

EFFECTS OF A NURSING INTERVENTION
UTILIZING PERSONAL DECISION-MAKING
ON ADHERENCE TO DIET AND FLUID RESTRICTIONS
BY HEMODIALYSIS PATIENTS

by
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ABSTRACT

An experimental study was undertaken to answer the question posed by the problem: "Does a nursing intervention which utilizes a decision-making model to assist patients in establishing personal goals for adherence to fluid and potassium restrictions significantly decrease weight gains between dialyses and pre-dialysis serum potassium levels, compared with the values for these variables in a control group which does not have the intervention?"

Sixteen chronic hemodialysis patients from one large teaching hospital were selected according to pre-established criteria, and then randomly assigned to either experimental or control conditions. The Experimental group was exposed to the nursing intervention, which was the independent variable. The nursing intervention consisted of an initial interview, during which the patients completed a Balance Sheet Procedure, and established personal goals for weight gain between dialyses and pre-dialysis serum potassium levels. Thereafter, for a period of five weeks, the patients in the Experimental group completed a Well-Being Rating Scale at each dialysis and charted their progress toward their goals on a Progress Sheet.

The dependent variables were between dialyses weight gains and pre-dialysis serum potassium levels. Data Pertaining to the dependent variables were collected on both Experimental and Control patients in all three phases of the study: the six month Pre-Intervention Phase, the five week Intervention Phase, and the three week Follow-Up Phase.

The Theoretical Framework on which the study was based is Janis and Mann's Conflict Theory (1968), and their Balance Sheet Procedure, which was used to facilitate personal decision-making and goal setting

by patients in relation to between dialyses weight gains and pre-dialysis serum potassium levels.

The results indicated that the Experimental group obtained significantly lower pre-dialysis serum potassium levels during the Intervention Phase than the Control group, but there were no significant differences between the two groups in weight gains between dialyses. The Well-Being Rating Scales completed by the Experimental patients indicated that well-being tended to increase slightly over the study period, and was significantly related to the achievement of the goals the patient had established for weight gains and potassium levels. A negative correlation was found between well-being and weight gain. The implications of these findings for the nursing care of hemodialysis patients are discussed, and recommendations for further research are presented.

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CHAPTER I

INTRODUCTION

The patient with chronic renal failure who is dependent on hemodialysis to sustain his life is faced with a multitude of problems which have repercussions in all areas of his personal and social life. These problems range from the psychological stress that accompanies learning to cope with life artificially maintained by machinery, to the daily annoyances of having to adhere to a medical regimen. Observations of patients on long term hemodialysis in the clinical setting reveal that both patients and the dialysis staff express great concern and devote much of their attention and time to the problems created by the consequences of non-adherence to the diet and fluid restrictions, which represent a significant portion of the hemodialysis regimen. In spite of patient education programs which frequently involve doctors, nurses and dietitians who all reinforce the same information, patients continue to experience these difficulties with their diet and fluid restrictions.

Nurses in hemodialysis settings are confronted with the evidence of non-adherence to the dietary regimen and the attendant difficulties this presents both in terms of patient comfort and well-being, and in terms of the management of dialysis for these patients. Concern for patient welfare leads to an attempt on the part of the dialysis staff to encourage patient adherence through repeated reminders of the necessity for the restrictions, and frequently progress to warnings and threats of the consequences to the patient of continued non-adherence.

What too often develops is a vicious cycle where patients

cannot meet staff expectations and withdraw from the staff when the latter attempt to lecture them about their failure to adhere to their restrictions. Staff, sensing that their messages are not "getting through", intensify their attempts by frequent repetition of increasingly threatening information. The patient often begins to feel that his inability to adhere to the diet and fluid restrictions reflects a lack of character, and his self-esteem decreases. The patient responds by further withdrawal from the staff, and the cycle is complete.

Why do patients have such difficulties in adhering to their diet and fluid restrictions? More importantly, what can nurses do to intervene into this cycle and effect increased patient adherence to the diet and fluid restrictions?

PURPOSE OF THE STUDY

The present study was an attempt to demonstrate increased patient adherence to fluid and potassium restrictions through a nursing intervention which provided patients with the opportunity to establish their own goals within a decision-making model.

PROBLEM STATEMENT

Does a nursing intervention which utilizes a decision-making model to assist patients in establishing personal goals for adherence to fluid and potassium restrictions significantly decrease weight gains between dialyses and pre-dialysis serum potassium levels, compared with the values for these variables in a control group which does not have the intervention?

HYPOTHESES

1. There will be no significant difference in adherence to fluid restrictions between hemodialysis patients exposed to a nursing inter-

intervention utilizing goal setting in a decision-making model and hemodialysis patients who were not exposed to the intervention as measured by between dialyses weight gains.

Alternative hypothesis: Between dialyses weight gains will be significantly lower for hemodialysis patients exposed to a nursing intervention which utilized goal setting within a decision-making model than for hemodialysis patients not exposed to the intervention.

2. There will be no significant difference in adherence to the diet restrictions between dialysis patients exposed to a nursing intervention utilizing goal setting in a decision-making model and hemodialysis patients who were not exposed to the intervention as measured by pre-dialysis serum potassium levels.

Alternative hypothesis: Pre-dialysis serum potassium levels will be significantly lower for hemodialysis patients exposed to a nursing intervention which utilized goal setting in a decision-making model than for hemodialysis patients not exposed to the intervention.

DEFINITION OF TERMS

1. Hemodialysis - "Dialysis, as it applies to clinical medicine may be defined as the removal of undesirable substances from the body by diffusive transfer across a semi-permeable membrane. It affords a direct means for correcting the chemical and clinical abnormalities of severe uremia."¹

2. Compliance - Compliance may be defined as "the extent to which the

¹L.W. Bluemele, "Dialysis," in Diseases of the Kidney, eds., M.B. Strauss and L.G. Welt (2d. ed.; Boston: Little, Brown and Co., 1971), p. 343.

patient's behavior, in terms of taking medications, following diets or executing other life-style changes, coincides with the clinical prescription."²

3. Between Dialyses Weight Gains - Between dialyses weight gains is the difference between the patient's pre-dialysis weight and his most recent post-dialysis weight.
4. Pre-Dialysis Serum Potassium - Pre-dialysis serum potassium is the serum potassium level in the patient's blood immediately prior to dialysis as measured by flame photometry.
5. Balance Sheet Procedure - The Balance Sheet Procedure is a decision-making tool adapted from Janis and Mann.³ It refers to the identification of the positive and negative consequences of adherence and non-adherence to the diet and fluid restrictions. (See Appendix A.)
6. Goal Setting Contract - Goal setting refers to the establishment of a written statement of the patient's goals in relation to between dialyses weight gains and pre-dialysis serum potassium levels. (See Appendix B.)
7. Well-Being Rating Scale - The Well-Being Rating Scale refers to the scale developed by the investigator to determine the patient's experience of the consequences he had identified in the Balance Sheet Procedure. (See Appendix C.)
8. Pre-Intervention Phase - The Pre-Intervention Phase refers to the six month period immediately preceding the initiation of the nursing intervention.

²D.L. Sackett and R.B. Haynes (eds.), Compliance With Therapeutic Regimens (Baltimore: The Johns Hopkins University Press, 1976), p. xi.

³I.L. Janis and L. Mann, "A Conflict Theory Approach to Attitude Change and Decision-Making," in Psychological Foundations of Attitudes, eds., A. Greenwald, T. Brock and T. Ostrom (New York: Academic Press, 1968), pp. 329-363.

9. Intervention Phase - This phase began with the first dialysis after the Experimental patients completed the interview, Balance Sheet Procedure and goal setting and continued for a total of fifteen dialyses. During this phase data on the between dialyses weight gains and pre-dialysis serum potassium levels were collected for both groups in the study. In addition, the Experimental group patients completed the Well-Being Rating Scale at each dialysis.
10. Follow-Up Phase - The Follow-Up phase refers to the nine dialyses immediately following the last dialysis of the intervention phase. Data on the between dialyses weight gains and pre-dialysis serum potassium levels continued to be collected for both groups, but neither group was approached by the investigator.

ASSUMPTIONS

1. Between dialyses weight gains and pre-dialysis serum potassium levels are valid indicators of adherence to the dietary and fluid restrictions in chronic hemodialysis patients.
2. Adherence to the dietary and fluid restrictions results in a higher level of health and well-being for the patient.

LIMITATIONS

1. The sample consists of only in-centre hemodialysis patients in one large renal unit. Both the experimental and control groups were drawn from that group of patients which dialyzes three times per week during the day. They may, therefore, not be representative of home dialysis patients, hemodialysis patients from other units, hemodialysis patients who dialyze during the night or patients who dialyze only twice per week. This limits the generalizability of the findings.
2. Data were obtained on a small sample (Experimental N=8, Control N=8). This must be taken into account when interpreting the findings.

OUTLINE OF THE STUDY

The present report is the description of an experimental study of the effects of a nursing intervention utilizing personal goal setting by patients in relation to between dialyses weight gains and pre-dialysis serum potassium levels within a decision-making model on their adherence to diet and fluid restrictions. The research design involves selection of a sample according to pre-established criteria and random assignment of subjects to either Experimental or Control conditions.

The Experimental group was exposed to the nursing intervention which consisted of decision-making and personal goal setting in relation to between dialyses weight gains and pre-dialysis serum potassium levels. The Experimental group patients also completed a Well-Being Rating Scale at each dialysis and charted their progress toward their goals on a Progress Sheet for the fifteen dialyses comprising the Intervention Phase. The nursing intervention was the independent variable.

The dependent variables were between dialyses weight gains and pre-dialysis serum potassium levels, and data on these variables were collected for all patients in the study in all three phases: the six month Pre-Intervention Phase, the fifteen dialyses during the Intervention Phase, and the nine dialyses during the Follow-Up Phase.

SIGNIFICANCE TO NURSING

In view of the fact that restrictions of fluid and certain foods is vitally important to the health and well-being of hemodialysis patients and that they experience much difficulty in adhering to these restrictions, it appears that interventions aimed at improving adherence to the diet and fluid restrictions are important. Although it is the responsibility of the physician to prescribe the restrictions for the patient, and of the dietitian to interpret these restrictions to the patient and his

family and help them establish the diet plan, it is the nurse who is in the best position to assist the patient in following these restrictions on the long-term basis required due to her continuous contact with him.

In relation to the research on compliance to medical regimens, Marston comments that, "Nearly all the research to date has been conducted by physicians or behavioral scientists....the problems of encouraging people with known disease conditions to follow their physicians' recommendations are appropriately of concern to nursing."⁴

The nursing staff has the opportunity to observe the patient's response to the restrictions and can intervene early and over prolonged periods with the patient. The nurse is in a strategic position to evaluate continually the patient's response to her intervention. There exists very little information of specific interventions which the nurse can utilize to improve her patient's adherence to the therapeutic regimen. Theoretically at least, the benefits of such an intervention would include better physical and emotional health for the patient, decreased incidence of complications, decreased health care costs, and increased satisfaction for the patient and his family.

