializing, etc. Therefore, renal patients have some latitude in the degree to which the "patient role" is the dominant role. Of course, the extent to which the "patient role" is the dominant one for renal patients is determined by a combination of factors including the patient's physical condition, personality, the family's views and needs, the professional health staff's actions, and the behavior of significant others towards the patient.

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<sup>1</sup>Gene Kassenbaum and Barbara Baumann, "Dimensions of the Sick Role in Chronic Illness," in Jaco, Patients, Physicians, and Illness, p. 143.



The person encountering end stage renal disease moves from the social position of health to the institutionalized "sick role". This stressful event of renal illness requires the person to mobilize resources to cope with the situation. The level of adjustment is dependent upon the severity of the illness and upon the degree to which the patient is able to conform to the "patient role". The "patient role" includes the expectation that the patient cooperate with the health professionals and comply with the medical and dietary regimen. The compliant, cooperative patient is in the best position to maximize social functioning and resume social roles. The non-compliant renal patient's physical condition can quickly deteriorate blocking the resumption of social roles and task performance, and ultimately, can result in death. However, the patient, environment, and transactions need to "fit" in order for the patient to be able to optimally comply with the medical/dietary regimen.

#### Psychosocial Functioning

As previously noted, renal disease affects many aspects of the patient's life and creates numerous stresses. Anger<sup>1</sup> identifies the following as stresses encountered by the dialysis patient: 1) dealing with the fact that one has a fatal disease; 2) acceptance of a dialysis regimen and program; 3) physical and emotional changes due to uremia, specifically, lethargy, apathy, weakness; 4) threats to financial security and frequently an actual decrease in income; 5) conflict

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<sup>1</sup>Anger, op. cit.

over independence and dependence, particularly the dependence on a machine for survival; 6) frustration of basic drives, food, water, sex. (All dialysis patients are on restricted diets and limited water intake and Levy<sup>1</sup> notes that over seventy percent of dialysis patients have sexual problems.); 7) changes in family relationships, such as role reversal, if the patient had been the breadwinner; 8) threat of injury, such as the concern that the fistula or shunt may become clotted, or the dialyzer may rupture; 9) fear of death - Walser notes "the Machine is always a constant reminder of the fragility of his life."<sup>2</sup> When other patients at the center die, the patient is again reminded of his or her own situation.

Anger<sup>3</sup> states there are several common emotional responses to the above stresses. One emotional response is the feeling of rebellion. Probably the most common feeling is depression. Other emotional responses include feelings of helplessness and hopelessness. In an attempt to deal with these feelings, the patients utilize different defense mechanisms. De-Nour et al.<sup>4</sup> found the patient's main defense mechanisms to be denial, displacement, isolation, projection, and reaction formation. Glassman<sup>5</sup> and Short<sup>6</sup> found denial to be the predominant defense

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<sup>1</sup>Levy, op. cit.

<sup>2</sup>Dianne Walser, "Behavioral Effects on Dialysis," Canadian Nurse, 70:23-25 May 1974.

<sup>3</sup>Anger, op. cit.

<sup>4</sup>A.K. De-Nour, et al. "Emotional Reactions of Patients on Chronic Hemodialysis," Psychosomatic Medicine, 30:521-33, 1968.

<sup>5</sup>Barry Glassman, and Allen Siegal, "Personality Correlates of Survival in a Long Term Hemodialysis Programme," Archives of General Psychiatry, Vol. 22 (June, 1970), pp. 566-574.

<sup>6</sup>M.J. Short and W. P. Wilson, "Roles of Denial in Chronic Hemodialysis," Archives of General Psychiatry, 20:433-37, 1969.

mechanism. While the use of denial allows for anxiety to be controlled, it also can block the patient from accepting the 'patient role' and can affect compliance.

According to Levy,<sup>1</sup> the patient usually progresses through several stages. The first stage is the Honeymoon Period marked by feelings of confidence and hope. This period lasts from six weeks to six months. The second stage is the Disenchantment or Discouragement Period which is characterized by sadness, hopelessness, depression, and helplessness. The final stage is the Long Term Adaptation where the patient accepts his disease and limitations. Of course all patients do not complete all the stages, nor progress at the same rate.

In terms of the long term adaptation, Friedman<sup>2</sup> discusses the psychosocial adjustment of hemodialysis patients. We found his results reflective of other studies on the levels of psychosocial adjustment of dialysis patients. The patients (N=20) in this study averaged 27.9 days of hospitalization during a one year period. Based on a five day week, 31 percent of the patients' time was consumed by dialysis or dialysis related activities. The group as a whole had a reduced income due to the illness. Patients who worked had shorter work weeks. Social relationships were frequently disrupted because of the patients' reversal of normal diurnal sleep patterns. The staff

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<sup>1</sup>N.B. Levy, "The Psychology and Care of the Maintenance Hemodialysis Patient," Heart and Lung, 2:400-405 May/June, 1973.

<sup>2</sup>Friedman, op. cit.

felt that close to 75 percent of the patients rarely or never followed their physicians' advice about their diet. In another study, De-Nour<sup>1</sup> established that rehabilitation of dialysis patients is generally poor, with only about one third working full time.

Family support is another important factor. Friedman<sup>2</sup> notes that family members suffer from periodic depressions, but the stress of dialysis often creates a closer relationship between spouses. He also found that unmarried young adults have considerable difficulty because of their restricted social life. Foster<sup>3</sup> found that 79 percent of surviving patients had established and maintained a nuclear family, whereas only 42 percent of non-survivors had a nuclear family.

In summary, the psychosocial functioning of dialysis patients is significantly affected by the onset of renal disease. The patients are faced with many changes and stresses that require major adjustments in their life styles. However, the actual level of psychosocial functioning is highly related to the degree to which the patient accepts the "patient role" and is able to comply with the medical regimen. Because this illness has numerous repercussions on the family, the family's relationship with the patient is of paramount importance. The family is an important element in helping the patient accept and adjust to the "patient role". The family needs to be flexible in order

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<sup>1</sup>A.K. De-Nour and J.W. Czaczkes, "The Influence of Patients' Personality on Adjustment of Chronic Dialysis," Journal of Nervous and Mental Disease, 162:323, 1976.

<sup>2</sup>F.G. Foster, et al., "Psychobiologic Factors and Individual Survival on Chronic Renal Hemodialysis - A Two Year Study Follow-Up Part I," Psychosomatic Medicine, 35:64, 1973.

to adjust to the changing demands of the illness, and in relation to the level of the patient's capabilities to function. The family plays an important role in assisting the patient to maintain autonomy, independence, and a positive self-image.

### Concept of Compliance

Parsons<sup>1</sup> notes that the patient is obligated to seek competent medical supervision, and to cooperate with his physician in order to expedite his recovery. According to Marston,<sup>2</sup> compliance becomes a normative expectation that the patient will cooperate and comply with the medical recommendations. Davis<sup>3</sup> states that compliance can be said to exist when the patient carries out his doctor's orders with regard to the medical regimen. Webster's New World Dictionary<sup>4</sup> defines compliance as "giving in to a request, wish, demand, or acting in accordance with a request, order, rule, etc." These definitions of compliance seem to place the onus on the patient, and do not consider the validity of the request, nor the quality of the transaction between the patient and health delivery system, or other factors in the environment. Compliance needs to be viewed as a more complex phenomenon than the patient giving into a request, or following the doctor's orders.

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<sup>1</sup>Parsons, Patients, Physicians, and Illness.

<sup>2</sup>Mary-Vesta Marston, "Compliance with Medical Regimens: A Review of the Literature," Nursing Research, Vol. 19, No. 4 (Jul/Aug 1970), pp. 312-323.

<sup>3</sup>M.S. Davis, "Predicting Non-Compliant Behavior," Journal of Health and Social Behavior, Vol. 8 (December 1967), pp. 265-272

<sup>4</sup>Webster's New World Dictionary of the American Language, Second Ed. 1970, p. 290.

Compliance can be viewed from an ecological framework which includes the patient, patient's environment (family, friends, employer, housing, income, etc.), the health delivery system, and the interactions between these various elements. Compliance can be viewed as a good "fit" between the different components of the ecological field. The good "fit" in the ecological system enables the patient to be able to successfully adapt to the "patient role", which facilitates compliance behavior and maximum health. Compliance behavior occurs when the patient's coping skills and behaviors are adequately matched with the environmental stresses and resources, and the interactions between the patient and environment facilitate this match.

Non-compliance can be seen as the lack of a good "fit" and a breakdown in the degree of cooperation within the ecological system, which results in decreased benefits for the participants. Non-compliance could be caused by a lack of "fit" among a number of factors in the patient's ecological field, e.g., the patient's personality, actions or coping skills, some part of the patient's environment, an unreasonable request by the health delivery system, faulty interactions between the health delivery system and the patient, etc. Non-compliance reflects that the components in the patient's ecological field are not operating in harmony, or do not adequately "fit" together.

The following are examples of what might be considered non-compliance or the result of an inadequate "fit". A patient who is depressed and attempts to cope by eating or drinking binges, is continuously confronted by the staff for excessive between-dialysis weight gains (non-compliance). The staff's confrontation with this

patient tends to evoke guilt which exacerbates the patient's feelings of worthlessness and seems to increase the depression. There is a lack of "fit" between the staff's method of handling the patient and the patient's present mental status. With another patient, the staff's confrontation might result in a better "fit" and greater compliance. Another example of a lack of "fit" is a discrepancy between the physician's goals and the patient's means. The physician may prescribe a number of necessary medications, but the patient is unable to afford all of them. The patient decides to take the medication but not at the required daily rate. The patient's behavior can be labelled as non-compliant, but the non-compliance can be more accurately described as the lack of "fit" between two components of the patient's ecological field.

In terms of this study, renal patients' compliance would be reflected by a good "fit" between the patient, patient's environment, health delivery system, and their interactions, vis-à-vis the prescribed medical/dietary regimen. Ideally, the patient has, or is developing the necessary coping skills which would allow for the maximum adaptation. Also the environment would be responsive to the patient's needs and coping style providing nutritive and supportive elements.

If the patient's ecological field is operating in synchrony, compliance behavior should be the outcome. Compliance behavior would include the patient taking the prescribed medications, following the diet, dialyzing a certain number of times per week, keeping appointments (medical, dietary, social service, etc.), and actively participating in fully understanding and assisting in their own treatment. The

specific means for the measurement of compliance behavior for this study will be discussed in Chapter V.

#### Compliance with the Medical Regimen

We will review a number of studies which have examined the issue of compliance for different types of illnesses. Compliance has been measured a number of ways such as pill counts,<sup>1</sup> urine tests,<sup>2</sup> patient report,<sup>3</sup> and observation of the patients.<sup>4</sup> A multitude of factors have been examined to see what their relationship is with compliance behavior. Marston,<sup>5</sup> in a review of the literature on medical compliance, found that the demographic variables of age, sex, socio-economic status, religion, marital status, and race did not appear to be consistently associated with compliance. She found mixed reports on the effects of education. Education had either no association with compliance, or as education increased so did non-compliance. In another study, De-Nour<sup>6</sup> found that as education increased so did dietary compliance and level of functioning. In general, specific demographic variables that consistently affect compliance have not yet been identified.

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<sup>1</sup>A.B. Bergman and R.J. Werner, "Failure of Children to Receive Penicillin by Mouth," New England Journal of Medicine, 268:1334-1338, (June 13, 1963).

<sup>2</sup>W. Fox, "Problem of Self-administration of Drugs: With Particular Reference to Pulmonary Tuberculosis," Tuberculosis, 39:269-274 (Oct. 1958).

<sup>3</sup>Elizabeth Neely and Maxine Patrick, "Problems of Aged Persons Taking Medications at Home," Nursing Research, 17:52-55, Jan-Feb. 1968.

<sup>4</sup>Julia Watkins, et al. "Observations of Medication Errors Made By Diabetic Patients in the Home," Diabetes, 16:229-230, (March 1966).

<sup>5</sup>Marston, Nursing Research.

<sup>6</sup>A.K. De-Nour, and J.W. Czaczkes, "Adjustment to Chronic Hemodialysis," Israel Journal of Medical Science, Vol. 10, No. 5 (May 1974), p. 498.



Davis<sup>1</sup> and Francis<sup>2</sup> established an association between the complexity of the medical regimen and non-compliance. As the number of medications increased and the number of instructions for taking the medications increased, the degree of compliance decreased. Johnson<sup>3</sup> determined that recommendations regarding diet showed the greatest decrease in level of compliance over time.

The patient's relationship with the physician has also been examined. Davis<sup>4</sup> established that the patterns of communication between the patient and doctor accounted for some of the non-compliance. If doctors seek information from the patient without providing feedback, the patient is less likely to follow the doctor's orders.

Sackett<sup>5</sup> determined that convenience of follow-up care and mastery of factual information about the illness were not associated with increased compliance. Factors such as locus of control, and patient's intelligence have also been studied. Attempts have been made to examine the patient's orientation toward control and compliance behavior.<sup>6</sup> There has not been any clear indication that a patient's

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<sup>1</sup>M.S. Davis, "Physiologic, Psychological and Demographic Factors in Patient Compliance with Doctor's Orders," Medical Care, 6:115 (Mar/Apr 1968).

<sup>2</sup>Vida Francis, et al., "Gaps in Doctor-Patient Communication: Patients' Response to Medical Advice," New England Journal of Medicine, 280:535-540 (March 6, 1969).

<sup>3</sup>W. L. Johnson, Conformity to Medical Recommendations in Coronary Disease

<sup>4</sup>M.S. Davis, "Variations in Patient's Compliance with Doctor's Advice: An Empirical Analysis of Patterns of Communication," American J. Public Health, 58:274-288 (Feb. 1968).

<sup>5</sup>Sackett, op. cit.

<sup>6</sup>Marston, op. cit.

score on the Rotter Internal/External Scale is correlated with compliance to the medical regimen. In terms of intelligence, Sand<sup>1</sup> found that higher intelligence quotients were associated with better cooperation and emotional adjustment. Winokur<sup>2</sup> found no relationship between intelligence and compliance. Borkman<sup>3</sup> found intelligence not related to dietary compliance but that it was a help in rehabilitation efforts.

The influence of the family has also been studied. The relationship between the family and the patient seems to have some influence on compliance behavior. Elling<sup>4</sup> established an association between family discord and non-compliance. Family cohesiveness during crises was associated with increased levels of compliance (Eichhorn).<sup>5</sup> McDonald<sup>6</sup> found the family and family relationships to have an impact upon the follow-up care for patients with rheumatic fever. They determined that illness of other family members negatively influenced the patients' follow-up. Good interpersonal family relationships were associated with good cooperation, whereas interpersonal conflict produced poorer cooperation.

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<sup>1</sup>P. Sand, et al., "Psychological Assessment of Candidates for Hemodialysis Program," Annual Internal Medicine, 64:602-610, 1966).

<sup>2</sup>M.Z. Winokur et al., "Intelligence and Adjustment to Chronic Hemodialysis," J. Psychosomatic Research, 17:29-34, 1973.

<sup>3</sup>T. Borkman, "Patient Compliance with Hemodialysis Regimen: Study Relating Selected Factors to Patient Compliance," (Unpublished report, 1969).

<sup>4</sup>Ray Elling, et al., "Patient Participation in a Pediatric Program," Journal Health and Human Behavior, 1:183-191 (Fall 1960).

<sup>5</sup>R.L. Eichhorn, et al., "Compliance to Perceived Therapeutic Advice," Proceedings of the Purdue Farm Cardiac Seminar, W.H. Morris (ed.) Lafayette, Ind.: Agricultural Experiment Station, September 1958.

<sup>6</sup>Mary E. MacDonald, et al., "Social Factors in Relation to Participation in Follow-up Care of Rheumatic Fever," The Journal of Pediatrics, Vol. 62, No. 4 (April 1963), pp. 503-513.

There does not seem to be much research on therapeutic interventions and their effects on compliance behavior. In one study, Sackett<sup>1</sup> randomly assigned hypertensive individuals to an experimental group which received instruction on hypertension and treatment. The results indicated that the experimental group far exceeded the control group on knowledge about hypertension and its treatment, but their level of compliance (taking medications) did not improve.

#### Dialysis Patients' Compliance

There have been several studies which examined the compliance behavior of renal patients. Blackburn<sup>2</sup> studied the levels of compliance by measuring the patients' chemistries (potassium and phosphorous), and the between dialysis weight gains. These measures are reflective of the degree to which the patient is following prescribed dietary and medical regimens. Blackburn established that women were more compliant in reference to potassium intake. Length of time on dialysis was a variable related to compliance. The longer patients had been on dialysis, the less they were potassium and phosphorous compliant. Weight gain was negatively correlated with education. As education increased, the patients' weight gain compliance decreased.

De-Nour and Czaczkas<sup>3</sup> examined the relationship of personality factors and the patient's compliance with the medical regimen (diet). The authors found that patients with low frustration tolerance were

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<sup>1</sup>Sackett, op.cit.

<sup>2</sup>Blackburn, op. cit.

<sup>3</sup>De-Nour, J. of Nervous and Mental Disease

less compliant, as were those patients who received primary and secondary gains from their illness. A primary gain was the relief from a basic conflict, e.g., independence-dependence conflict. Secondary gain would be the benefits derived from some lessening of role or task obligations, change in source of income, decreased work responsibilities, etc. In terms of compliance, the authors determined that about 25 percent of the patients were rated as good, whereas 40 percent were classified as poor compliers. The more depressed the patient, the greater the non-compliance with the medical regimen. However, in another study, De-Nour<sup>1</sup> found that anxiety and/or depression did not influence compliance.

Hartman and Becker<sup>2</sup> utilized their Health Belief Model's formulations when examining the issue of dialysis patients' compliance with the prescribed medical and dietary regimen. They postulated that compliance behavior is influenced by several subjective dimensions, such as motivation, perceived susceptibility, severity, benefits and barriers. Their findings indicated that patients who worried less about the consequences of non-compliant behavior were the more compliant ones but patients who perceived the sequelae of non-compliance as severe were also compliant. Compliant patients perceived the benefits from adhering to the regimen as greater than the non-compliant

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<sup>1</sup>De-Nour, Israel J. Medical Science

<sup>2</sup>Paula Hartman and Marshall Becker, "Non-Compliance with Prescribed Regimen Among Dialysis Patients," Dialysis and Transplantation, Vol. 7, No. 10 (October 1978), pp. 978-989.

patients. In terms of barriers, Hartman and Becker found mixed findings, e.g., some compliant patients stated they found the medication instructions more complicated than the non-compliant patients.

In summary, a number of variables have been examined in an attempt to better understand compliance with the medical regimen. In general, demographic variables such as sex, age, race, religion, marital status, socio-economic status and education have not been shown to be consistently associated with compliance. Convenience of follow-up care, increased medical information, intelligence, and locus of control are other researched variables for which there are mixed findings regarding compliance. The lack of more consistent findings may reflect the diversity of demographic characteristics between studies coupled with different types of methods used and differences due to the diversity of illnesses studied.

A positive relationship with the doctor seems to be related to compliance. Other variables which seem to emerge as more consistently related to compliance are: length of time on dialysis, the complexity of the medical regimen, the degree of depression, the level of frustration tolerance, perceived severity and degree of concern regarding consequences of non-compliant behavior, and family discord.

From this review of the literature, the author's clinical observations and interactions with dialysis patients and discussions with staff, we developed questions which would, hopefully, identify variables associated with dialysis patients' compliance and non-compliance with their prescribed medical and dietary regimen. We decided to group the questions into five domains: 1) demographic,

2) intra-personal (emotion, cognition, belief), 3) inter-personal (family, friends, etc.), 4) health delivery system (relationship with staff, provision of information, etc.), and 5) environmental factors such as housing, neighborhood, ability to afford medications and so forth. This study replicates aspects of other studies in terms of measuring demographic variables, certain intra-personal and inter-personal variables, and the patient's cognitive sphere. The ecological perspective offers the vantage point of viewing these different areas in a more holistic manner. This perspective helped us include less researched aspects of the patients' ecological field such as coping activities and environmental factors.

## CHAPTER IV

### METHODOLOGY

In this chapter we discuss the design of this study and the sources utilized for data collection. Pre-test method, sampling, and the data collection procedures will be explained as will the setting for the interviews, obstacles encountered, confidentiality, and patient refusals. We conclude the chapter with a presentation of the data analysis procedures.

As previously mentioned, the research topic of compliance behavior emerged from this writer's participation in interdisciplinary staff meetings at the Brooklyn Kidney Center. Non-compliant patients continually presented multiple management problems to the staff yet there seemed to be a dearth of information on why they were non-compliant and even fewer ideas on how to increase their compliance.

Intense discussions with various staff members helped initially identify some potential factors that might be related to compliance. After reviewing the literature on compliance studies, we initially identified five major domains of the patients' ecological field as likely sources of influence upon the compliance behavior of patients. These five domains were demographic, intra-personal, interpersonal, health delivery system, and environmental factors.

### Design

The general format of this study is descriptive with data collection on a one-time only survey basis. We felt a cross-sectional approach best suited the purpose of this study which was to begin to identify variables associated with dialysis patients' compliance behavior. The utilization of a cross-sectional approach to understanding compliance behavior allowed us to collect data in a variety of areas; demographic, intra-personal, inter-personal, health delivery system, and environmental. This approach provided data which could be used to explore the sources of influence upon patients' compliance with the prescribed medical and dietary regimen. This cross-sectional approach did not answer the question of the stability of these associations. However, a longitudinal study of compliance behavior was not feasible due to financial constraints and time limitations.

A. sample size of fifty-five allowed us to examine a number of different sub-groups with individuals ranging from very compliant to very non-compliant. We also examined sub-groups which were differentiated by age, sex, race, and length of illness among others. The patients' responses to the items on the different scales further differentiated certain groupings.

### Data Sources

Sources utilized for data collection included the patient, the staff, the nursing card index, and the medical chart. We decided to use a structured interview schedule as the main instrument for data collection in securing information from the patient. This instrument contained forced-choice questions and open-ended questions in order to explore the patients'



ideas more fully. Two standardized scales were also utilized. One scale, was the Profile of Mood States,<sup>1</sup> which was utilized to measure the patient's feeling state during the week which preceded the interview. The second standardized scale used was Rosenberg's Self-Esteem scale,<sup>2</sup> a ten question scale that measures the self- acceptance aspect of self-esteem. The medical charts and nursing card index provided information on the patients' medical condition, some demographic information, and information on the monthly blood chemistries and inter-dialytic weight gains. The blood chemistries and between dialysis weight gains are the major dependent measures for this study. If discrepancies emerged within the various sources of data, we then consulted selected staff, e.g., primary nurse, social worker, and/or the patient, in order to obtain the correct information.

#### Structured Interview Questionnaire

The majority of items on the thirty-one page questionnaire were constructed with Likert-type responses on either a five or seven point scale. In constructing the instrument, we utilized questions from Hartman and Becker's protocol.<sup>3</sup> We felt that these questions had previously been tested and would also provide us the opportunity to

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<sup>1</sup>Douglas McNaire, et al., Profile of Mood States (San Diego: Educational and Industrial Testing Service, 1971).

<sup>2</sup>Morris Rosenberg, Society and Adolescent Self-Image (Princeton, N.J.: Princeton University Press, 1965).

<sup>3</sup>Hartman and Becker, op. cit.

compare our findings with theirs. We also had a number of questions that included probing by the interviewer, in order to gain more specific information from the patients' viewpoint. There were some open-ended questions so that patients could explain in their own words some of the factors they felt affected their ability to be compliant with their medical and dietary regimen. (See Appendix A for a copy of the structured interview questionnaire.)

As previously mentioned we selected five major domains of the patients' ecological field for the independent variables in this study. The major components within the demographic domain were: age, sex, race, religion, marital status, employment status, birth place, education, and income. Within the intra-personal domain we asked questions pertaining to the patients' health beliefs and attitudes, affective states, frustration tolerance, coping skills, self-esteem, internal-external control, knowledge of diet and medical regimen, and questions directed at identifying typical behavior patterns. The inter-personal domain included questions about the patient's family and their relationship to the patient, patients' friends and neighbors, and the degree to which the patients' felt these "significant others" understood them and the illness. Within the health delivery system, we examined the patients' relationships and degree of satisfaction with the health care system and staff, the staff's provision of information, transportation to the Center, travel time and distance of the Center from the patients' homes. In the last domain, the patients' environmental field, the variables examined were patients' perceptions of neighborhood and available services, crises within the last year, ability to afford certain medical necessities, and the amount of medical

expenses the patient paid monthly.

As previously mentioned, we incorporated two standardized scales within the questionnaire. The Profile of Mood States is a sixty-five item adjective checklist which provides information on the patient's affective states.<sup>1</sup> Affective states measured were the degree of depression, anger, tension, confusion, fatigue, and vigor. In order to control for level of reading ability, the interviewer read each adjective to the patient and the patient selected one of the five responses which best described how he or she had been feeling during the past week. Patients were informed that if they did not understand any of the words to let the interviewer know so that synonyms could be offered.

The other standardized scale was Rosenberg's Self-Esteem scale,<sup>2</sup> utilized in order to ascertain a measurement of the patient's degree of self-acceptance. This ten question scale had Likert-type responses, ranging from Strongly Agree to Strongly Disagree. The interviewer read each question to the patient, and the patient chose one of the responses. An overall total self-esteem score was calculated for each patient.

### Pilot Study

All questions in the structured interview instrument were reviewed by various staff members at the Brooklyn Kidney Center and Long Island College Hospital. Physicians, social workers, nurses and dieticians were consulted and provided feedback on the questions. The instrument was pre-

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<sup>1</sup>McNair, op. cit. (See Appendix A, p.297 for Profile of Mood States form.)

<sup>2</sup>Rosenberg, op. cit. (See Appendix A, p.269 for Rosenberg's Self-Esteem Scale.)

tested at Long Island College Hospital on a population which is very similar to the one that was actually studied at the Brooklyn Kidney Center. Four patients were interviewed so the interviewer could identify unclear and/or repetitive questions. Some questions were eliminated as redundant or non-productive, and attempts were made to shorten the length of the interview. The pre-test patients were also queried as to their feelings about the testing procedure, and were asked for suggestions on improving the questionnaire and the procedure. The interviewer was able to learn about the impact of the procedure on the patient, patient's endurance, as well as develop a style which hopefully would help produce accurate and truthful participation by the patient.

#### Sampling Procedure

The Brooklyn Kidney Center, a free-standing satellite dialysis center, is the location from which we selected the sample for this study. Patients are dialyzed at the Center three times a week on either a Monday, Wednesday, Friday or Tuesday, Thursday, Saturday schedule. There were three shifts of patients each day and patients were dialyzed four to five hours each treatment.

In February 1979, the population at the Center consisted of 131 patients. Prior to the selection of a sample for this study, 12 patients were excluded - six because they could not understand English adequately, two because they were blind, two because they were deaf, and two because they had severe psychiatric problems.

The mean age of this excluded group was 54 which is eight years older than the mean of the sample (46 years old). This

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may be partially explained by the six patients who could not speak or understand English very well, probably reflecting immigration to this country at an older age with less opportunity for learning English. Four of the patients were excluded for medical reasons, i.e., blindness or deafness, symptoms often associated with the progression of diabetes and old age. Seven of these excluded patients were males and five were females. Percentagewise this is comparable to the interviewed sample. The mean time on dialysis for these 12 patients was 43 months, as compared to the sample which had a mean of 48 months. These patients did not differ markedly on demographic characteristics or on compliance levels when compared to the sample. For a comparison of compliance levels, see Chapter V, p. 83.

From the remaining population of 119 patients, a random sample of 60 was selected which equally represented patients from morning, afternoon, and evening shifts. Ten patients from each of the six shifts were randomly selected so we would have equal representation of patients from all shifts. Because assignment of patients to shifts may not be a random procedure, i.e., certain groups of working patients are not on the day shift, we felt selection of patients from all shifts was important. Patients admitted to the hospital due to medical complications were maintained in the sample. The duration of the patient's hospitalization was usually less than two weeks and only six patients were hospitalized during the six months of the study. After the initial selection of patients into the sample, two patients left the Center for other dialysis centers and replacements were randomly drawn from the appropriate shift.

Fifty-five of the 60 selected patients were interviewed for this study. Five patients who refused to be interviewed did not differ markedly on demographic characteristics or levels of compliance behavior when compared to the group of interviewed patients.

#### Setting Of The Interviews

The Brooklyn Kidney Center is located off Flatbush Avenue near Prospect Park, on the edge of a fairly stable white, middle class area and a transitional, low income, predominately Black and Hispanic populated neighborhood. The population at the Center reflects the diversity of its location in terms of patients from different races, religions, economic classes, etc. The Brooklyn Kidney Center is a two floor building with a waiting room which can seat about fifteen patients. There is one large room on the first floor where the twenty-two dialysis machines are arranged in three rows. Two of the rows are against the length of the walls and the third row is in the middle of the room facing one of the other rows of machines. The vast majority of patients have other patients sitting on both sides of them and are also looking across the room (approximately ten feet) to other patients.

Patients at the Center sit in a semi-reclinable chair and the dialysis machines are located to one side of the chair. There is a nursing station located at one end of the room from which approximately 75 percent of the patients are visible. Usually one dialysis technician is assigned to three or four patients and sits facing the patients so that they can monitor progress during the dialysis treatment and also respond quickly to emergencies. Blood pressures are checked

every half hour and saline is given periodically or as needed when the patient's blood pressure drops too quickly. A typical staffing pattern for the day shift is four or five technicians, three nurses and a Head nurse. Other staff on the first floor consist of a porter, and two ward clerks. During the afternoon shift an additional two nurses join the staff. The night shift has two or three nurses and five or six technicians.

Physicians are present at the Center three times a day in order to make rounds on each shift of patients. Physicians are on the premises on the average of less than six hours, while patients are on the premises for a total of about sixteen hours each day. The amount of time physicians are present at the unit has been an ongoing "bone of contention" between administration and the patients. The patients would feel more comfortable if a physician were always present in case of an emergency. Administration feels that because the Center is a free standing satellite unit, with a putative stable population, total medical coverage is not required. There are a total of four physicians who provide coverage at the Center. There is one physician who covers the morning and part of the afternoon shift. The other three physicians cover the other part of the afternoon shift and the night shifts. These three physicians also provide coverage for Saturday, therefore many of the patients see more than one physician each week.

The second floor of the building is comprised of administrative staff offices. The physicians have an office on this floor. The two social workers, the administrator, the dietician, registrar, medical records clerk and two secretarial staff are located on this floor. There is a conference room which is ideal for family or patient group

meetings, however, patients physically have difficulty climbing the stairs, so there is a structural obstacle to full utilization of the conference room by patients.

#### Data Collection Procedure

Initially we had considered interviewing patients either before or after dialysis treatments. This plan, however, posed several problems. First, patients often are very reluctant to come early to dialysis treatments or stay afterwards. Secondly, it would have required changing numerous transportation arrangements because many of the patients are brought to the Center by ambulette or car service. Thirdly, patients may feel discomfort prior to dialysis because of fluid overload if they have been abusing their fluid intake. Fourthly, patients often are "drained" and quite tired after their treatment. We also considered the idea of requesting patients to come in on one of the days between their dialysis treatments. However, we decided against this because we felt it would significantly affect the number of patients who would cooperate in the study. Other staff members also informed us of the difficulty they have had trying to have the patients come in for special meetings on non-dialysis days. Because most of the patients are rather inactive during their dialysis treatments, we felt they would be most receptive to the idea of participating in the study if asked while on dialysis. We also contacted other researchers of dialysis populations and they informed us that interviewing patients while on the machine was preferred by patients.

After selecting the sample, we conferred with the social workers, several nurses, and the dietician about which patients they felt would



be receptive to being interviewed first. We felt it was important to interview potentially cooperative patients first for three reasons. First, it would allow the interviewer to refine the interviewing procedures and techniques in the least stressful situations. Secondly, successful interviews would show the staff that this research study would not be disruptive to their normal routine nor place extra demands on them. We had attempted to let the majority of the staff know about the study prior to beginning the interviewing. Thirdly, it was important for the informal patient communication network to be supportive of the research study. Successful initial interviews would help establish increased patient trust and hopefully, willingness by others to participate in the study. The interviewer always attempted to select a staff person who had a good relationship with the patient to be the one to introduce the interviewer to the patient. Staff members selected were nurses, technicians, the dietician, and the social workers.

After being introduced to the patient, the interviewer handed a consent form to the patient and then briefly explained the study.<sup>1,2</sup> The consent form was then read to the patient. If the patient refused, the interviewer then attempted to explore concerns or fears about participating in the study. If they were still unsure about participating, we left the consent form with them and asked them to think about participating, checking back with them at a later date. Three patients unequivocally said they would not participate, so we did not leave the consent form with them.

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<sup>1</sup>See Appendix B for Statement of Introduction.

<sup>2</sup>See Appendix C for copy of Consent Form.

Following the signing of the consent form by the patient and a witness, patients were asked if they had any initial questions. If there were no questions, then the interview was begun by handing them the first response card.<sup>1</sup> The interviewer explained the procedure of the interview and then read the first question to the patient. All subsequent questions in the questionnaire were read to the patients as we felt that this was the best procedure to control for a range of reading abilities. Patients were encouraged to ask questions at any time or ask to have the questions re-read to them, if they felt they did not understand. From the response cards the patient would select the number or word which corresponded closest to how he or she felt about the question. While the majority of the patients selected their responses off the cards, a few did not look at the cards and the interviewer would read the options for answering to the patient. Sometimes these patients would say that they could not see the cards because they did not have their glasses.

There were a couple of patients who were quite reticent to answer questions directly and needed a good deal of encouraging by the interviewer. These few patients (approximately three) seemed to want to respond to most questions in a yes/no format instead of selecting from the range of responses, e.g., strongly agree, moderately agree, etc. The interviewer recorded a response which seemed to approximate the more generalized response of the patient. While this approximation procedure was not as accurate as the interviewer had desired, there

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<sup>1</sup>See Appendix D for an example of the Response Card.

were two compensating factors. First, the interviewer would check the patient's response on one question with another similar question. That is, if the patient agreed to the interviewer marking number four for one question, the interviewer on a similar question would ask if it was the same as before, more, or less. Therefore, we believe that there was at least internal consistency for the patient. Secondly, this writer did all the interviews so there was consistency in the method of approximations used by the interviewer.

### Confidentiality

As previously described, the interview setting did not lend itself to ideal confidential interviews. Because of the close proximity of patients to each other and the staff's interruptions, there was some lack of privacy. There were several factors which helped compensate, however. One factor was the high noise level which assisted in providing a modicum of privacy. Another factor was that the majority of questions could be answered by a number which corresponded to words, e.g., number one equalled strongly agree with the question. Therefore, if a patient responded with only numbers there was a good deal of confidentiality. Whenever a staff person or patient interrupted us, we would stop the interview until the person left the vicinity. None of fifty-five patients interviewed complained about a lack of privacy.

### Obstacles Encountered

There were several obstacles which the interviewer encountered while conducting the interviews. As mentioned, noise was a factor which sometimes affected the interview with the patient. During the day and

afternoon shifts the patients played bingo and the numbers were read over a loudspeaker. Depending on the proximity of the loudspeaker, the patient, at times, had difficulty in hearing the question read by the interviewer. If there was any indication that the patient did not hear the question, the interviewer repeated it. The stress of the competing noise was probably more of a problem for the interviewer than the patient, because of the large number of questions that had to be read. During the night shift many patients watched television or listened to their radios. For some interviewed patients these noises seemed to be an initial distraction, but usually once the interview began they were able to concentrate and focus their attention on the task.

Another particular obstacle during the interview was the periodic interruptions by the staff. Scheduled interruptions consisted of the blood pressure checks and the administration of saline. Usually these interruptions were brief and did not constitute much of a problem and even provided a break from the rather lengthy interview.

Unscheduled interruptions took two forms, specifically, interference by other patients or staff and patient sickness during dialysis treatments. Sometimes staff or patients would stop by to say "hello" or shout something at the patient. These were somewhat frequent occurrences, usually short in duration and not too problematic for the interviewing process. In a couple of situations the interruption took the form of a patient in the next chair becoming a third party to the interview. When reading a question to the patient, the patient in the next chair might comment about it, laugh, or answer the question. Often

the patient being interviewed would have a short conversation with the other patient. The interviewer usually just ignored the interruption and continued to read the next question, or would make some kind of a joke about a group interview. The third party patient would normally stop participating after a few minutes. We felt this behavior reflected an interest in the study. In fact, some patients even asked about the purpose of the study and a brief explanation of the purpose was offered. Invariably the patient would then ask if he or she were also going to be interviewed. We would tell the patient either yes or no, and this seemed to suffice.

The other type of unscheduled interruption occurred when the patient became ill. When being dialyzed, if too much fluid is removed too quickly, the patient's blood pressure drops rapidly and the patient may experience "blackout" or go into "shock". The interviewer learned the early signs of dropping blood pressure, e.g., yawning, sleepy eyes, etc., so a nurse could be called and saline administered. Two times patients did experience "blackout" during the interview. However, shortly after being given saline they wished to continue the interview. A few patients became nauseous during the interview. Depending on how they felt, we either continued the interview in a few minutes or arranged to continue on another day.

The majority of interviews were completed in one session. Thirty-nine patients (71%) were interviewed in one session; fourteen (25%) required two sessions and one patient took three sessions. One patient stood out because he was very depressed and would become overcome with sleep during the interview, thus requiring five sessions to complete

the questionnaire. The interviewer felt the patient was in no hurry to finish the questionnaire because it provided him a format in which to "talk" to someone. In fact, several days after completing the interview the patient asked the interviewer with positive anticipation if there would be any more sessions.

All 55 interviews were completed between March 1979 and May 1979. The average length of the interviews was one hour and forty-one minutes. The shortest interview required one hour and ten minutes as the patient quickly answered each question. The longest interview required a total of two hours and forty minutes. This interview was with the patient who needed five sessions to complete the questionnaire. He was very slow in responding to each question and often questions had to be repeated several times because his concentration was quite poor and his retention of directions was also limited.

With the vast majority of patients, the interviewer felt that the rapport was very good and cooperation was at a high level. There were a few patients who were somewhat suspicious about the research project. They wanted to know how the information was going to be utilized, how they had been chosen, etc. There were two patients who after completing the entire questionnaire again asked what the study was all about and how we would use their answers. The interviewer assured them of confidentiality, and explained the purpose of the study again and the idea of grouped data.

All the patients, except one, who agreed to participate in the study completed the entire questionnaire. The one exception completed the majority of the questionnaire but for certain sections refused to

answer the questions. For example, when asked questions about following the renal diet, he flatly stated he had never been on a diet, therefore that series of questions was left blank.

#### Patients Who Refused

Of the 60 patients selected for inclusion in the sample, 55 were interviewed and five patients refused to participate in the study. We will briefly describe these five patients' responses to the request for their participation in the study. We followed the normal procedure of having a staff person introduce the interviewer to the patient. The first patient said: "Where have you been the last five or six years when I first got sick? Why now? I don't like to think or talk about dialysis because it upsets me. I just want to laugh or joke about it." The patient appeared to be rather upset and angry, so the interviewer supported the patient's decision not to participate. This patient's response came as a surprise to the interviewer and several of the staff as he had always seemed jovial and rather good-natured. However, it appears that his behavior and easy going manner was part of his coping style and covered some of his feelings about being on dialysis. The staff seemed to have accepted his behavior and seldom had challenged him to discuss his feelings. Parenthetically, the social worker's note on his initial psychosocial evaluation reported difficulty with him answering questions, and his frequent response that he would take the fifth amendment. The interviewer spoke to the patient again about a week later and he again informed the interviewer that it upset him too much to talk about being on dialysis. He also stated that if we were around five years from now he would agree to be interviewed.

The second patient just shook his head indicating "no" while we were explaining the study to him. He did not want to explain why he did not want to participate. Unfortunately, we were not judicious enough in selecting the appropriate staff person to introduce us to this particular patient. This patient was an alcoholic and quite suspicious. A better procedure would have been to have the social worker talk with the patient separately and explain the study. The social worker had a much better relationship with the patient than the staff person we elected to introduce the interviewer. In later consultation, the social worker expressed doubt as to whether he would have participated under any conditions based on his usual pattern of responding to requests by staff members.

The third patient stated that he didn't think he could answer all the questions. This patient had been sitting next to another patient who had been interviewed the week earlier. This other patient had become upset and cried when she discussed her father's death. We think that this patient's crying may have upset the above patient and affected his decision to participate. Another important variable was that the refusing patient had not been feeling physically well during dialysis treatments for a number of weeks. However, later when he was feeling better he was still resistant to being interviewed.

