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TREATMENT PREFERENCES AND REGIMEN COMPLIANCE OF HEMODIALYSIS PATIENTS: ASSESSMENT AND CORRELATES

The Ohio State University ............................ Ph.D. 1984

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TREATMENT PREFERENCES AND REGIMEN COMPLIANCE OF HEMODIALYSIS PATIENTS: ASSESSMENT AND CORRELATES

DISSERTATION

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By
Daryl Goldman, B.A., M.A.

* * * *

The Ohio State University
1984

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This dissertation is lovingly dedicated to my parents, Claire and Jay Goldman, and Doris Bradley.
ACKNOWLEDGEMENTS

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CHAPTER 1

Introduction

**End Stage Renal Disease**

End Stage Renal Disease (ESRD) is said to exist when the kidneys are no longer capable of carrying out their various functions at a level necessary to maintain life, and when the return of renal function is not anticipated. Worldwide, renal failure affects approximately 150 to 200 million people a year. Although more than half of these people have diseases of a generalized nature for which artificial substitution of kidney function would only minimally prolong life or would not materially change its quality, the rest would benefit from such treatment (Levy, 1981). Hemodialysis became a viable means of providing long-term artificial substitution of kidney function with the development of the arteriovenous shunt, a permanent blood access route (Scribner, Caner, Buri, & Quinton, 1960). Currently, hemodialysis is the treatment of choice for ESRD patients who would benefit from artificial substitution of kidney function. Even those patients who are waiting for a kidney transplant typically begin treatment with hemodialysis.
The Stresses of a Hemodialysis Treatment Program

Although the technical and medical aspects of hemodialysis have improved, and dialysis patients experience fewer physical complications, hemodialysis is still very stressful for patients, their families, and the staff of the dialysis unit (Armstrong, 1978; Friedrich, 1980; Kaplan De-Nour & Shanan, 1980; Leonard, 1981; Reichsman & Levy, 1972; Speidel, Koch, Balck, & Kneiss, 1981; Wright, Sand, & Livingston, 1966).

When the kidneys cease to function properly, waste products and fluid accumulate in the body, causing body chemistry to become abnormal. This results in a clinical constellation of symptoms known as uremia. The constellation usually occurs when 85% to 90% of kidney function has been destroyed by disease. As a consequence of uremia and renal insufficiency, the cellular metabolism of many parts of the body, particularly the heart and circulatory system, gastro-intestinal tract, and nervous system, is affected. This progressive disorder is often manifested by changes in the pH (acid-base balance) of body fluids, an excess of total body water, an accumulation of retained wastes and toxins, disturbances in normal mineral and electrolyte balance, deterioration of enzyme function, and abnormal physiology of many endocrine functions of the body. Eventually patients with renal failure and uremia may develop abnormalities of nearly every organ of the body. A comprehensive list of uremia-related dysfunctions is presented in Appendix A. The reader is referred to Robbins and Angell (1976) and Schoenfeld and Humphreys (1976) for a description of these and
other aspects of renal failure and uremia.

Dialysis patients have very little respite from their illness. While many other chronically ill patients can experience a remission, and escape direct confrontation with their illness for short periods of time, dialysis patients must receive three to five hours of dialysis two to three times a week. They also need to comply with a complex dietary and fluid regimen for the rest of their lives (Levy, 1981). The ESRD patient's survival is dependent upon the careful regulation of the intake of fluid, sodium, potassium, phosphorous, calcium, protein, and calories.

Even when receiving regular treatment and complying with the medical regimen, hemodialysis patients are susceptible to numerous physical complications. ESRD patients have "normal" renal function only while on the dialysis machine. The dialysis procedure itself is stressful for internal organs, particularly when patients have been noncompliant with the treatment regimen and when increased machine pressure must be applied during dialysis to remove excess fluids and wastes. Increased machine pressure exacerbates cardiovascular problems common among dialysis patients and causes immediate negative side effects such as leg cramps. Appendix B, taken from Schoenfeld and Humphreys (1976), presents an extensive list of uremic symptoms which improve with dialysis, symptoms which persist or progress despite adequate dialysis, and symptoms which develop during the course of dialysis.

As a result of their illness and treatment, dialysis patients are confronted with important actual and potential losses in
vocational, financial, social, physical, and emotional areas (Abram, 1974; Blodgett, 1981-1982; Kaplan De-Nour, Shaltiel, & Czaczkes, 1968; Wright, Sand, & Livingston, 1966). For example, many patients starting dialysis have either lost their jobs or have had to markedly reduce their work activity as a result of poor health; these same and other patients have had to markedly reduce their involvement in household, school, and outside activities. Patients commonly face loss of physical strength and stamina, freedom, potential life expectancy, self-esteem, and most importantly their sense of control over their lives. In an extensive survey of dialysis patients Friedrich (1980) found that the decreased ability to make long-range plans engendered the greatest amount of anxiety for the largest number of patients who had started dialysis treatment.

The dialysis procedure itself can be a source of distress. Patients must cope with the insertion and removal of two needles into the arteriovenous shunt, the sight of blood circulating outside of the body, the danger of blood clots forming in the arteriovenous shunt, frequent exposures to emergency situations, long hours of immobility, and occasional physical side effects such as dizziness and leg cramps.

The regular and frequent dialysis treatments render the patient highly dependent for his or her survival on a machine, a procedure, and medical personnel. As a number of researchers have noted, the dialysis patient's sense of dependence may jeopardize feelings of self-worth and may weaken the will to live (Abram,
Each patient, drawing on both internal and environmental resources, struggles to resolve the psychological difficulties posed by his or her dependence and by the various losses entailed by the illness. Reichsman and Levy (1972) emphasize that sensitivity to these concerns on the part of persons close to the patient may significantly affect the patient's adjustment.

Adjustment to Hemodialysis

Over the course of the last 20 years nearly 2,000 studies have dealt with the psychological, social, and treatment problems encountered by dialysis patients (Blodgett, 1981-1982). The majority of studies indicate that global adjustment to dialysis is not a useful concept. Most patients have both strengths and weaknesses with regard to adjustment. Moreover, there also appears to be an interrelationship among some aspects of adjustment, but not others (Kaplan De-Nour, 1981).

Depression

Depression as a mood or syndrome is the most common psychological complication of patients undergoing hemodialysis, as it is with patients suffering from other chronic illnesses (Armstrong, 1978; Levy, 1979, 1981). There is, however, no definitive information regarding the incidence, severity, and duration of depression in dialysis patients. The reported incidence of moderate and/or severe depression in various studies ranged from 20% to 80% (Kaplan De-Nour, 1980). Comparisons among the studies are
complicated by a number of methodological issues, such as the subjects' length of time on dialysis, the criteria and instruments employed to define and measure depression, and differences in patient populations associated with differences in criteria for initiating treatment.

Ziarnik, Freeman, Sherraud, and Calsyn (1977) reported that a group of patients who died during the first year of dialysis were significantly more depressed immediately prior to initiating treatment than a group of patients who lived from three to ten years after starting dialysis treatment. They did not, however, report whether the patients were matched on factors such as age, degree of renal function, or the presence of medical complications. Their study suggests the need for more research to investigate the relationship between longevity in dialysis patients and psychological states, especially as a significant positive relationship between recovery from surgery and psychological states both prior to surgery and during recovery has already been well documented (Kendall & Watson, 1981; Langer, Janis, & Wolfer, 1975).

Suicide

A number of studies reported that one third to nearly one half of dialysis patients admit to experiencing suicidal ideation (Foster, Cohn, & McKegney, 1973; Holcomb & MacDonald, 1973; Shulman, Pacey, & Diebold, 1974). In large scale studies, the incidence of suicide for dialysis patients has been reported as .7% (Abram, Moore, & Westervelt, 1971), 1% (Kaplan De-Nour, 1980), and 5% (Siddiqui, Fitz, Lawton, & Kirkendall, 1970). Individual
dialysis units have reported the incidence of suicide as high as 14% (Czaczkes & Kaplan De-Nour, 1978). These figures on suicide fatalities are higher than the suicide rate for the general population (.013%) reported by the National Center for Health Statistics (1980). To date, a comparison of the suicide rate of dialysis patients with that of patients with other chronic illnesses has been precluded by the lack of adequate data for the other patient populations (Kaplan De-Nour, 1980).

An important finding which has emerged from the research on the deaths of dialysis patients is that a large number of deaths are due to passive noncompliance with the medical regimen. Such noncompliance has been interpreted as a form of suicide, as patients are well aware of the well established relationship between compliance with the medical regimen and survival on dialysis (Borkman, 1976; Merrill, 1975; Scribner, Fergus, Boen, & Thomas, 1965). In their extensive review of the incidence of suicide on 127 dialysis units caring for a total of 3,478 patients, Abram, Moore, and Westervelt (1971) obtained the following information. Twenty patients committed suicide, 17 unsuccessfully attempted suicide, 22 died due to voluntary withdrawal from their hemodialysis program, and an additional 117 deaths could be attributed to failure to comply with the medical regimen. In another study, Kaplan De-Nour and Czaczkes (1972) reported that 8 out of 10 patients who died at one dialysis center were identified as non-compliers.
Noncompliance: A Critical, Widespread Phenomenon

Incidence

Noncompliance with various aspects of the medical regimen appears to be widespread. Levy (1973) discussed research reporting that 15% to 93% of dialysis clinic populations intermittently undermine dietary/fluid restrictions. Kaplan De-Nour and Czaczkes (1976) found that the compliance of more than one half of the patients they observed ranged from "fair" to "great abuse." Other investigators have confirmed that dialysis patients frequently engage in fluid and dietary binges that may seriously endanger their lives (Gelfman & Wilson, 1972; Joel & Wieder, 1973; Kirilloff, 1981). In a long-term study of 53 patients, Blackburn (1977) found that 25% were noncompliant with potassium restrictions, 40% were noncompliant with phosphorous restrictions, and 51% were noncompliant with fluid restrictions. Noncompliance with fluid restrictions frequently resulted in patients gaining from 8 to 20 pounds between sessions, rather than the recommended weight gain of 3 to 4 pounds.

The findings reported above argue strongly for further research on compliance. A number of investigators have already attempted to ascertain factors related to degree of compliance with the medical regimen of dialysis patients.

Demographic Variables and Compliance

There does not seem to be a clear relationship between the sex of the patient and compliance with the dialysis regimen. In a
review of relevant investigations, Sackett and Haynes (1976) found 3 studies which reported that women were more compliant, 3 studies which reported that men were more compliant, and 25 studies which found no association between sex of the patient and compliance. Kirilloff (1981) found compliance to be unrelated to sex, age, race, or education, and maintained that her findings were consistent with her review of the research in this area.

**Length of Time on Dialysis and Compliance**

Conflicting evidence has been reported regarding the relationship between length of time on dialysis and compliance. Blackburn (1977) found that physiological assessments of compliance with the medical regimen decreased as the amount of time in treatment increased. While Hartman and Becker (1978) and Yanitsky (1983) found that nurses' ratings of patients' compliance with the general medical regimen increased with time on dialysis, Kaplan De-Nour and Czaczkes (1976) did not find such a relationship, and reported that patients' patterns of compliance appeared fairly well established by six months. Although O'Brian (1980) detected a significant positive relationship, Cummings (1980) detected a significant negative relationship between patients' self-ratings of compliance and time in treatment.

**Intelligence, Understanding, and Compliance**

In 1973 federal legislation was passed in the United States which makes hemodialysis treatment available to all ESRD patients who would benefit from such treatment (Borkman, 1976). Prior to this time the number of patients who would benefit from dialysis
far exceeded the opportunities for treatment. Dialysis units were forced to develop criteria for determining priority for treatment. Patients' intelligence (measured or estimated) was overtly and covertly employed as a criterion for dialysis treatment (Winokur, Czaczkes, & Kaplan De-Nour, 1973). Subsequent research has provided evidence that a basic understanding of the medical regimen has a stronger relationship to compliance than intelligence (Borkman, 1976; Winokur, Czaczkes, & Kaplan De-Nour, 1973), and that nurses' estimates of patients' understanding of restrictions are a significantly better predictor of compliance than are nurses' estimates of patients' intelligence (Borkman, 1976). However, Kirilloff (1981) and Blackburn (1977) have shown that knowledge of restrictions is not in itself sufficient to maintain compliance; they found that both compliant and noncompliant patients understood their dietary and fluid restrictions.

Beliefs About Health and Compliance

There is conflicting evidence concerning the relationship of health beliefs and compliance. Hartman and Becker (1978) found that less compliant patients tended to be less worried about their kidney disease and about their health in general. While such patients were concerned about carrying out the dialysis staff's instructions and their potential vulnerability to the consequences of noncompliance, they still maintained that the sequelae of noncompliance during the next year would not have serious consequences. Noncompliant patients expressed less faith in the efficacy of every aspect of therapy, tended to see more barriers to
compliance, felt less control over their situation, and were more willing to derive secondary gain from the sick role. Yanitski's (1983) findings were partially supportive of these results, and Kirilloff (1981) provided evidence that patients' beliefs regarding the need to adhere to restrictions had a stronger relationship to compliance than did knowledge of the restrictions. Cummings, Becker, Kirscht, and Levin (1982) and Bollin and Hart (1982) failed to obtain support for a relationship between health beliefs and compliance. In each of the latter two studies, patients with varying levels of compliance held similar views of the severity of their illness and their susceptibility to illness. Cummings et al. (1982) found that situational factors, such as the cost and benefits associated with health-related behaviors, were significantly related to compliance. Unfortunately, each of the studies which examined beliefs about health and compliance behavior employed different measures of health beliefs and compliance, making comparisons among them difficult.

Psychological Factors and Compliance

Kaplan De-Nour and Czaczkes (1976) and Kaplan De-Nour (1980) reported that severe (but not moderate) depression greatly affected patients' regimen compliance. In this connection it is important to keep in mind that the depression may, at least in part, be a reaction to the dietary restrictions themselves. While more information is needed on the reciprocal relationship between depression and compliance, this finding does provide further confirmation of the interrelationship of the physical and emotional
Kaplan De-Nour (1980) and Levy (1979), among others, have posited that dialysis, because it entails serious losses, restrictions, frustrations, and pains, engenders considerable aggression. Interestingly, Mock and Kopel (1977) found that dialysis patients scored low on measures of aggression. These authors suggest that dialysis patients mobilize defenses such as reaction formation, introjection, and projection to handle the high levels of aggression produced by dialysis. Other studies also appear to indicate that dialysis patients are reluctant to express anger directly, possibly because of fear of rejection by family or staff (Gentry & Davis, 1972; Roper, Raulston, & Cramer, 1977). Kaplan De-Nour (1980) suggests that many psychological complications observed in dialysis patients are caused by defenses mobilized to handle aggression. She suggests, for example, that depression may be a result of introjection of angry feelings, that paranoid ideation may be a result of projection of these feelings, and that passive noncompliance with the medical regimen which places patients in direct conflict with staff's personal concerns and medical demands may be a form of displacement of aggression towards staff.

Blodgett (1981-1982) has suggested that dialysis patients' noncompliance with the medical regimen may be associated with the need to deny the life-threatening nature of their illness. A number of dialysis researchers have suggested that denial, particularly of the life-threatening nature of the illness, is the primary defense mechanism used by dialysis patients, and have
described the adaptive function of denial (Abram, 1974; Kaplan De-Nour, 1981; Reichsman & Levy, 1972; Short & Wilson, 1969). However, it is clear that denial may have highly maladaptive consequences, as when it leads to noncompliance with the medical regimen.

A number of studies have indicated that, compared with non-dialysis patient controls, dialysis patients, as assessed by Rotter's (1966) I-E Scale show a greater degree of externality (i.e., the tendency to attribute self-relevant outcomes to external forces over which they have no control, such as fate, chance, or luck) (Goldstein & Reznikoff, 1971; Kilpatrick, Miller, & Williams, 1972; Milatt & Allain, 1974). Wilson, Murzakari, Schneps, and Wilson (1974) found that patients' degree of externality increased with length of time on dialysis, while Poll and Kaplan De-Nour (1980) failed to obtain differences in degree of externality as a function of time on dialysis. Gentry and Davis (1972) suggest that the nature and stresses of chronic hemodialysis lead patients to be externally oriented, as a means of coping with the anxiety raised by the reality that they must relinquish a good deal of their control to dialysis personnel and to the machine for their survival.

Various researchers have associated dialysis patients' defensive reactions, psychological complications, and noncompliance with the failure to experience a sense of control over one's life and treatment (Beard, 1969; Glassman & Siegel, 1970; Kaplan De-Nour, Shanahan, & Garty, 1978; Short & Alexander, 1969; Viederman, 1978).
With the exception of one study (Blackburn, 1977), the research in this area indicates a significant positive relationship between internal locus of control scores (indicating acceptance of responsibility for one's own actions and feeling in control of what happens to oneself) and nurses' assessments of patients' compliance with dietary and fluid restrictions (Hartman & Becker, 1978; Kilpatrick, Miller, & Williams, 1972; Poll & Kaplan De-Nour, 1980).

Thus far, only one study has examined the responses of dialysis patients on the Multidimensional Health Locus of Control (MHLC) Scales developed by Wallston, Wallston, and DeVellis (1978) to study individual's perceptions of the source of reinforcement for health-related behaviors. Hatz (1978) reported that a small sample of dialysis patients (n = 19) tended to rate themselves as less internally oriented, more dependent on powerful others (e.g., doctors, nurses, and family) for direction in their health care, and less accepting of the role of chance or fate in their health than did other chronic illness patients, college students, and healthy adults examined in previous research (Wallston, Wallston, & DeVellis, 1978).

Family Support and Compliance

Many authors have suggested that, in general, both the course of chronic illness and the course of rehabilitation are influenced by the availability of family/friendship social support systems (e.g., Coe, 1978; Litman, 1979; Safilios-Rothschild, 1970). The same suggestion has been made with particular reference to dialysis patients (Crammond, Knight, & Lawrence, 1967; Kossoris, 1970;
Short & Wilson, 1969). Wright, Sand, and Livingston (1966) noted that relatively successful adjustment to dialysis was associated with relatively strong family support. Hartman and Becker (1978) found strong empirical evidence for better compliance among patients with, than without, a spouse, and less compliance among patients with relatively little social support. Abram, Moore, and Westervelt (1971) found that an absence of family support was evident in most of the cases of patients who either made a direct suicide attempt or who died because of noncompliance with the medical regimen.

O'Brian (1980) attempted to explain the positive relationship between family support and compliance with the medical regimen in terms of George Mead's (1934) symbolic interactionism. Mead used the term "significant other" to refer to persons whose behavior, attitudes, and expectations are considered important and/or influential by an actor in terms of governing the latter's behavior. Mead proposed that people's behavior may be understood only in terms of their social group membership, and that most of their actions are predicated on their perceptions of the attitudes and expectations of the significant others in their social system. Consistent with this formulation, O'Brian (1980) found a significant positive relationship between patient compliance with the dialysis regimen and perceptions of family or friends' expectations about compliance. This relationship between perceived expectations and compliance was significant at both six months and three years after starting dialysis.
Steidel, Finkelstein, Wexler, Feigenbaum, Kitsen, Kliger, and Quinlan (1980) found the following family variables significantly correlated with dialysis patients' compliance with the medical regimen: 1) the family's ability to efficiently negotiate and solve problems, 2) a strong coalition between parents in families with children, 3) children's and parents' mutual respect for each others' privacy, 4) openness and receptivity to the feelings and opinions of other family members, 5) shared leadership and control by parents, and 6) the regular articulation and acceptance of responsibility for one's own actions (as opposed to locating responsibility in family members). Short and Alexander (1969) have noted that the practical demands of renal failure and the subsequent changes in family dynamics are capable of straining even the most stable families and friendships.

**Patient-Staff Relationships and Compliance**

Staff on the dialysis unit also function as "significant others" to renal patients. Intense emotional relationships have been reported to develop between nurses and patients as a function of the critical and continuous nature of the treatment itself. Patients and the nursing staff spend from 9 to 15 hours a week together, sometimes over the course of several years. In addition to providing nursing services, nurses and technicians often function as educators, counselors, and confidants. The nursing staff has definite expectations for patients and is in a position to bestow or withhold approval in accordance with those expectations.
Some have observed that the attitudes, expectations, and communication patterns of the nursing staff of dialysis units strongly influence the compliance behavior of renal patients (Finnerty, Jr., 1978; Kaplan De-Nour & Czaczkes, 1971, 1974; Steckel, 1974; Wertzel, Vollrath, Ritz, & Ferner, 1977). O'Brien (1980) found a significant positive relationship between patients' compliance and their perceptions of the expectations of both their family and dialysis staff. Interestingly, the impact of the family's expectations was strongest when patients first started dialysis (at six months), but the expectations of the staff had their greatest impact on patient compliance after three years of dialysis. This shift in the strength of the impact of family and staff expectations could be a function of the strengthening of the patient-staff relationship over time.

The apparently strong association between staff expectations and patient compliance calls for a close examination of the dialysis patient-staff relationship. This would seem to be of particular importance as different units have reported different rates of patient compliance (Kaplan De-Nour, Czaczkes, & Lilos, 1972; Levy, 1973; Kirilloff, 1981). There is evidence that differences in opinions and expectations exist between: 1) patients and staff; 2) staff from different disciplines; and 3) treatment teams from different units.

Patient-staff agreement. The few studies which have compared patients' and staff's expectations and opinions have found discordant perceptions on a number of issues. Kaplan De-Nour and
Czaczkes (1971) found little agreement between patients' and their medical staff's perceptions of the suffering associated with dietary and fluid restrictions, the dialysis procedure, and restrictions in life-style. These authors reported that dialysis staff associated higher levels of distress with dietary and fluid restrictions and lower levels of distress with restrictions in life-style than did the dialysis patients. The only area in which there was agreement was that having to do with perceptions of the degree of distress associated with the patients' physical condition between treatments. Consistent with these findings is Friedrich's (1980) report that dialysis patients associated relatively greater distress with psychosocial problems related to their illness than with the dietary and fluid restrictions of the medical regimen. Although dialysis patients have been shown to rate themselves as suffering more with respect to some rather than other aspects of their illness, nephrologists and nurses have been shown to regard patients as either suffering or not suffering equally in all aspects (Kaplan De-Nour & Czaczkes, 1971).

Bedell, Kilpatrick, Robinson, Gilbert, and Miller (1978) found that patients' self-reports of anxiety over the course of several dialysis sessions differed significantly from the assessments of patients' anxiety made by the nursing staff. Patients reported experiencing increasingly higher states of anxiety as a dialysis session proceeded, while nurses perceived patients as being the most anxious at the beginning of a treatment session.
Tucker, Mulkeme, Panides, and Ziller (1981) found that patients and nursing staff disagree as to what actually constitutes adjustment. Significantly more patients than nurses viewed the friendliness of patients during treatment, good hygiene, punctuality, mature interactions with staff, infrequency of depression, interest in medical charts, low frequency of phone calls to the unit, participation in treatment, maintenance of social contacts, good relations with family, good reactions to needle insertion, and a healthy independence from family as crucial to adjustment to dialysis.

The problem of patient-staff disagreement is not unique to dialysis. A review of the research in this area provides evidence of patient-physician disagreement on patients' physical condition (Linn, Hunter, & Linn, 1980; Deniston & Jette, 1980), psychological adjustment to chronic illness (Derogatis, Abeloff, & McBeth, 1976), and treatment goals during psychotherapy (Polak, 1970). Furthermore, Archer and Amuso (1980) found important discrepancies between staff's and patients' perceptions of characteristics of the same residential psychiatric unit.