As a nurse involved in the care of patients with chronic renal failure, this investigator is concerned about the effects, in particular, the long-term pathophysiological effects, of non-compliance with the diet and fluid restrictions in hemodialysis patients. Increased morbidity results in more frequent hospital admissions, which add to the overall health-care costs, and results in the loss of work and a disruption in family life for the patient. Most serious of course, is premature or

⁴M.V. Marston, "Compliance With Medical Regimens: A Review of the Literature," Nursing Research, 19:312, July-August, 1970.

sudden death from potassium overload, which is a very real possibility in this patient group.

The maintenance, protection and enhancement of the self-esteem and dignity of the patient group involved was the fundamental concern which prompted the selection of this research topic. Discussions of dietary compliance is an area of particular frustration to both the patient and the nursing staff. Very often the situation begins with explanations of what is expected of the patient, progresses to warnings and occasional threats of dire consequences of non-compliance, and deteriorates to a stalemate of hopeless resignation on both sides. Patients often complain that they are lectured to like children and point out, quite correctly, that the nurse does not know what it is like to constantly deny oneself the pleasures of certain foods and beverages. Resentment is a commonly expressed emotion.

In recognition of the dependent, non-adult status patients often feel they are assigned, this study attempts to place the interaction between the patient and the nurse in regard to the dietary regimen on an equal basis by giving the patient the control over establishing goals for himself.

ETHICAL CONSIDERATIONS

All patients participating in the study signed a consent form which was also signed by his attending physician and a witness. (See Appendix D.) The methodology did not require deception of any group in order to prevent knowledge of the real purpose of the study, nor did any group suffer the lack of necessary treatment, including visits by doctors and dietitians. The purpose of the study was explained to both groups. Patients were told that certain demographic information would be obtained from their charts, but that neither names nor any other identifying

information would be used.

All patients were informed that participation in the study involved allowing one milliliter of blood to be taken at the beginning of each dialysis for eight weeks, for a total of twenty-four milliliters over the study period, and that their pre and post dialysis weights would be recorded to determine weight gains between dialyses. The amount of blood required was minimal, although it is recognized that patients with chronic renal failure, and especially those on hemodialysis are anemic. The blood specimen was obtained at the beginning of dialysis, using the needle that was inserted for the purpose of dialysis, or from the arterio-venous shunt if the patient had one, which eliminated the necessity of an extra venipuncture to obtain the sample.

SUMMARY AND FOLLOWING CHAPTERS

This chapter describes the difficulties that hemodialysis patients experience in adhering to the diet and fluid restrictions and the lack of effective nursing intervention to promote this adherence. The problem investigated in the study, the hypotheses tested, and the assumptions and limitations are stated, and terms defined. The significance of the problem to the nursing care of this group of patients and the ethical considerations are discussed.

In the next chapter, a selected review of the pertinent literature is provided which briefly covers the normal functions of the kidney, renal failure and hemodialysis. The regimen which hemodialysis patients are prescribed is discussed, and the major findings of the research on compliance are highlighted, with special emphasis on the findings of studies of compliance using hemodialysis patients. Finally, a description of the theoretical framework upon which this study was based is presented.

In Chapter III, the methodology is given, with a description

of the setting in which the study took place, the criteria for sample selection, and the research design. A detailed description of the data collection procedures and the research tools used is provided; and additional research questions are posed. Finally, the methods used to analyze the hypotheses and additional research questions are enumerated.

An analysis of the characteristics of the study sample and the responses of the Experimental group to the nursing interview, the Balance Sheet and Goal Setting Procedures is included with the presentation of the findings in relation to the testing of the hypotheses and analysis of the additional research questions in Chapter IV.

The implications of these findings for the nursing care of hemodialysis patients and the recommendations for further research are presented in Chapter V.

CHAPTER II

REVIEW OF THE PERTINENT LITERATURE

The nature and scope of the problem of non-adherence to the diet and fluid restrictions in hemodialysis patients can be more fully appreciated by an understanding of the functions of the normal kidney, what occurs when these normal functions are lost, and a description of the consequences of non-adherence to the regimen in this patient population. In addition to these topics, the discussion in this chapter focuses on the present state of knowledge of compliance behavior and the rationale for the selection of Janis and Mann's Decision-Making framework.

THE NORMAL KIDNEY

In health, the kidney is the single most important organ for the regulation and maintenance of the internal milieu of the body, within the narrow limits compatible with life. It accomplishes this by selectively excreting, secreting, and reabsorbing fluids, electrolytes, and the waste products of metabolism. The kidney also serves as the major site of removal of the metabolic breakdown products of medications, poisons and other toxins; and plays an important role in the normal mineralization of bones, and in the production of red blood cells.¹

¹M.R. Wills, The Biochemical Consequences of Chronic Renal Failure (Leicester: The Cavendish Press Ltd., 1971), p.12.

RENAL FAILURE

The end result of a disturbance in renal function is an alteration in the constitution of the internal environment, which is of fundamental biochemical significance in the maintenance of life. The patient can often survive in relative comfort until about ninety percent of his glomerular filtration is lost.²

The consequence of chronic renal failure is a profound and lethal upset in the internal biochemical balance of the body, known as uremia. The Uremic Syndrome is compounded of numerous pathophysiological and biochemical changes reflecting decreased excretory, tubular, metabolic and regulatory activities of the kidney. The clinical syndrome of uremia involves all of the body's systems, due not only to the retained metabolic products, but also to the associated changes in electrolyte and acid-base homeostasis.³

Brundage summarizes these homeostatic upsets. They include: azotemia, as a result of the retention of nitrogenous compounds such as urea, uric acid and creatinine; electrolyte imbalances, caused by the retention of sodium, potassium, chloride and magnesium; acid-base imbalances, caused by the retention of hydrogen ions and a failure of the phosphate buffer system; calcium and phosphate imbalances, caused by a retention of phosphate and poor absorption of calcium from the gut, and hematological imbalances, caused by decreased production of erythropoietin by the kidney and a decreased life-span of red blood cells. There is also

²J.D. Harrington and E.R. Brener, Patient Care in Renal Failure (Philadelphia: W.B. Saunders Co., 1973), p.47.

⁴Wills, op.cit., p.25.

an increased tendency to bleed, probably related to a deficiency in the number and quality of platelets.⁴

Hekelman and Ostendarp state that these disturbances affect virtually all body systems and create distressing symptoms for the patient. Neurologically, there is fatigue, decreased mental and physical vigor, restlessness, insomnia, psychotic behavior, muscle twitching and cramps, sensory and motor peripheral neuropathies, confusion, convulsions and coma. The gastrointestinal system is also affected, with anorexia, nausea and vomiting, stomatitis, diarrhea, and even gastrointestinal bleeding being common problems. The skin frequently becomes dry and scaly, severely itchy and takes on a yellowish-brown discoloration, and there is the likelihood of bruising and petechia due to the increased bleeding tendency.⁵

Most of these symptoms can be completely reversed and others at least controlled by intermittent hemodialysis. This treatment is reserved for the terminal stage of total renal failure when conservative measures for controlling the uremic symptoms are no longer effective, and the patient's glomerular filtration rate has dropped to three to five percent of normal.⁶

⁴D.J. Brundage, Nursing Management of Renal Problems (St. Louis: The C.V. Mosby Co., 1976), pp. 43-49.

⁵F.P. Hekelman and C.A. Ostendarp, "Nursing Approaches to Conservative Management of Renal Disease," Nursing Clinics of North America, 10:438-441, September, 1975.

⁶Harrington and Brener, loc. cit.

HEMODIALYSIS

In spite of the fact that the first workable dialyzer was actually used by Abel, Rawntree and Turner in 1913⁷, and several models were developed over the years by other workers, dialysis for the treatment of chronic renal failure has only become a reality within the past two decades. This lag was caused by the mechanical and technical difficulties involved in implementing dialysis. The three fundamental problems were: the lack of a dependable and reproducible dialyzing membrane, a good anticoagulant, and most importantly for patients with chronic renal failure, the lack of blood stream access for repeated treatments.⁸

The discovery by Scribner and his colleagues of the Teflon-Silastic shunt which could be used for repeated access to the circulation surmounted the final obstacle and opened the way for chronic hemodialysis.⁹ Since the early 1960's hemodialysis facilities have expanded rapidly. Although the technical and engineering problems have not been solved completely, hemodialysis is now a relatively simple, safe, and effective method for maintaining the lives of thousands of individuals with end-stage renal disease. However, this artificial means of preserving life is not without its problems and drawbacks. As Abram points out, "Dialysis makes you feel better. It does not make you feel well."¹⁰

⁷J.J. Abel, L.G. Rawntree and B.B. Turner, "The Removal of Diffusable Substances from the Circulating Blood by Means of Dialysis," Transactions of the Association of American Physiologists, 28:41, 1913.

⁸C.F. Gutch and M.H. Stoner, Review of Hemodialysis for Nurses and Dialysis Personnel (2d. ed.; St. Louis: The C.V. Mosby Co., 1975), p.38.

⁹W.E. Quinton, D.H. Dillard and B.H. Scribner, "Cannulation of Blood Vessels for Prolonged Dialysis," Transactions of the American Society for Artificial Internal Organs, 6:104, 1960.

¹⁰H.S. Abram, G.L. Moore and F.B. Westervelt, "Suicidal Behavior in Chronic Dialysis Patients," American Journal of Psychiatry, 127: 1202, March, 1971.

PHYSICAL PROBLEMS ASSOCIATED WITH CHRONIC HEMODIALYSIS

Despite the fact that dialysis corrects the major biochemical abnormalities of uremia, the patient on long term hemodialysis is faced with continuing physical problems. Some of these are the result of the fact that hemodialysis can only approximate, at best, the function of the normal kidney in ridding the body of uremic toxins, and also that this is an intermittent procedure. In between dialyses, toxic wastes build up in the blood and then are rapidly removed in four to eight hours on dialysis. The effects of this rapid shift of large volumes of fluid and waste products is not fully known. Still other problems arise from the hemodialysis procedure itself.

Ford has identified these continuing physical problems as: anemia, which leads to lethargy, fatigue, weakness, and an inability to sustain physical effort; bone disease, which manifests itself in bone and joint pain, calcification of soft tissues, and pathological fractures; insomnia; pruritus; peripheral neuropathies; anorexia, nausea and vomiting and muscle wasting; an increased susceptibility to infection; and the dialysis disequilibrium syndrome, which may cause nausea, vomiting, headache and even convulsions when the patient is on dialysis.¹¹

Vertes discusses the problem of hypertension in chronic hemodialysis patients and the tendency for them to become volume overloaded which can create or exacerbate cardiovascular problems, shortness of breath and pulmonary edema.¹²

In an effort to minimize these negative symptoms and to increase the patient's well-being and physical health, a specially tailored diet

¹¹L. Ford, "A Question of Balance: The Effects of Chronic Renal Failure and Long-Term Dialysis," The Canadian Nurse, 75:23-24, March, 1977.