The fourth patient who refused to be interviewed, began screaming at the interviewer when he and the staff member approached the patient. The patient said: "I already told you I didn't want to talk to you." She was quite upset and the interviewer just stated that he would not bother her anymore. In reality, the interviewer had never directly



talked to this patient about the study. She had been sitting next to a patient who had been interviewed several days earlier. In fact, this patient had even talked to the patient being interviewed during the session and probably listened to the entire interview. This fourth patient is rather eccentric and has some psychiatric problems but refused to see a psychiatrist for an evaluation. Her angry response to the interviewer upset several of the staff because they felt she was constantly being rude and bizarre in her general behavior. Two additional points are interesting about this patient and the situation. First, the social worker's notes in the chart stated that this patient had resisted completing the initial psychosocial interview. Secondly, none of the staff had clearly identified this patient as one that we should exclude from the sample because of her emotional instability. Our sense is that the staff may be accepting her as functioning and coping at a higher level than actually is the case.

The fifth patient was a very angry and suspicious person who seemed to have a relationship with only one or two of the staff. The majority of the staff stayed away from him. While he does come in for his treatments, he is often late. He had previously refused to participate in other types of research conducted at the Center, e.g., a nerve conduction study. The social worker's note also indicated that he refused to answer questions when she was trying to complete the psychosocial evaluation form. We selected the staff person who had the best relationship with the patient and she selected a time which she felt he might be receptive to thinking about participating in the study. He flatly refused and even became angry about being asked.

Demographically these five patients are very similar to those in the interviewed sample. The mean age of this group was 45 which is just one year younger than the sample's mean of 46. Eighty percent of this group was male as compared to 66 percent in the interviewed sample. The mean time on dialysis was 51 months as compared to the sample which had a mean of 48 months. Sixty percent of this group was married and 40 percent single, as compared with 47 percent married and 18 percent single in the interviewed sample. The interviewed sample consisted of 73 percent Black, 18 percent white, and 9 percent Hispanic. The group of patients who refused to be interviewed were 80 percent Black and 20 percent Hispanic. One might speculate that because the interviewer was white that this may have increased the level of mistrust already present in these five patients. Comparison of this group of patients with the sample in terms of compliance levels will be presented in Chapter V, p. 83.

#### Data Analysis Procedures

From the questionnaire and medical charts, data was collected on the five designated areas of independent variables (demographic, intra-personal, inter-personal, health delivery system, and environment), and on the five dependent measures of compliance. Data was coded, i.e., the responses to the questions were placed in specified categories. Some categories needed to be combined because there were insufficient responses in the more specific categories, e.g., Hispanic and white patients were combined because of the small number of Hispanic patients (N=5).

Item analysis of related questions was completed in order to create composite indexes with maximum reliability. These composite indexes were then analyzed with the five measures of compliance behavior. The five measures of compliance, phosphorous and potassium levels, between dialysis weight gains, an Overall Compliance Index, and the patients' self-report of compliance were all treated as continuous variables. We identified the variables significantly associated with compliance by utilizing correlational analyses and tests of significance.

In Chapter XI, as a method of summary analysis for each of the five dependent measures, we utilized multiple regression analysis of selected variables. This procedure assisted us in identifying those independent variables which explained the greatest amount of variance for each of the dependent measures of compliance behavior.

CHAPTER V  
MEASUREMENT OF COMPLIANCE BEHAVIOR

Researchers have attempted to measure compliance by a number of different methods. These methods have included patients' self-reports,<sup>1</sup> counting pills,<sup>2</sup> urine tests,<sup>3</sup> staff's observation of patients' compliance,<sup>4</sup> and laboratory results.<sup>5</sup> In this study we chose five measures to assess a patient's compliance behavior with reference to the medical and dietary regimen prescribed by the medical staff. Three of these measures, serum phosphorous and potassium levels and between dialysis weight gains, constitute objective data taken from the patients' monthly laboratory results and medical charts. We felt these to be reasonably reliable and valid indicators of how well the patients were complying with their medical and dietary regimens. As a routine practice in this setting, patients receive feedback on how

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<sup>1</sup>Neely and Patrick, op. cit., 52-55.

<sup>2</sup>Bergman and Werner, op. cit., pp. 1334-1338

<sup>3</sup>Fox, op. cit., pp. 269-274.

<sup>4</sup>Watkins, et al., op. cit., pp. 229-230.

<sup>5</sup>Blackburn, op. cit.

well they are complying at least monthly on potassium and phosphorous levels and on weight gains each time they are dialyzed. The fourth measure we used was an overall compliance index constructed by combining the three objective measures. For the fifth measurement of compliance, we utilized the patients' subjective reports of their compliance behavior.

In this Chapter, we discuss the three objective measures just identified, the construction of the Overall Compliance Index, and the patients' self-reports of compliance. We also present statistics regarding the extent of compliance and non-compliance of the patients in this study. In the last section of this Chapter, we compare the compliance levels of patients included in the sample with those of the patients excluded before sampling, as well as those patients who refused to be interviewed.

#### Phosphorous Compliance

Monthly blood chemistries help the staff evaluate whether or not the patient is following the prescribed diet, taking the appropriate medications, and being given adequate hours of dialysis treatments. Because the kidneys are not functioning, certain foods need to be avoided so that fewer toxins are introduced into the body. Even with the strictest diet, toxins still accumulate and need to be removed by dialysis. However, dialysis does not remove phosphorous from the body so this chemical needs to be controlled by dietary procedures and medications. In order to maintain good phosphorous levels, a patient needs to restrict the intake of milk products and other foods which are high in phosphorous and he/she must take a phosphorous

binder several times a day. Phosphorous medications such as Amphogel or Basegel bind phosphorous to other elements so they can be eliminated with the feces. Phosphorous levels are a good measure of compliance behavior because they are a reliable indicator of whether or not the patient is following the medical and dietary regimen. It should be noted that phosphorous compliance is important because long term non-compliance can cause bone disease.

We reviewed monthly laboratory reports from January 1979 to June 1979 and recorded the phosphorous levels for each patient in the sample. A mean phosphorous level score was then calculated for each patient. For data analysis purposes, we treated the patients' phosphorous mean scores as a continuous variable. The mean phosphorous score for all patients was 5.0 mg. per 100 ml., and the range was between 2.5 and 8.6 mg. per 100 ml. Any patient missing a laboratory value was given the sample's mean score for that month. This procedure for handling missing values was utilized for all three measures of compliance behavior. On the average there were less than a total of four missing phosphorous and potassium values per month, and less than two missing between dialysis weight gains per month.

Other studies have also utilized phosphorous levels as a measure of compliance behavior. Hartman and Becker<sup>1</sup> defined phosphorous compliance as phosphorous levels between 3.5 and 5.0 on four of six measurement times. Non-compliance was defined as phosphorous levels

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<sup>1</sup>Hartman and Becker, op. cit.

higher than 5.0 on four of six measurement times. In a 50 patient sample, they found 39 percent compliant and 61 percent non-compliant. Blackburn<sup>1</sup> defined phosphorous compliance as levels between 3.5 and 5.0, 50 percent of the time. Patients included in Blackburn's sample (N=53) were on dialysis between three and 14 months which constituted the measurement period. She found 62 percent of her patients were compliant and 38 percent non-compliant.

#### Potassium Compliance

In this study, potassium levels are a reliable indicator of dietary compliance but not of compliance with medications as none of the patients in the Center are given medications to control potassium levels. It is important to monitor potassium because excessive levels of potassium in the blood can cause irregular heart beats and lead to heart failure. Since potassium levels can rise suddenly, it is important that patients avoid foods and beverages that are high in potassium, e.g., chocolate, bananas, and orange juice. We reviewed the monthly laboratory reports of potassium levels from January 1979 to June 1979 and recorded the potassium levels for each patient in the sample. A mean potassium level score was then calculated for each patient and for data analysis procedures we treated these mean scores as a continuous variable. The mean potassium score for the patients was 5.6 mEq per liter and the range

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<sup>1</sup>Blackburn, op. cit.

was between 4.5 and 6.7 mEq per liter.

Other studies have also utilized potassium levels as a measure of compliance behavior. Hartman and Becker<sup>1</sup> defined potassium compliance as levels below 5.8, and non-compliance as scores above 5.8 on four of six measurement times. They found 74 percent of their patients to be compliant and 26 percent of the patients non-compliant. Blackburn<sup>2</sup> defined potassium compliance as levels between 3.5 and 5.0. Compliance was defined as falling within these limits 50 percent of the time (three to 14 months). She found 79 percent of her patients compliant and 21 percent non-compliant.

#### Between Dialysis Weight Gains

With the loss of kidney function, dialysis patients are unable to eliminate fluids effectively. Patients are advised to limit their fluid intake so they will not become fluid overloaded thus taxing the cardiovascular-respiratory system. Patients are weighed before each dialysis treatment and immediately afterwards. These pre-dialysis and post-dialysis weights are recorded in the medical charts. In order to actually compute the between dialysis weight gains we took the patients' post-dialysis weights and subtracted them from their pre-dialysis weight at the time of the next dialysis treatment. A monthly mean of between dialysis weight gains was computed for each

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<sup>1</sup>Hartman, op. cit.

<sup>2</sup>Blackburn, op. cit.



patient from January 1979 to June 1979. We then computed each patient's overall between dialysis weight gain mean for the entire period. The mean between dialysis weight gain for patients was 4.71 pounds and the range was between 1.64 and 7.56 pounds.

Two other research projects of dialysis patients' compliance behavior utilized slightly different procedures for calculating compliance levels for between dialysis weight gains. Hartman and Becker<sup>1</sup> established a four pound weight gain between treatments as the cut-off point for measuring compliance. They then measured patients' weight gains for a six month period. Good compliance was defined as a patient's weight gain falling within the acceptable limits (below four pounds) on four of the six measurement times. Utilizing this criteria they found 78 percent of their patients were compliant and 22 percent non-compliant. Blackburn<sup>2</sup> also utilized a cut-off point of four pounds between dialysis treatments. Her sample included patients who had been on dialysis for between three months and 14 months. Positive compliance was defined as falling within acceptable limits 50 percent of the time. She found 49 percent of her patients were compliant and 51 percent were non-compliant.

In the research reported here, we did not establish a pre-set cut-off point to differentiate compliance and non-compliance levels. We did this for several reasons. First, there is no nationwide agreed

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<sup>1</sup>Hartman, op. cit.

<sup>2</sup>Blackburn, op. cit.

upon cut-off point for differentiating compliance from non-compliance. Secondly, even among the staff at the Brooklyn Kidney Center there are divergent opinions on how much patients should actually gain between dialysis treatments as well as what constitutes acceptable chemistries. Thirdly, with the improvement in the dialysis equipment, increased amounts of fluid and toxins can be removed and patients and some staff may feel that patients can be more liberal in their dietary and fluid intake.

#### Overall Compliance Index

The fourth dependent measure of compliance utilized is an Overall Compliance Index. In order to create an Overall Index of Compliance Behavior, we first tested the degree of association between the three objective measures of compliance (see Table 1). The alpha level of internal reliability was .55 for the composite score based on the three measures. Next, we standardized each of the three measures as all of them had different means and standard deviations. Lastly, we constructed an Overall Compliance Index by combining each patient's scores on the three objective measures into a single score. This Overall Compliance Index was utilized later when analyzing the independent variables in each of the ecological domains.

TABLE 1  
CORRELATIONS OF THE THREE  
OBJECTIVE MEASURES OF COMPLIANCE  
(N=55)

Objective Measures	Intercorrelations Among Items			Corrected Item-Total Correlations <sup>a</sup>
	Phosphorous	Potassium	Between Dialysis Weight Gains	
Phosphorous Levels	1.0			.45
Potassium Levels	.40	1.0		.39
Between Dialysis Weight Gains	.36	.24	1.0	.37

Note: Alpha level of internal reliability for this index is .55.

<sup>a</sup> Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

#### Patients' Self-Report of Compliance Behavior

In addition to the four objective measures of compliance behavior, we also asked the patients for their subjective assessment of how close they felt they came to following various aspects of their medical and dietary regimen. We asked the patients to assess how well they followed; 1) instructions on medications; 2) their diet; 3) fluid intake; 4) all the staff's instructions in general. We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these four items (see Table 2). The alpha level

of internal reliability for the items in the Self-Report Index was .72. The fairly high alpha level and the fact that the corrected item-total correlations are of moderate strength seem to indicate that these items form a good Overall Index of Patients' Self-Report of Compliance.

TABLE 2  
CORRELATIONAL ANALYSIS OF  
PATIENTS' SELF-REPORT OF COMPLIANCE INDEX  
(N=55)

Self-Report Items	Intercorrelations Among Items				Corrected Item-Total Correlations <sup>a</sup>
	Item 1	Item 2	Item 3	Item 4	
1. How close do you come to following all instructions on medications?	1.0				.54
2. How close do you come to your diet?	.39	1.0			.53
3. How close do you come to fluid instructions?	.36	.36	1.0		.43
4. How close do you come to following all the staff's instructions?	.48	.46	.29	1.0	.54

Note: Alpha level of internal reliability for this index is .72.

<sup>a</sup>Correlation is between each item and the sum of all other items in index with the item itself deleted to correct for auto-correlation.

We then summed each patient's scores on these items in order to construct the Overall Self-Report of Compliance Index. In Table 3, we present the correlations between each of the four areas of patient self-report of compliance, the Overall Self-Report Index, and the four objective measures of compliance.

TABLE 3  
CORRELATIONS BETWEEN PATIENTS' SELF-REPORT OF COMPLIANCE  
BEHAVIOR AND OBJECTIVE MEASURES OF COMPLIANCE

Self-Report	Objective Measures of Compliance			
	Phosphorous	Potassium	Weight Gain	Overall Objective Index
1. How close do you come to following all instructions on medication?	.01	.12	-.12	-.00
2. How close do you come to your diet?	-.22	-.08	-.14	-.20
3. How close do you come to fluid instructions?	-.30**	-.02	-.14	-.21
4. How close do you come to following all the staff's instructions?	.11	-.07	-.12	-.14
5. Overall Index of Patient Self-Report	-.21	-.02	-.18	-.18

\*\*Correlation was significant at the .01 level for an N of 55.

A priori, one would expect the highest correlations between patient self-report on medication compliance and the objective measure of phosphorous levels; diet with potassium levels; fluid instructions with between dialysis weight gains; and self-report on all instructions with the Overall Objective Compliance Index. We did not find this speculated pattern of correlations between the patients' self-reports and the four objective measures.

The lack of a greater number of associations between the patients' self-reports of compliance behavior and their individual objective measures may be the result of the staff providing inconsistent feedback to patients on their actual medical reports, a lack of specific education for patients, or patients' denial or distortions. While we may not be able to decipher at this point the cause of the lack of more associations, knowing the patients' perceptions of their compliance is critical. How can patients be expected to improve their compliance behavior when they feel that their compliance is already acceptable? In Chapter XI we will present the variables associated with the patients' self-report of compliance.

#### Extent of Compliance and Non-Compliance

For the purpose of quantifying the extent of compliance and non-compliance of the patients in this study, we utilized the acceptable range of values indicated on the computerized laboratory reports. For phosphorous compliance, the range is between 3.5 and 5.0 mg. per 100 ml. For potassium compliance, the acceptable range is between 3.5 and 5.0 mEq per liter. There is no clear cut

laboratory criteria for between dialysis weight gains but four pounds is generally the one espoused by the Brooklyn Kidney Center and is the one utilized by Hartman and Becker<sup>1</sup> and Blackburn<sup>2</sup> in their studies.

As previously discussed, a mean compliance score was calculated for each patient for the three objective measures over a six month period of time. By utilizing the aforementioned acceptable ranges for compliance, we found 56 percent of the patients were compliant with respect to phosphorous and 44 percent non-compliant. With regard to potassium only 15 percent of the patients were compliant and 85 percent non-compliant. When utilizing a cut-off point of four pounds for between dialysis weight gains, 33 percent of the patients were compliant and 67 percent non-compliant, (see Table 4).

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<sup>1</sup>Hartman, op. cit.

<sup>2</sup>Blackburn, op. cit.

TABLE 4

EXTENT OF COMPLIANCE AND NON-COMPLIANCE ON THREE OBJECTIVE MEASURES  
(N=55)

Objective Measures	Percentages
<b>Phosphorous<sup>a</sup></b>	
Compliant	56
Non-compliant	44
<b>Potassium<sup>b</sup></b>	
Compliant	15
Non-compliant	85
<b>Between Dialysis Weight Gains<sup>c</sup></b>	
Compliant	33
Non-compliant	67

<sup>a</sup>Phosphorous compliance was defined as patients' mean scores between 3.5 and 5.0 mg. per 100 ml.

<sup>b</sup>Potassium compliance was defined as patients' mean scores between 3.5 and 5.0 mEq per liter.

<sup>c</sup>Between dialysis weight gain compliance was defined as patients' mean scores below 4.0 pounds.

Patients in this sample were generally most compliant with respect to phosphorous and least compliant with potassium. Assuming the patients are aware of the acceptable ranges for compliance, the compliance levels for this sample are not very good. One possible explanation for this finding is that the staff does not readily accept the computerized laboratory ranges of compliance. For example, some staff do not become concerned until a phosphorous or



potassium score exceeds 6.0. In terms of between dialysis weight gains, the staff varies greatly concerning acceptable limits. Presumably, the more variation in staff's expectations, the more likely some patients may select the least restrictive limit.

The difference in compliance levels between phosphorous (56%) and potassium (15%) is considerable. One possible explanation for the better compliance on phosphorous is that phosphorous levels can be affected in two ways. A patient can strictly monitor the intake of foods containing phosphorous or they can increase the amount of phosphorous binding medications. Potassium levels can only be controlled through dietary compliance.

In the next section, we will compare the compliance levels between the patients interviewed for this study, patients excluded before sampling, and those patients who refused to be interviewed.

#### Compliance Levels For Patients Interviewed, Excluded, and Refusals

As previously discussed, 12 patients were excluded before the sample was selected and five of the 60 patients selected refused to participate in the study. We decided to exclude 12 patients because of language problems, and medical or psychiatric reasons. We wished to know if these excluded patients and the ones who refused differed in terms of compliance behavior.

In order to test whether there were significant differences between these three groups of patients, we used a one-way analysis of variance. As seen in Table 5 there were no statistically significant differences in the variances of these groups of patients on the three measures of compliance.

TABLE 5  
 ANALYSIS OF VARIANCE FOR PATIENTS INTERVIEWED, EXCLUDED, AND REFUSALS  
 ON PHOSPHOROUS AND POTASSIUM, AND  
 BETWEEN DIALYSIS WEIGHT GAINS

Compliance Measures	Source of Variation	Sum of Squares	Degrees of Freedom	Mean Squares	F
Phosphorous	Between Groups	4.4	2	2.2	1.1
	Within Groups	139.2	69	2.0	
Potassium	Between Groups	.7	2	.33	.9
	Within Groups	22.7	69	.35	
Between Dialysis Weight Gains	Between Groups	3.9	2	2.0	1.3
	Within Groups	108.5	69	1.6	

Note:  $F_{2,69, .05} = 3.13$

#### Summary

The five dependent measures of compliance selected for this study were phosphorous and potassium levels, between dialysis weight gains, the Overall Objective Compliance Index, and the Patients' Self-Reports of Compliance. We operationally defined the first three objective measures of compliance as mean scores calculated for a six month period. The Overall Compliance Index was constructed by

standardizing the three objective measures and combining them into an overall score for each patient. While the patients' self-reports, the fifth dependent measure, did not consistently correspond to the objective measures, we felt that knowing the patients' perceptions of their compliance was important for furthering our understanding of compliance behavior.

We found 56 percent of the patients compliant with respect to phosphorous, 33 percent compliant on between dialysis weight gains, and only 15 percent compliant on potassium. We speculated that the poor compliance levels may be partially a result of differing staff opinions on what are acceptable limits for compliance. Nevertheless, non-compliance is serious as high potassium levels can cause heart failure and being fluid overloaded taxes the cardiovascular-respiratory system.

We compared compliance levels between the interviewed sample, excluded patients and those patients who refused to participate in the study. We found that these three groups did not significantly differ on phosphorous and potassium levels, or on between dialysis weight gains.

## CHAPTER VI

## DEMOGRAPHIC VARIABLES AND COMPLIANCE BEHAVIOR

Mr. F., a twenty-two year old, white, male, high school dropout, has worked a variety of unskilled jobs in the past six years and continues to reside with his mother and three siblings. He has been on dialysis for four years and is a well-liked patient who "hangs around" the dialysis unit conversing with patients and staff. He still tends to act adolescent and this is reflected in his compliance behavior. In a bravado type manner, he states that he sees no need to follow his dietary regimen. His monthly chemistries are typically poor and he is frequently fluid overloaded.

Mr. E. is a seventy-one year old, Black, male, high school graduate who was gainfully employed as a plumber prior to his retirement. He and his wife have four children and five grandchildren whom they see several times a month. Mr. E. has been on dialysis for two years and is an amicable patient who seldom causes problems for the staff except in terms of dietary compliance. He is somewhat senile and tends not to recall the foods which are prohibited by his renal diet and often drinks fluids to excess when not closely supervised by his family or the staff.

While Mr. F. and Mr. E. seem to be quite different in terms of various demographic characteristics, their compliance with the medical and dietary regimen is similar. As previously mentioned, demographic variables constituted one of the ecological domains of independent variables. In this chapter, we will provide a look at the demographic characteristics of the patients who were interviewed for this research project. We will be focusing on the following question: Are there associations between demographic variables (i.e., age, sex, race, education, etc.), and the patients' degree of compliance with their medical and dietary regimen?

### Demographic Characteristics of the Sample

Racially, this sample differs quite markedly from the national dialysis population. Seventy-three percent of the sample is Black, 18 percent white, and 9 percent Hispanic. The higher percentage of Blacks in the sample is probably a result of the specific catchment area that the Brooklyn Kidney Center services. National statistics indicate that there are 23 percent Black dialysis patients, while Blacks only represent 12 percent of the population of this country.<sup>1</sup> This disproportionate number of Black patients nationally probably reflects the fact that hypertension, which can lead to renal failure, is more prevalent in Blacks than whites, and in males than females.

There were 66 percent males and 34 percent females in the group of interviewed patients. Nationally, the dialysis population is about equally divided.<sup>2</sup> The mean age of the sample is 46 with a range from 22 to 72 years of age. This compares fairly closely to national figures which show a mean age of 50 years.<sup>3</sup> The national statistics include patients involved in all types of treatment modalities, i.e., hospital-based, satellite centers, and home dialysis. The slightly lower mean age of this sample is probably due to the fact that younger, more medically stable patients are

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<sup>1</sup>National Association of Patients on Hemodialysis and Transplantation News, Great Neck, New York, August, 1979, p. 32.

<sup>2</sup>Ibid. p. 32

<sup>3</sup>Ibid. p. 32

usually referred to satellite centers.

Generally, the patients in the sample tend to be married and Protestant with half the sample having completed at least a high school education. In terms of marital status, 47 percent are married, 20 percent separated, 16 percent single, 12 percent divorced and 4 percent widowed. Fifty-eight percent of the sample are Protestant, 29 percent Catholic, 9 percent Jewish, and 4 percent are of other religions or have no religious preference. Educationally, the sample has 52 percent who did not complete high school, 26 percent high school graduates, 22 percent who attended some college, and 2 percent who are college graduates. The mean number of years in school was 11.2.

Ethnically, those in the sample described themselves as 27 percent Afro-American, 15 percent West Indian, 9 percent Jewish, 7 percent Italian, 6 percent Spanish, and the 12 percent as other specific ethnic groups. Twenty-five percent did not identify with a specific ethnic group, but listed themselves as American. Sixty-six percent of the patients were born outside the New York City area and 34 percent in the area. Those born outside New York City tended to originate from the Caribbean Islands or the southern United States moving to this area at the mean age of 22 and the median age of 19.

When queried about current income, 15 percent of the patients did not wish to discuss the topic. Many of the patients live on marginal incomes and sometimes work "off the books" in order to make ends meet and therefore might have been hesitant to discuss

the topic of income. For those who responded, 49 percent have a family income of \$6,000 or less; 26 percent between \$6,000 and \$12,500, and 25 percent over \$12,500. When we explored their financial situation in more depth, we found that 55 percent considered their income to be worse now than before becoming a dialysis patient, 33 percent reported increased income, and 11 percent indicated their income remained the same. The family income needed to provide for an average household size of 3.1 persons.

Patients in this sample tended to fall into the lower socioeconomic classes as calculated by the Hollingshead formula.<sup>1</sup> Using information on both educational levels and occupational status for 34 of the 55 patients and data on the spouses' education and occupation for 12 more of the patients, we were able to calculate the Social Class index for a total of 46 of the 55 patients. Twenty-five percent of the patients fell into Social Class V which reflects the least amount of education and unskilled labor employment. Forty eight percent were in Social Class IV which was the mean category for the sample. Twenty-five percent fell into Class III, two percent into Class II and none in Class I.

While length of time on dialysis is not strictly a demographic variable, it is an important descriptive one in the field of nephrology. The mean time on dialysis for the patients was 48 months, and the median time was 42 months. The patients' length of time on dialysis ranged from six months to 11.5 years. Patients in Hartman

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<sup>1</sup>August B. Hollingshead, Social Class and Mental Illness: A Community Study. New York: Wiley Press, 1958.

and Becker's<sup>1</sup> study were on dialysis a mean of 18 months and Blackburn's<sup>2</sup> patients an average of 18.6 months. This study's sample of patients have been on dialysis a considerably longer period of time when compared to the other two studies. No national statistics are available for average length of time on dialysis.

The demographic characteristics of the sample are similar to those of the entire population of the Brooklyn Kidney Center as measured in November 1978. Seventy percent of the population at that time was Black. The mean age was 47 with 59 percent males and 41 percent females. Regarding marital status, 47 percent were married, 19 percent were single, 19 percent separated, 8 percent divorced, and 7 percent widowed. In terms of religion, 58 percent were Protestant, 29 percent Catholic, 8 percent Jewish and 5 percent other religions. The mean time on dialysis was 43 months and median time was 38 months.

#### Data Analysis

Because of an insufficient number of patients in some categories, we recoded certain variables by collapsing categories. Place of birth was categorized into patients born in the New York City area (N=19) and those born other places (N=36). Marital status was recorded into two groups, married (N=26) and others (N=29). The latter group was comprised of single, widowed, divorced, and separated individuals. Race was also recoded into two groups.

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<sup>1</sup>Hartman, op. cit.

<sup>2</sup>Blackburn, op. cit.



Because of the large number of Black patients (N=40) in the sample, we combined white patients (N=10) and Hispanic patients (N=5). Data analysis pertaining to religion focused on only Protestants (N=32) and Catholics (N=16).

#### Demographic Variables and Compliance Behavior

We wanted to know if there were demographic characteristics which were correlated with compliance or differentiated compliant from non-compliant patients. We found significant correlations between the compliance measures and the demographic variables of age, education, length of time on dialysis, and socio-economic status. Sex, place of birth and employment status differentiated patients on at least one of the five measures of compliance behavior.

#### Age

In Table 1, we see that age was significantly correlated with between dialysis weight gains. Younger patients were less compliant than older patients ( $r = -.26$ ). One possible speculative explanation for this finding is that younger patients may have maintained a more active social life with friends which includes partying, consumption of alcohol, etc. Another possible explanation relates to the idea of autonomy and control as younger patients may experience the impact of illness as more of a threat to those areas. These patients may attempt to reestablish their sense of autonomy and control by not following some of their medical and dietary instructions.

**TABLE 1**  
**CORRELATIONS BETWEEN DEMOGRAPHIC VARIABLES**  
**AND MEASURES OF COMPLIANCE BEHAVIOR**

Demographic Variables	Measures of Compliance				
	Phosphorous	Potassium	Between Dialysis Weight Gain	Overall Compliance Index	Patients' Self-Report
Age (N=55)	-.05	.07	-.26*	-.11	.14
Education (N=55)	-.12	.03	-.31**	-.18	.04
Length of Time on Dialysis (N=55)	-.30**	-.17	-.01	-.22	.00
Socio-economic status (N=46)	.25*	-.03	.26*	.15	.02

\* Correlation was significant at the .05 level and adjusted for size of sample.

\*\*Correlation was significant at the .01 level for N=55.

### Education

Education was another demographic variable associated with compliance behavior, specifically, between dialysis weight gains. The patients with less education were less compliant ( $r = -.31$ ). One possible explanation for this finding is that patients with higher levels of education may have a better understanding of the medical

and dietary regimen. This idea was substantiated when we correlated education and the patients' overall knowledge score of their regimen ( $r = -.32$ ,  $p = .01$ ). Higher knowledge scores may reflect that these patients understand the variety of ways that fluids can be introduced in the diet, e.g. soups, water, beverages, fruits, etc., and therefore are better able to monitor their between dialysis weight gains.

#### Length of Time on Dialysis

Length of time on dialysis was another variable statistically associated with one of the dependent measures (see Table 1). The shorter the length of time on dialysis, the less the patients were compliant with respect to phosphorous levels ( $r = -.30$ ). The greater non-compliance for newer dialysis patients might be explained in terms of the patients' non-acceptance of their illness, and the subsequent lack of feeling responsible for controlling their phosphorous levels, by regulating their diet and taking their phosphorous binder.

An alternative explanation is that physicians are altering the dosages of medications more frequently during the initial phase of the illness while they are attempting to determine the appropriate levels for the patients. These alterations of dosages could lead to the patient being over or undermedicated, and/or confusing the patient on the directions for taking the medications. Patients, who have been on dialysis longer, may have already altered their eating habits, are more consistent in taking their medications, and the physicians may not be changing their regimen as often.

Another explanation for the greater compliance behavior by patients on dialysis longer, relates to patient mortality. Patients who are extremely non-compliant do not survive for a long period of time. Patients, who are in their third or fourth year of dialysis, are probably represented by a greater proportion of compliant patient than non-compliant ones.

#### Socio-Economic Status

When we correlated socio-economic status with the five measures of compliance, we found two statistically significant associations (see Table 1). The lower the socio-economic status, the greater the non-compliance with respect to phosphorous compliance ( $r=.25$ ) and between dialysis weight gains ( $r=.26$ ). Patients in the lower socio-economic status may not have the available income to always purchase the phosphorous binding medication at the required times. Another possibility is that inherent in the occupations of the lower socio-economic statuses may be conditions which are detrimental to phosphorous compliance and between dialysis weight gains. Work patterns or locations may be more varied in some ways than for those in higher socio-economic occupations, e.g., a construction worker who changes work sites, swing shifts, etc. These variations may make it more difficult to regiment oneself to medication consumption or to have access to proper foods, or monitoring fluid intake.

#### Sex

As seen in Table 2 the demographic variable of sex differentiated compliant and non-compliant patients with respect to between dialysis

weight gains and the Overall Compliance Index. Male patients were less compliant than female patients on both of these dependent variables. The greater non-compliance with respect to between dialysis weight gains might be related to the higher incidence of alcohol consumption among males. If a patient has a drinking problem, it is usually very hard to cease consumption and this would result in higher weight gains. Male patients may, in general, be less familiar with dietary compliance, food exchanges, etc., than female patients. When confronted with needing to monitor protein intake, low sodium and potassium products, a decrease in high phosphorous foods, and so forth, the deficiency in previous knowledge makes it harder for male patients to modify their prior eating habits. This idea was somewhat substantiated when we compared male patients and female patients on their overall knowledge of the regimen. Male patients had less knowledge than female patients ( $t=1.63$ ,  $df=53$ ,  $p=.06$ ).

While it is difficult to measure the extent of the relationship between non-compliance and mortality rates, most renal staff believe there is a relationship. We do know that the death rates for male dialysis patients is higher than for female patients in almost every age group.<sup>1</sup>

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<sup>1</sup>End Stage Renal Disease Second Annual Report to Congress, FY 1980, Department of Health and Human Services, p. 42.

TABLE 2  
RELATIONSHIP BETWEEN DEMOGRAPHIC VARIABLES  
AND MEASURES OF COMPLIANCE BEHAVIOR

Demographic Variables	Measures of Compliance										
	Phosphorous		Potassium		Between Dialysis Weight Gains		Overall Compliance Index		Patients' Self-Reports		
	Mean	t-value	Mean	t-value	Mean	t-value	Mean	t-value	Mean	t-value	
<u>Sex</u>											
Males	5.11		5.59		5.22		.50		19.21		
Females	4.92	.56	5.52	.48	3.74	4.81**	-.94	2.41*	19.42	.56	
<u>Place of Birth</u>											
New York City	5.47		5.74		4.91		.80		18.20		
Other	4.82	1.87*	5.48	1.70*	4.61	.82	-.42	1.98*	19.82	-1.26	

\*  $p \leq .05$ , one tail test.

\*\* $p \leq .01$ , one tail test.

#### Place of Birth

The demographic variable of place of birth was significantly associated with phosphorous and potassium compliance and the Overall Objective Compliance Index (see Table 2). Patients born outside the New York City area were more compliant with respect to these measures than patients born in the New York City area. Differing life styles or sets of beliefs may be able to explain some of the differences between the patients born in the New York City area and those born

other places. This idea is somewhat substantiated by another set of findings. Patients born outside the New York City area reported that they thought the sequelae of non-compliance would be more serious to them, than patients born in the area ( $t=.26$ ,  $df=53$ ,  $p=.01$ ). Patients who felt the consequences of non-compliance would be very serious, were more compliant with respect to potassium compliance ( $r= -.23$ ,  $N=55$ ,  $p=.05$ ).

#### Employment Status

In order to compare patients with regard to employment status, we selected the four largest subgroups, employed ( $N=11$ ), unemployed ( $N=13$ ), retired ( $N=15$ ), and homemakers ( $N=12$ ), and utilized a one-way analysis of variance. As seen in Table 3, these sub-groups were significantly different with respect to between dialysis weight gains and the Overall Compliance Index.

TABLE 3  
ANALYSIS OF VARIANCE FOR EMPLOYMENT STATUS  
BY MEASURES OF COMPLIANCE

Employment Status	Measures of Compliance									
	Phosphorous		Potassium		Between Dialysis Weight Gains		Overall Compliance Index		Patients' Self- Reports	
	Mean	F Value	Mean	F Value	Mean	F Value	Mean	F Value	Mean	F Value
Employed	4.74		5.59		4.55		-.33		19.18	
Unemployed	5.34		5.54		5.13		.51		19.31	
Retired	5.60	2.21	5.68	.60	5.44	7.61***	1.21	4.59***	19.40	.02
Homemakers	4.53		5.39		3.51		-1.68		19.67	

\*\*\*

F 3,47, .001 = 4.23

We then compared these sub-groups of patients by the use of t-tests in order to ascertain which sub-groups of patients were most compliant with respect to the two above mentioned measures of compliance.



TABLE 4

## ANALYSIS OF THE RELATIONSHIPS BETWEEN EMPLOYED, UNEMPLOYED, RETIRED, AND HOMEMAKERS AND THE MEASURES OF COMPLIANCE

Selected Measures of Compliance <sup>a</sup>				
Employment Status	Between Dialysis Weight Gains		Overall Compliance Index	
	mean	t-value	mean	t-value
Employed	4.55		-.33	
Retired	5.44	-2.11*	.52	-2.64*
Employed	4.55		-.33	
Homemakers	3.51	2.38*	-1.67	1.56
Unemployed	5.13		.52	
Homemakers	3.51	3.47**	-1.67	2.14*
Retired	5.44		1.21	
Homemakers	3.51	5.56***	-1.67	3.22**

<sup>a</sup>These are the only two dependent measures in which the overall F-values warranted further detailed analysis by use of t-tests.

\*p  $\leq$  .05, one tail test.

\*\*p  $\leq$  .01, one tail test

\*\*\*p  $\leq$  .001, one tail test.

Employed patients were more compliant than retired patients with respect to between dialysis weight gains and the Overall Compliance Index. Perhaps employed patients fear that becoming fluid overloaded or having other health complications would seriously affect their capacity to function on the job and, therefore, they may be motivated to more carefully observe their fluid and dietary instructions.

Homemakers were significantly more compliant than employed,

unemployed, or retired patients with respect to between dialysis weight gains. Eleven of the 12 patients in this category were females and as previously discussed, females were more compliant with respect to between dialysis weight gains.

Homemakers were also more compliant with respect to the Overall Compliance Index when compared to unemployed, or retired patients. Homemakers, being predominately females, may generally have a better dietary knowledge than the other two predominately male groups. As previously discussed, females had higher overall knowledge scores on the renal regimen than male patients ( $t=1.63$ ,  $df=53$ ,  $p=.055$ ).

Retired patients were the poorest compliers on between dialysis weight gains and the Overall Compliance Index. One explanation for this finding is that if retirement was a result of the kidney failure, then the patient has to make two major adjustments at one time. One adjustment is to retirement, and the other is to a chronic illness and a rigorous medical and dietary regimen. This type of double crisis may adversely affect a person's ability to adjust to the complex regimen of dialysis.

#### Summary

Patients interviewed for this study were predominately male, middle aged, Black, married, high school educated, born outside the New York City area, with a household size of three, living on an annual income of less than \$6,000, who suffered a decrease in income when becoming a dialysis patient due to the loss of employment. The mean time on dialysis for these patients was forty-eight months.

Sex, age, socio-economic class, education, length of time on

dialysis, place of birth, and employment status were significantly associated with one or more of the five dependent measures of compliance. Generally, older, females, with more education and higher socio-economic status, other than New York City born, who had been on dialysis longer were more compliant. Being either employed or a homemaker was also associated with better compliance behavior.

The profile of the patients most at risk for non-compliance is generally, younger male, with less education, of lower socio-economic status, unemployed, New York City born and new to dialysis. Needless to say, some of these characteristics place the individual in a disadvantaged position in this society without the complications of a chronic illness. The impact of renal failure may further affect the ecological balance. For example, unemployed or retired males are less compliant when contrasted with employed males or females. This may indicate that renal failure has seriously disrupted these patients' social roles and functions. Not only do these patients have to deal with the adjustment to a chronic illness but they may have lost the support of familiar roles, e.g. the loss of employment, increased dependency, and so forth.

Social workers and the health care team need to pay special attention to potentially high risk patients and develop programs which would help mediate the impact of the illness and decrease further disruptions in social roles, and so forth.

We feel that some of these findings might be further elucidated when other variables such as attitudes about illness, family relation-

ships, etc., are discussed in later chapters. In Chapter XI, we will attempt to better understand the relationship of these demographic variables and the compliance measures by the use of multiple regression analysis.

## CHAPTER VII

### THE IMPACT OF RENAL FAILURE AND DIALYSIS TREATMENTS ON PATIENTS' LIVES AND ON THEIR COMPLIANCE BEHAVIOR

Mr. B., a fifty year old, Black male whose kidney failure was caused by glomerulonephritis, had been gainfully employed as a salesman prior to his illness. Because his job required standing most of the day, he was too physically exhausted by his illness to continue in this capacity. His wife had to begin working to meet the financial needs of the family.

Mr. B. suffered a loss of self-esteem in that he could no longer provide for his family. His marital relationship was adversely affected by his depression and the sexual problems which developed after he began dialysis treatments three times a week. He had great difficulty following dietary and fluid restrictions. While his wife and family attempted to help him monitor his diet, this became a "bone of contention" and created further disharmony within the family. Mr. B. reported that almost every area of his life had been greatly affected by his illness and dialysis treatments.

Which major life areas are most affected by renal failure and dialysis treatments? Are serious disruptions more frequent in males? Blacks? older patients? If the patient's life is greatly affected by the illness, will he or she be less compliant with the medical and dietary regimen? These are some of the questions we sought to elucidate in this study.

In this chapter, we first identify those areas patients reported most affected by the illness and required treatments. Secondly, we examine how the illness and subsequent treatment impacted differentially

upon various subgroups of patients. Finally, we analyze the relationship between the patients' reports of the impact of the illness and their compliance with the medical and dietary regimen. It should be noted that since we did not think that patients would be able to differentiate clearly between the impact of the illness and their response to dialysis treatments, we addressed them as a single phenomenon. Thus, throughout this chapter, when discussing the impact of illness, we are also including the impact of the dialysis treatments and the medical and dietary regimen.