Interdisciplinary agreement. Kaplan De-Nour and Czaczkes (1971) reported that nurses, as compared with doctors, view the same patients as undergoing greater suffering. Moreover, in a study by Kaplan De-Nour and Czaczkes (1974) nephrologists rated the same patients as significantly and substantially better adjusted on 15 of 21 criteria, than did liaison psychiatrists and dialysis unit nurses. Nurses and technicians who work with
patients during dialysis have been shown to disagree on what constitutes patient adjustment (Becker, Brown, & Walker, 1977).

Within-unit consensus. Kaplan De-Nour and Czaczkes (1971) and Kaplan De-Nour, Czaczkes, and Lilos (1972) found that some dialysis unit treatment teams have a team opinion, i.e., a consensual system of values regarding required and praised behavior, while other teams do not. The authors report that even on those teams with a team opinion there is great variability in what is actually expected of patients. For example, on a given team all members may agree that dialysis patients should return to work, while individual team members may disagree on the amount of time patients should be expected to work. Those units which had a team opinion reported higher rates of patient compliance and staff satisfaction than did units without a team opinion. Interestingly, those teams with the highest expectations for patients had the lowest rate of patient compliance and staff satisfaction. Roper, Raulston, and Cramer (1977) in comparing three dialysis units found that the units differed markedly with respect to their methods of dealing with noncompliant patients, patients’ feelings while on dialysis, degree of patient-staff agreement on various issues, and staff comfort with discussing anger.

The Reciprocal Nature of the Patient-Staff Relationship

The high degree of stress associated with nursing on dialysis units is well documented (Crammond, Knight, & Lawrence, 1967; Kaplan De-Nour & Czaczkes, 1971; Levy, 1979; Menzies & Stewart, 1968). Dialysis staff are in intimate contact with patients for
long periods of time and must come to terms with the actuality that dialysis patients suffer almost constantly, frequently develop complications, and are never cured. The staff is sometimes the target of displaced anger which patients might more appropriately harbor toward family or any other number of possible sources of stress (DeVeber & MacDonald, 1969). Patients sometimes place themselves in direct conflict with staff by noncompliance with the medical regimen, by purposefully or unintentionally sabotaging staff efforts to keep them alive. Patients' attempts to achieve autonomy or a greater sense of control through noncompliance serve to alienate staff and to preclude the kinds of communication essential for the resolution of patient-staff conflict (Viederman, 1978).

There are reports that the close relationship that staff has with dialysis patients can result in adverse emotional involvement, e.g., guilt, possessiveness, overprotectiveness, or withdrawal (Kaplan De-Nour & Czaczkes, 1971; Klenow, 1979; Wertzel, Vollrath, Ritz, & Ferner, 1977).

Several researchers have discussed staffs' use of denial; more specifically, staffs' denial of the seriousness or the hopelessness of the patients' condition, and the denial of patients' ambivalence about living, an ambivalence that is sometimes manifest by noncompliance (Abram, 1974; Anger & Anger, 1976; Goldstein, 1972; Short & Wilson, 1969). It has been suggested that staffs' use of denial underlies the unrealistically high expectations of some treatment teams (Alexander, 1976; Becker, Brown, & Walker, 1977; Kaplan De-Nour & Czaczkes, 1971; Kaplan De-Nour, Czaczkes, & Lilos,
1972). Such unrealistic expectations further frustrate patients who are already having problems in achieving optimal adjustment. For example, patients might respond to unrealistic staff expectations by giving up or acting out through noncompliance, which in turn would increase staff frustrations and lead to the further mobilization of denial and the continuation of unrealistic demands. It was mentioned earlier that patients on units with extreme expectations have poorer rates of compliance (Kaplan De-Nour & Czaczkes, 1971).

Kaplan De-Nour (1980) notes that the demands and frustrations of working with dialysis patients can lead to increased aggression in staff. She suggests that one way that the staff may deal with this aggression is through reaction formation, resulting in the unusually strong devotion to work which appears typical of dialysis staff. She believes that this devotion, in turn, leads to increased frustration, as it results in expectations that, realistically, cannot be met. One report found that those nurses who had the greatest involvement with patients were also those who were inclined to be the most rejecting (Kaplan De-Nour & Czaczkes, 1976). The finding of a higher than normal incidence of depression among dialysis nurses led Wertz, Vollrath, Ritz, and Femer (1977) to suggest that some nurses mobilize introjection to deal with the job-induced aggression and frustrations. Kaplan De-Nour (1980) suggests that when staff do not deal with their anger toward patients, this anger is displaced onto other staff, resulting in the dissension so frequently observed on dialysis units.
Individualized Treatment Programs

This review of the dialysis literature indicates that researchers agree that ESRD is very stressful and that noncompliance with aspects of the medical regimen is a serious problem among dialysis patients. Although dialysis research is not univocal regarding which patient characteristics and beliefs predict compliance, or which treatment approaches best promote compliance, there does appear to be considerable agreement regarding the individuality of dialysis patients and the need to tailor the treatment environment to meet each patient's unique needs (e.g., Becker, 1979; Blodgett, 1981-1982; Fishman & Schneider, 1972; Hull, 1976; Kaplan De-Nour, 1980; Levy, 1979; Smith, Curtis, McDonald, & de Wardener, 1969).

An important basis for employing a highly individualized approach to treatment derives from research associated with Murray's (1938) Need-Press Model. This model posits that a person's behavior is a function of the interaction of the person's needs and the characteristics of the environment. The model prompts the speculation that dialysis patients' compliance behavior is, in part, dependent upon the congruence of their unique pattern of needs with their home, work, social, and treatment environments.

Research With Other Patient Populations

Several reviews of research involving medical patient populations have concluded that patients' perceptions of illness, prevention, and treatment needs are essential to achieve a full

Extensive research with Moos' (1974) Ward Atmosphere Scale (WAS), developed to assess the social climate of hospital-based psychiatric treatment programs, illustrates the importance of highly individualized treatment approaches. Moos' (1974) research with 23 psychiatric units revealed that the greater the similarity patients perceived between their actual and ideal treatment environments, the higher the patients rated their satisfaction with their treatment unit, their positive feelings for staff, and their ability to attain their treatment goals, and the lower patients rated their level of anxiety. Nevid, Capurso, and Morrison (1980) employed Moos' (1974) Community-Oriented Programs Environment Scale (COPES) to assess the perceptions of real and ideal community-based treatment environments of a group of psychiatric patients living in various family-care homes. These authors found that as the congruence between patients' ratings of their present and ideal treatment environment increased, patients' ratings of their satisfaction with their treatment environment increased, and staff's ratings of the incidence of patients' overtly psychotic and acting-out behavior decreased.

Moos (1974) and Kish, Solberg, and Uecker (1971) reported that psychiatric patients' locus of control (Rotter's I-E Scale) was significantly correlated with their perceptions of their treatment environment, satisfaction with their treatment environment,
length of hospitalization, and adjustment ratings by staff. These authors contend that locus of control is an important patient characteristic to consider when designing treatment programs. A study by Cromwell, Butterfield, Brayfield, and Curry (1977) supports this contention. Cromwell et al. (1977) reported that not one of sixty myocardial infarction patients who were treated in programs whose orientation was congruent with their locus of control (i.e., internal locus of control patients/high patient participation programs; external locus of control patients/low patient participation programs) returned to the hospital or died within 12 weeks of treatment. All those who had recurring myocardial infarctions or died within 12 weeks of treatment were patients treated in incongruent locus of control/treatment environment programs.

**Research With Dialysis Patients**

Research with dialysis patients reveals a number of factors which might be of significance when designing treatment interventions on dialysis units. For instance, Diamond (1980) reported that dialysis patients' preferred strategy for managing their dialysis treatment was significantly related to the number of physical symptoms they experienced. Sproles (1977) discovered that dialysis patients' willingness to participate in classes relating information about ESRD was associated with their sense of control over illness-related behavior. Friedrich (1980) found that the distress dialysis patients associated with physical and psychosocial problems related to their illness varied as a function of their age, sex, marital status, work status, and education.
This latter finding is of particular interest given Cheek's (1982) report that dialysis patients' perceptions of their illness were associated with their level of compliance.

**The Present Study**

Thus far there have been no investigations of the impact of various types of treatment environments on the functioning of dialysis patients. An important initial step in such investigations would entail the systematic assessment of patients' perceptions of and attitudes toward their treatment environments, with particular attention to how these perceptions and attitudes are related to patient characteristics. The potential importance of such assessment is underscored by the findings, discussed earlier, which reveal serious discrepancies between patients' views of various aspects of their treatment experience and staff beliefs regarding that same experience.

The major focus of the present study was to examine patients' preferences with regard to their treatment, with special attention to the relationship of such preferences to perceptions of severity of illness, perceptions of illness-related distress, sense of control over health-related behavior, and level of compliance. The following working hypotheses were evaluated in the present investigation.

**Hypothesis I.** Dialysis patients' self-ratings of severity of illness and degree of self-reported illness-related distress will be positively related to preferences for support, personal problem
orientation, staff control, and practical orientation, and negatively related to preferences for involvement and autonomy in the treatment environment.

**Hypothesis II.** Dialysis patients' degree of internality in health-related matters will be positively related to preferences for involvement, support, practical orientation, and autonomy, and negatively related to preferences for staff control in the treatment environment.

**Hypothesis III.** The strongest predictors of patients' compliance will be self-reported illness-related distress and internal health locus of control. It is anticipated that compliance will be positively related to patients' degree of internality in health-related matters, and negatively related to self reports of illness-related distress.

**Hypothesis IV.** Dialysis patients' reports of illness-related distress will be negatively related to their degree of internality in health-related matters, and positively related to their belief that their health is largely a function of chance or fate.

Given the paucity of research on dialysis patients' perceptions of their treatment environment and illness, the present study explored a variety of relationships among the patient measures that were not addressed by the above hypotheses. Additionally, the present study compared patients' and nurses' perceptions of patients' compliance and severity of illness.
CHAPTER 2

Method

Subjects

One hundred End Stage Renal Disease (ESRD) patients who were receiving regular dialysis treatments participated in this research. The participants were recruited from three dialysis units in the San Francisco Bay Area. Thirty-six of the participants were patients on Unit A, a 21-chair private dialysis center in San Francisco's East Bay which serves an ethnically and socio-economically varied population. Twenty-seven of the participants were patients on Unit B, a 14-chair private dialysis center in suburban Marin County which serves a more affluent, predominantly Caucasian population. The remaining 37 of the participants were patients on Unit C, a 22-chair center in a San Francisco hospital which, like Unit A, serves an ethnically and socio-economically varied urban population. The reader is referred to Appendix C for additional information regarding the three participating dialysis units.

Candidates for participation in the study were informed that such participation was entirely voluntary, and efforts were made to reduce the likelihood that patients would feel pressured into cooperation. The social worker from each unit was asked to identify all patients who met all of the following criteria: 1) they had
been receiving regular dialysis treatments at their center for at least two months, 2) they were at least 18 years of age, 3) they did not have any difficulties with their sight or hearing which would preclude their reading the questionnaire or communicating with the investigator, 4) they could read and comprehend written material in English, and 5) they could, in the social worker's opinion, focus their attention on a task for 30 to 60 minutes.

The social workers distributed a letter of introduction to patients meeting these criteria. The letter explained the nature and conditions of the study (Appendix D). The investigator arranged to meet individually with each patient who had informed the social worker of his or her willingness to discuss participation in the study. At this meeting the investigator further explained the purpose of the study, discussed issues of confidentiality, and clarified participants' rights as experimental subjects. The investigator made it clear that the patient had the prerogative of withdrawing from the study at any time without jeopardizing his or her treatments. All patients who gave their consent to participate subsequently completed the study.

One hundred of the 107 patients identified as potential subjects chose to participate in this research. Table 1 provides information for each unit regarding the number of patients participating, the number of patients who refused to participate, and the number of patients who did not meet the criteria for participation.

The participants ranged in age from 19 to 81 years (\( \bar{M} = 51 \) years, \( SD = 14.9 \) years). The selection procedure described above
<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>No. Ineligible</th>
<th>No. Refused</th>
<th>No. Participating</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unit A</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>31</td>
<td>12</td>
<td>1</td>
<td>18</td>
</tr>
<tr>
<td>Females</td>
<td>22</td>
<td>2</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Unit B</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>16</td>
<td>2</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Females</td>
<td>15</td>
<td>1</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>Unit C</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>30</td>
<td>11</td>
<td>1</td>
<td>18</td>
</tr>
<tr>
<td>Females</td>
<td>38</td>
<td>17</td>
<td>2</td>
<td>19</td>
</tr>
</tbody>
</table>
resulted in an approximate 50:50 ratio of male to female participants in each of the units. Overall, 50 males and 50 females participated.

Fifty-six of the participants were Caucasian, 28 were Black, and the remaining 16 were either of Hispanic, Asian, Middle Eastern, or Filipino origin. Over one half of the participants reported being married (53), while the remaining participants reported themselves as never having been married (22), as divorced or separated (13), or as widowed (12). Participants' education ranged from 6 to 19 years of schooling (M = 13.13 years, SD = 2.66 years); 81 of the participants completed 12 years of school, 19 finished college, and 3 completed 4 or more years of graduate school.

Sixty-three of the participants reported that before starting dialysis treatments they had worked full-time, 8 reported that they had worked part-time, and 29 reported that they had not been working at all. The start of dialysis occasioned a major shift in work status, with 14 participants reporting that they worked full-time, 18 reporting they worked part-time, and 68 indicating that they did not work outside of their home, and were unable to perform household chores on a regular basis.

Length of time on dialysis at the outset of the study ranged from 2 to 238 months, with a median duration of 24.5 months (M = 45.44 months, SD = 44.38 months). The amount of time participants were dialyzed each session ranged from 3 to 5 hours; 27 participants received 3-hour treatments, 24 received 3.5-hour treatments, 40 received 4-hour treatments, 7 received 4.5-hour treatments, and
2 received 5-hour treatments. Eighty-seven of the participants were dialyzed three times a week, 12 were dialyzed twice a week, and 1 was dialyzed once a week. Nineteen of the participants had an unsuccessful kidney transplant. Thirty-three participants reported being interested in having a kidney transplant sometime in the future, while 17 were uncertain about this, and 50 were satisfied with their current status on dialysis. Table 2 provides a breakdown of these data by unit.

**Staff Raters**

The member(s) of the nursing staff who had had the most direct clinical experience with the patients and who were most familiar with the patients' laboratory data were identified for each unit by staff consensus. These staff raters were asked to complete a form requesting evaluation of the severity of the patients' illness and the degree of patients' compliance with their treatment regimen. The head nurses on Units A and C and the evening and day charge nurses on Unit B were selected for and agreed to undertake the evaluations. The two charge nurses were selected in lieu of the head nurse on Unit B because the head nurse on that unit played more of an administrative and less of a caretaker role than did the head nurses on Units A and C.
Table 2

Characteristics of Patients from the Three Dialysis Units

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Unit</th>
<th>Unit</th>
<th>Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
<td>B</td>
<td>C</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>19-81</td>
<td>25-81</td>
<td>23-78</td>
</tr>
<tr>
<td>M</td>
<td>47.5</td>
<td>55.0</td>
<td>51.0</td>
</tr>
<tr>
<td>SD</td>
<td>16.4</td>
<td>13.5</td>
<td>13.5</td>
</tr>
<tr>
<td>Months on dialysis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>3-238</td>
<td>2-107</td>
<td>6-168</td>
</tr>
<tr>
<td>M</td>
<td>51.7</td>
<td>35.5</td>
<td>44.8</td>
</tr>
<tr>
<td>SD</td>
<td>53.8</td>
<td>30.7</td>
<td>43.0</td>
</tr>
<tr>
<td>Median</td>
<td>32.5</td>
<td>24.0</td>
<td>25.0</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>39%</td>
<td>80%</td>
<td>54%</td>
</tr>
<tr>
<td>Non-caucasian</td>
<td>61%</td>
<td>20%</td>
<td>46%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 12 years</td>
<td>11%</td>
<td>15%</td>
<td>30%</td>
</tr>
<tr>
<td>High school graduate</td>
<td>31%</td>
<td>26%</td>
<td>22%</td>
</tr>
<tr>
<td>Some college</td>
<td>58%</td>
<td>59%</td>
<td>48%</td>
</tr>
<tr>
<td>Current work status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>17%</td>
<td>12%</td>
<td>14%</td>
</tr>
<tr>
<td>Part-time</td>
<td>20%</td>
<td>23%</td>
<td>11%</td>
</tr>
<tr>
<td>Not working</td>
<td>64%</td>
<td>65%</td>
<td>76%</td>
</tr>
<tr>
<td>History of unsuccessful transplant</td>
<td>17%</td>
<td>8%</td>
<td>30%</td>
</tr>
<tr>
<td>Views on transplants</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wants a transplant</td>
<td>36%</td>
<td>35%</td>
<td>30%</td>
</tr>
<tr>
<td>Uncertain</td>
<td>25%</td>
<td>19%</td>
<td>5%</td>
</tr>
<tr>
<td>Does not want a transplant</td>
<td>39%</td>
<td>46%</td>
<td>65%</td>
</tr>
</tbody>
</table>

\[a_n = 36\]

\[b_n = 27\]

\[c_n = 37\]
Tests and Measurements

Patients' Treatment Preferences

Patients' preferences for their ideal dialysis treatment environment were assessed by the Ideal Dialysis Unit Survey (IDUS), a scale modeled after the short-form of Moos' (1974) Ward Atmosphere Scale (WAS) and developed for the present study. The IDUS retained the 10 scales which comprise the WAS, i.e., Involvement, Support, Spontaneity, Autonomy, Practical Orientation, Personal Problem Orientation, Anger and Aggression, Order and Organization, Program Clarity, and Staff Control. Each of the 4 items of the 10 Moos scales was adapted for relevance to a dialysis population. The reader is referred to Appendix E for a description of each scale and the 4 items which comprise it. The original True-False scoring system was changed to a 6-point Likert-type scale as the latter is more likely to be sensitive to variability. The IDUS presents patients with statements concerning treatment preferences, and asks the respondent to indicate the degree to which that statement reflects his or her own preferences. Two or three of the items on each IDUS scale are worded to reflect the concept embodied in the total scale, while the remaining items reflect the opposite (Appendices E and F).

Table 3 presents the average internal consistencies (Cronbach Alpha) for each of the 10 adapted scales for the sample of 100 dialysis patients who participated in this study, along with the average internal consistencies (Kuder Richardson Formula 20).
Table 3
Reliability Measures for the Ward Atmosphere Scale and the Ideal Dialysis Unit Survey

<table>
<thead>
<tr>
<th>Scale</th>
<th>Internal Consistencies</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ideal Dialysis Unit Survey</td>
<td>Ward Atmosphere Scale</td>
<td></td>
</tr>
<tr>
<td>Involvement</td>
<td>.61</td>
<td>.78</td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>.35</td>
<td>.65</td>
<td></td>
</tr>
<tr>
<td>Spontaneity</td>
<td>.50</td>
<td>.55</td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td>.44</td>
<td>.55</td>
<td></td>
</tr>
<tr>
<td>Personal Problem Orientation</td>
<td>.65</td>
<td>.59</td>
<td></td>
</tr>
<tr>
<td>Practical Orientation</td>
<td>.60</td>
<td>.76</td>
<td></td>
</tr>
<tr>
<td>Anger and Aggression</td>
<td>.55</td>
<td>.76</td>
<td></td>
</tr>
<tr>
<td>Order and Organization</td>
<td>.12</td>
<td>.75</td>
<td></td>
</tr>
<tr>
<td>Program Clarity</td>
<td>.29</td>
<td>.59</td>
<td></td>
</tr>
<tr>
<td>Staff Control</td>
<td>.34</td>
<td>.59</td>
<td></td>
</tr>
</tbody>
</table>

^a Cronbach alpha.

^b Kuder-Richardson coefficients.
reported for each of the original 10 scales for patients from 23 psychiatric units (Moos, 1974). As Table 3 shows, the internal consistencies for the adapted scales were generally lower than those for the original scales. While the majority of the internal consistencies for the adapted scales fall within the lower end of the generally acceptable range for measures of this type, several scales, particularly Order and Organization, and Program Clarity, produced very low internal consistencies. The reader is advised to keep these findings in mind while interpreting the analyses involving the IDUS scales.

**Health Locus of Control**

Subjects' sense of control over their health was measured by the Multidimensional Health Locus of Control (MHLC) Scales are developed by Wallston, Wallston, and DeVellis (1978). The MHLC Scale is composed of three subscales designed to assess the extent to which patients regard the responsibility for their health-related behavior as attributable to themselves (Internal Scale), to powerful others such as doctors, nurses, family, or friends (Powerful Others Scale), and to chance (Chance Scale). Each of the three scales is composed of six statements. Participants are asked to indicate the degree to which they agree or disagree with each statement by marking a 6-point Likert-type scale (Appendix G).

**Treatment-Related Distress**

Friedrich's (1980) Problems Inventory (PI) was employed to assess patients' perceptions of the distress they experienced in response to the physical and psychosocial problems associated with
dialysis. This scale assesses the distress patients associated with each of 13 physical problems common during dialysis, 20 physical problems commonly experienced between dialysis treatments, and 35 psychosocial problems frequently faced by dialysis patients during and between treatments. An additional item regarding short-term planning was added to the last scale by the current investigator on the basis of recommendations from the staff on Units A and B. Instructions for the PI request that the respondent indicate for each problem the degree of distress that it created during the past month. The response options are: no distress, slightly distressing, moderately distressing, very distressing, and extremely distressing. Instructions for the scale explain that distress may be due to feelings such as anxiety or unhappiness created by having a problem, or to such factors as the physical discomfort caused by the problem. Friedrich (1980) reports that when the PI was readministered to dialysis patients approximately 2 weeks after they initially completed the inventory, 63% of the items received identical distress ratings and 89% of the items were within 1 point of agreement with the original ratings (Appendix H).

Satisfaction With the Treatment Environment

Patients' general satisfaction with the treatment environment of their current dialysis unit was assessed by their responses to the question, "Overall, how satisfied are you with the care that you receive at this clinic?". Patients were asked to indicate their response by circling the number on a 7-point scale, anchored at one end by "not at all satisfied" and at the other end by
"very satisfied." This method of assessment was adopted from Cummings' (1980) research with dialysis patients (Patients' Survey, Appendix I).

Severity of Illness

Following Cummings (1980), patients' perceptions of the severity of their illness was assessed by their responses to the question, "Compared to most dialysis patients, how severe do you think your illness is?". Responses were made along a 7-point scale which ranged from "not at all severe" to "very severe" (Patients' Survey, Appendix I).

The staff raters on each unit indicated their assessments of the severity of each participant's illness by responding to a similarly worded question along the same 7-point scale (Nurses' Survey, Appendix J).

Demographic Information

A Personal Data Sheet was employed to collect information about participants' sex, age, race, marital status, education, work status before and after starting dialysis, months on dialysis, number of treatments per week, history of kidney transplants, and participants' views about having a transplant in the future. Participants were also asked to identify those persons who had been the most helpful to them since the start of dialysis treatments, and those persons from whom they would like more assistance. An item regarding participants' income level was included on this scale but was not included in the analyses because only seven participants
provided this information.\textsuperscript{1} A statement at the end of the Personal Data Sheet encouraged patients to share any additional comments or information about their illness and treatment (Appendix K).