¹²V. Vertes, "Management of Hypertension Associated With Chronic Renal Failure," Postgraduate Medicine, 52:123-126, February, 1972.

is prescribed for each individual, which is designed to reduce the intake of substances which contribute to these distressing symptoms.

DIET AND FLUID RESTRICTIONS IN CHRONIC RENAL FAILURE

Gutch and Stoner point out that in order to achieve the same results as do the normal kidneys, dialysis would have to be continuous, which at the present stage of technological sophistication is both undesirable and impractical. Thus a compromise between what is best for the patient's health, and the practical considerations of time, facilities and money is reached by having patients dialyze two or three times per week. In between dialyses the waste products and excess fluids accumulate. For the sake of the patient's health, well-being and comfort, it is undesirable that he become overloaded with these waste products between dialyses. Rapid shifts of large volumes of fluid, urea, potassium and other substances can make the patient very ill, and could be dangerous.¹³

Oehlart states that the aim of diet therapy for patients on hemodialysis is to maintain the patient in biochemical control between dialyses and to avoid the development of complications. She says that while the actual diet and fluid restrictions vary with the individual patient, in general, protein, sodium, potassium and fluids are restricted to some degree.¹⁴

Gutch and Stoner emphasize the importance of dietary management, "It is vitally important to remember that for the patient, dialysis is an intermittent treatment for his lack of kidney function. Proper diet and fluid management are his continuous treatment. Overall management

¹³Gutch and Stoner, op.cit., p. 154.

¹⁴C.F. Oehlart, "An Assessment of Dietary Control in Patients on Hemodialysis," in Nursing and The Nephrology Patient, ed. L. Schlotter (Flushing, New York: Medical Examination Publishing Co., Inc., 1973), p.58.

involves both, and no amount of dialysis can compensate for inappropriate intake."¹⁵

The consequences for the patient which result from excess intake of protein, sodium, potassium and fluid can range from mildly annoying pruritus to sudden death from potassium overload. In addition to physical manifestations between dialyses, excessive intake of food and fluid create unique problems for the patient during dialysis when they are rapidly removed from the circulation.

Davidson and Scribner state that excessive protein intake is reflected in a high blood urea nitrogen level. This has been implicated as the cause of the altered intellectual and emotional states that are frequently found in patients with chronic renal failure. High blood urea nitrogen levels are also believed to be responsible for the dialysis disequilibrium syndrome, and may be cause peripheral neuropathies.¹⁶

Levinsky and Relman state that fluid and sodium work together in maintaining fluid balance. An overload of fluid can cause elevated blood pressure, resulting in vascular problems, increased kidney damage, increased risk of cerebral vascular accident, visual problems, pulmonary edema, congestive heart failure, and systemic edema.¹⁷

Excessive intake of potassium leads to an elevation of the serum potassium level in patients on hemodialysis, who are unable to excrete this substance through the kidneys. This, says Harrington and Brenner can cause electrocardiographic changes, cardiac arrhythmias and eventually

¹⁵Gutch and Stoner, op. cit., p.153.

¹⁶R.C. Davidson and B.H. Scribner, A Physician's Syllabus for the Treatment of Chronic Renal Failure (Seattle, Washington: Seattle Artificial Kidney Center, 1967), p.7.

¹⁷N.G. Levinsky and A.S. Relman, "Fluid and Electrolyte Balance," in Medicine, eds., C.S. Keefer and R.W. Wilkins (Boston: Little, Brown and Co., 1970), p.836.

cardiac standstill. Other manifestations of excessively high serum potassium include flaccid paralysis, slow respirations, anxiety, convulsions and anesthesia.¹⁸

The medical regimen prescribed for the dialysis patient is possibly one of the most difficult of any regimen, both in terms of learning the regimen and of carrying it out. This, coupled with the fact that the patient is expected to follow it on a long term basis, perhaps the rest of his life, creates an especially formidable task.

Brundage summarizes the proscriptions and prescriptions of the hemodialysis regimen, which include: hemodialysis appointments and restriction of protein, potassium, sodium and fluid and various medications.¹⁹ Hekelman and Ostendarp indicate that the prescribed medications amount to a major regimen by themselves, and include such necessary drugs as phosphate-binding medications in addition to vitamins, calcium, Vitamin D, antihypertensives, stool softeners or laxatives, sedatives and sleeping pills.²⁰

MEASURING PATIENT COMPLIANCE TO DIETARY AND FLUID RESTRICTIONS

Measuring compliance to the dietary and fluid aspects of the hemodialysis regimen would ideally include measurement of those physiological parameters used in the clinical area to estimate the patient's balance of protein, sodium, potassium and fluid. However, there is considerable evidence that several of these measurements are subject to influence by several factors unrelated to the patient's dietary intake. Koushanpour states that the blood urea nitrogen level

¹⁸Harrington and Brener, op. cit., p.41.

¹⁹Brundage, op. cit., pp.59-67.

²⁰Hekelman and Ostendarp, op. cit., pp.444-446.

can be found to be elevated by protein catabolism, thyroid hormone, congestive heart failure, dehydration, and stress, such as surgery, infection, burns, and severe toxicity.²¹ Burnbeck states that the blood urea nitrogen level in chronic hemodialysis patients will rise if the patient is in a negative nitrogen balance. This will occur in spite of decreased protein intake if insufficient high-quality protein is consumed. Under these conditions, a high blood urea nitrogen level indicates destruction of the body's protein stores to supply calories for energy, tissue repair, and maintenance.²²

Levinsky and Relman point out that the physiologic mechanisms that regulate sodium and water metabolism are closely interrelated and neither can be considered in isolation. Plasma sodium concentration reflects the relative proportions of sodium and water, not the absolute amount of sodium in the body.²³

While blood pressure tends to reflect the patient's sodium and fluid balance, it too can be influenced by several factors. According to Vertes, blood pressure in chronic hemodialysis patients can be influenced by stress and anxiety, drugs, such as antihypertensives, and certain pathophysiological states such as renin-dependent hypertension.²⁴

For the patient on dialysis, who is usually anuric or oliguric, fluids ingested between dialyses cannot be excreted and therefore are retained in the body until removed by ultrafiltration during the next dialysis. Gutch and Stoner therefore conclude, that for the patient with

²¹E. Koushanpour, Renal Physiology: Principles and Functions (Philadelphia: W.B. Saunders Co., 1976), p.504.

²²L.I. Burnbeck, "Conservative Care of Patients With Renal Failure," in Nursing and The Nephrology Patient, ed. L. Schlotter (Flushing, New York: Medical Examination Publishing Co., 1973), p.41.

²³Levinsky and Relman, op. cit., pp.835-836.

²⁴Vertes, op. cit. p.125.

chronic renal failure on hemodialysis, changes in body weight between dialyses provides the best indicator of fluid balance.²⁵

Natelson and Natelson state that because potassium is the major cation within the cell, and almost all natural foods are composed of cells, people who cannot excrete potassium are in danger of accumulating dangerously high levels of potassium in their blood.²⁶ Potassium is lost in small amounts in the feces and through the skin, but the major exit site is through the kidneys, where eighty to ninety percent of the potassium is excreted.²⁷ Although Hayes and Robinson have suggested that there is evidence of an increase in potassium concentration in the feces of uremic individuals, which is not associated with overt diarrhea, steatorrhea or obvious alteration in the intestinal transit time,²⁸ this accounts for a very small proportion of the daily ingestion of potassium and is ineffective in controlling the high serum potassium levels found in patients with chronic renal failure. As a result, says Bernbeck, potassium levels rise in the blood of individuals with renal failure, often to dangerously high proportions. This is augmented by the acidosis that exists in renal failure, as potassium tends to move out of the cells in exchange for hydrogen ions in the presence of acidosis.²⁹

Thus the estimate of the patient's compliance to the protein and sodium restrictions is made by indirect means, which have been shown to

²⁵Gutch and Stoner, op. cit., p.150

²⁶S. Natelson and E.A. Natelson, Principles of Applied Clinical Chemistry (New York: Plenum Press, 1975). p.130.

²⁷Ibid, p.121.

²⁸C.P. Hayes and R.R. Robinson, "Fecal Potassium Excretion in Patients on Chronic Intermittent Hemodialysis," Transactions of the American Society for Artificial Internal Organs, 11:244, 1965.

²⁹Bernbeck, loc. cit.

be influenced by several factors in addition to the patient's dietary intake. In contrast, weight gains between dialyses and serum potassium levels tend to reflect more accurately the patient's consumption of fluid and his intake of potassium respectively. Because potassium is found in virtually all natural foods, the pre-dialysis serum potassium level is an important indicator of the patient's adherence to his dietary restrictions. The literature supports the selection of these two variables: between dialyses weight gains and pre-dialysis serum potassium levels, as indicators of the patient's compliance to fluid and potassium restrictions. Additional support is provided by previous research of dietary and fluid compliance in hemodialysis patients by Chidoda³⁰ and Pierce³¹, both of whom used between dialyses weight gains and pre-dialysis serum potassium levels as dependent measures of compliance to the regimen.

While adherence to the diet and fluid regimen is a problem in hemodialysis populations, these patients are not alone in their inability to comply consistently with their medical regimens. Compliance to medical regimens has received much attention from researchers, and some general patterns and conclusions are now emerging from this field. In the next section, this research is examined to detect the major trends that have been found to influence compliance behavior.

³⁰S.M. Chidoda, "A Descriptive Study of Compliance With Medical Regimen: Dialysis and Diabetic Patients," (unpublished Master's thesis, McGill University, 1976).

³¹P.H. Pierce, "Influence of a Nurse-Patient Relationship Upon Hemodialysis Patients' Decision to Adhere to a Diet as a Task of Adaptation," (unpublished Master's thesis, Yale University, 1975).

RESEARCH ON COMPLIANCE TO MEDICAL REGIMENS

The complexity of compliance behavior and its determinants is reflected in the volume of literature on the subject and the number of factors which have been investigated. Sackett and Haynes identified over 150 individual factors as possible determinants of compliance in the more than two hundred articles on compliance they reviewed.³²

There is a lack of uniformity among such studies in the operational definition of compliance. Moreover, due to a lack of objective and precise measures of patient compliance, a multitude of methods have been used: patient report, pill and bottle counts, rate of refill of prescriptions, return clinic visits, direct observation, physiological parameters such as weight and blood pressure, and blood and urine assays. Many of these methods are notably inaccurate, says Marston; such as the patient's report of his compliance.³³

The accuracy with which patient compliance can be estimated is somewhat better in hemodialysis patients. Kaplan De-Nour and Czaczkes point out that in these patients, accurate and objective data in the form of weight changes and blood chemistry values are easily obtained.³⁴ However, this does not hold true for the majority of studies of compliance, and thus it is difficult to compare different studies to make generalizations about the factors which influence compliance behavior.

³²R.B. Haynes and D.L. Sackett, in collaboration with D.W. Taylor, B.C. Hackett, E. Luterbach, and J.R. Cloak, "An Annotated Bibliography; Including Notes on Methodologic Standards for Compliance Research," in Compliance With Therapeutic Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), pp.193-287.