#### Major Life Areas Affected

While we knew that kidney failure and the subsequent adjustment to dialysis treatments presages pervasive changes in patients' lives, we wanted to further understand the specific areas and the degree to which illness and treatment impacted on each. The domains covered were eating habits, leisure time pursuits, sexual activity, social contacts, family relationships, vacation activities, friendships, employment activities, self-esteem, sense of security and the ability to enjoy life. Patients were asked to indicate whether each of these areas was greatly, moderately, mildly, or not at all affected.

Table 1 lists the eleven specific areas affected by the illness ordered from the most affected area (1) to the least affected area (11). As seen in Table 1, the five areas most affected were employment activities, vacation activities, leisure time pursuits, eating habits, and sexual activity. These were categorized as behavioral activities. Fifty-three percent or more of the patients in this survey reported that

**TABLE 1**  
**SELF-DESCRIBED IMPACT OF KIDNEY DISEASE**  
**ON DIFFERENT AREAS OF PATIENT'S LIFE**  
**(N=55)**

Different Life Domains	Affected Greatly	Degree of Impact of the Illness			Totals
		Moderately Affected	Mildly Affected	Not Affected At All	
(percentaged across)					
1. Employment Activities	45.5	20.0	14.5	20.0	100.0
2. Vacation Activities	41.9	14.5	20.0	23.6	100.0
3. Leisure Time Pursuits	32.7	23.7	30.9	12.7	100.0
4. Eating Habits	24.5	30.9	18.1	25.5	100.0
5. Sexual Activity	30.9	21.8	14.6	32.7	100.0
6. Ability to Enjoy Life	21.8	18.2	20.0	40.0	100.0
7. Self-Esteem	14.5	21.8	25.5	38.2	100.0
8. Sense of Security	9.1	27.3	29.1	34.5	100.0
9. Relationship with Friends	20.0	10.9	23.6	45.5	100.0
10. Social Contacts	16.4	23.6	25.5	34.5	100.0
11. Family relationships	14.5	14.5	18.3	52.7	100.0

**NOTE:** Instruction to the respondent: "Now I would like you to rate the impact of your kidney disease on these different areas of your life. For example, how has being a kidney patient affected your eating habits, self-esteem, etc."

these five areas were greatly or moderately affected as a result of becoming a dialysis patient. The next three areas conceptualized as affective include ability to enjoy life, self-esteem, and sense of security. The last three domains categorized as relational encompass relationships with friends, social contacts, and family. In order to determine if the impact of the illness differentially affected various subgroups of patients, each of the above eleven domains was statistically analyzed with the various demographic variables, sex, age, race, education, marital status, income, time on dialysis, socio-economic status, place of birth, and religion.

#### Behavioral Activities

Let's turn first to a discussion of the impact of the illness on the five behavioral activities seeking to illuminate whether certain subgroups are differentially affected by the kidney disease and its treatment requirements. Some of the patients' individual comments will be included in order to clarify how they experienced the impact of their illness on these different areas. Table 2 and 3 display the patients' reports of the impact of the illness on behavioral activities differentiated by selected demographic variables.

#### Employment

Employment was the area which patients reported being most affected. Sixty-five percent of the patients said employment activities were either greatly or moderately affected by being a dialysis patient. When employment was analyzed by the demographic variables, education was the only variable significantly correlated (See Table 3). The higher the



TABLE 2  
 IMPACT OF ILLNESS ON BEHAVIOR LIFE AREAS AS DIFFERENTIATED BY  
 SEX, MARITAL STATUS AND RELIGION

Demographic Variables	Behavioral Areas									
	Employment Activities		Vacation Activities		Leisure Time Pursuits		Eating Habits		Sexual Activity'	
	Mean	t-value	Mean	t-value	Mean	t-value	Mean	t-value	Mean	t-value
<b>Sex</b>										
Males (N=36)	2.25		2.39		2.47		2.67		2.53	
Females (N=19)	1.79	1.38	2.00	1.11	1.79	2.64*	2.44	2.14	2.42	0.30
<b>Marital Status</b>										
Married (N=26)	1.85		2.15		2.35		2.62		2.12	
Other (N=29)	2.31	-1.46	2.34	-0.57	2.14	0.73	2.28	1.11	2.83	-2.19*
<b>Religion</b>										
Protestant (N=32)	2.17	0.0	2.31	0.83	2.65	0.0	2.22	-1.76*	2.47	-0.25
Catholic (N=16)	2.13		2.00		2.25		2.81		2.56	

\* $p \leq .05$ , one tail test.

**TABLE 3**  
**CORRELATIONS BETWEEN THE IMPACT OF ILLNESS ON**  
**BEHAVIORAL AREAS AND SELECTED DEMOGRAPHIC VARIABLES**

Demographic Variables	Employment Activities	Vacation Activities	Leisure Time Pursuits	Eating Habits	Sexual Activity
Income (N=47)	-.03	-.18	-.04	-.02	-.26*
Education (N=55)	.28*	.16	.26*	-.01	.29*
Length of Time on Dialysis (N=55)	.10	-.06	.22*	.11	.21

\*Correlations were significant at the .05 level, adjusted for different size N's.

educational level, the less the reported impact of illness on employment activities ( $r=.28$ ). One explanation for this finding relates to the type of employment opportunities available to those with higher levels of education. Many white-collar, desk-type positions require higher levels of education, while unskilled manual-type labor requires less education. These latter positions tend to be more physically demanding, and would be more adversely affected by limitations imposed by renal failure.

This explanation seems to be supported when this sample is viewed in terms of the socio-economic status distribution. The Hollingshead<sup>1</sup> formula was used to calculate the socio-economic statuses for the sample. We obtained data on both the educational level and occupation for 46 of the 55 patients. When the patients' reports of impact on employment activities were analyzed by social class, there was a significant negative correlation. The lower the socio-economic class, the more the patients reported their employment activities had been affected ( $r=-.23$ ,  $N=55$ ,  $p=.06$ ).

If patients reported that an area of their lives had been greatly or moderately affected by their illness, the interviewer asked in what ways. In terms of employment activities, 36 patients responded to this question. Thirty-three of their comments could be classified as negative; e.g., "I had to quit work. I don't have physical strength for my job, home, or children. I can't walk up steps and am tired. My boss isn't sensitive to my feelings and my limits." Two patients had strokes prior to their kidney failure and they felt that the stroke is what affected their employment activities. One patient seemed more optimistic

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<sup>1</sup>Hollingshead, op. cit.

stating, "my illness sets limits and guidelines, but I can manage it."

#### Vacation Activities

Fifty-six percent of the patients stated that their vacation activities had been greatly or moderately affected by their illness. However, when the area of vacation activities was analyzed by various demographic variables, there were no statistically significant associations. We had expected to find that those in the upper socio-economic statuses would be less affected through using their superior financial resources to purchase additional services that would enable them to continue former vacation activities. This was not borne out by the analysis, however. The comments of patients who stated that their vacation activities had been greatly or moderately affected by the illness revealed concerns that cut across all social classes. A number of patients stated they were afraid to go to a new center at a vacation site some distance from home because they did not know the staff. Other patients identified the limited time available for travel. One patient commented, "It's hard to go anywhere. I'm tied down three nights a week." Others noted the fact that there were no dialysis centers in other countries they wished to visit, such as Panama, or even in some rural areas of the United States.

#### Leisure Time Pursuits

Fifty-six percent of the patients stated that their leisure time pursuits had been greatly or moderately affected by their illness. When the impact on these activities was analyzed by demographic variables,

sex, education, and length of time on dialysis showed significant results (see Tables 2 and 3).

Males reported that their leisure time pursuits were less affected than females. One might speculate that males would experience a greater disruption in their leisure time pursuits because of a general inclination towards sports and physical activities. However, because the sample mean age is 46, physically oriented activities may not have had the significance they would have had if a younger sample of patients had been studied.

Another possible explanation for the difference between males and females relates to the amount of time and energy available for leisure time pursuits. Twenty-four males in the sample classified themselves as unemployed or retired, whereas only four females fell into these two categories. It seems plausible that retired and/or unemployed individuals would have more time and energy for leisure pursuits than those patients who are employed or are homemakers. Eleven of 19 women listed themselves as homemakers. The role of homemaker or mother is somewhat fixed and the responsibilities may remain even after the occurrence of illness. Also the responsibilities of managing a house and/or child care may deplete the energy of these women leaving less for leisure time pursuits. This idea was partially substantiated by the comments of 29 patients. Six of the respondents, five of whom were women, used words like "tired," "weak," or "no energy." Some stated, "I'm too tired or weak to do things." and "I can't go dancing and do things because I'm tired." The majority of the other 23 respondents noted a general decrease in activities.

A separate question regarding degree of activity was asked of all fifty-five respondents. The patients were asked? "Are you more active, the same, or less active now than before you became a dialysis patient?" Seventy-five percent said they were less active now whereas only five percent said they were more active. Renal failure for the vast majority of these patients means a decrease in general activity and a marked restriction of their leisure time activities.

The impact of renal failure and dialysis treatments on leisure time pursuits was also significantly associated with educational level. The higher the levels of schooling, the less the impact of the illness ( $r=.26$ ). One explanation for this finding is that people with more education may select activities which are more intellectual or cultural. When confronted with an illness that limits physical energy, the illness would not conflict as radically with their normal leisure time activities.

Length of time on dialysis was also significantly associated with the patients' reports of the degree of impact on their leisure time pursuits. The longer a patient had been on dialysis, the less the leisure time activities were reported affected ( $r=.22$ ). This finding probably reflects adjustment to the limitations of the illness. Patients who have been on dialysis longer may have been able to develop activities that are within the limitations imposed by their illness and consequently feel that their leisure time pursuits have been less affected.

#### Eating Habits

The impact of kidney failure and dialysis treatments on the patients' eating habits was another area explored in the interview. Fifty-six

percent of the patients reported their eating habits were greatly or moderately affected by their illness. When the area of eating habits was analyzed by different demographic variables, sex and religion showed significant associations (See Table 2).

Males reported their eating habits were less affected than those of females. One possible explanation for this finding is that the males in the study do not adhere to their dietary regimen as rigorously as females, and therefore feel less of an impact. This explanation was not supported by the concrete dietary measures of potassium and phosphorous compliance, as males and females did not significantly differ on these two measures. However, males and females may differ on eating habits in other ways. For example, males may use more salt or eat foods with higher levels of sodium than women. This would result in increased fluid intake and retention. This premise was somewhat substantiated by the finding that males were significantly less compliant with respect to between dialysis weight gains ( $t=4.81$ ,  $df=53$ ,  $p=.000$ ).

The other significant finding differentiated subgroups by religion. Catholics reported less of an impact on their eating habits than Protestants. We have no ready explanation for this finding.

We asked the patients to comment about the ways in which their eating habits had been affected. Many patients noted a loss of appetite, while others reported that they ate less and could not eat their favorite foods. One patient commented: "I had to give up a lot of foods and give up my usual restaurants." Another patient stated: "I've had a good appetite all my life and now its really hard to stick with a diet." In general, patients identified the marked changes and difficulties

encountered in making a healthy adjustment to the prescribed renal dietary regimen.

### Sexual Activity

The last of the behavioral variables to be discussed here is the patients' reports of the impact of illness on their sexual activity. Fifty-three percent of the patients said their sexual activity had been greatly or moderately affected by their kidney disease and dialysis treatments.

Scribner estimated that "about one-third of men on hemodialysis are totally impotent, one-third partially impotent, and one-third not impotent at all."<sup>1</sup> Levy found that "the initiation and continuation of hemodialysis was associated with a worsening of sexual function in 35 percent of the men and 24 percent of the women, while only 9 percent of the men and 6 percent of the women experienced improvement in sexual function."<sup>2</sup> He felt that this decrease in sexual function could be a result of the dialysis treatments affecting certain hormones or a consequence of the psychological impact of dialysis. Levy states that "patients' sexual function may worsen on programs of hemodialysis because of the emasculating effect of being on such a program, caused by reversal in family role, passivity, and dependency engendered by this procedure."<sup>3</sup>

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<sup>1</sup>Belding Scribner, Panel: Living or Dying: Adaptations to Hemodialysis, in Living or Dying: Adaptation to Hemodialysis, N.G. Levy (ed.) (Springfield, Ill.: Charles C. Thomas, 1974), pp. 3-29.

<sup>2</sup>N.B. Levy, "Sexual Factors and Rehabilitation," Dialysis and Transplantation, Vol. 7, No. 6 (June 1978), p. 592.

<sup>3</sup>Ibid., p. 592.



The three demographic variables of education, marital status, and income were significantly related to the extent of the impact of illness on sexual activity (See Tables 2 and 3). Patients with higher levels of education reported less of an impact on their sexual activity than those with lower levels of education ( $r=.29$ ). One possible explanation for this finding is that patients with higher levels of education may have been exposed to alternative ideas for dealing with sexual problems and a broader spectrum of values with reference to sexual behaviors. When confronted with the limitations imposed by renal failure, i.e., a decrease in physical energy and less sexual drive, they may be able to modify previous sexual behavior patterns as a means of coping with the new situation.

Married patients reported their sexual activity was more affected than those not married. This may in part be explained by the dissonance created by disruption of stable, ongoing sexual activity patterns. Patients' normal sexual activity would be markedly affected particularly during the acute stages of the illness. Patients with a consistent pattern of sexual activity may have more difficulty denying the changes which are concomitant with decreased physical energy and desire for sexual activity. Awareness of changes in sexual activity might be less and the tendency to deny easier among those patients without regular sexual partners or with those with whom opportunity for contact was less frequent than in ongoing, living together arrangements such as marriage.

Patients with higher incomes reported their sexual activity was more affected than those with lower incomes ( $r= .26$ ). We have no

ready explanation for this finding.

Thirty patients who stated that their sexual activity had been greatly or moderately affected responded to further inquiry with only negative comments. Thirty percent of the patients stated that they had no desire for sex. Twenty-seven percent of the patients mentioned decrease in stamina and lack of energy.

#### Affective Areas

The next three areas, ability to enjoy life, self-esteem, and sense of security relate to the patients' sense of well-being and are conceptualized as affective areas. Table 4 displays the patients' reports of the impact of the illness on these areas as differentiated by selected demographic variables.

TABLE 4  
CORRELATIONS BETWEEN THE IMPACT OF ILLNESS ON  
AFFECTIVE AREAS AND SELECTED DEMOGRAPHIC VARIABLES

Demographic Variables	Affective Areas	
	Ability to Enjoy Life	Self-Esteem
Education (N=55)	.20	-.35*
Income (N=47)	-.26*	-.11

\*Correlations were significant at the .05 level, adjusted for different size N's.

Ability to Enjoy Life

Forty percent of the patients stated that their ability to enjoy life had been greatly or moderately affected by their renal disease. Generally, the patients stated that they were unable to engage in many previous activities because of physical limitations. One patient stated: "I can't do the things I want like take vacations and go to restaurants." Another patient summarized many of the difficulties encountered by dialysis patients, saying: "I get tired a lot, and don't enjoy things with other people. The buses, subways, and shopping are all hassles now, and I can't afford to take a taxi. I also need someone with me because I can't carry the packages."

When the ability to enjoy life was analyzed by various demographic variables, income was the only one that showed a significant association (see Table 4). Patients reporting less income stated that their ability to enjoy life had been less affected by their illness than those reporting higher incomes ( $r = -.26$ ). One explanation for this findings is that patients with lower incomes may not have experienced as severe changes in their financial resources as the higher income group. Patients living on marginal incomes prior to their kidney failure would have about equivalent incomes when becoming eligible for Social Security Disability or Supplemental Security Income. Patients who had been earning better incomes may experience greater relative changes in their financial standings, which would probably affect their life styles to a greater extent. For example, if one has had the available income to take long vacations to other countries, etc., this activity may be considerably decreased with subsequent loss of income. Another change has to do

with eating habits. Often individuals with higher incomes can afford and do go out to eat at restaurants more often. Patients usually decrease the frequency of eating out, because of the difficulty with eating foods which are compatible with their renal diet.

### Self-Esteem

We also inquired about the impact of the patients' illness on their feelings of self-esteem. Thirty-six percent of the patients indicated that their self-esteem had been greatly or moderately affected by their illness. When the patients' reports of the impact of their illness on their self-esteem was analyzed by demographic variables, education was significantly correlated (See Table 4).

Patients with higher levels of education reported that their self-esteem was not as greatly affected as those with lower educational levels ( $r = -.35$ ). One possible explanation for the correlation between education and self-esteem has to do with the person's sense of self-esteem prior to experiencing kidney failure. Patients with higher educational levels may have had greater self-esteem prior to illness because of their educational accomplishments and concomitantly more prestigious employment and higher incomes. Even when faced with drastic life changes due to their illness, they may still have greater reserves of positive feelings to draw upon. While we did not have data on the patients' levels of self-esteem prior to illness, we did find a significant correlation between educational levels and levels of self-esteem as measured by Rosenberg's Self-Esteem Scale<sup>1</sup> at the time of the interview. Patients with higher levels of education had higher levels of self-esteem ( $r = -.41, p = .00$ ).

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<sup>1</sup>Rosenberg, op. cit.

Another explanation for this finding is that patients with higher educational levels may be more readily able to continue their life styles including employment, intellectual, and cultural interests. The idea of self-esteem being related to continuing a certain life style is given credence by the findings that patients with higher education levels reported their employment activities were less affected ( $r=.28$ ), and their ability to enjoy life was less affected ( $r=.20$ ,  $p=.07$ ).

When patients who reported that their self-esteem had been greatly or moderately affected were asked to elaborate, they related that they felt less capable, independent, and productive than before their kidney failure. Some patients felt they could no longer take care of their family and meet the expectations of various roles, e.g., husband, employee, mother, etc. One patient's comment reflected the potential impact of this illness on one's self-perception and self-esteem. He said: "I don't feel like a normal human being anymore."

#### Sense of Security

We thought that a life-threatening illness such as kidney failure would have considerable impact on a patient's sense of security. When patients were asked to rate the impact of their illness on this variable, surprisingly, only 36 percent of the patients indicated that their sense of security had been greatly or moderately affected as a result of their kidney failure. When the impact of the illness on the patients' sense of security was analyzed by the demographic variables, there were no statistically significant associations.

When we asked the patients who had reported being greatly or moderately affected how their sense of security had been affected, 31 percent said they felt more vulnerable financially. Other comments related to the unpredictability of the illness and feelings of emotional insecurity.

### Relational Areas

The last three areas to be discussed, relationship with friends, social contacts, and family relationships are conceptualized as relational areas. Tables 5 and 6 show the patients' reports of the impact of the illness on these areas as differentiated by selected demographic variables.

TABLE 5  
CORRELATIONS BETWEEN THE IMPACT OF ILLNESS ON  
RELATIONAL AREAS AND SELECTED DEMOGRAPHIC VARIABLES

Demographic Variables	Relational Areas		
	Relationship With Friends	Social Contacts	Family Relationships
Education (N=55)	.38*	.07	.15
Income (N=47)	.24*	-.05	-.02
Time on Dialysis (N=55)	-.04	.09	.26*

\*Correlations were significant at the .05 level, and adjusted for different size N's.

TABLE 6

IMPACT OF ILLNESS ON RELATIONAL LIFE AREAS  
AS DIFFERENTIATED BY PLACE OF BIRTH

Demographic Variables	Relational Areas					
	Relationship With Friends		Social Contacts		Family Relationships	
	Mean	t-value	Mean	t-value	Mean	t-value
Place of Birth						
New York City	2.47		2.53		2.68	
Born (N=19)		-2.24*		-1.11		.2.08*
Born Outside NYC Area (N=36)	3.19		2.92		3.31	

\*  $p < .05$ , one tail test.

#### Relationship with Friends

Thirty-one percent of the patients reported that their relationships with friends had been greatly or moderately affected by their illness. When the impact of the illness on relationships with friends was analyzed by the demographic variables, education, income, and place of birth showed statistically significant associations (See Tables 5 and 6).

The higher the patients' education, the less they reported that their relationships with friends had been affected ( $r = .38$ ). This again may reflect friendships developed around more intellectual or cultural

interests which are more readily maintained in the face of illness and treatment requirements. Another possibility is that persons with higher levels of education may have broader interests and more alternatives around which they can develop and sustain friendships.

Patients with higher incomes reported that their relationships with friends were less affected than those patients with lower income levels ( $r=.24$ ). This may reflect greater financial resources and a certain life style which may be less disrupted by dialysis treatments. Individuals with higher incomes can afford various types of transportation which would allow them to visit friends outside their specific locale. People with limited incomes may have to forego visiting if it means the rigorous task of negotiating public transportation.

Patients who were born outside the New York City area reported that their relationships with friends were less affected than those patients born in the New York City area. One possible explanation is that people who migrate develop a larger network of friends, as part of coping with the relocation, and that these bonds are less disrupted by the impact of their illness. This explanation is somewhat substantiated by the finding that patients born in places other than New York City reported having more friends ( $t=1.41$ ,  $df=53$ ,  $p=.09$ ). These two groups of patients did not differ on the amount of time they spent with their friends or on the patients' reports about how well their friends understood their kidney disease and treatment requirements.

Patients who stated that their relationships with their friends had been greatly or moderately affected were asked to elaborate. They reported that they see their friends less, and cannot participate in



many of their previous activities, such as drinking, partying, engaging in physical activities, etc. Nearly a third of the patients who responded to our in depth inquiry indicated that they had stopped seeing friends, and not vice versa.

### Social Contacts

We also inquired about the impact of the patients' kidney disease on social contacts. Forty percent of the patients stated that their social contacts had been greatly or moderately affected by their illness. When this area was analyzed by the different demographic variables, no significant associations were found. Of those patients who said their social contacts had been greatly or moderately affected, 75 percent said they do not go out at all or go out less. Many of the patients' comments suggested a movement toward isolation and indicated experiencing a general sense of loss. However, one patient seemed to have a somewhat philosophical view of his situation, stating: "Life has stopped somewhat. This illness slows your life down. You learn that a lot of different things become important. It makes you feel sorry for people who take things for granted."

### Relationship with Family

The last relational area investigated was the impact of the illness on the patients' relationship with his/her family. Twenty-nine percent of the patients stated the relationships with their families had been greatly or moderately affected by their illness. When this area was analyzed by different demographic variables, length of time on dialysis and place of birth showed significant associations. Patients who had been

on dialysis longer, reported their relationships with their families had been less affected by their illness than those patients on dialysis for a shorter period of time ( $r=.26$ ). This finding probably reflects an adjustment to dialysis by both patients and families. After the initial crisis of the illness, patients and families would likely reestablish certain levels of equilibrium.

Patients born outside the New York City area reported that their relationships with their families were less affected than those patients born in the area. One possible explanation for this finding is that individuals or families that migrated to this area tended to have a greater reliance on the family. Those patients who migrated to this area were Black patients who tended to be from the Caribbean Islands or the southern parts of the United States. The sense of family may have been stronger for this group of patients, thus the impact of the illness on family relationships was felt less.

We asked those patients who stated that their relationship with their family had been greatly or moderately affected to elaborate. Of the 15 patients who responded to this inquiry, 80 percent felt that the impact on the family had been negative. Problems included difficulties with children, divorce, sexual problems, and less contact with the family. For the three patients who felt that their relationships with the family improved, one felt the family was closer, another said they treat him nicer, and the third patient just said it was better.

#### Impact of Illness and Compliance Behavior

One may speculate on the association between impact of illness and compliance behavior in several ways. For example, one might argue

that the greater the impact of the illness, the more the person would comply in order to attempt to reestablish an equilibrium closest to the pre-kidney failure level of functioning. On the other hand, one could argue to the contrary that the greater the impact of the illness, the more discouraged a patient would become leading to increased apathy and lack of caring as to whether or not the medical and dietary regimen were followed. For those patients who felt that the illness had not greatly affected their lives, one might expect to see a trend toward continued non-compliant behavior prompted by the feeling that there was no need to modify their behavior. On the other hand, one could also argue that these very patients might worry about the potential hazards of non-compliant behavior and therefore try to be more compliant to avoid having their lives greatly affected.

We did an inter-item correlational analysis in order to ascertain the degree of relatedness of the eleven areas previously discussed (see Table 7). The alpha level of internal reliability for these eleven areas was .82. The high alpha level and the fact that the corrected item-total correlations are of moderate strength seem to indicate that these items form a very good Overall Impact of Illness Index. The one exception on the inter-item correlations was the patients' reports of the impact on family relationships. However, because this is an important variable for social workers we included it in the Index.

We then summed each patient's scores on the eleven items in order to construct the Overall Impact Scale. We correlated this Overall Impact Scale with the dependent measures of phosphorous and potassium levels, between dialysis weight gains, an overall compliance index, and patients'

TABLE 7

CORRELATIONAL ANALYSIS OF THE IMPACT OF THE ILLNESS  
ON THE ELEVEN AREAS OF THE PATIENT'S LIFE

	Eating Habits	Leisure Time	Sexual Activ- ity	Social Con- tacts	Family Rala- tions	Vacation Activity	Employ- ment Friends	Self- Esteem	Secur- ity	Enjoy Life	Corrected Item-Total Correlation <sup>a</sup>	
Eating Habits	1.0										.51	
Leisure Time Pursuits	.54	1.0									.60	
Sexual Activity	.22	.25	1.0								.44	
Social Contacts	.48	.46	.13	1.0							.58	
Family Relationships	.14	.12	.24	.21	1.0						.27	
Vacation Activities	.23	.35	.33	.45	-.01	1.0					.41	
Relationship with Friends	.29	.48	.15	.58	.26	.22	1.0				.54	
Employment Activities	.35	.33	.44	.22	.12	.33	.16	1.0			.41	
Self-Esteem	.19	.40	.26	.32	.33	.08	.48	.11	1.0		.53	
Sense of Security	.32	.21	.37	.32	.24	.21	.36	.33	.67	1.0	.56	
Ability to Enjoy Life	.35	.44	.29	.33	.07	.32	.32	.15	.48	.39	1.0	.51

NOTE: Alpha level of internal reliability for the items in this index is .82.

<sup>a</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

self-reports of compliance. Surprisingly, there were no statistically significant associations ( $p \leq .05$ ). One possible explanation for the absence of significant findings is that the extent of the impact of illness may differentially affect patients. As we speculated earlier, the extent of the impact of the illness may act as a motivator or inhibitor of compliance behavior.

Our next step was to look at each of the eleven areas and the measures of compliance behavior. Correlational analysis of each of the areas with the five dependent measures showed a total of only six statistically significant associations (see Table 8). We must add a cautionary note that given the small number of significant correlations, it is possible that some of these findings are a result of probability.

TABLE 8  
CORRELATIONAL ANALYSES OF SELECTED LIFE AREAS  
AND FIVE MEASURES OF COMPLIANCE

Life Areas	Measures of Compliance				
	Phosphorous Levels	Potassium Levels	Between Dialysis Weight Gain	Overall Compliance Index	Patients' Self-Report of Compliance
Family Relationships	-.23*	-.10	-.23*	-.25*	.14
Relationships with friends	-.03	-.01	-.26*	-.13	.08
Social Contacts	-.10	.19	-.09	-.00	.25*
Sense of Security	-.06	.26*	.06	.17	-.09

\*Correlation significant at the .05 level, for N=55.

There were significant negative correlations between the impact of the illness on family relationships and three of the dependent measures of compliance behavior. In other words, the greater the impact on family relationships, the less the compliance with respect to phosphorous ( $r=-.23$ ), between dialysis weight gain ( $r=-.23$ ), and the Overall Compliance Index ( $r=-.25$ ). As family relationships become disrupted by role reversals, increased financial pressures, and the stresses of the treatment requirements, the family may have greater difficulty in supporting the patient's adaptation to the medical and dietary regimen. Compliance may also become a control issue over which the family expresses its dysfunctional adaptation to the illness. For example, families may become overly zealous in wanting the patient to rigidly follow the medical and dietary regimen with the patient subsequently rebelling by being non-compliant. Further speculations on the role of the family vis-à-vis the patients' compliance behaviors will be discussed in Chapter IX.

Another significant finding was the relationship between the impact of the illness on friendships and compliance behavior. The greater the impact on friendship, the less the patient's compliance with respect to between dialysis weight gain ( $r=-.26$ ). While we have no ready explanation for this finding, this area warrants further attention by the health care team, as this appears to be one which could be influenced by professional interventions.

The other significant finding was that patients who identified themselves as compliant experienced a greater disruption in terms of social contacts ( $r=.25$ ). Patients have identified and/or may perceive

social events as difficult because others often do not realize their need to restrict their sodium intake, amount of fluids, certain foods, etc. Hosts may either not provide the proper food substitutes or may encourage the patient to be non-compliant in terms of saying "have another drink," etc. Because of these stresses the patient, who wants to be compliant may avoid these social events. While this behavior may assist them in being more compliant with their medical and dietary regimen, the results may be deleterious to their social life.

We also found that patients who reported less of an impact on their sense of security were less compliant with respect to potassium levels ( $r=.26$ ). This finding may be viewed from the perspective of the dysfunctional utilization of the defense mechanism of denial. Realistically, renal failure poses many potential problems and assaults to one's sense of security. If a patient denies the limitations and potential problems of the illness, then one could also deny the need to follow the diet, which could result in non-compliant behavior.

#### Summary

Renal failure has a pervasive impact on patients' lives. In this study we found that the behavioral areas of employment activities, sexual activities, eating habits, vacation activities, and leisure time pursuits were the aspects most affected by renal failure and the subsequent adaptation to a dialysis regimen.

Less educated, married female patients, new to dialysis, seem to be hit the hardest by the impact of renal failure and dialysis treatment. Patients with less education reported more of an impact regarding employ-

ment activities, leisure time pursuits, sexual activity, self-esteem and relationships with friends. Higher educational levels seem to mediate the impact of the illness on the patient. Perhaps patients in these categories have greater internal and external resources to draw upon while making changes necessitated by the illness and treatment regimen.

Female patients reported a greater disruption with respect to leisure time pursuits and eating habits than male patients. Being a relatively new patient to dialysis seems to impact greatest on the areas of leisure time pursuits and family relationships. Married patients experienced a greater upheaval in terms of their sexual activity than those not married.

The lack of an abundance of associations between the impact of the illness and compliance behavior, lends some credence to the idea of differential reactions to illness. As discussed previously, we feel that the degree of impact of the illness may act as a motivator or inhibitor with respect to adjusting and complying with the medical and dietary regimen, however, this warrants further research. Understanding which groups of patients are most affected by the impact of renal failure will assist the health care team in providing the maximum support.



## CHAPTER VIII

### THE ROLE OF INTRA-PERSONAL VARIABLES AND COMPLIANCE BEHAVIOR

Mr. S. is a forty-three year old Black male who until eight months ago was actively employed as a dock worker. His kidney failure was a result of hypertension which had never been diagnosed. One day he began to feel ill and after several days of being unable to work, he went into the hospital. He was diagnosed as having uremia and placed on dialysis the following day. He was admitted to the hospital several times in the past few months because his fistula was not working properly. The patient appears depressed to the staff and they think he may also be taking drugs or alcohol. He tends to become fluid overloaded frequently.

Ms. A., a sixty-year old, separated, Hispanic female who immigrated to New York City from South America in the 1950s, has been on dialysis for one year. She is a devout Catholic and is actively involved with the Church. Her several grown children are in frequent phone contact with her and visit weekly. Ms. A. is rather quiet and withdrawn during dialysis but her understanding of her prescribed regimen is quite good as are her compliance levels. In the past, she was less compliant for a short period of time but this seemed to be associated with upset when one of her children was in a serious car accident. She was able to utilize the social worker and other staff during this crisis period.

Mr. W. is a twenty-seven year old married Black male who has been on dialysis for three years. He avidly reads everything he can find on kidney failure and dialysis treatments. He monitors his dietary and fluid intake very closely and this is reflected in his monthly chemistries and between dialysis weight gains which are excellent. He seems to have a very high level of self-esteem and states that if he follows his prescribed regimen, he will remain healthy. When confronted with personal problems, he reaches out to other patients, friends, and staff.

Are there specific coping activities which help patients deal with the crisis of illness? Do these patients' attitudes toward illness and following a prescribed medical regimen affect their compliance behavior? Are their affective states, levels of knowledge about the prescribed medical and dietary regimen, or self-esteem related to their compliance behavior? These are some of the questions that we will be seeking to better understand.

#### Life Crises and Compliance Behavior

Crises often upset one's normal routine and probably affect dialysis patients' adherence to their medical and dietary regimen. As discussed in Chapter III, crises in patients' lives have been identified as being associated with non-compliant behavior. We wanted to know the extent to which the patients in this sample had experienced a life crisis in the past twelve months. Each patient was asked the following question: "Now I want to ask you about whether any major changes or crises have happened to you or your family in the past twelve months? Has anyone you have known well died, divorced or separated, lost a job, moved out of your house or out of the city, had a serious illness or accident, or experienced other upsetting events?"

Sixty-four percent (N=35) of the patients stated that they had experienced one or more of these crises in the last year, while 36 percent (N=20) reported no major life crises for this period of time. When we compared these two groups of patients on the five dependent measures of phosphorous and potassium levels, between dialysis weight gains, the Overall Objective Compliance Index, and the Patient's Self-Report of

Compliance, we found one significant association. Patients who had experienced crises within the past 12 months were significantly less compliant with respect to between dialysis weight gains, then the group of patients who had not experienced any in this time period. (see Table 1).

If a patient had begun to adjust to the renal diet, some of the major sources of phosphorous and potassium have probably been eliminated from their diet. When a crisis occurs they may not deviate markedly from their general dietary behavior, however, fluid intake may be another issue. Renal patients have clearly identified thirst as a constant problem and maintaining the required limits on fluid intake is a major concern. When a crisis occurs, the patient may not have the required reserve of energy or "will power" to maintain the strict fluid intake restriction (often one quart a day) therefore they become non-compliant with respect to between dialysis weight gains.

Another possible explanation relates to the patients' capacities to recognize or communicate to the staff upsetting events in their lives. Perhaps patients who have experienced upsetting events have difficulty connecting these events with changes in their compliance behavior. When there are problems with dietary compliance, as reflected in monthly reports of phosphorous and potassium levels, the staff usually just reminds the patients to be more compliant. However, this author observed that when a patient begins to come in for dialysis treatments fluid overloaded, the staff will immediately notice and comment on this behavior. If the behavior persists, the staff usually begins to explore with the patient the reasons for the change in behavior. Becoming fluid overloaded may be patients' non-verbal attempts to alert the staff that they are in

TABLE 1

MEANS OF MEASURES OF COMPLIANCE ACCORDING TO  
WHETHER PATIENT EXPERIENCED EARLIER CRISES

Life Crises <sup>a</sup>	Measures of Compliance									
	Phosphorous		Potassium		Between Dialysis Weight Gains	Overall Objective Index	Patients' Self- Reports			
	Mean	t-value	Mean	t-value	Mean	t-value	Mean	t-value		
Yes - Life Crises in past 12 months (N=35)	5.15		5.53		4.99		.24		18.99	
		.82		-.55		2.18*		1.06		-.83
No - Reported Crises in past 12 months (N=20)	4.87		5.61		4.23		-.42		19.95	

<sup>a</sup>Question posed to respondent: "Now I want to ask you about whether any major changes or crises have happened with you or your family in the past twelve months. Has anyone you have known well: died, divorced or separated, lost a job, moved, had a serious illness or accident, or anything similar?"

\*p < .05, one-tail test.

need of help.

Coping Activities and  
Compliance Behavior

We wanted to better understand how these patients might cope with life crises and whether different coping activities were associated with varying levels of compliance behavior.

The interviewer read the following statement to each patient. "People handle or cope with difficult or upsetting situations (such as being a dialysis patient) in different ways. Tell me how often you use the following ways when you are dealing with a difficult situation." Patients were then read a list of fifteen alternative responses for handling a crisis situation, and were asked to state the degree to which they employed each of the activities. For each coping activity the patient had five choices for responding: always, frequently sometimes, seldom, or never. Table 2 presents the fifteen coping activities ordered from the most commonly utilized (#1) to the least utilized activity (#15).

We utilized factorial analysis as a guide in determining which of these fifteen coping activities tended to cluster together. We used only one statistical pass in selecting the items for the indexes. For the purpose of this research, we chose to deal with only the eight items which we identified as clustering together into two separate groups which had the themes of reaching out to other people and avoidance. Let's now look at these two coping indexes and their relationship to the compliance measures.

TABLE 2  
 COPING ACTIVITIES UTILIZED TO DEAL WITH LIFE CRISES<sup>a</sup>  
 (N=55)

Coping Strategy	<u>Mean Score</u>
1. I look for ways to improve myself and my situation.	1.8 <sup>b</sup>
2. I just rely on myself.	2.1
3. I just keep thinking that things will get better.	2.2
4. I pray or go to church/synagogue.	2.3
5. I throw myself into some activity, such as work, clubs, something.	3.0
6. I rely or depend on my family to help me with the situation.	3.2
7. I get angry or upset.	3.3
8. I just don't think about my situation.	3.4
9. I sleep a lot.	3.5
10. I talk about my problems with other people.	3.8
11. I seek professional help, such as a psychologist, psychiatrist, social worker.	4.0
12. I just want to run away from the problem.	4.1
13. I look for help from my friends.	4.1
14. I have a drink or use medications.	4.1
15. I just break down and don't handle it.	4.4

NOTE: This scale was constructed by the author.

<sup>a</sup>Instruction to the respondent: "People handle or cope with difficult or upsetting situations (such as being a dialysis patient) in different ways. Tell me how often you use the following ways when you are dealing with a difficult situation."

<sup>b</sup>The lower the mean score, the more the coping strategy is utilized. Always = 1, Frequently = 2, Sometimes = 3, Seldom = 4, Never = 5.

The first group of coping activities included five items: "I just don't think about my situation. I talk about my problems with other people. I just rely on myself. I rely or depend on my family to help me with the situation. I look for help from my friends." In order to construct a coping index for these five activities, we needed to reverse the scores for items one and three as they were negatively correlated with the other items. As seen in Table 3, the inter-item correlations for this combined coping index showed an alpha level of internal reliability of .70. The fairly strong correlated item-total correlations and the moderately high alpha level indicates that these items form a good index. We then summed each patient's scores on the five items in order to construct a combined index.

The second group of coping activities included three items: "I just want to run away from the problem. I have a drink or use medications. I look for ways to improve myself and my situation." In order to construct a coping index for these three items, we needed to reverse the scores for item three as it was negatively correlated with the other items. As seen in Table 5, the inter-item correlations for this combined index showed an alpha level of .57. This does not seem to be a very strong index as the alpha level is only fair and the corrected item-total correlations are just of moderate strength. The next step in constructing this combined index was summing the patient's scores for the three items.

When we correlated these two Coping Indexes with the dependent measures of compliance, we found six statistically significant associations (See Table 5). In terms of the first Coping Index, we found that the more the patients reached out to others and the less they relied upon

TABLE 3  
CORRELATIONAL ANALYSIS OF THE COPING INDEX OF ITEMS  
RELATED TO THE USE OF OTHER PEOPLE

Coping Activity	Intercorrelation Among Items					Corrected Item-Total Correlation <sup>a</sup>
	Cope 1	Cope 2	Cope 3	Cope 4	Cope 5	
1. <sup>b</sup> I just don't think about my situation	1.0					.41
2. I talk about my problems with other people.	.25	1.0				.50
3. <sup>b</sup> I just rely on myself.	.18	.32	1.0			.47
4. I rely or depend on my family to help me with the situation.	.30	.33	.40	1.0		.41
5. I look for help from my friends.	.38	.46	.29	.30	1.0	.49

NOTE: Alpha level of internal reliability of this index was .70.

<sup>a</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

<sup>b</sup>Patients scores were reversed for this item.



TABLE 4

CORRELATIONAL ANALYSIS OF THE COPING INDEX  
OF ITEMS RELATED TO AVOIDANCE

Coping Activity	Intercorrelation Among Items			Corrected Item-Total Correlation <sup>a</sup>
	Cope 1	Cope 2	Cope 3	
1. I just want to run away from the problem	1.0			.44
2. I have a drink or use medi- cations	.42	1.0		.43
3. <sup>b</sup> I look for ways to improve myself and my situation	.27	.21	1.0	.31

NOTE: Alpha level of internal reliability of this index was .57.