Compliance With the Medical Regimen

This study employed two measures of patient compliance: patients' self-ratings and staff's ratings. The decision to obtain both patients' and staff's ratings of compliance was based on the evidence cited earlier that dialysis patients and staff differ in their perceptions of patients' responses to treatment and the shortage of research examining patients' perceptions of their compliance. Patients and staff-raters were asked to rate the extent to which the patients followed the instructions for taking medications, adhered to the prescribed diet, and complied with the fluid restrictions. The wording of the questions and the 7-point Likert-type scales were the same as those employed by Cummings (1980) in his research with dialysis patients (Appendices I and J).

The decision not to employ a physiological measure of compliance utilizing laboratory data, a frequently used method of assessment in dialysis research, was based on the problems inherent in the interpretation of laboratory data. Information obtained from a review of the ESRD literature (e.g., Robbins & Angell, 1976; Schoenfeld & Humphreys, 1976) and consultation with the medical staff of the units participating in this investigation indicated

\textsuperscript{1}The social workers on the three units indicated that dialysis patients are especially reluctant to provide financial information because of their concern that it might somehow influence their financial assistance for treatment.
that the interpretation of laboratory data is not a totally objective procedure. The rater interpreting the laboratory data must take into consideration a number of important factors obtained only from first-hand knowledge of the patient's overall condition. This allows for the possibility of the rater's own bias affecting compliance ratings. The reader is referred to Appendix L for a detailed explanation of the factors which affect physiological assessments of compliance. Considering the difficulty obtaining a compliance assessment based solely on laboratory data or solely on staff knowledge of the patient obtained from interaction on the unit, the staff-raters participating in this investigation were instructed to base their ratings of patients' compliance on their personal interactions with the patients and to use laboratory data from the patients' records to supplement their assessments.

**Procedure**

All interactions between the investigator and the patients took place on a one-to-one basis during a regularly scheduled dialysis session. The investigator initiated contact with those patients who had informed their social worker of their interest in discussing the study further. If at this point a patient indicated that he or she was still interested but was too tired or in too much pain at the time, another meeting was arranged during an upcoming dialysis session. Patients who were willing to speak to the investigator were given a more detailed explanation of the study and of what would be required of them should they choose to
participate. Each patient was then given a copy of the "Experimental Subjects' Bill of Rights" and of the "Consent to be a Research Subject" form, and asked to read these carefully (Appendices M and N). The investigator then reviewed the major points of the forms with the patient. Those patients who continued to express a desire to participate in the study were asked to sign the consent form, and were given a copy of that form and of the Bill of Rights.

Once consent was obtained, the participant was given the test booklet which contained the Patients' Survey, Ideal Dialysis Unit Survey, Multidimensional Health Locus of Control Scales, Problems Inventory, and Personal Data Sheet. Each participant was instructed to complete the questionnaires at his or her own pace without discussing the questions with staff or with other patients. All instructions were printed in the test booklet. Thirty-nine of the participants requested assistance in recording their responses. These participants had the fistula (blood access) in the arm of their dominant hand, making motion with that hand uncomfortable and/or interfering with blood flow, thereby triggering the machine's alarm system. In these instances the investigator sat to the side of the participant and recorded responses on a blank piece of paper. So that the respondents would not feel that confidentiality was compromised by having to recite responses out loud, they were assured that the investigator and others who might overhear them did not have access to the questions at the time of responding. Responses were transferred from the paper to the test booklet after
the testing session was completed. If the participant requested an explanation of a question he or she was instructed to answer the question according to his or her best interpretation of its meaning. There was no additional conversation with participants who required assistance recording test responses. Upon completion of the questionnaires the investigator checked over the test booklets and asked participants to complete, to the best of their ability, any questions they had missed. Completion of the entire set of questionnaires took from 30 to 60 minutes.

The staff raters were asked to complete a Nurses' Survey for each of the patients on their respective units who had participated in the study. As noted earlier, the items on this survey were parallel to the items on the Patients' Survey. The nurses were asked to complete their ratings within one week of the patient's participation in the study.
CHAPTER 3
RESULTS

Preliminary Analyses

The interrelationship among patients' self-ratings of compliance to the three components of the treatment regimen—medication, diet, and fluid intake—were assessed by Pearson product-moment correlations. Patients' self-ratings of compliance with the instructions for their medication were positively correlated with patients' self-ratings of compliance with their diet, $r = .47$, $p < .0001$, and with their fluid intake restrictions, $r = .44$, $p < .0001$. Patients' self-ratings of compliance with their diet were positively correlated with their self-ratings of compliance with their fluid intake, $r = .68$, $p < .0001$. Similarly, the interrelationships among nurses' ratings of patients' compliance to the three components of the treatment regimen were assessed by Pearson product-moment correlations. Nurses' ratings of patients' medication compliance were positively correlated with nurses' ratings of patients' dietary compliance, $r = .76$, $p < .0001$, and fluid compliance, $r = .60$, $p < .0001$. Nurses' ratings of patients' dietary compliance were positively correlated with their ratings of patients' fluid compliance, $r = .70$, $p < .0001$. These results are
congruent with Cummings, Kirsch, Becker, and Levin's (in press) findings with a dialysis population. On the basis of the obtained correlations, the three separate compliance ratings for the patients were pooled to create a composite compliance rating. The same procedure was followed for the nurses' separate ratings. From this point on the compliance ratings will be referred to as the patients' composite compliance ratings and the nurses' composite compliance ratings.

The decision to analyze male and female participants' data together was based on the results of several _t_ tests for independent groups which failed to reveal significant sex differences for compliance (patients' and nurses' composite compliance ratings), illness-related distress (Problems Inventory), and preferences regarding the treatment environment (Ideal Dialysis Unit Survey). A significant sex difference was obtained for the Internal Scale of the Multidimensional Health Locus of Control Scales, with male participants scoring significantly higher than female participants on this scale, _t_(97) = 2.04, _p_ < .005. However, significant sex differences were not obtained for the Powerful Others and Chance Scales of the Multidimensional Health Locus of Control Scales.

While most analyses were performed on the data for the entire patient sample, combined across the three units, several analyses involved inter-unit comparisons. For this reason Kruskall-Wallis analyses of variance by ranks tests and chi-square analyses were employed to examine differences among the three units in the distribution of participants' age, education, race, number of months
on dialysis, current work status, and history of kidney transplants. The three units differed significantly only with respect to their distribution of Caucasian and noncaucasian participants, $X^2(2) = 35.25, p < .0001$. Subsequent Mann-Whitney U tests revealed no significant relationships between participants' race and their preferences for their treatment environment (Ideal Dialysis Unit Survey), health locus of control (Multidimensional Health Locus of Control Scales), illness-related distress (Problems Inventory), or compliance (nurses' composite compliance ratings). These findings suggest that inter-unit analyses would not be seriously affected by the skewed distribution of participants' race. The results of the analyses involving inter-unit differences are presented in the sections which address the dependent variable under examination.

**Hypotheses**

**Hypothesis I**

Dialysis patients' self-ratings of severity of illness and degree of self-reported illness-related distress will be positively related to preferences for support, personal problem orientation, staff control, and practical orientation, and negatively related to preferences for involvement and autonomy in the treatment environment.

Partial support was obtained for Hypothesis I. The interrelationships among participants' responses to the 10 Ideal Dialysis Unit Survey scales, Problems Inventory scales, and participants' global ratings of the severity of their illness (Patients' Survey)
were examined by Pearson product-moment correlations. Results indicated that participants' perceptions of distress associated with various physical and psychosocial problems during and between dialysis treatments (Problems Inventory) were not significantly related to their preferences regarding their treatment environment (Ideal Dialysis Unit Survey). However, several of the participants' preferences regarding their treatment environment did vary as a function of their global ratings of the severity of their illness. More specifically, the more severe participants rated their condition, the more they indicated a preference for a unit high in the features embodied in the Support, \( r = .23, p < .05 \), Personal Problem Orientation, \( r = .20, p < .05 \), and Practical Orientation, \( r = .21, p < .05 \), scales of the Ideal Dialysis Unit Survey. These findings need to be interpreted with care, given the small proportion of variance accounted for by the correlations and the failure to obtain significant correlations with the Problems Inventory measures.

**Hypothesis II**

Dialysis patients' degree of internality in health-related matters will be positively related to preferences for involvement, support, practical orientation, and autonomy, and negatively related to preferences for staff control in the treatment environment.

Pearson product-moment correlations did not establish any significant relationships between participants' Internal Health Locus of Control Scale scores (Multidimensional Health Locus of Control Scales) and their scores on any of the 10 scales of the Ideal Dialysis Unit Survey.
There was evidence, however, that treatment environment preferences did vary as a function of participants' Powerful Others and Chance Scale scores (Multidimensional Health Locus of Control Scales). Both Powerful Others and Chance Scale scores were positively related to Staff Control Scale scores ($r = .29, p < .005$ and $r = .30, p < .005$, respectively), indicating that the greater the belief that powerful others or chance factors determine health, the greater the preference for staff authority and power on the treatment unit. Chance Scale scores were negatively related to Autonomy Scale scores, $r = -.22, p < .05$, indicating that the greater the belief that chance factors determine health, the lower the preference for assuming responsibility for one's own care during dialysis sessions.

**Hypothesis III**

The strongest predictors of patients' compliance will be self-reported illness-related distress and internal health locus of control beliefs. It is anticipated that compliance will be positively related to patients' internality in health-related matters, and negatively related to self-reports of illness-related distress.

The finding that patients' self-reported illness-related distress was a strong predictor of compliance provided modest support for Hypothesis III. This relationship was apparent for both patients' and nurses' ratings of patients' compliance.

A stepwise multiple regression analysis with 23 predictor variables was performed to determine which variables contributed the greatest variance to the patients' composite ratings of
compliance. The predictor variables included the 10 scales of the Ideal Dialysis Unit Survey, the 3 scales of Friedrich's Problems Inventory, and the 3 Multidimensional Health Locus of Control Scales. Also included, because there has been disagreement among dialysis researchers concerning their relationship to compliance, were patient characteristics such as age, sex, number of months on dialysis, education, the presence of a helpful spouse, the presence of a helpful family member, and satisfaction with the treatment unit.

Six predictor variables were each found to contribute significant amounts of variance to the criterion variable of patients' composite compliance ratings. Together, they accounted for 40% of the variance of patients' composite compliance ratings, with a final multiple correlation of .63, $F(6,91) = 10.09, p < .0001$. Patients' self-reports of satisfaction with their treatment environment contributed the greatest amount of variance to patients' composite compliance ratings. Respectively smaller, yet significant, amounts of variance were added by the amount of time patients had been receiving dialysis treatments, the presence of a helpful spouse, preferences for order and organization on the unit (Ideal Dialysis Unit Survey), preferences for involvement and interaction on the unit (Ideal Dialysis Unit Survey), and the degree of distress associated with psychosocial problems related to dialysis (Problems Inventory). Table 4 presents the amount of variance each of these predictor variables contributed and the direction of the relationships. The remaining 17 predictor variables failed to add
<table>
<thead>
<tr>
<th>Source of Variance</th>
<th>% Variance Accounted For</th>
<th>F-to-enter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with treatment environment</td>
<td>18%</td>
<td>21.1****</td>
</tr>
<tr>
<td>Time in treatment</td>
<td>6%</td>
<td>7.4**</td>
</tr>
<tr>
<td>Presence of a helpful spouse</td>
<td>5%</td>
<td>6.4**</td>
</tr>
<tr>
<td>Order and Organization Scale (IDUS)</td>
<td>4%</td>
<td>6.0**</td>
</tr>
<tr>
<td>Involvement Scale (IDUS)</td>
<td>4%</td>
<td>5.8**</td>
</tr>
<tr>
<td>Distress related to psychosocial problems (PI)</td>
<td>3%</td>
<td>4.3*</td>
</tr>
</tbody>
</table>

Note. IDUS = Ideal Dialysis Unit Survey. PI = Problems Inventory. N = 100. df = 6,91.

*P < .05
**P < .01
***P < .001
****P < .0001
significant amounts of variance to the criterion variable of patients' composite compliance ratings. The final equation for the regression analysis for patients' ratings was as follows:

\[ 4.92 + 1.66 \text{ (patient satisfaction with unit)} - 0.02 \text{ (length of time in treatment)} + 1.74 \text{ (helpful spouse)} + 0.23 \text{ (Order and Organization)} - 0.15 \text{ (Involvement)} - 0.11 \text{ (psychosocial distress)}. \]

A stepwise multiple regression analysis, with the same 23 predictor variables as those used for the regression analysis reported above for patients' composite compliance ratings, was performed to determine which predictor variables accounted for the most variance for nurses' composite ratings of patients' compliance. Four of the predictor variables were identified as contributing significant variance. Together, these four predictor variables contributed 27% of the variance for nurses' ratings, with a final multiple correlation of 0.52, \( F(4, 93) = 8.52, p < 0.0001 \). Patients' self-reports of their satisfaction with their treatment environment contributed the greatest amount of variance to nurses' composite compliance ratings. Additional variance was contributed by patients' age, and the degree of distress patients associated with physical problems both between and during dialysis treatments. Table 5 presents the amount of variance each of these predictor variables contributed to the criterion variable and the direction of the relationship. The 19 predictor variables not mentioned here failed to account for significant amounts of variance. The final equation for this regression analysis was as follows: 

\[ 3.48 + 1.12 \text{ (patient satisfaction with unit)} + 0.08 \text{ (age)} - 0.49 \text{ (physical}} \]
Table 5

Regression Analysis Results for Nurses' Composite Compliance Ratings

<table>
<thead>
<tr>
<th>Source of Variance</th>
<th>% Variance Accounted for</th>
<th>F-to-enter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with treatment environment</td>
<td>13%</td>
<td>14.2****</td>
</tr>
<tr>
<td>Age</td>
<td>5%</td>
<td>6.7***</td>
</tr>
<tr>
<td>Distress from physical problems between treatments (PI)</td>
<td>5%</td>
<td>5.8**</td>
</tr>
<tr>
<td>Distress from physical problems during treatments (PI)</td>
<td>4%</td>
<td>4.4*</td>
</tr>
</tbody>
</table>

Note. PI = Problems Inventory. N = 100. df = 4,93.

* \(p < .05\)
** \(p < .01\)
*** \(p < .001\)
**** \(p < .0001\)
distress between treatment) + .44 (physical distress during treatments).

**Hypothesis IV**

Dialysis patients' reports of illness-related distress will be negatively related to their internality in health-related matters, and positively related to their belief that their health is largely a function of chance or fate.

Pearson product-moment correlations were employed to examine the relationship between participants' Internal and Chance Scale scores and responses to each of the three scales of the Problems Inventory. Chance Health Locus of Control Scale scores were positively related to the distress participants associated with psychosocial problems related to dialysis, \( r = .26, p < .005 \). Thus, as participants' belief that their health condition was a function of chance factors increased, they were more likely to report greater distress from psychosocial problems. Aside from this finding the results of this study do not support Hypothesis IV. Participants' Internal Health Locus of Control Scale scores were not significantly correlated with the distress they associated with either physical problems during treatments, physical problems between treatments, or psychosocial problems related to dialysis (Problems Inventory). Participants' Chance Health Locus of Control Scale scores were not significantly correlated with the distress they associated with physical problems during or between dialysis treatments.
Additional Findings

Dialysis Patients' Preferences for their Treatment Environment

Caution must be exercised when considering the results of the analyses involving the Ideal Dialysis Unit Survey's scales. As mentioned in the Method Section, the internal consistencies for the scales of the Ideal Dialysis Unit Survey were generally lower than those for Moos' (1974) Ward Atmosphere Scales from which they were adapted. Furthermore, Pearson product-moment correlations performed among the scales of the Ideal Dialysis Unit Survey yielded significant interscale correlations (Table 6).

The Ideal Dialysis Unit Survey. The means and standard deviations for participants' scores on each of the 10 scales of the Ideal Dialysis Unit Survey are presented in rank order in Table 7. Participants were most favorably disposed to the treatment environment characteristics of high peer and staff support (Support Scale) and clarity of rules and procedures (Program Clarity Scale). Participants indicated that strong group spirit and active interaction (Involvement Scale) were the characteristics of the treatment environment next in relative importance. Participants were least favorably disposed toward environments with high staff power and authority (Staff Control Scale). Participants also indicated relatively low preferences for assuming responsibility for their own care during treatment sessions (Autonomy Scale) and discussing their problems, from outside the unit, with peers or staff during sessions (Personal Problem Orientation Scale). Intermediate
Table 6
Inter-Correlations Among the Ideal Dialysis Unit Survey Scales

<table>
<thead>
<tr>
<th>Scale</th>
<th>#1</th>
<th>#2</th>
<th>#3</th>
<th>#4</th>
<th>#5</th>
<th>#6</th>
<th>#7</th>
<th>#8</th>
<th>#9</th>
<th>#10</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Involvement</td>
<td>1.00</td>
<td>.60***</td>
<td>.56***</td>
<td>.03</td>
<td>.50***</td>
<td>.60***</td>
<td>.10</td>
<td>.14</td>
<td>.17</td>
<td>.05</td>
</tr>
<tr>
<td>#2 Support</td>
<td>1.00</td>
<td>.53***</td>
<td>.01</td>
<td>.55***</td>
<td>.71***</td>
<td>.30**</td>
<td>.13</td>
<td>.36**</td>
<td>.04</td>
<td></td>
</tr>
<tr>
<td>#3 Spontaneity</td>
<td>1.00</td>
<td>.23*</td>
<td>.54***</td>
<td>.48***</td>
<td>.41***</td>
<td>.06</td>
<td>.32**</td>
<td>-.11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#4 Autonomy</td>
<td>1.00</td>
<td>.25*</td>
<td>.10</td>
<td>.16</td>
<td>-.04</td>
<td>.09</td>
<td>.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#5 Personal Problem Orientation</td>
<td>1.00</td>
<td>.60***</td>
<td>.30**</td>
<td>.03</td>
<td>.15</td>
<td>.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#6 Practical Orientation</td>
<td>1.00</td>
<td>.37***</td>
<td>.03</td>
<td>.26**</td>
<td>.09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#7 Anger and Aggression</td>
<td>1.00</td>
<td>-.08</td>
<td>.36***</td>
<td>-.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#8 Order and Organization</td>
<td>1.00</td>
<td>.11</td>
<td>-.13</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#9 Program Clarity</td>
<td>1.00</td>
<td>.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#10 Staff Control</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05; **p < .01; ***p < .001; ****p < .0001
Table 7

Participants' Preferences Regarding Treatment Environments

<table>
<thead>
<tr>
<th>Ideal Dialysis Unit Survey Scale&lt;sup&gt;a&lt;/sup&gt;</th>
<th>M</th>
<th>SD</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support</td>
<td>7.87</td>
<td>3.82</td>
<td>9.0</td>
</tr>
<tr>
<td>Program Clarity</td>
<td>7.66</td>
<td>3.81</td>
<td>7.0</td>
</tr>
<tr>
<td>Involvement</td>
<td>4.18</td>
<td>4.96</td>
<td>5.0</td>
</tr>
<tr>
<td>Spontaneity</td>
<td>3.79</td>
<td>5.28</td>
<td>4.5</td>
</tr>
<tr>
<td>Practical Orientation</td>
<td>2.90</td>
<td>5.99</td>
<td>4.0</td>
</tr>
<tr>
<td>Anger and Aggression</td>
<td>2.60</td>
<td>5.61</td>
<td>4.0</td>
</tr>
<tr>
<td>Order and Organization</td>
<td>2.44</td>
<td>4.55</td>
<td>2.0</td>
</tr>
<tr>
<td>Personal Problem Orientation</td>
<td>-1.14</td>
<td>6.38</td>
<td>-1.0</td>
</tr>
<tr>
<td>Autonomy</td>
<td>-2.03</td>
<td>5.66</td>
<td>-1.0</td>
</tr>
<tr>
<td>Staff Control</td>
<td>-4.09</td>
<td>4.92</td>
<td>-5.0</td>
</tr>
</tbody>
</table>

Note.  N = 100

<sup>a</sup>Ideal Dialysis Unit Survey scale scores ranged from -12 to 12.
between these high and low preferences were participants' preferences for expression of feelings with staff and peers (Spontaneity Scale), staff assistance with long-term and short-term planning (Practical Orientation Scale), open expression of anger between patients and staff (Anger and Aggression Scale), and high levels of organization (Order and Organization Scale). The mean, median, and standard deviation for each of the Ideal Dialysis Unit Survey items are presented in Appendix 0.

T-tests for independent groups were performed to compare differences in mean scores among the scales of the Ideal Dialysis Unit Survey. Table 8 presents the numerous significant differences among the 10 scales.

Pearson product-moment correlations were employed to examine the relationships between each of the 10 Ideal Dialysis Unit Survey scales and patient variables such as age, education, current work status, time in treatment, and views about kidney transplants. Age was negatively correlated with scores on the Autonomy Scale, \( r = -.32, p < .001 \), and Personal Problem Orientation Scale, \( r = -.21, p < .05 \), and positively correlated with responses on the Program Clarity Scale, \( r = .20, p < .05 \), and Staff Control Scale, \( r = .32, p < .001 \). Length of time in treatment was negatively correlated with responses on the Staff Control Scale, \( r = -.24, p < .05 \). Kruskall-Wallis analyses of variance by ranks tests indicated that level of education was significantly associated with scores on the Support, Autonomy, Order and Organization, and Staff Control Scales (Table 9). Mann-Whitney U tests were performed to examine
<table>
<thead>
<tr>
<th>Scale (Mean)</th>
<th>#1</th>
<th>#2</th>
<th>#3</th>
<th>#4</th>
<th>#5</th>
<th>#6</th>
<th>#7</th>
<th>#8</th>
<th>#9</th>
<th>#10</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Support (7.9)</td>
<td>.4</td>
<td>6.0****</td>
<td>6.2****</td>
<td>7.1****</td>
<td>7.8****</td>
<td>9.2****</td>
<td>12.2****</td>
<td>15.2****</td>
<td>19.3****</td>
<td></td>
</tr>
<tr>
<td>#2 Program Clarity (7.7)</td>
<td>5.7****</td>
<td>5.9****</td>
<td>6.7****</td>
<td>7.6****</td>
<td>8.9****</td>
<td>12.1****</td>
<td>14.9****</td>
<td>19.0****</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#3 Involvement (4.2)</td>
<td>.5</td>
<td>1.7*</td>
<td>2.1*</td>
<td>2.6**</td>
<td>6.7****</td>
<td>8.8****</td>
<td>12.0****</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#4 Spontaneity (3.8)</td>
<td>1.1</td>
<td>2.0*</td>
<td>1.9*</td>
<td>5.9****</td>
<td>7.7****</td>
<td>10.7****</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#5 Practical Orientation (2.9)</td>
<td>.4</td>
<td>.6</td>
<td>4.7****</td>
<td>6.3****</td>
<td>9.1****</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#6 Anger and Aggression (2.6)</td>
<td>.2</td>
<td>4.5****</td>
<td>6.0****</td>
<td>8.9****</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#7 Order and Organization (2.4)</td>
<td>4.6****</td>
<td>6.4****</td>
<td>9.8****</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#8 Personal Problem Orientation (-1.1)</td>
<td>1.1</td>
<td>3.7***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#9 Autonomy (-2.0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2.9**</td>
<td></td>
</tr>
<tr>
<td>#10 Staff Control (-4.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05; **p < .01; ***p < .001; ****p < .0001
Table 9

The Relationship of Level of Education to Participants' Treatment Environment Preferences and Health Locus of Control

<table>
<thead>
<tr>
<th>Scale</th>
<th>n</th>
<th>M</th>
<th>H-value&lt;sup&gt;a&lt;/sup&gt;</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support Scale (IDUS)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 12 years</td>
<td>19</td>
<td>7.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>26</td>
<td>9.00</td>
<td>7.59</td>
<td>.02</td>
</tr>
<tr>
<td>Some college</td>
<td>55</td>
<td>7.62</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Autonomy Scale (IDUS)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 12 years</td>
<td>19</td>
<td>-4.62</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>26</td>
<td>-0.62</td>
<td>6.44</td>
<td>.04</td>
</tr>
<tr>
<td>Some college</td>
<td>55</td>
<td>-1.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Order and Organization Scale (IDUS)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 12 years</td>
<td>19</td>
<td>.37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>26</td>
<td>3.46</td>
<td>6.77</td>
<td>.03</td>
</tr>
<tr>
<td>Some college</td>
<td>55</td>
<td>2.67</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Staff Control Scale (IDUS)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 12 years</td>
<td>19</td>
<td>-3.21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>26</td>
<td>-2.23</td>
<td>7.28</td>
<td>.03</td>
</tr>
<tr>
<td>Some college</td>
<td>55</td>
<td>-5.27</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Chance Health Locus of Control Scale (MHLC)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 12 years</td>
<td></td>
<td>22.26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td></td>
<td>16.92</td>
<td>7.19</td>
<td>.03</td>
</tr>
<tr>
<td>Some college</td>
<td></td>
<td>17.91</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. IDUS = Ideal Dialysis Unit Survey; MHLC = Multidimensional Health Locus of Control Scales.

