The Effects of Self-Management Training on Fluid Compliance in Hemodialysis Patients

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THE EFFECTS OF SELF-MANAGEMENT TRAINING ON
FLUID COMPLIANCE IN HEMODIALYSIS PATIENTS

by

Glen Roland Peterson

A Dissertation
Submitted to the
Faculty of The Graduate College
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THE EFFECTS OF SELF-MANAGEMENT TRAINING ON FLUID COMPLIANCE IN HEMODIALYSIS PATIENTS

Glen Roland Peterson, Ph.D.
Western Michigan University, 1981

Seventeen adult, chronic hemodialysis out-patients were assessed on measures of: Compliance, beliefs about their health, and depression. The Multidimensional Health Locus of Control Scale was used to assess Internal Locus of Control (LOC), Chance LOC, or Powerful Other LOC. An assessment instrument was developed by the author using the Health Belief Model, and was administered to all subjects. This was designed to give a numerical value to patients' beliefs about the severity of their illness, beliefs about their susceptibility to the consequences of noncompliance, beliefs about the benefits of compliance, beliefs about the barriers that might stand in the way of compliance, and a measure of general health-related motivation. The Beck Depression Inventory was used to measure depression. Fluid compliance was measured by comparing performance over several months with criteria established specifically for each subject. Nine subjects fit the operational definition of noncompliance and were given self-management training that consisted of self-monitoring and cognitive restructuring. A single subject design was used, comparing each person's performance after the intervention with his or her performance before the intervention. Significant results were obtained with four subjects. However, uncontrolled sources of variability may have accounted for some of the apparent effects.
of the independent variable. Several other clinically significant results were of interest. Noncompliant patients were found to be significantly more depressed than compliant patients. The technique of operationally defining the population at risk was useful and was recommended as a standard procedure to give the staff a more accurate assessment of patient performance. The use of the Health Belief Model appears to have some consistency and may have predictive value. However, the sample was too small for claims of significance. The model proved to be clinically useful. Some patients took interest in the training in self-monitoring, and for some persons this appears to be an effective strategy to improve compliance. Also, the technique was successful in discriminating those who were accurate estimators of their fluid intake from those who were not accurate estimators. Finally, a clinically significant finding was that several noncompliant subjects were fully aware of the consequences of fluid overloading, the severity of their illness, and the benefits of compliance, and still chose to overload on fluids. They were articulate in their awareness of the fact that, for them, the value of the short-term reinforcer outweighed the ultimate punisher.
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Glen Roland Peterson
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CHAPTER I

INTRODUCTION

Review of the Literature

The role of psychological factors in health care is a fact that has been accepted for years. However, just within the past few years an explosion of interest has resulted in the publication of scores of books, hundreds of journal articles, the appearance of the Journal of Behavioral Medicine, and the emergence of a new profession— the psychologist employed in a health care setting.

Perhaps because of increasing concern over health cost containment, one of the areas of special interest has been the subject of compliance in health care. Prior to 1974, only 245 scientific articles had been written on the subject of compliance (Haynes, Taylor & Sackett, 1979). "Compliance" now has its own subject heading in Index Medicus. Several excellent books on compliance have been published recently (Barofsky, 1977; Cohen, 1979; Haynes et al., 1979; Sackett & Haynes, 1976). The most thorough of these books went to press in 1978 (Haynes et al., 1979), and it contains 1,422 references, 853 of which are annotated references to original studies of compliance. However, compliance studies with hemodialysis patients are relatively rare.

Within the medical population, hemodialysis patients are a very special group of persons. In 1978, approximately 30,000 Americans were

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undergoing maintenance hemodialysis (Friedman, 1978). Their lives are sustained only by obedience to a demanding machine, and by adherence to a difficult regimen of diet and medication.

Compliance in renal patients is generally assessed by one or more critical physiological measures.

Weight gains between dialysis sessions are a measure of fluid intake. Without kidney function, fluid intake must be limited, because most fluid can be removed from the body only by dialysis.

Potassium is a critical measure because the kidney is no longer able to filter it out of the system. High Potassium levels may result from eating citrus fruit or green vegetables, and the patient may go into cardiac arrest.

Phosphorus is an important measure because of its interaction with Calcium, and the potential decalcification of bones that may be one result of high serum Phosphorus.

Blood Urea Nitrogen (BUN) is a measure of protein catabolism and is an indicator of the patient's total nutritional status.

The complexity of renal disease and dialysis is discussed in Appendix A, where these measures are explained in greater detail. At this point, however, it is sufficient to say that hemodialysis patients are very restricted to a low salt, low fluid, low Potassium, low Phosphorus, low protein, and high calorie diet. Compliance is difficult. Noncompliance is common. Cohen (1979) estimates 50 percent to 60 percent noncompliance for chronic patients where treatment is preventive in nature. Following are some studies that examine the problem of compliance with hemodialysis patients.
Blackburn (1977) studied 53 hemodialysis patients over a period of three to fourteen months. The measures of compliance studied were Potassium levels, Phosphorus levels, and weight gains between sessions. Data were tabulated, and if a patient were outside the acceptable range over 50 percent of the time, he or she was labelled noncompliant. The acceptable ranges were: Potassium, 3.5 to 5.0 mEq/L; Phosphorus, 3.5 to 5.0 mg per 100 ml; Weight gains, up to 4 lbs. per interval between sessions.

She found 79 percent of the sample were Potassium compliant, 62 percent Phosphorus compliant, and 49 percent weight compliant. She found a significant inverse relationship between years of education and compliance with weight gains. She also found that staff perceptions of compliance agreed with the actual data. She administered the Rotter Locus of Control Scale but found no significant correlations with any measure of compliance.

Borkman (1976) did a compliance study with hemodialysis patients. However, the study used no objective measures. It was not designed to answer the question, "Do more intelligent patients comply?" Rather, it was designed to determine if staff estimates of intelligence and understanding were correlated with staff estimates of compliance, and she found this to be true. In her questionnaire, the four measures of compliance were fluid intake, salt and protein restrictions, and shunt care.

Barnes (1976) did a compliance study with a single subject. The target behavior was fluid intake, and the criterion was set at 2 lbs/day. The fact that he used only one subject, and the conditions under which
that subject volunteered, are methodological problems that make generalization difficult, but the study is a good illustration of the problems inherent in working with hemodialysis patients as research subjects.

The researcher used a token economy to reward the patient with points when he gained less than 2 lbs/day. Verbal praise was also used as a reinforcer.

The subject had come into the unit in a crisis situation. He was required to travel 260 miles for dialysis and was inclined to skip some sessions. The patient had been off dialysis for only three days but had gained 18 lbs, and his blood pressure was up to 250/160. His lungs were filling up with fluid. Under those conditions, he agreed to go on a token economy. Barnes found that self-monitoring and verbal praise were effective interventions to improve compliance, even after six months follow-up.

Magrab and Papadopoulou (1977) also used a token economy with four adolescent hemodialysis patients. Their main goal was to teach dietary compliance. The subjects could choose such rewards as toys and crochet yarn to cash in their tokens. After 18 sessions, they reported significant results on several dependent measures, including BUN, Potassium, and weight gains.

Hart (1979) used a within-group design to implement a token economy in a chronic dialysis unit. He defined noncompliance as a Potassium level reading of over 5 mEq/L, or weight gains over 5 percent of dry weight for each patient. He reported statistically significant results for the first session after the intervention. As incentives, he used
tokens that could be exchanged for shorter dialysis periods, hot hospital meals, the privilege of skipping a dialysis session, and snacks at the hospital canteen.

De-Nour and Czaczkes (1976) did an extensive study of hemodialysis patients, part of which was a compliance study. Their experimental question was whether they could predict who would be compliant. The evaluations were all subjective. For example, in assessing compliance, the researcher placed patients in one of three categories: Good, fair, or bad. Good was defined as weight gains up to 1 kg between sessions, Potassium levels of 6.0 mEq/L or less, but occasionally up to 6.5 mEq/L, and BUN below 70 mg%. Fair was defined as weight gains up to 1.5 kg between sessions and rarely up to 2.0 kg, Potassium levels from 6.0 mEq/L to 6.8 mEq/L, and BUN from 70 mg% to 90 mg%. Bad was defined as weight gains rarely under 2 kg between sessions, Potassium levels near 7.0 mEq/L and frequently over, and BUN usually above 90 mg%.

The aim of their study was to gather data on the influence of certain personality factors on adjustment to chronic hemodialysis, and compliance was one of the measures of adjustment. Personality factors were assessed in a one-hour interview, and their predictions were based on that information. Their results were significant. They demonstrated their ability to accurately predict if a person would be good, fair, or bad on measures of compliance. The statistical analysis was done with chi-square tests, with $p \geq .001$. Based on those data, they claimed to have demonstrated a cause-and-effect relationship between noncompliance and depression, suicidal tendencies, anxiety, and psychotic complications.
In an earlier study, the same researchers (De-Nour & Czaczkes, 1972) also claimed to establish causal relationships between personality factors and compliance. They assessed compliance with diet according to the following definitions:

1. **Excellent** -- Weight gains between dialyses never above .5 kg. Pre-dialysis Potassium levels never above 6.0 mEq/L, and BUN levels steady.

2. **Good** -- Weight gains between dialyses from .5 kg to 1.0 kg. Pre-dialysis Potassium levels usually 6.0 mEq/L or less, occasionally going up to 6.5 mEq/L. Pre-dialysis BUN usually steady, but may show occasional jumps.

3. **Fair** -- Weight gains between dialyses mostly 1.0 kg to 1.5 kg, rarely going up to 2.0 kg. Pre-dialysis Potassium from 6.0 to 6.8 mEq/L.

4. **Some Abuse** -- Weight gains between dialyses from 1.5 kg to 2.0 kg, occasionally going up to 2.5 kg or even 3.0 kg. Potassium most of the time near 7.0 mEq/L.

5. **Great Abuse** -- Weight gains always above 2.0 kg or most of the time above 2.5 kg. Potassium frequently above 7.0 mEq/L.

Of the 43 patients studied, 5 were Excellent, 10 were Good, 8 were Fair, 13 showed Some Abuse, and 7 Great Abuse. These definitions were then combined, and all persons in the categories of Excellent, Good and Fair were referred to as Good (n = 23). The others (n = 20) were referred to as Abusers. Ten of their patients died, 8 of which were Abusers.

Again, the authors correlated personality factors with abuse, and found significant relationships (p > .01), which enabled them to make their predictions accurately.
MacElveen, Hoover, and Alexander (1975) studied patient/staff dynamics in terms of cooperation and compliance. They randomly selected 74 patients from 163 who were in a home dialysis training program. To establish a measure of cooperation, they assessed patients and staff for common goals and means, mutuality of perception, and trust. They compared those measures with various other measures and found that cooperation was an important variable in improved physical status, compliance, greater total activity, and morale (as measured by the Behavior Morale Scale).

A review article by Brown (1979) notes many factors leading to non-compliance, including biological factors, psychological factors, sociological factors, ethnic and cultural factors, and economic factors, and asserts that assessment must attend to all of these. He does not mention patient/staff interaction as a factor.

In a correlational study, Hartman & Becker (1978) compared compliance behavior with various cognitive variables. Her purpose was to evaluate the Health Belief Model as a predictor of compliance. According to the Health Belief Model (Becker, Maiman & Kirscht, 1977), compliance is a function of patients' beliefs along several subjective dimensions:
1) Their motivation in respect to health matters; 2) their belief about susceptibility to a condition or consequence; 3) their belief about the severity of their condition; 4) their belief about the benefits that might accrue as a result of healthy behaviors, and 5) their beliefs about the presence of financial, psychological, or other barriers to improved health.

In the Hartman study, 50 patients were assessed and given a compliance rating of high, medium or low. Her results showed several
cognitive dimensions correlated with compliance. She found:

1. Patients' general health concerns are poor predictors of compliance with Potassium and Phosphorus regimens.

2. Patients compliant with fluid intake believe they are less vulnerable to other serious illnesses.

3. Persons who perceive their condition as more serious are more compliant.

4. Compliers believe they have greater control over life's events.

5. Noncompliers are less worried about their health in general, and their kidney disease in particular.

6. Noncompliers believe it would not be very serious if they were to experience the consequences of noncompliance within the next year.