<sup>a</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

<sup>b</sup>Patients' scores for this item were reversed.

just themselves--or denied the situation--the more compliant they were with respect to phosphorous ( $r=.25$ ), potassium ( $r=.40$ ), between dialysis weight gains ( $r=.29$ ), and the Overall Objective Index ( $r=.42$ ). These findings tend to support the importance of maintaining and utilizing a social support network in coping with the stresses of renal failure and the prescribed medical and dietary regimen. The utilization of denial or not thinking about the situation may include denying the necessity of

following the prescribed regimen. Patients who stated they just relied on themselves are probably also denying the extent to which they need other people in order to survive and cope with this illness. Realistically, the patient depends on the staff for a safe and successful dialysis treatment.

TABLE 5  
CORRELATION BETWEEN TWO COMBINED INDEXES OF  
COPING ACTIVITIES AND THE FIVE MEASURES OF  
COMPLIANCE BEHAVIOR

Coping Indexes	<u>Measures of Compliance</u>				
	Phosphorous Levels	Potassium Levels	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self-Report
Coping Index 1 <sup>a</sup> Theme-Use of Other People	.25*	.40**	.29*	.42***	-.09
Coping Index 2 <sup>b</sup> Theme of Avoidance	-.28*	-.12	-.10	-.22*	-.20

<sup>a</sup>Items in this Index included: I don't think about my situation. I talk to other people about my problems. I just rely on myself. I rely or depend on my family to help me with the situation. I look for help from my friends.

<sup>b</sup>Items in this Index included: I just want to run away from the problem. I have a drink or use medications. I look for ways to improve myself and my situation.

\*Correlation was significant at the .05 level, for N=55.

\*\*Correlation was significant at the .01 level, for N=55.

\*\*\*Correlation was significant at the .001 level, for N=55.

We found the second Coping Index significantly correlated with phosphorous levels ( $r = -.28$ ), and the Overall Objective Index ( $r = -.22$ ), (see Table 4). The Coping Index has the theme of avoiding the stressful situation or attempting to master the situation by changing oneself or the environment. Hartman<sup>1</sup> conceptualized three approaches to successful adaptation, alloplastic (changing aspects of the environment) autoplatic (changing oneself) or leaving the situation. Our findings seem to indicate that patients who attempt to actively master their situations are better able to adhere to certain aspects of the prescribed regimen than those patients who seek to avoid the situation.

While the correlations between the Coping Indexes and certain compliance measures were statistically significant, they only indicate the presence of associations and do not identify which variable precedes the other. It is plausible that non-compliance, i.e., high levels of phosphorous, potassium and weight gains, debilitate the patient physically or emotionally and may precede a withdrawal from others, more reliance of oneself, more denial and less energy to attempt to improve the situation. Conversely, compliant patients may feel better physically and emotionally and this may facilitate interactions with others, and create less need for denial and more energy to improve their situation.

#### Patients' Attitudes and Compliance Behavior

In this section, we will be discussing the patients' attitudes about the likelihood of certain medical events occurring, the seriousness

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<sup>1</sup>Heinz Hartmann, Ego Psychology and the Problem of Adaptation (1939) (New York: International Universities, 1958).

of these events, and the degree to which they worry about them. Patients' reports of other factors affecting their compliance with the medical and dietary regimen will also be included.

In our questionnaire, we utilized a series of items previously tested by Hartman and Becker<sup>1</sup> and included in their Health Belief Model.<sup>2</sup> These questions were aimed at eliciting the perceptions and attitudes of the patients about susceptibility and severity of illness, and the degree of concern about illness and the sequelae of non-compliance.

In order to elicit the patients' attitudes about their susceptibility to the possible effects of non-compliance behavior, we asked them the following question: "Now I'm going to ask you for each of the following items, how likely you think it is that this could happen to you during the next year?" The eight items were: acquire very high levels of potassium in your blood; store up too much fluid in your body between treatments; experience cramps in your legs; develop bone disease; become very weak; have a heart attack; to into a coma; get very depressed. The patients were asked to chose a response from a seven point Likert scale ranging from almost certain to happen, to no chance at all. We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these eight items. The alpha level of internal reliability for the Susceptibility Index was .85 (see Table 6). The

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<sup>1</sup>Paula Hartman, Dialysis and Transplantation, *op. cit.*

<sup>2</sup>M. H. Becker, *et al.* "Selected Psychosocial Models and Correlations of Individual Health-Related Behaviors," Medical Care, 15 (Supl) 27-46, 1977,

TABLE 6

CORRELATIONAL ANALYSIS OF PATIENTS' BELIEFS OF SUSCEPTIBILITY INDEX<sup>a</sup>

Items in Index	Intercorrelation Among Items								Corrected Item-Total Correlation <sup>b</sup>
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	
1. Getting very high levels of potassium in your blood	1.0								.53
2. Store up too much fluid in your body between treatments	.58	1.0							.62
3. Get cramps in your legs	.25	.52	1.0						.41
4. Develop bone disease	.43	.30	.21	1.0					.58
5. Become very weak	.42	.52	.33	.60	1.0				.70
6. Have a heart attack	.18	.36	.34	.53	.53	1.0			.61
7. Go into a coma	.47	.31	.23	.59	.47	.59	1.0		.67
8. Get very depressed	.35	.46	.23	.27	.54	.48	.60	1.0	.58

NOTE: Alpha level of internal reliability for this index is .85.

<sup>a</sup>Instruction to the respondent: "Now I'm going to ask you, for each of these things, how likely you think it is that it could happen to you during the next year?"

<sup>b</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

high alpha level and the strong corrected item-total correlations indicate that this is a very good Index. We then summed each patient's scores on the eight items in order to construct the Overall Susceptibility Index.

We then explored the patients' perception of the severity of these medical events. We read the same list of eight items to the patients and asked them: "Suppose each of these things were to happen to you in the next year. How serious would each one be to you?" We followed the same procedure of inter-item correlation analysis (see Table 7), and constructed an Overall Seriousness Scale. The alpha level of internal reliability for this overall scale was .88. Again, the high alpha level and strong corrected item-total correlations indicate that these items form a very good Index.

The next set of attitudinal questions related to the patients' degree of concern (worry) about the previous list of events. We made several modifications in this list of items. For example, we deleted the depression item and added: "Do you worry about the appearance of your arm with the fistula?" and "The appearance of your skin?" We also added four additional questions relating to their kidney disease, other concerns, needing dialysis treatments, and following the staff's instructions. The complete list of questions is provided in Table 8. We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these fourteen items (see Table 8). The alpha level of internal reliability was .90. This Index is one of the strongest as it has a very high alpha level and very good corrected item-total correlations. We then summed each patient's scores on the fourteen items in order to construct an Overall Concern Scale.

TABLE 7

CORRELATIONAL ANALYSIS OF PATIENTS' BELIEFS ABOUT SEVERITY OF SEQUELAE OF NON-COMPLIANT INDEX<sup>a</sup>

Items in Index	Intercorrelation Among Items								Corrected Item-Total Correlation <sup>b</sup>
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	
1. Get very high levels of potassium potassium in your blood	1.0								.58
2. Store up too much fluid in your body between treatments	.61	1.0							.48
3. Get cramps in your legs	.48	.44	1.0						.57
4. Develop bone disease	.41	.35	.47	1.0					.68
5. Become extremely weak	.41	.33	.50	.66	1.0				.75
6. Have a heart attack	.41	.16	.31	.61	.68	1.0			.71
7. Go into a coma	.46	.29	.37	.55	.68	.92	1.0		.73
8. Get very depressed	.27	.51	.42	.45	.51	.51	.55	1.0	.62

NOTE: Alpha level of internal reliability is .88.

<sup>a</sup>Instruction to the respondent: "Here is this list again. Suppose each of these things were to happen to you in the next year. How serious would each one be to you?"

<sup>b</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

TABLE 8  
CORRELATIONAL ANALYSIS OF PATIENTS' CONCERN ABOUT SEQUELAE OF NON-COMPLIANCE INDEX<sup>a</sup>

Items in Index	Intercorrelation Among Items															Corrected Item-Total Correlation <sup>b</sup>	
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10	Item 11	Item 12	Item 13	Item 14	Item 15		
1. How would you rate how worried you are about your kidney disease?	1.0																.60
2. Compared to other concerns, how worried are you about your health?	.56	1.0															.52
3. How much do you worry about needing dialysis treatments?	.45	.38	1.0														.66
4. How worried are you about being able to do all the things the staff tells you to do?	.32	.41	.52	1.0													.54
5. Getting high levels of potassium in your blood	.34	.36	.55	.29	1.0												.61
6. Your body storing up too much fluid between treatments	.39	.35	.48	.38	.66	1.0											.60
7. Getting cramps in your legs	.05	.24	.37	.45	.43	.49	1.0										.42
8. Getting bone disease	.31	.21	.37	.15	.41	.34	.15	1.0									.55
9. Becoming very weak	.54	.57	.44	.38	.31	.30	.31	.51	1.0								.69
10. Having high blood pressure	.33	.36	.44	.26	.37	.40	.28	.63	.61	1.0							.61
11. The possibility of having a heart attack	.63	.35	.37	.41	.34	.44	.31	.40	.67	.52	1.0						.71
12. The possibility of going into a coma	.47	.30	.40	.27	.66	.44	.29	.54	.49	.55	.60	1.0					.66
13. The appearance of your arm with the fistula	.36	.18	.50	.38	.21	.14	.11	.38	.23	.43	.43	.27	1.0				.49
14. The appearance of your skin	.41	.28	.34	.47	.23	.37	.19	.26	.36	.12	.53	.31	.64	1.0			.53

NOTE: Alpha level of internal reliability in this index is .90.

<sup>a</sup>Instruction to the respondent: "Even among people who have a health problem, some people are very worried about their health, while others are not as worried. How worried are you about....?"

<sup>b</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.



When we correlated these three attitudinal Indexes with the measures of compliance, we found three statistically significant associations (see Table 9). The Overall Susceptibility Index was not statistically correlated with any of the compliance measures. However, Hartman and Becker found in their study that compliant patients were far less likely than non-compliant patients to feel these problems could happen to them during the next twelve months. They state that "the patients believe (or have come to believe) their adherence to the prescribed therapy will successfully protect them from the untoward consequences of poorly controlled disease, i.e., that their actions make them less susceptible to sequelae usually associated with non-compliance."<sup>1</sup> One possible explanation for the discrepancy in this study's findings and their study is the idea that some compliant patients may think these problems could happen to them, and therefore follow their medical and dietary regimen as an attempt to forestall the occurrence of these events.

The Overall Seriousness Scale was correlated with potassium compliance. The more the patient said these events would be serious, the more compliant they were with respect to potassium compliance ( $r=-.23$ ). One might speculate that if a patient perceived a greater severity of an event, this might act as a stimulant toward greater compliance. Hartman and Becker<sup>2</sup> found that the patients' perception of the severity of these events was correlated with phosphorous compliance and between dialysis weight gains. They found that the higher the level of perceived

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<sup>1</sup>Paula Hartman, op. cit., p. 981.

<sup>2</sup>Ibid.

**TABLE 9**  
**CORRELATIONS BETWEEN AMOUNT OF CONCERN AND BELIEFS**  
**ABOUT SUSCEPTIBILITY AND SEVERITY AND**  
**FIVE MEASURES OF COMPLIANCE**

Beliefs Indexes	Measures of Compliance				
	Phospho- rus	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Report
Overall Susceptibility Index	-.13	-.17	.06	-.10	-.01
Overall Severity Index	-.05	-.23*	.10	-.08	-.04
Overall Concern Index	-.15	-.35**	-.12	-.28*	-.06

\*Correlation was significant at the .05 level, for N=55.

\*\*Correlation was significant at the .01 level, for N=55.

severity, the greater the degree of compliance. This study's findings and Hartman and Becker's findings seem to indicate that if patients perceive the sequelae of non-compliance as very serious, they then tend to be compliant.

As seen in Table 9, the Overall Concern Index was significantly associated with two of the dependent measures of compliance. We found the greater the degree of concern about these events, the more compliant the patients were with respect to potassium levels ( $r = -.35$ ) and the Overall

Compliance Index ( $r = -.28$ ).

This study's findings about the patients' degree of concern are consistent with the earlier formulations and assumptions of the Health Belief Model. Specifically, the Health Belief Model assumed that the more patients worried about their illness, the more likely they were to be motivated to take appropriate actions to manage the illness. However, Hartman and Becker<sup>1</sup> found that often the ones who worried the least were the most compliant patients. Their explanation for this finding was that compliant patients may be doing everything they are supposed to be doing and/or are following the medical recommendations as closely as possible and, therefore, are not worried about the sequelae of non-compliance. We believe that patients who are worried are utilizing less denial about their illness, and thus are realistic about the possible hazards of the illness and potential sequelae of non-compliance.

This study's findings suggest that patients who perceive a greater severity of the sequelae of non-compliance and are concerned about the possible effects of non-compliance tend to be more compliant. As previously discussed, some of our findings are consistent with the current Health Belief Model's formulations and with Hartman and Becker's study, and other findings are more consistent with the earlier formulations of the Health Belief Model. The lack of greater consistency between this study and Hartman and Becker's may be attributable to the difference in the racial and cultural compositions of the two groups, and concomitantly

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<sup>1</sup>Ibid.

different attitudes about illness and compliance behavior. In their study, there were eighteen percent non-white patients as compared to eighty-two percent in this study.

Again we must consider an alternative explanation for the significant correlations between the Overall Severity and the Overall Concern Indexes and the measures of compliance. Non-compliance may affect one's perceptions of severity and levels of concern with respect to the potential sequelae of non-compliance behavior. That is, a patient who knows his/her chemistries and weight gains are poor may need to perceive the sequelae of non-compliance as less important, because to realistically face them might cause them more harm than denying the potential effects of non-compliance.

#### Potential Attitudinal and Situation Barriers and Compliance Behavior

We also explored other potential attitudinal and situational barriers which could affect a patient's compliance with their medical and dietary regimen. Patients were asked several questions relating to situations, affective states, and beliefs about their medication compliance. We asked the patients: "Do you ever not take medications because you get too busy and forget to? Do you ever not take your medications because you don't care, you feel down, depressed? Have you ever stopped taking medications when you thought you felt better? Do you feel better when you don't take your pills? and Do you ever not take your medications because you don't think they are necessary?"

We reversed the scores for item three and then did an inter-item correlational analysis in order to ascertain the degree of relatedness

of these five items. The alpha level of internal reliability for these items was .71 (see Table 10). The fairly high alpha level and the strong corrected item-total correlations indicate that these five items form a good Index. We summed each patient's scores on these items and constructed an Overall Medication Barrier Index.

In terms of barriers to compliance with the dietary instructions, we asked the following three questions: "Do you ever not follow your diet because you don't care, you are down or depressed? Have you ever accepted a drink or some food that was off your diet because you are uncomfortable about refusing it? Do you ever not follow your diet because you don't think it is necessary?" We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these three items. The alpha level of internal reliability for these items was .66 (see Table 11). This is not a very strong index as the alpha level is only fair and the corrected item-total correlations are just of moderate strength. We summed each patient's scores on these three items and constructed an Overall Dietary Barrier Index.

When we correlated the Medication Barrier and Dietary Barrier Indexes with the five measures of compliance, there were six statistically significant associations (See Table 12). The Medication Barrier Index was correlated with three of the dependent measures. The more often patients stated they experienced these various barriers, the less compliant they were with respect to phosphorous compliance ( $r=-.40$ ), Overall Objective Compliance Index ( $r=-.23$ ), and the Patients' Self-Reports of Compliance ( $r=.51$ ). These findings are consistent with other studies<sup>1,2</sup> and support

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<sup>1</sup>Paula Hartman, op. cit.

<sup>2</sup>Blackburn, op. cit.

TABLE 10  
 INDEX OF BARRIERS TO MEDICATION COMPLIANCE  
 (N=55)

Items in Index	Intercorrelations Among Items					Corrected Item-Total Correlations <sup>a</sup>
	Item 1	Item 2	Item 3	Item 4	Item 5	
1. Do you ever not take medications because you get too busy and forget to?	1.0					.56
2. Do you ever not take your medications because you don't care, you feel down, depressed?	.42	1.0				.53
3. Have you ever stopped taking medications when you thought you felt better?	.30	.29	1.0			.48
4. Do you feel better when you don't take your pills?	.57	.38	.42	1.0		.70
5. Do you ever not take your medications because you don't think it is necessary?	.44	.61	.56	.73	1.0	.77

NOTE: Alpha level of internal reliability for this index is .81.

<sup>a</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

**TABLE 11**  
**CORRELATIONAL ANALYSIS OF BARRIERS TO**  
**DIETARY COMPLIANCE**

Barriers	Intercorrelation Among Items			Corrected Item-Total Correlation <sup>a</sup>
	Item 1	Item 2	Item 3	
Do you ever not follow your diet because you don't care, you are down, depressed?	1.0			.63
Have you ever accepted a drink or some food that was off your diet because you were uncomfortable about refusing it?	.51	1.0		.40
Do you ever not follow your diet because you don't think it is necessary?	.49	.22	1.0	.41

NOTE: Alpha level of internal reliability for this index is .66.

<sup>a</sup>Correlation is between each item and the sum of all other items in the Index with the item itself deleted to correct for auto-correlation.

the idea that there are internal and external barriers which may affect a patient's compliance with their medication instructions. The patient, by their own report ( $r=.51$ ), tend to confirm the idea that there are specific barriers to their being more compliant with the prescribed regimen. It would be important for the health care team to explore these various areas with individual non-compliant patients in order to

identify the specific barriers which may be affecting the patients' compliance behavior.

TABLE 12  
CORRELATIONS BETWEEN BARRIERS TO  
MEDICATION AND DIETARY COMPLIANCE  
AND THE MEASURES OF COMPLIANCE

Barriers	Measures of Compliance				
	Phospho- rous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Report
Overall Medication Barrier Scale	-.40**	.01	-.12	-.23*	.51***
Overall Dietary Barrier Scale	-.14	-.09	-.32**	-.25*	.52***

\*Correlation was significant at the .05 level, for N=55.

\*\*Correlation was significant at the .01 level, for N=55.

\*\*\*Correlation was significant at the .001 level, for N=55.

The Dietary Barrier Index was significantly correlated with three of the dependent measures of compliance (see Table 12). The more often patients stated that they experienced these various barriers, the less compliant they were with respect to between dialysis weight gains ( $r=-.32$ ) and the Overall Compliance Index ( $r=-.25$ ), and the more often they identified themselves as being non-compliant ( $r=.52$ ). Again these findings



substantiate the idea of specific situational or emotional barriers to compliance behavior. The patients' self-reports of compliance are consistent with the results of the objective measures.

Cognitive Understanding of the  
Medical and Dietary Regimen

Another area of importance is the patients' cognitive understanding of their medical and dietary regimen. One would not expect compliance behavior from a patient who had no understanding of the regimen. We approached this area of cognitive understanding of the regimen from two perspectives, the actual level of understanding and the patients' subjective reports of their degree of understanding.

We examined three areas related to the patients' cognitive understanding and compliance behavior including the amount of formal schooling, the actual level of the patients' knowledge of their medical and dietary requirements, and the patients' reports of their subjective understanding of the regimen. As mentioned in Chapter VI, the greater the number of years of formal schooling, the more the compliance with respect to between dialysis weight gains ( $r=-.31$ ). While this finding may be useful for attempting to screen potentially non-compliant patients, it is not a variable which can be easily modified. However, the actual level of the patients' knowledge about their medical and dietary regimen is something which could be influenced.

Patients were asked thirteen questions relating to their diet, fluid intake, and medications. Some of these questions had been previously utilized in Blackburn's study,<sup>1</sup> and all the questions were

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<sup>1</sup>Blackburn, *op. cit.*

reviewed by several dieticians in order to select questions which were assumed to be common knowledge for dialysis patients at the Brooklyn Kidney Center. (See Appendix A, pp. 273 to 275 for list of questions.) We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these thirteen items (see Table 13). The alpha level of internal reliability was .78. The fairly high alpha level and the fact that the corrected inter-item correlations are of moderate strength indicates that these items form a good Index. We summed each patient's scores on these items in order to construct an Overall Objective Knowledge Index. The mean of this scale was 17.4 and the scores ranged between 13 and 22.

We thought that of possibly equal importance with the actual level of knowledge would be the patients' subjective views of their own degree of understanding about their medical and dietary regimen. Patients were asked to rate their degree of understanding of their diet, kidney disease, medications, and fluid instructions. We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these four items (see Table 14). The alpha level of internal reliability was .60. This does not seem to be a very strong Index as the alpha level is not that high and one of the corrected item-total correlations is somewhat weak. We did, however, construct an Overall Subjective Understanding Index by summing each patient's scores on these four items.

When we correlated the Overall Objective Knowledge Index and the Overall Subjective Knowledge Index with the five measures of compliance, there was a total of four statistically significant associations (see Table 15). The higher the Objective Knowledge score, the greater the

TABLE 13  
CORRELATIONAL ANALYSIS OF THE PATIENTS'  
KNOWLEDGE ABOUT THEIR MEDICAL AND DIETARY REGIMEN<sup>a</sup>  
(N=55)

Items	Intercorrelations Among Items													Corrected Item-Total Correlations <sup>c</sup>	
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10	Item 11	Item 12	Item 13		
Item 1 <sup>b</sup>	1.0														.48
Item 2	.11	1.0													.34
Item 3	.35	.19	1.0												.51
Item 4	.22	.23	.07	1.0											.39
Item 5	.27	.22	.27	.29	1.0										.40
Item 6	.30	.11	.51	.08	.35	1.0									.41
Item 7	.11	.30	.34	.01	.08	.13	1.0								.31
Item 8	.40	.18	.21	.21	.37	.12	.06	1.0							.42
Item 9	.19	.17	.19	.15	.10	.25	.24	.48	1.0						.46
Item 10	.16	.19	.08	.25	.16	.11	.14	.13	.32	1.0					.31
Item 11	.14	.03	.14	.26	.18	.19	.13	.31	.37	.12	1.0				.32
Item 12	.29	.31	.41	.33	.25	.35	.29	.24	.28	.17	.09	1.0			.54
Item 13	.44	.17	.38	.27	.27	.17	.16	.21	.20	.26	.20	.33	1.0		.49

NOTE: Alpha level of internal reliability for this index is .79.

<sup>a</sup>Instruction to the respondent: "Now I would like to ask you some questions about your diet and medications. I am going to give you some responses to each question, and I want you to tell me which is correct."

<sup>b</sup>The entire list of questions and response choices are in Appendix A; Structured Interview Schedule pp.113 to 115.

<sup>c</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

TABLE 14  
CORRELATION ANALYSIS OF THE PATIENTS' SUBJECTIVE  
UNDERSTANDING OF MEDICAL AND DIETARY REGIMEN  
(N=55)

Subjective Understanding	Intercorrelations Among Items				Corrected Item-total Correlation <sup>a</sup>
	Item 1	Item 2	Item 3	Item 4	
1. How well do you feel you understand your diet?	1.0				.50
2. How well do you feel you understand your fluid instructions?	.58	1.0			.47
3. How well do you feel you understand your medications and instructions?	.44	.35	1.0		.46
4. How well do you understand your kidney disease?	.13	.11	.22	1.0	.19

NOTE: Alpha level of internal reliability for these items is .60.

<sup>a</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

compliance with respect to phosphorous ( $r=.23$ ) and the Overall Compliance Index ( $r=.23$ ). Phosphorous compliance requires an understanding of the dietary restrictions and the role of the phosphorous binding medication. Patients with lower knowledge scores may not understand the importance of

both of these factors, and may be paying attention to only one of them which might account for their being less compliant.

TABLE 15  
CORRELATIONS BETWEEN OBJECTIVE AND SUBJECTIVE  
KNOWLEDGE SCALES AND FIVE MEASURES OF COMPLIANCE

Knowledge Areas	Phosphorous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self-Reports
Objective Knowledge Scale	.23*	.12	.16	.23*	.15
Subjective Knowledge Scale	.28*	.19	.14	.24*	-.03

\*Correlation was significant at the .05 level, for N=55.

The association between higher knowledge scores and the Overall Compliance Index seems to support the idea, albeit in moderate fashion, that for most patients a basic understanding of the medical and dietary regimen is a necessary factor for better compliance.

As seen in Table 15, the Overall Subjective Knowledge Index was significantly correlated with phosphorus compliance ( $r=.28$ ) and the Overall Compliance Index ( $r=.24$ ). The more a patient felt he understood the regimen, the better the compliance behavior with respect to phosphorous and the Overall Compliance Index. If patients "felt" that they

understood the regimen, they may have been more motivated to be compliant.

Self-Esteem, Locus of Control,  
and Affective States

In this last section, we discuss the relationships between the patients' self-esteem, locus of control, and affective states as they relate to compliance behavior.

We speculated that patients with higher levels of self-esteem would care more about their health and would be more compliant with the medical and dietary regimen. In order to test this, we utilized Rosenberg's Self-Esteem Scale<sup>1</sup> which focuses upon self-acceptance (see Appendix A p 259 for the Self-esteem questions). We asked the patients to respond to ten questions with the following response choices: strongly agree, agree, disagree, strongly disagree. After reversing the patients' scores on the appropriate questions, we did an inter-item correlational analysis in order to ascertain the degree of relatedness of these items (Table not presented). The alpha level of internal reliability for these ten items was .77. We summed each patient's scores on the ten items in order to construct the Overall Self-Esteem Index and correlated this index with the five measures of compliance.

- As seen in Table 6, there were no significant associations. However, the general trend of all the correlations, except potassium, are in the predicted direction. Perhaps a self-esteem scale which relates more specifically to a dialysis patient's situation is needed. For

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<sup>1</sup>Rosenberg, op. cit.

example, the following two questions: "I am able to do things as well as most other people." and "I certainly feel useless at times." leave ambiguity as to whom the patient is comparing himself--with other dialysis patients or normally healthy individuals. If a dialysis patient compares himself to individuals without serious health problems, he may score low in self-esteem when he is actually giving a realistic assessment of his situation. In other words, it is questionable as to whether or not these questions actually tap self-esteem for this population. Another weakness of the items is that they are not sensitive enough to differentiate among dialysis patients who are being realistic and those who are utilizing denial. For example, a patient who used denial excessively could receive a higher self-esteem score than a better adjusted, more realistic patient with actually more positive self-regard.

TABLE 16

CORRELATIONS BETWEEN SELF-ESTEEM, LOCUS OF CONTROL  
AND AFFECTIVE STATES AND THE MEASURES OF COMPLIANCE

Indexes	Measures of Compliance				
	Phospho- rous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Report
Self-Esteem	.16	-.02	.20	.15	-.17
Locus of Control	.20 <sup>a</sup>	-.04	-.05	.05	-.19 <sup>a</sup>
Affective States	.10	-.21 <sup>a</sup>	-.06	-.08	-.20 <sup>a</sup>

<sup>a</sup>Correlation was significant at the .10 level, for N=55.

### Locus of Control

We had speculated that patients who had an internal locus of control would be more compliant. An internal locus of control reflects a belief that the people can exert influence and modify their current situation.<sup>1</sup> We asked the patients three questions: "In most situations I can control what happens. You can do a lot to keep illness from happening. and If I take care of myself, I can avoid illness."

We did an inter-item correlational analysis in order to determine the degree of relatedness of these three items. (Table not presented.) The alpha level of internal reliability for these items was .67. We summed each patient's scores on these three items in order to construct an Overall Control Orientation Index. This Overall Index was then correlated with the five dependent measures of compliance, and there were no statistically significant associations (see Table 16).

However, there were two statistical trends ( $p \leq .10$ ), between the Control Index and phosphorous ( $r=.20$ ), and the patients' self-reports ( $r=-.19$ ). The higher the internal control orientation, the greater the compliance with phosphorous, and the more often the patients designated themselves as being compliant. Phosphorous compliance does require consuming phosphorous binding medication several times a day and this could be perceived as an active way of dealing with the illness, i.e., taking pills may make the patients feel like they are controlling the potential negative effects of the illness. The patients' self-

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<sup>1</sup>J.B. Rotter, "Generalized Expectancies for Internal Versus External Control for Reinforcement," Psychological Monographs 80:1 1966.



reports also seem to indicate that if they feel they can exert control, they report themselves as being more compliant. However, the lack of more significant correlations seems to suggest that the patient's orientation toward control is not a reliable variable for understanding compliance behavior.

### Affective States

In this study, we utilized the Profile of Mood States<sup>1</sup> in order to measure patients' affective states. The affective states included tension, depression, anger, vigor, fatigue, and confusion. The patients were read 65 adjectives and asked to state whether in the last week they felt a certain way--not at all, a little, moderately, quite a bit, extremely. (See Appendix A p.297 for a list of the adjectives.) We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these six affective states and deleted the vigor scale as it did not correlate with the rest of the scales (Table not presented). The alpha level of internal reliability for these five remaining affective states was .90. The patients' scores were standardized as each scale had a different mean and standard deviation. In order to construct an Overall Affective Index, we summed each patient's scores on the five scales and correlated this index with the five dependent measures of compliance.

Although there were no statistically significant associations, there were two statistical trends ( $p \leq .10$ ), between the Affective Index and potassium ( $r = -.21$ ) and the Patients' Self-report of Compliance

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<sup>1</sup>McNaire, op. cit.

( $r=-.20$ ). The higher the patient's affective scores indicating the presence of depression, confusion, etc., the greater the compliance with potassium. One possible explanation for this finding may be that when patients are depressed, tense, etc., they rely more on other people who help monitor the intake of foods high in potassium. One cautionary note should be added with respect to the relationship between affective states and compliance behavior. The affective states focused on a one week period of time while the objective compliance measures were calculated for a six month period. In order to ascertain a more valid relationship between affective states and compliance behavior, one would need to monitor and measure the affective states for a longer period of time.

Patients who identified themselves as compliant reported lower levels of confusion, depression, etc., than those patients who identified themselves as non-compliant ( $r=-.20$ ). This finding is consistent with our speculation that this group of negative affects would be detrimental to compliance behavior.

#### Inter-Index Correlational Analysis

While each of the individual indexes may contribute some information on patients' compliance behavior, there is an issue relating to the overlap of patients' responses on these variables. In order to ascertain some understanding of the overlap we did an inter-index correlational analysis of the indexes in this chapter which showed significant associations (see Table 17).

TABLE 17  
 CORRELATIONS BETWEEN THE SIGNIFICANT  
 VARIABLES WITHIN THE INTER-PERSONAL DOMAIN

Intercorrelation Among Items								
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8
Coping Index- Reaching Out to Others	1.0							
Coping Index- Avoidance	-.01	1.0						
Overall Seriousness Index	-.22	-.04	1.0					
Overall Concern Index	-.29	-.23	.36	1.0				
Medication Barrier Index	-.01	.36	-.12	.01	1.0			
Dietary Barrier Index	-.01	.41	-.04	-.10	.60	1.0		
Objective Knowledge Index	.30	-.30	-.08	-.05	-.11	.14	1.0	
Overall Subjective Knowledge Index	.31	-.18	-.24	-.06	-.15	-.25	.21	1.0

The strongest correlation was between the Medication Barrier Index and the Dietary Barrier Index ( $r=.60$ ). This was expected because some of the same questions were utilized, however, we felt it was important to look at compliance with medications and dietary instructions separately. Another fairly strong correlation was between the Overall Concern Index and the Seriousness Index ( $r=.36$ ). Again this correlation makes sense because if one identifies a consequence of non-compliance as serious, they will probably also worry about the potential occurrence of such an event. The Coping Index of Avoidance was correlated with the Medication Barrier Index ( $r=.36$ ) and the Dietary Barrier Index ( $r=.41$ ). These correlations identify some potential overlap between patients whose coping activities include avoidance and the patients who stated they more often experience various barriers to medication and dietary compliance. Generally, the absence of many strong correlations suggests these Indexes do not greatly overlap.

#### Critique of the Significance of This Chapter's Findings

There were nine variables or indexes in this chapter which were associated with one or more of the dependent measures of compliance. Life crises in the 12 months prior to the interview and the patients' perceptions of the severity of the consequences of non-compliance were only associated with one dependent variable. The variables of coping with stressful events by avoidance, the Degree of Concern Index, the Objective Knowledge Index, and the Subjective Knowledge Index were each associated with two measures of compliance. Only the Coping Index relating to reaching out to others, and the Barriers to Medication and

Dietary Indexes were associated with three of the dependent measures.

The fact that some of these variables were related to only one or two of the dependent measures and the absence of stronger correlations cautions us to treat with some degree of tentativeness the findings related to compliance behavior. These limitations indicate the necessity of seeking to refine measurement procedures and utilizing theories which may have more conceptual validity when assessing variables related to dialysis patients' compliance behaviors.

#### Summary

Generally, the findings in this chapter indicate the importance of understanding the patients' attitudes, beliefs, and perceptions of situations which impact on their compliance behavior, and the role of coping activities utilized when dealing with crises.

We found that life crises were associated with non-compliance. Coping behaviors such as reaching out to others, a desire to improve oneself, less reliance on denial or avoidance were associated with higher levels of compliance behavior. These findings indicate the importance of the health care team being attuned to reported crises in the patients' lives and their usual coping activities.

Patients who perceive the effects of non-compliance as serious and worry about the potential results of non-compliance were more compliant. Patients also identified the negative effects on their compliance behavior of feeling depressed, of being too busy, and of not believing in the benefits of the medication or diet.

As we had assumed, we found the greater the patients' objective knowledge of the medical and dietary regimen, the better their compli-

ance behavior. If patients "felt" they had a good understanding of their regimen, they also tended to be more compliant.

We did not find, as predicted, that patients with higher levels of self-esteem were more compliant. Whether patients tended to have internal or external orientations toward control also failed to differentiate compliant and non-compliant patients. Given the fact that patients identified depression as a barrier to compliance, we were surprised that the Affective Index was not associated with compliance behavior. The lack of significant results relating to self-esteem, locus of control and affective states and compliance behavior may well reflect the lack of precision of these scales in measuring these variables for the specific population of dialysis patients.

## CHAPTER IX

### INTER-PERSONAL VARIABLES AND COMPLIANCE BEHAVIOR

Mrs. P. is a forty-six year old, white female who has been a dialysis patient for four years. She had one transplant which only lasted for a month and she then had to return to dialysis. She seems to be very angry and constantly complains about inadequate medical care and a lack of attention from her family. She states that her family does not help her follow her dietary regimen as they purchase foods which are "off" her diet. Mrs. P. has lost contact with all of her pre-dialysis friends and currently reports having no friends or neighbors with whom she can relate. Mrs. P.'s compliance with her medical and dietary regimen is sporadic.

Mr. C. is a thirty-eight year old, Black male who seems to have an excellent relationship with other patients and staff. He has been dialyzing at this Center for three years and can utilize the staff for assistance when personal problems arise. His family is very supportive and they make special efforts to prepare the foods which are prescribed for his renal diet. He has been able to maintain a large network of friends and reports that they do not tempt him to deviate from his prescribed diet. Mr. C. is proud that his monthly chemistries are excellent and that he is seldom fluid overloaded.

When patients become fluid overloaded or their monthly chemistries are high, the staff frequently questions the patients' motivations and attempts to encourage them to do better. While all patients spend between 12-15 hours a week at the dialysis center, they probably spend more time with family members, friends and neighbors. These "significant others" can play important roles in helping patients become more compliant. In this chapter, we examine the relationship between the role of "significant

others" and the patients' compliance behavior. Let's first look at the role of the family.

Family Understanding and Patients' Compliance Behavior

We asked the patients four questions with regard to how well they thought their families understood their (1) kidney disease, (2) diet/fluid instructions, (3) physical and (4) emotional effects of the illness. We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these four items (See Table 1). The alpha level of internal reliability was .73. The fairly high alpha level and the fact that the corrected item-total correlations are of moderate strength seem to indicate that these four items form a good Family's Understanding Index.

We then constructed an overall Family Understanding Index by summing each patient's scores on these four items. When we correlated this Family Understanding Index with the five dependent measures of compliance, we found one statistically significant correlation (See Table 2).

The more the patients felt that their families understood, the more compliant they were with respect to between dialysis weight gains ( $r=.28$ ). We have no objective data on the actual level of family members' understanding of the patients' illness or dietary and fluid instructions, although these matters are usually discussed with the patient's family. The patient's perception that the family understands may be important in two ways. First, the family may indeed understand the medical and dietary regimen and actively assist the patient in monitoring diet plans,



TABLE 1

**CORRELATIONS BETWEEN FAMILY UNDERSTANDING  
AND PATIENT COMPLIANCE<sup>a</sup>**

Areas of Family Understanding	Intercorrelation Among Items				Corrected Item-Total Correlation <sup>b</sup>
	Item 1	Item 2	Item 3	Item 4	
1. Kidney Disease	1.0				.53
2. Diet and Fluid Instructions	.47	1.0			.44
3. Physical Effect of kidney disease on patient	.43	.20	1.0		.55
4. Emotional effect of kidney disease on patient	.33	.39	.65	1.0	.60

NOTE: Alpha level of internal reliability for these items is .73.

<sup>a</sup>Instructions to the respondent: "Now I would like to ask you some more questions about your family. How well do you think your family (or household) understands your . . . .?"

<sup>b</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

fluid intake, etc., and the patient being aware of this support may be further motivated to make efforts to comply. Secondly, if the patient feels that the family understands, this may be an indicator that compliance has not become a control issue over which the family and patient express family problems or discord.

TABLE 2  
CORRELATION BETWEEN FAMILY UNDERSTANDING INDEX  
AND MEASURES OF COMPLIANCE

Index	<u>Measures of Compliance</u>				
	Phospho- rous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Reports
Overall Family Understanding Index	.20	-.08	.28*	.18	-.11

\*Correlation is significant at the .05 level for N=55.

#### Conceptual Frameworks and Patients' Compliance

In order to attempt to understand the potentially complex relationship between the patient's family and compliance behavior, we used several conceptual frameworks reflecting family structure and functions. These are only offered as starting points for an understanding of the complexities of this arena. The limitations of our speculations are based on the fact that we utilized an insufficient number of questions to fully explore these conceptual frameworks and that they are not based on objective data of the family functioning, but rather the patients' perceptions of such. With these limitations in mind, we proffer the following conceptual frameworks: organized-disorganized, supportive-non-supportive, and enmeshed-disengaged. Because of an insufficient number of questions we

did not construct any combined indexes, therefore, individual questions will be presented and may be utilized in more than one continuum.

### Organized-Disorganized Families

We speculated that greater family disorganization would be associated with higher levels of patient non-compliance. We asked two questions about family organization, specifically, if there were fairly regular meal schedules and consistent tasks or responsibilities within the home. When we correlated these two questions with the five dependent measures, we found two statistically significant associations (See Table 3).

TABLE 3

CORRELATIONS BETWEEN FAMILY ORGANIZATION  
AND PATIENT'S COMPLIANCE BEHAVIOR

Family Organization Questions	Phospho- rous	Potassium	Measures of Compliance		Patients' Self- Reports
			Dialysis Weight Gains	Overall Compliance Index	
Does your family eat meals at the same times each day?	.12	-.11	.30**	.14	.18
Would you say that each family member has and does certain regular jobs around the house, i.e., cooks, fixes things, cleans, shops, etc.?	.24*	-.01	.04	.12	-.03

\*Correlation was significant at the .05 level for N=55.

\*\*Correlation was significant at the .01 level for N=55.

If families did not eat meals at the same time each day, then patients tended to be less compliant with respect to between dialysis weight gains ( $r=.30$ ). If family members did not have regular jobs around the home, then patients tended to be less compliant with phosphorous ( $r=.24$ ). Greater structure and organization within the family probably facilitates dietary and medication compliance. For example, phosphorous binders are taken several times a day usually with meals. If a family's general organization including eating habits are haphazard, it would probably be more difficult for the patient to be consistent in taking the phosphorous binder.

The dietician often encourages patients to monitor their fluid intake by pouring into a quart jar an equal amount of water for any fluid consumed. When the jar is full, they know that they have gained a couple of fluid pounds. When family life is disorganized, this type of task would be more difficult as it requires remembering, consistency, and discipline.

#### Supportive-Non-supportive Families

We speculated that patients who felt their families were supportive would be more compliant. We asked patients, "How available is your family to help you if needed?" and "Is your food prepared separately from the rest of your family because of your special diet?" When we correlated the responses to these questions with the five dependent measures of compliance, there was two statistically significant associations and two statistical trends (See Table 4).