<sup>a</sup>Kruskall-Wallis analyses of variance by ranks tests; df = 2,97.
group differences for these four scales of the Ideal Dialysis Unit Survey; Bonferroni adjustments were made on the p-values from these analyses to compensate for the large number of comparisons performed. Analyses revealed that participants with a high school education indicated significantly greater preferences for staff and peer support ($M = 9.00$) than did participants with less than 12 years of education ($M = 7.05$), $p < .05$. Participants with less than 12 years of education indicated significantly lower preferences for order and organization on the unit ($M = .37$) than did participants with 12 years of education ($M = 3.46$), $p < .05$. Participants with less than 12 years of education indicated substantial, but not significantly different, preferences for assuming responsibility for self-care during sessions ($M = -4.63$) than did participants with 12 years of education ($M = -.62$), $p < .06$. The differences detected for preferences for staff control did not achieve significance when inter-group comparisons were performed.

**Inter-unit differences in treatment environment preferences.**

Kruskall-Wallis analyses of variance by ranks tests were performed to examine inter-unit differences in responses to the 10 Ideal Dialysis Unit Survey scales. Significant inter-unit differences were evident for the Involvement Scale ($H(2,96) = 17.01$, $p < .0005$), Support Scale, $H(2,96) = 6.17$, $p < .05$, and Spontaneity Scale, $H(2,96) = 8.94$, $p < .01$. The differences among the three units approached, but did not attain, significance for responses to the Personal Problems Orientation Scale, $H(2,96) = 5.68$, $p < .06$. Newman-Keuls comparisons performed for the Involvement Scale
revealed that participants from Unit B indicated a significantly greater preference for patient and staff involvement and for interaction on their unit ($M = 7.42$) than did the participants from either Unit A ($M = 2.61$) or Unit C ($M = 3.60$), $p's < .01$; significant differences between Units A and C on the Involvement Scale were not detected. Newman-Keuls comparisons revealed that Unit B participants ($M = 9.15$) reported preferring a unit significantly greater in peer and staff support ($M = 9.15$) than did Unit C participants ($M = 6.87$), $p < .05$. Finally, Newman-Keuls comparisons indicated that Unit B participants ($M = 5.65$) exceeded Unit C participants ($M = 2.22$) in their preferences for a unit fostering the open expression of feelings between patients and staff (Spon-taneity Scale), $p < .05$.

**Dialysis Patients' Health Locus of Control**

**The Multidimensional Health Locus of Control Scales.** The mean Internal Health Locus of Control Scale score for the participants in this investigation was $25.00$ ($SD = 6.29$). Participants obtained a mean score of $24.51$ ($SD = 6.43$) on the Powerful Others Health Locus of Control Scale, and a mean score of $18.48$ ($SD = 6.88$) on the Chance Health Locus of Control Scale. To enable comparisons, Appendix P presents these and other means from research with other patient populations for comparison.

As mentioned above, Kruskall-Wallis analyses of variance by ranks tests indicated that there were no significant differences among the units on any of the Multidimensional Health Locus of Control Scales, and $t$ tests for independent groups revealed sex
differences for only the Internal Scale, $t(97) = 2.09, p < .05$. Pearson product-moment coefficients indicated that the Internal Scale scores were positively correlated with Powerful Others Scale scores, $r = .49, p < .0001$, and that Powerful Others Scale scores were positively correlated with Chance Scale scores, $r = .37, p < .0005$. However, Internal and Chance Scale scores were not significantly correlated, $r = .01, n.s.$ Participants' pattern of responding to the three Multidimensional Health Locus of Control Scales was similar to that reported by Hartke and Kunce (1982), but different from that reported by Wallston et al. (1978).

Several additional Pearson product-moment correlations involving the three Multidimensional Health Locus of Control Scales attained significance. Participants' reports of their satisfaction with their treatment environment were positively correlated with their Internal and Powerful Others Scale scores, $r = .31, p < .005$ and $r = .28, p < .005$, respectively. Participants' Powerful Others Scale scores were also positively correlated with age, $r = .27, p < .01$, and negatively correlated with years of education, $r = -.22, p < .05$. Participants' Chance Scale scores were negatively correlated with time in treatment, $r = -.24, p < .05$.

Kruskall-Wallis analyses of variance by ranks tests detected significant differences in the chance health locus of control beliefs as a function of level of education (Table 9). Mann-Whitney U tests, with Bonferroni adjustments, revealed that participants with less than 12 years of education ($M = 22.26$) indicated a significantly stronger belief that chance factors determine
their health than did participants with 12 years of education
(M = 16.92), p < .05.

Compliance with the Medical Regimen

Patient-nurse agreement. Table 10 presents patients' and
nurses' mean ratings of medication, dietary, and fluid compliance.
Also shown are patients' and nurses' composite compliance ratings.
These data are presented separately for Units A, B, and C, as well
as for the units combined.

Pearson product-moment correlations revealed significant posi-
tive relationships between patients' and nurses' ratings of medica-
tion compliance, \( r = .42, p < .0001 \), dietary compliance, \( r = .32, \\
p < .0001 \), and fluid compliance, \( r = .45, p < .0001 \), as well as
patients' and nurses' composite compliance ratings, \( r = .52, \\
p < .0001 \).

Wilcoxon signed-ranks tests were computed to examine the dif-
ferences between patients' and nurses' composite and separate
compliance ratings. Table 11 shows that dialysis patients attrib-
uted a greater degree of compliance to themselves than nurses
attributed to them. This was true whether the ratings under con-
sideration were the composite compliance ratings or the separate
ratings of compliance with medication, diet, or fluid intake.
These findings are inconsistent with previous research (Cummings
et al., in press).

Inter-unit differences. Wilcoxon signed-ranks tests were
employed to examine the differences among the various compliance
ratings of patients and nurses from the three units. Table 11
Table 10

Mean Compliance Ratings of Patients and Staff from the Three Dialysis Units

<table>
<thead>
<tr>
<th>Measure of compliance</th>
<th>Unit</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>A, B, &amp; C Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Compliance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>14.97 16.77 15.73 15.72</td>
</tr>
<tr>
<td>Patients' ratings</td>
<td></td>
<td>14.97</td>
<td>16.77</td>
<td>15.73</td>
<td>15.72</td>
</tr>
<tr>
<td>Nurses' ratings</td>
<td></td>
<td>12.23</td>
<td>15.46</td>
<td>13.51</td>
<td>13.48</td>
</tr>
<tr>
<td>Medication Compliance</td>
<td></td>
<td>5.61</td>
<td>6.31</td>
<td>5.92</td>
<td>5.89</td>
</tr>
<tr>
<td>Patients' ratings</td>
<td></td>
<td>5.61</td>
<td>6.31</td>
<td>5.92</td>
<td>5.89</td>
</tr>
<tr>
<td>Nurses' ratings</td>
<td></td>
<td>4.56</td>
<td>5.42</td>
<td>4.70</td>
<td>4.81</td>
</tr>
<tr>
<td>Dietary Compliance</td>
<td></td>
<td>4.80</td>
<td>4.96</td>
<td>4.76</td>
<td>4.83</td>
</tr>
<tr>
<td>Patients' ratings</td>
<td></td>
<td>4.80</td>
<td>4.96</td>
<td>4.76</td>
<td>4.83</td>
</tr>
<tr>
<td>Nurses' ratings</td>
<td></td>
<td>4.03</td>
<td>5.00</td>
<td>4.11</td>
<td>4.28</td>
</tr>
<tr>
<td>Fluid Compliance</td>
<td></td>
<td>4.60</td>
<td>5.50</td>
<td>5.05</td>
<td>5.01</td>
</tr>
<tr>
<td>Patients' ratings</td>
<td></td>
<td>4.60</td>
<td>5.50</td>
<td>5.05</td>
<td>5.01</td>
</tr>
<tr>
<td>Nurses' ratings</td>
<td></td>
<td>3.71</td>
<td>5.04</td>
<td>4.70</td>
<td>4.40</td>
</tr>
</tbody>
</table>
Table 11

Differences between the Mean Compliance Ratings of Patients and Nurses from the Three Dialysis Units

<table>
<thead>
<tr>
<th>Measure of compliance</th>
<th>Unit</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>A, B, &amp; C</th>
<th>Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Composite compliance rating</td>
<td></td>
<td>2.74**</td>
<td>1.31</td>
<td>2.22***</td>
<td>2.24****</td>
<td></td>
</tr>
<tr>
<td>Medication compliance rating</td>
<td></td>
<td>1.05**</td>
<td>.89**</td>
<td>1.22***</td>
<td>1.08****</td>
<td></td>
</tr>
<tr>
<td>Dietary compliance rating</td>
<td></td>
<td>.77*</td>
<td>.04</td>
<td>.65*</td>
<td>.55**</td>
<td></td>
</tr>
<tr>
<td>Fluid compliance rating</td>
<td></td>
<td>.89**</td>
<td>.46</td>
<td>.35</td>
<td>.61**</td>
<td></td>
</tr>
</tbody>
</table>

Note. Significance determined by Wilcoxon signed-ranks tests.

*p < .05; **p < .01; ***p < .001; ****p < .0001
indicates that Units A, B, and C differ with respect to the number of areas of compliance in which there is significant patient-nurse disagreement. On Unit A, patients' ratings were significantly greater than nurses' ratings for all four compliance ratings. On Unit B, the only significant patient-nurse disagreement about patients' compliance concerned medication compliance, with patients consistently rating their compliance as significantly greater than did the nurse-raters from Unit B. On Unit C, patients consistently rated their compliance as greater than that attributed to them by the nurses, with the exception of compliance with fluid restrictions.

Kruskall-Wallis analyses of variance by ranks tests indicated significant differences among the three units for nurses' composite compliance ratings, \( H(2,96) = 7.63, \ p < .05 \). Newman-Keuls comparisons revealed that the nurses from Unit B (\( M = 15.46 \)) rated their patients' compliance significantly greater than did nurses from Unit A (\( M = 12.23 \)) rated their patients' compliance, \( p < .05 \).

Kruskall-Wallis analyses of variance by ranks tests did not reveal significant differences among the three units for patients' composite ratings of compliance.

Distress Associated with the Physical and Psychosocial Problems of Dialysis

Participants' responses to the Problems Inventory. The percentage of participants who reported experiencing moderate to extreme distress with respect to each of the 13 physical problems commonly experienced during dialysis is presented in Table 12. One half of the participants reported that the fatigue and weakness
Table 12
Percentage of Patients Who Associated Moderate to Extreme Distress with Physical Problems During Dialysis Treatments

<table>
<thead>
<tr>
<th>Problems Inventory Item</th>
<th>Present investigation</th>
<th>Friedrich's study (1980)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weak and &quot;tired out&quot;</td>
<td>50%</td>
<td>56.3%</td>
</tr>
<tr>
<td>Muscle cramps</td>
<td>47%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Itching</td>
<td>40%</td>
<td>32.6%</td>
</tr>
<tr>
<td>Restless</td>
<td>34%</td>
<td>38.3%</td>
</tr>
<tr>
<td>Pain with needles</td>
<td>32%</td>
<td>22.6%</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>24%</td>
<td>26.0%</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>22%</td>
<td>25.5%</td>
</tr>
<tr>
<td>Headaches</td>
<td>22%</td>
<td>18.5%</td>
</tr>
<tr>
<td>Nausea</td>
<td>19%</td>
<td>10.2%</td>
</tr>
<tr>
<td>Body aches</td>
<td>17%</td>
<td>18.7%</td>
</tr>
<tr>
<td>Dizziness</td>
<td>10%</td>
<td>9.4%</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>10%</td>
<td>6.2%</td>
</tr>
<tr>
<td>Problems with eyesight</td>
<td>8%</td>
<td>12.8%</td>
</tr>
</tbody>
</table>

\[ a \_n = 100 \]

\[ b \_n = 97 \]
they experienced at the end of dialysis sessions was moderately to extremely distressing. One third of the participants indicated that they were either very or extremely distressed by this problem. Muscle cramps (47%) and itching (40%) were identified as the next most distressing physical problems during dialysis.

Table 13 presents the percentage of participants who reported experiencing moderate to extreme distress in connection with physical problems between dialysis treatments. Difficulty sleeping at night ranked as the most distressing physical problem between treatments (47%). Fatigue and weakness again ranked high (43%), as did shortness of breath (39%) and unsatisfied thirst (38%).

Participants' ratings of the distress associated with psychosocial problems are shown in Table 14. Two psychosocial problems, difficulty making long-range plans (58%) and decreased activity in outside interests (57%), were the problems rated as moderately to extremely distressing by the greatest number of participants. Thirty eight percent of the participants indicated that these two problems were either very or extremely distressing to them. It appears that the psychosocial problems viewed as the most distressing by the most participants were related to uncertainty of the future (i.e., difficulty making long-range plans, distress about one's uncertain future, and concern about shortened lifespan), social role changes (i.e., decreased activity in outside interests and decreased workload), financial problems (i.e., worry about managing financially, concern about medical bills, and about having less money), and the impact of the illness on one's family. Dietary
Table 13

Percentage of Patients Who Associated Moderate to Extreme Distress with Physical Problems Between Dialysis Treatments

<table>
<thead>
<tr>
<th>Problems Inventory item</th>
<th>% of Patients Present Investigation</th>
<th>% of Patients Friedrich's study (1980)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty sleeping</td>
<td>47%</td>
<td>42.7%</td>
</tr>
<tr>
<td>Exhaustion, lack of energy</td>
<td>43%</td>
<td>50.5%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>39%</td>
<td>38.7%</td>
</tr>
<tr>
<td>Thirst</td>
<td>38%</td>
<td>33.0%</td>
</tr>
<tr>
<td>Pain in bones</td>
<td>35%</td>
<td>32.9%</td>
</tr>
<tr>
<td>Numbness/tingling in hands, feet</td>
<td>32%</td>
<td>31.6%</td>
</tr>
<tr>
<td>Sexual changes</td>
<td>29%</td>
<td>44.6%</td>
</tr>
<tr>
<td>Bad taste in mouth</td>
<td>29%</td>
<td>21.0%</td>
</tr>
<tr>
<td>Itching</td>
<td>28%</td>
<td>40.0%</td>
</tr>
<tr>
<td>Weight gain</td>
<td>25%</td>
<td>26.6%</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>23%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Decreased appetite</td>
<td>20%</td>
<td>16.6%</td>
</tr>
<tr>
<td>Headaches</td>
<td>20%</td>
<td>15.8%</td>
</tr>
<tr>
<td>Dizziness</td>
<td>19%</td>
<td>17.9%</td>
</tr>
<tr>
<td>Nausea</td>
<td>18%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Problems with eyesight</td>
<td>13%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Infection in fistula</td>
<td>12%</td>
<td>5.3%</td>
</tr>
<tr>
<td>Cloudy thinking</td>
<td>12%</td>
<td>22.0%</td>
</tr>
<tr>
<td>Problems with bleeding</td>
<td>11%</td>
<td>11.4%</td>
</tr>
<tr>
<td>Frightening dreams</td>
<td>4%</td>
<td>6.2%</td>
</tr>
</tbody>
</table>

\[ n_a = 100; \quad n_b = 97. \]
Table 14

Percentage of Patients Who Associated Moderate to Extreme Distress with Psychosocial Problems Related to Dialysis

<table>
<thead>
<tr>
<th>Problems Inventory items</th>
<th>% of Patients Present investigation</th>
<th>Friedrich's study (1980)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty with long-range planning</td>
<td>58%</td>
<td>65.9%</td>
</tr>
<tr>
<td>Not as active in outside interests</td>
<td>57%</td>
<td>52.2%</td>
</tr>
<tr>
<td>Uncertain future</td>
<td>48%</td>
<td>50.5%</td>
</tr>
<tr>
<td>Financial worries</td>
<td>47%</td>
<td>43.3%</td>
</tr>
<tr>
<td>Decreased workload due to dialysis</td>
<td>46%</td>
<td>60.7%</td>
</tr>
<tr>
<td>Shortened lifespan</td>
<td>41%</td>
<td>44.9%</td>
</tr>
<tr>
<td>Concerns re medical bills</td>
<td>40%</td>
<td>39.6%</td>
</tr>
<tr>
<td>Family distressed by one's illness</td>
<td>34%</td>
<td>49.5%</td>
</tr>
<tr>
<td>Less money to spend due to dialysis</td>
<td>33%</td>
<td>35.0%</td>
</tr>
<tr>
<td>Unable to get up during dialysis</td>
<td>32%</td>
<td>40.4%</td>
</tr>
<tr>
<td>Treatment disrupts time with family</td>
<td>30%</td>
<td>32.0%</td>
</tr>
<tr>
<td>Difficulty with short-range planning</td>
<td>30%</td>
<td>-----</td>
</tr>
<tr>
<td>Others eat foods one cannot eat</td>
<td>29%</td>
<td>35.1%</td>
</tr>
<tr>
<td>See friends less frequently</td>
<td>27%</td>
<td>38.1%</td>
</tr>
<tr>
<td>Less attractive due to dialysis</td>
<td>25%</td>
<td>27.6%</td>
</tr>
<tr>
<td>Treatment interferes with other activities</td>
<td>24%</td>
<td>20.8%</td>
</tr>
<tr>
<td>Problems Inventory items</td>
<td>% of Patients Present Investigation&lt;sup&gt;a&lt;/sup&gt;</td>
<td>% of Patients Friedrich's study (1980)&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>-----------------------------------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Concerned about one's appearance</td>
<td>23%</td>
<td>21.6%</td>
</tr>
<tr>
<td>Need for financial assistance</td>
<td>22%</td>
<td>32.0%</td>
</tr>
<tr>
<td>Dialysis interferes with work time</td>
<td>22%</td>
<td>26.5%</td>
</tr>
<tr>
<td>Concern re: functioning of fistula</td>
<td>20%</td>
<td>22.7%</td>
</tr>
<tr>
<td>Uninformed re: physical changes</td>
<td>20%</td>
<td>21.7%</td>
</tr>
<tr>
<td>Travel expenses for treatment</td>
<td>19%</td>
<td>16.0%</td>
</tr>
<tr>
<td>The need to depend on others during treatment</td>
<td>19%</td>
<td>24.5%</td>
</tr>
<tr>
<td>Family worried re: donating a kidney</td>
<td>18%</td>
<td>18.5%</td>
</tr>
<tr>
<td>Fearful for one's life when machine malfunctions</td>
<td>18%</td>
<td>15.0%</td>
</tr>
<tr>
<td>Others helping during dialysis</td>
<td>17%</td>
<td>33.0%</td>
</tr>
<tr>
<td>Worry re: dialysis equipment</td>
<td>17%</td>
<td>14.4%</td>
</tr>
<tr>
<td>Unrealistic expectations by others</td>
<td>17%</td>
<td>19.0%</td>
</tr>
<tr>
<td>Diet is tasteless</td>
<td>16%</td>
<td>19.6%</td>
</tr>
<tr>
<td>Forgotten by friends</td>
<td>14%</td>
<td>13.4%</td>
</tr>
<tr>
<td>Lack of information about illness</td>
<td>12%</td>
<td>9.3%</td>
</tr>
<tr>
<td>Lack of privacy during dialysis</td>
<td>10%</td>
<td>9.5%</td>
</tr>
<tr>
<td>Difficulty with transportation</td>
<td>8%</td>
<td>7.4%</td>
</tr>
<tr>
<td>Little chance to be alone</td>
<td>5%</td>
<td>7.5%</td>
</tr>
<tr>
<td>Little understanding of diet</td>
<td>5%</td>
<td>7.2%</td>
</tr>
<tr>
<td>Not enough people to turn to</td>
<td>4%</td>
<td>9.6%</td>
</tr>
</tbody>
</table>

<sup>a</sup> <i>N</i> = 100.  <sup>b</sup> <i>N</i> = 97.  <sup>c</sup> Item not included in Friedrich's (1980) study.
problems, which are often ranked by health professionals as among the most distressing problems for patients, were ranked low by the patients in this study. This was especially the case in connection with problems with the diet being tasteless (16%) and lack of understanding of the diet (5%).

Pearson product-moment correlations were employed to examine the relationships among the scales of the Problems Inventory. Distress from physical problems during dialysis was positively correlated with distress from physical problems between dialysis treatments, $r = .70, p < .0001$. Distress from physical problems between dialysis treatments was positively correlated with distress from psychosocial problems, $r = .65, p < .0001$. And, distress from physical problems during treatment and distress from psychosocial problems were positively correlated, $r = .57, p < .0001$. Friedrich (1980) did not report inter-scale correlations from her research with the Problems Inventory.

Comparisons with Friedrich's findings. Pearson product-moment correlations were employed to examine the relationship between Problems Inventory responses of the dialysis patients in the present study and responses given by Friedrich's (1980) patient sample. High positive correlations were obtained for the degree of distress the two samples of dialysis patients associated with 13 physical problems during treatments, $r = .94, p < .0001$, 20 physical problems between treatments, $r = .85, p < .0001$, and 35 psychosocial problems related to dialysis, $r = .94, p < .0001$. Mean discrepancies between the distress ratings of the two samples
were calculated for the items of the three problem areas. The average difference in the distress ratings of the two samples of dialysis patients, across problems, was quite small: 4.6% for physical problems during treatments, 5.5% for physical problems between treatments, and 4.6% for psychosocial problems related to dialysis.

**Relationship with illness-related distress.** Several additional significant Pearson product-moment correlations involving the Problems Inventory were obtained. Participants' reports of their satisfaction with their treatment environment were negatively correlated with the distress they associated with physical problems both during and between dialysis sessions, $r = -.22, p < .05$ and $r = -.29, p < .005$, respectively. The distress participants associated with psychosocial problems related to dialysis was positively correlated with participants' desire for a kidney transplant in the near future, $r = .24, p < .05$.