7. Noncompliers have less faith in every aspect of their therapy.

8. Noncompliers believe they can still do "OK" even though they do not follow the prescribed regimen closely.

9. Noncompliers see a wide range of barriers to their progress.

10. Noncompliers are relatively less satisfied with the staff's instructions.

Discussion

Studies of compliance with hemodialysis patients have mixed results. The major problem with these studies is a pervasive lack of operational definitions. For example, the study by De-Nour and Czaczkes (1976) contains some of the more complete operational definitions; yet they are not replicable, and the definitions are inadequate for several
reasons. Words such as "occasionally," "rarely," "frequently," and "usually," are vague. Further, days of the readings are not specified. If a person has been off dialysis for three days, BUN and Potassium readings will be overestimated compared to a person who has dialyzed the previous day. Patients rarely dialyze at identical intervals. It is reasonable to assume that a patient coming off dialysis at noon on Friday and then not returning until Monday morning will put on more than 1 kg of fluid. The same patient, however, if dialyzing the very next day, probably should not put on that much fluid. Also, a 100 kg healthy young man can tolerate much more fluid than a frail, older, 47 kg patient with a weak heart. Some of the patients in their study were dialyzing only twice per week. Those persons could be gaining only 4 kg over the seven-day period -- a very reasonable amount -- and still be classified as noncompliant.

Most of the studies of compliance are observational or correlational studies (Blackburn, 1977; Borkman, 1976; De-Nour & Czaczkes, 1972, 1976; Hartman & Becker, 1978; MacElveen et al., 1975). Their purpose was to find correlations that might serve as predictors of compliance or that might provide other clues for the causes of noncompliance.

However, three of the studies are controlled studies, designed to change compliance behavior by intervening with an experimental group of patients (Barnes, 1976; Hart, 1979; Magrab & Papadopoulou, 1977).

The study by Barnes has limited value because of the considerable methodological flaws. Whether the change observed was due to the token economy or his single subject's brush with death is really not known.
An interesting theoretical and ethical issue is found in the Barnes study. The patient was rewarded with 240 cc of water in exchange for a certain number of tokens. Establishing water as a reinforcer where fluid intake may lead to the ultimate punishment is questionable. One might protest that water is reinforcing, and that the researcher is putting the patient on a schedule of reinforcement that is life-giving. Nevertheless, fluid is also punishing in a very meaningful physiological sense because the body is no longer able to process it. Perhaps it would be better to emphasize the punishing dimension of fluid rather than the reinforcing dimension.

A similar theoretical issue is raised by the Hart (1979) study. Shorter dialysis periods and the privilege of skipping a dialysis session are established as reinforcers. The rationale behind that is questionable. Dialysis is an inevitable and inescapable contingency of life for renal patients. To emphasize the punishing characteristics of dialysis may not be in the best interest of the patient. Further, to tell the patient he or she may be rewarded with shorter dialysis times may have exactly the opposite effect. The patient may decide to overload even more on fluids, if the only punishing consequence is longer dialysis times (Note 1).

The study by Hart (1979) also has other problems. His data were combined so that the mean group weight (10 subjects) prior to the experimental condition was compared to the mean group weight after the intervention. Mean group weights are not physiologically significant for any given one of his 10 subjects. His baseline data contained only three data points, and there were only four data points recorded after the intervention. The effects of his token economy are questionable.
The study by Magrab and Papadopoulou (1977) is a well-controlled study with four adolescents. Their criteria for weight gains — 2 lbs between sessions — was very restrictive. Some of their subjects were dialyzing only twice per week. That means that in a period of four days, they could gain only 1 lb per day. Nevertheless, they had excellent results, reducing weight gains by 45 percent during the experimental period. Unfortunately, the study was brief, and there is no evidence that the increased compliance would be maintained if the token economy were withdrawn. During the reversal stage, in fact, weight gains returned to pre-experimental levels.

This study is the only well-controlled and replicable experimental study of compliance with hemodialysis patients reported in the literature. Whether the token economy would work with adults is a further experimental question.

The assessment of personality factors does not appear to be a promising approach to hemodialysis patients. The results of such a study may provide some correlational evidence for hypothesizing that certain personalities may be more noncompliant. However, that still does not provide information on the causes of noncompliance or how to change the noncompliant behavior. There is very little evidence to suggest that personality characteristics cause noncompliance, any more than there is evidence that the noncompliance causes the personality characteristics.

A behavioral approach to noncompliance may be promising, but at this point there is evidence only for its success with children, and there is no evidence that the compliant behavior might be maintained. Furthermore, hemodialysis patients already lead a very regimented and
systemitized life. Any additional system of rewards or punishers may simply be too much additional systemitizing for already regimented lives. Also, the behavior of interest is very complex. Drinking is not a behavior that can just be reinforced or punished. A certain amount of drinking is essential for survival, but excessive drinking may be fatal. Finally, the potential for coercion with hemodialysis patients must give the researcher pause. Hemodialysis patients are a captive population for 10 or 15 hours per week. The patients are not asking for help to be more compliant. In most cases it is the health professional who is taking the initiative to improve compliance. It is not the patients who see noncompliance as a problem. There are no journal articles about noncompliance that have been written by patients. The "voluntariness" of a patient participating in a program to increase compliance is questionable just by virtue of the fact that the patients are in a coercive setting.

The Health Belief Model is promising because of its clinical utility. This approach has been used increasingly over the past few years (Becker et al., 1977), but only recently has this model been applied to hemodialysis patients (Hartman & Becker, 1978). Maladaptive cognitions can be identified and quantified and used as the basis of counseling with the non-compliant patient. If, for example, the patient has unrealistic beliefs about his or her susceptibility to the consequences of non-compliant behavior, the counselor or staff could work with that patient to help adjust his or her expectations accordingly.

The article by Hartman & Becker (1978) is one of the better articles in the recent literature on hemodialysis patients. Her approach warrants further investigation.
Conclusion

The problem of noncompliance with hemodialysis patients is extensive. The few studies that exist are marked by methodological problems and the lack of operational definitions.

Noncompliance must be formulated as a problem for the patient and not as a problem only of the health profession. That means that the role of the health professional is not to impose a system of beliefs or behaviors on the patients, but to help the patient understand all the consequences of his or her behavior, and to help the patient change any behavior he or she wants to change.

The approach to the problem of noncompliance must be very comprehensive. First of all, accurate assessment of the patient's behavior is essential. Reliable measures of compliance must be established, and the patient's performance must then be compared to realistic criteria for that patient.

Cognitions must also be assessed. The trauma of end-stage renal disease often results in significant negative self-talk which may mediate self-destructive behavior.

This study proceeded in two phases. First of all, a sample of hemodialysis patients was assessed, and the population at risk was operationally defined. Then, those who were interested in participating in the second phase received self-management training, which consisted of self-monitoring and cognitive restructuring. The hypothesis was that patients operationally defined as noncompliant could improve on some measure of compliance if they became better managers of their behavior.
Haynes et al., (1979) report successful results on measures of compliance with a wide range of medical outpatient populations with self-management training. Most self-management training programs consist of self-monitoring training and some type of counseling.

The self-management training would result in short-term improvements. However, long-term improvements must be considered. It was hypothesized that improved physical well-being and shorter dialysis times would maintain the behavior over a longer period of time.
CHAPTER II

METHOD

Subjects

All subjects were out-patients receiving regular maintenance hemodialysis at the Bronson Methodist Hospital Kidney Center in Kalamazoo, Michigan. Ten men and eight women agreed to participate in the study. The average age was 50, with a range from 21 to 78. Twelve of the subjects had no kidney function, and the other six varied in urine output from very little to 1,500 cc/24 hours. Three were employed full-time, two part-time, and the others were unemployed. All had been on dialysis at least three months, and one had been on dialysis for 16 years, excepting a few years of successful transplant. Only three were living independently. All others had family support.

At the beginning of the study, all subjects except one were being dialyzed three times per week, on one of various schedules: M-W-F, T-Th-S, M-T-Th, or M-W-Th. One subject was dialyzing only Mondays and Thursdays. All but three subjects had been surgically prepared with fistulae in their forearms for vascular access. Two had cannulae, and one had a femoral shunt.

Procedure

Patients were asked by the social worker, dietician, or head nurse if they would be willing to talk to a psychology student who was
interested in asking questions about their thoughts and feelings about
the disease and what they were doing to try to comply with their diets
and medications. Those staff members compiled a master list of persons
who agreed.

The author then spoke to each of the potential subjects individ­
ually, asking if he or she would be willing to participate in a study.
All were told that they would be required to answer some personal questions
about their feelings and beliefs, that the author would have access to
their medical records, and that perhaps they would be asked later to try
to make some changes in their regimen of diet and medication. The entire
research project was explained verbally, and then each potential subject
was given a written description that had been approved by the hospital's
Human Use Committee (Appendix B). The patients were encouraged to think
about it, read the description at home, and then ask any questions they
might have about the study. Eighteen persons then signed an informed
consent form (Appendix C).

Before starting the intervention, the author made rounds with the
medical staff for two weeks. This was done to increase exposure, to
be introduced to the patients, and to control for the probability of
an effect due to the presence of the experimenter.

In the assessment phase, all subjects were asked to fill out the
Multidimensional Health Locus of Control (MHLOC) Scale–Form A, the Beck
Depression Inventory, and an Assessment Questionnaire (Appendix D)
composed by the author and based on the Health Belief Model.

The author then examined the records of all subjects, and compared
weight gains between sessions with the criteria established for each
subject.

Following the assessment phase, nine persons who were assessed as noncompliant on fluid gains participated in the intervention phase of the experiment -- self-management training. That phase consisted of cognitive restructuring and training in self-monitoring.

The author was solely responsible for gathering and tabulating the data, and for implementation of the intervention.

At the conclusion of the study, all subjects were given a printed summary of the results (Appendix F).

Measures

MHLOC

Locus of Control (LOC) is a cognitive concept initially developed by Rotter (1966). He designed a scale to assess whether persons were Internally (I) or Externally (E) controlled. The assumption was that a person's generalized expectancies for reinforcement were important mediators of behavior. He inferred that Internally controlled persons had higher expectancies for reinforcement. Initially, research seemed to support the notion that high I's took more interest in health-related matters than high E's. However, in an excellent and comprehensive review of Locus of Control and health-related behaviors, Strickland (1978) noted that Internal beliefs may not always be facilitative when health is increasingly uncontrollable.

The continued alertness of internals and their attempts at mastery behavior is most appropriate when events are actually controllable. When individuals persist in efforts that bring no relief, then they may find themselves...
to be actually exacerbating the undesirable characteristics of the situation in which they find themselves. (p. 1205)

Other researchers have been working for several years on variations of the LOC scale that might be validated for chronically ill populations (Kirscht, 1972; Wallston, Wallston, Kaplan & Maides, 1976).

Kirscht (1972) used a 6-item scale and received rather weak support for his hypothesis that activities and intentions were correlated with expectancy for control. Wallston et al. (1976) developed the first Health Locus of Control (HLOC) Scale based on the earlier work of Levenson, who had argued that LOC was not a unidimensional construct. Levenson suggested that internal and external beliefs are orthogonal. Externality may embrace two concepts: Belief that Powerful Others (P) are in control, or that nothing is in control because we live in a Chance (C) universe (Wallston & Wallston, 1981, p. 8). The Wallstons applied these principles to further research on LOC and developed the Multidimensional Health Locus of Control Scale (Wallston, Wallston & DeVellis, 1978), which is now available in two forms, A and B. The alpha reliabilities for the MHLOC scales range from .67 to .86. Concurrent and discriminant validity were established by correlating the scales with Levenson's original scales for I, P and C. The three scales of the MHLOC were said to have discriminant validity because they each correlated positively with the theoretical counterparts of Levenson's scales, and each correlated negatively or weakly with the other two scales.

Current research is mixed on the MHLOC. The most recent data is in a chapter of a new book awaiting publication (Wallston & Wallston, 1981). In that chapter, the authors cite all known research on the scales, all

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of which averages out to some support for the construct validity of MHLOC. They conclude that the MHLOC scale is best used along with some other measure of the value of health-related behavior. They specifically mention the Health Belief Model as one such measure of health-related values (p. 17).

The present study was not an attempt to validate the MHLOC scale; rather, it was used in combination with the Health Belief Model as a useful kind of clinical assessment.

Assessment Questionnaire

This questionnaire was developed by the author and was based on the Health Belief Model (Hartman & Becker, 1978). The hypothesis was that beliefs on several cognitive dimensions, combined with expectancies for reinforcement as measured by the MHLOC scale, would provide a complete cognitive assessment of the subjects.

The Health Belief Model was first formulated by a group of social scientists working at the U. S. Public Health Service in the early 1950's (Haynes et al., 1979). The model was first applied in a systematic way to hemodialysis patients by Hartman & Becker (1978), who found several statistically significant correlations between certain maladaptive health beliefs and noncompliance. Her protocol was very extensive, including over 100 items and several different scales of responding. Those scales were not equivalent. For example, the answer to one group of statements might range from "Not worried at all" to "Extremely worried," over a 7-point scale. Another group of statements might require responses ranging from "Nothing" to "A great deal" or "Not at all" to "Very
successful." Her purpose was to provide a scale of responses that would best fit the group of statements for the cognitive dimension of interest. However, the protocol appears quite cumbersome and some of the items appeared to lack content validity.