TABLE 4  
CORRELATIONS BETWEEN DEGREE OF FAMILY SUPPORT  
AND MEASURES OF COMPLIANCE BEHAVIOR

Family Support Questions	Measures of Compliance				
	Phosphorous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self-Reports
If you needed some help, would these family members be available to help you out?	.32**	.02	-.10	.09	-.08
Is your food prepared separately from the rest of your family because of your special diet?	.07	.18 <sup>a</sup>	.14	.18 <sup>a</sup>	-.45***

<sup>a</sup>Correlation was significant at the .10 level for N=55.

\*\*Correlation was significant at the .01 level for N=55.

\*\*\*Correlation was significant at the .001 level for N=55.

Patients who reported that their families were available if needed were more compliant with respect to phosphorous ( $r=.32$ ). Perhaps the patients' perceptions of family support increases their motivation to be compliant and maintain better health. Also, these families may prepare meals consistent with dietary instructions and remind the patient to take

medications. Non-compliant patients reported their families were not available to help if needed. These families may actually be physically and emotionally unavailable, thus less able to provide support for the patients' adaptation to the medical and dietary regimen.

There are alternative ways of looking at these findings, however. Compliant patients may feel better in general and therefore perceive their families as being more understanding, organized, and available than they are in reality. Conversely, non-compliant patients' perceptions may be affected by their non-compliance and they may see their families in a more negative light. Non-compliant patients may project the responsibility for their non-compliant behavior onto other people, for example, blaming their families for not being organized, understanding and available even though in reality the families do have these characteristics.

We also found that patients who reported that their meals were prepared separately because of their special diets were more compliant with respect to potassium ( $r=.18$ ) and the Overall Compliance Index ( $r=.18$ ) and they reported themselves as more compliant ( $r=-.45$ ). When a family goes to the effort to prepare special meals which conform to the patient's dietary instructions, there may be double benefits. First, the patient's dietary intake insures better compliance because of the close proximity of the dietary instructions. Secondly, the patient would probably perceive the family as supportive and interested.

### Enmeshed-Disengaged Families

The enmeshed-disengaged family conceptual framework is used to organize the findings of the correlations between family questions and patients' compliance behavior which were in the opposite direction from what we had expected. When examining this group of predominately unexpected findings, a pattern seemed to emerge which was consistent with the framework developed by the family theorist, Salvadore Minuchin.<sup>1</sup> Minuchin discusses families and family functioning in terms of a continuum from enmeshed to disengaged. Briefly, he states that optimum family functioning is represented by the middle of the continuum while more dysfunctional family behavior is represented by the extremes. A well-functioning family is one that can meet the emotional needs of individual family members providing support during periods of stress while also allowing for the development of individuality and autonomy in each member.

The enmeshed family is characterized by family members who are overly involved with each other emotionally and do not allow emotional distance necessary for autonomy and independent functioning. There tends to be a merging of emotional boundaries which can lead to difficulties around feelings of responsibility for oneself, for example, allowing the patient to be responsible for his or her behavior vis-à-vis diet and fluid instructions. On the other end of the continuum are disengaged families characterized by the sense that "there is a family but nobody belongs." Members may feel very little emotional bonding with other members which can lead to a lack of mutual support.

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<sup>1</sup>Salvadore Minuchin, Families and Family Therapy (Cambridge: Harvard University Press, 1974).

Let's first look at the five questions which seem to support the idea of a relationship between enmeshed families and non-compliant patient behavior: "When a crisis or big problem hits your family, does everyone work together in dealing with the problem? In terms of taking your medications and following your diet, do you think your family expects too much from you? Some families fight a lot, that is, have disagreements and arguments. How would you rate your family? Family life has its problems. Where would you say that your family falls on a scale from having 'just a few problems' to having 'a great many problems?' Families often describe themselves as being really close or not too close. How would you describe your family in relation to being close?" When we correlated these questions with the five measures of compliance, we found five statistically significant associations and four statistical trends (See Table 5).

The more patients stated that their families worked together during crisis periods, the less the compliance with potassium ( $r=-.25$ ). We had speculated the opposite, that is, that the families which coped with crisis by unifying would have more compliant patients. Shifting to Minuchin's paradigm,<sup>1</sup> non-compliant patients' families may become so overly involved during crisis periods that the patients may feel incompetent to deal with the situation. The patient may seek a sense of autonomy and competence by being non-compliant.

Patients who felt their families expected too much from them in terms of dietary and fluid instructions were less compliant with respect to potassium ( $r=-.28$ ). There probably is a middle range of family expectations that assist patients in complying. Either too rigid or



TABLE 5

CORRELATIONS BETWEEN ENMESHED DIMENSION OF FAMILY FUNCTIONING  
AND THE MEASURES OF COMPLIANCE

Family Questions	Measures of Compliance			Overall Compliance Index	Patients' Self-Reports
	Phosphorous	Potassium	Between Dialysis Weight Gains		
When a crisis or big problem hits your family, does everyone work together in dealing with the problem?	.16	-.25*	.07	.00	-.20 <sup>a</sup>
In terms of taking your medications and following your diet, do you think your family expects too much from you?	.06	-.28*	.07	-.12	-.21 <sup>a</sup>
Some families fight a lot, i.e., have disagreements and arguments. How would you rate your family?	-.10	-.30**	-.10	-.23*	-.28*
Family life has its problems. Where would you say that your family falls on a scale from having "just a few problems" to having a "great many problems"?	-.05	-.19 <sup>a</sup>	.08	-.03	.00
Families often describe themselves as being really close or not too close. How would you describe your family?	.00	-.19 <sup>a</sup>	.12	-.03	-.06

<sup>a</sup>Correlation was significant at the .10 level for N=55.

\*Correlation was significant at the .05 level for N=55.

\*\*Correlation was significant at the .01 level for N=55.

too lax expectations would not be a productive means of encouraging compliance. The non-compliant patients in this study tended to report that their families expected too much of them which could create feelings of inadequacy or resentment fostering non-compliant behavior.

Patients who described their families as having only a few fights were less compliant with respect to potassium ( $r=-.30$ ) and the Overall Compliance Index ( $r=-.23$ ). Again, we had expected that families with few fights would be associated with higher rather than lower levels of compliance. One explanation for this finding is that non-compliant patients may be reporting fewer fights because the family is enmeshed. The expression of dissatisfaction is not encouraged and while the patient may feel upset or angry, these feelings are denied or not verbalized. Perhaps, the patients' feelings are expressed behaviorally in the form of non-compliance.

The patients' self-reports for the three previously discussed questions are not consistent with the objective findings. That is, patients who viewed themselves as compliant but were in reality not compliant with the objective measures, reported their families worked together in crisis situations ( $r=-.20$ ), that their families expected a lot of them ( $r=-.21$ ) and that there were few family disagreements ( $r=-.28$ ). This finding is consistent with the ideas that these patients may be enmeshed within their family system and need to deny the presence of problems, and that this denial may generalize to their compliance with their medical and dietary regimen. These patients who do not accurately describe their own compliance behavior may also have distorted perceptions of their families.

Two other statistical trends seem to lend support to the idea of greater non-compliance among patients of enmeshed families. Patients who reported only a few family problems were less compliant with potassium ( $r=-.19$ ) as were patients who reported very close family relationships ( $r=-.19$ ). We had speculated findings in the opposite direction for both of these questions. We felt that close knit families with few problems would be associated with higher levels of patient compliance. Perhaps the families are overly involved and this leads patients to an over evaluation of closeness and a denial of the extent of family problems. Denial or unrealistic assessment of situations may generalize to such behaviors as compliance with the medical and dietary regimen.

On the other end of the enmeshed-disengaged continuum, we found four questions which tended to support the idea of non-compliance being associated with disengaged families (see Table 6). Patients who stated that their families never seriously questioned or doubted the doctor's advice were less compliant with respect to potassium ( $r=.28$ ). One possible explanation for this finding is that the patient experiences the family's lack of questioning the doctor as a lack of interest which may decrease motivation to be compliant. Another possible explanation is that the patient may be non-compliant as a means of attracting the family's attention with the hope of getting family members more involved.

The patients who identified themselves as compliant, but were actually non-compliant on an objective index, stated their families rarely questioned the doctors' advice ( $r=.28$ ). Perhaps these patients are attempting to present themselves and their families as "good," i.e., not trouble makers, passive, obedient, etc., when in reality the patient

TABLE 6  
CORRELATION BETWEEN DISENGAGED DIMENSION OF FAMILY FUNCTIONING AND THE  
MEASURES OF COMPLIANCE BEHAVIOR

Family Questions	Measures of Compliance				
	Phosphorous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Reports
Has your family ever seriously questioned or doubted your doctor's advice?	-.12	.28*	.00	.07	.28*
Does your family eat meals at the same times each day?	.12	-.11	.30**	.14	-.18
Would you say that each family member has and does certain regular jobs around the house?	.24*	-.01	.04	.12	-.03
If you needed some help, would these family members be available to help you out?	.32**	-.02	-.10	.09	-.08

\*Correlation was significant at the .05 level for N=55.

\*\*Correlation was significant at the .01 level for N=55.

is having difficulty with respect to potassium compliance.

Patients who reported that their families did not have regular meal schedules were less compliant with respect to between dialysis weight gains ( $r = .30$ ), and patients who said family members did not have regular jobs around the house were less compliant with phosphorous ( $r = .24$ ). As previously discussed, these questions may reflect a level of disorganization in the family, but they may also indicate that the family members are disengaged. The non-compliant patients may be receiving little or no emotional or concrete support in following the rigors of their regimens such as taking medications with each meal or monitoring their fluid intake.

Patients who reported that their family members were not available to help them when needed were less compliant with respect to phosphorous ( $r = .32$ ). As previously discussed, these patients may feel a lack of support from family members. The reported lack of family availability may also indicate that family members are disengaged and unavailable to the patient at crucial times.

While the findings for these four questions may indicate that non-compliant patients are from disengaged type families, there is an alternative explanation. Non-compliant patients may perceive their families as unorganized and uninvolved, when in reality the family may not have these characteristics. Non-compliant patients' perceptions could be distorted by the non-compliance or they may need to project the blame for their non-compliant behavior onto the family.

While we feel that our findings may fit into an enmeshed-disengaged paradigm, there are several shortcomings to this approach. First, there

were an inadequate number of questions which make it difficult to truly assess this paradigm. Secondly, because the findings are correlational, it is plausible that non-compliant patients' behaviors can cause families to either become overly involved or disengaged. From this author's clinical contacts with dialysis patients' families, we know that the families' adaptation to a member being on dialysis is difficult and can lead family members to be overindulgent and undermine the patient's independence. On the other hand, the fear that the patient may die frequently evokes a desire to maintain some emotional distance from the patient which could be perceived as disengagement. The impact of kidney failure on the patient and family may accentuate the polarization of responses and behaviors into the extremes of overinvolvement or insufficient involvement.

#### Relationship Between Friends and Patients' Compliance

The potential influence of friends on the patients' compliance behavior was another area that we explored. Patients were asked the following two questions: "How well do you think your friends understand (1) your kidney disease and (2) your fluid and diet restrictions?" Again, we did not collect objective data on friends' degrees of understanding but rather utilized patients' perceptions. When we correlated these two questions with the measures of compliance behavior, we found two statistically significant associations (see Table 7).

TABLE 7  
CORRELATIONS BETWEEN FRIENDS' UNDERSTANDING  
AND PATIENTS' COMPLIANCE

Friends' Under- standing	<u>Measures of Compliance</u>				Patients' Self- Reports
	Phosphor- ous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	
How well do you feel your friends under- stand your kidney disease?	.10	.20 <sup>a</sup>	.22 <sup>*</sup>	.23 <sup>*</sup>	.00
How well do you feel your friends under- stand the limits on your diet and fluid intake?	.15	.15	.07	.17	.09

<sup>a</sup>Correlation was significant at the .10 level for N=55.

<sup>\*</sup>Correlation was significant at the .05 level for N=55.

The more patients felt that their friends understood their kidney disease, the greater the compliance with regard to between dialysis weight gains ( $r=.22$ ), and the Overall Compliance Index ( $r=.23$ ). Patients may feel that an understanding friend is a source of support. If a friend did have knowledge of the patient's illness and imposed limitations, he or she could assist in monitoring dietary or fluid intake. Assistance might also take the form of selecting restaurants which cook low-sodium

foods and not tempting the patient to eat foods not allowed by the diet. Possibly of greater importance is that the friend may be emotionally supportive to the patient. Acknowledging and not undervaluing the patient's feelings and reactions may greatly assist the patient in coping with illness. As mentioned in Chapter VIII, those patients who could reach out to others when coping with stressful situations tended to be more compliant.

We asked two additional questions pertaining to available support from significant others. We inquired whether the patients had friends or neighbors to call if they were sick and needed help. As seen in Table 8, the availability of a neighbor differentiated compliant from non-compliant patients, whereas the availability of a friend was not statistically related to compliance behavior.

The patients who reported that they had a neighbor to call upon if needed were more compliant with respect to phosphorous, potassium, between dialysis weight gains, and the Overall Compliance Index. These patients may feel the support of their neighbors which may in turn give them additional strength and motivation and help combat isolation and the feeling of hopelessness. Non-compliant patients without neighborhood support may feel overwhelmed by the illness as well as isolated. Another possibility is that the availability of a neighbor may be indicative of a more stable life pattern which could provide a useful structure when coping with the demands and stresses of renal failure. Conversely, the lack of an available neighbor may reflect a changeable life style which does not mesh as well with the demands of a dialysis regimen, i.e., three times per week dialysis, special diet, fluid restrictions, and so forth.



TABLE 8  
RELATIONSHIP BETWEEN AVAILABILITY OF FRIENDS AND NEIGHBORS  
AND MEASURES OF PATIENT COMPLIANCE

Availability	<u>Measures of Compliance</u>				
	Phosphorous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Reports
	Mean t-value	Mean t-value	Mean t-value	Mean t-value	Mean t-value
<b>Neighbor to Call</b>					
Yes (N=42)	4.82	5.47	4.55	-0.49	19.19
No (N=13)	5.78	5.87	5.23	1.57	19.54
	-2.59**	-2.47**	-1.69*	-3.13***	-0.33
<b>Friend to Call</b>					
Yes (N=47)	5.03	5.55	4.77	-0.00	19.28
No (N=8)	5.10	5.68	4.36	.01	19.25
	-0.20	-0.65	0.83	-0.01	0.02

\* $p \leq .05$ , one tail test.  
 \*\* $p \leq .01$ , one tail test.  
 \*\*\* $p \leq .001$ , one tail test.

### Inter-Index Correlational Analysis

While each variable contributes some information on patients' compliance behavior, we wanted to examine the possibility of overlap. In order to determine some understanding of the potential overlap, we did an inter-index correlational analysis of the variables in this chapter which showed significant associations (see Table 9).

As seen in Table 9, there were generally very low correlations between the variables. The Family Understanding Index was strongly correlated with the questions about the family eating meals at the same time ( $r=.50$ ), and whether a family worked together during crisis periods ( $r=.45$ ). The absence of stronger correlations between items seems to indicate that there was not much overlap between the patients' responses on these variables.

### Critique of the Significance of This Chapter's Findings

There was a total of 11 variables in this chapter associated with one or more of the dependent measures of compliance. Eight of these variables were associated with only one of the dependent measures. The question about patients' families who seriously questioned the doctor's advice was associated with two of the compliance measures. The question about family disagreements was related to three of the measures and the availability of a neighbor to call significantly differentiated patients on four of the compliance measures.

One of the major limitations of this chapter was the reliance on mostly single items and the absence of more constructed indexes. The

TABLE 9  
CORRELATIONS BETWEEN THE SIGNIFICANT VARIABLES WITHIN  
THE INTER-PERSONAL DOMAIN

Variables	Intercorrelation Among Items									
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
1. Family Understanding Index	1.0									
2. Does your family eat meals at the same time each day?	.50	1.0								
3. Would you say that each family member has certain regular jobs around the house?	.12	.17	1.0							
4. If you needed some help, would these family members be available?	.38	.17	.06	1.0						
5. Is your food prepared separately from the rest of the family because of your diet?	-.06	.04	-.07	-.20	1.0					
6. When a crisis hits your family, does everyone work together in dealing with it?	.45	.38	.20	.33	.00	1.0				
7. In terms of medications and diet, do you think your family expects too much of you?	.13	.04	.01	.20	.01	.08	1.0			
8. How would you rate your family in terms of the degree of disagreements?	.10	.08	.01	.04	.10	.18	.17	1.0		
9. Has your family ever seriously questioned your doctor's advice?	.00	-.08	-.42	-.02	-.11	-.33	.05	-.29	1.0	
10. How well do you feel your friends understand your kidney disease?	.17	.12	.19	-.08	-.00	-.03	-.13	-.16	.13	1.0

fact that the majority of the variables were related to only one or two of the five dependent measures requires that we treat these findings with some degree of tentativeness. The absence of stronger correlations also affects the definiteness of these findings. A greater effort is needed in order to improve measurement procedures and seek family and social network theories which has more relevance for this dialysis population.

Summary

In general, our findings suggest that if a patient feels that the family has an understanding of their kidney disease, and the medical and dietary regimen, it is helpful to the patient in terms of compliance. If a family is organized and supportive of the patient, compliance tends to be better.

Patients' unexpected responses on several questions caused us to reconceptualize the families in an enmeshed to disengaged frame of reference. Patient non-compliance was more frequently associated with either extreme of this continuum. If families and patients were able to strike a balance between the extremes of overinvolvement and disengagement, this would probably provide the maximum amount of support while allowing for a healthy degree of autonomy on the part of the patient. The balance between support and autonomy might lead to more responsible compliance behavior.

We found that patients who reported having an understanding friend were more compliant. The availability of a neighbor to call upon if sick was significantly correlated with all the objective measures of compliance. Friends and neighbors may be able to provide a variety of types of assistance to patients which might influence their compliance behavior. This assistance may assume the form of making shopping trips to purchase the prescribed foods, reminding the patient of dietary or fluid limitations, being emotionally supportive of the patient's feelings and needs, and as a general resource in coping with the stresses of the illness and dialysis treatments.

## CHAPTER X

### RELATIONSHIP OF HEALTH DELIVERY SYSTEM AND ENVIRONMENTAL FACTORS AND THE PATIENTS' COMPLIANCE

Mr. T. is a fifty-six year old, Black, single, male who has been on dialysis for one year. He had a stroke three years ago which left him partially paralyzed. He has no phone, and refused to have a home attendant assist him with the household tasks of cooking, laundry, cleaning, etc. The staff is concerned about him as he is fairly isolated and there is a potential fire hazard when he cooks. His relationship with the doctors and staff is positive. His limited income requires that he take public transportation which poses difficulties for him as it takes him an hour and a half to come to the Center. He is a very motivated patient, has a volunteer job at a hospital and his compliance behavior is generally good.

Mrs. W. is a forty-five year old, married, Black, female whose husband is an executive at a bank. Her husband brings her to the Center where she has been dialyzed for three years. She has been on dialysis for a total of five years, two years at another location. She was transferred to the present Center because the previous one (hospital based) had become overcrowded necessitating the transfer of the more stable patients to satellite centers. She is very angry at being transferred as the present Center is a considerable distance from her home. She feels she does not receive adequate medical care and constantly complains to the staff. While the staff has attempted to respond to her various requests and needs, she remains angry and critical. Her compliance levels are generally poor, but she blames the staff and lack of proper medical care as the causes of her poor monthly chemistries and high between dialysis weight gains.

In this Chapter, we focus on aspects of the health delivery system such as patients' general attitudes towards physicians, relationships with the physicians at the Center, patients' degrees of satisfaction with staff, and the staff's provision of information as

these variables relate to patients' compliance. We then discuss environmental factors such as the transportation time to the Center, the patients' housing and neighborhood situation and the ability to afford medication as these variables relate to compliance behavior.

#### Attitudes Toward Physicians

We explored the patients' perceptions of physicians in general and the patients' attitudes toward their relationships with their physicians at the Center. We asked the patients to indicate levels of agreement with the following statements in order to ascertain their perceptions of physicians in general; "Doctors rely on drugs and pills too much. No two doctors will agree on what is wrong with a person. Too many doctors think you cannot understand the medical explanation of your illness, so they do not bother explaining it. A lot of doctors do not care whether or not they hurt you. Doctors should be a little more friendly than they are. Doctors often don't give me a chance to tell them exactly what my problem is."

We did an inter-item correlational analysis in order to determine the degree of relatedness of these six items (see Table 1). The alpha level of internal reliability for the items in this General Attitude Toward Physicians Index was .74. The fairly high alpha level and the fact that the corrected item-total correlations are of moderate strength indicate that these items form a good index. We then summed each patients' scores on the six items in order to construct an Overall Attitude Toward Physicians Index.

TABLE 1  
CORRELATIONAL ANALYSIS OF PATIENTS' PERCEPTIONS  
OF PHYSICIANS IN GENERAL<sup>a</sup>

Items in Index	Intercorrelation Among Items						Corrected Item-Total Correlation <sup>b</sup>
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	
1. Doctors rely on drugs and pills too much.	1.0						.43
2. No two doctors will agree on what is wrong with a person.	.21	1.0					.40
3. Too many doctors think you cannot understand the medical explanation for your illness, so they do not bother explaining it.	.18	.25	1.0				.41
4. A lot of doctors do not care whether or not they hurt you.	.47	.29	.25	1.0			.53
5. Doctors should be a little more friendly than they are.	.14	.19	.29	.34	1.0		.41
6. Doctors often don't give me a chance to tell them exactly what my problem is.	.42	.36	.36	.51	.45	1.0	.66

Note: Alpha level of internal reliability for this index is .74.

<sup>a</sup>Instruction to the respondent: "Here are some statements that people have made about doctors and health care. Please tell me how much you agree or disagree with each of the statements."

<sup>b</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.



We next sought to evaluate the patients' perceptions of their relationship with the physician whom they see the most at the Center. We asked the patients the following questions; "Do you feel Dr. \_\_\_\_\_ takes the time to explain things to you? Do you feel he is warm and sensitive most of the time with you? Do you feel you and Dr. \_\_\_\_\_ work as a team? That is, really work together to solve your medical problems? Do you like him to lay down the law to you, i.e. tell you exactly what to do and not do? Do you have confidence that he knows what is best for you? When he says or does something you don't understand, do you immediately ask him to explain it to you?"

We did inter-item correlational analysis of these six items in order to ascertain the degree of relatedness (see Table 2). The alpha level of internal reliability was .86. The high alpha level and the strong corrected item-total correlations indicate that these items form a good index. We then summed each patient's scores on these six items in order to construct an Overall Index of Relationship with Physicians.

**TABLE 2**  
**CORRELATIONAL ANALYSIS OF THE PATIENTS' PERCEPTIONS**  
**OF THE RELATIONSHIP WITH THEIR PHYSICIANS<sup>a</sup>**

Items in Index	Intercorrelation Among Items						Corrected Item-Total Correlation <sup>b</sup>
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	
1. Do you feel Dr. _____ takes the time to explain things to you?	1.0						.69
2. Do you feel he is warm and sensitive most of the time with you?	.70	1.0					.79
3. Do you like him to lay down the law to you, i.e. tell you exactly what to do and not do?	.35	.57	1.0				.57
4. Do you feel you and Dr. _____ work as a team?	.62	.68	.54	1.0			.75
5. Do you have confidence that he knows what is best for you?	.52	.67	.53	.61	1.0		.65
6. When he says or does something you don't understand, do you immediately ask him to explain it to you?	.55	.39	.28	.40	.21	1.0	.47

Note: Alpha level of internal reliability for this index is .86.

<sup>a</sup> Instruction to the respondent: Now I would like to ask you some questions about your relationship with your doctor here at the Center."

<sup>b</sup> Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

When we correlated the Attitude Toward Physicians Index and the Relationship with Physicians Index with the five dependent measures of compliance, there was only one statistically significant association (see Table 3).

TABLE 3  
CORRELATIONS BETWEEN PATIENTS' PERCEPTIONS OF PHYSICIANS  
INDEXES AND FIVE MEASURES OF COMPLIANCE BEHAVIOR

Indexes	Measures of Compliance				
	Phosphorous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Reports
Attitude toward Physicians in General	.14	.23*	.02	.17	.07
Perceptions of Relation- ship with Center Physician	.06	.00	.10	.07	-.05

\*Correlation was significant at the .05 level for N=55.

The more positive the patients' perceptions of physicians in general, the less compliant they were with respect to potassium compliance - the opposite of what we had speculated. A pattern begins

to emerge with this finding and seems to be corroborated by other findings in this section on the health delivery system. Specifically, the non-compliant patients report that they are more satisfied with the Center, staff, and program while the compliant patients are more critical. Perhaps these non-compliant patients are afraid to openly criticize the Center for fear they may be confronted about their non-compliant behavior. A type of self-protective collusion may develop where the patients don't attack the staff for their shortcomings and vice versa. These patients may deny their discontent and also maybe denying the extent of their own non-compliance. Compliant patients on the other hand feel more secure from criticism from the staff therefore they report more realistically on some of their dissatisfactions and attitudes toward physicians.

Another possible explanation for this finding relates to the idea of response sets. The patients interviewed were predominately minority patients and the interviewer was white. Perhaps some of these patients responded to this set of statements in a particular manner and attempted to anticipate what the interviewer may be expecting rather than report what they actually thought about each statement.

#### Satisfaction with Staff and Provision of Information

Patients were asked to evaluate how satisfied they were with the quality of care they received, the instructions, the nurses, technicians, social workers, physicians, and dietician. We did an inter-item correlational analysis of these items in order to determine

the degree of relatedness (see Table 4). The alpha level of internal reliability was .71 and would increase to .74 if we deleted social workers from the analysis. However, we felt it was important to include social workers in the analysis and it only slightly affected the subsequent findings. The fairly high alpha level and the fact that the corrected inter-item correlations are generally of moderate strength indicates that this is a good index, but certainly not one of the strongest ones. We summed each patient's scores on these seven items and constructed an Overall Satisfaction Index.

TABLE 4  
 CORRELATIONAL ANALYSIS OF PATIENTS' SATISFACTION  
 WITH STAFF AND QUALITY OF CARE<sup>a</sup>

Items in Index	Intercorrelation Among Items							Corrected Item-Total Correlation <sup>b</sup>
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	
1. Quality of Care	1.0							.56
2. Physicians	.12	1.0						.32
3. Nurses	.40	.45	1.0					.48
4. Staff's Instructions	.66	.23	.37	1.0				.56
5. Social Workers <sup>c</sup>	.07	.05	.19	.01	1.0			.00
6. Dietician	.21	.29	.41	.20	.29	1.0		.38
7. Technicians	.44	.09	.19	.60	.03	.34	1.0	.40

Note: Alpha level of internal reliability for this index is .71.

<sup>a</sup>Instruction to respondent: "People have different feelings about the dialysis unit and its staff. Could you tell me how satisfied you are with. . .?"

<sup>b</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

<sup>c</sup>We decided to include social workers as part of the index even though the corrected item-total correlation is .00. Deleting this item from the scale would increase the alpha level of internal reliability to .74 and decrease the strength of the one significant correlation from  $r=.23$  to  $r=.22$  ( $p \leq .05$ ).

Along with the issue of the degree of satisfaction we also inquired about the patients' perceptions of the provision of information. We specifically asked about the frequency they were told about: 1) their kidney disease, 2) medications and why they need them, 3) the general procedures of the Center, and 4) their diet. We did an inter-item correlational analysis in order to ascertain the degree of relatedness of these four items (see Table 5). The alpha level of internal reliability was .61. This index does not seem to be a strong one as the alpha level is only fair and the corrected item-total correlations are just of moderate strength. We then summed each patient's scores on these four items and constructed a Provision of Information Index.

TABLE 5  
CORRELATIONAL ANALYSIS OF THE PATIENTS' PERCEPTIONS OF  
THE STAFF'S PROVISION OF INFORMATION<sup>a</sup>

Items in Index	Intercorrelation Among Items				Corrected Item-Total Correlation <sup>b</sup>
	Item 1	Item 2	Item 3	Item 4	
1. Kidney disease	1.0				.40
2. Medications and why you need them	.40	1.0			.43
3. The general procedures at the Center	.33	.22	1.0		.39
4. Your diet	.10	.30	.30	1.0	.32

Note: Alpha level of internal reliability for this index is .61.

<sup>a</sup>Instruction to respondent: "How often has a staff member at the Center talked to you about the following areas. . .?"

<sup>b</sup>Correlation is between each item and the sum of all other items in the index with the item itself deleted to correct for auto-correlation.

We correlated the Overall Satisfaction Index and the Provision of Information Index with the five dependent measures of compliance and found two statistically significant associations (see Table 6).



TABLE 6  
CORRELATIONS BETWEEN PATIENTS' SATISFACTION WITH  
CENTER AND FIVE MEASURES OF COMPLIANCE

Indexes	Phosphorous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Reports
Satisfaction with Staff and Quality of Care	.09	.23*	-.03	.13	.10
Provision of Information to Patient	.00	-.14	.03	-.05	.31**

\* Correlation was significant at the .05 level for N=55.

\*\*Correlation was significant at the .01 level for N=55.

We had speculated that higher levels of satisfaction would be associated with higher levels of compliance. However, we found that non-compliant patients reported higher levels of satisfaction with the staff and quality of care than compliant patients. Again we think that non-compliant patients may be afraid of reprisals from the staff if they verbalize any displeasure with the staff or overall care at the Center. An alternative explanation centers around the concept of denial. If patients deny dissatisfaction with the staff, then they may also deny their own non-compliant behavior.

The findings on the patient's attitudes toward physicians and the patients' degree of satisfaction with the staff may be interpreted in still another way. Perhaps these findings indicate that compliant patients may be able to incorporate the physicians and staff's advice and then apply it to their daily routines and behaviors. This ability for self-directed care and responsibility diminishes the patients' dependency on the staff which in turn allows for a more realistic appraisal of their attitudes and feelings about the staff. Non-compliant patients, perhaps being less self-directed, may be more dependent on the staff and not as able to accurately evaluate their attitudes toward physicians or degree of satisfaction with the staff.

We had also speculated that the provision of more information would be associated with higher levels of compliance. We found that patients who identified themselves as non-compliant reported that they more frequently received information from the staff. This finding is actually consistent with the clinical observations of this author. In an attempt to increase compliance levels, the staff frequently provides information to non-compliant patients. Unfortunately, the information is often communicated in a rather parental, lecturing style which may generate resistance in the majority of patients who are having trouble following their medical and dietary regimen. Frequently, there is an absence of full exploration into why the patient thinks they are having trouble complying with the regimen.

### Transportation

A common complaint among dialysis patients at this Center is the issue of transportation. Ideally, centers would be dispersed so patients would not have to travel great distances. However, centers are often located on the basis of convenience of the health care system rather than the patient. We asked the patients, "How long does it take you to get to the center?" Twenty-six percent of the patients spent more than one hour travelling to obtain treatment.

Patients who travelled longer to the Center were less compliant with respect to phosphorous ( $r=.34$ ,  $N=55$ ,  $p=.01$ ). Phosphorous levels are controlled by medication and dietary compliance. Patients who travel over an hour to the Center are away from home for between six and seven hours on dialysis days. This means they may either eat one or two meals enroute to and from the Center. This routine is probably not conducive to medication consumption or access to proper foods. Compliant patients may have a more stable meal schedule which is structured around dialysis treatments and is not affected by many hours of travel.

We also asked patients whether transportation to the Center was a problem for them and 33 percent acknowledged that it was a problem. When we compared patients who said transportation was a problem with those for whom it was not a problem, there were two statistically significant results (see Table 7). Patients who reported that transportation was a problem were less compliant with respect to phosphorous and also identified themselves as being less compliant. As previously discussed, problems with transportation may upset the

patients' meal schedules which in turn could affect the patients' consumption of phosphorous binding medications.

Another possibility is that problems with transportation generate feelings of resistance in the patients which leads to less desire to cooperate or follow their medical and dietary instructions. However, an alternative explanation might be that non-compliance may negatively influence patients' perceptions so they report other issues such as transportation in a more negative light.

#### Patients' Perceptions of Needed Services

We asked the patients whether they felt there were services that they wanted which were not being provided at the Center. Forty-four percent stated they felt that additional services were needed. When we compared this group with the ones who thought there was no need for additional services, there was one statistically significant result (see Table 7). Patients who saw the need for additional services were less compliant with respect to between dialysis weight gains. Monitoring fluid intake is a rather difficult task and these patients may be requesting additional help. Compliant patients may not see the need for additional services as they are not having problems complying with the medical and dietary regimen.

TABLE 7  
 MEANS OF MEASURES OF COMPLIANCE ACCORDING TO WHETHER PATIENTS PERCEIVE TRANSPORTATION AS  
 A PROBLEM AND IF ADDITIONAL SERVICES WERE NEEDED AT THE CENTER

Measures of Compliance										
Phosphorous		Potassium		Between Dialysis Weight Gains		Overall Compliance Index		Patients' Self- Reports		
Mean	t-value	Mean	t-value	Mean	t-value	Mean	t-value	Mean	t-value	
<b>Transportation Problems<sup>a</sup></b>										
Yes (N=18)	5.46	1.75*	5.61	.37	4.91	.79	.56	1.30	17.10	-2.56**
No (N=37)	4.85		5.54		4.61		-.27		20.31	
<b>Additional Services Needed<sup>b</sup></b>										
Yes (N=24)	4.84	-1.12	5.50	-.77	5.06	1.79*	-.02	-.05	19.46	.03
No (N=31)	5.21		5.61		4.41		.01		19.13	

\* $p < .05$ , one-tail test.

\*\* $p < .01$ , one-tail test.

<sup>a</sup>Instruction to respondent: "Generally, would you consider transportation to the Center a problem for you?"

<sup>b</sup>Instruction to respondent: "Are there any services or anything that you think should be available here at the Center that would help you stick with your diet and medical instructions better?"

We asked the patients who felt additional services were needed to elaborate. Three major areas emerged from the patients' comments. One was the need for discussion groups. Patients felt that these groups could be used to discuss problems, receive information, and share ideas. One patient stated: "We need rap groups so doctors have the time to explain things to us and we need help expressing our hostility." Parenthetically, in the two and a half years that this author consulted at the Center, there were only two community meetings and one short-term group with the patients. When the social work staff attempted to initiate group services, there were various sources of resistance. One major obstacle was the transportation system. The transportation companies that many of the patients utilized would not alter their schedules to adjust to some patients staying later in order to attend group sessions. The administration of the Center did not seem committed enough to the idea of groups to apply the necessary pressure on the transportation companies. A second obstacle was the physical layout of the Center. The only room which was large enough for group meetings and could provide the required privacy was located on the second floor. Many of the patients could not climb the steps to this room because of physical problems or weakness and there is no elevator.

The second major area was the need for more information. Patients wanted to know more about their diet, proper foods, recipes, etc. Some patients wanted a cooking class so they could learn how to prepare the foods correctly. Some patients felt the Center should sell the proper foods and should dispense the required medications.

The third area was related to lack of staffing and activities. Patients felt there needed to be a doctor and social worker present in the facility during all dialysis times. Patients also wanted more activities such as bingo, arts and crafts during the dialysis treatments.

#### Environmental Factors and Patients' Compliance Behavior

We attempted to identify environmental factors which may be associated with patients' compliance behavior. We began by asking the patients questions about their neighborhood. Specifically, we wanted to know how the patients evaluated their neighborhood in terms of safety, cleanliness, transportation services, and whether there was a store nearby where they could purchase foods which were compatible with their dietary instructions. We had speculated that a patient living in an unsafe neighborhood with poor transportation services and no nearby store would have more difficulty with compliance. However, when we analyzed these variables with the five measures of compliance behavior, there were no statistically significant associations. Perhaps these questions did not elicit the more specific barriers or problems that interfere with patients' compliance.

We also speculated that patients whose housing arrangements did not provide privacy and adequate space would have trouble being compliant. Renal disease and dialysis treatments usually decrease patients' physical energy and stamina and they often need to rest following dialysis treatments. A patient who did not have privacy or adequate space may be further depleted of energy and may lose motivation to be compliant. Again when we analyzed these two

variables in relation to the compliance measures, there were no statistically significant associations.

There was one question which did differentiate compliant from non-compliant patients. The question was, "Are there times when you don't buy a prescription or go to the doctor or hospital, because you cannot afford the cost?" When we correlated the patients' responses to this question with the five dependent measures of compliance there were three statistically significant associations (see Table 8). Patients who stated there were times when they could not afford medical services, were less compliant with respect to phosphorous ( $r=-.23$ ) and between dialysis weight gains ( $r=-.25$ ). It would appear that some patients may be existing on such marginal incomes that if an unplanned medical cost arises, they are forced to postpone taking the appropriate action or buying the necessary medications until they receive their next check. Patients who identified themselves as non-compliant stated there were times when they could not afford medical services because of the cost ( $r=.22$ ).



TABLE 8  
CORRELATIONS BETWEEN ABILITY TO AFFORD MEDICAL SERVICES  
AND THE FIVE MEASURES OF COMPLIANCE<sup>a</sup>

	Measures of Compliance				
	Phosphorous	Potassium	Between Dialysis Weight Gains	Overall Compliance Index	Patients' Self- Reports
Ability to Afford Medical Services <sup>a</sup>	-.23*	.04	-.25*	-.20	.22*

\*p  $\leq$  .05, one-tail test

<sup>a</sup>Instruction to respondent: "Are there times when you don't buy a prescription or go to the doctor or hospital, because you cannot afford the cost?"

#### Inter-Index Correlational Analysis

While each of the individual indexes may contribute some information on patients' compliance behavior, there is an issue relating to the overlap of patients' responses on these various variables. In order to ascertain some understanding of the overlap, we did an inter-item correlational analysis of these indexes (see Table 9).

TABLE 9  
CORRELATIONS BETWEEN THE SIGNIFICANT VARIABLES WITHIN THE  
HEALTH DELIVERY SYSTEM AND ENVIRONMENTAL DOMAINS

Variables	Item 1	Item 2	Item 3	Item 4
Attitudes Towards Physicians in General	1.0			
Satisfaction with Staff and Quality of Care	-.05	1.0		
Provision of Information Index	-.18	-.21	1.0	
Ability to Afford Medical Services	.07	-.18	-.02	1.0

As seen in Table 9, there were generally very low correlations between these variables. The strongest correlation was the negative one between the Provision of Information Index and the Satisfaction with Staff Index ( $r = -.21$ ). The absence of stronger correlations between items seems to indicate that there was not much overlap between the patients' responses on these indexes.

#### Critique of the Significance of This Chapter's Findings

There were six variables or indexes in this Chapter associated with one or more of the dependent measures of compliance.

Transportation problems and the inability to afford medical services at times were variables associated with two measures of

compliance. The Attitudes Towards Physicians Index, the Satisfaction with Staff and Quality of Care Index, the Provision of Information Index and the patients' perceptions of the need for additional services were each associated with only one dependent measure of compliance.

The fact that all of these variables were related to only one or two of the five dependent measures requires that we treat these findings with some degree of tentativeness. The absence of stronger correlations also mutes the definiteness. These limitations indicate the necessity of seeking to improve measurement procedures and developing theories which may have more conceptual and pragmatic validity when assessing variables related to dialysis patients' compliance behavior.

#### Summary

Surprisingly, when exploring the variables within the health delivery system that were significantly correlated with the dependent measures of compliance we encountered unexpected findings. Non-compliant patients reported more positive general attitudes toward doctors and were more satisfied with the staff and quality of care than the compliant patients. One possible explanation for this finding is that non-compliant patients may be less critical of the Center because they are afraid that if they are critical, the staff may reprimand them regarding their non-compliant behavior. Another possibility is that if non-compliant patients deny their dissatisfaction with the staff, they may also deny the extent of their

own non-compliant behavior.

These unexpected findings may also be indicative of the presence of response sets. Some patients may have reported attitudes or feelings which they thought the interviewer may be expecting rather than reporting their actual attitudes. Another possible explanation relates to the ideas of dependence and the capacity for self-directed care. Compliant patients may be able to integrate the staff's advice into their daily routines and behaviors which increases their ability for self-care and diminishes their dependence of the staff. These patients may be able to more accurately report their feelings and attitudes because they are not clouded by feelings of dependency.

An alternative explanation is that the staff treats compliant and non-compliant patients differently. Perhaps the staff reaches out to non-compliant patients as a means of attempting to increase their compliance behavior and are less responsive to compliant patients. While this is a possibility, it is not one that was readily confirmed by this author's clinical observation and interactions with staff. Generally, the staff seems to gravitate toward pleasant, social, patients whether or not they tend to be compliant or non-compliant.