³³M.V. Marston, "Compliance With Medical Regimens: A Review of the Literature," Nursing Research, 19:313-314, July-August, 1970.

³⁴A. Kaplan De-Nour and J.W. Czaczkes, "Personality Factors in Chronic Hemodialysis Patients Causing Noncompliance With Medical Regimen," Psychosomatic Medicine, 34:333, July-August, 1972.

A few serious investigators have prepared excellent reviews of the literature on compliance which reveal some major trends that appear to hold true from study to study and provide an overview of those variables which influence compliance behavior. The following discussion presents a summary of these major findings, with a special emphasis on studies conducted in hemodialysis settings. Following this, some of the theoretical frameworks on which interventions to effect compliance have been based are discussed briefly.

According to Parsons' Sick Role Construct, an individual who becomes ill assumes the rights and obligations of the sick role. He is exempt from his usual role obligations and assumes no blame for his condition, but at the same time is expected to seek competent medical supervision and to cooperate with his physician in order to expedite his recovery.³⁵

The situation described by Parsons is clearly an acute, reversible episode of illness from which the individual recovers. However, Petroni's study of the influence of such variables as age, sex, and chronicity on patients' perceived legitimacy of the sick role, revealed that the assumption of the sick role is judged to be more legitimate for persons with chronic illness than those with acute illness.³⁶

Thus it may be assumed that even for chronically ill persons such as hemodialysis patients there is a normative expectation that patients will cooperate with the medical authority they seek out. Yet the actual

³⁵T. Parsons, The Social System (Chicago: The Free Press, 1951).

³⁶F.A. Petroni, "The Influence of Age, Sex and Chronicity in Perceived Legitimacy of the Sick Role," Sociological and Social Research, 53:180-193, January, 1969.

degree of cooperation falls far short of this expectation. Published reports of compliance behavior indicate that from four percent to one hundred percent of patients fail to follow their medical regimens.³⁷

Davis estimates that for any given treatment group, at least a third of the patients will fail to comply with their doctor's recommendations.³⁸

Reliable figures for the degree of patient non-compliance are difficult to obtain for hemodialysis patients. Kaplan De-Nour and Czaczkes have reported only fair to poor compliance to the diet in forty out of a group of fifty-two hemodialysis patients they studied, indicating a non-compliance rate of almost eighty percent.³⁹ In discussing the results of a later study of factors contributing to non-compliance to the diet in hemodialysis patients, they report, "On the whole, adherence to the diet seemed to be rather poor; about half of the patients could be regarded as abusers of this part of the medical regimen."⁴⁰

In a survey of 201 hemodialysis centers in the United States, consisting of over three thousand hemodialysis patients, Abram, Moore and Westervelt reported 117 deaths as a result of non-adherence to the treatment regimen in such ways as the "...ingestion of large amounts of fluids and foods forbidden by the dialysis regimen."⁴¹

Thus it appears that the problem of non-adherence to the diet and fluid restrictions in hemodialysis populations is significant.

³⁷Marston, op. cit., p.312.

³⁸M.S. Davis, "Variations in Patients' Compliance With Doctors' Orders: Analysis of Congruence Between Survey Responses and Results of Empirical Investigations," Journal of Medical Education, 41:1039, 1969.

³⁹A. Kaplan De-Nour and J.W. Czaczkes, "Personality and Adjustment to Chronic Hemodialysis," in Living or Dying: Adaptation to Hemodialysis, ed., N.B. Levy (Springfield, Ill., Charles C. Thomas, Pub., 1974), p.122.

⁴⁰Kaplan De-Nour and Czaczkes, "Noncompliance," p.333.

⁴¹H.S. Abram, G.L. Moore and F.B. Westervelt, "Suicidal Behavior in Chronic Dialysis Patients," American Journal of Psychiatry, 127:119-124, March, 1971.

The findings of the literature on compliance to medical regimens will be summarized under the following headings: demographic features of patients, features of the disease, features of the therapeutic regimen, features of the therapeutic source, features of the patient-therapist interaction, and sociobehavioral features of patients.

DEMOGRAPHIC FEATURES OF PATIENTS

Marston, in her review of the literature on compliance discusses the findings of more than eighty studies. Research into the effects of the demographic characteristics of patients on compliance to therapeutic regimens is conflicting; although some studies suggest that demographic variables may be predictive of compliance, the evidence from several studies is contradictory. Marston concludes that, "Demographic variables such as age, sex, socioeconomic status, education, religion, marital status and race, when examined apart from other variables have rarely been predictive of compliance with medical regimens."⁴²

This conclusion is supported by Davis, who found that demographic variables were not predictive of compliant behavior in a group of 156 outpatients he studied.⁴³ In his extensive review of the literature on compliance, Haynes concludes that the effect of demographic factors would appear to be much greater upon access to health services than upon compliance with therapy among patients who are already in the system.⁴⁴

⁴²Marston, op. cit., p.317.

⁴³M.S. Davis, "Variation in Patients' Compliance With Doctors' Orders: Medical Practice and Doctor-Patient Interaction," Psychiatry in Medicine, 2:42, 1971.

⁴⁴R.B. Haynes, "A Critical Review of the 'Determinants' of Patient Compliance With Therapeutic Regimens," in Compliance With Therapeutic Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), p.30.

FEATURES OF THE DISEASE

Severity of the illness being treated may influence whether the individual seeks and follows medical advice. Watts found that the more severe the condition or symptoms, the more likely the individual was to seek and follow medical recommendations.⁴⁵ However, the results of a study by Elling have shown the opposite tendency: the more severe the illness, the less likely were patients to follow the doctor's orders.⁴⁶

Haynes reviewed more than fifty studies investigating the effects of the disease on patient compliance to the therapeutic regimen, covering such areas as: diagnosis, severity of the illness, duration of the illness, effects of previous bouts of the disease, the recency of the last attack, effects of previous therapy, the degree of disability and the symptoms of the disease. He concluded that, except for a consistent finding that a psychiatric diagnosis is associated with non-compliance, one could not identify the non-complier by his diagnosis, nor by the features of his disease.⁴⁷

FEATURES OF THE THERAPEUTIC REGIMEN

Davis points out that a medical regimen is a composite of recommendations and that patients may comply with all, some, or none of the advice.⁴⁸ Strauss states that regimens are not just automatically accepted. They are judged on the basis of efficiency, legitimacy, or both. Also, they are judged on social rather than medical bases. He identified the conditions that determine whether or not patients will

⁴⁵D.D. Watts, "Factors Related to the Acceptance of Modern Medicine," American Journal of Public Health, 56:1205-1212, August, 1966.

⁴⁶R. Elling et al., "Patient Participation in a Pediatric Program," Journal of Health and Human Behavior, 1:183-191, Fall, 1960.

⁴⁷Haynes, op. cit., p.30.

⁴⁸Davis, "Survey Responses," p.1044.

adhere to a prescribed regimen. Compliance, says Strauss, will be more likely if: a) there is an initial or continuing trust in the physician or whoever else prescribes the regimen, b) no rival supercedes the physician in his legitimating, c) there is evidence that the regimen works either to control symptoms or the disease itself, or both, d) no distressing, frightening side effects appear, e) the side effects are outweighed by symptom relief or by sufficient fear of the disease itself, f) there is a relative noninterference with important daily activities, either of the patient or of the people around him, g) the regimen's perceived good effects are not outweighed by a negative impact on the patient's sense of identity.⁴⁹

The very characteristics of the regimen, says Strauss, constitute important contributing conditions for adhering to, relaxing, or even rejecting the prescribed regimen altogether. Thus, the ease with which the regimen is learned, the amount of time, expense and energy it takes, and the discomfort or side effects that occur will influence the degree to which the patient will adhere to it. Regimens which contribute to the patient's social isolation or cause him to be stigmatized by others are unlikely to be followed.⁵⁰

Haynes reports that a review of the literature indicates that one of the few features of the regimen about which there are no dissenting reports concerns the degree of behavioral change the regimen requires of the patient. Passive cooperation is most easily attained, and active cooperation is less easily achieved. A steep gradient has been demonstrated

⁴⁹A.L. Strauss, Chronic Illness and the Quality of Life (St. Louis: The C.V. Mosby Co., 1975), pp.21-22.

⁵⁰Ibid, p.27.

in which the compliance exhibited by patients who must acquire new habits, such as taking medications; is much greater than that exhibited by those who must alter old behaviors, such as dietary or vocational habits, which exceeds in turn, that of those who must break personal habits.⁵¹

These conclusions are also supported by Davis, who found that the greater the effect of the illness and its treatment in interfering with the activities of daily living, the less likely the patient was to follow the doctor's advice.⁵²

Research suggests that an inverse relationship exists between compliance and the difficulty of the regimen. Davis and Eichhorn found that when more than one recommendation was made, patients were unlikely to follow all of them.⁵³ Also, Francis found that compliance was lower for patients for whom both drugs and other recommendations were made than for those with simpler regimens.⁵⁴ Johnson has stated that recommendations regarding diet show the greatest decrease in compliance over time.⁵⁵

Haynes suggests that the degree of behavior change required in a regimen may also explain the decline in compliance that accompanies increasingly complicated regimens. He reports that there is a relationship between the length of time that patients are under treatment and

⁵¹Haynes, op. cit., p.31.

⁵²M.S. Davis, "Physiologic, Psychological and Demographic Factors in Patient Compliance With Doctors' Orders," Medical Care, 6:121, 1968.

⁵³M.S. Davis and R.L. Eichhorn, "Compliance With Medical Regimens: A Panel Study," Journal of Health and Human Behavior, 4:247, Winter, 1963.

⁵⁴V. Francis et al., "Gaps in Doctor-Patient Communication: Patients' Response to Medical Advice," New England Journal of Medicine, 280:539, March 6, 1969.

⁵⁵W.L. Johnson, "Conformity to Medical Recommendations in Coronary Heart Disease" (paper presented at the American Sociological Association meeting, September 2, 1965, Chicago, Ill.).

their compliance, with compliance decreasing over time.⁵⁶

In summary, the research indicates that patients who are required to follow a difficult and complex regimen that necessitates a major change in personal habits, and must follow this regimen for long periods are unlikely to achieve a high degree of compliance. This describes the type of regimen that hemodialysis patients are prescribed, and suggests possible explanations for the degree of non-compliance observed in these patients.

FEATURES OF THE THERAPEUTIC SOURCE

Haynes reports the findings of several studies which indicate that health professionals are unable to distinguish between non-compliers and compliers among their own patients; tending to overestimate the degree of compliance achieved.⁵⁷

In hemodialysis patients, where immediate and relatively objective evidence of non-compliance is more readily available from the patients' weight gains, blood pressures and pre-dialysis blood chemistries, this may not be the case. Pierce reports that staff members tended to underestimate the compliance of the hemodialysis patients in her study.⁵⁸

Kaplan De-Nour and Czaczkes report that they successfully predicted hemodialysis patients' dietary compliance after twelve months of dialysis from a personality assessment made before they began dialysis.⁵⁹

⁵⁶Haynes, op. cit., p.32.