Therefore, this author decided to prepare an original list of items (Appendix D) and write them so that all responses would be on the same scale -- from "Strongly Agree" to "Strongly Disagree." This was a 6-point scale, identical to that of the MHLOC scale, and it eliminated ambivalent responses.

One group of statements was prepared to represent each construct of the Health Belief Model: Belief about the severity of the disease, belief about susceptibility to the consequences of noncompliance, belief about the benefits of compliance, beliefs about barriers to compliance, and general health-related motivation.

For the sake of consistency, six items were selected from each group to score. That number was somewhat arbitrary but was chosen because there are six items on each scale of the MHLOC scale. Each of the six items was scored on a scale from 1 to 6. The six items were selected by the author as the six that best represented the inference for that group of items. A higher score always represented a stronger inference. Therefore, the 6 was always the critical direction. For any given item, strong agreement or strong disagreement may have been the critical direction, depending on how the item was worded. Items were worded positive or negative and were mixed to avoid a positive or negative bias in responding. Where necessary, the scale was inverted so that the 6 always represented the critical direction and the stronger
inference.

The highest score, therefore, would be equal to the following inferences:

<table>
<thead>
<tr>
<th>Scale</th>
<th>Items</th>
<th>Inference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susceptibility (SUSC)</td>
<td>6</td>
<td>&quot;I am not susceptible to the consequences of noncompliance.&quot;</td>
</tr>
<tr>
<td>Severity (SEVR)</td>
<td>6</td>
<td>&quot;My disease is not very severe.&quot;</td>
</tr>
<tr>
<td>Barriers (BARR)</td>
<td>6</td>
<td>&quot;Too many things stand in the way of my complying.&quot;</td>
</tr>
<tr>
<td>Motivation (MOTV)</td>
<td>6</td>
<td>&quot;I am not very interested in the course of this disease.&quot;</td>
</tr>
<tr>
<td>Benefits (BENE)</td>
<td>6</td>
<td>&quot;There are no benefits to compliant behavior.&quot;</td>
</tr>
</tbody>
</table>

The utility of this scale rests on the legitimacy of the inferences resulting from the responses. No item analyses were attempted, and this part of the assessment was seen as exploratory.

**Depression**

As a measure of affect, the Beck Depression Inventory (BDI) was administered to all subjects. Depression is ubiquitously reported with hemodialysis patients. The purpose of administering the scale here was to determine the extent of depression for the patients in this unit and to compare the responses of compliant patients to the responses of non-compliant patients.

The BDI has been used extensively with a wide range of clinical populations. It has content, concurrent, and construct validity (Beck, 1967). A number of studies have reported split-half reliabilities in
the 90's, and high correlations with clinical observations (Beck, 1972).

**Physiological Measures**

The necessity of a replicable, consistent operational definition of noncompliance was evident from the examination of earlier studies. Therefore, this was accomplished in the assessment phase of this study by using the following measures:

**Potassium.** Potassium levels were taken weekly in the hemodialysis unit and always on Mondays or Tuesdays after the patient had been off dialysis since the previous Friday or Saturday. Because the readings were taken immediately after the long weekend, criteria levels were established for everyone at 5.5 mEq/L. The assumption was that a mid-week Potassium reading would be closer to 5.0 mEq/L, which is quite acceptable.

**Phosphorus.** Phosphorus levels are a measure of two behaviors: The amount of Phosphorus ingested, and the degree of compliance with a Phosphate-binding medication regimen. Phosphorus levels were taken at the same time as Potassium levels, and criteria were established, for the same reasons, at 5.5 mg/100 ml for all subjects. For both Potassium and Phosphorus, noncompliance was defined as readings above the criteria levels more than 50 percent of the time.

**Weight gains.** The criteria for weight gains between sessions were established for each subject using five considerations (Note 2):

1. Total body weight and muscle mass
2. Cardiovascular reserve
3. Dialysis schedule
4. Hypertension with fluid gain
5. Other complications, such as a weak heart.

There were actually two criteria established for each patient:
A maximum allowable daily amount, and a maximum allowable amount regardless of how many days a patient was off dialysis. These criteria were established by the medical staff and varied widely from subject to subject. Allowable weight gains ranged from .7 kg per day to 1.25 kg per day. Maximum allowable gains between sessions ranged from 2.0 kg to 3.5 kg. The latter figure was for a 6' 4" man whose dry weight was around 120 kg. He was allowed 3.5 kg when he was off dialysis for three days.

Extended baselines were recorded for all subjects, to account for variations due to uncontrollable sources such as sickness. A patient who has diarrhea for three days will lose a significant amount of fluid, and, if fluid gains between sessions is the measure of compliance, that would show up on the chart as very compliant behavior. This is an unavoidable weakness in the dependent measure that can be accommodated only by long baselines.

For each patient, weight gains were recorded, by date, over a period of several months. For an example, see Table 1. In a second column, the criteria were recorded for that patient for that day. The third column was the amount over or under criteria. Using this method of tabulation, the patient and the staff had a running account of patient behavior in relationship to specific criteria.
### TABLE 1

EXAMPLE OF RECORD OF WEIGHT GAINS COMPARED TO CRITERIA

<table>
<thead>
<tr>
<th>Subject</th>
<th>Date</th>
<th>Gain</th>
<th>Criteria</th>
<th>Over Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1980</td>
<td>December</td>
<td>2.4</td>
<td>1.6</td>
<td>.8</td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>3.9</td>
<td>2.5</td>
<td>1.4</td>
</tr>
<tr>
<td></td>
<td>27</td>
<td>3.5</td>
<td>1.6</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>29</td>
<td>2.9</td>
<td>1.6</td>
<td>1.3</td>
</tr>
<tr>
<td>1981</td>
<td>January</td>
<td>3.9</td>
<td>2.5</td>
<td>1.4</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>4.8</td>
<td>2.5</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>3.3</td>
<td>1.6</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>8</td>
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<td>1.2</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>4.8</td>
<td>2.5</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>3.4</td>
<td>1.6</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>3.1</td>
<td>1.6</td>
<td>1.5</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>2.8</td>
<td>2.5</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>4.1</td>
<td>2.5</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>22</td>
<td>2.6</td>
<td>1.6</td>
<td>1.0</td>
</tr>
<tr>
<td></td>
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<td>.9</td>
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<tr>
<td></td>
<td>27</td>
<td>4.5</td>
<td>2.5</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
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<td>2.5</td>
<td>2.5</td>
<td>0.0</td>
</tr>
<tr>
<td>February</td>
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<td>4.4</td>
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<tr>
<td></td>
<td>5</td>
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<td>2.5</td>
<td>-.9</td>
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<td></td>
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<td>4.3</td>
<td>2.5</td>
<td>1.8</td>
</tr>
<tr>
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<td>1.6</td>
<td>2.0</td>
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<tr>
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<td>19</td>
<td>3.5</td>
<td>1.6</td>
<td>1.9</td>
</tr>
<tr>
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<td>21</td>
<td>3.3</td>
<td>1.6</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
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<td>1.4</td>
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<td>.9</td>
</tr>
<tr>
<td></td>
<td>28</td>
<td>2.1</td>
<td>1.6</td>
<td>.5</td>
</tr>
<tr>
<td>March</td>
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<td>4.2</td>
<td>2.5</td>
<td>1.7</td>
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<tr>
<td></td>
<td>5</td>
<td>2.9</td>
<td>1.6</td>
<td>1.3</td>
</tr>
<tr>
<td></td>
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<td>2.9</td>
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<td>1.3</td>
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<td>1.7</td>
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<td>-.8</td>
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<tr>
<td></td>
<td>12</td>
<td>2.5</td>
<td>1.6</td>
<td>.9</td>
</tr>
</tbody>
</table>

Criteria level for this subject has been established at .8 kg/day, but never more than 2.5 kg between sessions.
Reliability of the data on the physiological measures was assured by the following techniques:

1. All recording of baseline data was done by the author, directly from the dialysis unit flow sheets. Random reliability checks of the accuracy of the flow sheets were accomplished by comparing the data on the flow sheets, which are cumulative, with the run sheets for a given day. A student reliability checker looked randomly for errors in recording.

2. The author and the student reliability checker did all mathematical computations independently and compared answers. Accuracy of the graphs was checked in the same way.

3. Reliability of the blood level readings is controlled by rigorous hospital lab procedures which compare all readings with standard parameters. Occasional split-samples are processed as a double check.

4. Reliability of the weight gain data was also assured. Most patients weighed themselves when they came in. The scale used was a Scale-Tronix Model 5005 Digital Read-Out with self-zeroing. Any unusual or unexpected entries in the record were checked by the nursing staff. Some patients were more reliable than others, and the unreliable patients were frequently double checked.

**Self-management Training**

Self-management training was implemented with all subjects who met the operational definition of noncompliance on any one of the three physiological measures.
Cognitive Restructuring

This was a rather loosely defined intervention, occasionally called Rational Emotive Therapy (RET). The term "cognitive restructuring" is used here in a broad sense. Several researchers have systematized a cognitive-behavioral approach to therapy. RET (Ellis, 1962) emphasizes the importance of "irrational beliefs" that may lead to maladaptive behavior. Goldfried, Linehan and Smith (1978) refer to their therapy as rational restructuring or cognitive restructuring, and it is basically a technique of self-talk to improve self-control. Meichenbaum (1977) labelled one technique "self-instructional training." This technique is a way of practicing desired behavior while verbalizing it at the same time, with the intention of fading out the self-instruction once the behavior is under control. Beck (1970) saw the human personality in a kind of dualistic structure, consisting of the mature system and the primitive system, and the goal of therapy was to argue with the arbitrary inferences, over-generalizations, and magnifications of the primitive system.

The common denominator of all these therapies is that they are insight-oriented. They are theoretically based in the assumption that humans develop maladaptive behavior through cognitive processes, and that these cognitive processes must change before the behavior will change (Foreyt & Rathjen, 1978, p. 13).

One objective of this research was to assess the subjects on several cognitive dimensions, according to the Health Belief Model. This would provide a broad range of clinically significant comments with
which the subjects had agreed or disagreed. Differences between the response sets of compliant and noncompliant subjects were assessed. In the intervention phase of the study, noncompliant subjects were counseled, using their responses as a point of departure. For example, if a noncompliant subject scored very high on the Susceptibility (SUSC) scale, this was a topic of discussion for the cognitive restructuring phase of the study.

**Self-monitoring**

Self-monitoring has been used primarily as a data-collection device and has been a basic component of most self-control programs (Haynes et al., 1979, p. 184). Recently, however, self-monitoring has been used more as an intervention. Haynes et al. (1979) summarized the research on this technique with medical populations and noted several compliance studies. The sum of his findings was that by itself self-monitoring may not be effective. However, when used with other techniques, it may be effective for both short-term and long-term changes. He cited one study that suggested that the influence of self-monitoring can be strengthened when: 1) The patient is motivated to change; 2) the behavior being observed is easy to discriminate; 3) recording materials are easy to use; 4) the patient is instructed in how to self-monitor; 5) recording occurs in close proximity to the behavior; 6) feedback is provided; and 7) the patient knows the report will be checked for accuracy.

Those seven items are all sound behavioral principles and were the basis of a self-monitoring procedure for the subjects in this study.
In consultation with the hemodialysis unit dietician, a fluid-intake form was developed, keeping in mind those seven principles (Appendix E). The purpose was to help persons noncompliant with fluid intake to become better estimators of what they were drinking. The form was designed to compare three measures: Their goal for a given day, an estimate of their total intake for that day, and actual weight gain between sessions. If they became skilled at estimating their intake, they would be able to estimate their total weight gain between sessions.

Each patient was instructed in the use of the form as part of the self-management training.

**Experimental Design**

The design was quasi-experimental. Random selection and random assignment gave way to the principle of enlisting all willing subjects. Matched groups with this population are virtually impossible. For the assessment phase, the cognitive and affective measures of compliant patients were compared to those measures of the noncompliant patients. For the intervention, a single-subject design was used. Data prior to the intervention were compared to data after the intervention. Finally, all baseline data were compared to all treatment data to determine if the average rate of compliance had improved for the duration of the treatment phase.
CHAPTER III

RESULTS

All data were analyzed with a Statistical Package for the Social Sciences (SPSS).

Multidimensional Health Locus of Control (MHLOC)

The scores of compliant subjects were compared to the scores of noncompliant subjects on the MHLOC (Table 2). High scores on the subscales indicate: Internal Locus of Control (I); Chance Locus of Control (C); or Powerful Other Locus of Control (P). On the average, noncompliant subjects scored higher on the I scale. However, the sample is quite small and the results of an Analysis of Variance (ANOVA) were not statistically significant.