Interestingly, participants' perceptions of distress related to their physical problems during or between dialysis sessions, as reflected by their responses to the Problems Inventory, were not related to their global ratings of the severity of their illness. However, participants' perceptions of distress related to their psychosocial problems, as reflected by their responses to the Problems Inventory, were significantly correlated with their global ratings of the severity of their illness, $r = .20, p < .05$. 
Additional Patient Variables

This study detected a number of significant relationships in addition to those already reported. Again, in view of the large number of relationships examined, the reader is advised to exercise caution interpreting the findings.

A significant Pearson product-moment correlation was obtained between patients' and nurses' ratings of patients' severity of illness, $r = .20$, $p < .05$. T-tests for independent measures did not detect a significant difference between patients' and nurses' ratings of patients' severity of illness. Patients' and nurses' ratings of severity of illness were related to different patient variables. Nurses' ratings of the severity of patients' illness were positively correlated with the length of time patients' had been in treatment, $r = .22$, $p < .05$. As reported above, patients' self-reports of severity of illness were positively correlated with the distress they associated with psychosocial problems and with their scores on the Support, Personal Problem Orientation, and Practical Orientation Scales of the Ideal Dialysis Unit Survey. Patients' self-reports of severity of illness were also positively correlated with the desire for a kidney transplant, $r = .29$, $p < .005$.

Participants' reports of their satisfaction with their treatment environment (Patients' Survey) ranged from 3 to 7 on a 7-point scale, with the majority of participants reporting being very satisfied with the care that they receive at their dialysis center ($M = 6.38$, $SD = .97$).
Participants' age correlated positively with satisfaction with their treatment environment, $r = .21, p < .05$. Participants' age was negatively correlated with desire for a kidney transplant, $r = -.27, p < .01$.

Table 15 presents in rank order the percentage of participants who rated each of 11 categories of people as having been very supportive since the beginning of dialysis treatments. The greatest number of participants rated their doctors and nurses as having been very helpful. Spouses, family members, and other dialysis unit personnel were each reported as having been very supportive by the next largest number of participants.

The percentage of participants desiring more help from any of the 11 types of potential helpers is presented in Table 16. Doctors were cited most frequently (17%) as the persons from whom more help was desired. Each of the other 10 categories received a low number of responses ($\leq 5\%$).

Caution needs to be exercised when interpreting this data on support systems as this was the last task required of participants, many of whom were fatigued by this point. Moreover, there was some inconsistency between participants' responses on the questionnaire and comments patients wrote at the end of the questionnaire or shared with the investigator after testing was completed.

Several participants wrote comments and suggestions in a section provided for this at the end of the test booklet. A number of these comments will be presented in the Discussion Section.
Table 15
Percentage of Participants Who Reported Receiving Help Adjusting to Dialysis

<table>
<thead>
<tr>
<th>Helpful group</th>
<th>% of participants acknowledging help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>76%</td>
</tr>
<tr>
<td>Nurses</td>
<td>60%</td>
</tr>
<tr>
<td>Family</td>
<td>54%</td>
</tr>
<tr>
<td>Spouse</td>
<td>49%</td>
</tr>
<tr>
<td>Social worker</td>
<td>47%</td>
</tr>
<tr>
<td>Friends</td>
<td>45%</td>
</tr>
<tr>
<td>Dietician</td>
<td>41%</td>
</tr>
<tr>
<td>Other patients</td>
<td>22%</td>
</tr>
<tr>
<td>Others</td>
<td>13%</td>
</tr>
<tr>
<td>Clergy</td>
<td>9%</td>
</tr>
<tr>
<td>Mental health workers</td>
<td>5%</td>
</tr>
<tr>
<td>Helpful group</td>
<td>% of participants desiring more help</td>
</tr>
<tr>
<td>----------------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>Doctors</td>
<td>17%</td>
</tr>
<tr>
<td>Spouse</td>
<td>5%</td>
</tr>
<tr>
<td>Friends</td>
<td>5%</td>
</tr>
<tr>
<td>Family</td>
<td>4%</td>
</tr>
<tr>
<td>Mental health workers</td>
<td>4%</td>
</tr>
<tr>
<td>Social workers</td>
<td>2%</td>
</tr>
<tr>
<td>Dieticians</td>
<td>2%</td>
</tr>
<tr>
<td>Nurses</td>
<td>2%</td>
</tr>
<tr>
<td>Others</td>
<td>2%</td>
</tr>
<tr>
<td>Clergy</td>
<td>0%</td>
</tr>
<tr>
<td>Other patients</td>
<td>0%</td>
</tr>
</tbody>
</table>
CHAPTER 4
DISCUSSION

Overview

This research represents the first systematic assessment of dialysis patients' preferences regarding their treatment environment. Although a number of studies have examined and compared the treatment environments of different dialysis units (e.g., Kaplan De-Nour, 1980; Kaplan De-Nour & Czaczkies, 1972; Kroemeke & Nassar, Jr., 1980), and several studies have presented nephrologists' and dialysis nurses' views on various characteristics of dialysis units (e.g., Kaplan De-Nour & Czaczkies, 1971, 1974; Kaplan De-Nour et al., 1972; Levy, 1973; Roper et al., 1977), there has not been any research which has systematically examined patients' preferences regarding aspects of their dialysis units' treatment environment. A major purpose of this study was to examine dialysis patients' preferences regarding treatment environments, and the relationship of these preferences to patients' beliefs concerning the severity of their illness and illness-related distress, sense of control over health-related behavior, and level of compliance to the medical regimen. In part, these variables were chosen for study on the basis of previous research which indicated that they were related to the treatment preferences of psychiatric and myocardial
A second major aim of the present research was to obtain evidence concerning the interrelationships among dialysis patients' degree of compliance, health locus of control, and illness-related distress. Several investigations have provided preliminary information about interrelationships among these three factors, and have pointed to the need for further systematic research in this area (Cheek, 1972; Dimond, 1980; Pritchard, 1977). The present investigation was the first to examine both dialysis patients' and nurses' assessments of patients' compliance in relation to these variables. The investigation tested four hypotheses which were formulated on the basis of recent empirical findings and on the suggestions of dialysis health-care providers and researchers. Given the paucity of research on dialysis patients' perceptions of their treatment needs, a variety of relationships among the patient measures were explored in addition to those dictated by the four hypotheses.

Preliminary Analyses and Findings

Several preliminary findings need to be reviewed prior to discussion of the tests of the hypotheses.

The decision to pool male and female participants' data for the analyses was based on the absence of a significant sex difference on all but one of the patient measures. The male and female participants' responses differed significantly on the Internal Health Locus of Control Scale. This significant sex difference is inconsistent with previous research employing the
Multidimensional Health Locus of Control Scales (Wallston et al., 1978), but is consistent with Blackburn's (1977) finding that male and female dialysis patients' responses on Rotter's I-E Scale differed significantly. The absence of a sex difference on the Powerful Others Health Locus of Control Scale, Chance Health Locus of Control Scale, and compliance ratings is consistent with previous research in this area (Kirilloff, 1981; Sackett & Haynes, 1976; Wallston et al., 1978).

Most of the statistical analyses involving participants' compliance with the treatment regimen utilized a composite compliance rating created by pooling the medication, diet, and fluid restriction compliance ratings. The decision to employ a composite rating was based on the finding of high intercorrelations among nurses' and among patients' ratings for the three compliance domains. These high intercorrelations are consistent with previous research with dialysis patients and staff (Cummings, Kirscht, Becker, & Levin, in press).

While most of the analyses were performed on the data for the entire patient sample, combined across the three units, this study also examined inter-unit differences for the major patient measures. Preliminary analyses revealed that there were no major differences among the three units in the distribution of participants' age, education, number of months on dialysis, current work status, or history of kidney transplants. The three units differed significantly only with respect to the distribution of Caucasian and noncaucasian participants. Subsequent analyses revealed no
significant relationships between participants' race and their perceptions of their treatment needs (Ideal Dialysis Unit Survey), health locus of control (Multidimensional Health Locus of Control Scales), illness-related distress (Problems Inventory), or compliance (patients' and nurses' composite compliance ratings). These findings suggest that inter-unit analyses are not seriously affected by the distribution of patients' race. The results of the analyses involving inter-unit differences are presented in the sections which address the dependent variable under consideration.

Hypotheses

A summary of the findings relevant to the hypotheses, a comparison of the findings with those of previous research, and the implications of the findings are presented below. The relationships among the various patient characteristics and patient measures that were not addressed by the hypotheses, as well as suggestions for future research, will be presented in later sections.

Hypothesis I

Partial support was obtained for Hypothesis I which addressed the relationship of dialysis patients' self-ratings of severity of illness (Patient Survey) and illness-related distress (Problems Inventory) to patients' perceptions of their treatment needs (Ideal Dialysis Unit Survey).

This investigation found that the dialysis patients' self-ratings of severity of illness were significantly related to their preferences for three aspects of the treatment environment. The
more severe participants perceived their illness, the more likely they were to prefer support from doctors, nurses, and peers (Support Scale), discussion of personal problems with staff and peers (Personal Problem Orientation Scale), and staff assistance in developing short-range\(^2\) and long-range plans to deal with the impact of dialysis both on and off the dialysis unit (Practical Orientation Scale). These findings are consistent with results for other patient populations which have found that patients' perceptions of the severity of their illness are positively correlated with seeking help from medical professionals (Battistella, 1971; Becker, Nathan-son, Drachman, & Kirscht, 1977; Kegeles, 1963; Tash, O'Shea, & Cohen, 1969).

Dimond (1980) reported that dialysis patients with relatively fewer medical complications were more likely to manage their daily lives through careful short-term planning than were patients who experienced relatively greater medical complications. She speculated that dialysis patients with many medical complications may find it futile to try to assume control over their condition, while patients in better health may have already experienced the benefits of assuming control and thus be more likely to find short-term planning more worthwhile. Dimond (1980) further speculated that dialysis patients who anticipate daily demands and carefully plan

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\(^2\)An example of short-range planning would be telling a host ahead of time about one's dietary and fluid restrictions so that one is not tempted to deviate from one's diet.
to meet all or some of these demands can control some of the stresses on their bodies, and thus reduce complications and improve physical stability. In this connection it is interesting that in the present study, self-ratings of severity of illness were not significantly related to sense of control over health-related behavior (Multidimensional Health Locus of Control Scales).

Contrary to Hypothesis I, a significant positive relationship was not obtained between participants' self-ratings of severity of illness and preferences for staff control with respect to rules, regulations, and scheduling (Staff Control Scale). Nor was a significant negative relationship obtained between participants' severity ratings and preferences for patient and staff involvement and interaction during treatment sessions (Involvement Scale) and patients' responsibility for their own care during dialysis sessions (Autonomy Scale). The absence of these predicted relationships is not easily explained.

Also contrary to Hypothesis I, patients' ratings of the distress they experienced in response to physical and psychosocial problems during and between dialysis sessions (Problems Inventory) were not significantly related to their treatment environment preferences (Ideal Dialysis Unit Survey). Although dialysis patients' treatment environment preferences did not vary as a function of the amount of distress reflected in their total scores for a given Problems Inventory category, it is possible that patients' treatment environment preferences vary as a function of the distress associated with specific problems. Support for this possibility
will be presented in the section on illness-related distress (Problems Inventory). Another possible explanation for the absence of a relationship between dialysis patients' illness-related distress and treatment environment preferences is that patients suffering severe distress may have been more inclined to report a lower level of distress than they actually experienced. This possibility is also discussed in the section reviewing the participants' responses to the Problems Inventory.

**Hypothesis II**

Hypothesis II, which addressed the relationship between dialysis patients' degree of internality in health-related matters (Internal Health Locus of Control Scale) and treatment environment preferences was not supported. Participants' Internal Health Locus of Control Scale scores were not related to their scores on any of the 10 Ideal Dialysis Unit Survey scales.

For over a decade researchers have been attempting to establish a relationship between medical patients' treatment environment preferences and locus of control, as assessed by Rotter's I-E Scale, or health locus of control, as assessed by the Health Locus of Control Scale or the Multidimensional Health Locus of Control Scales (Wallston et al., 1978; Wallston, Wallston, Kaplan, & Maides, 1976). Wallston and Wallston's (1981) extensive review of the literature in this area found some evidence in favor of a relationship between medical patients' functioning in different treatment environments and their locus of control or health locus of control, although the support was less than conclusive. Aside from the
present investigation, only two other studies have examined the relationship between dialysis patients' health locus of control and preferences for certain treatment environment dimensions. Employing the Health Locus of Control Scale, an earlier version of the Multidimensional Health Locus of Control Scales, Sproles (1977) found a positive relationship between dialysis patients' degree of internality and their desire to attend classes, on their unit, which presented information about kidney disease. Binik and Devins (1979) failed to find any differences between mean Health Locus of Control Scale scores of patients who selected, or were selected for, home dialysis, patient-managed hospital dialysis, or staff-assisted hospital dialysis. Wallston and Wallston (1981) suggested the possibility that the high degree of dependence engendered by End State Renal Disease overrides dispositional differences in beliefs about control. They pointed out that relying on a machine is clearly not conducive to internal health locus of control beliefs, even when the patient operates the machine. This explanation may be of particular relevance in explaining the results of both Binik and Devins' (1979) and the present investigation.

Participants' Powerful Others Health Locus of Control and Chance Health Locus of Control Scale scores were positively related to preferences for staff authority and power in the treatment environment (Staff Control Scale). It seems likely that patients who view their health as a function of the care they receive from health professionals, or the result of chance factors, would be more likely to prefer others to make treatment decisions. Chance
Health Locus of Control Scale scores were also positively related to preferences for assuming responsibility for one's own care during dialysis sessions (Autonomy Scale). It seems likely that patients who view their health as a function of chance and who believe that their own actions are futile, would be more likely to perceive less benefit from performing health-related behaviors.

Wallston et al. (1978) encourage the use of all three Multi-dimensional Health Locus of Control Scales whenever possible, and suggest that researchers choose the scales best suited to the variables under study when design limitations are imposed. These authors have suggested that health locus of control beliefs are likely to play a more significant role in the explanation of health behavior when such beliefs are examined in conjunction with such factors as perceived severity of illness, health motivation, social support, attitudes toward health professionals, perceived costs and benefits of specific actions, and the value of good health, than when considered alone.

**Hypothesis III**

Partial support was obtained for Hypothesis III, which stated that dialysis patients' self-ratings of illness-related distress (Problems Inventory) and degree of internality in health-related matters (Internal Health Locus of Control Scale) will be strong predictors of both patients' and nurses' composite compliance ratings. Details regarding the contribution of illness-related distress and internal health locus of control to compliance ratings will be presented below in the sections discussing the variables.
which contributed significant amounts of variance to patients' and nurses' composite ratings of compliance.

**Patients' composite compliance ratings.** Patients' satisfaction with their treatment environment accounted for the greatest proportion of variance in patients' composite ratings of compliance. The positive relationship between satisfaction and compliance appears consistent with Kaplan De-Nour et al.'s (1972) finding of greater patient compliance on dialysis units with more realistic staff expectations of patients. One might assume that the more realistic expectations fostered better patient-staff relationships and patient satisfaction. The participants in the present study who indicated greater satisfaction with their treatment environment may have in fact been better compliers because their treatment needs were being met.

The length of time that patients had been receiving dialysis treatments contributed the second largest proportion of variance to patients' composite compliance ratings. The longer the dialysis patients had been in treatment, the less compliant they rated themselves. Only two other studies have examined the relationship of time in treatment to dialysis patients' self-ratings of compliance. Cummings et al.'s (in press) research findings were consistent with those of the present study, while O'Brian (1980) reported that dialysis patients' self-ratings of compliance increased over time.

Gentry and Davis (1972) speculated that dialysis patients' compliance with the medical regimen decreases with time in treatment.
because patients find it increasingly futile to perform the necessary health-related behaviors. This study's findings that participants' chance health locus of control beliefs decreased, rather than increased, with time in treatment, does not provide support for this speculation. There are several explanations which appear to be more plausible. For instance, several participants reported that their ability to judge the extent and frequency of modifications they may make in the medical regimen, before experiencing severe sequelae, improved with time in treatment, and their tolerance of the negative consequences of minor deviations from the medical regimen increased with time in treatment. These two changes may lead to increased prevalence of minor deviations from the medical regimen with time in treatment. Patients who have been receiving dialysis treatments for a longer period of time may have a different relationship with staff and feel more secure about their health-related behavior than newer patients. Not only may dialysis patients who have been in treatment for longer periods of time be less compliant, but they may also be more likely to acknowledge their noncompliance.

Presence of a helpful spouse accounted for the third largest proportion of variance for patients' self-ratings of compliance. Patients who indicated that they had a helpful spouse tended to rate themselves as more compliant with the medical regimen than patients who did not have a spouse or did not perceive their spouse as helpful. It should be noted that not all patients who indicated that they had a spouse indicated that that person had been helpful
with their adjustment to dialysis.

O' Brian (1980) found that dialysis patients' self-ratings of compliance were positively associated with their perceptions of their families' and friends' expectations regarding compliance. Cummings, Becker, Kirsch, and Levin (1982) did not find a significant relationship between dialysis patients' self-ratings of compliance and their reports of family support. However, these investigators did obtain a significant negative relationship between patients' self-ratings of compliance and incidence of family problems.

Although 49% of the participants indicated that their spouse had helped with their adjustment to dialysis, the participants varied with respect to what they considered helpful. Some participants reported that their spouse helped them by performing specific behaviors which made compliance possible, e.g., prepared meals which were consistent with dietary and fluid restrictions, did not tempt the participant with forbidden food. Other participants indicated that their spouse helped provide an emotionally supportive environment which provided the strength and motivation to engage in the necessary health-related behaviors for compliance.

The dialysis patients' scores on the Order and Organization Scale of the Ideal Dialysis Unit Survey accounted for the fourth largest proportion of variance for patients' self-ratings of compliance. The greater the patients' scores on the Order and Organization Scale, the higher they rated their compliance with the medical regimen. High scores on this scale presumably indicate
that patients prefer both patients and staff to ensure that sessions proceed on schedule, that confusion and chaos is minimized, and that patients know in advance who will be responsible for their treatment. The reader is advised to exercise caution when interpreting this finding, given the low internal consistency of the Order and Organization Scale (alpha = .12).

Participants' scores on the Involvement Scale of the Ideal Dialysis Unit Survey contributed the fifth largest proportion of variance to patients' self-ratings of compliance. Degree of preference for involvement and interaction with staff and peers was negatively related to compliance. Interestingly, Unit B participants, who indicated the greatest preference for involvement on the unit and appeared to have the greatest involvement on and off the unit (see Appendix C), actually had the highest self-ratings of compliance, although the inter-unit differences in self-ratings of compliance were not statistically significant.

The sixth and last variable to contribute significant variance to patients' self-ratings of compliance was patients' self-reported distress associated with psychosocial problems commonly experienced by End Stage Renal Disease patients. As participants' self-reports of psychosocial distress increased, their self-ratings of compliance decreased. This finding lends partial support to Hypothesis III, which predicted a relationship between compliance and illness-related distress. The obtained negative relationship seems best understood in light of the evidence that degree of self-reported psychosocial distress was positively associated with self-reported
severity of illness, with the predisposition to view one's health as a function of chance factors, and with the desire to have a kidney transplant which would result in the discontinuation of dialysis treatments. This finding that dialysis patients' perceptions of their illness-related distress are significantly associated with their ratings of compliance is consistent with the growing body of literature which has found that patients' perceptions of their illness affects their willingness to cooperate with prescribed treatment (Becker, 1979; DiMatteo & DiNicola, 1982; Haynes, 1979).

Nurses' composite ratings of patients' compliance. Participants' reports of their satisfaction with their treatment environment also accounted for the greatest proportion of variance for nurses' composite ratings of patients' compliance. Nurses' ratings of patients' compliance increased as participants' reports of satisfaction with their treatment unit increased. None of the other variables which provided significant independent variance for patients' self-ratings of compliance provided significant independent variance for nurses' ratings of patients' compliance.

Participants' age contributed the second largest proportion of variance to nurses' ratings of patients' compliance. Nurses' ratings of patients' compliance increased as patients' age increased. Cummings (1980) reported similar findings utilizing the same measure of compliance as employed in the present study. The positive relationship between patients' age and nurses' ratings of patients' compliance is of particular interest since age was commonly used as a selection factor in determining eligibility for
dialysis prior to 1973. It was widely believed that older patients would have poorer survival and greater adjustment problems than younger patients (Blodgett, 1981-1982). It appears that dialysis staff continue to hold this belief even though research has found little correspondence between age and various measures of adjustment to dialysis (Adler, 1975; Cohen, Comty, & Shapiro, 1970; Kirilloff, 1980; Lewis, Foster, De la Pirente, & Scurlock, 1969). Interestingly the present investigation did not reveal a significant relationship between patients' age and patients' perceptions of their compliance.

The distress patients associated with physical problems between and during dialysis sessions contributed the third and fourth largest proportion of variance to nurses' ratings of patients' compliance. This finding provided further support for Hypothesis III. Nurses' ratings of patients' compliance decreased as patients' self-reported distress from physical problems between treatments increased. Patients reporting greater distress from physical problems between treatments may have experienced a reduced capacity to carry out the planning necessary for compliance. It does not appear that reduced compliance was related to an increased sense of futility about compliance, since patients' Chance Health Locus of Control Scale scores were not correlated with physical distress scores. It is conceivable that staff utilize patient reports of distress from physical problems between treatments as an index of compliance since physical problems between treatments are sometimes a sequelae of noncompliance.
The positive relationship between nurses' composite ratings of patients' compliance and patients' self-reports of distress from physical problems during dialysis sessions is difficult to explain in light of the negative relationship between compliance and physical problems. It is possible that staff has greater contact with patients who relate higher levels of distress from physical problems during dialysis. Staff may rate these patients as more compliant due to their greater investment of time and emotional energy into the care of these patients.

Additional comments concerning Hypothesis III. The present investigation did not obtain support for Hypothesis III's contention that dialysis patients' and nurses' composite compliance ratings are related to patients' degree of internality in health-related matters (Internal Health Locus of Control Scale). The majority of the past research with dialysis patients has found a significant positive relationship between internality and compliance with the medical regimen (Hartman & Becker, 1978; Kilpatrick, Miller, & Williams, 1972; Poll & Kaplan De-Nour, 1980). The differences between the findings of the present investigation and those of previous research may be attributable to the former's use of a health-specific locus of control measure, and the latter's use of a general locus of control measure.

Neither the present study nor previous research with medical patients has revealed a relationship between Chance Health Locus of Control Scale scores and compliance with the medical regimen (Hatz, 1978; Levin & Schulz, 1980; Lowenstein, 1979). While Hatz's
(1978) research with a small dialysis sample suggested a positive association between patients' Powerful Others Health Locus of Control Scale scores and adherence with fluid restrictions (physiological assessment), the present study did not detect such an association.

Patient ratings of satisfaction with the treatment environment was the only variable which was a relatively strong predictor of both patients' and nurses' ratings of patients' compliance. This finding suggests that although there is some common basis for nurses' and patients' assessments of compliance, there are some important differences in contributing factors.