Transportation to the Center, which for 26 percent of the patients is over an hour, is a common problem. We found that patients whose travel time to the Center was longer, were less compliant with respect to phosphorous. If patients spend between five and seven hours on dialysis days travelling and being treated, their meal schedules are probably disrupted which may affect their consumption

of phosphorous binding medications. Problems with transportation may also increase patients' feelings of resentment and increase their resistance to following the medical and dietary instructions.

When patients were asked to identify services needed at the Center, they felt discussion groups were important so they could receive more information and air problems. Patients also wanted additional information about their diet, recipes, proper foods, etc. The absence of a doctor and social worker on some shifts and the lack of activities during dialysis were two other services which the patients felt were necessary but were not being provided.

We were not very successful in identifying environmental variables associated with patients' compliance behavior. The quality of the neighborhood in terms of safety, cleanliness, transportation services, and access to proper foods was not statistically related to patients' compliance. Housing arrangements such as adequate space and privacy were also not significantly associated with compliance. However, patients who at times could not afford medical services were less compliant with respect to phosphorous and between dialysis weight gains. This finding is important because while income per se was not related to compliance, the availability of money at critical times did seem to be linked. Perhaps Centers need to have emergency funds, medications, and other resources available to patients so that the temporary absence of funds does not affect their ability to comply with the medical and dietary regimen.

## CHAPTER XI

### MULTIPLE REGRESSION ANALYSES OF PATIENTS' COMPLIANCE BEHAVIOR

In the previous chapters, we relied mainly on correlational analysis and tests of significance to identify significant associations between various independent variables and the five measures of compliance, phosphorous, potassium, between dialysis weight gains, the Overall Objective Compliance Index, and patients' self-reports of compliance. We will now examine these findings utilizing multiple regression analyses. The reader will note that for this analysis some variables were coded in dummy variable form. This form of coding requires dichotomizing a nominal scale so that each category creates a variable that differentiates the category from the remaining category. For example, treating place of birth as a dummy variable, we coded being from New York City as 1 and all others as 0. This permits using the variable as a correlate of the dependent variables in a multiple correlational analysis. The main objective of multiple correlation/multiple regression analysis is to account for variance in the patients' compliance behavior using a set of predictor variables.

We selected ten demographic variables which we felt were relevant to our effort to understand variance in the dependent variables. Age, income, education, and length of time on dialysis were entered into the regression analysis as continuous variables. Race was treated as a

dummy variable dichotomized between Blacks (N=40) as one group, and whites and Hispanics (N=15) combined as the other group. In terms of place of birth, patients were grouped into New York City born (N=19) and born other places (N=36). Marital status compared married (N=26) versus all others (N=29) (separated, divorced, single, and widowed). Employment status contrasted employed subjects (N=11) versus all others (N=44) (unemployed, retired, homemakers, and students). We also created the interactional variable of age/sex by multiplying patient age by sex. In Table 1, we present the correlations between these ten variables.

As seen in Table 1, there was a strong negative correlation between sex and education with females having higher levels of education ( $r=-.24$ ). There was a strong positive correlation between marital status and age ( $r=.55$ ). Married patients tended to be the older patients. Married patients also had higher incomes ( $r=.35$ ), their employment status was generally other than employed ( $r=-.20$ ), and they had lower levels of education ( $r=-.25$ ). The higher family income reported may be a result of disability benefits received, possibly coupled with the spouse being employed. Race was highly related to place of birth ( $r=.41$ ). Black patients more often were born in other areas such as the Caribbean, southern United States, etc. Black patients tended to be younger ( $r=.27$ ), not married ( $r=.24$ ), and had higher levels of education ( $r=-.33$ ).

Younger patients were more often employed than older patients ( $r=-.32$ ). Younger patients are probably in better overall health than older patients and this would enable them to more easily maintain jobs. Also, the category of older patients probably contains the majority of

TABLE 1

CORRELATIONS OF INDEPENDENT VARIABLE  
UTILIZED IN REGRESSION ANALYSES

Independent Variables	Race	Sex	Place of Birth	Marital Status	Employment Status	Education	Length of Time on Dialysis	Age	Income
1. Race <sup>a</sup> (WHITE/HISPANIC, Blacks)	1.0								
2. Sex <sup>a</sup> (MALE, Female)	.10	1.0							
3. Place of Birth <sup>a</sup> (NEW YORK CITY, Other)	.41	-.04	1.0						
4. Marital Status <sup>a</sup> (MARRIED, Other)	.24	.08	.00	1.0					
5. Employment Status <sup>a</sup> (EMPLOYED, Other)	.00	.08	.02	-.20	1.0				
6. Education	-.33	-.24	-.11	-.25	.17	1.0			
7. Length of Time on Dialysis	-.07	.06	.04	-.11	.12	.05	1.0		
8. Age	.27	-.19	-.05	.55	-.32	-.12	-.27	1.0	
9. Income	.15	.11	-.01	.35	.09	.08	-.13	.07	1.0

<sup>a</sup>The categories indicated by capital letters are those selected as dichotomous variables, which were coded as 1; and those in lower case were coded as 0.



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patients who classified themselves as retired. There is also a trend in the field of nephrology to place patients on dialysis regardless of their age. This author's clinical observation at the Brooklyn Kidney Center and the Long Island College Hospital was that there was a remarkable increase in the number of older patients being placed on dialysis.

Younger patients had been on dialysis for longer periods of time ( $r=-.27$ ). Some of the younger patients had been on dialysis between five and ten years; they generally suffered fewer medical complications and health problems which increased their chances for survival.

#### Measures of Compliance

We chose five dependent measures of compliance in order to evaluate the different aspects of dialysis patients' compliance behavior. Phosphorous is an indicator of how well patients are following instructions about medications and diet. Potassium is a reliable indicator of dietary compliance as none of the patients in the sample were taking medications to control potassium levels. Between dialysis weight gains is a good measure of how well the patients are monitoring their fluid intake and foods which are high in fluid content. The Overall Compliance Index is a good indicator of general compliance with the medical and dietary regimen as it was constructed from the individual measures of phosphorous, potassium and between dialysis weight gains. The Patients' Self-Reports of Compliance Index adds the subjective dimension. This Index was the patients' evaluation of how closely they came to following the staff instructions in general and the instructions about their medications, diet and fluid intake.

In Table 2, we present the correlations between these five indexes. Naturally, the highest correlations are between the Overall Compliance Index and the three objective measures of compliance, phosphorous, potassium and between dialysis weight gains, as the Overall Index was constructed from these three measures. There is a fairly strong correlation between phosphorous and potassium ( $r=.40$ ). This is probably because they both measure aspects of dietary compliance. The Patients' Self-Reports of Compliance is negatively correlated with all the objective measures of compliance. The lack of positive correlations may be a result of the staff not providing accurate feedback, a lack of specific education for the patients, or patients' denial or distortions.

#### Phosphorous Compliance

As seen in Table 3, length of time on dialysis and place of birth emerged as the strongest predictors of patients' compliance with respect to phosphorous. Patients who had been on dialysis longer were more compliant with respect to phosphorous and this variable showed a statistically significant standardized regression coefficient of  $-.38$ . Length of time on dialysis accounts for nine percent of the variance added.

**TABLE 2**  
**CORRELATIONS BETWEEN THE FIVE DEPENDENT**  
**MEASURES OF COMPLIANCE**

<b>Phosphorous</b>	<b>Phosphorous</b>	<b>Potassium</b>	<b>Between Dialysis Weight Gains</b>	<b>Overall Compliance Index</b>	<b>Patients' Self-Reports of Compliance</b>
<b>Phosphorous</b>	1.0				
<b>Potassium</b>	.40	1.0			
<b>Between Dialysis Weight Gains</b>	.36	.24	1.0		
<b>Overall Compliance Index<sup>a</sup></b>	.79	.73	.71	1.0	
<b>Patients' Self-Reports of Compliance<sup>b</sup></b>	-.21	-.02	-.18	-.18	1.0

<sup>a</sup>The Overall Compliance Index was constructed by standardizing each patient's scores on phosphorous, potassium, and between dialysis weight gains and then summing them.

<sup>b</sup>The Patients' Self-Reports of Compliance Index was constructed from four questions. The patients were asked to evaluate how closely they came to following the staff's instructions in general, and the instructions about their medications, diet, and fluid intake.

TABLE 3  
 MULTIPLE REGRESSION ANALYSIS OF PHOSPHOROUS COMPLIANCE  
 (N=55)

Independent Variable	Zero-Order Correlation	Beta	Variance Added	Cumulative Multiple R <sup>2</sup>
Length of time on Dialysis	-.30	-.38**	.09	.09
Place of Birth (NEW YORK CITY, Other) <sup>a</sup>	.25	.35*	.07	.16
Income <sup>b</sup>	-.13	-.15	.03	.19
Sex (MALES, Females) <sup>a</sup>	.08	.87	.02	.21
Age/Sex <sup>c</sup>	.03	-.78	.02	.23
Employment Status (EMPLOYED, Other) <sup>a</sup>	-.13	-.08	.01	.24
Race (WHITE, HISPANIC, Blacks) <sup>a</sup>	.01	-.18	.01	.25
Age	-.05	.24	.01	.26
Education	-.12	-.06	.00	.26
Marital Status (MARRIED, Other) <sup>a</sup>	-.05	.03	.00	.26

Multiple Correlation = .51

Multiple Correlation Squared = .26

NOTE: For this and subsequent regression analyses:

<sup>a</sup>The categories indicated by capital letters are those selected as dichotomous variables, which were coded as 1; and those in lower case were coded as 0.

<sup>b</sup>Income as a variable had eight missing values which were replaced by the overall mean income level in order to increase the sample size to 55 for these analyses.

<sup>c</sup>This interactional variable was created by multiplying sex by age.

\*Significant:  $p \leq .05$

\*\*Significant:  $p \leq .01$

In Chapter III, we proffered four possible explanations for the higher levels of non-compliance for patients new to dialysis. First, newer patients may not be accepting the fact that they have a chronic illness, and this lack of acceptance may lead to not feeling responsible for controlling their phosphorous by regulating their diet and taking their medications. Secondly, physicians apparently alter the dosages of medication more frequently during the initial phase of the illness. These more frequent changes may confuse the patient and thus affect compliance behavior. Thirdly, patients who have been on dialysis longer may have already altered their eating habits and are more consistent in taking their prescribed medication. Lastly, patients who are extremely non-compliant do not survive for a long period of time. Patients who are in their fourth or fifth year of dialysis, are probably represented by a greater proportion of compliant than non-compliant patients.

Patients born other than in the New York City area were more compliant with phosphorous and this variable showed a statistically significant standardized regression coefficient of .35. Place of birth accounts for seven percent of the variance added. We thought that differing life styles or sets of beliefs may explain some of the differences between these two groups of patients. This idea was somewhat substantiated by another set of findings. Patients born outside the New York City area reported that they thought the sequelae of non-compliance would be more serious to them than patients born in the area ( $t=.26$ ,  $df=53$ ,  $p=.01$ ). Patients who felt that the consequences of non-compliance would be very serious, were more compliant with

respect to potassium compliance ( $r = -.23$ ,  $N=55$ ,  $p = .05$ ).

In summary, 26 percent of the variance for phosphorous compliance is accounted for by the independent variables we utilized. While modest, the amount of variance accounted for is similar to those commonly found in social and behavioral studies.

#### Potassium Compliance

As seen in Table 4, there were no variables which were statistically significantly related to potassium compliance. The variable of race accounts for 6 percent of the variance added. The combined group of white and Hispanic patients was less compliant than the Black patients. One possible explanation for this finding is that one of the staples of the Hispanic diet is bananas which are high in potassium. Perhaps these patients were unable to effectively alter their intake of foods which are high in potassium.

Income accounted for 4 percent of the variance added. Patients with lower incomes were less compliant with respect to potassium. Perhaps the income of these patients restrict their food choices and necessitate buying foods which are not most compatible with their prescribed diet.

In summary, 23 percent of the variance for potassium compliance is accounted for by the 10 independent variables utilized. Race and income accounted for a total of 10 percent of the variance.

#### Between Dialysis Weight Gains

As seen in Table 5, there were no variables which were significantly related to between dialysis weight gains. We must note, however, that

TABLE 4  
 MULTIPLE REGRESSION ANALYSIS OF POTASSIUM COMPLIANCE  
 (N=55)

Independent Variable	Zero-Order Correlation	Beta	Variance Added	Cumulative Multiple R <sup>2</sup>
Race (WHITE, HISPANIC, Blacks)	.25	.19	.06	.06
Length of Time on Dialysis	-.18	-.24	.02	.08
Place of Birth (NEW YORK CITY, Other)	.23	.19	.02	.10
Education	.03	.24	.01	.11
Marital Status (MARRIED, Other)	.17	.35	.02	.13
Income	-.07	-.27	.04	.17
Age	.07	.18	.02	.19
Sex (MALES, Females)	.06	.79	.01	.20
Age/Sex	.07	-.72	.02	.22
Employment Status (EMPLOYED, Other)	.03	.07	.01	.23

Multiple Correlation = .48

Multiple Correlation Squared = .23

the variable of sex was strongly correlated ( $r=.55$ ), and it only becomes not statistically significant because of the number of variables entered into the regression analysis. The variable which accounts for the majority of the explained variance was sex. Thirty percent of the variance added was accounted for by this variable. Males are less compliant than females on the variable of between dialysis weight gains. In Chapter VI, we speculated that the greater non-compliance for males may be related to a higher incidence of alcohol consumption. If a patient has a drinking problem, it is usually very hard to cease consumption and this would result in higher weight gains. Another possible explanation relates to the fact that males, in general, may be less familiar with dietary compliance, food exchanges, fluid content of different foods, etc. The deficiency in knowledge may make it harder for male patients to effectively modify their prior eating habits.

Another possible explanation for male patients' greater non-compliance relates to the degree of social role disruption that they may have experienced. Not only do these patients have to deal with the adjustment to a chronic illness, but they have lost the support of familiar roles, e.g., the loss of employment, the role of breadwinner, and so forth. Role reversals also have debilitating effects on male patients as they may now be expected to assume more household responsibilities as their spouse seeks employment. Generally, there is a social expectation that males are independent and the effects of renal failure places the patient in a more dependent position vis-a-vis staff and probably family. These various role disruptions and con-



TABLE 5

MULTIPLE REGRESSION ANALYSIS OF  
BETWEEN DIALYSIS WEIGHT GAINS

Independent Variable	Zero-Order Correlation	Beta	Variance Added	Cumulative Multiple R <sup>2</sup>
Sex (MALES, Females)	.55	.74	.30	.30
Education	-.31	-.14	.03	.33
Age/Sex	.40	-.29	.04	.37
Employment Status (EMPLOYED, Other)	-.06	-.13	.01	.38
Place of Birth (NEW YORK CITY, Other)	.11	.08	.01	.39
Length of Time on Dialysis	-.01	-.10	.01	.40
Age	-.26	-.20	.00	.40
Marital Status (MARRIED, Other)	.03	.12	.01	.41
Income	-.02	-.08	.01	.42
Race (WHITE, HISPANIC, Black)	.14	.06	.00	.42

Multiple Correlations = .65

Multiple Correlation Squared = .42

comitant emotional upheaval may seriously affect male patients' abilities to adjust to a dialysis regimen and their medical and dietary instructions.

The interactional variable of age/sex accounts for four percent of the variance added. Older male patients emerged as being most non-compliant while younger female patients were most compliant. The combination of being male and probably less knowledgeable about the sodium and fluid contents of foods coupled with being older and probably more set in one's dietary ways may account for the greater non-compliance among older males. Conversely, younger women being more knowledgeable about dietary issues in general, coupled with being less set in their ways may account for the greater compliance of this group.

A total of 42 percent of the variance for between dialysis weight gains is accounted for by the independent variables that we utilized. The vast majority of this total was accounted for by the one variable of sex which contributed 30 percent of the variance added.

#### Overall Objective Compliance Index

The Overall Objective Compliance Index was constructed by standardizing each patient's scores on phosphorous, potassium, and the between dialysis weight gains and then summing them.

As seen in Table 6, length of time on dialysis was the only variable which was significantly related to this Index. Length of time on dialysis accounts for six percent of the variance added. Patients, who had been on dialysis longer, were more compliant. As indicated earlier, these patients have probably learned to eliminate the major sources of phosphorous and potassium from their

diet, have become more consistent in medication consumption, and have learned ways to monitor their fluid intake. Also, this group of patients represent the survivors who are probably more compliant in general.

The variable of sex accounts for 10 percent of the variance added. Again, males are less compliant with respect to the Overall Compliance Index. This finding probably reflects male patients' lack of familiarity with dietary issues, coupled with the potentially more severe social role disruptions which were discussed earlier.

Place of birth accounts for 8 percent of the variance added. Patients born outside the New York City area were more compliant. Our only speculation is that these patients may have certain values, beliefs, or life styles which are more congruent with compliance behavior.

In summary, 34 percent of the variance for the Overall Compliance Index is accounted for by the ten independent variables utilized. Of this total, length of time on dialysis, sex, and place of birth, contributed 24 percent of the variance added.

#### Patients' Self-Reports of Compliance

As seen in Table 7, there are no variables significantly related to the Patients' Self-Report of Compliance. Surprisingly, the ten variables utilized in the regression analysis could only account for a total of 7 percent of the variance added. As you will recall, this Index was negatively correlated with the four objective measures of compliance, each of which had between 23 and 42 percent of the variance explained by these same ten variables. This raises the question of the

TABLE 6  
 MULTIPLE REGRESSION ANALYSIS OF  
 OVERALL COMBINED INDEX<sup>a</sup>

Independent Variable	Zero-Order Correlation	Beta	Variance Added	Cumulative Multiple R <sup>2</sup>
Sex (MALES, Females)	.31	1.07	.10	.10
Place of Birth (NEW YORK CITY, Other)	.26	.28	.08	.18
Length of Time on Dialysis	-.22	-.32*	.06	.24
Age/Sex	.22	-.80	.03	.27
Income	-.10	-.23	.02	.29
Marital Status (MARRIED, Other)	.07	.22	.04	.33
Employment Status (EMPLOYED, Other)	-.07	-.06	.01	.34
Age	-.11	.09	.00	.34
Race (WHITE, HISPANIC, Black)	.17	.03	.00	.34
Education	-.18	.01	.00	.34

Multiple Correlation = .57

Multiple Correlation Squared = .34

<sup>a</sup>This Index was constructed by standardizing each patient's scores on phosphorous, potassium, and between dialysis weight gains and then summing them.

\*Significant  $p < .05$ .

validity of this Index. Perhaps the four questions which asked patients to evaluate how closely they came to following the medical and dietary instructions did not accurately tap the patients' perceptions of their compliance behavior.

TABLE 7  
 MULTIPLE REGRESSION ANALYSIS OF PATIENTS' SELF-REPORTS  
 OF COMPLIANCE  
 (N=55)

Independent Variable	Zero-Order Correlation	Beta	Variance Added	Cumulative Multiple R <sup>2</sup>
Place of Birth (NEW YORK CITY, Other)	-.17	0.17	.03	.03
Marital Status (MARRIED, Other)	.16	.12	.03	.06
Age/Sex	.14	.10	.00	.06
Education	.04	.10	.01	.07
Race (WHITE, HISPANIC, Black)	-.00	.05	.00	.07
Age	.14	.05	.00	.07
Length of Time on Dialysis	-.00	.03	.00	.07
Employment Status (EMPLOYED, Other)	-.01	.02	.00	.07
Sex (MALES, Females)	.08	.00	.00	.07
Income	.07	.01	.00	.07

Multiple Correlation = .27

Multiple Correlation Squared = .07.

Place of birth contributed 3 percent of the variance added.

Patients born outside the New York City area identified themselves as being more compliant. The Patients' Self-Reports of Compliance with respect to place of birth are consistent with the findings on the objective measures of compliance, i.e., patients who identified themselves as compliant were actually compliant on the objective measures. The variable of Place of Birth is one of the few where there was a consistency between the patient's subjective assessment of compliance and the objective measures. Because of this consistency, future research should be directed at eliciting more of the specific perceptions of this group of patients in order to identify important behaviors, values or beliefs that are related to compliance.

Marital status accounts for 3 percent of the variance added. Married patients identified themselves as being more compliant than those patients not married. Marital status did not differentiate compliant from non-compliant patients on the four objective measures. Perhaps, married patients need to perceive themselves as compliant as they do not want to upset or worry their families. That is, married patients (compliant and non-compliant) may feel they always need to report to their families that they are compliant so the family will not become upset. When participating in this research project, these patients may have responded with their typical response set of stating that they were compliant.

Variables Not Entered in  
Regression Analyses

We want to briefly identify variables which were significantly related to the compliance measures but were not included in the regression analyses. There are hints in the data that these variables may potentially help us to better understand compliance behaviors. These findings will be discussed in more depth in the next chapter. Two variables were significantly associated with all four objective measures of compliance. Whether the patient had a neighbor to call when in need of help significantly differentiated compliant from non-compliant patients on all four measures. Patients with such a neighbor were more compliant with respect to phosphorous ( $t=-2.59$ ), potassium ( $t=-.2.47$ ), between dialysis weight gains ( $t=-.1.69$ ), and the Overall Compliance Index ( $t=-.313$ ). The other variable was the patients' coping activities. Patients whose coping activities included reaching out to others, less reliance on only themselves, and less denial were more compliant with respect to phosphorous ( $r=.25$ ) potassium ( $r=.40$ ), between dialysis weight gains ( $r=.29$ ), and the Overall Compliance Index ( $r=.42$ ).

Four variables were associated with three of the measures of compliance. Patients born outside the New York City area were more compliant with respect to phosphorous ( $t=1.87$ ), potassium ( $t=1.70$ ), and the Overall Compliance Index ( $t=1.98$ ). Patients who reported experiencing barriers to medication compliance such as feeling too depressed or busy to take medications, not believing they were necessary, etc., were less compliant with respect to phosphorous ( $r=-.40$ ), Overall

Compliance Index ( $r=-.23$ ), and identified themselves as non-compliant ( $r=.51$ ). Patients who reported experiencing barriers to dietary compliance such as not following their dietary regimen because they were too busy, felt depressed, etc., were less compliant with regard to between dialysis weight gains ( $r=-.32$ ), the Overall Compliance Index ( $r=-.25$ ), and identified themselves as non-compliant ( $r=.52$ ). Patients who reported that there were times when they did not seek medical services because they could not afford the cost were less compliant with respect to phosphorous ( $r=-.23$ ), between dialysis weight gains ( $r=-.25$ ) and identified themselves as non-compliant ( $r=.22$ ).

#### Summary

The respective amounts of variance explained by the ten independent variables for each of the dependent measures was: between dialysis weight gains - 42 percent, Overall Combined Index - 34 percent, phosphorous - 26 percent, potassium - 23 percent, and the Patients' Self-Report of Compliance - 7 percent.

Of the 42 percent total variance explained for between dialysis weight gains, 30 percent was accounted for by the variable of sex with male patients being least compliant. As previously discussed, male patients may experience severe changes in their ecological field such as loss of employment, role reversals in the family, increasing dependence on others, and may lack specific dietary knowledge. This finding identifies the importance of the health care team focusing particular attention in the form of education and support for male patients as they run a greater risk of having problems with fluid overload.



The moderate amounts of variance explained for phosphorous, potassium and the Overall Compliance Index help identify certain characteristics that may place patients at higher risk for non-compliance. These patient characteristics are being new to dialysis; born in the New York City area; being young, White or Hispanic and male.

The least amount of variance explained was for the Patients' Self-Reports of compliance--only 7 percent. This finding indicates the need for more rigorous exploration of other variables which influence the accuracy of patients' self-reports, and raises the issue of what are the best indicators of patients' compliance with their medical and dietary regimen.

As previously discussed, we sought to select variables which are generally believed to be reliable indicators of patients' compliance behavior. Seemingly, the three objective measures of phosphorous, potassium and between dialysis weight gains would be good indicators of patients' compliance. However, each of these is subject to various influences. For example, the medical staff may give discrepant directions or acceptable limits for each of these measures. Phosphorous levels can be affected by changing the dosage of phosphorous binding medications as well as by regulating dietary intake. Potassium, while an objective chemical measure, can be influenced by the patients' culture and its choice of staples, e.g., the Hispanic patients and their reliance on platanos or bananas.

These three measures are also affected by the efficiency of the dialysis procedure. Some machines and dialysis coils are more efficient in removing the various toxins and fluids from the patients' blood.

A patient may be exercising excellent compliance with the prescribed regimen yet these chemistries are increasing because of ineffective removal during the dialysis treatments. Fluid weight removal also varies by the efficacy of the machine and the staff's emphasis on extracting fluid, the patient's ability to tolerate increased coil pressure and so forth. So, while these objective chemical measures are an excellent starting point for measuring patients' compliance behavior there are numerous potential confounding effects. Further exploration into reliable objective means for measuring patients' compliance is needed.

As an attempt to broaden the approach to measuring compliance we utilized the patients' self-reports. However, as discussed, this variable was negatively correlated with the objective measures and this raises some questions about the validity of the Patients' Self-Report of Compliance Index. Ideally, patients would be able to accurately describe their relative degree of compliance with the instructions they receive from the staff. The lack of positive correlations between the subjective and objective measures raises issues such as the patients' degree of denial or distortions, the potential influence of differing staff expectations or instructions, and the degree to which patients are accurately appraised of their compliance levels on the objective measures. Perhaps the questions we asked to elicit the patients' perceptions did not fully tap their assessment of their compliance behavior. One might assume that patients who have been on dialysis longer would be able to more accurately

identify their own compliance levels. However, length of time on dialysis accounted for zero percent of the variance in the regression analysis on the Patients' Self-Reports of Compliance. We feel that knowing the patients' perceptions of their compliance behavior is critical and this area warrants further research.

## CHAPTER XII

### CONCLUSIONS

Dialysis patients are faced with life-threatening circumstances. Some patients seem to be actively self-destructive as they continue to use non-prescribed drugs, consume excessive amounts of alcohol and other fluids, seriously abuse their dietary instructions, and fail to take the prescribed medications. There are also patients who seem to fight to survive against all odds. One vignette described a blind, diabetic, partially paralyzed woman with cancer who has a tremendous "will" to live. While motivation and desire to live are critical components in the adjustment to renal failure, many other factors affect a patient's adjustment to the dialysis regimen. We attempted to explore the influence of a number of variables within the patient's ecological field which may affect the patient's struggle to survive and adjust to the prescribed regimen.

In this chapter, we discuss the major findings of this study viewed within the context of an ecological perspective. Secondly, we speculate toward a theory of compliance. Thirdly, we present our conception of a suitable program for increasing the patients' compliance levels and the role of the social worker within this

program. Lastly, we offer a critique of this research project and recommendations for future studies of dialysis patients' compliance behavior.

### Major Findings

As mentioned in the previous chapters, coping activities and the availability of a neighbor were the only variables which emerged as being associated with all four objective measures of compliance. We first want to focus on these two variables as they can be used as an example of an ecological fit between intra-personal characteristics and the social network. Secondly, we discuss the demographic variables which place sub-groups of patients at greater risk for social disruptions. Lastly, we focus on the "fit" between the health delivery system and selected patient characteristics such as attitudes, knowledge, and so forth.

Coping takes place within an inter-personal context. In this study, how a patient coped with crisis situations was strongly related to compliance behavior. Patients who tended to reach out to others and did not solely rely on themselves and who continued to think about the current crisis were more compliant with respect to all four of the objective measures of compliance. This finding tends to support the importance of maintaining and utilizing a social support network in coping with the stresses of renal failure and the prescribed medical and dietary regimen. The ability to continue to focus on the crisis situation implies that the patient is not utilizing the defense mechanism of denial. If a patient readily utilizes denial this could generalize to other stressful situations

such as following the rigorous medical and dietary regimen. Patients who stated they just relied on themselves are probably also denying the extent to which they need other people in order to survive and cope with this illness.

Assuming the patient possesses the necessary coping skills, they are not likely to be effectively utilized if the patient has no social network to backstop his own efforts. When sifting through various inter-personal variables one emerged with impressive repetition. The availability of a neighbor to call upon when in need of help significantly differentiated compliant and non-compliant patients on all four objective measures. The availability of neighbors might represent a concrete resource of these patients. Patients are often depleted of energy which makes simple tasks like carrying a bag of groceries difficult. A neighbor who is willing to help with shopping can be of invaluable help. Neighbors may also represent a source of psychological support. Knowing there is someone nearby to help if an emergency arises would be quite comforting. An interested neighbor might also be able to offer encouragement during periods of despair or lapses in motivation to be compliant. The availability of a neighbor could be a sign of a degree of community stability which includes other types of social contacts such as merchants, mailmen, etc. Our sense is that an available neighbor might be a reliable indicator of the presence of a viable social support network for the patient.

Clinically, an ecological perspective helps the social worker to focus on how different variables may fit together. Some patients have an existing social network but their typical coping activities

do not mesh well with it. For example, a patient may have friends and family who are available, but the patient tends to withdraw from them during stressful periods. The patient reports not wanting to worry or burden these people, but also does not cope effectively with the situation. This patient will need assistance in how to utilize the existing social network. Other patients may possess these positive coping behaviors but lack a viable social network.

The family is one critical component of the social network. The findings related to the patients' perceptions of the family hold potentially important directions for further exploration. Apparently, families that lack organization, internal support, or tend toward either of the extremes of overinvolvement or disengagement from the patient may increase the likelihood that the patients will have problems with compliance. While we can't identify whether the patients' non-compliance creates these family characteristics or vice versa, a clear mandate emerges for the health care team to energetically seek to involve the patients' families. At the least, the families can be an invaluable resource for many patients during crisis periods and realistically the family probably serves a critical function in assisting and determining the patients' level of adaptation to the rigors of the dialysis regimen.

Families are also struggling with the numerous upheavals caused by a family member developing a chronic illness, particularly one that requires massive changes in diet and is associated with frequent loss of energy, extensive changes in normal activities and routines, and raises the constant spectre of death. Ideally, the

patient's family is organized, emotionally supportive, and appropriately involved with helping the patient manage the illness. However, many families do not possess such capabilities prior to the onset of a chronic illness and it is understandable how these functions could be negatively influenced by the illness. In order to help families and patients develop a viable partnership in tackling the rigorous tasks associated with the dialysis regimen, the health care team needs to make itself available to these families.

Families that are disorganized may require that the social worker assist them in mobilizing the necessary social resources to help stabilize the family system. Families that tend to be enmeshed with the patient and overly involved with the management of the regimen will need assistance in assuming a more functional distance. The social worker will also need to develop non-threatening techniques for including the families of patients who seem to be disinterested or disengaged. Perhaps, multiple family sessions which included the spectrum of family organizations would provide a sense of safety, provide support and information about the various functional ways the families can assist in the patients' successful adaptation to dialysis. For some families, the social worker may need to reach out on a more individual basis, as they may find a group too threatening.

From an ecological perspective the social worker would need to assess the degree of fit between the patient's needs, behaviors, and coping style and the family's degree of availability, supportiveness and involvement. Patients who rely heavily on other people as a means



of coping would not fit well with a disengaged type family system. A very independent patient and an overly involved family would also represent a less than ideal fit which could create problems around compliance. For example, the patient may rebel at the family's involvement by not paying attention to the proper dietary requirements.

Let us now look at the group of demographic variables which may place some patients at a higher risk for experiencing role disruptions. From the multiple regression analyses and the findings in Chapter VI, certain characteristics seem to be more frequently associated with non-compliance, specifically, being male, unemployed or retired, young, new to dialysis and born in the New York City area.

In general, one might describe a person's ecological field as in functional balance when he/she is employed or financially secure, has adequate housing, positive inter-personal relationships, health, access to services and so forth. A social worker utilizing an ecological perspective would attempt to ascertain the degree to which characteristics of the patient may affect a desired goal or outcome. For dialysis patients the goal is maximum health and social functioning. However, there may be factors which impede the achievement of these goals.

In this study, being a male was highly related to non-compliance. We posited three possible explanations for this finding. First, males have a higher incidence of alcoholism than females. If a patient has a drinking problem, it is usually very hard to cease consumption and this would result in higher between dialysis weight gains. From the staff's report, a number of patients have a drinking problem. Secondly,

males in general may be less familiar with dietary compliance, food exchanges, fluid content of different foods, etc. Male patients scored lower on the knowledge questions than female patients ( $t=1.63$ ,  $p = .06$ ). The deficiency in previous and current knowledge may make it harder for male patients to effectively modify their prior eating habits.

Lastly, male patients may experience greater role disruptions. Not only do these patients have to deal with the adjustment to a chronic illness, but they have lost the support of familiar roles, e.g., the loss of employment, the role of breadwinner, athletic pursuits, and so forth. Family roles are also affected by the illness. Male patients who have had to quit working may be expected to assume more household responsibilities as their spouses seek employment. Being a role model for the children's athletic pursuits may be greatly curtailed by the lack of energy. Male patients may experience the increased dependency on the staff and family as an assault to their self-image. These various disruptions in life style may seriously affect male patients' abilities to adjust to the dialysis regimen and the medical and dietary instructions.

Younger patients seemed to have more problems with compliance. The twenties and thirties is a period of time that is usually focused on pursuing educational plans, career choices, the development of interpersonal relationships, marriage and child rearing. Renal failure can seriously affect these areas. Employment may become impossible due to the amount of time spent dialyzing, the loss of energy, the effects of discrimination against people with chronic illnesses, etc. Social

relationships can be affected because of the restrictions on dietary and fluid intake and the lack of energy. Patients report that the process of courting and marriage becomes difficult because they often see themselves as less than desirable. They also have concerns about their ability to function sexually which impedes the development of relationships. For married patients, they also experience disruptions around sexual activities, leisure time pursuits, struggle with role reversals and so forth.

These multiple role disruptions for younger patients may result in less motivation to be compliant. Younger patients may also have social networks which are more easily disrupted by the patient's illness. For example, if a younger patient has established a social network which is oriented toward physical activities, partying, etc., the patient may begin to withdraw from this network, unable to fully participate in these activities. As discussed previously, the availability of a social network and coping activities which include reaching out to others are both important for better compliance. The massive role disruptions for younger patients may seriously affect their social network and coping abilities.

Another plausible explanation for younger patients' greater non-compliance relates to the idea of the need for control and autonomy. Younger patients may feel that the illness and prescribed regimen are controlling them and assaulting their sense of autonomy. These feelings may result in a type of rebellion where the patients disregard the medical and dietary instructions as an attempt to gain a sense of control and exert autonomous action.

Patients born in the New York City area were generally less compliant than those patients born outside the area. This finding continues to puzzle us. Perhaps differing beliefs about the perceived seriousness of the consequences of non-compliance may explain some of this finding. Patients born outside the New York City area perceived these consequences as more serious and were more compliant with respect to potassium. Another possible explanation relates to the idea that when these people relocated to this area they developed a stronger social network as a means of coping with the change. As previously discussed, the social network is an important resource in the patients' adaptation to the illness and prescribed regimen. The relationship between place of birth and compliance needs further explanation.

Patients new to dialysis had more problems with compliance. As mentioned before, there are several possible explanations for this finding. First, newer patients may not be accepting the fact that they have a chronic illness, and this lack of acceptance may lead to not following their prescribed medical and dietary regimen. Secondly, the physicians do alter the dosages of medications more frequently during the initial phase of the illness. These changes may confuse the patient and thus affect their compliance behavior. Thirdly, patients who have been on dialysis longer may have already modified their eating habits and have developed more consistent routines for medication consumption. Fourthly, patients who are extremely non-compliant usually develop other medical complications and do not survive for as long a period of time. Lastly, patients new to

dialysis may be in the throes of multiple social role disruptions which increases the difficulty of adjusting to this new life routine which is dictated by the dialysis treatment schedule and regimen.

The social worker and staff need to be cognizant that some patients may be at greater risk for non-compliance because of the massive social role disruptions they experience. Armed with this information the staff may be able to develop programs which decrease the impact of the illness on these specific high risk patients and enhance their adaptation to the dialysis regimen.

The last general area of major findings to be discussed is the relationship between the health delivery system and certain patient characteristics, specifically, the patients' level of knowledge about their regimen and their perceptions of potential barriers to compliance.

Ideally, the health delivery system is responsive to the needs of patients and provides services which are compatible with increasing compliance. Let us look at the fit between the patients' objective and subjective knowledge of their regimen and the health delivery system's efforts to enhance this knowledge. Patients with lower objective knowledge scores and patients who felt they did not understand their medical and dietary regimen were less compliant with respect to two of the objective measures of compliance. However, non-compliant patients reported that they were more satisfied with the staff and quality of care and received more information from the staff regarding their kidney disease and instructions than the compliant patients.

One possible explanation for this finding is that non-compliant patients are exaggerating their level of satisfaction and amount of

information they received. These patients may be afraid to be critical of the staff for fear of counter-criticisms or because they are overly-dependent on the staff and are not able to accurately evaluate them. Another possibility is that the information these patients are receiving is not presented in a manner which readily facilitates their learning. As previously discussed, non-compliant patients are often lectured about the potential hazards of being non-compliant which may cause the patient to "tune out" and not absorb relevant factual information. While some staff actively seek to educate the patients, there is no unified education plan at the Center. This probably increases the chances of the patients receiving diverse opinions on which procedures or instructions are the best.

Patients who identified themselves as non-compliant perceived a need for additional services at the Center. One possible explanation for this finding is that these patients could be projecting a responsibility for their non-compliance on to the lack of services. On the other hand, the services they identified as needed seem highly related to problems related to compliance. For example, patients wanted discussion groups so they could be better educated about the illness and also express feelings about their adjustment to dialysis. They also specifically identified the need for specific information about their diet, ideas for cooking the proper foods, etc. These two services relate to the role of knowledge and compliance and the next area to be discussed, that of barriers to compliance.

Patients who stated they experienced barriers to medication and dietary instructions were less compliant with respect to two of the

objective measures and also identified themselves as non-compliant. Specific barriers included being too busy, feeling depressed, not believing that following the instructions will help, the inability to refuse food that was off their diet, and not following the instructions because they were feeling better.

Patients who reported they did not seek medical services or buy medications at times because they could not afford the cost were less compliant with respect to two objective measures and identified themselves as non-compliant. This represents another barrier patients experience which adversely affects their compliance. The Center has no formal procedure for dispensing medications to patients who cannot afford to consistently purchase them.

The import of identifying specific barriers to compliance is that it may increase the possibility of early identification of these barriers and lead to more effective attempts to ameliorate their impact. For example, discussion groups that provided information as well as discussed these potential barriers to compliance might help prepare the patients to deal more effectively with these situations.

The group of findings relating to objective and subjective knowledge and barriers to compliance coupled with the patients' degree of satisfaction and attitudes toward the staffs' provision of information, indicate a misfit between the patients' needs and the staff's intentions. That is, the staff would like the patients to be knowledgeable and compliant, yet there are aspects of the health care team's approach that are not consistent with this aim such as the lack of an organized educational program, the absence of discussion groups, and some disregard

for the importance of an individualized exploration of the barriers that patients report as affecting their ability to be compliant.

In summary, the major findings can be viewed as representing the lack of positive "fits" between aspects of the patients' ecological field. We identified the importance of a fit between the patients' coping styles and the availability of a social network. We also identified the fact that certain demographic characteristics may place select patients at higher risk for experiencing greater social role disruptions. Lastly, we noted the importance of a positive fit between the health delivery system's program and actions and certain attributes of the patients, mainly their objective and subjective knowledge of their medical and dietary regimen and their identification of potential barriers to compliance.



### Toward a Theory of Compliance

Different theories may attempt to explain compliance behavior based on their set of propositions. For example, an individual utilizing a psychoanalytic theory might explain non-compliance in terms of the patient's resistance to treatment or an internalized wish for self-destruction. An ego psychology theory might explain non-compliance as a result of the patient's ego deficiencies such as the lack of necessary secondary autonomous functions or the ability to exercise learned complex behaviors such as following a complex medical and dietary regimen. A behavioral theory might conceptualize non-compliance as the result of improper reinforcement of behavior such as the family or staff paying more attention to non-compliant behaviors than compliant ones. A person utilizing role theory would probably explain non-compliance as the product of role conflicts between patient and staff, role reversals within the family and so forth. A sociologist might explain non-compliance as a result of the patient's experiencing anomie or social isolation in mass society. While each of these theories make valuable contributions they seem to either lack specificity or the breadth to encompass or explain the multitude of factors that are associated with compliance behavior.