Health Beliefs

The Assessment Questionnaire (Appendix D) based on the Health Belief Model appears to have some consistency. On every scale of maladaptive health beliefs, noncompliant subjects have a higher average score than compliant subjects (Table 3). The results, even though consistent, are not statistically significant when analyzed with ANOVA.

Depression

The Beck Depression Inventory (BDI) was administered to 15 subjects, 9 of whom were assessed as noncompliant. The average scores of the two
TABLE 2

COMPARISON OF PERFORMANCE ON THE MHLOC* SCALE FOR COMPLIANT AND NONCOMPLIANT SUBJECTS

<table>
<thead>
<tr>
<th>Subject</th>
<th>Noncompliant Subjects</th>
<th>Compliant Subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I **</td>
<td>C</td>
</tr>
<tr>
<td>AN</td>
<td>28.5</td>
<td>16</td>
</tr>
<tr>
<td>LB</td>
<td>19</td>
<td>18</td>
</tr>
<tr>
<td>AL</td>
<td>29.5</td>
<td>23.5</td>
</tr>
<tr>
<td>AG</td>
<td>31</td>
<td>10</td>
</tr>
<tr>
<td>EG</td>
<td>25</td>
<td>17</td>
</tr>
<tr>
<td>RM</td>
<td>24</td>
<td>15</td>
</tr>
<tr>
<td>IE</td>
<td>24</td>
<td>13</td>
</tr>
<tr>
<td>OD</td>
<td>24</td>
<td>12.5</td>
</tr>
<tr>
<td>UV</td>
<td>31</td>
<td>31</td>
</tr>
</tbody>
</table>

* Multidimensional Health Locus of Control Scale
** I = Internal Locus of Control
   C = Chance Locus of Control
   P = Powerful Other Locus of Control

ONE-WAY ANOVA: "I" Scale only

<table>
<thead>
<tr>
<th>Source</th>
<th>D.F.</th>
<th>Sum Sq.</th>
<th>Mean Sq.</th>
<th>F-Ratio</th>
<th>F-Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betw Grp.</td>
<td>1</td>
<td>29.182</td>
<td>29.182</td>
<td>1.2345</td>
<td>.2829</td>
</tr>
<tr>
<td>With Grp.</td>
<td>16</td>
<td>378.22</td>
<td>23.64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>17</td>
<td>407.40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subject</td>
<td>Noncompliant Subjects</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-----------------------</td>
<td>-----------------</td>
<td>-----------------</td>
<td>-----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td></td>
<td>SUSC</td>
<td>SEVR</td>
<td>BARR</td>
<td>MOTV</td>
<td>BENE</td>
</tr>
<tr>
<td>AN</td>
<td>6</td>
<td>11</td>
<td>6</td>
<td>14.5</td>
<td>14</td>
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<tr>
<td>AL</td>
<td>6</td>
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<td>6</td>
<td>8</td>
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</tr>
<tr>
<td>AC</td>
<td>15</td>
<td>15</td>
<td>-</td>
<td>12.5</td>
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</tr>
<tr>
<td>EG</td>
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<td>10</td>
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<tr>
<td>OJ</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OP</td>
<td>6</td>
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<td>8</td>
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<td>15</td>
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</tr>
<tr>
<td>MA</td>
<td>12</td>
<td>14</td>
<td>10</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>WM</td>
<td>11.5</td>
<td>22.5</td>
<td>21.5</td>
<td>16</td>
<td>12</td>
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<tr>
<td>AK</td>
<td>11</td>
<td>10</td>
<td>6</td>
<td>10</td>
<td>6</td>
</tr>
</tbody>
</table>

**Average:** 10.4 11.3 11.8 12.9 13.5 9.8 9.6 7.8 10.8 11.6

*SUSC = Susceptibility*
*SEVR = Severity*
*BARR = Barriers*
*MOTV = Motivation*
*BENE = Benefits*

**ONE-WAY ANOVA**

<table>
<thead>
<tr>
<th>Source</th>
<th>D.F.</th>
<th>Sum Sq.</th>
<th>Mean Sq.</th>
<th>F-Ratio</th>
<th>F-Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betw Grp.</td>
<td>1</td>
<td>63.797</td>
<td>63.798</td>
<td>3.314</td>
<td>.0732</td>
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<td>With Grp.</td>
<td>67</td>
<td>1289.81</td>
<td>19.251</td>
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<td></td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>1353.61</td>
<td>19.251</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
groups were compared, and the noncompliant subjects were found to be significantly more depressed than the compliant subjects (Table 4).

**Self-management Training**

Results of the self-management training are presented on graphs in Figures 1-7. Note that the graphs do not present all the data because baselines were very long. All baseline and treatment observations for noncompliant subjects are presented in Appendix G. The data were analyzed with ANOVA, and several statistically significant results were noted.

1. **Differences in the means** — Subjects CE (Figure 1) and WM (Figure 2) made significant improvements in their fluid intake when baseline data were compared to treatment data.

   **ANOVA: SUBJECT CE**

<table>
<thead>
<tr>
<th>Source</th>
<th>D.F.</th>
<th>Sum Sq.</th>
<th>Mean Sq.</th>
<th>F-Ratio</th>
<th>F-Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
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<td>4.62440</td>
<td>4.62440</td>
<td>4.15339</td>
<td>.0461</td>
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<td>Within Groups</td>
<td>58</td>
<td>64.57742</td>
<td>1.11340</td>
<td></td>
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<tr>
<td>Total</td>
<td>59</td>
<td>69.20183</td>
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<td></td>
<td></td>
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</tbody>
</table>

   **ANOVA: SUBJECT WM**

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<thead>
<tr>
<th>Source</th>
<th>D.F.</th>
<th>Sum Sq.</th>
<th>Mean Sq.</th>
<th>F-Ratio</th>
<th>F-Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>1</td>
<td>20.7443</td>
<td>20.7444</td>
<td>35.7084</td>
<td>.0000</td>
</tr>
<tr>
<td>Within Groups</td>
<td>66</td>
<td>38.3419</td>
<td>.5809</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>59.0863</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. **Differences in variability** — The variability in the data has medical significance for this population. Changes in the variability was not a goal of this study and was only noted after the data were analyzed.

A simple F-test was run on several subjects to determine whether the variability of the treatment data was significantly different from
TABLE 4

COMPARISON OF PERFORMANCE ON THE BDI* FOR COMPLIANT AND NONCOMPLIANT SUBJECTS

<table>
<thead>
<tr>
<th>Subject</th>
<th>Noncompliant Subjects</th>
<th>Compliant Subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>AN</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>AL</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>AG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AC</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>EG</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>IE</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>OD</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>UV</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>OJ</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>OP</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>UR</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>CE</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>MA</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>WM</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>AK</td>
<td></td>
<td>2</td>
</tr>
</tbody>
</table>

**Total:** 99 31

**Average:** 11 (n=9) 5.17 (n=6)

---

**ANOVA**

<table>
<thead>
<tr>
<th>Source</th>
<th>D.F.</th>
<th>Sum Sq.</th>
<th>Mean Sq.</th>
<th>F-Ratio</th>
<th>F-Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betw Grp.</td>
<td>1</td>
<td>122.5000</td>
<td>122.500</td>
<td>7.48238</td>
<td>.0170</td>
</tr>
<tr>
<td>With Grp.</td>
<td>13</td>
<td>212.8333</td>
<td>16.3718</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>14</td>
<td>335.3333</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Figure 1. Subject CE -- Weight Gains Compared to Criteria

*Criteria: 1 kg/day, 3 kg maximum gain between sessions.
Figure 2. Subject WM — Weight Gains Compared to Criteria

*Criteria: .7 kg/day, 2 kg maximum gain between sessions.
the variability of the baseline data \( \text{simple } F = \frac{\text{larger } s^2}{\text{smaller } s^2}, \) with d.f. = \( n_1 - 1, n_2 - 1 \).

Subjects IE (Figure 3) and AN (Figure 4) both show significant improvements in the variability of the treatment data.

### Simple F-test

<table>
<thead>
<tr>
<th>Subject</th>
<th>Treatment</th>
<th>Baseline</th>
<th>Treatment</th>
<th>Baseline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations</td>
<td>17</td>
<td>35</td>
<td>20</td>
<td>36</td>
</tr>
<tr>
<td>Mean</td>
<td>1.111</td>
<td>1.399</td>
<td>.335</td>
<td>.667</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>.377</td>
<td>.658</td>
<td>.453</td>
<td>.798</td>
</tr>
<tr>
<td>F-value</td>
<td>3.037</td>
<td>3.097</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-tail prob.</td>
<td>.021</td>
<td>.011</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. **Average improvement** -- Six of the nine subjects participating in the treatment phase made some improvement, even though only four of those were statistically significant. Therefore, all baseline data were compared to all treatment data, and it was found that overall the treatment was highly significant.

### t-test

<table>
<thead>
<tr>
<th></th>
<th>Treatment</th>
<th>Baseline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations</td>
<td>177</td>
<td>361</td>
</tr>
<tr>
<td>Mean</td>
<td>.514</td>
<td>.759</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>1.018</td>
<td>1.008</td>
</tr>
<tr>
<td>t-value</td>
<td>2.637</td>
<td></td>
</tr>
<tr>
<td>2-tail prob.</td>
<td>.009</td>
<td></td>
</tr>
</tbody>
</table>
Figure 3. Subject IE — Weight Gains Compared to Criteria

*Criteria: .7 kg/day, 2 kg maximum gain between sessions.
Figure 4. Subject AN -- Weight Gains Compared to Criteria

*Criteria: 1.3 kg/day, 3.5 kg maximum gain between sessions.
CHAPTER IV

DISCUSSION

Results of the cognitive and behavioral assessments show a relationship between health beliefs and compliance. The results of the assessment of Health Locus of Control (HLOC) do not give support to the hypothesis that Externally controlled persons are more noncompliant than Internally controlled persons. If anything, these results give support to the hypothesis (Strickland, 1978) that Internally controlled persons are more noncompliant, although those findings were not statistically significant with this small sample. Support for this latter hypothesis was also found in the anecdotal data which will be discussed below.

The assessment based on the Health Belief Model (HBM) offers some promise as a clinically useful instrument. Even without doing an item analysis, however, it was apparent that some of the items were not content valid. If the inferences were correct, subjects would score approximately the same on each scale. For example, if a noncompliant person believed there were many barriers standing in the way of compliance, all 6 items scored on that scale would approach the high (6) end of that scale. If barriers were not the problem for that particular noncompliant subject, all 6 items would approach the low (1) end of the scale. However, that was not the case. In several instances, persons scored a "6" for one item on a scale, and a "1" for another item on the same
scale, giving evidence that the item may not be clear or the inference may be incorrect.

The scale obviously has some utility, however. The fact that on every scale the noncompliant subjects scored higher than the compliant subjects suggests some content validity for this approach. Further research on the scale, using a large number of items with a larger population, could result in the development of an instrument with predictive validity.

The results of the Beck Depression Inventory (BDI) are consistent with previous findings that depression among hemodialysis patients is common, and that the rate of depression is higher for noncompliant patients. This suggests some predictive validity in the use of the BDI as an assessment instrument. No causal relationships are suggested here. Other factors may be responsible for the depression and the noncompliance.

Results of the self-management training are mixed. Of the four persons who showed statistically significant positive changes in performance, uncontrolled sources of variability may be partially responsible for spuriously mimicking the value of the independent variable.

Subject CE, for example, shows a significant difference in means before and after the intervention (Figure 1). Statistically, this proved to be a significant difference. However, a closer examination of the data shows significant variance in the performance in the treatment phase. A patient fluctuating from one side of the criteria level to the other is not healthy. The fact that subject CE lowered the average amount of weight gains during the treatment testifies to good progress, but the patient is still almost as ill, and her behavior is still not under control.
The data on subject UV (Figure 5) illustrate a fairly uncommon problem with fluid abusers. It was discovered that most patients are good estimators of their fluid intake, whether they are compliant or noncompliant. However, UV was not a good estimator. This subject simply could not understand where the weight gain was coming from. He consistently underestimated his weight gains. However, the self-monitoring training was effective. Within two weeks, he became an excellent estimator of his fluid gains between sessions. Nevertheless, this did not significantly change his rate of fluid abuse. From baseline to treatment he lowered his fluid intake by an average of only .1 kg, which was not statistically significant.

The case of UV was interesting for other reasons also. This person is a responsible, intelligent and introspective man who was compliant for several years. However, about one year ago (according to staff report), he changed his attitude about fluid compliance and now has no intentions of making any changes. Nevertheless, his data show much greater consistency in the treatment phase, however abusive.