**Hypothesis IV**

In general, the results of the present investigation do not support Hypothesis IV, which stated that dialysis patients' internal and chance health locus of control (Multidimensional Health Locus of Control Scales) will vary as a function of patients' self-ratings of their illness-related distress (Problems Inventory). Participants' Internal Health Locus of Control Scale scores were not significantly associated with either physical or psychosocial problems during or between dialysis treatments (Problems Inventory). Participants' Chance Health Locus of Control Scale scores were not significantly associated with physical problems during or between dialysis sessions; however, participants' Chance Health Locus of Control Scale scores were positively related to the distress they associated with psychosocial problems related to dialysis (Problems Inventory). Whether a chance health locus of control orientation heightens distress, or whether prolonged distress induces a chance
health locus of control orientation, is not ascertainable from the present data. It is possible, of course, that both processes operate in a spiraling manner.

Additional Findings

Dialysis Patients' Preferences for their Treatment Environment

The Ideal Dialysis Unit Survey. The relatively low internal consistencies and the relatively high inter-scale correlations of several of the Ideal Dialysis Unit Survey scales raise questions about the current adaptation of Moos' (1974) Ward Atmosphere Scale for use in assessing preferences for dialysis treatment environments. It was unfortunate that limitations in the accessibility of samples of dialysis patients precluded pilot research for refinement of the scales. Given the shortcomings of the Ideal Dialysis Unit Survey scales employed in the present investigation, the reader is advised to exercise caution when interpreting the findings involving the Ideal Dialysis Unit Survey.

Overall, participants indicated the greatest preferences for peer and staff support (Support Scale) and for clarity of unit rules, procedures, and responsibilities (Program Clarity Scale). They also indicated a relatively strong preference for a high level of involvement and interaction among patients and staff on the unit (Involvement Scale). Participants showed the lowest degree of preference for a ward environment in which staff hold a high degree of authority and power with respect to rules, regulations, and scheduling of sessions (Staff Control Scale). They also indicated
relatively low preferences for assuming responsibility for their own care during sessions (Autonomy Scale) and for discussing their outside personal problems with staff or peers during sessions (Personal Problem Orientation Scale).

It appears that the participants, in general, were positively disposed toward treatment environments in which rules and regulations are clear and the lines of power are well delineated (Program Clarity Scale), and negatively disposed toward environments in which staff hold all of the power and authority with respect to the rules and regulations (Staff Control Scale). A number of investigators have noted that dialysis patients feel highly dependent for their survival upon the dialysis staff, and suggest that this sense of dependence may jeopardize patients' feelings of self-worth (Abram, 1974; Alexander, 1976; Blodgett, 1981-1982; Viederman, 1978). It may be that participants' negative feelings about staff control on the unit may be understood as a reaction to the sense of dependence.

Participants' desire to share power with, and be less dependent upon staff, appears to be restricted to the domain of rules and regulations. It does not appear to encompass direct participation in their dialysis treatment (Autonomy Scale). Over one half of the participants strongly agreed that staff should have complete responsibility for patients' care during dialysis treatment. Less than one quarter of the participants expressed a strong desire to be responsible for minor problems with the machine, and only about 14% of the participants indicated a strong preference to engage in
self-care, i.e., weigh themselves before and after treatments, monitor their own blood pressure during treatment, and record this information. The participants' relatively low mean score on the Autonomy Scale is similar to Moos' (1974) findings with psychiatric patients.

Participants' relatively negative feelings about discussing their personal problems with staff and peers may derive from a desire to maintain some degree of distance between themselves and the personnel responsible for their survival. The distance may help patients preserve their sense of individuality and/or sense of self-worth in a situation where they feel that others are running their lives. For those patients who have difficulty accepting the permanence of their condition such distance may also serve to limit the degree of their emotional attachment to staff and other patients. Alternatively, patients' relative disinclination to discuss personal problems on the unit may reflect the view that nurses and technicians are responsible only for patients' medical care, and not responsible for patients' psychological and emotional well-being.

Participants' relatively weak preferences for sharing their feelings with staff and peers (Spontaneity Scale) and expressing their anger with staff and other patients (Anger and Aggression Scale) may be related to the ambivalence many patients expressed regarding their treatment. Several participants in this study reported that there are a number of things that they dislike about their condition and unit; however, they refrain from expressing such concerns because they believe that they should be grateful'
that dialysis is available to keep them alive, and that the nurses work very hard to make them comfortable. Moreover, some patients expressed the belief that expressing anger or complaining about depression would be tantamount to being a "bad patient."

Age and education appear to contribute significantly to the variation in preferences for support, autonomy, personal problem orientation, order and organization, program clarity, and staff control on the unit. This finding underscores the importance of considering patients' age and education level in the day-to-day management of the dialysis unit.

**Inter-unit differences in treatment environment preferences.**

Inter-unit differences for participants' responses on the Involvement, Support, Spontaneity, and Practical Orientation Scales of the Ideal Dialysis Unit Survey either approached or attained significance. Although it is beyond the scope of the present study to determine the source of the differences, it should be noted that the three units which participated in the present investigation did vary with respect to a number of environmental factors and treatment preferences. The reader is referred to Appendix C for a detailed description of the three participating dialysis units.

**Dialysis Patients' Multidimensional Health Locus of Control**

Internal Health Locus of Control Scale. The dialysis patients who participated in this research received lower scores on the Internal Health Locus of Control Scale than those reported by Wallston et al. (1978) for samples of chronic illness patients,
college students, healthy adults, and persons engaged in preventative health behaviors (see Appendix P). Unfortunately, statistical comparisons of the Internal Health Locus of Control Scale scores of the participants in the present investigation with those of Wallston et al.'s (1978) samples were not carried out because the necessary data for the latter samples were not reported. This study's findings of dialysis patients' relatively low feelings of responsibility for illness-related behavior is consistent with the findings of Hatz (1978) on the health locus of control of a small sample (N = 19) of dialysis patients. Dialysis patients' relatively low feelings of responsibility for their health status is understandable in light of the fact that dialysis is, at best, a maintenance procedure. Only in rare cases does strict adherence to the medical regimen and dialysis treatments improve one's renal functioning.

**Powerful Others Health Locus of Control Scale.** Participants in the present study received higher scores on the Powerful Others Health Locus of Control Scale than those reported by Wallston et al. (1978) for samples of chronic illness patients, college students, healthy adults, and persons engaged in preventative health behaviors. Once, again, statistical comparison analyses could not be performed because the necessary data for each of the samples were not reported. The dialysis patients who participated in Hatz's (1978) research also received relatively high Powerful Others Health Locus of Control Scale scores.
Dialysis patients' relatively strong belief that powerful others control their health is not surprising in light of the conditions and contingencies of their treatment. From the initial phases of their disease, End Stage Renal Disease patients are encouraged to have frequent contact with a number of medical personnel. Prior to dialysis they are required to make frequent visits to renal clinics or to private nephrologists in order to monitor their deteriorating, irreversible condition. The decision to prepare for and start dialysis is typically made by the nephrologist. Frequently, patients are very ill or in a coma when they begin dialysis, and thus are very dependent on the dialysis nurses from the start of treatment. Except in the cases where patients receive dialysis at home or are involved in a self-care program, dialysis patients rely on staff to insert the needles, care for the machine, monitor their condition, and care for other personal needs during treatment. Patients' deteriorating physical condition necessitates increased reliance on relatives, friends, and social service agencies.

**Chance Health Locus of Control Scale.** The dialysis patients in this research received higher scores on the Chance Health Locus of Control Scale than those reported by Wallston et al. (1978) for samples of chronic illness patients, college students, healthy adults, and persons engaged in preventative health behaviors. As with the previous two Multidimensional Health Locus of Control Scales, statistical comparison analyses could not be performed because the necessary data for Wallston et al.'s (1978) samples
were not reported. Interestingly, the only other study which examined dialysis patients' responses to the Multidimensional Health Locus of Control Scales (Hatz, 1978) revealed Chance Health Locus of Control Scale scores lower than those of the dialysis patients in the present investigation. The participants' belief that their health is a function of chance factors is understandable in light of the numerous uncontrollable factors which affect the course of their illness.

Patterns of scores on the Multidimensional Health Locus of Control Scales. This study revealed significant positive relationships between dialysis patients' scores on the Internal Health Locus of Control and Powerful Others Health Locus of Control Scales, and between the Powerful Others Health Locus of Control and Chance Health Locus of Control Scales. The relationship between scores on the Internal Health Locus of Control and Chance Health Locus of Control Scales was not significant. These findings are in agreement with those of Hartke and Kunce (1982) who studied the factorial structure of the Multidimensional Health Locus of Control Scales for a sample of medical patients (N = 98). Both the present and Hartke and Kunce's (1982) findings are inconsistent with Wallston et al.'s (1978) inter-scale correlations obtained from the sample of healthy adults (N = 118) used to standardize the final version of the Multidimensional Health Locus of Control Scales. Wallston et al. (1978) did not find any relationship between the Internal Health Locus of Control and Powerful Others Health Locus of Control Scale scores, or between the Powerful Others Health Locus of Control
and Chance Health Locus of Control Scale scores, but did find a significant negative relationship between subjects' responses to the Internal Health Locus of Control and Chance Health Locus of Control Scales. A comparison of the response patterns of the participants in the present investigation, Hartke and Kunce's (1982) research, and Wallston et al.'s (1978) four samples suggests that medical patients and healthy adults evidence different patterns of responding to the three Multidimensional Health Locus of Control Scales.

Additional findings involving the Multidimensional Health Locus of Control Scales. In addition to the results already reported for the Multidimensional Health Locus of Control Scales a number of other findings in which these scales were involved are worth noting. Participants' scores on the Internal Health Locus of Control Scale were positively correlated with their reports of satisfaction with their treatment environment. Moos (1974) and Kish, Solberg, and Uecker (1971) reported parallel correlations between psychiatric patients' ratings of satisfaction with their treatment environment and their scores on Rotter's I-E Scale. Kish et al. (1971) noted that the obtained differences in perceptions of the treatment environment associated with locus of control may be realistically based, as the internally-oriented psychiatric patients were perceived by their staff as having greater potential for improvement and may have received preferential treatment by staff. The same process may be operative on dialysis units. Patients may perceive the milieu more positively when the milieu
is in fact more congenial to their needs.

Participants' powerful others health locus of control beliefs were also positively correlated with reports of satisfaction with the treatment environment. Dialysis treatment fosters a good deal of dependence on powerful others such as nephrologists, nurses, technicians, dieticians, and social workers. It seems likely that the belief that powerful others are responsible for one's health is, in some ways, adaptive for dialysis patients. Dialysis patients who hold this belief may be more satisfied with their treatment unit because their real and ideal treatment environments are more congruent. Dialysis staff may also respond more positively to patients who believe that powerful others are largely responsible for their health.

The present investigation's finding that participants' Powerful Other Health Locus of Control Scale scores increased with age is consistent with previous findings with other patient populations (Wallston & Wallston, 1981; Wallston et al., 1978). It seems likely that the relatively poorer health of older patients leads to greater contact with the medical establishment, and thus to a stronger belief that medical professionals are in control of one's health. The significant negative relationship obtained between participants' Powerful Other Health Locus of Control Scale scores and education is consistent with research examining the health locus of control of patient populations (Hartke & Kunce, 1982; Wallston & Wallston, 1981).
Although Internal Health Locus of Control and Powerful Other Health Locus of Control Scale scores did not vary significantly with length of time in treatment, Chance Health Locus of Control Scale scores significantly decreased as time in treatment increased. This change was surprising in light of previous research on shifts in dialysis patients' locus of control. Wilson, Murzekari, Schneps, and Wilson (1974) reported that dialysis patients' external locus of control increased with time in treatment. This apparent discrepancy between the present and previous findings might somehow be attributable to the differences in the scales employed. Wilson et al. (1974) employed Rotter's I-E Scale, which is a general measure of locus of control, while the present investigation employed the Multidimensional Health Locus of Control Scales, which assess health-specific locus of control.

Dialysis patients may give greater weight to chance as a factor influencing their health in the early stages of dialysis because their efforts to keep themselves from having to start dialysis have failed and they find themselves in a situation in which they perceive little control. Subsequently, the extent to which chance is regarded as important decreases, perhaps because patients are successfully practicing behavior which maintains some degree of physical stability. This does not necessarily mean that dialysis patients feel they have a high degree of control over their health, nor does this contradict the finding that dialysis patients experience relatively low internal health locus of control. Participants' internal and chance health locus of control beliefs
were not significantly correlated.

**Dialysis Patients' Compliance with the Medical Regimen**

**Patient-nurse agreement.** According to both patients' and nurses' ratings, patients were most compliant in following the instructions regarding phosphate-binding medication, and least compliant in adhering to dietary restrictions. Although the dialysis patients' and nurses' composite ratings of patients' compliance were positively correlated, the dialysis patients' reported greater compliance than did the nurses. These findings are in accord with those of Cummings (1980) who, using the same compliance scales as employed in the present study, examined the compliance ratings of a comparable number of dialysis patients and nurses. Aside from the present study, the investigations by Cummings and his colleagues (Cummings, 1980; Cummings, Becker, Kirsch, & Levin, 1982; Cummings et al., in press) have been the only ones to compare dialysis patients' and nurses' perceptions of patients' compliance. The reader is referred to Appendices Q and R for a detailed comparison of Cummings et al.'s (in press) results with those of the present study.

Few studies with medical patients have employed patients' self-ratings of compliance. This may reflect awareness of the documented tendency of patients to overestimate their compliance with medical recommendations in comparison with physiological compliance and health outcome measures (e.g., Cummings et al., in press; Gordis, Markowitz, & Lillenfeld, 1969).
Dialysis patients and nurses have been shown to disagree in a number of areas in addition to the assessment of compliance. The Introduction reviewed research which indicated significant patient-nurse discrepancies in assessments of patients' anxiety and of the suffering associated with different aspects of dialysis. Other discrepancies involved judgments about the treatment environment and about the most effective way of managing noncompliant patients. These patient-staff differences do not justify discounting patients' assessments, but illustrate the importance of obtaining patients' perspectives whenever possible. Staff may have greater access to physiological data, have more clinical training, and be in a position to be more "objective," but patients experience the disease first hand and have important information not readily accessible to staff. The absolute discrepancies notwithstanding, positive correlations between patients' and nurses' assessments indicate that the two groups are basing their ratings on some common ground. Rather than disregard patients' assessments as overestimates, the differences between patients' and nurses' ratings of patients' compliance might be used profitably as a therapeutic tool. Discussions about how patients and nurses arrive at their assessments might be used to increase communication and understanding between patients and nurses.

Unit differences in compliance ratings. This study revealed significant differences among units in nurses' composite ratings of patients' compliance. The nurses from Unit B rated their patients' compliance as significantly greater than Unit A nurses rated the
compliance of their patients. No significant differences in nurses' ratings were evident between Units A and C, or Units B and C.

Examination of the three separate compliance ratings of patients and nurses from the three units indicated that the units differed with respect to the number of areas of compliance in which there was significant patient-nurse disagreement. Unit B, which had the highest nurses' ratings of patients' compliance, had the highest congruence of patients' and nurses' compliance ratings. The patients and nurses on Unit B significantly disagreed with each other only with respect to patients' compliance with the instructions for taking the phosphate-binding medication. On Unit A, patients' ratings were significantly greater than nurses' ratings for diet and medication compliance. The patients and nurses on Unit C had significantly different ratings for all three areas of compliance. This author suggests that the differences in the characteristics of the three dialysis units and the treatment environment preferences of the patients from the three units contributed to the differences in nurses' compliance ratings and the degree of patient-nurse agreement concerning compliance.

**Dialysis Patients' Perceptions of Illness-Related Distress**

Friedrich's Problems Inventory. The mean Problems Inventory responses of the dialysis patients who participated in the present investigation were highly correlated with the mean Problems Inventory responses of Friedrich's (1980) dialysis sample. The two samples of dialysis patients associated similar degrees of distress with each of 13 physical problems commonly experienced during
dialysis sessions, with each of 20 physical problems commonly experienced between dialysis treatments, and with each of 35 psychosocial problems related to dialysis treatment.

Both Friedrich's (1980) research and the present study indicated that fatigue/weakness, muscle cramps, itching, restlessness, and painful needle insertions, were the physical problems during treatment which were identified as moderately to extremely distressing by the greatest number of dialysis patients.

Both Friedrich's (1980) research and the present investigation indicated that difficulty sleeping at night, lack of energy, shortness of breath, thirst, pain in bones, numbness and tingling in the hands and feet, sexual changes, bad taste in the mouth, and itching were the physical problems commonly experienced between dialysis sessions which were identified as moderately to extremely distressing by the largest number of patients.

In both the present and in Friedrich's (1980) study the problem most frequently rated as moderately to extremely distressing was a psychosocial problem, difficulty making long-range plans. This lends support to health professionals' contention that uncertainty about the future is a major concern of dialysis patients (Beard, 1969; Blodgett, 1981-1982; Kaplan De-Nour, 1980). The psychosocial problems that were the most distressing to the greatest number of dialysis patients from both samples were related to such uncertainty, and to social role changes, financial solvency, and the impact of the illness on the family.
In the present study an additional psychosocial item, pertaining to difficulty making short-range plans, was included in the Problems Inventory. Approximately one third of the patients indicated that difficulty making short-range plans created moderate to extreme distress. It is suggested that this item be included in future administrations of the Problems Inventory.

The high inter-correlations among the scales of the Problems Inventory detected by this research do not appear extraordinary. It seems likely that experiencing extreme distress from weakness, constant thirst, or shortness of breath, leads to less effective functioning in social and work environments. This in turn, would be expected to generate increased distress about psychosocial problems.

Illness-related distress: Additional relationships. Participants' ratings of satisfaction with their treatment unit were negatively correlated with the distress they associated with physical problems experienced both during and between dialysis sessions. The distress participants associated with psychosocial problems related to dialysis was not significantly correlated with their satisfaction with their treatment unit. It may well be that dialysis patients regard the physical problems of dialysis as the shared responsibility of patients and staff, and psychosocial problems as the personal responsibility of patients.

The participants' self-ratings of severity of illness were positively correlated with the distress they associated with psychosocial problems related to dialysis, but not significantly
related to the distress they associated with physical problems during or between dialysis sessions. This finding is consistent with research with other patient populations which found that social and psychological factors have a stronger affect on patients' perceptions of the severity of their illness and need to seek medical care than do physical symptoms (DiMatteo & DiNicola, 1982; Haynes, 1979; Zola, 1973).

A positive correlation was obtained between distress associated with psychosocial problems and the desire to have a kidney transplant. Interestingly, distress associated with physical problems was not significantly associated with desire for a kidney transplant. In this connection it might be recalled that distress related to psychosocial problems, but not to physical problems, was positively correlated with ratings of severity of illness, which in turn was associated with desire for a kidney transplant.

Friedrich (1980) reported that the distress participants associated with particular Problems Inventory items was related to their age, sex, education, work status, frequency of sessions, time in treatment, location of treatment, marital status, and history of kidney transplants. Unlike Friedrich's (1980) research, the present investigation did not examine the association between specific Problems Inventory items and patient-characteristics; however, it did examine the relationship between participants' scores on the three Problems Inventory scales and patient-characteristics. It did not detect any significant relationships between the scales and the patient-characteristics.
It seems important to note that the responses to the items on Friedrich's Problems Inventory were sometimes at variance with patients' comments to the investigator. For example, on the questionnaire one participant reported experiencing "no distress" in connection with the four hours of restricted movement on dialysis. After he completed the questionnaire he was observed getting out of his chair, stretching his muscles, grimacing, and complaining loudly to the nurses. The nurses explained that he frequently complained about restlessness during sessions. On a later occasion he told the investigator, "I feel like I'm tied to this damn machine and I get so restless." Another patient stated that she did not want to write down that certain problems caused her extreme distress because she wanted to "forget" about the distress to convince herself that dialysis is worth going through. She commented that writing the response was more "binding" than telling the investigator. Still another patient explained the discrepancy in his responses as follows:

I don't usually admit anything upsets me. If I do, why, that's like complaining, isn't it? It isn't gonna make the problem go away and I'll just look like a big cry-baby to the staff. As much as I've got my gripes, I appreciate all the stuff this place does for me.

Additional Patient Variables

The present study did not detect a significant difference between patients' and nurses' ratings of patients' severity of illness. Moreover, a low positive correlation was obtained between nurses' and patients' ratings. The literature reviewed in the
Introduction concerning the congruence of patients' and nurses' perceptions of dialysis patients' condition and treatment consistently reported significant differences between the two. No explanation for the discrepancy between the present and earlier research is readily apparent.

Dialysis patients' and nurses' ratings of severity of illness were not, however, related to the same factors. As already noted, patients' self-ratings of severity of illness were positively related to their preferences on the Support, Personal Problem Orientation, and Practical Orientation Scales of the Ideal Dialysis Unit Survey, and to self-reported level of distress from psychosocial problems; and also positively correlated with degree of desire for a kidney transplant. In sharp contrast, nurses' ratings of patients' severity of illness were only related to the amount of time patients had been in treatment. These findings illustrate the importance of obtaining patients' perceptions regarding treatment issues.

Participants' satisfaction with their treatment environment increased with age. The physical changes and limitations of End Stage Renal Disease and dialysis may embody a greater contrast in lifestyle for younger, as compared with older patients. Younger patients' lower satisfaction with their treatment environment may be an expression of their anger or frustration regarding their physical limitations. Moreover, older patients do not, in general, have the option of receiving a kidney transplant, and thus may be more appreciative of dialysis than younger patients.
The degree of participants' satisfaction with their treatment unit was high, with relatively little variability in the ratings of satisfaction. This is somewhat puzzling in light of the level of tension, passive-aggressive behavior, and noncompliance reported by dialysis staff. It is possible that the participants did not totally believe that their responses would be kept confidential. It is also possible that dissatisfied patients needed to justify why they did not speak out and demand changes or a transfer to another unit. This investigator suggests a third explanation as more plausible. Although many patients may not have been getting all of their needs met on their unit, they may have been grateful for the availability of dialysis, and recognized the staff's hard work. Moos (1974) speculated that patients alter their expectations to match the characteristics of their unit's treatment environment. Results may have been different had other units been tested. The three units which participated in this research each had good reputations within the dialysis community.

Length of time in treatment was found to be negatively correlated with level of education and with the desire for a kidney transplant. No explanation for the relationship between time in treatment and education is readily apparent. Regarding desire for a transplant, it may be that those patients who had been in treatment for the longest period of time were those who either could not have a kidney transplant or who had undergone an unsuccessful transplant. The significant negative relationship obtained between age and desire for a kidney transplant may at least in part be
explained by the reduced possibility of a kidney transplant after age 55.

Final Observations and Suggestions

The findings of the present investigation underscore the importance of ensuring that dialysis staff familiarize themselves with the ways in which patients view their illness, adjustment, and treatment needs. The present investigation found that dialysis patients strongly favored certain treatment environment dimensions over others. It also found that dialysis patients' preferences regarding their treatment environment varied as a function of age, education, time in treatment, perceptions of severity of illness, powerful others health locus of control, chance health locus of control, self-ratings of compliance, and dialysis unit affiliation. Particularly great variability in preferences was detected for those aspects of the treatment environment represented by the Spontaneity, Practical Orientation, Anger and Aggression, Personal Problem Orientation, and Autonomy Scales of the Ideal Dialysis Unit Survey. Moreover, patients' satisfaction with their treatment environment was the best predictor of both patients' and nurses' compliance ratings, and patients' treatment environment preferences were significantly associated with both compliance and severity of illness.