The Health Belief Model<sup>1</sup> seems to be more comprehensive in encompassing a multitude of variables that impact upon the patients' compliance actions. This model postulates that "the likelihood of an individual's complying with a preventive health recommendation is

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<sup>1</sup>Becker op. cit.

a function of his/her beliefs along the following subjective dimensions: level of motivation or "arousal" relative to health matters; perceived level of personal susceptibility to a particular condition and/or its sequelae; perceived degree of severity of the condition (i.e. that the occurrence of the condition or its sequelae would have a moderately serious impact); estimation of the recommended health action's potential benefits or efficacy in preventing or reducing susceptibility and/or severity; and views or possible psychological and other barriers or costs related to the proposed action."<sup>1</sup> This model includes other key variables such as demographic characteristics, patient/physician relationship, etc., but does not seem to adequately tap environmental variables which can affect compliance.

An ecological perspective provides us with an orienting point for conceptualizing the vast number of potential influencing factors that may impinge upon patients' compliance behaviors. Assuming permission to generalize beyond our findings, we would like to speculate on a theory of compliance based on an ecological perspective. First, we think that non-compliance is produced by one or more lack of positive "fits" between key elements within the patients' ecological field. While some of these less than adequate "fits" may affect multiple patients, they tend to be more specific for each patient. For example, if the staff utilized defective machines or dialysis coils and the patients lacked knowledge about the functioning

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<sup>1</sup>Hartman and Becker op. cit.

of the dialysis equipment, this could result in non-compliant chemistry levels for a number of patients. Perhaps a more common event is that various aspects of each non-compliant patient's ecological field do not adequately fit together.

Secondly, we think there is an interaction phenomenon between variables in the patients' ecological field including the effects of non-compliance. Let us look at a couple of examples. We noted that certain coping activities and a viable social network seem to fit together in a manner which was associated with higher compliance levels. However, some coping activities may facilitate the maintenance of a social network while other may diminish it. The impact of illness may adversely affect patients' coping styles or how individuals in a patient's social network will respond and interact with them. The potential interactive effect of the non-compliance on certain independent variables is another example. If a patient is non-compliant, this may initiate a negative cycle where the family either becomes overly involved or withdraws. This over-involvement or withdrawal may further perpetuate the patients' non-compliance as the patient either seeks to establish some autonomy or attempts to re-engage the other family members by their behavior.

Ultimately, we think that a theory of compliance can be developed utilizing an ecological perspective as a frame of reference. Perhaps, certain inadequate "fits" between aspects of the patients' ecological field will emerge as particularly strong predictors of non-compliant behavior. Attention will also have to be given to identifying or controlling for the interactional phenomena and this

may be best approached by utilizing longitudinal research designs. Clearly, this research project did not test such a theory, but it may have contributed points of departure for more indepth research studies.

Recommendations for Programming  
and the Role of the Social Worker

Let us speculate on some components of a suitable program for improving dialysis patients' compliance behavior for a population that is similar to the one studied in this research project. Based on the findings of this project we would recommend a multiple approach to service delivery.

Screening potentially high risk patients would be a preliminary step. Younger, unemployed, males, new to dialysis might be given special attention including a more comprehensive psychosocial evaluation, referral to other programs within the Center, early contact with the family and so forth.

The social worker would, hopefully, develop a format for initial psychosocial evaluations which elicits information that relates to the person's coping style, availability of a social network, the family's degree of involvement, the patient's beginning level of knowledge about dialysis and the medical and dietary instructions, the patient's attitudes about illness, and the identification of potential barriers to compliance. Of course, all of this information would not be gathered in the first interview, nor would it be appropriate to do so. However, the commitment to explore these areas early in the patient's adaptation to dialysis seems imperative. Other staff members would be able to contribute additional information about these specific areas.

Traditionally, the health care team seems to view compliance as within the purview of the patient and tends to focus most interventions on the individual non-compliant patient. Naturally, the initial

exploration of the problem of non-compliance and the development of a positive working relationship with the patient is probably best developed within the context of a one-to-one relationship. In addition to the primary nurse, dietician, and doctor, the social worker also needs to develop such a relationship.

One component of a more extensive program would seek to enhance the patients' levels of knowledge about their illness, medications and dietary instructions. Material could be distributed which explains this information and might be presented in the form of a self-teaching manual. In order to compensate for some patients' low reading abilities, audio or video tapes may need to be available. Selected trained volunteers could assist in conveying information on dietary issues such as appropriate food exchanges, the amounts of phosphorous, potassium and sodium that are contained in various foods, the fluid amounts in foods, food preparation, etc. Multi-lingual material and volunteers are required to meet the needs of this diverse dialysis population.

A second component might be the development of a type of self-help group within the Center. Volunteers and patients could assist in the educational process and may be able to develop a referral/resource network to handle common problems such as housing needs and forms, dialysis supplies, inexpensive access to medications, referral to training programs, self-help groups, etc. The social worker could provide the necessary expertise of coordinating this group, providing appropriate information, and handling the more complex issues which often arise.

Thirdly, the staff could institute a group program where patients have access to different groups depending on their specific needs. A general orientation group seems required as the initial stages of dialysis are often stressful, frightening and overwhelming. General information, emotional support, and the development of peer supports would be some of the aims of this group.

A more traditional type therapy group could be made available to patients who have continuing problems in adjusting to the illness, dealing with non-compliance problems, or personal problems which interfere with their social functioning. Perhaps patients would more readily utilize an in-center group rather than being referred to other agencies as patients often seek to avoid being labelled as having a psychiatric problem.

A fourth component of this program would be focused on the dialysis patients' families. One recommendation is that the staff does a more structured exploration of the families' functioning at periodic intervals particularly during the first year of the patients' dialysis treatments. Another recommendation would be the use of family conferences with the patient and their family.

This author helped initiate family conferences at the Brooklyn Kidney Center. This experience was quite positive as many families commented that even after two or three years of a family member being on dialysis no one had spoken with them about the illness and its effects. Some families probably received information while the patient was initially hospitalized, however, because this tends to be a very stressful time they probably were unable to fully understand or integrate

this information. While the program met the designated purpose of answering the families' questions and providing them with information, it could clearly not modify more serious concerns, such as long standing family patterns, other family problems and so forth.

This author's clinical observations of families during these conferences lends support for the findings that were grouped within the engaged-disengaged conceptual framework. We observed that some families seemed to be overly involved with the patient's management of their medical and dietary instructions. This overinvolvement assumed the form of family members becoming "watchdogs" and observing and commenting on any infraction or deviation from the prescribed regimen. Patients seemed to respond to this process by becoming very angry or withdrawing from the family. We felt that this family cycle might lead to further non-compliant behavior as the patient may attempt to gain control or assert a sense of autonomy.

We also encountered families who seemed to be disengaged, e.g., repeated family conferences would be arranged for families and they would either forget or cancel at the last minute. At times, this was devastating to the patients as they had to wait for the family, and ultimately meet with the health care team alone. Patients sometimes portrayed the organizational problems and communication patterns of the family by not informing the family of the correct date, distorting the purpose of the meeting, and so forth. Ironically, some of the families which could have received useful information and support from the staff, were the ones who because of their multi-problems were unable to attend the family conference meetings. The Center was not prepared



or staffed sufficiently to provide home visits. However, in this proposed program there will be sufficient staff so home visits would be available if necessary.

The last component of this proposed program would be the utilization of multiple family groups. Multiple family groups seem indicated based on the findings of this study as non-compliant patients were frequently associated with families that have the characteristics of being disorganized, non-supportive, disengaged or overly involved. A family group session could be provided for families new to dialysis. The social worker and staff could provide useful information to facilitate the patients' and families' adaptation to their new life routine. Families could provide emotional support to each other and may be able to "model" more positive attributes to families that are having more difficulties. For example, a family which is overinvolved with the patient's management of illness might be assisted in learning how to be available at a more functional distance. Families that are overly concerned about the patient's health and so afraid of the idea of death that they disengage from the patient, would learn that the patients are not so fragile. This group would provide support at the critical initial phase of the illness, increase the families' knowledge, develop a relationship with the staff, and allow the social worker to assess the families' level of functioning. Based on the staff's assessment, certain families may be identified as needing additional assistance.

The membership of these multiple family groups could be broadened to include "significant others" such as friends, relatives, or neighbors.

The focus of this group would remain basically the same, i.e., to increase the members' knowledge and understanding of renal failure and the dialysis regimen, develop positive relationships with the staff, etc. The staff would be better able to assess the patients' social networks. One important function of this group is that it would probably decrease patients' withdrawal from their social network. Patients who might withdraw because of feeling that others would not understand them might be more likely to maintain contact with those in their social network. Also, members of the patients' social network would probably learn how to better assist the patients emotionally and in other ways with regard to their adaptation to the dialysis regimen.

In sum, this proposed program would rely on a multiple service approach that would be based on a thorough understanding of less than adequate fits within the patients' ecological fields. The social work staff need to be able to accurately assess the different areas of the patients' ecological field, assist in the development and functioning of the various programs, and help match the individual patient need with the appropriate services. Hopefully, the patients appropriate linkage with the Center's programs or outside resources would help increase the adaptive fit within the patient's ecological field which in turn would facilitate their adjustment and compliance with the dialysis regimen.

Critique of This Study and  
Recommendations for Future Studies

This study could have been stronger if financial and time constraints had not limited the sample size. While the interviewed sample of 55 patients helped us identify some of the associations between

certain variables and the compliance measures, the strength of these findings would be enhanced if the sample size were increased. The high proportion of Blacks (73%) in the sample also may influence the applicability of these findings to the national dialysis population. Ideally, a larger sample of patients would be studied which would have a better distribution of different racial groups.

The choice of this writer as interviewer may have had both positive and negative effects. The interviewer was a consultant to the Center and had a good relationship with the staff which facilitated the access to the Center and implementation of the research project. However, the patients may not have truly believed that their responses would be confidential and this may have influenced their answers to the questions. The fact that the interviewer was white and the majority of the patients were Black and Hispanic might have further affected the patients' responses. An interviewer or interviewers who were not part of the staff and who were Black or Hispanic would be another possible modification of this study.

In terms of the structured interview questionnaire, several parts would need to be modified. First, the Self-Esteem Scale and the Profile of Mood States Scale might be altered to be more specific for a dialysis population. Secondly, questions that more accurately tap the family structure and functions need to be utilized. Thirdly, some questions did not fully assess the role of the variable. For example, marital status informed us of the patients' definition of their statuses, but did not measure the more important aspect, namely the quality of current relationships. Lastly, the areas of assessing the role of the

health delivery system and environmental factors need rigorous work. In general, the different scales and questions need to be refined with more extensive pre-testing in order to improve the reliability and validity of these scales.

The selection of variables that accurately assess compliance behavior needs continued scrutiny. To utilize both objective and subjective measures seems highly indicated. The objective measures are necessary as they may be indicators of future health problems if they become too elevated. While phosphorous, potassium and between dialysis weight gains are generally regarded as reliable and important objective measures, other measures need to be explored that might be better indicators of compliance and are even less subject to the influence of other factors.

The utilization of the patients' subjective assessment of their compliance seems critical. The four questions that we used to ascertain the patients' self-reports of compliance did not seem to accurately assess this area. More specific questions directed at the different objective measures are probably needed. Perhaps the patients need to be asked to estimate their average weight gains and phosphorous and potassium levels so these could be compared directly with the objective findings. It is difficult to imagine how the staff can work with patients to improve compliance levels when there is a marked difference in the patients' perceptions of their compliance and the actual objective measures.

We think that the exploration of dialysis patients' compliance behaviors holds exciting possibilities for future studies. The informa-

tion garnered from this research project identifies some of the areas of the patients' ecological field that need more in-depth evaluation, such as the role of the family, patients' coping activities, etc. A longitudinal study of selected cohorts of dialysis patients seems to be a logical next step. Selecting patients before they begin dialysis or who are new to dialysis and trying to determine certain baseline facts about their personalities, family structure and functions, relationships to their social networks, and their societal roles would be necessary. We could then monitor the influence of the illness and dialysis regimen on aspects of the patients' ecological field that were related to the compliance measures. This approach would also help us understand the role of crises and other changes within the patients' lives vis-à-vis compliance behavior.

Another research project could attempt to measure the influence of selected interventions on the patients' compliance levels. For example, one could introduce an organized educational program and then see if increasing patients' knowledge of their medical and dietary regimen would decrease the levels of non-compliance behavior. Interventions focused on the family or social network might also be developed to see if they can increase compliance levels.

A research project might be oriented toward actively including the patient in monitoring their own compliance levels. One could compare the patients' subjective assessments with selected objective measures. The staff could explore the discrepancies if they existed and work with the patients so they could more accurately evaluate their own compliance. This process may have salutary results in terms of

increasing the patients' sense of responsibility for their compliance and might also develop a more positive working relationship between the staff and patients.

Another approach to patients' degree of participation in the treatment process would be to compare compliance levels for home dialysis patients, hospital based patients, in-center limited care and in-center self-care patients. We think this would provide useful information but this approach would be subject to multiple confounding factors such as the philosophy of the specific center, the general health of the patients, the educational program of each facility and so forth.

In summary, this research project successfully identified a number of variables associated with dialysis patients' compliance behaviors. These findings can be viewed from an ecological perspective which seems to enhance our understanding of how variables in the patients' ecological field may influence patients' compliance. Future research studies are needed in order to identify factors that are consistently associated with compliance behaviors, so hopefully, interventions can be implemented that will increase the patients' compliance levels, health, and social functioning.

## Appendix A

## HEMODIALYSIS QUESTIONNAIRE

(HAND CARD 1)

1. Here is a general health scale from 1-7, where one is "very poor health" and seven is "excellent health." Where on this scale would you rate the way your general health has been for most of your life?

Very Poor						Excellent
(1)	(2)	(3)	(4)	(5)	(6)	(7)

2. - and how would you rate your general health now?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

3. - and finally, how would you rate your general health compared to other persons you know who are receiving dialysis treatments?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

(TAKE CARD 1, HAND CARD 2)

4. Even among people who have a health problem, some people are very worried about their health, while others are not as worried. Here is a 7 point "worry scale" where 1 is not worried at all and 7 is extremely worried.

First, how would you rate how worried you are about your kidney disease?

Not Worried						Extremely
At All						Worried
(1)	(2)	(3)	(4)	(5)	(6)	(7)

5. - we all have many things to worry about, and health is just one of them. Compared to other concerns you have, how worried are you about your health?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

(Not Worried  
At All)

(Extremely  
Worried)

6. - and how much do you worry about needing dialysis treatments?

(1) (2) (3) (4) (5) (6) (7)

7. - and how worried are you about being able to do all the things the dialysis staff tell you to do?

(1) (2) (3) (4) (5) (6) (7)

8. Now I am going to read you a list of things, and I want you to tell me how worried you are about each:

Not Worried  
At All

Extremely  
Worried

A. Getting high levels of potassium in your blood.

(1) (2) (3) (4) (5) (6) (7)

B. Your body storing up too much fluid between treatments.

(1) (2) (3) (4) (5) (6) (7)

C. Getting cramps in your legs.

(1) (2) (3) (4) (5) (6) (7)

D. Getting bone disease.

(1) (2) (3) (4) (5) (6) (7)

E. Becoming very weak.

(1) (2) (3) (4) (5) (6) (7)

F. Having high blood pressure.

(1) (2) (3) (4) (5) (6) (7)

G. The possibility of having a heart attack

(1) (2) (3) (4) (5) (6) (7)



(Not Worried  
At All)

(Extremely  
Worried)

H. The possibility of going into a coma

(1) (2) (3) (4) (5) (6) (7)

I. The appearance of your arm with the fistula

(1) (2) (3) (4) (5) (6) (7)

J. The appearance of your skin

(1) (2) (3) (4) (5) (6) (7)

9. Now I'm going to ask you, for each of these things, how likely you think it is that it could happen to you during the next year? Number 1 on the scale is "no chance at all" and number 7 is "almost certain to happen." How likely do you think that in the next 12 months you could:

No Chance  
At All

Almost  
Certain  
To Happen

A. Get very high levels of potassium in your blood

(1) (2) (3) (4) (5) (6) (7)

B. Store up too much fluid in your body between treatments

(1) (2) (3) (4) (5) (6) (7)

C. Get cramps in your legs

(1) (2) (3) (4) (5) (6) (7)

D. Develop bone disease

(1) (2) (3) (4) (5) (6) (7)

E. Become very weak

(1) (2) (3) (4) (5) (6) (7)

F. Have a heart attack

(1) (2) (3) (4) (5) (6) (7)

G. Go into a coma

(1) (2) (3) (4) (5) (6) (7)

(No Chance  
At All)

(Almost  
Certain  
To Happen)

H. Get very depressed

(1) (2) (3) (4) (5) (6) (7)

(TAKE CARD 3, GIVE CARD 4)

10. Here is this list again. Suppose each of these things were to happen to you in the next year. How serious would each one be to you? For example, how serious would it be to you if you were to:

Not At All  
Serious

Extremely  
Serious

A. Get high levels of potassium in your blood.

(1) (2) (3) (4) (5) (6) (7)

B. Have too much fluid in your body between treatments

(1) (2) (3) (4) (5) (6) (7)

C. Get cramps in your legs

(1) (2) (3) (4) (5) (6) (7)

D. Develop bone disease

(1) (2) (3) (4) (5) (6) (7)

E. Become extremely weak

(1) (2) (3) (4) (5) (6) (7)

F. Have a heart attack

(1) (2) (3) (4) (5) (6) (7)

G. Go into a coma

(1) (2) (3) (4) (5) (6) (7)

H. Get very depressed

(1) (2) (3) (4) (5) (6) (7)

(TAKE CARD 4, GIVE CARD 5)

11. In general, on days when you're not on dialysis, how difficult would you say it is for you to get through the day?

Not Difficult At All						Extremely Difficult
(1)	(2)	(3)	(4)	(5)	(6)	(7)

(TAKE CARD 5, GIVE CARD 6)

Here are some statements that people have made about doctors and health care. Please tell me how much you agree or disagree with each of the statements.

Strongly Agree	Moder- ately Agree	Agree Some- what	Neither Agree Nor Disagree	Disagree Some- what	Moder- ately Disagree	Strongly Disagree
-------------------	--------------------------	------------------------	-------------------------------------	---------------------------	-----------------------------	----------------------

12. Doctors rely on drugs and pills too much.

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

13. No two doctors will agree on what is wrong with a person.

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

14. When patients do not get well, it is often because they don't follow their doctor's advice.

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

15. Too many doctors think you cannot understand the medical explanation of your illness, so they do not bother explaining it.

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

16. A lot of doctors do not care whether or not they hurt you.

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

17. Doctors should be a little more friendly than they are.

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

18. Doctors often don't give me a chance to tell them exactly what my problem is.

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

(TAKE CARD 6, GIVE CARD 7)

Here are some questions about how people see themselves. Please tell me how much you agree or disagree with each statement.

- |   | Strongly Agree | Agree | Disagree | Strongly Disagree |
|---|----------------|-------|----------|-------------------|
| 19. I feel that I'm a person of worth (or value), at least on an equal basis with others. | (1)            | (2)   | (3)      | (4)               |
| 20. I feel that I have a number of good qualities.  | (1)            | (2)   | (3)      | (4)               |
| 21. All in all, I am inclined to feel that I am a failure.                                | (1)            | (2)   | (3)      | (4)               |
| 22. I am able to do things as well as most other people.                                  | (1)            | (2)   | (3)      | (4)               |
| 23. I feel I do not have much to be proud of.   | (1)            | (2)   | (3)      | (4)               |
| 24. I take a positive attitude toward myself.   | (1)            | (2)   | (3)      | (4)               |
| 25. On the whole, I am satisfied with myself.   | (1)            | (2)   | (3)      | (4)               |
| 26. I wish I could have more respect for myself.  | (1)            | (2)   | (3)      | (4)               |
| 27. I certainly feel useless at times.  | (1)            | (2)   | (3)      | (4)               |
| 28. At times, I think I am no good at all.  | (1)            | (2)   | (3)      | (4)               |

(TAKE CARD 7, GIVE CARD 8)

Now here are some statements about how things happen. Please tell me how much you agree or disagree with each of these statements.

- |   | Strongly<br>Agree | Moder-<br>ately<br>Agree | Agree<br>Some-<br>what | Neither<br>Agree<br>Nor<br>Disagree | Disagree<br>Some-<br>what | Moder-<br>ately<br>Disagree | Strongly<br>Disagree |
|---|-------------------|--------------------------|------------------------|-------------------------------------|---------------------------|-----------------------------|----------------------|
| 29. Events (or things) usually take their own course no matter what you do.   | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |
| 30. In most situations I can control what happens.  | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |
| 31. Whenever I hear about some disease I think I might get it.  | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |
| 32. A real problem when I am ill is that it prevents <u>me</u> from doing things I want to do.  | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |
| 33. When it comes to my health, I trust my own feelings more than a doctor's opinion.   | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |
| 34. When I am feeling sick, one good thing is that I don't have to do my usual activities.  | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |
| 35. I depend a lot on my doctor for taking care of health problems.   | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |
| 36. You can do a lot to keep illness from happening.  | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |
| 37. In taking care of my usual illnesses, I find that some of the things I try at home work better than the things the doctors prescribe. | (1)               | (2)                      | (3)                    | (4)                                 | (5)                       | (6)                         | (7)                  |

	(Moder- ately Agree)	(Agree Some- what)	(Neither Agree nor Disagree)	(Disagree Some- what)	(Moder- ately Disagree)	(Strongly Disagree)
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38. If I take care of myself, I can avoid illness.

(1)            (2)            (3)            (4)            (5)            (6)            (7)

39. I try to do exactly what the doctor tells me to do, without questions.

(1)            (2)            (3)            (4)            (5)            (6)            (7)

40. I think my health will be worse in the future than it is now.

(1)            (2)            (3)            (4)            (5)            (6)            (7)

41. When I'm sick, I try to keep it to myself.

(1)            (2)            (3)            (4)            (5)            (6)            (7)

42. I spend a great deal of the day thinking about my illness.

(1)            (2)            (3)            (4)            (5)            (6)            (7)

43. I feel actively involved in my own treatment.

(1)            (2)            (3)            (4)            (5)            (6)            (7)

44. I'm one of those people that get frustrated easily.

(1)            (2)            (3)            (4)            (5)            (6)            (7)

(TAKE CARD 8, GIVE CARD 9)

	Very Well	Moderately Well	Not Very Well	Not At All
--	-----------	--------------------	------------------	---------------

45. How well do you feel you understand your diet?

(1)            (2)            (3)            (4)

46. How well do you feel you understand your fluid instructions?

(1)            (2)            (3)            (4)

47. How well do you feel you understand your medications and instructions?

(1)            (2)            (3)            (4)

	(Very Well)	(Moderately Well)	(Not Very Well)	(Not At all)
48. How well do you understand your kidney disease?	(1)	(2)	(3)	(4)

(TAKE CARD 9, GIVE CARD 10)

Now I would like you to rate the impact of your kidney disease on these different areas of your life. For example, how has being a kidney patient affected:

	Affected Greatly	Moderately Affected	Mildly Affected	Not Affected At All
49. Your eating habits	(1)	(2)	(3)	(4)

If #1, #2, Probe \_\_\_\_\_

50. Leisure time activities	(1)	(2)	(3)	(4)
-----------------------------	-----	-----	-----	-----

51. Sexual activity	(1)	(2)	(3)	(4)
---------------------	-----	-----	-----	-----

52. Social contacts	(1)	(2)	(3)	(4)
---------------------	-----	-----	-----	-----

53. Family relationships	(1)	(2)	(3)	(4)
--------------------------	-----	-----	-----	-----

54. Taking vacations	(1)	(2)	(3)	(4)
----------------------	-----	-----	-----	-----

	(Affected Greatly)	(Moderately Affected)	(Mildly Affected)	(Not Affected At All)
55. Relationships with friends	(1)	(2)	(3)	(4)
(Probe)	<hr/>			
56. Employment activities	(1)	(2)	(3)	(4)
<hr/>				
57. Your self esteem, i.e., how you feel about yourself	(1)	(2)	(3)	(4)
<hr/>				
58. Sense of security	(1)	(2)	(3)	(4)
<hr/>				
59. Your ability to enjoy life	(1)	(2)	(3)	(4)
<hr/>				

(TAKE CARD 10, GIVE CARD 11A)

Now I would like to ask you some questions about your diet and medications. I am going to give you some responses to each question, and I want you to tell me which is correct.

60. When sodium builds up in the body:
- Calcium gathers with it
  - Fluid gathers with it
  - Phosphorus gathers with it
  - Protein gathers with it
61. You must carefully choose what types of fruits and vegetables you eat because some are:
- High in protein
  - High in potassium
  - High in sodium



62. Bologna, salami, hot dogs, and pastrami should be avoided because they are too high in \_\_\_\_\_?

(TAKE CARD 11A, GIVE CARD 11B)

63. Do fruits have a lot of fluid in them?
- A. Yes
  - B. No
64. Chocolate, nuts and raisins are examples of foods which are:
- A. High in fluid
  - B. High in protein
  - C. High in potassium
65. Since you are limited in the amount of protein you can eat, you should choose high quality protein. Such as:
- A. Bologna, beans, fruits
  - B. Chicken, lamb, fish
  - C. Breads, hot dogs, bacon
  - D. Green vegetables, breads, bacon

(TAKE CARD 11B, GIVE CARD 11C)

66. Generally, you should gain no more than \_\_\_\_\_ pounds per day between dialysis treatments?
- A.  $2\frac{1}{2}$ - $3\frac{1}{2}$
  - B. 1 -  $1\frac{1}{2}$
  - C. 6 - 8
  - D. 3 - 4
67. Why is it important to have sweets and desserts included in your diet?
- 
68. What can happen if you gain too much fluid weight between treatments? treatments? (Check all that are true)
- A. Nothing
  - B. Shortness of breath
  - C. Swelling in the face and ankles
  - D. Feeling light headed
  - E. Blood pressure can go up

(TAKE CARD 11C, GIVE CARD 11D)

69. It is okay to drink a lot of fluid right before dialysis because all the fluid is taken off during the dialysis treatment.

- A. True
- B. False

70. Monthly blood samples show how well you are keeping to your medication and diet schedule.

- A. True
- B. False

(TAKE CARD 11D, GIVE CARD 12)

71. What can happen if your potassium is too high? (Check all that are true)

- A. Nothing
- B. Heart may beat irregularly or unevenly
- C. Could cause death
- D. Shortness of breath
- E. Dizziness

72. What happens to your body when your phosphorus stays too high over a long period of time? (Check all that are true)

- A. Heart may beat unevenly
- B. Dizziness
- C. Develop bone disease
- D. Itching
- E. Nothing

(TAKE CARD 12)

73. Can you tell me all the medications you are supposed to be taking presently?

Name of Medication	Dose	Frequency	Name of Medication	Dose	Frequency

74. What is the name of the medicine you take to keep your phosphorus within the normal range? \_\_\_\_\_

(If patient does not know answer to #74, review it from card index, so can continue with #75.)

(If patient is not using a phosphorus binder, go to question #78.)

(HAND CARD 13)

75. How well do you think it does its job, that is, how effective is it?

Not At All						Very, or a Great Deal
------------	--	--	--	--	--	--------------------------

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

76. And does the medicine ever make you feel bad? - I mean, does it have any bad side effects?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

77. And how difficult would you say it is for you to take it the way you're supposed to?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

78. Thinking of all the medications you're taking together, how much do you feel they really help you?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

79. And how complicated would you say the instructions are for taking your medications?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

80. And overall, how difficult is it for you to follow your medication instructions?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

81. Most people with health problems find it impossible to follow all their doctor's orders exactly. How close would you say you come to following all the instructions about your medications?

(1)	(2)	(3)	(4)	(5)	(6)	(7)
-----	-----	-----	-----	-----	-----	-----

(Very, or a  
Great Deal)

(Not At All

82. And how closely do you feel you have to follow the instructions about medications in order to "do OK" - that is, not get into any difficulty?

(1) (2) (3) (4) (5) (6) (7)

(TAKE CARD 13, GIVE CARD 14)

83. Do you ever not take medications because you get too busy and forget to?

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

84. Do you ever not take your medications because you don't care, you feel down, depressed?

(1) (2) (3) (4) (5)

85. Do you feel pain or discomfort every day because of your kidney disease?

(1) (2) (3) (4) (5)

86. Have you ever stopped taking medications when you thought you felt better?

(1) (2) (3) (4) (5)

87. Have you ever felt that your medications affected your sexual activity?

(1) (2) (3) (4) (5)

If #1, 2 or 3, then ask if it increased \_\_\_\_ or decreased \_\_\_\_ sexual activity?

88. Do you feel better when you don't take your pills?

(1) (2) (3) (4) (5)

89. Do you ever not take your medications because you don't think it necessary?

(1) (2) (3) (4) (5)

(TAKE CARD 14)

90. Do you have difficulty swallowing tablets? Yes \_\_\_\_\_ No \_\_\_\_\_
- Capsules? Yes \_\_\_\_\_ No \_\_\_\_\_
- Taking liquid medicines? Yes \_\_\_\_\_ No \_\_\_\_\_

(GIVE CARD 15)

Now I'd like to ask you some more questions about your diet.

91. Suppose you followed your diet instructions exactly, how much good do you think it would do for you?

Not At All

Very, or a  
Great Deal

- |  |     |     |     |     |     |     |     |
|--|-----|-----|-----|-----|-----|-----|-----|
|  | (1) | (2) | (3) | (4) | (5) | (6) | (7) |
|--|-----|-----|-----|-----|-----|-----|-----|
92. How close would you say you come to following all the instructions about your diet?
- |  |     |     |     |     |     |     |     |
|--|-----|-----|-----|-----|-----|-----|-----|
|  | (1) | (2) | (3) | (4) | (5) | (6) | (7) |
|--|-----|-----|-----|-----|-----|-----|-----|
93. And how closely do you feel you have to follow the instructions about the diet in order to "do OK" - that is, not get into any difficulty?
- |  |     |     |     |     |     |     |     |
|--|-----|-----|-----|-----|-----|-----|-----|
|  | (1) | (2) | (3) | (4) | (5) | (6) | (7) |
|--|-----|-----|-----|-----|-----|-----|-----|
94. Now let's talk about limits on taking in fluids. Do you happen to know your daily fluid limit? Yes \_\_\_\_\_ No \_\_\_\_\_  
What is it? \_\_\_\_\_
95. Suppose you followed your fluid instructions exactly, how much good do you think it would do for you?
- |  |     |     |     |     |     |     |     |
|--|-----|-----|-----|-----|-----|-----|-----|
|  | (1) | (2) | (3) | (4) | (5) | (6) | (7) |
|--|-----|-----|-----|-----|-----|-----|-----|
96. How close would you say you come to keeping to the fluid restrictions?
- |  |     |     |     |     |     |     |     |
|--|-----|-----|-----|-----|-----|-----|-----|
|  | (1) | (2) | (3) | (4) | (5) | (6) | (7) |
|--|-----|-----|-----|-----|-----|-----|-----|
97. And how closely do you feel you have to follow the instructions about fluids in order to "do OK" - that is, not get into any difficulty?
- |  |     |     |     |     |     |     |     |
|--|-----|-----|-----|-----|-----|-----|-----|
|  | (1) | (2) | (3) | (4) | (5) | (6) | (7) |
|--|-----|-----|-----|-----|-----|-----|-----|

98. Finally, let's put all these instructions about medications, fluid and diet together, and let me first ask you how difficult you find it in general to follow the dialysis staff's instructions?

Not At All

(Very, or a  
Great Deal)

(1) (2) (3) (4) (5) (6) (7)

99. And how close would you say you come in general to following these instructions?

(1) (2) (3) (4) (5) (6) (7)

100. And how close do you feel you have to come to following these instructions in order to "do OK"?

(1) (2) (3) (4) (5) (6) (7)

(TAKE CARD 15, GIVE CARD 16)

101. Do you ever not follow your diet because you don't care, you are down, depressed?

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

102. Have you ever accepted a drink or some food that was off your diet because you were uncomfortable about refusing it?

(1) (2) (3) (4) (5)

103. Do you ever not follow your diet because you don't think it is necessary?

(1) (2) (3) (4) (5)

104. Now I would like to ask you some questions about your relationship with your doctor here at the Brooklyn Kidney Center. Which doctor do you usually see here? \_\_\_\_\_

105. Do you feel Dr. \_\_\_\_\_ takes the time to explain things to you?

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

(Always) (Frequently) (Sometimes) (Seldom) (Never)

106. Do you feel he is warm and sensitive most of the time with you?  
 (1) (2) (3) (4) (5)
107. Do you like him to lay down the law to you, i.e., tell you exactly what to do and not do?  
 (1) (2) (3) (4) (5)
108. Do you feel you and Dr. \_\_\_\_\_ work as a team? That is, really work together to solve your medical problems?  
 (1) (2) (3) (4) (5)
109. Do you ever get into fights or hassles with him?  
 (1) (2) (3) (4) (5)
110. Do you have confidence that he knows what is best for you?  
 (1) (2) (3) (4) (5)
111. When he says or does something you don't understand, do you immediately ask him to explain it to you?  
 (1) (2) (3) (4) (5)

(TAKE CARD 16, GIVE CARD 17)

112. How do you rate your relationship with Dr. \_\_\_\_\_?

Extremely Satisfactory	Mostly Satisfactory	Slightly Unsatisfactory	Extremely Unsatisfactory
(1)	(2)	(3)	(4)

(TAKE BACK CARD 17)

113. When you talk to your doctor, do you like him to talk to you about your condition or do you like him to just treat it?  
 Talk \_\_\_\_\_ Treat \_\_\_\_\_ Both \_\_\_\_\_
114. Does Dr. \_\_\_\_\_ usually talk to you about your condition or mostly just treat it?  
 Talk \_\_\_\_\_ Treat \_\_\_\_\_ Both \_\_\_\_\_

115. When something physically concerns you, how long is it until you decide to bring it to the attention of the doctor?

Less than 1 day: \_\_\_\_\_  
 2 - 3 days \_\_\_\_\_  
 4 - 7 days \_\_\_\_\_  
 1 - 2 weeks \_\_\_\_\_  
 1 month or more \_\_\_\_\_

116. Do you have another doctor for your kidney disease outside the Brooklyn Kidney Center?

Yes \_\_\_\_\_ No \_\_\_\_\_ If no, explore who is the referring doctor.

117. Have you seen any other doctor besides the one here at the Center in the last 6 months?

Yes \_\_\_\_\_ No \_\_\_\_\_

118. How often do you see Dr. \_\_\_\_\_?

Once a week \_\_\_\_\_  
 Once every month \_\_\_\_\_  
 Once every 3 months \_\_\_\_\_  
 Once every 6 months \_\_\_\_\_  
 Once each year \_\_\_\_\_

(GIVE CARD 18)

119. Do you feel Dr. \_\_\_\_\_ takes the time to explain things to you?

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

120. Do you feel he is warm and sensitive most of the time with you?

(1)	(2)	(3)	(4)	(5)
-----	-----	-----	-----	-----

121. Do you like him to lay down the law to you, i.e., tell you exactly exactly what to do and not do?

(1)	(2)	(3)	(4)	(5)
-----	-----	-----	-----	-----

122. Do you feel you and Dr. \_\_\_\_\_ work as a team? That is, really work together on solving your medical problems?

(1)	(2)	(3)	(4)	(5)
-----	-----	-----	-----	-----



(Always) (Frequently) (Sometimes) (Seldom) (Never)

123. Do you ever get into fights or hassles with him?  
 (1) (2) (3) (4) (5)
124. Do you have confidence that he knows what is best for you?  
 (1) (2) (3) (4) (5)
125. When he says or does something you don't understand, do you immediately ask him to explain it to you?  
 (1) (2) (3) (4) (5)

(TAKE CARD 18, GIVE CARD 19)

126. How do you rate your relationship with your doctor?

Extremely Satisfactory	Mostly Satisfactory	Slightly Unsatisfactory	Extremely Unsatisfactory
(1)	(2)	(3)	(4)

(TAKE CARD 19)

127. When you talk to your doctor, do you like him to talk to you about your condition or do you like him just to treat it?  
 Talk \_\_\_\_\_ Treat \_\_\_\_\_ Both \_\_\_\_\_
128. Does Dr. \_\_\_\_\_ usually talk to you about your condition or mostly just treat it?  
 Talk \_\_\_\_\_ Treat' \_\_\_\_\_ Both \_\_\_\_\_

Now I would like to ask you some questions about your current living situation, that is who you are living with now.

130. What is the first name of each of the people who live in your household, let's start with the oldest.

FIRST NAME	AGE	RELATIONSHIP	HEALTH	HELP WITH CARE?
1.				
2.				
3.				
4.				
5.				

Have we missed anyone such as lodgers, or people who usually live here but are away on business or travelling, at school or in the hospital?

131. Do you live in an apartment \_\_\_ or a house \_\_\_? If a house do you rent \_\_\_ own it \_\_\_?

132. Do you feel there is enough room or space for everyone?

Yes \_\_\_ No \_\_\_

133. Do you have an opportunity for privacy when you need it?

Yes \_\_\_ No \_\_\_

134. How would you rate your neighborhood?

Very Safe \_\_\_ Somewhat Safe \_\_\_ Not Safe \_\_\_  
at all

Very Clean \_\_\_ Somewhat Clean \_\_\_ Not Clean \_\_\_  
at all

Very Good \_\_\_ Somewhat Good \_\_\_ Not Good \_\_\_

Public  
Transportation

135. Do you have a phone? Yes \_\_\_ No \_\_\_

136. How often do you go out to eat? Every meal \_\_\_\_\_ Daily \_\_\_\_\_  
 Every Other Day \_\_\_\_\_, Weekly \_\_\_\_\_ Biweekly \_\_\_\_\_ Monthly \_\_\_\_\_  
 Other \_\_\_\_\_
137. Is there a food store near you that you can get all the necessary  
 foods you need to follow your diet? Yes \_\_\_\_\_ No \_\_\_\_\_
138. Is there a homemaker or homeattendant that comes to your house?  
 Yes \_\_\_\_\_ No \_\_\_\_\_  
 If yes, for you? \_\_\_\_\_ Someone else in family \_\_\_\_\_ Who \_\_\_\_\_
139. Have you changed your place of residence within the past 12  
 months? Yes \_\_\_\_\_ No \_\_\_\_\_  
 If yes, how many times? \_\_\_\_\_

Now I would like to ask you some questions about your family.

140. Do you have family that live in the New York City area?  
 Yes \_\_\_\_\_ No \_\_\_\_\_  
 If yes, how often do you (S) see// (P) phone?

NAME	RELATIONSHIP	D	EOD	W	BW	M	O
1.							
2.							
3.							
4.							
5.							
6.							
7.							
8.							
9.							
10.							

D=daily EOD = every other day W = weekly BW = Bi-weekly  
 M = monthly O = other

(GIVE CARD 20)

141. Are these different family members available to you if you need help?

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

Now I would like to ask you some more questions about your family (or the people you live with, if not family.)  
 Live alone \_\_\_\_ With family \_\_\_\_ With others \_\_\_\_

142. How well do you think your family (or household) understands your kidney disease, that is, what caused it, etc.

They understand	Very Well	Pretty Well	Not Very Well	Not At All
	(1)	(2)	(3)	(4)

143. How well do you think your family understands your diet and fluid restrictions?

(1)	(2)	(3)	(4)
-----	-----	-----	-----

144. How well do you feel your family understands how your kidney disease has affected you physically?

(1)	(2)	(3)	(4)
-----	-----	-----	-----

145. How well do you feel they understand how it has affected you emotionally?

(1)	(2)	(3)	(4)
-----	-----	-----	-----

(TAKE CARD 20, GIVE CARD 21)

146. When a crisis or big problem hits your family, does everyone work together in dealing with the problem?

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

147. Has your family ever seriously questioned or doubted your doctor's advice?

(1)	(2)	(3)	(4)	(5)
-----	-----	-----	-----	-----

If #1,2,3, ask in what situations? \_\_\_\_\_

148. In terms of taking your medications and following your diet, do you think your family expects too much from you? That is, expects you always to do it exactly.

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

149. Does your family eat meals at the same times each day?

(1)	(2)	(3)	(4)	(5)
-----	-----	-----	-----	-----

150. Would you say that each family member has and does certain regular jobs around the house, i.e., cooks, fixes things, cleans, shops, does dishes, etc.?