Subject MA (Figure 6) is another example of a person whose weight gains are wildly out of control. MA is a patient who readily verbalizes his need to be in control. Control is a significant issue in every aspect of his life. His score on the MHLOC(I) scale was 34 — about 10 points above the norm — which may be interpreted as strong Internal control beliefs. During the cognitive restructuring he argued,

Drinking just a little bit would be like giving in to the disease -- like letting it be the boss in my life.

Following all that diet stuff is like saying the disease has control.
Figure 5. Subject UV -- Weight Gains Compared to Criteria

**Baseline**

*Criteria: .8 kg/day, 2.5 kg maximum gain between sessions.*
Figure 6. Subject MA — Weight Gains Compared to Criteria

*Criteria: 1 kg/day, 3 kg maximum gain between sessions.*
He confirmed that attitude in subsequent contacts.

That adolescent logic may be interpreted by some as denial, or a need for dominance, even over death. Whatever interpretation is given to the behavior, the behavior itself is dangerous. It is to be noted that on April 21 he came in with 4.8 kg over his already liberal criterion of 3 kg. That adds up to 7.8 kg in less than three days. The heart labors to push all that fluid through the body, and heart failure is a highly probable long-term consequence.

Subject IE (Figure 3) reduced his weight gains over criteria from 1.4 kg between sessions during baseline to 1.11 kg between sessions during treatment. This subject also scored very high (31) on the I scale of the MHLOC.

Subject IE is another very articulate and introspective person, and one of the four subjects that scored high on the BDI, indicating significant depression. This person believes he has less than one year to live, and the doctors confirm that prognosis. He has been on dialysis for 16 years, and rigid compliance is no longer of primary importance to him. In the short time he has to live, he wants to indulge in some good food and drink, although he expressed an interest in reducing his weight gains to a more reasonable level.

This case is an example of a person influenced by uncontrolled variables that may have mimicked the effects of the independent variable. He was trying to reduce his weight gains to a criterion that was acceptable to him. (He believed the criteria established by the medical staff was much too restrictive and therefore had established his own criteria.) He had tried several techniques, like the addicted smoker.
who tries to cut back from three packs a day to two packs a day. One technique for IE was hypnotism. Shortly after the beginning of self-management training he began seeing a hypnotist at a local holistic health center with the hope that the hypnotist would make fluid intake more aversive. He reported lack of success. The results are presented in Figure 3.

Subject AN (Figure 4) is another example of uncontrolled variables. Naturally, throughout the course of the study, the regular hemodialysis unit staff was attempting to do the same thing as the researcher, in their own way. These are all highly qualified, competent and caring staff members, who are very watchful, and who apply their own bag of tricks whenever they are able. Subject AN was on home dialysis training, and this was a highly-valued goal for him. At one point, shortly after the beginning of self-management training, the nurse in charge of his home training threatened to terminate his training if he were not able to reduce his fluid intake between sessions. For the following two weeks he demonstrated excellent control. His own explanation for his dramatic improvement was that the dialysis machine had not been operating properly — that the salt level in the dialysate solution was improperly equilibrating, and was therefore increasing the salt in his system, making him thirsty. There was some evidence to support that interpretation, according to one member of the nursing staff.

For the last two weeks of the experimental period, subject AN's weight gains once again went out of control, but he was allowed to go on home dialysis anyhow. For several months of baseline, his mean value of
fluid overload over criteria was .67 kg. After treatment it dropped to .33 kg.

Subject AL (Figure 7) averaged .25 kg during the baseline period and reduced that to .12 kg average over criteria after treatment. This subject also reported being very pleased with the self-monitoring training. He quickly adapted the form for his own use and found it to be helpful in improving the estimates of his fluid intake. At the termination of the study he was averaging just slightly over the criteria level and no longer needed the fluid intake form to help him estimate fluid gains.

Subject WM (Figure 2) is the one dramatic example of successful treatment. For several months prior to treatment she had averaged .9 kg over the level recommended by the staff. After treatment she was consistently under criteria level (-.27 kg).

Obviously, something about the treatment was successful for at least two-thirds of the patients defined as noncompliant. Just exactly what is the active ingredient is still debatable.

The cognitive restructuring component of the treatment was loosely defined, deliberately, to allow for variations in style with different subjects. With some subjects, that part of the intervention was very argumentative and confrontive. With other subjects, the sessions could hardly be called cognitive restructuring at all, but they were more akin to supportive therapy.

Patients have their own agenda. The presence of a psychologist in the unit is an opportunity for them to unload other problems. At
Figure 7. Subject AL -- Weight Gains Compared to Criteria

*Criteria: 1 kg/day, 3 kg maximum gain between sessions.
times the problem of the researcher staying on task was insurmountable. Subjects want to talk about interactions with staff members, problems at home, fear of death, or a grandson who just made the basketball team. In such an environment, it is impossible to implement any intervention without first of all actively listening to the patient.

Four of the subjects were significantly depressed (EG, IE, MA, and WM). Yet, the intervention was self-management training, not therapy for depression. It is impossible not to do both.

The researcher in a hemodialysis unit necessarily has a lot of contact with the unit dietician, head nurse, and social worker, and is aware of their attempts to help patients. Yet, in order to establish experimental control, their activities must be independent of the research. Nevertheless, the researcher will find himself reinforcing the activities of those staff members while interacting with the patients. That stems from a very basic and necessary commitment first of all to the welfare of the patient, and secondly to the integrity of the research project. This researcher unashamedly gave priority to the former.

For example, one subject was complaining of her thirstiness and dry mouth. The researcher's response was "Have you tried just rinsing out your mouth and spitting out the water instead of swallowing it? Have you tried sucking in ice chips?" Those responses are educational interventions, pure and simple. That is not exactly the same as self-monitoring or cognitive restructuring.

These comments are not by way of apology, nor a disclaimer, nor a mea culpa. Rather, they are a recognition of the difficulty in controlling all relevant variables when working with a chronically ill
out-patient population.

Some of the data give evidence for the problems of using weight gains between sessions as a dependent measure. Subject CE, for example, is defined as compliant in the treatment phase. Yet, half the time, she is well over the criteria. Her average is below criteria (-.2 kg).

For purposes of operationally defining the population at risk, noncompliance was defined as a frequency measure -- being over the criteria half the time. However, for the statistical analysis of significance, the means were used, not the frequency. Means are not always physiologically significant. A person whose mean weight gains are always right at criteria level may be a person who always comes in with exactly the criteria level of weight gain, or a person who fluctuates between 2 kg over and 2 kg under criteria. The latter person is not healthy. Therefore, mean values may not be the best measure. Frequency values may not be a good measure either. A subject might be below criteria 60 percent of the time, and the other 40 percent of the time be dangerously over criteria. That person is at risk.

Weight gains between sessions may be an inaccurate measure of compliance behavior for other reasons. A person with nausea and diarrhea for three days may become seriously dehydrated. This will show up on the chart as weight loss or very compliant behavior. Then, when the person is well again, normal weight gains getting the subject back up to dry weight will show up as noncompliant behavior.

A patient's dry weight is generally quite stable. However, some persons do gain dry weight (fat) or lose it. This also shows up on
the chart as noncompliant or compliant behavior.

Other events in the subject's life may be sources of uncontrolled variability. One patient reported, "I always do better in the Spring. I am more active, I get out more often, and I don't just sit around eating and drinking." Incidentally, this person did not do better in the Spring (see Figure 7). One way to control for this variability would be to analyze baseline data over a period of several years.

Nevertheless, for all the uncontrollable sources of variability, there still is a significant main effect of the intervention. This approach to the problem of fluid noncompliance in hemodialysis patients is basically sound.

One previously reported problem is that of maintenance of the improved compliance behavior, once the intervention is terminated. In this research, some subjects were observed for as long as one month after the intervention, but longer periods of observation are needed.

Long-term reinforcing consequences are necessary for maintenance. In this population, there are very few long-term or short-term reinforcing consequences available. A possible reinforcer could be reduced dialysis times, although this is not necessarily reinforcing for all the subjects.

The dialysis theory of kinetic modeling builds patient performance into the dialysis prescription, although the modeling is generally done only monthly. The patient is rewarded for a pattern of compliance rather than for performance on a given day. For the person who values less dialysis time, this would be an effective maintenance factor. Kinetic modeling is discussed in more detail in Appendix A.
CHAPTER V

CONCLUSION

The Health Belief Model (HBM) is an effective means of cognitive assessment for hemodialysis patients, and an instrument based on that model may have some predictive validity. Research on such an instrument may be productive. The first step would be to find a population large enough to do an item analysis on a large number of items.

The MHLOC scale may provide additional information for clinicians, but more research is needed if this is to be used as a predictor of health related behaviors.

Self-management training is an effective intervention overall. The degree of effectiveness varies markedly from one subject to another.

Further research by psychologists with hemodialysis patients is needed. The sources of variability are difficult to control, but the end product is the improved welfare of the patients, which must always be the primary concern.
REFERENCE NOTES

1. During the research, one of the patients said, "Cutting back on my hours of dialysis doesn't mean anything. Once I get hooked up to this damned thing, I might as well stay hooked up for another hour."

2. These considerations were established by the medical staff at Bronson Hospital, Kalamazoo, Michigan.
INTRODUCTION TO RENAL DISEASE AND DIALYSIS

For almost 15 years now, hemodialysis has become a common and accepted treatment for renal failure (De-Nour, 1980). From the beginning, the emotional problems of machine-dependent living have caught the interest of psychologists. Several books have been published on the subject (Friedman, 1978; Czaczkes & De-Nour, 1978; Levy, 1974). The October, 1979 issue of Medical Times is a desk reference on how to help hemodialysis patients cope.

The kidneys are complex organs. They are responsible for the filtration of body fluids and the maintenance of their chemical balance. Because of that complexity, this review paper will begin with an introduction to the kidney and renal disease. As much as possible, the material will be presented in non-technical language.

Much of the information in the first section is common knowledge within the trade, and therefore is not referenced, except for items that might be debatable. Generally, the material was synthesized from several textbooks (Anderton, Parson & Jones, 1978; Curtis & Williams, 1975; Friedman, 1978; Forland, 1977; Maude, 1977; Lancaster, 1979; Leonard, 1979; Netter, 1973).

A. Structure of the Kidneys

For all they do, the kidneys are surprisingly small organs. They lie immediately under the back muscles, in the lumbar region. In the normal adult, each kidney is about 11 cm. long, 2.5 cm. thick, 5 cm. wide,
and weighs between 120 and 170 grams (Netter, 1973).

The kidneys are supplied by the renal artery which rises from the aorta. The arteries quickly divide into smaller branches, until they become afferent (entering) arterioles, entering the glomerulus. The glomerulus is one component of the basic architectural unit of the kidney, called the nephron. The nephrons are the filtering units. The kidney may include a million or more nephrons. The nephron consists of the glomerulus and its collecting tubules.

The arterioles enter the glomeruli. At this point, the arterioles are just visible to the naked eye. The tiny glomerulus is enclosed by a capsule (Bowman's Capsule) which consists of a single layer of cells. Within this capsule, the arterioles divide again into about eight capillary tufts. This is where the filtration occurs. Those tufts unite again, and remove the filtered plasma via the efferent (exiting) arterioles, which eventually bring the blood to the renal vein and the inferior vena cava.

Within the nephron, by the process of osmosis and diffusion, the filtration occurs. While most of the fluids are reabsorbed into the blood, some are not. Those fluids not reabsorbed are concentrated and collected in the tubules, which eventually drain what is now urine into the bladder for voiding.

B. Physiology of the Kidney

The kidneys maintain the chemical composition and volume of the blood and extracellular fluid. Normal kidneys filter the total plasma volume every 30 minutes. About 99 percent of the major plasma
constituents filtered are reabsorbed by the tubules and are not excreted in the urine. Put another way, every 24 hours about 180 liters are filtered. Of that amount, about 1-3 liters are excreted as urine. All other fluids are returned to the blood.

The filtration function is highly selective. Individual substances are filtered out at different rates. For example, about 90 percent of organic acids are excreted in one passage through the organ. However, less than 1 percent of glucose or amino acids is excreted.

The size of the molecule is relevant to the rate of filtration. Larger molecules are excreted less easily than small molecules. The capillaries freely allow water and electrolytes to pass into the space in the capsule, but larger molecules, such as proteins, are retained. Therefore, indication of certain levels of protein in the urine may be indicative of kidney disease.

The acid-base balance of the body is maintained by the kidneys, through excretion and the production of bicarbonate. The body ingests acid, and it generates acid as a product of metabolism. The kidneys excrete the excess.

Regulation of Potassium balance is a critical function of the kidneys. Potassium may build up in the body of persons without renal function, and that may have severe effects — such as cardiac arrest.

The kidneys have an endocrine function also. They secrete an enzyme, renin, which is stimulated by sodium loss and which prevents further sodium loss. Renin regulates blood pressure. The kidneys also control the secretion of the hormone erythropoietin, which is critical in the stimulation of bone marrow and the production of red blood cells.
Consequently, persons with kidney disease are always anemic.