⁵⁷Ibid, p.33.

⁵⁸Pierce, op. cit., p.87.

⁵⁹Kaplan De-Nour and Czaczkes, "Personality and Adjustment," p.122.

FEATURES OF THE PATIENT-THERAPIST INTERACTION

Haynes reports that all studies on the relationship between the degree of supervision and compliance have found a positive association. Thus, hospitalized patients are more compliant than day patients, who are more compliant than out-patients. Furthermore, increases in compliance have been shown when the frequency of out-patient visits is increased, when home visits are added, when the patient's family is recruited to assist in supervision, when objective evidence of non-compliance is fed back to the patient, and when continuity of care is provided. The second consistent finding is that the patient's stated level of satisfaction with the therapist and clinic is correlated with compliance, and that compliance is positively associated with the patient's conclusions that his expectations have been met by his therapist.⁶⁰

The effects of doctor-patient communication on compliance was investigated by Davis, using Bale's Interaction Process Analysis. He found that all types of doctor-patient communication were associated with non-compliance except: solidary relationship, evaluative congruence, and tension-release; and of these, only tension-release was significantly correlated with patient compliance.⁶¹

No study could be found which investigated the effects of the care-giver -patient relationship on hemodialysis patients' adherence to their diet and fluid restrictions, nor of the effects of structuring the interaction to provide for continuity of care or home visits.

⁶⁰Haynes, op. cit., p.35.

⁶¹M.S. Davis, "Variations in Patients' Compliance With Doctors' Advice: An Empirical Analysis of Patterns of Communication," American Journal of Public Health, 58:283, February, 1968.

SOCIOBEHAVIORAL FEATURES OF PATIENTS

Investigations into the mediating psychological variables have yielded little toward the understanding of compliance. Marston cautions against the assumption that psychological tests, which have been validated on groups of university students will be valid for groups of chronically ill persons.⁶²

Adjective check-lists have been used in some studies to describe the characteristics of complying and non-complying patients. Davis found that outpatients who were described by their doctors as responsive, cooperative, grateful, articulate, intelligent, and formal were more likely to comply with the doctor's recommendations than were those described as authoritarian, demanding, overbearing, and obstructive; but there was no significant correlation between dependent-submissive ratings and compliance.⁶³

Research by Janis and others into the use of fear communications has indicated that, when accompanied by practical instructions for reducing or eliminating the threat, fear communications are effective in motivating people to undertake diagnostic and preventive health measures. However, the relationship between fear arousal and willingness to follow the suggested therapy appears to be curvilinear, and when the level of fear arousal is very high, the individual is less likely to remember or follow the specific measures to avoid the threat.⁶⁴

⁶²Marston, op. cit., p.321.

⁶³Davis, "Physiologic," p.121.

⁶⁴I.L. Janis and S. Feshback, "Effects of Fear-Arousing Communications," Journal of Abnormal Social Psychology, 48:78-92, 1953; see also I.L. Janis and R.F. Terwilliger, "An Experimental Study of Psychological Resistance to Fear-Arousing Communications," Journal of Abnormal Social Psychology, 65:403-410, 1962.

Swinehart suggested that messages that are repeated too often can produce hostility toward the communicator, greater rigidity in attitudes and forgetting or distortion of previously received information. This is especially true if the message is fear-producing.⁶⁵ Thus, frequent repetition of threatening information by nurses to hemodialysis patients in an attempt to promote compliance is ineffective and moreover, may produce hostility toward the staff by the patients and interfere with the learning of the very information the staff seeks to impart.

Marston concludes that the literature on compliance to medical regimens supports the fact that knowledge alone concerning the illness and its treatment has not provided sufficient motivation for patients to follow their regimens.⁶⁶ This conclusion receives support from the frequent observation made in dialysis settings that providing the patient with information concerning the diet and fluid restrictions does not guarantee that the patient will actually adhere to these restrictions.

Haynes reports that the influence of the family appears to be considerable in studies of compliance. Compliance is higher among patients with intact, "supportive" families and lower among those from unstable families.⁶⁷

Attitudes toward work have been related to compliance with medical regimens. Goldstein and Eichhorn found that in general, high work-oriented individuals are likely to report non-compliance and low work-oriented individuals report a high degree of compliance with doctors'

⁶⁵R. Swinehart, Seek Wisely to Prevent, ed., J. Wakefield (London: Her Majesty's Stationery Office, 1973), p.172.

⁶⁶Marston, op. cit., pp.320-321.

⁶⁷Haynes, op. cit., p.36.

recommendations in their study of a group of cardiac patients who were advised to decrease their work loads.⁶⁸

Other characteristics that were found to predict both present and future compliance according to Haynes' review of the literature, include a history of compliance with a previous regimen, and compliance with one or more aspects of the present regimen the patient is following.⁶⁹

The Health Belief Model formulated by Rosenstock and others⁷⁰ receives support from the literature for its predictive value in compliance studies. The model makes predictions of an individual's compliance behavior from his attitudes toward illness, his belief in personal susceptibility to illness, his perceived seriousness of the consequences, and his belief that some course of action is available to him to avoid these consequences. Becker, in his summary of the research in the use of the model, found support for the following: individuals with a negative attitude toward illness are more willing to follow medical advice in order to avoid serious consequences, and those who regard the disease as serious, and that they are personally susceptible, and to a lesser extent, that there is an available, effective therapy to avoid the threat, are more willing to comply with medical recommendations.⁷¹

In summary, the evidence from studies of the relationship of various sociobehavioral patient characteristics to compliance supports

⁶⁸B. Goldstein and R.L. Eichhorn, "The Changing Protestant Ethic: Rural Patterns in Health, Work and Leisure," American Sociologic Review, 26:557-565, August, 1961.

⁶⁹Haynes, op. cit., p.36.

⁷⁰I.M. Rosenstock, "Why People Use Health Services," Milbank Memorial Fund Quarterly, 44:94-124, July, 1966.

⁷¹M.H. Becker, "Sociobehavioral Determinants of Compliance," in Compliance With Medical Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), p.41.

the following conclusions: first, the Health Belief Model appears to be of predictive value; second, a gap exists between the patient's knowledge of his disease and therapy and his compliance with that therapy; third, compliance with one aspect of the regimen favours compliance with other aspects; and finally, the stability and support of the patient's family are strongly correlated with his or her compliance.

Haynes' review of 185 studies on compliance suggests that the following characteristics are associated with non-compliance to medical regimens: psychiatric diagnosis; regimens which are complex, involve a great degree of behavioral change, and are of long duration; inefficient and inconvenient clinics; inadequate supervision; patient dissatisfaction with therapy; inappropriate health beliefs; previous or present non-compliance with medical regimens; and finally, family instability.⁷²

INTERVENTIONS TO PROMOTE COMPLIANCE

Becker points out that research into the factors associated with patient compliance, while providing information concerning this phenomenon, are deficient because the majority of these factors are not amenable to change. Characteristics of the regimen, patient-physician relationship and the waiting time in clinics can be altered to some degree to promote greater patient cooperation, but other factors such as demographic, physiological and sociobehavioral characteristics of patients are relatively enduring and unalterable.⁷³

Haynes reviewed over forty studies that reported clinical maneuvers to improve compliance, and has divided these studies into three classifications based on the strategy used: educational, behavioral and

⁷¹Haynes, op. cit., p.39.

⁷²Becker, op. cit., p.40.

a mixture of these two, or combined strategies. He examined the findings for methodological soundness, clinically significant results, and the degree to which the strategy was effective in promoting therapeutic outcomes. While the methodologic rating was similar for all strategies, it appears that the behavioral and combined strategies hold a substantial edge over educational strategies in terms of improving both compliance and therapeutic outcomes.⁷³

EDUCATIONAL STRATEGIES

Rosenberg states that a resumé of the data from studies using educational strategies proves the thesis that planned, organized patient education, when provided as a part of routine patient care, can and does increase adherence to a prescribed medical regimen.⁷⁴ However, Neufeld's conclusion is that the evidence that patient education improves compliance is convincing on neither methodologic nor educational grounds.⁷⁵

BEHAVIORAL STRATEGIES

Barofsky states that the physician's management of the therapeutic regimen constitutes an example of operant behavior occurring in a social situation. Behavioral therapeutics is concerned with the recognition and treatment of behaviors that interfere with optimal health and its achievement and are therefore, "non-adaptive". Barofsky identifies three

⁷³R.B. Haynes, "Strategies for Improving Compliance: A Methodologic Analysis and Review," in Compliance With Medical Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), pp.69-74.

⁷⁴S.G. Rosenberg, "Patient Education: An Educator's View," in Compliance With Therapeutic Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), p.98.

⁷⁵V.R. Neufeld, "Patient Education: A Critique," in Compliance With Therapeutic Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), p.88.

strategies that have been shown to affect patient compliance to medical regimens: first is the use of behavior modification techniques which include differential reinforcement, extinction, shaping, modelling, and desensitization, and can be developed into the strategies of aversive counterconditioning, self-control procedures, family-patient monitoring or feedback modelling of self-care, and desensitization to aversions. The success of any behavior control procedure, he says, depends on making explicit the consequences of a patient's behavior to him. The second strategy is the use of all members of the health delivery team to increase the number of contacts the patient has with the reinforcement of compliance behaviors. The third strategy seeks to improve compliance by providing social control in the form of a patient contract which specifies what the patient can expect and what is expected of him. Barofsky finds support for these strategies in the literature.⁷⁶

COMBINED STRATEGIES

Fink describes a combined strategy, the consensual regimen, which is a product of a particular type of negotiation between the patient and the health care providers, where the regimen represents a consensus or mutual contract.⁷⁷ In a study utilizing a consensual contract and a "management specialist" who dealt with both the family and the child, families reported increased feelings of personal worth, conviction of the interest and respect of the provider and institution toward the health status of the child and family, and a sense that the provider showed

⁷⁶I. Barofsky, "Behavioral Therapeutics and the Management of Therapeutic Regimens," in Compliance With Therapeutic Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), pp.100-109.

⁷⁷D.L. Fink, "Tailoring the Consensual Regimen," in Compliance With Therapeutic Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), p.110.

appreciation of individual family circumstances.⁷⁸

STUDIES OF COMPLIANCE IN HEMODIALYSIS POPULATIONS

Kaplan De-Nour and Czaczkes studied compliance to the diet and fluid restrictions in forty-three hemodialysis patients. They found that a low frustration tolerance and primary and secondary gains from the sick role were most frequently associated with non-compliance and these differentiated significantly between compliers and non-compliers.