(1)	(2)	(3)	(4)	(5)
-----	-----	-----	-----	-----

151. Do you and your family ever not have enough money to buy the necessary food for your diet?

(1)	(2)	(3)	(4)	(5)
-----	-----	-----	-----	-----

152. Is your food prepared separately from the rest of your family because of your special diet?

(1)	(2)	(3)	(4)	(5)
-----	-----	-----	-----	-----

If No, would you feel comfortable asking to have your food prepared separately? Yes \_\_\_\_\_ No \_\_\_\_\_

153. Do you feel the food you now eat in your home is similar to the food you and your family ate when you were a child?

Yes \_\_\_\_\_ No \_\_\_\_\_

(TAKE CARD 21, GIVE CARD 22)

154. Family life has its problems. Where would you say your family falls on a scale from having "just a few problems" to having "a great many problems"?

Just a Few Problems						A Great Many Problems
(1)	(2)	(3)	(4)	(5)	(6)	(7)

155. Some families fight a lot, that is have disagreements and arguments. How would you describe your family?

Just a Few Fights						A Great Number of Fights
(1)	(2)	(3)	(4)	(5)	(6)	(7)

(TAKE CARD 22, GIVE CARD 23)

155. Some families fight a lot, that is, have disagreements and arguments. How would you describe your family?

Just A Few Fights					A Great Number of Fights	
(1)	(2)	(3)	(4)	(5)	(6)	(7)

(TAKE CARD 23, GIVE CARD 24)

156. Families often describe themselves as being really close or not too close. How would you describe your family in relation to being close?

Extremely Close					Not Close At All	
(1)	(2)	(3)	(4)	(5)	(6)	(7)

(TAKE CARD 24)

Now I would like to ask you some questions about your friends.

157. Would you say you have?

A lot of friends? \_\_\_ A few friends? \_\_\_ No friends? \_\_\_

158. About how many hours a week do you spend with your friend(s)?

Less than 5 \_\_\_ Less than 10 \_\_\_ Less than 20 \_\_\_  
More than 20 \_\_\_ Other \_\_\_\_\_

159. Do your friends know you have a kidney disease? Yes \_\_\_ No \_\_\_

(IF YES, HAND CARD 25) (IF NO, GO TO QUESTION 162)

160. How well do you feel your friends understand your kidney disease?

Very Well	Moderately Well	Not Very Well	Not At All
(1)	(2)	(3)	(4)

161. How well do you feel your friends understand the limits on your diet and fluid intake?

(1)	(2)	(3)	(4)
-----	-----	-----	-----

## (TAKE CARD 25)

162. If you got sick and needed to contact a friend, do you have one you feel comfortable calling day or night? Yes \_\_\_\_ No \_\_\_\_

163. Do you have a neighbor you can call on if you need help?

Yes \_\_\_\_ No \_\_\_\_

## (HAND CARD 26)

People have very different feelings about the dialysis unit and its staff. Could you tell me how satisfied you are with:

Not At All  
Satisfied

Extremely  
Satisfied

164A. The overall quality of care here at the Center

(1) (2) (3) (4) (5) (6) (7)

B. The transportation arrangements for coming in for treatments.

(1) (2) (3) (4) (5) (6) (7)

C. Your relationship with the doctors here.

(1) (2) (3) (4) (5) (6) (7)

D. Your relationship with the nurses here.

(1) (2) (3) (4) (5) (6) (7)

E. The instructions the staff gives you

(1) (2) (3) (4) (5) (6) (7)

F. Your relationship with your social worker

(1) (2) (3) (4) (5) (6) (7)

G. The way the dialysis is performed

(1) (2) (3) (4) (5) (6) (7)

H. Your relationship with the nutritionist (dietician)

(1) (2) (3) (4) (5) (6) (7)

I. Your relationship with the technicians

(1) (2) (3) (4) (5) (6) (7)

**(TAKE CARD 26)**

Now I want to ask you about whether any major changes or crises have happened with you or your family in the past 12 months. Has anyone you know well:

**(HAND CARD 27 IF ANY YES RESPONSES)**

165. Who?	When?	How upsetting was it for you				
		Extremely	Moderate	Upset	Mild	Not Upset
<b>A. Died?</b>						
_____		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
<b>B. Gotten divorced or separated?</b>						
_____		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
<b>C. Lost a job or was fired?</b>						
_____		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
<b>D. Moved out of house or city?</b>						
_____		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
<b>E. Had a serious accident or illness</b>						
_____		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
<b>F. Other</b>						
_____		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)
		(1)	(2)	(3)	(4)	(5)



(TAKE CARD 27, GIVE CARD 28)

Now I would like you to tell me whether the following people have made it easier or harder for you to follow your medical and dietary instructions, i.e., do they do anything that helps you or gets in the way of following the instructions?

Much Easier						Much Harder
<b>166. A. Your friends at home (neighbors)</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>B. The staff here at BKC</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>C. Other patients</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>D. Your employer (if applicable)</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>E. Husband/Wife/Partner</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>F. Children</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>G. Parents</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>H. The people you live with</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>I. Other relatives</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)
<b>J. Friends at work</b>						
(1)	(2)	(3)	(4)	(5)	(6)	(7)

167. Do you belong to NAPHT? (National Association of Patients on Hemodialysis and Transplantation) Yes \_\_\_\_ No \_\_\_\_.  
If Yes, when did you join? \_\_\_\_\_

(HAND CARD 29)

168. How has being on dialysis or having a kidney disease affected your leisure time activities?

Do More Activities	Do the Same Amount	Do Less Activities
(1)	(2)	(3)

(TAKE CARD 29, GIVE CARD 30)

169. Now as opposed to before becoming a dialysis patient, do you enjoy your leisure time:

Enjoy Much More	Slightly More	About the Same	Slightly Less	Much Less
(1)	(2)	(3)	(4)	(5)

(TAKE CARD 30, GIVE CARD 31)

170. In your usual weekly activities are you:

Moderately Physically Active	Somewhat Physically Active	Slightly Physically Active	Never Physically Active
(1)	(2)	(3)	(4)

(TAKE CARD 31)

171. How many different doctors have you talked to about your kidney disease in the last two months? \_\_\_\_\_?

Do you remember their names?  
Yes \_\_\_\_ No \_\_\_\_ If Yes, list

---



---



---



---

How many prescribed medication for you: \_\_\_\_\_ Who? \_\_\_\_\_

---



---

(171)

Gave specified medical instructions to follow? \_\_\_\_\_ Who? \_\_\_\_\_

Did any of the instructions conflict, you know one doctor asked you to do one thing and the other doctor something different: Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, What did you do? Followed neither \_\_\_\_\_  
 Picked the one I thought was best \_\_\_\_\_  
 Went back to one doctor and told him the problem \_\_\_\_\_

172. When do you recall being first told that you had a kidney problem?

Date \_\_\_\_\_ Number of years/ months ago \_\_\_\_\_

About how soon after being told you had a kidney problem did you begin dialysis?

Number of years/months \_\_\_\_\_

173. Have you ever had a transplant? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, how many? \_\_\_\_\_ How long did each function? \_\_\_\_\_

If No, do you plan to have a transplant? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, are you on an organ donor list? Yes \_\_\_\_\_ No \_\_\_\_\_

174. Do you have any urine output? Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, how much would you estimate?

Less than one cup \_\_\_\_\_ Less than two cups \_\_\_\_\_ Other \_\_\_\_\_

175. Do you wear a medical alert tag? Yes \_\_\_\_\_ No \_\_\_\_\_

Now I would like to ask you some questions about your transportation here to the Center and your medical expenses.

176. First, how do you get to the Center?

- |                       |                |
|-----------------------|----------------|
| A. Walk               | F. Car service |
| B. Bus                | G. Ambulette   |
| C. Own car            | H. Subway      |
| D. Someone else's car | I. Other _____ |
| E. Ambulance          |                |

177. How long does it take you to get to the Center? \_\_\_\_\_ minutes
178. Generally, would you consider transportation to the center a problem for you? Yes \_\_\_\_\_ No \_\_\_\_\_
179. Is there another dialysis center that would be easier for you to go to? Yes \_\_\_\_\_ No \_\_\_\_\_ Don't Know \_\_\_\_\_
180. Are there some medical bills or expenses that are not covered by your insurances or Medicare? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, What? \_\_\_\_\_ Estimated Monthly Expense \_\_\_\_\_

_____	_____
_____	_____
_____	_____

(HAND CARD 32)

181. Are there times when you don't buy a prescription or go to the doctor or hospital, because you cannot afford the cost?

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

If #1,2,3, in what situations? \_\_\_\_\_

(TAKE CARD 32, GIVE CARD 33)

182. How often has a staff member at the Center talked to you about the following areas:

	Very Often	Frequently	Some-Times	Seldom	Never
A. Your kidney disease	(1)	(2)	(3)	(4)	(5)
B. Your medications and why you need them	(1)	(2)	(3)	(4)	(5)
C. The general procedures at the Center, the place, the way it is run	(1)	(2)	(3)	(4)	(5)
D. Your diet	(1)	(2)	(3)	(4)	(5)

(TAKE CARD 33, HAND CARD 34)

183. People handle or cope with difficult or upsetting situations (such as being a dialysis patient) in different ways. Tell me how often you use the following ways when you are dealing with a difficult situation.

Always	Frequently	Sometimes	Seldom	Never
A. I just keep thinking that things will get better.				
(1)	(2)	(3)	(4)	(5)
B. I pray or go to church/synagogue.				
(1)	(2)	(3)	(4)	(5)
C. I sleep a lot.				
(1)	(2)	(3)	(4)	(5)
D. I seek professional help, such as a psychologist, psychiatrist, social worker.				
(1)	(2)	(3)	(4)	(5)
E. I get angry or upset.				
(1)	(2)	(3)	(4)	(5)
F. I just don't think about my situation.				
(1)	(2)	(3)	(4)	(5)
G. I talk about my problems with other people.				
(1)	(2)	(3)	(4)	(5)
H. I just rely on myself.				
(1)	(2)	(3)	(4)	(5)
I. I just want to run away from the problem.				
(1)	(2)	(3)	(4)	(5)
J. I rely or depend on my family to help me with the situation.				
(1)	(2)	(3)	(4)	(5)
K. I have a drink or use medications.				
(1)	(2)	(3)	(4)	(5)

(Always)      (Frequently)      (Sometimes)      (Seldom)      (Never)

L. I throw myself into some activity, such as work, clubs, something.

(1)                      (2)                      (3)                      (4)                      (5)

M. I look for help from my friends.

(1)                      (2)                      (3)                      (4)                      (5)

N. I just break down and don't handle it.

(1)                      (2)                      (3)                      (4)                      (5)

O. I look for ways to improve myself and my situation.

(1)                      (2)                      (3)                      (4)                      (5)

(Take CARD 34)

184. What advice would you offer a new dialysis patient in order to help him/her adjust or cope with being a dialysis patient?

185. Do you think your kidney disease will keep you from fulfilling some of your future plans or ideas? Yes \_\_\_\_\_ No \_\_\_\_\_  
If Yes, What?

186. Can you describe to me when and how it is hardest for you to follow your diet and medical instructions? What people make it harder?

187. Can you describe to me when and how it is easiest for you to follow your diet and medical instructions? What people make it easier?

188. Are there any services or anything that you think should be available here at the Center, that would help you stick with your diet and medical instructions better? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, What?

NAME \_\_\_\_\_ DATE \_\_\_\_\_

Below is a list of words that describe feelings people have. Please read each one carefully. Then fill in CNE space under the answer to the right which best describes HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY

W-12345-6789

The numbers refer to these phrases.

- 0 = Not at all
- 1 = A little
- 2 = Moderately
- 3 = Quite a bit
- 4 = Extremely

	0	1	2	3	4		0	1	2	3	4
						21. Hopeless					
						22. Relaxed					
						23. Unworthy					
						24. Spiteful					
T						25. Sympathetic					
						26. Uneasy					
						27. Restless					
D						28. Unable to concentrate					
						29. Fatigued					
						30. Helpful					
A						31. Annoyed					
						32. Discouraged					
						33. Resentful					
						34. Nervous					
						35. Lonely					
						36. Miserable					
F						37. Muddled					
						38. Cheerful					
						39. Bitter					
C						40. Exhausted					
						41. Anxious					
						42. Ready to fight					
						43. Good natured					
						44. Gloomy					
						45. Desperate					
						46. Sluggish					
						47. Rebellious					
						48. Helpless					
						49. Weary					
						50. Sawtoothed					
						51. Alert					
						52. Deceived					
						53. Furious					
						54. Efficient					
						55. Trusting					
						56. Full of pep					
						57. Saccharine					
						58. Warmness					
						59. Forgetful					
						60. Carefree					
						61. Terrific					
						62. Guilty					
						63. Vigorous					
						64. Uncertain about things					
						65. Sushed					

MAKE SURE YOU HAVE ANSWERED EVERY ITEM.

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189. Are you now working, unemployed, retired, a student, a homemaker, or what? (Check as many as apply)

- A. \_\_\_\_\_ Working (Ask Section 1)  
 B. \_\_\_\_\_ Unemployed (Ask Section 2)  
 C. \_\_\_\_\_ Retired (Ask Section 3)  
 D. \_\_\_\_\_ Student (Ask Section 4)  
 E. \_\_\_\_\_ Homemaker (Ask Section 5)  
 F. \_\_\_\_\_ Other \_\_\_\_\_ (Ask Section 6)

Section 1 (Employed)

190. What is your present occupation? (Description of activities)

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A. How many hours do you work each week?

Less than 10	11-20	21-30	31-40	41+
(1)	(2)	(3)	(4)	(5)

B. How long have you held this job?

Less than 1 Year	1-2 Years	3-5 Years	6-10 Years	11+ Years
(1)	(2)	(3)	(4)	(5)

C. Is this work your regular occupation? Yes \_\_\_\_\_ No \_\_\_\_\_

If No, why are you not now working in your regular occupation?

- (1) Because of health reasons related to dialysis  
 (2) No job openings  
 (3) Did not like regular occupation  
 (4) Other \_\_\_\_\_

## (GIVE CARD 35)

191. How do you think that working has affected your self-esteem or feelings about yourself?

- Has greatly increased my self-esteem  
 Has increased it  
 Has not had any effect on it  
 Has decreased it  
 Has greatly decreased my self-esteem

## (TAKE CARD 35)

192. Has being a dialysis patient made it easier or more difficult to do your job?

- Easier  
 Had no effect  
 Made it more difficult

193. Is there anything about working that has made it easier or harder for you to follow your medical and dietary instructions?

Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, what?

Section 2 (Unemployed)

194. Have you looked for a job within the last year? Yes \_\_\_\_\_ No \_\_\_\_\_

195. Have you had contact with the Office of Vocational Rehabilitation (OVR) within the last year? Yes \_\_\_\_\_ No \_\_\_\_\_

196. When did you last work?

- (1) Less than 6 months ago  
 (2) 6 months to 1 year  
 (3) 1 - 2 years  
 (4) 3 - 5 years  
 (5) 5 - 10 years  
 (6) 10 years +

197. What kind of work were you doing? \_\_\_\_\_

---

198. How did you happen to stop working when you did?

- A. Retired by company on reaching retirement age
- B. Unable to find work at regular occupation
- C. Wanted to enjoy leisure time
- D. Health; too ill to work
- E. Health; related specifically to kidney disease
- F. Did not enjoy work
- G. Financially it was wiser not to work
- H. Other

199. How many hours a week were you working?

- (1) Less than 10
- (2) 10 - 20
- (3) 21 - 30
- (4) 31 - 40
- (5) 41+

200. Would you say that being not employed turned out better or worse than you expected?

- (1) Better
- (2) About as expected
- (3) Worse

(GIVE CARD 35)

201. How do you think that not working has affected your self-esteem or feelings about yourself?

- Has greatly increased self-esteem
- Has increased it
- Has had no effect on my self-esteem
- Has decreased it
- Has greatly decreased my self-esteem

(TAKE CARD 35)

202. Is there anything about being unemployed that has made it easier or harder for you to follow your medical and dietary instructions?  
 Yes  No  If YES, what \_\_\_\_\_

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### Section 3 (Retired)

203. What was your main occupation? \_\_\_\_\_

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204. How many hours did you work each week?
- (1) Less than 10
  - (2) 11 - 20
  - (3) 21 - 30
  - (4) 31 - 40
  - (5) 40+
205. How long did you work at that job? \_\_\_\_\_ years
206. How do you think that being retired has affected your self-esteem or feeling about yourself?
- A. Has greatly increased my self-esteem
  - B. Has increased my self-esteem
  - C. Has had no effect on my self-esteem
  - D. Has decreased my self-esteem
  - E. Has greatly decreased my self-esteem

(TAKE CARD 35)

207. Would you be interested in returning to some type of employment?  
Yes \_\_\_\_\_ No \_\_\_\_\_ Maybe \_\_\_\_\_
208. Would you be interested in participating as a volunteer?  
Yes \_\_\_\_\_ No \_\_\_\_\_ Maybe \_\_\_\_\_
209. Would you say that being retired turned out better or worse than you expected?  
(1) Better                      (2) About as expected                      (3) Worse
- If worse, Why? \_\_\_\_\_
210. Is there anything about being retired that has made it easier or harder for you to follow your medical and dietary instructions?  
Yes \_\_\_\_\_ No \_\_\_\_\_  
If Yes, what?

Section 4 (School)

211. Are you a full time \_\_\_\_\_ or a part-time student?

(GIVE CARD 35)

212.. How do you think that being a student has affected your self-esteem or feelings about yourself?

- Has greatly increased my self-esteem  
 Has increased it  
 Has had no effect on my self-esteem  
 Has decreased it  
 Has greatly decreased my self-esteem

(TAKE CARD 35)

213. Has being a dialysis patient made it easier or more difficult for you to do your school related activities?

- Easier  
 Had no effect  
 Made it more difficult

214. Is there anything about being a student that has made it easier or harder for you to follow your medical and dietary instructions?  
 Yes  No  If Yes, what?

Section 5 (Homemaker)

215. How many hours a week are you involved with homemaker activities such as fixing meals, shopping, child care, laundry, etc.?

- (1) Less than 10  
 (2) 10 - 20  
 (3) 21 - 30  
 (4) 31 - 40  
 (5) 40+

(GIVE CARD 35)

216. How do you think that these homemaker activities have affected your your self-esteem or feeling about yourself?

- Has greatly increased my self-esteem  
 Has increased my self-esteem  
 Has had no effect on my self-esteem  
 Has decreased my self-esteem  
 Has greatly decreased my self-esteem

## (TAKE CARD 35)

217. Has being a dialysis patient made it easier or more difficult to do your regular homemaker activities?

- Easier  
 Had no effect  
 Made it more difficult

218. Is there anything about being a homemaker that has made it easier or harder for you to follow your medical and dietary instructions? Yes  No  If Yes, what?

Section 6 (Other Activities)

219. How do you spend the majority of your time during the week?

Specify \_\_\_\_\_

220. How many hours a week are you involved in this activity?

- (1) Less than 10  
 (2) 10 - 20  
 (3) 21 - 30  
 (4) 31 - 40  
 (5) 41+

## (GIVE CARD 35)

221. How do you think this activity has affected your self-esteem or feelings about yourself?

- Has greatly increased my self-esteem  
 Has increased my self-esteem  
 Has had no effect on my self-esteem  
 Has decreased my self-esteem  
 Has greatly decreased my self-esteem

## (TAKE CARD 25)

222. Has being a dialysis patient made it easier or more difficult to do your present activity?

- Easier  
 Had no effect  
 Made it more difficult

223. Is there anything about being \_\_\_\_\_ that has made it easier or harder for you to follow your medical and dietary instructions? Yes \_\_\_\_\_ No \_\_\_\_\_ If yes, what?

Now some general questions:

224. How much formal schooling have you had?

Grade school	01	02	03	04	05	06	
Junior high	07	08	09				
High school	10	11	12	Graduated			
College	13	14	15	16	Graduated		
Graduate school	17	18	19	20	Graduated		
Vocational training	21	22					
Other	_____						

225. At the present time, are you married, widowed, divorced, separated - or have you never been married?

Married  
 Single  
 Divorced  
 Widowed  
 Separated

226. What is your present religion?

Protestant (Ask A)  
 Catholic  
 Jewish  
 Muslim  
 Other (Specify) \_\_\_\_\_  
 None

- A. What denomination is that?

Baptist  
 Episcopalian  
 Jehovah's Witnesses  
 Methodist  
 Presbyterian  
 Seventh Day Adventists  
 Other: (Specify) \_\_\_\_\_

227. How often do you go to church or temple to attend religious services?

- Once a week or more  
 2 or 3 times a month  
 about once a month  
 a few times a year  
 other

228. How much of a role does religion play in your life now?

- (1) A great deal  
 (2) Some  
 (3) Little  
 (4) None

229. Now I'd like to ask you some questions about your parents. In what country was your mother born?

United States (Ask A) \_\_\_\_\_  
 Other \_\_\_\_\_  
 Don't Know \_\_\_\_\_

A. In what state?

New York \_\_\_\_\_  
 Other \_\_\_\_\_

230. And your father - where was he born?

United States (Ask A) \_\_\_\_\_  
 Other \_\_\_\_\_  
 Don't Know \_\_\_\_\_

A. In what state?

New York \_\_\_\_\_  
 Other \_\_\_\_\_

231. Where were you born?

New York City \_\_\_\_\_  
 Other \_\_\_\_\_

A. At what age did you move to the New York City area? \_\_\_\_\_

Now I'd like to ask you about race and nationality. (GIVE CARD 36)

232. What race do you consider yourself?

White  
 Black  
 Hispanic  
 Oriental  
 Other (Specify) \_\_\_\_\_



(TAKE CARD 36)

233. Most people have ties to some ethnic group or heritage background. What would you call your major ethnic tie or background?

<input type="checkbox"/> Afro American	<input type="checkbox"/> Italian
<input type="checkbox"/> African	<input type="checkbox"/> Greek
<input type="checkbox"/> Puerto Rican	<input type="checkbox"/> Irish
<input type="checkbox"/> West Indian	<input type="checkbox"/> Spanish
<input type="checkbox"/> South American	<input type="checkbox"/> Western European
<input type="checkbox"/> Muslim	<input type="checkbox"/> Eastern European
<input type="checkbox"/> Jewish	<input type="checkbox"/> Central European
<input type="checkbox"/> Cuban	<input type="checkbox"/> Oriental
<input type="checkbox"/> American Indian	<input type="checkbox"/> American
<input type="checkbox"/> Mexican	<input type="checkbox"/> Other (Specify) _____

(TAKE CARD 37, GIVE CARD 38)

234. How strongly do you identify with your ethnic or cultural group?

Very Strongly	Moderately	Somewhat	Little	None
(1)	(2)	(3)	(4)	(5)

(TAKE CARD 38)

235. Is any language other than English frequently spoken in your home? Yes \_\_\_\_\_ No \_\_\_\_\_  
If Yes, what languages?

Spanish	Yes	No
Italian	Yes	No
Greek	Yes	No
French	Yes	No
Other	Yes	No

- (If the patient speaks another language at home, then GIVE CARD 39).  
Have you ever had trouble understanding what the staff is saying to you?

Always	Frequently	Sometimes	Seldom	Never
(1)	(2)	(3)	(4)	(5)

(TAKE CARD 39)

Now I would like to ask you some questions about your financial situation. What are all the sources from which you get your present income?

## (TAKE CARD 39 Cont'.)

- (1)  Husband's (wife's) earnings  
 (2)  Children or other relative's earnings  
 (3)  Social Security  
 (4)  Social Security Disability  
 (5)  SSI  
 (6)  Pension from private industry, union, governmental agency  
 (7)  Public Assistance  
 (8)  Savings  
 (9)  Bonds or Investments  
 (10)  Income from property  
 (11)  Other \_\_\_\_\_
237. Taking into consideration all sources of income, what was your total income last year for yourself and your immediate family? (Before taxes). Just tell me the letter that corresponds to your income. (Hand patient the card.)
238. Is your standard of living better today - that is, are you better off now or is it worse than during most of your lifetime?
- (1)  Better today  
 (2)  Worse today  
 (3)  Same  
 (4)  Everybody's worse off today
239. If better today, is it related to being a dialysis patient?  
 Yes  No  If Yes,
- (1)  am eligible for better medical coverage  
 (2)  receive more financial benefits  
 (3)  Other \_\_\_\_\_
240. If worse off, is it related to being a dialysis patient?  
 Yes  No  If Yes,
- (1)  increased expenses related to medical problems/dialysis  
 (2)  loss of income of main breadwinner  
 (3)  Other \_\_\_\_\_
241. If the main breadwinner is not the patient, then
- Spouses occupation \_\_\_\_\_  
 Spouses education \_\_\_\_\_

DO YOU HAVE ANY QUESTIONS OF ME?



## APPENDIX B

Hello, I'm Roger Sherwood and I am a social worker at Long Island College Hospital and here at the Brooklyn Kidney Center. I am going to be doing a study to learn about attitudes and concerns that people on dialysis have about their health in general, the medical care they receive, and also learn about the things which affect a person's ability to follow their medical and dietary instructions.

I would like you to help me with this important study by answering some questions. I think you'll find the questions interesting. Your participation in the study will require about 1½ to 2 hours of your time.

Of course, your answers are completely confidential and anonymous and they will be stored in a locked cabinet that only I have access to.

The results of this study will help the staff better understand the things which affect your ability to follow the medical and dietary instructions and other concerns you have about your medical care. The results should benefit the patients here at the Brooklyn Kidney Center as well as other dialysis patients.

Your participation in this study is voluntary and you may withdraw at anytime without prejudice with regard to your care here by physicians and staff.

Do you have any questions of me at this time? Okay, first I would like to read you this consent form and then have you sign it.

Okay, in general, brief answers will be very helpful, and most of the answers will come from the cards I hand you. We will be using rating scales.

Suppose I ask you how you would rate how you feel today? From the card you might choose "very poor" or "excellent" or somewhere in between the two extremes.

Is this clear? Okay, let's begin with this question.

Element Number \_\_\_\_\_

## APPENDIX C

## THE LONG ISLAND COLLEGE HOSPITAL

## Division of Nephrology

CONSENT FORM

It is my understanding that my participation in this project may help identify factors which affect kidney patients' ability to follow their medical/dietary instructions, and help staff better understand concerns patients have about their medical care.

I understand that I will be interviewed by a staff member of Long Island College Hospital and Brooklyn Kidney Center. I understand that I may ask and expect full answers to any question I may have during the course of the study, that I may withdraw for any reason whatsoever from the study, without prejudice with regard to further care by the physicians and staff.

I also understand that my responses to all the questions are confidential, and all data will be stored in a locked file cabinet that only the interviewer has access to.

I also understand that a designated member of the hospital's Human Subjects Review Committee will be available at 780-4653 to discuss any problems or grievances I may have during my participation in the project; and that my name may not be released to anyone without my specific consent.

Patient Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness Signature \_\_\_\_\_ Date \_\_\_\_\_

## APPENDIX D

## CARD NUMBER 3

VERY CONCERNED							NOT CONCERNED AT ALL
(1)	(2)	(3)	(4)	(5)	(6)	(7)	

<sup>a</sup> Respondents were handed 5x8 cards with different response choices for the various questions.

## BIBLIOGRAPHY

- Abram, H.S.; Moore, G.L.; and Westervelt, F.R. "Suicidal Behavior in Chronic Dialysis Patients." American Journal of Psychiatry 127 (1971):1199-1204.
- Anger, Diane. "The Psychologic Stress of Chronic Renal Failure and Long Term Hemodialysis." Nursing Clinics of North America 10 (September 1975):449-460.
- Bartlett, Harriett M. The Common Base of Social Work Practice. Washington, D.C.: National Association of Social Workers, 1970.
- Becker, Marshall, et al. "A New Approach to Explaining Sick-Role Behavior in Low-Income Populations." American Journal of Public Health 64 (March 1974):205-217.
- Becker, M.H., et al. "Selected Psychosocial Models and Correlations of Individual Health-Related Behaviors." Medical Care 15 Supplement (1977):27-46.
- Bergman, A.B. and Werner, R.J. "Failure of Children to Receive Penicillin by Mouth." New England Journal of Medicine 268 (June 13, 1963):1334-1338.
- Blackburn, Sue L. "Dietary Compliance of Chronic Hemodialysis Patients." Journal of the American Dietetic Association Research 70 (January 1977):31-37.
- Buchanan, Denton C., et al. "Psychological Adaptation to Hemodialysis." Dialysis and Transplantation 5 (February/March 1976):36-42.
- Davis, M.S. "Predicting Non-Compliant Behavior." Journal of Health and Social Behavior 8 (December 1967):265-272.
- Davis, M.S. "Variations in Patients' Compliance With Doctors' Orders; Analysis of Congruence Between Survey Responses and Results of Empirical Investigations." Journal of Medical Education 41 (November 1966):10.37-48.
- Davis, M.S. "Physiologic, Psychological and Demographic Factors in Patient Compliance With Doctor's Orders." Medical Care 6 (March/April 1968):115.
- Davis, M.S. "Variations in Patient's Compliance with Doctors' Advice; an Empirical Analysis of Patterns of Communication." American Journal of Public Health 58 (February 1968):274-288.
- De-Nour, A.K., and Czaczkes, J.W. "Adjustment to Chronic Hemodialysis." Israel Journal Medical Science 10 (May, 1974), pp. 498-506.

- De-Nour, A.K., et al. "Emotional Reactions of Patients on Chronic Hemodialysis." Psychosomatic Medicine 30 (1968):521-33.
- De-Nour, A.K., and Czaczkes, J.W. "The Influence of Patients' Personality on Adjustment of Chronic Dialysis." Journal of Nervous and Mental Disease 162(1976):323.
- De-Nour, A.K. and Czaczkes, J.W. "Personality Factors in Chronic Hemodialysis Patients Causing Noncompliance with Medical Regimen." Psychosomatic Medicine 34 (1972):333-344.
- Department of Health and Human Services Health Care Financing Administration. "End-Stage Renal Disease Second Annual Report to Congress." Baltimore, Maryland, Fy 1980. (Typewritten.)
- Department of Health, Education, and Welfare, Health Care Financing Administration, Federal Health Insurance for the Aged and Disabled. "Conditions for Coverage - Supplies of ESRD Services; Requirements for Self-Dialysis Units and Self-Dialysis Services." Federal Register 43, No. 203, 19 October 1978, 48949.
- Department of Health, Education, and Welfare, Social Security Administration, Renal Disease. "Condition: Minimal Service Requirements for a Renal Dialysis Facility or Renal Dialysis Center." Federal Register 41, No. 108, 3 June 1976, 22520.
- Department of Health, Education, and Welfare, Social Security Administration, Renal Disease. "Condition: Minimal Service Requirements for a Renal Transplantation Center." Federal Register 41, No. 108, 3 June 1976, 22520.
- Eichhorn, R.L. et al. "Compliance to Perceived Therapeutic Advice." Proceedings of the Purdue Farm Cardiac Seminar. Edited by W.H. Morris, Lafayette, Indiana: Agricultural Experiment Station, September 1958.
- Elling, Ray, et al. "Patient Participation in a Pediatric Program." Journal Health and Human Behavior 1 (Fall 1960):183-191.
- Foster, F.G. et al. "Psychobiologic Factors and Individual Survival on Chronic Renal Hemodialysis - A Two-Year Study Follow-up, Part I." Psychosomatic Medicine 35 (1973):64.
- Fox, W. "Problem of Self-Administration of Drugs: With Particular Reference to Pulmonary Tuberculosis." Tuberculosis 39 (October 1958):269-274.
- Fox, Renee, and Swazey, Judith P. The Courage to Fail. Chicago: The University of Chicago Press, 1975.



- Francis, Vida, et al. "Gaps in Doctor-Patient Communication: Patients' Response to Medical Advice." New England Journal of Medicine 280 (March 6, 1969):535-540.
- French, John. "Adjustment as Person-Environment Fit." In Coping and Adaptation, pp. 316-333. Edited by G.V. Coelho. New York: Basic Books, 1974.
- Friedman, Eli, et al. "Psychosocial Adjustment to Maintenance Hemodialysis." New York State Journal of Medicine (March 1, 1970): 629-637.
- Germain, Carel. "An Ecological Perspective on Social Casework." Social Casework 54 (June 1973):323-330.
- Germain, Carel and Gitterman, Alex. The Life Model of Social Work Practice. New York: Columbia University Press, 1980.
- Glassman, Barry, and Siegal, Allen. "Personality Correlates of Survival in a Long Term Hemodialysis Programme." Archives of General Psychiatry 22 (June 1970):566-574.
- Gordis, L., et al. "The Inaccuracy in Using Interviews to Estimate Patient Reliability in Taking Medications at Home." Medical Care 7 (January/February 1969):49-54.
- Gordon, William. "Basic Constructs for an Integrative and Generative Conception of Social Work." In The General Systems Approach: Contributions Toward an Holistic Conception of Social Work, pp. 5-11, edited by A. Gordon Hearn. New York: Council on Social Work Education, 1969.
- Greenberg, Irwin, et al. "Factors of Adjustment in Chronic Hemodialysis Patients." Psychosomatics 16 (Oct./Nov./Dec. 1975):178-185.
- Hartmann, H. Ego Psychology and the Problem of Adaptation. New York: International Universities Press, 1958.
- Hartman, Paula and Becker, Marshall. "Non-Compliance with Prescribed Regimen Among Chronic Hemodialysis Patients." Dialysis and Transplantation 7 (October 1978):978-989.
- Hochbaum, G. "Public Participation in Medical Screening Programs." Public Health Service Publication No. 572. Washington, D.C.: U.S. Government Printing Office, 1958.
- Hollingshead, August B. Social Class and Mental Illness: A Community Study. New York: Wiley Press, 1958.
- Janchill, Sister Mary P. "Systems Concepts in Casework Theory and Practice." Social Casework 50 (February 1969):74-82.

- Joel, Sheila and Wieder, Susanna. "Factors Involved in Adaptation of the Stress of Hemodialysis." Smith College Studies in Social Work 43 (1972-3):205.
- Johnson, W.L. "Conformity to Medical Recommendations in Coronary Heart Disease." Paper presented at American Sociological Association meeting, Chicago, Illinois, September 2, 1965. (mimeographed.)
- Joyce, C.R.B. "Patient Cooperation and the Sensitivity of Clinical Trials." Journal of Chronic Diseases 15 (November 1962):1025-1036.
- Kassenbaum, Gene, and Baumann, Barbara. "Dimensions of the Sick Role in Chronic Illness." In Patients, Physicians, and Illness, pp. 141-154. Edited by E.G. Jaco. New York: Free Press, 1958.
- Koos, E. The Health of Regionville: What the People Thought and Did About It. New York: Columbia University Press, 1954.
- Lazarus, Richard S., et al. "The Psychology of Coping: Issues of Research and Assessment." In Coping and Adaptation, pp. 249-315. Edited by G.V. Coelho. New York: Basic Books, 1974.
- Leistyna, J.A. and Macaulay, J.C. "Therapy of Streptococcal Infection. Do Pediatric Patients Receive Prescribed Oral Medications?" American Journal of Diseases of Children 111 (January 1966):22-26.
- Levy, N.B. "Sexual Factors and Rehabilitation." Dialysis and Transplantation 7 (June 1978):591-601.
- Levy, N.B. "The Psychology and Care of the Maintenance Hemodialysis Patient." Heart and Lung 2 (May/June 1973):400-405.
- Levy, Norman. "Sexuality and the Hemodialysis Patient." Hospital Physician (October 1975):21-25.
- Lipman, R.S., et al. "Neurotics who Fail to Take Their Drugs." British Journal of Psychiatry 111 (November 1965):1043-49.
- MacDonald Mary E., et al. "Social Factors in Relation to Participation in Follow-up Care of Rheumatic Fever." The Journal of Pediatrics 62 (April 1963):503-513.
- MacElveen, P.M. "Patient Outcome Success Related to Cooperation Among Patient, Partner, and Physician." Journal of American Association of Nurses and Nephrology Technicians 2 (1975):148-156.
- Maluccio, Anthony. "Action as a Tool in Casework Practice." Social Casework 55 (January 1974):30-36.

- Marston, Mary-Vesta. "Compliance with Medical Regimens: A Review of the Literature." Nursing Research 19 (July/August 1970): 312-323.
- McNaire, Douglas, et al. Profile of Mood States. San Diego: Educational and Industrial Testing Services, 1971.
- Mechanic, David. "Response Factors in Illness: The Study of Illness Behavior." In Patients, Physicians, and Illness, pp. 128-140. Edited by E. Gartly Jaco. New York: The Free Press, 1958.
- Mechanic, David. "Sex, Illness, Illness Behavior, and the Use of Health Services." Journal of Human Stress (December 1976):29-40.
- Mechanic, David. "Social Structure and Personal Adaptation: Some Neglected Dimensions." In Coping and Adaptation, pp. 32-46. Edited by G.V. Coelho. New York: Basic Books, 1974.
- Meyer, Carol. "Practice Models - The New Ideology." Smith College Studies in Social Work 43 (February, 1973):85-98.
- Minahan, Anne. "Theories and Perspectives for Social Work." Social Work 25 (November 1980):435.
- Minuchin, Salvatore. Families and Family Therapy. Cambridge: Harvard University Press, 1974.
- Murphy, Lois. "Coping, Vulnerability, and Resilience in Childhood." In Coping and Adaptation, pp. 69-100. Edited by G.V. Coelho. New York: Basic Books, 1974.
- Neely, Elizabeth and Maxine, Patrick. "Problems of Aged Persons Taking Medications at Home." Nursing Research 17 (January/February 1968): 52-55.
- Parsons, Talcott. "Definitions of Health and Illness in the Light of American Values and Social Structure." In Patients, Physicians, and Illness, pp. 107-127. Edited by E. Gartley Jaco. New York: The Free Press, 1958.
- Reichsman, Franz, and Levy, Norman B. "Problems in Adaptation to Maintenance Hemodialysis." Archives of Internal Medicine 130 (December 1972):859-865.
- Richmond, Mary E. Social Diagnosis. New York: Free Press, 1917.
- Rosenberg, Morris. Society and Adolescent Self-Image. Princeton, New Jersey: Princeton University Press, 1965.
- Roth, Harold and Berger, David. "Studies of Patient Cooperation in Ulcer Treatment." Gastroenterology 38 (April 1960):630-634.

- Rotter, J.B. "Generalized Expectancies for Internal Versus External Control for Reinforcement." Psychological Monographs 80 (1966):1.
- Sackett, David L., et al. "Randomised Clinical Trial of Strategies for Improving Medication Compliance in Primary Hypertension." The Lancet (Saturday, 31 May 1975):1205-1208.
- Sand, P., et al. "Psychological Assessment of Candidates for Hemodialysis Program." Annals Internal Medicine 64 (1966): 602-610.
- Scribner, Belding, et al. "Panel: Living or Dying: Adaptation to Hemodialysis." In Living or Dying: Adaptation to Hemodialysis, pp. 3-39. Edited by N.B. Levy. Springfield, Illinois: Charles C. Thomas, 1974.
- Schwartz, Morris and Schwartz, Charlotte. Social Approaches to Mental Patient Care. New York: Columbia University Press, 1964.
- Seabury, Brett. "The Contract: Uses, Abuses, and Limitations." Social Work 21 (January 1976):16-23.
- Short, M.J., and Wilson, W.P. "Roles of Denial in Chronic Hemodialysis." Archives of General Psychiatry 20 (1969):433-37.
- Studt, Elliot. "Social Work Theory and Implications for the Practice of Methods." Social Work Education Reporter 16 (June 1968):22-24.
- "The A's and B's of Medicine. National Association of Patients on Hemodialysis and Transplantation News, Edited by Juna Crowley, Great Neck, New York, February 1978, p. 21.
- Walser, Dianne. "Behavioral Effects of Dialysis." Canadian Nurse 70 (May 1974):23-25.
- Watkins, Julia D., et al. "Observation of Medication Errors Made by Diabetic Patients in their Home." Diabetes 16 (March 1966): 229-230.
- Webster's New World Dictionary of the American Language, 2nd Ed. (1970), S.V. Compliance.
- White, Robert W. "Strategies of Adaptation: An Attempt at Systematic Description." In Coping and Adaptation, pp. 47-68. Edited by G.V. Coelho. New York: Basic Books, 1974.
- Winokur, M.Z., et al. "Intelligence and Adjustment to Chronic Hemodialysis." Journal of Psychosomatic Research 17 (1973): 29-34.
- Zborowski, M. "Cultural Components in Response to Pain." Journal of Social Issues 8 (1952):16-30.