Another function of the kidneys is phosphorus excretion. In a normal person, about 10 percent of filtered phosphorus is excreted, and 90 percent is reabsorbed. As the glomerular filtration rate (GFR) falls, reabsorption decreases. This begins a complex cycle, involving an attempt of the body to compensate. The cycle involves calcium metabolism and the excessive secretion of parathyroid hormone. In patients whose kidney function falls below 25 percent of normal, bone disease is a danger because of the subsequent decalcification.

The kidneys have other functions, also. One important function is the conversion of a form of vitamin D. The other functions, of less significance for purposes of this review, may be studied in any one of several excellent books on the subject (Forland, 1977).

C. Diseases of the Kidneys

The type of renal disease and its etiology are critical in the determination of how to manage the disease.

**Acute** renal failure is the term used to describe any sudden impairment of renal function. There are many causes, including kidney stones, or trauma -- such as being shot in the kidney or an automobile accident. The distinguishing characteristic of acute renal failure is that it may be caused by nonrenal factors.

**Chronic** renal failure is the disease group of most interest for purposes of this review. Types of chronic renal failure may be organized in various ways. Following is an organization based on etiology (Netter, 1973).
1. **Primarily glomerular disease.**

This is by far the largest category of renal diseases. There are several types of glomerulonephritis (inflammation of the glomerulus). Most of them are diffuse, and usually both kidneys are involved. The basic filtration unit ceases to function because of the inflammation and uremic poisoning results.

2. **Primarily tubular disease.**

In this category of disease, the collecting tubules are the first source of the problem. Chronic Potassium depletion, chronic hypercalcemia (too much Calcium), or heavy metal poisoning may be responsible for the deterioration of the tubules.

3. **Vascular diseases.**

These diseases may be hereditary or acquired. The arteries supplying the kidneys may be narrow or strangulated, resulting in a lack of sufficient blood supply to the kidneys (ischemia). In nephrosclerosis, the arteries are hardened, having the same result. Malignant hypertension is included in this category.

4. **Infections.**

The most common disease in this category is pyelonephritis, an infection which may begin in the urethra or bladder and work its way up the ureters into the kidney. The infection may permanently destroy renal functioning.

5. **Obstructive diseases.**

The body may form various clots, or obstructions, which may block the passage or urine at any one of several points. An example is kidney stones (properly called calculi). If the urine is blocked, it backs up,
creating pressure in the kidney. The high concentration of toxins may permanently destroy kidney function.

6. **Metabolic diseases.**

Diabetes may affect all elements of the kidneys. Eventually, this may lead to pyelonephritis. Primary hyperthyroidism is included in this category, along with various other diseases which begin with a disturbed metabolic process and result in kidney failure.

7. **Collagen disease.**

The origin of this disease is unknown, but researchers suspect a certain kind of hypersensitivity results in inflammatory lesions in the small blood vessels and the capillaries. Often, the kidneys are involved, and the disease is usually fatal. It receives its name because it also causes lesions in collagen, a type of albumin in body tissue.

8. **Congenital and hereditary diseases.**

A hereditary defect may result in the kidneys developing scores of cysts (Polycystic kidneys). Congenital defects include structural anomalies, such as kidneys that have grown in the wrong place, or attached to each other, or kidneys with grossly malformed parts. Any of these may result in renal failure.

D. **Measurement and Monitoring of Renal Disease**

"Renal function" is synonymous with "glomerular filtration rate" (GFR). The rate at which the glomeruli filter the body fluids is generally measured by levels of creatinine in the blood. Creatinine is a waste product found in the blood as the result of protein metabolism in the muscle and is normally excreted. The level in healthy persons is
generally stable, and does not vary much with dietary protein intake or urinary volume. Therefore, the level of creatinine in the blood compared with the level of creatinine in the urine is an accurate measure of GFR.

Other physiological measures are also critical in the monitoring of end stage renal disease.

Blood Urea Nitrogen (BUN) is an accurate measure of protein catabolism, and therefore a good indicator of the patient's total nutritional status. This is the major control variable in "kinetic modeling," or, "Urea kinetics," which is discussed on page 63.

Weight gains between sessions are critical to the patient's health. Moisture in food is generally metabolised and passed via perspiration or feces. But liquid intake generally stays in the body of a person with no renal function. One liter of fluid consumed will show up on the scale as an additional kilogram of weight to be removed by dialysis. The process of dialysis is slow. Every ounce must come off by the filtration process of the machine if the patient is to maintain his or her dry weight.

Blood pressure is a critical measure, especially during dialysis. Blood pressure and fluid volume are related. As fluid is removed from the system, the BP may drop to dangerously low levels.

Serum Potassium levels are critical because the kidneys are not able to excrete it. As Potassium increases, usually by the ingestion of foods high in Potassium, the danger of cardiac arrest increases. Potassium is removed by dialysis. The chemical composition of the dialysate may be changed to increase the dialysis of Potassium. In
practice, however, Potassium levels are generally measured only once every three or four weeks. So, a patient may come in for dialysis with dangerously high Potassium levels, and the staff might not be aware of it for several days, until the next reading. Patients who are known "Potassium abusers" have more frequent readings, and the dialysate composition is changed accordingly.

Serum Phosphorus is critical because of the interaction with Calcium and eventual decalcification of the bones. Phosphorus levels may be controlled by the patient with dietary management and with taking medications. "Phosphate binders" combine with Phosphorus in the gastrointestinal tract and are passed out with fesces. Basaljel and Amphojel are antacids that contain the Phosphate binder.

E. Management of Renal Disease

1. Dialysis.

Patients with end-stage renal failure will inevitably die of uremic poisoning unless their body chemistry can be corrected by means other than the kidney. Three kinds of dialysis are currently being used.

   a. Intermittent Peritoneal Dialysis -- This is the treatment of choice for some patients, especially if vascular access is difficult or the patient's heart is very weak. A dialysate solution is passed into the peritonium of the patient, where it washes over the bowel and peritoneal membrane. The surface area of the peritoneal membrane is approximately the same as the surface area of the glomeruli (1m$^2$ to 2m$^2$), and that surface serves as a semipermeable membrane for the passage of waste products from the blood into the dialysate. This process is often
done while the patient is at home, sleeping. The patient must be fitted surgically with a catheter to accommodate the dialysate flow. Peritonitis is a risk. And, the long-term effects of using the peritoneal membrane as a filter are not known. The major disadvantage of this technique is that it requires long hours attached to the machine -- about 30 hours/week.

b. **Continuous Ambulatory Peritoneal Dialysis (CAPD)** -- This technique has become increasingly popular within the past five years. The patient is usually fitted with a catheter, into which he or she introduces about 2 liters of dialysate solution, about 4 times per day. The dialysate washes over the peritoneal membrane, and, by osmosis and diffusion, picks up the waste products from the blood. After several hours, the patient drains out the fluid, disposes the bag, and introduces another 2 liters. This technique has many advantages. The main advantage is that the patient is mobile. In addition, there are fewer dietary restrictions than those imposed on persons receiving hemodialysis. The disadvantages are that the patient must be fitted with a catheter, the risk of peritonitis is high, and it requires about 30 minutes of careful attention four times per day. Also, the patient has an additional 2 liters of fluid in his or her abdomen, and that increases the size of the waist.

Overall cost of this technique is considerably less than the cost of hemodialysis, and that is a significant factor in the increasing popularity of this system.

c. **Hemodialysis** -- With this technique -- the most common dialysis technique -- the blood is filtered through an artificial kidney, which serves several functions of the human kidney. One critical problem
with this type of dialysis is the problem of vascular access (how to get the blood into the machine). Some patients are fitted with a cannula, or shunt, which may be placed in the arm, ankle, or thigh. These shunts need constant care and protection. A more popular solution to the problem of vascular access is to prepare a patient surgically with a fistula -- a process by which a vein and an artery are connected in the arm, creating a grossly enlarged area into which large needles can be easily placed.

Whatever the access, the blood is drawn into the dialysis machine with a blood pump that imitates normal heart pumping. The blood passes over a semi-permeable membrane, and by the process of osmosis fluids and waste products pass into the dialysate solution that is washing over the other side of the membrane. The membrane may have as much as $4m^2$ of surface area, but it is all rolled up in a coil. The machine has complex instrumentation, which indicates the rate of flow of the blood, and the pressure on the membrane. Heparin may be introduced to prevent clotting, and several alarm systems alert the staff to potential problems.

Modern technology has greatly improved the filtration function of the artificial kidney. Competing corporations have developed a variety of kidneys with various filtration potentials, and various surface areas. The dialysis machines may use a recirculated dialysate or a constant flow (single pass) that goes down the drain. Blood pumps may be adjusted to change the flow rate. The chemical composition of the dialysate may be altered to fit the needs of the patient.

The dialysis prescription is a medical decision that coordinates many variables in an attempt to achieve the best filtration of the most...
essential chemicals in the shortest amount of time. That prescription may include:

1. The size of the artificial kidney,
2. Frequency and duration of dialysis sessions,
3. Chemical composition of the dialysate,
4. Rate of blood flow,
5. Various standing orders specified for the individual needs of each patient.

The nursing staff constantly monitor the patients being dialyzed, and they adjust the machines according to the prescription.

Accompanying the various techniques of dialysis are various theories of dialysis. The management of renal disease does not have consensus in the medical establishment. In Kalamazoo, Michigan, for example, the two hospitals have contrasting ideas about how to dialyze patients. One hospital uses much longer dialysis times for their patients, and those prescriptions are based on a belief that longer times at slower rates are preferable for the patient's best health. The other hospital uses a theory called "Urea kinetics," or "kinetic modeling" (Gotch, Sargent, Keen & Lee, 1974; Gotch, Sargent, Keen, Seid & Foster, 1973; and Sargent, 1979).

Kinetic modeling uses several measures as components of a formula which determines the most effective dialysis. The basic consideration is the patient's total nutritional status - measured by BUN. A computer processes the information and prescribes the recommended time on dialysis and the size of the artificial kidney. On any given day the staff may override that prescription for reasons more pressing than total
nutritional status. For example, a patient who regularly overloads on fluid intake will have to dialyze for a longer period of time, even though his or her prescription, based on nutritional status, calls for shorter times. The difference may be as much as two hours per session.

Kinetic modeling is a relatively new concept but has a growing number of followers. The entire April, 1981 issue of "Dialysis & Transplantation," a leading trade magazine, is devoted to articles on this topic.

Regular maintenance hemodialysis, whether at home or in an outpatient clinic, requires about 4 to 6 hours, usually three times per week. That amount of time is costly and very aversive to the patients. Any means of making that time shorter would be appreciated by everyone involved.

2. Dietary Management.

The patient's diet is critical in the management of the disease. All physiological measures are regularly monitored by the medical staff and the unit dietician. As the disease progresses, as kidney function decreases, adjustments in the diet must be made, depending on the type of disease.

Low salt diets are essential for all renal patients. Low Potassium and low Phosphorus diets are essential for patients with minimal or no renal function. Fluid intake is more critical as the disease progresses. A patient still putting out 750cc. of urine per day might be able to safely ingest 1.5 liters of fluid per day. A fluid is defined as any liquid, and any food that melts at room temperature, such as ice cream or jello.
The determination of how much fluid may be safely ingested involves several considerations: (Reference Note 2)

a. Total body weight and muscle mass,
b. Cardiovascular reserve,
c. Dialysis schedule,
d. Hypertension with fluid gain,
e. Other complications of the disease.

One of the goals of dietary management is to reduce protein intake but maintain a high calorie intake. The renal dietician is responsible for those recommendations. There are cook books that list menus especially designed for renal patients (Cost, 1975).

3. Medications.

The incidence of adverse drug reactions is considerably greater in patients with renal failure than in those with normal renal function (Curtis & Williams, 1975). Normally, drugs are excreted in the urine. Therefore, those drugs will build up in renal patients. That accumulation may be toxic. In addition, some drugs may be metabolised more slowly in renal patients because of an enzyme imbalance.

Renal patients often need antibiotics, diuretics, antihypertensives (drugs to reduce blood pressure), immunosuppressives (drugs to prevent rejection of a transplanted kidney), antacids, and other types of drugs.

The diuretics must be used with great care because of a wide variety of side effects, including deafness. Besides that, when the glomerular filtration rate (GFR) falls below a certain level, they are ineffective.
The antihypertensives are used with great care because of the danger of hypotension (low blood pressure) and the possibility of increased damage to the kidneys.

The antacids, also called the Phosphate binders, are used to control the level of Phosphorus in the body, which is essential in the prevention of bone disease. The most commonly used drugs with renal patients are the antacids. They are dispensed in the form of tablets, liquid, or capsules, all of which may be unpleasant to swallow. Patients do not like them. However, if Phosphorus were controlled by the diet, patients would need less phosphate binding medication (Friedman, 1978, p. 183).