"Acting-out" behavior, which was found in both groups, was more severe in the non-compliant group. Denial of the sick role, suicidal and homicidal intentions, usually on the part of the patient's family, were less often associated with non-compliance to the diet and fluid restrictions. In this particular sample, almost half of the patients were considered as abusers of the dietary regimen.⁷⁹

Czaczkes and Kaplan De-Nour analyzed psychiatric and psychological factors of hemodialysis patients prior to beginning chronic hemodialysis in an effort to predict their compliance to the diet and fluid restrictions. They were able to successfully predict which patients would have "good", "fair" and "bad" compliance to the diet twelve months after they began dialysis, more than seventy-five percent of the time. Factors which were associated with non-compliance were a low frustration tolerance, inability to delay gratification, a tendency to act out aggressive feelings, denial of ill health and excessive gain from the sick

⁷⁸D.L. Fink et al., "The Management Specialist in Effective Pediatric Ambulatory Care," American Journal of Public Health, 59:527-533, 1969.

⁷⁹Kaplan De-Nour and Czaczkes, "Noncompliance," pp.333-344.

role; while obsessive-compulsive traits and a high frustration tolerance seemed to help patients comply with their restrictions.⁸⁰

Winokur and others made psychological and intelligence assessments prior to the initiation of patients into chronic hemodialysis programs and compared these with the dietary adherence and work levels six months after the start of therapy. They were unable to relate dietary adherence with intelligence, but showed a tendency for denial of the sick role and "acting-out" behavior to be associated with non-compliance.⁸¹

Chidoda utilized the Health Belief Model in her study of compliance to the medical regimen by hemodialysis patients and patients with diabetes mellitus. She found that hemodialysis patients with a high degree of perceived seriousness; that is, that they perceived their conditions to be serious, were less compliant than those with low perceived seriousness, contrary to the predicted results. The hypotheses, derived from the model, were not supported by the data, and Chidoda concludes that the Health Belief Model is not a valid predictor of behavior for chronically ill individuals.⁸²

In her study of compliance in hemodialysis patients, Pierce utilized the Balance Sheet Procedure developed by Janis and Mann⁸³ as an intervention designed to increase dietary compliance. Her results indicated that that the Balance Sheet Procedure was helpful in lowering the pre-dialysis serum potassium and between dialyses weight gains in some dialysis patients, but was not effective for the group as a whole.

⁸⁰Kaplan De-Nour and Czaczkes, "Personality and Adjustment," p.104.

⁸¹M.Z. Winokur et al., "Intelligence and Adjustment to Chronic Hemodialysis," Journal of Psychosomatic Research, 17:29-34, 1973.

⁸²Chidoda, loc. cit. p.89.

⁸³I.L. Janis and L. Mann, "A Conflict Theory Approach to Attitude Change and Decision-making," in Psychological Foundations of Attitudes, eds., A. Greenwald and others (New York: Academic Press, 1968), pp.329-363.

Pierce concluded that her results indicated that conscious, deliberative decision-making by the patient influences his ability to adhere to the dietary restrictions and she urged further use of the Balance Sheet Procedure in studies of compliance.⁸⁴

The literature on factors associated with compliance reveal that the medical regimens that chronic hemodialysis patients must follow make it unlikely that a high degree of compliance will occur. The regimen is complex, involves a major disruption of personal habits and patients are expected to continue it indefinitely. A review of the studies to date of compliance in hemodialysis patients reveals that the majority of such studies have been conducted by psychiatrists who have identified certain psychiatric diagnoses that are associated with non-compliance to the dietary regimen. As has been pointed out, factors which pertain to the personality, sociobehavioral or demographic characteristics of individuals are relatively enduring and unalterable. Such studies do not offer the nurse direction in establishing effective interventions to increase compliance. The study by Pierce is a notable exception, and the Balance Sheet Procedure utilized in her study will be discussed further in the Theoretical Framework.

The discussion which follows examines the psychological difficulties encountered by hemodialysis patients as a result of their disease and its treatment.

⁸⁴Pierce, op. cit., p.134.

PSYCHOLOGICAL PROBLEMS ASSOCIATED WITH CHRONIC HEMODIALYSIS

The physical problems which hemodialysis patients suffer, coupled with the stress of life on a machine and the necessity of adhering to a stringent medical regimen have created unique problems in body image and self-esteem for the patient. Wijssenbeek and Munitz note that the patient is continually confronted with the evidence of the existence of his disease by the arteriovenous shunt or the scars from the needling of his fistula. The attachment to the dialysis machine and the concomitant flowing of blood outside the body are potent causes for disturbances of the integrity of body image.⁸⁵

It has been suggested that there is perhaps no situation which is as stressful to patients and their families as chronic hemodialysis.⁸⁶ Shea has remarked that the emotional reaction to the need for chronic hemodialysis may represent the greatest obstacle to successful rehabilitation.⁸⁷ It is not surprising then, that soon after chronic hemodialysis programs became established, reports of the psychological stresses of adapting to life on a machine began to appear in the literature.

The formal psychiatric studies reflected the losses suffered by hemodialysis patients as a result of their disease, its treatment, or both, and suggested the underlying sources of conflict.

⁸⁵A. Wijssenbeek and A. Munitz, "Group Treatment in a Hemodialysis Centre," Psychiatry, Neurology and Neurosurgery, 73:213-220, 1970.

⁸⁶C. Hampers and E. Schupak, Long-Term Hemodialysis (New York: Grune and Stratton, 1967), p.147.

⁸⁷E.J. Shea et al., "Hemodialysis for Chronic Renal Failure: IV, Psychological Considerations," Annals of Internal Medicine, 62:558, March, 1965.

Wright outlines the psychological stress of hemodialysis in three categories: a) actual or threatened losses, such as the loss of body parts or functions, loss of membership in groups, failure of plans or ventures, changes in the way of life or living, loss of home, possessions or financial status, and the loss of one's job or occupation; b) injury or threat of injury, such as surgery, and the fear of losing the patency of one's shunt or fistula; c) frustration of drives or derivatives, such as dietary restrictions, and the loss of sexual satisfaction.⁸⁸

Kaplan De-Nour identified five sources of stress for hemodialysis patients. These are: a) dependency; on the machine and staff for hemodialysis treatments, b) frustration; the frustration of drives and the delay of gratification caused by the food and fluid restrictions, the inability to travel, and sexual problems, c) aggression; as a result of the many losses the patient suffers, such as the loss of financial status, position, appearance, and the loss of body functions, and also as a result of the restrictions of dialysis and his dependency on the treatment, d) the changes in body image; caused by repeated operations, the shunt, and the lack of urination, and e) the threat of death.⁸⁹

Finally, Abram has described the stresses for patients as: a) dependence versus independence needs in the patient, b) the relationship with an inanimate object, the hemodialysis machine, c) the

⁸⁸R.G. Wright, P. Sand and G. Livingstone, "Psychological Stress During Hemodialysis for Chronic Renal Failure," Annals of Internal Medicine, 64:611-621, March, 1966.

⁸⁹A. Kaplan De-Nour, "Psychotherapy With Patients on Chronic Hemodialysis," British Journal of Psychiatry, 116:207-215, February, 1970.

ambivalence over life and death, d) the role of denial as a major defence mechanism, and e) interpersonal conflicts with the dialysis personnel and the spouse.⁹⁰

In contrast to the psychiatric literature which proposes a medical model, pathophysiological approach to the reactions of patients to hemodialysis, Santopietro sees patients' reactions as a normal response to their stressful circumstances. She views the behavior of these patients as a means of expressing underlying emotional needs, which she identifies as: a) the need to grieve the losses suffered as a result of the disease, b) the need for identity in the face of a threat to one's self-concept, c) the need for safety and control of the environment, d) the need for communication of one's fears and hopes with significant others, e) the need for love and acceptance, and f) the need to establish one's optimal level of wellness.⁹¹

These articles give recognition to the fact that an artificial means of supporting life create psychological difficulties in those who are dependent on machines for survival and demand of them a complex adaptation process.

COPING WITH HEMODIALYSIS

According to Levy and Reichsman, the process of adaptation to dialysis involves three stages. The first phase or "Honeymoon Phase" is marked by increased physical well-being, confidence and hope. The

⁹⁰H.S. Abram, "Survival by Machine: The Psychological Stress of Chronic Hemodialysis," Psychiatry in Medicine, 1:41, 1971.

⁹¹M.S. Santopietro, "Meeting the Emotional Needs of Hemodialysis Patients and Their Spouses," American Journal of Nursing, 75:629, April, 1975.

"Disenchantment or Discouragement Period" follows and is characterized by sadness, hopelessness and helplessness. Finally, in the "Period of Long-Term Adaptation" the patient attempts to cope with his disease and treatment. They remark that some patients never reach the final stage.⁹²

Lipowski has stated that the process of learning to cope with a severe, life-threatening disease and an equally threatening treatment is a formidable task. Individuals resort to habitual modes of coping when faced with illness.⁹³

However, most people are ill-prepared to have to deal with problems of the scope and significance of those facing the dialysand. He must somehow find the resources for the cognitive and motor skills which are required for developing new coping strategies at a time when his physical and emotional energy are at their lowest. Anger states that:

"Deprived of usual methods of coping with stress, that is, eating, drinking, and sex, the dialysis patient may resort to the use of defence mechanisms in order to maintain a sense of equilibrium and self-worth."⁹⁴

There is much evidence to suggest that dialysis patients use denial extensively as their defence against anxiety. Short and Wilson found that psychological testing, using the Minnesota Multiphasic Personality Inventory showed that as time on dialysis progressed, patients used increasing levels of denial and repression, which in turn was associated with decreased anxiety.⁹⁵

⁹²F. Reichsman and N.B. Levy, "Problems in Adaptation to Maintenance Hemodialysis," Annals of Internal Medicine, 70:860, December, 1972.

⁹³Z.J. Lipowski, "Physical Illness and the Coping Process," Psychiatry in Medicine, 3:95, 1972.

⁹⁴D. Anger, "The Psychological Stress of Chronic Renal Disease and Long-Term Hemodialysis," Nursing Clinics of North America, 10:454, 1975.

⁹⁵M.J. Short and W.P. Wilson, "Roles of Denial in Chronic Hemodialysis," Archives of General Psychiatry, 20:433-437, April, 1969.

In effect says MacElveen, denial helps the patient to cope with the life and death issues and with the complications of his illness, and in this way helps to prevent severe depression. Denial thus serves an adaptive function for the patient and is seen as helpful as long as it is not so strong that he fails to follow his therapeutic regimen.⁹⁶

This view is supported by Gilmore, who suggests that defence mechanisms are not necessarily antithetical to successful coping, but may be part of the overall coping effort.⁹⁷

However, Goldstein proposed that denial could function to reduce compliance in hemodialysis patients. He found that a group of chronic hemodialysis patients scored significantly higher in denial as measured by the Minnesota Multiphasic Personality Inventory, and significantly more external on Rotter's Locus of Control Scale than a control group of patients without a life-threatening or severe medical condition.⁹⁸

According to Rotter, individuals perceive the source of reinforcement for their actions as either within themselves and therefore under their control, or under the control of powerful others or chance, and beyond their control.⁹⁹

Goldstein and Reznikoff propose that as a result of the continuous

⁹⁶P. MacElveen, "Cooperative Triad in Home Dialysis," in Communicating Nursing Research, Vol.III, ed., M. Batey (Boulder, Colorado: WICHE, 1972), p.137.