A situation involving a patient on Unit A illustrates the importance of taking into account patients' perceptions and opinions when designing treatment interventions. The patient, a 27 year old
male, frequently acted out on the unit by arriving late for treatments, by angry, provocative outbursts, and by attempting to leave the unit once the dialysis procedure had been initiated. He had told staff members a number of times that he believed that he could do a better job inserting his needles than they could. After two months of constant friction, the nurse in charge of his treatment, in exasperation, offered to teach him how to insert his own needles. He learned quickly, and his behavior on the unit improved drastically. He reported feeling more in control of his condition and of treatment than he had, and that he no longer felt it necessary to "assert his will" by acting in contrary ways on the unit. He was subsequently transferred to a home dialysis program in which he would have even more responsibility and control.

Research with Moos' (1974) Ward Atmosphere Scale has provided psychiatric units with important information for program development and the improvement of patient-staff communication (Archer & Amuso, 1980; Kish, Solberg, & Uecker, 1971; Moos, 1974). It is recommended that investigators refine the Ideal Dialysis Unit Survey scales and continue to examine the treatment environments of dialysis units. Consideration should be given to the use of the Ideal Dialysis Unit Survey, the Multidimensional Health Locus of Control Scales, and the Problems Inventory as therapeutic tools. For example, the Ideal Dialysis Unit Survey could be administered to dialysis unit personnel to stimulate discussion among staff with respect to views about the day-to-day management of patients, and about ways to handle common problems. The
participants' positive reactions to the Ideal Dialysis Unit Survey suggests that this instrument might also serve as a means of promoting patient-staff communication on sensitive issues. Patients and staff could each complete the Ideal Dialysis Unit Survey, and then discuss their perceptions and how they arrived at them.

The findings of the present investigation suggest that views about staff assistance with psychosocial problems should be a key issue in patient-staff discussions of treatment environment preferences. Participants indicated that many psychosocial problems related to dialysis created moderate to extreme distress for them. However, the findings of the present investigation also suggest that, in general, patients view psychosocial problems as within the patients' domain of responsibility, and physical problems as the shared responsibility of patients and staff. Dialogue between patients and staff is needed to clarify these and related issues, and to develop treatment interventions to help patients deal with the distress from psychosocial problems.

The present investigation found that time in treatment was significantly correlated with nurses' ratings of severity of illness, patients' self-ratings of compliance, chance health locus of control, preferences for staff control in the treatment environment, and views about kidney transplants. These findings confirm Blodgett's (1981-1982, p. 111) observation that, "there is no inherent reason to expect that a person on the first day of dialysis has the same concerns as an individual observing a tenth anniversary." Few studies have considered the length of time in
treatment as a significant influence on adjustment to dialysis. Those few studies which have done so have identified different stages and patterns of adjustment to dialysis treatment (Abram, 1969; Reichsman & Levy, 1972).

In conclusion, the findings of the present investigation suggest that formal procedures be adopted to evaluate dialysis patients' preferences regarding various aspects of their treatment environment and their perceptions of their illness at the time of their orientation to the dialysis center, and at regular intervals thereafter. It is recommended that patients and staff periodically compare their ideas and preferences concerning the treatment environment, as well as their perceptions of the patients' illness and adjustment to treatment. This author suggests that the scales employed in the present study be utilized for this purpose.
LIST OF REFERENCES


Klenow, D.J. (1979). Staff based ideologies in a hemodialysis unit. Social Science and Medicine, 13, 669-705.


APPENDIX A

The Uremic Syndrome
I. Neurological Symptoms
   A. Fatigue
   B. Sleep disturbances
   C. Headache
   D. Muscular irritability
   E. Lethargy
   F. Seizures
   G. Coma

II. Gastrointestinal symptoms
   A. Anorexia
   B. Nausea
   C. Vomiting
   D. Uremic fetor
   E. Gastroenteritis
   F. Gastrointestinal bleeding
   G. Peptic ulcer

III. Peripheral neuropathy
   A. Restless leg syndrome
   B. Parasthesias
   C. Motor weakness
   D. Paralysis

IV. Hematological symptoms
   A. Anemia
   B. Bleeding

V. Endocrinological symptoms
   A. Hyperparathyroidism
   B. Thyroid abnormalities
   C. Amenorrhea
   D. Infertility
   E. Sexual dysfunction

VI. Cardiovascular symptoms
   A. Hypertension
   B. Congestive Heart Failure
   C. Arteriosclerotic Heart Disease
   D. Pericarditis
   E. Myocardopathy
   F. Uremic lung

VII. Metabolic symptoms
   A. Carbohydrate intolerance
   B. Hyperlipidemia
   C. Nutrition
   D. Gout
VIII. Dermatological symptoms
   A. Pallor
   B. Pigmentation
   C. Pruritus
   D. Ecchymosis
   E. Excoriations
   F. Calcium deposition
   G. Uremic frost

IX. Ocular symptoms
   A. Red Eye Syndrome
   B. Band Keratopathy
   C. Hypertensive Retinopathy

X. Psychological symptoms
   A. Depression
   B. Anxiety
   C. Denial
   D. Psychosis

APPENDIX B

Consequences of Renal Failure Resulting in Uremic Symptoms and the Response to Chronic Dialysis Therapy
I. Symptoms Resulting from Abnormalities that Improve with Dialysis.
   A. Symptoms resulting from disorders of fluid, electrolyte, and acid-base metabolism.
      1. Volume excess or depletion
      2. Electrolyte imbalance: sodium, potassium, calcium, magnesium, phosphorous
      3. Acidosis
   B. Symptoms resulting from cardiovascular abnormalities in uremia.
      1. Hypertension
      2. Congestive heart failure
      3. Uremic lung
   C. Symptoms resulting from retained toxins, acquired metabolic abnormalities, or deficiency states.
      1. Neurological
      2. Hematological
      3. Gastrointestinal
      4. Dermatological
      5. Cardiopulmonary
      6. Endocrine-Metabolic
      7. Psychological

II. Symptoms Resulting from Abnormalities that Persist or Progress Despite Adequate Dialysis.
   A. Circulatory abnormalities producing symptoms in the dialyzed patient.
      1. Refractory hypertension
      2. Pericarditis
      3. Accelerated atherosclerosis
   B. Symptoms attributed to retained toxins, metabolic abnormalities, or deficiency states.
      1. Hematologic
      2. Endocrine-Metabolic
      3. Renal Osteodystrophy
      4. Psychological

III. Symptoms that Develop During the Course of Chronic Dialysis Treatment.
   A. Hepatitis
   B. Dialysis Dementia or Dyspraxic Syndrome
   C. Refractory Ascites
   D. Hypersplenism

APPENDIX C

Further Information about the Participating Dialysis Centers
Unit B is the smallest of the three treatment units, with the highest staff-patient ratio. It is a subsidiary of a private medical corporation and is situated in a two-story building in a suburban shopping plaza. Unit B's 14 patient stations (a reclining chair and dialysis machine) are arranged along three walls of a rectangular room, with an open nursing station occupying the fourth wall. The patient stations, in effect, form a semi-circle around the nursing station. The patient stations are placed far enough apart to afford some privacy, yet close enough to permit conversation among the patients and staff at the nursing station. Staff typically make popcorn for patients during sessions and patients frequently bring baked goods and other sweets for the staff. Staff and patients both contribute to birthday and holiday celebrations, and have on occasion met at a restaurant for a special lunch. Patients and staff maintain a small lending library and most patients read during dialysis sessions. Patients on this unit also frequently do paperwork, talk with staff, and take naps. Some patients bring a small television or radio from home. The patients' nephrologists frequently visit the unit, and the social worker meets with each dayshift patient twice a week, and with each evening patient once a week.

There is a high level of interaction among patients and staff, especially during the evening shift. With the help of the unit's social worker, the patients on this unit organized a patients' group which meets bimonthly to provide support and to plan activities for educating the public about dialysis. Patients recently donated a good deal of their own time to organize a public education
booth at the local county fair. Unit B is the only unit of the three with such a high level of patient activity. Not all patients are equally involved with unit activities, but generally those patients who are not involved speak positively of the others' involvement.

Unit A is considerably larger than Unit B with 23 patient stations, and has a lower staff-patient ratio. Unit A is situated in a three-story building near a busy urban intersection. As is the case with Unit B, it is a subsidiary of a private medical corporation. The patient stations on Unit A are arranged in two sets of parallel rows, with a good deal of space between stations. Some patients face each other, and some patients are back to back with other patients, but none of the patients directly face the nursing station which is at one end of the four rows of patient stations. Unit A is generally noisier than Unit B because of the larger size of this unit. Patients on Unit A typically sleep or watch television sets that they bring from home. More patients on this unit than on Unit B sleep through the sessions. Because of the relatively high patient census on this unit, the patients have less contact with the staff, especially the social worker, than do the patients on Unit B. The head nurse on this unit is very active in patient care and makes a special effort to keep informed about each patients' condition. The patients' doctors make fewer visits to this unit than do the doctors on Unit B, and there are no activities organized by, or for, the patients.
Unit C differs from Units A and B in that it is a unit in a private urban hospital. It is composed of one large and one small room, which are separated by a wall with a large window. The small room contains a single row of six patient stations which face a small staff desk. The 19 patient stations and the nursing station in the large room are arranged similarly to those on Unit A. Each patient station on Unit C is equipped with a television set and patients are supplied with headphones to keep noise levels at a minimum. The patient stations on Unit C are crowded closer together than on the other two units, and the majority of patients watch television (with headphones), read, or sleep during sessions. Patients on this unit appear to have the least contact with the unit social worker due to the high patient census. They complained the most about the infrequency of their doctors' visits to the unit. The unit is visited daily by hospital volunteers who sell reading material and snacks.
APPENDIX D

Letter of Introduction
Dear Dialysis Patient:

My name is Daryl Goldman. For my doctorate in Psychology I am conducting a research study concerning dialysis patients' beliefs and opinions about their treatment. I have prepared this brief explanation of my research to help you decide whether or not you would like to participate.

Most of the research on patients' beliefs and feelings about their treatment is written from the point of view of the doctors, nurses, social workers, and psychologists who work with dialysis patients. There is a need to explore what patients themselves feel about their treatment. This is especially important since each patient has his/her own unique needs and preferences. I plan to survey 100 dialysis patients in the next couple of months.

If you agree to participate, you will be asked to complete 5 forms that ask questions about your idea of an ideal dialysis unit, your experiences on dialysis, and your health. You will be asked to fill these out during one of your regular dialysis sessions. (I can help you write your responses if you have difficulty writing while on the machine.) In all, I will need from 30 to 60 minutes of your time. Your responses will be coded and your staff will not be aware of how you answer the questions.

I will also obtain your permission to have one of the nurses answer some questions about you.

You have the right to choose not to participate, and you may change your mind about participating at any point.

I appreciate your taking the time to read this letter of introduction. Please let your social worker know if you would be willing to speak to me further about participating in this study.

Thank you.

Sincerely,

Daryl Goldman, M.A.
APPENDIX E

Ideal Dialysis Unit Survey Scale Definitions

and Items
Involvement measures the degree of interaction and the involvement patients desire with staff and other patients while they are on dialysis.

1. I prefer a unit in which patients and staff always do something special for each other on holidays and birthdays.

11. I prefer a unit in which patients usually get interesting discussions going with other patients and staff.

21. I prefer a unit in which patients are proud of their unit.

31. I prefer a unit in which patients prefer to keep to themselves and sleep or watch T.V. during dialysis.

Support measures how much help and support patients want from other patients, nurses and doctors.

2. I prefer a unit in which patients always offer each other encouragement and support.

12. I prefer a unit in which staff think that patients' emotional condition (e.g. fears, anxieties, and feelings) is just as important as their physical condition.

22. I prefer a unit in which staff leave patients alone when they look depressed or anxious.

32. I prefer a unit in which the doctors make special visits to the unit to encourage their patients.

Spontaneity measures the extent to which patients think they should be able to express their feelings to the staff and other patients.

3. I prefer a unit in which patients are always pleasant and keep their real feelings to themselves.

13. I prefer a unit in which patients rarely share their feelings with each other.

23. I prefer a unit in which patients are encouraged to let staff know how they are really feeling.

33. I prefer a unit in which patients do not have to worry about what they are saying when staff are around.
Autonomy measures how much responsibility and involvement patients want to assume for their care during dialysis.

4. I prefer a unit in which staff do not insist that patients learn everything that they can about their condition and treatment.

14. I prefer a unit in which patients themselves weigh in, take their temperature, and monitor their blood pressure during treatment.

24. I prefer a unit in which patients are trained to take care of minor problems with their machines during dialysis.

34. I prefer a unit in which patients are encouraged to rely on staff to take care of everything during their dialysis sessions.

Personal Problem Orientation measures the extent to which patients want to share and get support for their personal problems from staff and other patients.

5. I prefer a unit in which staff rarely ask patients about their personal problems.

15. I prefer a unit in which patients are encouraged to discuss with staff their sexual problems.

25. I prefer a unit in which patients are encouraged to talk about the achievements and frustrations in their lives.

35. I prefer a unit in which patients hardly ever tell each other about their personal problems.

Practical Orientation measures the extent to which patients would like help from staff in dealing with the stresses of dialysis, problem solving, and planning for the future.

6. I prefer a unit in which staff help patients develop ways to deal with the stresses of dialysis in their daily lives.

16. I prefer a unit in which staff do not use their time to help patients solve problems they have outside the unit.

26. I prefer a unit in which staff encourage patients to make short-range (daily) plans outside the unit.

36. I prefer a unit in which staff do not help patients make plans for their future -- such as job plans, financial plans, or social plans.
Anger and Aggression measures the extent to which patients think they should be able to express their anger at staff and other patients, and the extent to which staff should be able to express their anger to patients.

7. I prefer a unit in which it is O.K. for patients to let staff know when they are angry at them.

17. I prefer a unit in which patients never gripe or criticize the staff.

27. I prefer a unit in which staff lets patients know when they are angry at them.

37. I prefer a unit in which staff do not show their anger when patients cheat on their diet or forget to take their medication.

Order and Organization measure the importance of rules and organization to patients; the rules in question apply to both patients and staff.

8. I prefer a unit in which there is not much emphasis on patients being prompt and sessions starting on time.

18. I prefer a unit in which there is a regular routine so that patients always know in advance who will hook them up to the machine.

28. I prefer a unit in which no one seems to mind if once in awhile problems arise and the unit gets chaotic.

38. I prefer a unit in which the staff always makes certain that patients finish their sessions on time so that the next patient will not be kept waiting.

Program Clarity measures how important it is to patients to be kept informed of the rules and regulations of the unit, who is in charge of their treatment, and what exactly is expected of them.

9. I prefer a unit in which patients are kept informed of changes in the rules and procedures of the unit.

19. I prefer a unit in which there are no hard and fast rules that patients must follow.

29. I prefer a unit in which staff always discuss changes in medication and diet with patients.
39. I prefer a unit in which patients know clearly which staff are primarily responsible for their care and who is in charge of the unit.

Staff Control measures how strict patients think that staff should be regarding rules, regulations, and schedules; it assesses the degree of authority and power patients think that staff should have.

10. I prefer a unit in which patients who are noncompliant with their diet and medications are punished for it.

20. I prefer a unit in which patients may interrupt staff when they are talking.

30. I prefer a unit in which patients know that they could be transferred to another unit if they do not cooperate with staff.

40. I prefer a unit in which staff consult patients when a scheduling or treatment change is necessary.
APPENDIX F

Ideal Dialysis Unit Survey
I am trying to find out what sort of unit a patient like yourself would consider ideal. For that purpose, I have listed below a number of statements that dialysis patients have made concerning their preferences for treatment. Please read each statement carefully and decide how much you AGREE or DISAGREE with that statement. Please indicate how much you AGREE or DISAGREE by writing the number of the response you choose in the space at the end of the statement. For instance, write +3 in the space at the end of a statement if you STRONGLY AGREE with it; write -3 in the space at the end of the statement if you STRONGLY DISAGREE with it.

+1 I AGREE SLIGHTLY -1 I DISAGREE SLIGHTLY
+2 I AGREE MODERATELY -2 I DISAGREE MODERATELY
+3 I AGREE STRONGLY -3 I DISAGREE STRONGLY

1. I prefer a unit in which patients and staff always do something special for each other on birthdays and holidays.

2. I prefer a unit in which patients always offer each other encouragement and support.

3. I prefer a unit in which patients are always pleasant and keep their real feelings to themselves.

4. I prefer a unit in which staff do not insist that patients learn everything that they can about their condition and treatment.

5. I prefer a unit in which staff rarely ask patients about their personal problems.

6. I prefer a unit in which staff help patients develop ways to deal with the stresses of dialysis in their daily lives.
7. I prefer a unit in which it is O.K. for patients to let staff know when they are angry at them.

8. I prefer a unit in which there is not much emphasis on patients being prompt and sessions starting on time.

9. I prefer a unit in which patients are kept informed of changes in the rules and procedures of the unit.

10. I prefer a unit in which patients who are noncompliant with their diet and medication are punished for it.

11. I prefer a unit in which patients usually get interesting discussions going with other patients and staff.

12. I prefer a unit in which staff think that patients' emotional condition (e.g., fears, anxieties, feelings) is just as important as their physical condition.

13. I prefer a unit in which patients rarely share their feelings with each other.

14. I prefer a unit in which patients themselves weigh in, take their temperature, and monitor their blood pressure during treatment.
15. I prefer a unit in which patients are encouraged to discuss with staff their sexual problems.

16. I prefer a unit in which staff do not use their time to help patients solve problems they have outside the unit.

17. I prefer a unit in which patients never gripe or criticize the staff.

18. I prefer a unit in which there is a regular routine so that patients always know in advance who will hook them up to the machine.

19. I prefer a unit in which are no hard and fast rules that patients must follow.

20. I prefer a unit in which a patient may interrupt staff when they are talking.

21. I prefer a unit in which patients are proud of their unit.

22. I prefer a unit in which staff leave patients alone when they look depressed or anxious.

23. I prefer a unit in which patients are encouraged to let staff know how they are really feeling.
24. I prefer a unit in which patients are trained to take care of minor problems with their machine during dialysis.

25. I prefer a unit in which patients are encouraged to talk about the achievements and frustrations of their lives.

26. I prefer a unit in which staff encourage patients to make short-range (daily) plans outside the unit.

27. I prefer a unit in which staff let patients know when they are angry at them.

28. I prefer a unit in which no one seems to mind if once in a while problems arise and the unit gets chaotic.

29. I prefer a unit in which staff always discuss changes in medication and diet with patients.

30. I prefer a unit in which patients know that they could be transferred to another unit if they do not cooperate with staff.

31. I prefer a unit in which patients prefer to keep to themselves and sleep or watch T.V. during dialysis.

32. I prefer a unit in which the doctors make special visits to the unit to encourage their patients.
33. I prefer a unit in which patients do not have to worry about what they are saying when staff are around.

34. I prefer a unit in which patients are encouraged to rely on staff to take care of everything during their dialysis sessions.

35. I prefer a unit in which patients hardly ever tell each other about their personal problems.

36. I prefer a unit in which staff do not help patients make plans for their future--such as job plans, financial plans, or social plans.

37. I prefer a unit in which staff do not show their anger when patients cheat on their diet or forget to take their medication.

38. I prefer a unit in which staff always make certain that patients finish their sessions on time so that the next patient will not be kept waiting.

39. I prefer a unit in which patients know clearly which staff are primarily responsible for their care and who is in charge of the unit.

40. I prefer a unit in which staff consult patients when a scheduling or treatment change is necessary.
APPENDIX G

Multidimensional Health Locus of Control Scales
This is a questionnaire designed to determine the way in which people view certain important health-related issues. Each item is a belief statement with which you may AGREE or DISAGREE. Beside each statement is a scale which ranges from STRONGLY DISAGREE (1) to STRONGLY AGREE (6). For each item, we would like you to circle the number which represents the extent to which you AGREE or DISAGREE with a statement. The more strongly you AGREE with a statement, then the higher will be the number you circle. The more strongly you DISAGREE with a statement, then the lower will be the number you circle. Please make sure you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

1. If I get sick, it is my own behavior which determines how soon I will get well again.

2. No matter what I do, if I am going to get sick, I will get sick.

3. Having regular contact with my physician is the best way for me to avoid illness.

4. Most things that affect my health happen to me by accident.

5. Whenever I don't feel well I should consult a medically trained professional.

6. I am in control of my health.
7. My family has a lot to do with my becoming sick or staying healthy. 1 2 3 4 5 6
8. When I get sick I am to blame. 1 2 3 4 5 6
9. Luck plays a big part in determining how soon I will recover from an illness. 1 2 3 4 5 6
10. Health professionals control my health. 1 2 3 4 5 6
11. My good health is largely a matter of good fortune. 1 2 3 4 5 6
12. The main thing which affects my health is what I do myself. 1 2 3 4 5 6
13. If I take care of myself I can avoid illness. 1 2 3 4 5 6
14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me. 1 2 3 4 5 6
15. No matter what I do, I'm likely to get sick. 1 2 3 4 5 6
16. If it's meant to be, I will stay healthy. 1 2 3 4 5 6
17. If I take the right actions, I can stay healthy. 1 2 3 4 5 6
18. Regarding my health, I can only do what my doctor tells me to do. 1 2 3 4 5 6
APPENDIX H

Problems Inventory
On the following pages are a number of statements that identify possible problems that may accompany hemodialysis. Some problems are reported by almost everyone; others are identified by only a few patients.

The statements are divided into two sections. SECTION 1 is concerned with problems during dialysis. SECTION 2 deals with problems between treatments.

INSTRUCTIONS. For each of the following statements, please try to indicate the amount of distress the problem creates for you by checking the appropriate space. Distress can be due to feelings such as anxiety and unhappiness created by a problem, or from other things such as the physical discomfort caused by the problem. Please try to answer all of the items.