F. Complications of Renal Failure and Dialysis

Hypertension is present in about 75 percent of persons on maintenance hemodialysis (Curtis & Williams, 1975). This must be carefully controlled. There is also a small number of patients for whom low blood pressure is a problem.

Bone disease is a danger because of the disturbance of Phosphorus and Calcium metabolism. Bone disease may also result from insufficient intake of vitamin D.

Peripheral neuropathy is a label given to a neurological disorder in which the patient loses feeling in his or her hands and feet. The disease affects both sensory and motor nerves, and generally involves the lower limbs first. Adequate dialysis can retard the progression of the disease (Curtis & Williams, 1975).
Muscles may become weak (myopathy) as a result of calcification of arteries feeding those muscles.

Painful cramps are common during dialysis. As fluid is removed from the blood, the intracellular fluid begins to move through the cell membranes into the bloodstream. When that happens too quickly, the muscles cramp painfully. Persons with excess fluid are especially susceptible.

Anemia is pervasive in renal patients, and many must periodically receive transfusions.

Hemolysis is the process by which red blood cells are destroyed. This is probably the result of the deposit of fibrin in the capillaries, and as the red blood cells pass over the fibrin they are literally torn apart.

Hyperkalemia is the name given to dangerously high levels of Potassium. It is still a significant cause of death in hemodialysis patients.

Pericarditis is the inflammation of the layer around the heart and is the result of an overworked heart. It can be minimized by adequate dialysis and careful dietary controls. The overworked heart may be the result of excessive fluid intake.

Heart failure may result from fluid overloading or the calcification of heart muscles.

Sterility and impotence are possible, although they are not inevitable.

Hepatitis is a possibility, due to the increase in blood transfusions. It is prevented only by the most rigorous standards of
cleanliness and sterility of equipment and procedures. The staff is also at risk, because of their frequent contact with the blood. In a clinic in Edinburgh, only 10 years ago, 24 percent of the patients and 33 percent of the staff died from an epidemic of hepatitis (Forland, 1977).

Changes in physical appearance and bodily integrity are very important to all persons. The hemodialysis patient often has severely scarred veins, similar to those of a heroin addict. The fistula, which is surgically prepared for easy blood access, is a large swelling on the forearm.

This list represents only some of the more serious complications of renal disease.

G. Social and Psychological Aspects of Renal Disease

Dialysis is a traumatic event. Some persons adjust very well to machine-dependent living. But, a very high proportion respond with depression, anxiety, anger, denial, and a host of other responses which will be further expanded in the main part of this review. One of the more troublesome responses is that of noncompliance with the medical regimen. The reasons for that are still being researched, but very few controlled studies exist on noncompliance in hemodialysis patients.
APPENDIX B

INFORMATION FOR VOLUNTEERS

Title of Study: The Effects of Self-management Training and Rational-Emotive Therapy on Compliance in Hemodialysis Patients.

Purpose: The purpose of this research is to gather information that might help hemodialysis patients. We are especially interested in why some patients are putting on too much weight between sessions, and are having difficulty controlling their blood chemistry. We would like to know what might be required to change that.

General Information: This study has the support of Bronson Hospital and the staff of the Hemodialysis Unit, and Western Michigan University. In the past, it has been discovered that when patients improve their self-management skills, it is easier for them to adhere to their diets and schedules of medications. So, in this study, the researcher will work with some patients to improve their self-management skills. He will do that in several ways.

First, he will talk to you about your thoughts and feelings. He will do that in a structured way, which is called "Rational-Emotive" Therapy. What that means, in plain language, is that he will be trying to help you establish the relationship between what you think about your health, how you feel about your health, and what you do about your health.

Then, if you believe you could be making improvements, he will help you make changes so that it will be easier for you to do what is recommended by the doctors and the dietician.

You will participate in the decision about how you might improve. You might also be asked to monitor your progress more closely than you are now.

Qualifications: Anyone who has been dialyzing regularly may volunteer for the study. The researcher will look at your medical records of the past few months, and determine if your weight gains are generally too high, and your blood chemistry is generally too dangerous for your best health. If you and the staff agree you could be doing better, we will then proceed with the rest of the study. That is when the researcher will be asking you some questions. He will also ask you to agree to monitor yourself quite closely for a few weeks, and to sign your name to that agreement.

You may withdraw from the study at any time.

Time: The study will last about two or three months. Very little time will be required outside the unit. Only the time it takes to record some information. And, while you are on the machine, the experimenter will occasionally want to talk to you, but not if you don't want to talk.

At the beginning and end of the experiment period, you will be asked to answer quite a few questions, which will take less than an hour.
Drugs: (No drugs are used in this study.)

Risks and benefits: Only interview procedures are used in this study, so there are no physical risks in the procedures. The benefits are that you might feel a little better, physically; you might be able to spend a little less time dialyzing; you might be able to reduce the risk of bone disease; you might feel better emotionally when you have the satisfaction of knowing you are doing the maximum amount possible for your health; and, the results of the research might help other patients.
APPENDIX C

INFORMED CONSENT FORM

Bronson Hospital, Hemodialysis Study

I, ________________________________, agree to participate in the procedures of this study, which were explained to me by Glen Peterson, the researcher.

I understand that the purpose of this study is to make some changes in how I control my treatment regimen.

I understand I will be monitoring myself more closely.

I understand there should be no bad effects of participating in this study. I have read, and I understand the risks and benefits.

I understand I will be answering some questions about my ideas and feelings about my health. I understand the researcher might be discussing those thoughts and feelings with me.

I have been given the opportunity to ask questions about the study, and they have been answered satisfactorily.

I understand I am free to withdraw my consent and stop my participation in the procedures of this study at any time, and that will not jeopardize further treatment at this clinic.

I understand that a copy of this form will be kept on file in the clinic, and I may review it at any time if I am thinking about changing my mind.

I understand the researcher has access to my medical and social records, and that he is bound by the same rules of confidentiality as the rest of the staff.

I understand that the information gained by this study is confidential. That means that only the staff here in the dialysis unit will be able to see the results. It also means that if the results of the research are published, there will be no way to trace the information to a specific individual, because the names of the subjects and other identifiers will be withheld.

I understand there is very little possibility of any injury while participating in the study, because all the procedures involve interviews only. Nevertheless, I understand that in the event of physical injury resulting from the research procedure, Dr. Grochowski will provide or arrange for medical care but will not pay for the medical care or provide additional compensation.

I have read the above forms, or they have been read to me, and my signature here indicates my willingness to participate in the study.

Volunteer Date

Researcher/Investigator Date

Witness Date

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APPENDIX D

ASSESSMENT QUESTIONNAIRE
Bronson Hospital Hemodialysis Unit

Volunteer: ______________________________
Date: ____________________________________

This is a questionnaire designed to determine the way in which different 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 that represents the extent to which you disagree or agree with the 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 that 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 the 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.

(The first 18 items are from the Multi-dimensional Health Locus of Control Scale MHLOC)

MHLOC Scale

1. If I get sick, it is my own behavior which determines how soon I get well again.  
   Strongly Disagree Moderately Disagree Slightly Disagree Slightly Agree Moderately Agree Strongly Agree
   1  2  3  4  5  6

2. No matter what I do, if I am going to get sick, I will get sick.  
   1  2  3  4  5  6

3. Having regular contact with my physician is the best way for me to avoid illness.  
   1  2  3  4  5  6

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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 professiona.  
6. I am in control of my health.  
7. My family has a lot to do with my becoming sick or staying healthy.  
8. When I get sick I am to blame.  
9. Luck plays a big part in determining how soon I will recover from an illness.  
10. Health professionals control my health.  
11. My good health is largely a matter of good fortune.  
12. The main thing which affects my health is what I myself do.  
13. If I take care of myself, I can avoid illness.  
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.  
15. No matter what I do, I'm likely to get sick.  
16. If it's meant to be, I will stay healthy.  
17. If I take the right actions, I can stay healthy.  
18. Regarding my health, I can only do what my doctor tells me to do.
Now following are some questions about what you believe concerning your susceptibility to further complications of kidney disease.

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>*1.</td>
<td>The doctor and/or other staff members really exaggerate the importance of my diet.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>My Basaljel (or Amphojel) will probably not prevent me from having bone disease.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*3.</td>
<td>If I drink a lot (more than the recommended amount) my blood pressure might go up as a result.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>The doctor and/or other staff members really exaggerate the importance of medications.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*5.</td>
<td>If I don't take my Basaljel (or Amphojel) on schedule, I increase the probability of getting bone disease.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*6.</td>
<td>If I put on too much weight (fluid) between dialysis sessions, I increase the probability of heart failure.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*7.</td>
<td>If I drink a lot, I increase the danger of fluid in my lungs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>If I eat a lot of food that is high in Potassium, I increase the probability of going into a coma.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*9.</td>
<td>If I put on a lot of fluid, I increase the chance of getting leg cramps during my next dialysis.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*Scored items. Others were not for research, but for clinical use.

**On these items the scale was inverted, so that the "6" was in the critical direction.
| 10. If I don't feel well physically, I might get depressed. | 1 2 3 4 5 6 |
| 11. My Basaljel (or Amphojel) is not nearly as important as the staff thinks. I can take it or leave it, and nothing will change much. | 1 2 3 4 5 6 |
| 12. If I were to follow all the recommendations of the staff, it could actually do some harm. I might feel terrible. | 1 2 3 4 5 6 |
| 13. Doctors rely too much on medicine (like the Basaljel or Amphojel). There are better ways of handling the problem of bone disease. | 1 2 3 4 5 6 |

The following statements are about how severely ill you believe you are.

*1. My kidney disease is very serious. | 1 2 3 4 5 6**
*2. I don't really need as many dialysis treatments as I am getting. | 1 2 3 4 5 6
*3. Regular dialysis appointments are not necessary. I could just come in whenever I feel that I need dialysis. | 1 2 3 4 5 6
4. My kidney disease will require constant care for the rest of my life. | 1 2 3 4 5 6
*5. I will always have to watch my diet, fluid intake, and medications. | 1 2 3 4 5 6**
6. Eventually, I might not have to take my Basaljel or Amphojel anymore. | 1 2 3 4 5 6
*7. I am not as sick as others seem to think I am. | 1 2 3 4 5 6
8. My health really depends on how well I am able to follow the prescribed regimen of diet and medications.  

9. I am able to eat and drink pretty much how I want, and still get by OK.  

Following are statements about what people think might keep them from following their regimen.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Moderately Disagree</th>
<th>Slightly Disagree</th>
<th>Slightly Agree</th>
<th>Moderately Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>*1. It is very difficult for me to take my meds.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*2. It is almost impossible for me to know how much fluid I am putting on between sessions.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*3. I don't really understand what my schedule of meds is supposed to be.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I actually do not know what foods are high in Potassium and Phosphorus.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. My diet is too complicated to follow.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Just when I think I have done everything right, my Potassium and Phosphorus are too high.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I understand everything about my schedule of diet and meds.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*8. Sometimes I just know I have not drunk as much fluid as the staff says I have. I don't know how the weight gets there.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*9. If the staff treated me differently, it would be a lot easier for me to follow their recommendations.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I don't have any way of knowing how much weight I put on between sessions.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
11. I could stick to my schedule of diet and meds more closely if the procedures didn't interfere so much with my life.

12. One reason I have difficulty following my regimen is that I have nobody at home to help me.

13. I would be more regular with taking my Basaljel (or Amphojel) if it didn't cost so much.

These are more questions about your attitudes about your health.

*1. I want very much to feel better.

*2. I want to do whatever will help me feel better.

3. I am very concerned about my kidney disease.

*4. I am very curious about how my body works -- for example, how it uses what I eat and drink.

5. I really can't be concerned about my health in the future.

6. I think I take care of my health better than most hemodialysis patients.

*7. I could take care of my health a lot better than I do now.

8. I take my meds and watch my diet about as well as I can.

*9. One good thing about feeling sick is that one doesn't have to go to work as much.
*10. Coming in for dialysis is OK, because I don't have much else to do.  

11. I don't think about my kidney disease very much.  

12. I would really like to spend less time dialyzing.  

This last group of statements is about your beliefs concerning the benefits of following the recommended regimen of diet and meds.  

*1. If my weight gains are within the recommended limits (less than 1 kg/day), I feel better.  

2. If I were to follow all the recommendations of the staff, the staff would treat me better.  

3. If I were to follow all the recommendations of the staff, my family would treat me better.  

*4. I can avoid further complications of kidney disease by following my dietary regimen.  

*5. If I were to follow the staff's recommendations, I could spend less time on the machine.  