⁹⁷J.V. Gilmore, The Productive Personality (San Francisco: Albion Publishing Co., 1974), p.137.

⁹⁸A.M. Goldstein, "Denial as a Function of Internal-External Control in Chronic Renal Failure" (unpublished doctoral dissertation, Fordham University, New York; 1971).

⁹⁹J.B. Rotter, "Generalized Expectancies for Internal Versus External Control of Reinforcement," Psychological Monographs, 80:1-28, 1966.

responsibility and anxiety dialysis patients face in maintaining their lives, they adopt an External Locus of Control framework and utilize massive amounts of denial in an attempt to cope with this anxiety. The end result is an inability to perceive the important role they play in keeping themselves alive through adherence to their diet and fluid restrictions. They recommend that dialysis patients be encouraged to see this role, and be assisted in managing their therapeutic regimens.¹⁰⁰

The recommendation that patients need encouragement to assume an active role in managing their regimens is echoed by Anger. She states that patients will be motivated to achieve their highest level of rehabilitation, only if they feel they are in control and have options in life from which to choose.¹⁰¹

This suggests a problem-solving approach, which Gilmore states is the final step in the coping process. This process involves: a) perceiving a stimulus or problem, b) appraising the alternative possibilities for resolving it, and c) arriving at some conclusion or decision regarding a course of action. The benefits of successful coping with a new situation which requires adaptation, he says, are a sense of mastery and increased self-esteem.¹⁰²

There is a distinction between compliance and the successful coping referred to above. The term "comply" has connotations of submissiveness of one person to the will of another. Blau points out that the patient is placed in a position where, "...he must subordinate him-

¹⁰⁰A.M. Goldstein and M. Reznikoff, "Suicide in Chronic Hemodialysis Patients From an External Locus of Control Framework," American Journal of Psychiatry, 127:1204-1207, March, 1971.

¹⁰¹Anger, op. cit., p.456.

¹⁰²Gilmore, op. cit., p.141.

self to the other and comply with his wishes as an inducement for furnishing the needed help."¹⁰³

This sense of powerlessness is closely linked with External Locus of Control. Rotter developed his Internal-External Locus of Control Construct on Seeman's work on powerlessness and alienation. Seeman defined powerlessness as the expectancy or the probability held by the individual that his own behavior cannot determine the outcome or reinforcement he seeks, and stated that this occurs when the individual's minimal standards for clarity in decision-making were not met.¹⁰⁴

Johnson states that powerlessness is equated with the perceived external control of events in the learning variable, expectancy. Operating as this learning variable, it could be expected to influence learning either in the sense of the acquisition of knowledge or of developing effective goal-directed behavior. The direction of this influence would be negative since knowledge or goal-directed behavior is simply irrelevant and unnecessary when the individual does not perceive that future events can be controlled by his own actions.¹⁰⁵

Providing opportunities for the patient to exercise control over himself and events that affect him are ways the nurse can combat powerlessness, according to Roberts.¹⁰⁶

Control behavior, Schutz states, refers to the decision-

¹⁰³P.M. Blau, Exchange and Power in Social Life (New York: Wiley and Sons, 1964), p.22.

¹⁰⁴M. Seeman, "On the Meaning of Alienation," American Sociological Review, 24:785-768, December, 1959.

¹⁰⁵D. Johnson, "Powerlessness: A Significant Determinant of Patient Behavior?" Journal of Nursing Education, 6:40, April, 1967.

¹⁰⁶S.L. Roberts, Behavioral Concepts and the Critically Ill Patient (Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1976), p.128.

making process between people.¹⁰⁷

Tancredi, a lawyer, has discussed the legal and ethical considerations of the dialysis situation as it relates to medical decision-making by the nurse. He emphasizes the tremendous power possessed by the nurse, and the possibility created by the hemodialysis patients' dependency on machinery to foster feelings of dehumanization and powerlessness in these patients. He proposes that nurses develop a model of medical decision-making which allows for effective patient participation. This partnership relationship would allow both the patient and the nurse to retain power to affect the course of treatment, as both would have power for making critical decisions.¹⁰⁸

The powerlessness and dependency of patients described in the above articles seems to describe the situation of the hemodialysis patient very well. He is dependent on others for life-saving intervention and is told that he must comply with an undesirable and difficult regimen, and that failure to do so will result in dire consequences or even death for him. When the patient fails to meet these expectations of the staff, he is admonished for his actions, and often made to feel that he has a lack of will-power and character.

Communication between the staff and the patient about the topic of dietary non-compliance is often self-defeating, and the patient continues in a state of guilt-shame over his lack of ability to adhere to his restrictions. He is not given the luxury of examining the problem in

¹⁰⁷ W.C. Schutz, FIRO: A Three-Dimensional Theory of Interpersonal Behavior (New York: Holt, Rinehart and Winston, Inc., 1960), p.86.

¹⁰⁸ L.R. Tancredi, "The Nurse, Medical Decision-Making and Ethics," in Nursing and the Nephrology Patient, ed., L.Schlottter (Flushing, New York: Medical Examination Pub. Co., 1973), pp.19-24.

terms of weighing the alternatives, looking at consequences, and seeking additional information, all of which are aspects of conscious, deliberative decision-making. The responsibility of the patient for his diet is not a shared responsibility, but an imposed one.

The literature supports the use of an intervention which allows patients to participate in the decision-making process in relation to his restrictions. An intervention which encourages patients to establish their own goals concerning the diet and fluid restrictions could increase patient adherence, while at the same time providing patients with an experience of successful coping, thereby enhancing their feelings of mastery, power, and self-esteem. A tool devised by Janis and Mann, which has been used in other areas to assist people in decision-making, is a means of assisting patients to examine alternatives to their behavior. This tool is discussed in the Theoretical Framework of the study, which follows.

THEORETICAL FRAMEWORK: THE DECISION-MAKING MODEL

Janis and Mann have developed a decision-making model which conceptualizes decisional conflicts in terms of a balance sheet which represents the potential gains, or positive incentives, and the potential losses, or negative incentives, that are anticipated by the decision-maker when he evaluates each alternative open to him.¹⁰⁹

One of the main hypotheses of the procedure is that a person who is experiencing conflict about carrying out a stressful course of action will display a greater readiness to rely on a counsellor's recommendations if: a) the counsellor conducts an initial interview, during which he

¹⁰⁹Janis and Mann, loc. cit.

asks for confidential information, such as the patient's feelings about his failure to control his eating behavior, and b) shows respect for disclosures of personal shortcomings by giving positive feedback in the form of explicit acceptance statements.¹¹⁰

The decisional balance sheet is intended primarily to reduce post-decisional regret by providing emotional inoculation for subsequent stress through anticipation of possible negative consequences. The anticipated gains, or benefits, and the anticipated losses, or costs, can be categorized into four major types of consequences: a) utilitarian gains or losses to self, b) utilitarian gains or losses to significant others, c) approval from significant others, and d) self-approval or self-disapproval.¹¹¹

The decision-making process optimally involves consideration of all relevant information. Attention to possible negative outcomes, which are often overlooked, is especially important because it minimizes post-decisional regret when and if such outcomes occur.¹¹²

Janis reports the results of several studies using the decisional balance sheet, and it appears to have a significant effect on the individual's commitment to a course of action, as measured by actual behavior. Thus, attendance at an early morning exercise group was significantly greater in an experimental group exposed to the Balance Sheet Procedure, than in a control group not exposed to the procedure;¹¹³

¹¹⁰I.L. Janis, Changing Behavior Through Counselling (New Haven: The Yale University Press, 1975), p.178.

¹¹¹I.L. Janis, "Stages in the Decision-Making Process," in Theories of Cognitive Consistency, ed., R.P. Abelson (Chicago: Rand McNally, 1968), pp. 577-588.

¹¹²Ibid

¹¹³Janis, Changing Behavior, p.31.

weight loss was significantly greater in a group exposed to the Balance Sheet Procedure in a weight reducing clinic, than in the control group which was not exposed to the procedure;¹¹⁴ and the group exposed to the procedure among a larger group who were attempting to stop smoking, actually smoked fewer cigarettes a year after the intervention than the individuals who were not exposed to the procedure.¹¹⁵

Mann used the Balance Sheet Procedure with a group of high school students in an attempt to induce them to consider relevant facts regarding their choice of college. In comparison with a control group of students from the same high school who were not exposed to the Balance Sheet Procedure, the experimental group tended to select a wider array of alternatives in formulating a decision, to take into account more self-related and fewer social considerations, to express less regret about their choice, and were less interested in receiving supportive, dissonance-reducing information in relation to their choice of college.¹¹⁶

Pierce used the Balance Sheet Procedure in her study of compliance in hemodialysis patients, with some suggestion that the procedure was effective in increasing compliance in some of the patients in her study group.¹¹⁷

These results tend to support the underlying theory that the decisional balance sheet assists individuals to clarify their choice of alternatives and to make more salient the fact that they do have choices.

¹¹⁴Ibid, p.23.

¹¹⁵Ibid, p.24.

¹¹⁶L. Mann, "Use of a Balance Sheet Procedure to Improve the Quality of Personal Decision-Making: A Field Experiment With College Applicants," Journal of Vocational Behavior, 2:291-300, March, 1972.

¹¹⁷Pierce, op. cit. p.142.

GOAL SETTING

Goal setting has been used successfully in administration. Generally referred to as Management by Objectives, it is essentially goal setting by employees. According to Robbins, Management by Objectives seeks to minimize external controls and maximize internal motivation through joint goal setting and self control.¹¹⁸

Carroll and Tosi report that research in the use of the Management by Objectives approach shows that specific goals result in significantly higher levels of performance than when subjects were just told to do their best. The process of setting goals was found to have a larger effect on performance than knowledge of results, or feedback alone.¹¹⁹

Zimbardo states that, "The act of making a pledge or promise known to others increases the individual's ego-involvement in the decision and increases his motivation to carry out his intent."¹²⁰

The establishment of goals for pre-dialysis serum potassium levels and between dialyses weight gains is a logical extension of the decision-making process, as it represents a decision to act, based upon prior consideration of the alternatives available.

¹¹⁸S.P. Robbins, The Administrative Process (Englewood Cliffs, New Jersey: Prentice-Hall Inc., 1976), p.138.

¹¹⁹S.J. Carroll and H.L. Tosi, Management by Objectives: Application and Research (New York: Macmillan Pub. Co., 1973), pp. 69-83.

¹²⁰P. Zimbardo and E.B. Ebbesen, Influencing Attitudes and Changing Behavior (Reading, Massachusetts: Addison-Wesley Pub. Co., 1970), p.13.