There are five possibilities for determining how much the problem bothers you. They are as follows:

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<th>0</th>
<th>1</th>
<th>2</th>
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<tbody>
<tr>
<td>No Distress</td>
<td>Slightly Distressing</td>
<td>Moderately Distressing</td>
<td>Very Distressing</td>
<td>Extremely Distressing</td>
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SECTION 1: PROBLEMS DURING DIALYSIS

Physical Problems During Dialysis

1. I feel sick to my stomach while on dialysis........................... ______ ______ ______ ______ ______
2. I have headaches during dialysis........ ______ ______ ______ ______ ______
3. I experience pain when the needles are inserted.................. ______ ______ ______ ______ ______
4. I feel restless during the procedure................................. ______ ______ ______ ______ ______
5. My eyes bother me--i.e., it is difficult to focus on television.. ______ ______ ______ ______ ______
6. I feel dizzy during dialysis....... ______ ______ ______ ______ ______
7. Toward the end of dialysis I feel weak and "tired out".............. ______ ______ ______ ______ ______
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<tr>
<th>Physical Problems During Dialysis</th>
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<td>No</td>
<td>Si</td>
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<td>8. My skin itches during dialysis</td>
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<td>9. During dialysis I feel very drowsy</td>
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<td>10. It is difficult to concentrate on what others are saying</td>
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<td>11. I have difficulty sleeping during dialysis</td>
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<td>12. During dialysis my body aches</td>
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<td>13. I have muscle cramps during dialysis</td>
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<tr>
<th>Other Problems During Dialysis</th>
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<tbody>
<tr>
<td>1. Travel expenses for treatment are a burden for me</td>
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<td>2. The treatment disrupts time spent with my family</td>
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<td>3. I worry that something may go wrong with the dialysis equipment</td>
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<td>4. I lack information about my illness</td>
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<td>5. I have little personal privacy during dialysis</td>
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<td>6. During dialysis I am unable to get up and move around</td>
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<td>7. My treatment interferes with my time available to work</td>
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<tr>
<td>8. I am concerned that the fistula or cannula may not work properly and interfere with dialysis</td>
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<tr>
<td>9. I have to lean on others during dialysis</td>
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</table>
Other Problems During Dialysis (Continued)

10. It is difficult to make arrange-
ments for transportation to
dialysis..............................................

11. I am not kept informed of physical
changes brought about by my illness or treatment..................

12. While on dialysis there are things
I want to do for myself that
others have to do for me..............

13. I do not have enough people to
turn to when problems arise...........

14. The treatment takes up so much
time, I don't have time for
anything else.........................

15. I am fearful for my life when the
dialysis equipment does not work
properly.................................

16. I have little chance to be by
myself during dialysis.............

SECTION 2: PROBLEMS BETWEEN TREATMENTS

Physical Problems Between Treatments

1. Between treatments I feel sick
to my stomach.......................

2. I have headaches between treat-
ments.................................

3. I feel exhausted and generally
lack energy between treatments....

4. My thinking seems "cloudy" and it
is difficult to concentrate on
things between treatments..........

5. I have infections or clotting in
my fistula or shunt................
### Physical Problems Between Treatments - (Continued)

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<td>6.</td>
<td>I have difficulty sleeping at night.</td>
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<td>7.</td>
<td>I have pain in my bones and joints.</td>
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<td>8.</td>
<td>I have numbness or tingling in my hands and feet.</td>
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<td>9.</td>
<td>I gain too much weight between treatments.</td>
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<td>10.</td>
<td>I get short of breath easily.</td>
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<td>11.</td>
<td>I experience sexual changes.</td>
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<td>12.</td>
<td>I have frightening dreams about dialysis.</td>
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<td>13.</td>
<td>I feel dizzy, as if &quot;I'm going to pass out&quot;.</td>
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<td>14.</td>
<td>I have problems with bleeding, such as nosebleeds.</td>
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<td>15.</td>
<td>My thirst is not satisfied when I follow my fluid restrictions.</td>
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<td>16.</td>
<td>I have little appetite.</td>
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<td>17.</td>
<td>My body itches between treatments.</td>
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<td>18.</td>
<td>I have a bad taste in my mouth.</td>
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<td>19.</td>
<td>My eyes bother me, and I relate this to my treatment.</td>
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<td>20.</td>
<td>I have high blood pressure before my dialysis treatments.</td>
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### Other Problems Between Treatments

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<tr>
<td>1.</td>
<td>I have little understanding of how to follow my restricted diet.</td>
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<td>2. I am concerned with my appearance.</td>
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<td>3. My illness has been distressing to my family</td>
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<td>4. Others frequently eat foods that I cannot eat</td>
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<td>5. Since beginning dialysis, I do not have as much money to spend...</td>
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<td>6. Since beginning dialysis, friends seem to have forgotten me.</td>
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<td>7. It is difficult to make long-range plans</td>
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<td>8. I am not as attractive as I used to be</td>
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<td>9. Others expect me to work harder than I can</td>
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<td>10. My diet has no taste to me</td>
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<td>11. The expense of the medical bills concerns me</td>
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<td>12. I see my friends less frequently</td>
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<tr>
<td>13. It bothers me sometimes to think that my future may be uncertain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Since beginning dialysis, I have had to decrease my work load</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. I am concerned that I may not have a full life span</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I worry about how I am going to manage financially</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I am not as active in outside interests as I used to be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Problems Between Treatments - (Continued)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>18. Family members are worried about the possibility of their being kidney donors</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>SI</td>
<td>Mod</td>
<td>Ver</td>
<td>Extr</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>19. I have to take financial assistance from outside sources</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>SI</td>
<td>Mod</td>
<td>Ver</td>
<td>Extr</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>20. I have difficulty making plans for each day because of my illness and treatment</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>SI</td>
<td>Mod</td>
<td>Ver</td>
<td>Extr</td>
</tr>
</tbody>
</table>
APPENDIX I

Patients' Survey
1) Overall, how satisfied are you with the care that you receive at this clinic?

   1  2  3  4  5  6  7
Not at all Satisfied
Very Satisfied

2) Compared to most dialysis patients, how severe do you think your illness is?

   1  2  3  4  5  6  7
Not at all Severe
Very Severe

3) How close would you say that you usually come to following the instructions for taking your phosphorous medicine?

   1  2  3  4  5  6  7
Hardly Ever Follow Instructions
Follow Instructions Exactly

4) How close would you say you usually come to staying on your diet?

   1  2  3  4  5  6  7
Hardly Ever Stay on Diet
Stay on Diet Exactly

5) How close would you say you usually come to keeping your fluid limit?

   1  2  3  4  5  6  7
Hardly Ever Keep to Fluid Limit
Keep to Fluid Limit Exactly
APPENDIX J

Nurses' Survey
1) Compared to most dialysis patients, how severe do you think __________ illness is?

Not at All    2 3 4 5 6 7
Severe

2) How close would you say that __________ usually comes to following the instructions for taking their phosphorous medication?

Hardly Ever    2 3 4 5 6 7
Follows Instructions

3) How close would you say that __________ usually comes to staying on their diet?

Hardly Ever    2 3 4 5 6 7
Stays on Diet

4) How close would you say that __________ usually comes to keeping to their fluid limit?

Hardly Ever    2 3 4 5 6 7
Keeps to Fluid Limit

Nurse's I.D.# ___________ Patient's I.D.# ___________
APPENDIX K

Personal Data Sheet
INSTRUCTIONS: Please respond to each question as it relates to you. Some answers require a check (v) in the appropriate space, and others require a short answer.

1) Your age

2) Sex: Male:________(1) Female:________(2)

3) Marital status:
   (1) Single
   (2) Married
   (3) Widowed
   (4) Divorced/Separated

4) Education:
   (1) Completed eighth grade
   (2) Completed high school
   (3) Some college
   (4) Completed college

5) Do you have any children?
   Yes_______ (1) No_______ (2)

6) Work status before dialysis: (job outside the home or homemaker)
   Full-time_______(1)
   Part-time_______(2)
   No job_______(3)
   Type of work: ______________________________________

7) Work status since beginning dialysis: (Job outside home or homemaker)
   Full-time_______(1)
   Part-time_______(2)
   No job_______(3)
   Type of work: ____________________________ Income: ________

8) Number of months on dialysis: ______________

9) Time of day you begin dialysis: ______________

10) Number of hours you dialyze per treatment: ______________

11) How often do you dialyze per week?
    (1) one ____ (2) two______ (3) three ____ (4) four ____

12) Please circle the days that you usually dialyze:
    Monday Tuesday Wednesday Thursday Friday Saturday Sunday

13) Have you had a kidney transplant:
    Yes ____ (1) No ____ (2)
14) Ethnic background: __________________________________________

15) In regard to kidney transplantation, which statement best describes your feelings at the present time?
(1) I would like to have a transplant. ____________________________________
(2) I am unsure whether I would want a transplant. __________________________
(3) I am satisfied with my status on dialysis and would rather not have a kidney transplant at the present time. __________________________

16) From the following list of resources, identify three that have helped you the most in managing your illness:
Wife or husband __________
Other family members __________
Minister, chaplain, or rabbi __________
Friends __________
Other patients __________
Social worker __________
Dietician __________
Nurses __________
Doctors __________
Mental health worker __________
Others __________________________________________

17) From the above list, please circle the individuals from whom you would like more assistance.

Thank you again for all of your time and assistance. If you have any comments or wish to provide further information, please use the space provided at the bottom or on the next page.
APPENDIX L

Factors Affecting the Interpretation of Laboratory Data
It should be recalled that the review of the dialysis literature in the Introduction indicated that uremia-related and dialysis-related dysfunctions affect blood levels of electrolytes, acid-base balance, and fluid retention, to some degree regardless of the patient's compliance with dietary and fluid restrictions or with the medication regimen. It also noted that patients vary greatly in the nature and degree of their uremia-related and dialysis-related dysfunctions. Overt secondary hyperparathyroidism is an example of a uremia-related dysfunction which raters need to be aware of when assessing patient compliance from laboratory data. Patients with this condition often have serum phosphorous levels greater than patients without hyperparathyroidism who have comparable renal function. This hyperphosphatemia causes bones to release calcium, resulting in decalcification of bone and increased blood calcium levels.

The laboratory assessment of patients' compliance with their fluid restrictions is typically indexed by patients' weight gain between dialysis treatments. Accurate assessments of fluid compliance necessitate consideration of the patients' degree of urinary output. Unfortunately, the majority of studies examining patients' fluid compliance have failed to control for this factor when calculating between-treatments weight gain.

A number of environmental factors which affect patients' laboratory data need to be considered when physiological assessments of compliance are made. One such factor is the reuse of the artificial kidney, that part of the dialysis machine which filters out
toxic wastes, electrolytes, and excess fluid, and adjusts the acid-base balance of the blood. Recycling the artificial kidney is a widespread practice among dialysis units. The reason for doing so is primarily an economic one, as each kidney costs approximately $20, and many health plans do not reimburse dialysis units for their cost. Two of the three units included in this research recycled their artificial kidneys, while the third unit used a new kidney for each treatment. The medical staff from the three units in this study report that artificial kidneys evidence slight decreases in filtration ability but may be used with a good degree of confidence six to eight times. The kidneys typically evidence a sudden drop in filtration some time between the sixth and eighth use. A patient dialyzed with such a kidney will exhibit abnormal laboratory values, which may be mistaken for noncompliance on the patient's part if the clinician is not aware of the state of the artificial kidney. Units A and B reuse their artificial kidneys until filtration ability decreases to 85%. Both patients and staff complain that a kidney with 15% fiber loss does not remove as much fluid as does a new artificial kidney.

Comparisons of patients' laboratory data is not only complicated by whether or not the patients are dialyzed with recycled artificial kidneys, but also by the method of cleaning the artificial kidneys. Some units, such as Units A and B, clean their artificial kidneys with a machine called the lexivatron which can also measure filtration ability; other units clean their kidneys by hand. These two methods of cleaning can result in different levels of membrane
permeability. The lexivatron, on occasion, miscalculates filtration and an unsuitable artificial kidney is used for a treatment, resulting in abnormal laboratory values.

Another environmental factor which needs to be considered when assessing compliance from physiological data is the quality of the water utilized for dialysis treatments. Federal recommendations for treating water for dialysis treatments did not exist before 1975. Prior to this time many dialysis centers used unfiltered tap water which varies greatly in mineral and trace element content. There are numerous reports of patients from a given unit experiencing elevated calcium and phosphorous levels, and in some cases aluminum intoxication or psychosis associated with elevated copper levels, due to their unit's water supply or a breakdown in their unit's water filtering system (Fortner-Frazier, 1981; Kerr, 1980).
APPENDIX M

Experimental Subject's Bill of Rights
The rights below are the rights of every person who is asked to be in a research study. As an experimental subject, I have the following rights:

1) To be told what the study is trying to find out.

2) To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice.

3) To be told about the frequent and/or important risks, side effects or discomforts of the things that will happen to me for research purposes.

4) To be told if I can expect any benefit from participating and, if so, what the benefit might be.

5) To be told the other choices I have and how they may be better or worse than being in the study.

6) To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study.

7) To be told what sort of medical treatment is available if any complications arise.

8) To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study.

9) To receive a copy of the signed and dated consent form.

10) To be free of pressure when considering whether I wish to agree to be in the study.

----------$----------

If I have other questions I should ask the researcher or the research assistant. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling (415) 666-1811 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing the Committee on Human Research, University of California, San Francisco, CA 94143.
APPENDIX N

Consent to be a Research Subject
Daryl Goldman, M.A., and Lewis B. Sachs, Ph.D. are doing a research study to learn more about the beliefs and feelings of dialysis patients. They have invited me to participate in this study because I am currently receiving regular dialysis treatments.

If I agree to be in this study, I will be asked to complete five short questionnaires about my feelings and beliefs regarding my dialysis treatment. I will be asked to do this during a regularly scheduled dialysis session. It should take from 30 to 60 minutes of my time. Ms. Goldman will have my permission to obtain information concerning my physical condition from a nurse on my unit.

All information will be kept as confidential as possible within the law. My responses will be coded and my name will be kept separate from my answers. The staff WILL NOT know how I respond to the questionnaires. Any information that personally identifies me will not be disclosed to anyone without my separate written consent.

The investigators hope to learn more about patients' feelings regarding their dialysis treatment in order to help dialysis units develop programs that meet patients' needs. My staff may gain information from this study which may help me or other patients in the long run.

I have talked to Ms. Goldman about this study and have had my questions answered. If I have any further questions, I can call her at: 750-2004 or 550-8593.

I have received a copy of this consent form and the Experimental Subject's BILL OF RIGHTS.

I have the right to refuse participation and the right to withdraw from the study at any time without jeopardizing my care at this center. Should I choose not to participate, I will still receive the level of care to which I am accustomed.

This dialysis center has no special program by which it provides compensation or medical treatment if injury occurs during biomedical or behavioral research.

Subject's Signature ___________________________ Date ___________________________
APPENDIX O

Dialysis Patients' Responses to Treatment

Environment Issues
Table 17

Dialysis Patients' Responses to Treatment Environment Issues

<table>
<thead>
<tr>
<th>Ideal Dialysis Unit Survey item</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>#40 Staff consult patients re scheduling or treatment changes.</td>
<td>2.73</td>
<td>.83</td>
<td>3.0</td>
</tr>
<tr>
<td>#32 Doctors make special visits to unit.</td>
<td>2.58</td>
<td>1.07</td>
<td>3.0</td>
</tr>
<tr>
<td>#21 Patients are proud of their unit.</td>
<td>2.58</td>
<td>1.07</td>
<td>3.0</td>
</tr>
<tr>
<td>#38 Sessions finish on time, so next patient is not kept waiting.</td>
<td>2.47</td>
<td>1.06</td>
<td>3.0</td>
</tr>
<tr>
<td>#29 Staff discuss medication and diet changes with patients.</td>
<td>2.46</td>
<td>1.34</td>
<td>3.0</td>
</tr>
<tr>
<td>#9 Patients kept informed of rules and procedures of unit.</td>
<td>2.46</td>
<td>1.47</td>
<td>3.0</td>
</tr>
<tr>
<td>#39 Patients know who is in charge of their care and the unit.</td>
<td>2.29</td>
<td>1.42</td>
<td>3.0</td>
</tr>
<tr>
<td>#12 Staff think that patients' feelings are important as their health.</td>
<td>2.22</td>
<td>1.51</td>
<td>3.0</td>
</tr>
<tr>
<td>#6 Staff help patients deal with stress.</td>
<td>2.12</td>
<td>1.64</td>
<td>3.0</td>
</tr>
<tr>
<td>#2 Patients support each other.</td>
<td>2.09</td>
<td>1.60</td>
<td>3.0</td>
</tr>
<tr>
<td>#23 Patients tell staff how they are really feeling.</td>
<td>1.98</td>
<td>1.78</td>
<td>3.0</td>
</tr>
<tr>
<td>#33 Patients can say anything in front of staff.</td>
<td>1.75</td>
<td>1.93</td>
<td>3.0</td>
</tr>
<tr>
<td>#34 Patients rely on staff for everything during dialysis.</td>
<td>1.73</td>
<td>1.85</td>
<td>3.0</td>
</tr>
<tr>
<td>#7 Patients tell staff when they are angry.</td>
<td>1.71</td>
<td>1.71</td>
<td>2.0</td>
</tr>
<tr>
<td>#11 Patients and staff have interesting discussions.</td>
<td>1.52</td>
<td>1.77</td>
<td>2.0</td>
</tr>
</tbody>
</table>
Table 17 (Continued)

<table>
<thead>
<tr>
<th>Ideal Dialysis Unit Survey item</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Patients and staff celebrate birthdays and holidays.</td>
<td>1.09</td>
<td>2.09</td>
<td>2.0</td>
</tr>
<tr>
<td>#31 Patients keep to themselves.</td>
<td>1.01</td>
<td>2.16</td>
<td>2.0</td>
</tr>
<tr>
<td>#27 Staff tell patients when they are angry with them.</td>
<td>.90</td>
<td>2.29</td>
<td>2.0</td>
</tr>
<tr>
<td>#37 Staff do not show anger when patients are noncompliant.</td>
<td>.60</td>
<td>2.27</td>
<td>1.0</td>
</tr>
<tr>
<td>#28 It is O.K. if unit gets chaotic.</td>
<td>.51</td>
<td>2.36</td>
<td>1.5</td>
</tr>
<tr>
<td>#3 Patients keep their feelings to themselves.</td>
<td>.38</td>
<td>2.30</td>
<td>1.0</td>
</tr>
<tr>
<td>#30 Patients could be transferred if they do not cooperate.</td>
<td>.37</td>
<td>2.60</td>
<td>2.0</td>
</tr>
<tr>
<td>#35 Patients do not share personal problems with each other.</td>
<td>.30</td>
<td>2.16</td>
<td>1.0</td>
</tr>
<tr>
<td>#25 Patients discuss outside problems and achievements with staff.</td>
<td>.30</td>
<td>2.29</td>
<td>1.0</td>
</tr>
<tr>
<td>#26 Staff encourage short-range planning.</td>
<td>.23</td>
<td>2.44</td>
<td>1.0</td>
</tr>
<tr>
<td>#20 Patients may interrupt staff.</td>
<td>.11</td>
<td>2.47</td>
<td>1.0</td>
</tr>
<tr>
<td>#24 Patients handle minor machine problems.</td>
<td>-.02</td>
<td>2.53</td>
<td>-1.0</td>
</tr>
<tr>
<td>#36 Staff do not help plan for the future.</td>
<td>-.13</td>
<td>2.40</td>
<td>-1.0</td>
</tr>
<tr>
<td>#5 Staff do not ask about personal problems.</td>
<td>-.20</td>
<td>2.49</td>
<td>-1.0</td>
</tr>
<tr>
<td>#18 Unit has a regular routine.</td>
<td>-.37</td>
<td>2.40</td>
<td>-1.0</td>
</tr>
<tr>
<td>#16 Staff do not help patients with outside problems.</td>
<td>-.42</td>
<td>2.34</td>
<td>-1.5</td>
</tr>
<tr>
<td>#13 Patients rarely share their feelings with each other.</td>
<td>-.44</td>
<td>2.28</td>
<td>-1.0</td>
</tr>
<tr>
<td>Ideal Dialysis Unit Survey item</td>
<td>Mean</td>
<td>SD</td>
<td>Median</td>
</tr>
<tr>
<td>-------------------------------------------------------------</td>
<td>------</td>
<td>-----</td>
<td>--------</td>
</tr>
<tr>
<td>#4 Patients not pushed to learn about their treatment.</td>
<td>-0.45</td>
<td>2.54</td>
<td>-0.20</td>
</tr>
<tr>
<td>#19 Unit has no hard and fast rules.</td>
<td>-0.45</td>
<td>2.32</td>
<td>-1.0</td>
</tr>
<tr>
<td>#17 Patients never complain.</td>
<td>-0.59</td>
<td>2.27</td>
<td>-1.0</td>
</tr>
<tr>
<td>#14 Patients weigh in, take their temperature, and monitor their blood pressure.</td>
<td>-0.73</td>
<td>2.30</td>
<td>-1.0</td>
</tr>
<tr>
<td>#8 Not much emphasis on patients being prompt.</td>
<td>-0.85</td>
<td>2.52</td>
<td>-2.0</td>
</tr>
<tr>
<td>#22 Staff leave depressed patients alone.</td>
<td>-0.98</td>
<td>2.18</td>
<td>-2.0</td>
</tr>
<tr>
<td>#15 Patients discuss their sexual problems with staff.</td>
<td>-1.34</td>
<td>2.19</td>
<td>-2.0</td>
</tr>
<tr>
<td>#10 Patients punished for being noncompliant.</td>
<td>-1.62</td>
<td>2.14</td>
<td>-3.0</td>
</tr>
</tbody>
</table>

Note: Mean responses range from -3 to +3.
APPENDIX P

Cross-Study Comparison of Mean Multidimensional Health Locus of Control Scale Scores
Table 18

Cross-Study Comparison of Mean Multidimensional Health Locus of Control Scale Scores

<table>
<thead>
<tr>
<th>Sample</th>
<th>N</th>
<th>Internal</th>
<th>Powerful Others</th>
<th>Chance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dialysis patients, present study</td>
<td>100</td>
<td>25.00</td>
<td>24.51</td>
<td>18.48</td>
</tr>
<tr>
<td>Dialysis patients, Hatz (1978)</td>
<td>19</td>
<td>24.00</td>
<td>23.10</td>
<td>14.78</td>
</tr>
<tr>
<td>Chronic patients, Wallston, Wallston, &amp; DeVellis (1978)</td>
<td>609</td>
<td>25.78</td>
<td>22.54</td>
<td>17.64</td>
</tr>
<tr>
<td>College students, Wallston, Wallston, &amp; DeVellis (1978)</td>
<td>749</td>
<td>26.68</td>
<td>17.87</td>
<td>16.72</td>
</tr>
<tr>
<td>Healthy adults, Wallston, Wallston, &amp; DeVellis (1978)</td>
<td>1287</td>
<td>25.55</td>
<td>19.16</td>
<td>16.21</td>
</tr>
<tr>
<td>Persons engaged in preventive health behaviors, Wallston, Wallston, &amp; DeVellis (1978)</td>
<td>720</td>
<td>27.38</td>
<td>18.44</td>
<td>15.52</td>
</tr>
</tbody>
</table>
APPENDIX Q

A Comparison of the Compliance Ratings of the Patients
and Nurses in the Present Investigation
and Previous Research
Table 19

A Comparison of the Compliance Ratings of the Patients and Nurses in the Present Investigation and Previous Research

| Area of Compliance | Medication | | Diet | | Fluid | |
|-------------------|------------|----------------|------|----------------|------|
|                    | M         | SD            | M    | SD            | M    | SD            |
| Patients' ratings | Present investigation | 5.89 | 1.61 | 4.84 | 1.71 | 5.03 | 1.80 |
| Cummings, Kirscht, Becker, & Levin (in press) | 6.02 | 1.21 | 4.88 | 1.47 | 5.00 | 1.41 |
| Nurses' ratings   | Present investigation | 4.81 | 1.69 | 4.28 | 1.62 | 4.40 | 1.89 |
| Cummings, Kirscht, Becker, & Levin (in press) | 4.18 | 1.55 | 4.07 | 1.24 | 3.87 | 1.45 |

aN = 100.
bN = 116.
APPENDIX R

The Correlation of Patients' and Nurses' Ratings of Compliance for the Present Investigation and Previous Research
Table 20

The Correlation of Patients' and Nurses' Ratings of Compliance for the Present Investigation and Previous Research

<table>
<thead>
<tr>
<th>Area of Compliance</th>
<th>Medication</th>
<th>Diet</th>
<th>Fluid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present investigation</td>
<td>0.42****</td>
<td>0.32***</td>
<td>0.45***</td>
</tr>
<tr>
<td>Cummings, Kirscht, Becker, &amp; Levin (in press)</td>
<td>0.28**</td>
<td>0.36****</td>
<td>0.21*</td>
</tr>
</tbody>
</table>

* p < .05  
** p < .01  
*** p < .001  
**** p < .0001