If I were to follow the prescribed regimen of diet and medication very carefully:  

*6. my heart might work more efficiently,  

*7. my lungs probably wouldn't fill up with fluid,  

*8. I probably wouldn't get leg cramps,  

9. I probably wouldn't get nauseous while on the machine,
10. the machine would work more efficiently,

11. the staff would have less work.
### Appendix E

**Record of Fluid Intake**

<table>
<thead>
<tr>
<th>Mornings (Before noon)</th>
<th>Afternoons (Before 5:00 PM)</th>
<th>Evenings (after 5:00 PM)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
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</tbody>
</table>

- My goal for the rest of today is: __________ Kg.
- Estimated gains today, Post-HD: __________ Kg.

<table>
<thead>
<tr>
<th>Date</th>
<th>Goal for today: __________ Kg.</th>
<th>Estimated gains today: __________ Kg.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>Goal for today: __________ Kg.</th>
<th>Estimated gains today: __________ Kg.</th>
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</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>Goal for today: __________ Kg.</th>
<th>Estimated gains today: __________ Kg.</th>
</tr>
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</table>

Goal for total gain, from: __________ Kg. to __________ Kg. = __________ Kg.

Total estimated gains: __________ Kg.

Actual weight gain between these dates was: __________ Kg.

Conversion table:
- 1 oz. = 30 cc.
- 8 oz. = 240 cc.
- 16 oz. = 480 cc.
- 100 cc. = .1 Kg.
- 500 cc. = .5 Kg.
- 1,000 cc. = 1 Kg.

Remember to record EVERYTHING that goes into the mouth!

Bronson HDU
The Effects of Self-management Training on Compliance in Hemodialysis Patients

A study completed at Bronson Methodist Hospital in Kalamazoo, Mich. in April, 1981.

Researcher: Glen Peterson, M.A.

Summary

The following summary is prepared for the subjects who participated in the study.

I want to thank you all for volunteering as subjects in the study. From now on, I will not be around the Unit very much, so I want to take this time to summarize what we have been doing.

THE FIRST PHASE OF THE STUDY

First of all, we measured several characteristics of everybody who volunteered.

A. YOUR BEHAVIOR. We wanted to know what you are doing about your health.

It is always difficult to measure what someone does. Obviously, we cannot follow people around and take notes on everything they do. So, to measure what you are doing to maintain your health, we measured three different things.

1. Weight gains between sessions. This is an important measure of healthy behavior. It is a fairly accurate measure of how much you are drinking.

   We asked the doctors what fluid gains were recommended for everyone in the study. In other words, what is the maximum allowable amount for each individual. The doctors considered several things in making this determination.

   a. Total body weight and muscle mass. Larger persons can safely put on more fluid than smaller persons.
   b. Cardiovascular reserve. (Total blood volume).
   c. Dialysis schedule. If a person is off dialysis for 4 days, they might put on more fluid than if off for 1 day.
   d. Hypertension with weight gain. Some persons' blood pressure increases dangerously with fluid intake.
e. Other complications. For example, heart disease.

So, the recommended level of fluid gain between sessions varied from one person to another. This was called the criteria level. In other words, it was your goal.

We made a table of all your weight gains between sessions, for the past few months, and compared these values to the criteria. So, for each day of dialysis over the past few months, we have a value that represents your fluid gain compared to your goal.

Some persons (about 1/2 the subjects in the study) were consistently under their criteria. They rarely were over the amount recommended for their best health. We labelled those persons "compliant," because they complied with the medical advice.

Other persons were consistently over the criteria. If a subject were over the criteria more than 1/2 the time, we labelled those persons "noncompliant," which is just another way of saying that those persons, for whatever reason, were putting on a lot more fluid than what was recommended by the doctors and the dietician.

2. Potassium levels. As you all know, kidney disease disturbs the Potassium balance of the body, and patients must be very careful about eating food with a lot of Potassium -- such as citrus fruit and bananas. By measuring the Potassium level in the blood every three weeks, we have a measure of how much Potassium you are eating. This is measured in a unit called "milequivalents per liter," or just mEq/L.

Considering that our blood samples are drawn on Mondays or Tuesdays (usually after persons have been off dialysis for 3 days), the criteria level, or goal, has been set by the doctors at 5.5 mEq/L.

Almost everyone in the study had safe Potassium levels. But, if a subject were consistently over the criteria level (more than 1/2 the time, we labelled them as "noncompliant" with their recommended low-Potassium diet.

3. Phosphorus levels. Finally, we looked at your Phosphorus levels over the past few months. Persons who were consistently over the criteria level (also set at 5.5 mEq/L.) were said to be "Phosphorus noncompliant." That can mean one or two things.

a. That person is eating foods that are high in Phosphorus, such as yogurt, and/or
b. That person is not taking the recommended medication to take phosphate out of the system. Those medications are your phosphate binders, and it is usually Basaljel or Amphojel.

We now have three measures of your behavior -- that is, what you do about your health:

a. Fluid gains between sessions.
b. Potassium levels.
c. Phosphorus levels.

All these things are critical for your good health -- or, your best possible health -- and all are things over which you have some control.
This completes the assessment of your behavior. Now, we are interested in what you believe about your health.

B. YOUR BELIEFS. Now that we know what you are doing about your health, we wanted to know what you are thinking about your health, and your kidney disease in particular.

Measuring what people think is even more difficult than measuring what people do. Typically, we find out what people think simply by asking them. But, if we just ask questions, we would get such a variety of answers that we are not able to summarize the results. So, quite often we find out what people think by presenting a list of statements, and asking persons if they agree or disagree with the statements. Most of you did this on the form called the "Assessment Questionnaire."

From this list, we summarized whether you agreed or disagreed with the following inferences:
1. "I am in control of my health."
2. "Other persons, more powerful than me, are in control of my health."
3. "Nobody is in control of my health. What happens to me is pretty much up to chance."
4. "I am not susceptible to the consequences when I don't do what is recommended by the doctors and the dietician."
5. "My disease is not very severe."
6. "A lot of other things keep me from doing what the doctors and dietician recommend."
7. "I am not especially motivated to make any changes."
8. "There are no benefits to doing what the doctors and the dietician recommend."

The first 18 statements on this form were from a "standardized" test. That means that it has been given to a lot of other people in the past -- including chronically ill persons -- and we can compare your responses to the way that they have responded. That test is called the "Multidimensional Health Locus of Control Scale," a mouthful of words that is best reduced to "MHLOC Scale."

The other statements on the form were created by me, and my interpretation of your responses is by "inference." That means I am giving it my best guess. To make up my list of statements, I followed an outline that some other persons have used in the past. That outline is called the "Health Belief Model." It seemed to work for some researchers in the past, so I decided to give it a try.

So now, we have two measures: What you do about your health, and what you believe about your health. Do you think they are related?

Perhaps persons in that group we labeled "noncompliant" are persons who believe their disease is not very severe, or who believe they are not susceptible to the consequences of their unhealthy behavior. Or, perhaps they are persons who believe that other powerful persons (such as nurses or doctors) are more in control of their health than they themselves.
What do you think? Perhaps you can make some good guesses. More on that later.

C. We now have 2 measures: What you do and what you think. The one final measure of interest is what you feel.

If we know what you do, what you think, and what you feel, we have a fairly good picture of you.

How do we measure what people feel?

Measuring feelings is at least as difficult as measuring thoughts or behaviors. But, hundreds of researchers have tried to measure feelings, usually with "Standardized measures." The feeling that is of most interest to us is the feeling of Depression. A lot of researchers have reported that hemodialysis patients are often depressed. So, we used a brief, standardized test to measure if you felt that way. It is called the "Beck Depression Inventory," and it appears to be quite a reliable and valid instrument.

At this point we were finished measuring things for a while. All this information is called "baseline" data.

Results of the first phase of the experiment:

In these results, we are comparing the two groups of persons: Those who we have labelled "compliant" and those we have labelled "non-compliant."

These results have only limited value. The two groups of persons compared were really not large enough so that we could make conclusive statements. Nevertheless, these findings appear to be consistent, and they are definitely interesting.

Final results will have to be analyzed more accurately, but some preliminary findings are:

1. Persons who are noncompliant with their diets are persons who have stronger beliefs about being in control of their health when compared to people who are compliant. In other words, they are more "internally controlled."

2. Persons who are noncompliant are persons who believe their kidney disease is less severe, when compared to persons who are compliant.

3. Persons who are noncompliant are persons who believe there are more barriers to compliance, when compared to persons who are compliant.

4. Persons who are noncompliant are persons who report being less interested in their disease and less motivated to change, when compared to persons who are compliant.

5. Persons who are noncompliant are persons who believe there are fewer benefits of compliance, when compared to persons who are compliant.

6. Persons who are noncompliant report being significantly more depressed than persons who are compliant.
THE SECOND PART OF THE STUDY

For the persons we labeled "compliant," this was the end of the study. For the persons we labeled "noncompliant," we tried to help them make some changes. This effort to help people change was called "self-management training," because we were trying to help those persons become better managers of their health behavior. We did this in two ways:

1. Cognitive restructuring. This label describes a way of talking to people about their beliefs -- the statements they make to themselves. So, if persons had some beliefs that seemed to be inaccurate, we talked about it. For example, perhaps some person disagreed with the statements that asserted they could do some things to improve their health. In that case, we would talk about the short-term and long-term consequences of behavior, and try to clarify what the person wanted, and determine how that would affect their health.

   Our assumption is that if persons believe there are no consequences to their behavior, they are less likely to comply with the recommended diet. Or, if a person believes there are no benefits to complying, they will be less likely to follow the recommendations of the staff.

2. Training in self-monitoring. Some persons are not accurate recorders, or estimators of what they eat and drink. They just can't believe how much fluid weight they are putting on between sessions, and they just can't imagine where that weight is coming from.

   To help those persons become better estimators of their intake, we broke down the days into smaller units, and provided a form with which they could keep an accurate record, until they could estimate their intake without it.

3. Contracting. We had planned to use this, but the three persons who were asked to participate didn't want to bother with it, so we dropped it.

   Results of this part of the study:

   In General:

   Several persons made significant improvements, but we are not sure why.
   Some persons made no improvements, and we do know why, at least according to their account of it.
   Some persons know exactly what they are doing and, even though they know it is detrimental to their health, they want to continue to do it. It just isn't worth the hassle to try to make any changes. They have made a decision to live with the consequences of fluid and Potassium overloading.
   Some persons believe they are just not able to do better, nor do they want to try.
   Some persons want very much to do better, but don't know how to go about it. They have tried several techniques, and none of them seem to work.
Specifically:

1. It is apparent that noncompliant persons are significantly more depressed than those persons who follow the recommended regimen of diet and fluid intake. But, we cannot say that the depression causes the noncompliance, nor that the noncompliance causes the depression. We just know they are somehow related.

2. It is apparent that noncompliant persons are persons who believe strongly in their ability to control their illness to whatever extent possible. This is surprising. I would expect that noncompliant persons are persons who believe they have no control over their lives or their health.

3. Noncompliant persons are less likely to believe their disease is severe.

4. Noncompliant persons are more likely to believe there are barriers standing in the way of following medical advice.

5. Noncompliant persons are less motivated to make changes.

6. Noncompliant persons are less likely to believe there are benefits to following medical advice.

7. Apparently, self-management training consisting of cognitive restructuring and self-monitoring is not a powerful enough intervention in itself to help a variety of persons make changes.

8. The subjects and the staff both saw value in establishing a specific goal for everyone. Some subjects had been confused about how much fluid they could put on between sessions.

9. The subjects and the staff both saw value in presenting the data graphically, and in relationship to your established goals. It helped to see long-term patterns. The staff was able to get a clearer picture of just exactly who was getting close to their recommended levels of fluid intake, Potassium and Phosphorus.

10. The first part of the research confirmed the findings of earlier research projects that have been reported in journals. (Specifically, about the rate of noncompliance in chronically ill populations, and about the prevalence of depression in noncompliant patients.)

11. Some persons made significant changes in their fluid intake, and now feel better because of that. This is the most important result of the study. Also, some persons might be able to dialyze for a shorter time than before.

12. The use of the Health Belief Model seems to be a good way for gathering information about what hemodialysis patients believe about their illness.

13. Even though the group was too small to prove anything, the results are significant enough to warrant further investigation.

14. The results of the study might be published, and that might help other researchers and other hemodialysis patients.

In addition, I have learned much from you about the problems of persons on dialysis. I have enjoyed working with all of you, without exception. You are all very unique and interesting persons, and I want to thank you for your time, your patience, and your openness.
A few of you will receive a few more questions to answer -- similar to those you have already answered. After that, the study is completed.

Thanks again,
### APPENDIX G

**ALL OBSERVATIONS FOR ALL SUBJECTS IN THE TREATMENT PHASE**

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*Indicates beginning of treatment phase
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