SUMMARY

This chapter presented a selected review of the literature pertinent to the study. Background information on the normal functions of the kidney, the physiological consequences of renal failure, and the development of hemodialysis as a treatment modality is presented. The continuing physical problems faced by chronic hemodialysis patients and the psychological sequela of life on dialysis are discussed. The research on compliance to therapeutic regimens is summarized, with emphasis on studies utilizing hemodialysis patients, and finally, the theoretical framework on which the study was based is presented.

CHAPTER III

METHODOLOGY

This chapter contains the description of the design of the study, the clinical setting and the criteria used to select the sample. The tools and methods used to collect and analyze the data are described. In addition to the hypotheses, several research questions are posed to deal with the data pertaining to the experimental group.

CLINICAL SETTING

The hemodialysis unit selected for the study is a self-contained unit in a large teaching hospital. There are fourteen in-centre beds available for hemodialysis on a twenty-four hour basis. Approximately sixty-two patients receive hemodialysis treatments two or three times per week, ranging from four to eight hours per dialysis.

CRITERIA FOR SAMPLE SELECTION

Patients who met the following criteria and agreed to participate in the study constituted the sample:

- a) eighteen years of age or over
- b) dialyze three times per week
- c) dialyze during the day; from 0800 hours to 2100 hours
- d) can read, write and understand English.

The patients selected were then randomly assigned to either experimental or control conditions.

RESEARCH DESIGN

An experimental design was used, with an Experimental and Control group. The independent variable was the nursing intervention which consisted of conducting an initial interview, assisting patients to consider the consequences of adherence and non-adherence to the diet and fluid restrictions, and then to establish their own goals for between dialyses weight gains and pre-dialysis serum potassium levels. These two measurements, between dialyses weight gains and pre-dialysis serum potassium levels, were the dependent variables.

The study was carried out in three phases: Pre-Intervention, which was the six month period prior to the initiation of the nursing intervention; Intervention Phase, which began with exposure of the Experimental group to the nursing intervention, and continued for a total of fifteen dialyses; and the Follow-Up Phase, which directly followed the Intervention Phase and continued for a total of nine dialyses. Data on the dependent variables were obtained for both the Experimental and Control group patients in all three phases.

The Pre-Intervention Phase represents a baseline measurement in which the two groups were compared on the dependent variables and demographic characteristics to determine whether they were similar in these variables prior to the intervention. During the Intervention Phase, the nursing intervention was carried out with the Experimental group patients, who also completed a Well-Being Rating Scale and charted their progress toward their goals on a Progress Sheet at each dialysis. In the Follow-Up Phase, between dialyses weight gains and pre-dialysis serum potassium levels continued to be collected for patients in both groups, but neither group was approached by the investigator.

HYPOTHESES

1. There will be no significant difference in adherence to the fluid restrictions between hemodialysis patients exposed to a nursing intervention utilizing goal setting in a decision-making model and hemodialysis patients who were not exposed to the intervention as measured by between dialyses weight gains.

Alternative Hypothesis: Between dialyses weight gains will be significantly lower for hemodialysis patients exposed to the nursing intervention than for those hemodialysis patients not exposed to the intervention.

2. There will be no significant difference in adherence to the diet restrictions between hemodialysis patients exposed to a nursing intervention utilizing goal setting in a decision-making model and hemodialysis patients who were not exposed to the intervention as measured by pre-dialysis serum potassium levels.

Alternative Hypothesis: Pre-dialysis serum potassium levels will be significantly lower for hemodialysis patients exposed to the nursing intervention than for those hemodialysis patients not exposed to the intervention.

DESCRIPTION OF TOOLS USED

1. Measurement of dependent variables (see Appendix E)

Measurement of weight was determined by each patient both pre and post dialysis on one scale. Blood specimens were drawn as the patient began dialysis, and were analyzed by the investigator.

2. Face Sheet (see Appendix F)

This form is a simple recording of the pertinent demographic data of all patients in the study. Information recorded included: a) age, b) sex, c) marital status, d) education (in years), e) employment status, f) number of months since last employment, g) length of illness (in years), h) length of time on dialysis (in months).

2. Interview Guide (see Appendix G)

This guide was devised by the investigator and constructed to achieve several objectives. As the basis for the nursing intervention which followed, the interview attempted to:

- a) orient the patient to the nature of the study by means of explanations given relative to the content area of the questions;
- b) elicit specific information from the patient in regard to his knowledge and understanding of the diet and fluid restrictions, his long-term goals and future plans, the nature of his support systems such as the significant people or things in his life, and his experiences with his diet and fluid restrictions. Knowledge of the patient's understanding of his diet and fluid restrictions was especially important, as a patient could not be expected to control his weight gains and potassium levels if he was unaware of what behaviors were required of him to achieve this;
- c) focus the patient's attention on what his long-term goals were, and attempt to have him relate these to the necessity for maintaining a high level of health and well-being.

The Interview Guide was pre-tested with six patients who, because they dialyzed at night, had no contact with the subjects of the study. These patients met the criteria for sample selection, but were excluded from the study because they dialyzed overnight. They were told that the investigator was doing a study on dialysis patients and the diet and fluid restrictions they are asked to follow. It was emphasized that they were not the study subjects, and that the purpose of asking them to answer the questions in the Interview Guide was to test the appropriateness of the content and wording of the items in the interview. They were encouraged to make observations and suggestions and to give their opinion

of the questions in the Interview Guide. When the test patients had completed the interview, they were asked the following questions:

1. Did you understand the questions?
2. Were the questions too long?
3. Was enough information given to make the questions understandable?
4. Did you feel that any of the questions were too personal?
5. Do you have any suggestions that would improve this Interview Guide?

The test patients appeared quite able to understand the questions as they answered appropriately. The questions dealing with knowledge of the diet and the meaning of the potassium level were understood, but the degree of vagueness and error in the answers was evident. The patients indicated that they understood the questions and did not find them too personal. They could readily identify the people and things that were important to them, and what their future goals were.

In questioning the patients about their knowledge of the potassium level, it was found that the question, "What is your understanding of the potassium level?" was too general and patients sought clarification in answering the question. Asking the two following questions: "What is the 'safe' range for potassium?" and "What happens when the potassium level is very high?" enabled the patients to answer, and provided the information necessary.

One patient suggested that the patient's urine output be determined as this would influence his weight gains and his difficulty with the fluid restrictions. On the basis of the results, the following changes were made in the Interview Guide:

Question 8. was reworded to read: "I would like to find out what your understanding of the potassium level is. For instance, what is the 'safe' range for the potassium level? What happens when the potassium level is

very high?"

Question 12. was added to determine whether there was a great variation among the patients in urine output and whether this affected the patient's ability to adhere to the fluid restrictions. This question read: "Do you have your own kidneys? What is your estimated daily urine output?"

3. Balance Sheet Procedure (see Appendix A)

After the patients in the experimental group had completed the interview, they were asked to consider the consequences of their decision to adhere or not to adhere to the diet and fluid restrictions. The form used was patterned after that developed by Janis and Mann¹, and required consideration of the possible gains and losses to the patient and his significant others that would follow for both adherence and non-adherence to the diet and fluid restrictions.

The patient was asked to consider such consequences under each of the following categories: a) gains to self, b) losses to self, c) gains to significant others, d) losses to significant others, e) approval from significant others, f) disapproval from significant others, g) self-approval, and h) self-disapproval.

4. Goal Setting Contract (see Appendix B)

After the patient had considered the consequences of his decision in regard to his diet and fluid restrictions, he was asked to set a goal for himself for pre-dialysis serum potassium levels and weight gains between dialyses. The patients wrote these goals and signed the page on which they were written.

¹I.L. Janis and L. Mann, "A Conflict Theory Approach to Attitude Change and Decision-Making," in Psychological Foundations of Attitudes, eds., A. Greenwald, T. Brock and T. Ostrom (New York: Academic Press, 1968), pp.329-363.

5. Well-Being Rating Scale (see Appendix C)

The questions in this scale were devised by the investigator to determine primarily the patient's experience of the consequences he had identified in the Balance Sheet Procedure. Two of the questions, Question 3. "How well did you feel physically?" and Question 12. "All things considered, how would you rate the past two days?", were intended to test the assumption that adherence to the diet and fluid restrictions results in increased health and well-being in hemodialysis patients.

The first two questions, "How well were you able to restrict your fluids?" and "How well were you able to 'stick' to your diet restrictions?", were included to obtain the patient's estimate of his adherence to the restrictions, but the score obtained on these two questions was not included in the overall "Well-Being Score". This scale was not pre-tested.

6. Progress Sheet (see Appendix H)

The patients in the Experimental group were each given a graph on which the values for the pre-dialysis serum potassium level, weight gain, and Well-Being Score obtained at each dialysis during the Intervention Phase could be plotted. The patient's goals for between dialyses weight gains and pre-dialysis serum potassium were outlined in red to give the patient a visual guide of his progress in relation to his goals.

DATA COLLECTION

The collection of the data proceeded in three phases:

1. Pre-Intervention Phase

This phase included the preliminary preparation for the study. The Interview Guide was pre-tested with six patients, and revisions made. All patients who met the criteria for inclusion in the study were identified

and approached by the investigator to obtain their cooperation. The patients who met the established criteria and agreed to participate were then randomly assigned to either experimental or control conditions. Following this, the consent forms (see Appendix D) were signed by the patient, his attending physician, and a witness.

The demographic data, and information concerning each patient's pre-dialysis serum potassium levels and between dialyses weight gains for the six month period prior to the intervention, were collected from the patients' charts.

2. Intervention Phase

At the beginning of this phase, the patients in the Experimental group were interviewed, completed the Balance Sheet Procedure and established their personal goals for between dialyses weight gains and pre-dialysis serum potassium levels. Beginning with the first dialysis after the Experimental group had completed the above procedures, and continuing for the next fifteen dialyses, all patients had one milliliter of blood drawn at the initiation of dialysis for the purpose of serum potassium determination, and had their weight gains recorded.

The Experimental patients were approached by the investigator while on dialysis and asked to complete the Well-Being Rating Scale and Progress Sheet. The Control patients were not approached by the investigator during the Intervention Phase. By previous agreement, the results of their serum potassium determinations were recorded on their daily dialysis sheets which they could examine.

3. Follow-Up Phase

Pre-dialysis serum potassium levels and between dialyses weight gains continued to be collected for all patients in the study for an additional nine dialyses after the Intervention Phase, but neither group was approached by the investigator.

DATA ANALYSIS

Both hypotheses were tested using the t-test to test for a significant difference in the between dialyses weight gains and pre-dialysis serum potassium levels between the Experimental group patients and the Control group patients during the Intervention Phase. The t-test is also used to test for a significant difference between the Experimental and Control group patients on these two variables in the Pre-Intervention and Follow-Up Phases, and for a significant difference in the between dialyses weight gains and pre-dialysis serum potassium levels between phases, within each group. The 0.05 level of significance is used for all statistical tests of the data.

ADDITIONAL RESEARCH QUESTIONS

In order to maximize the information available in the data, the following additional research questions were posed:

1. Were the results obtained for between dialyses weight gains and pre-dialysis serum potassium levels significantly related to the demographic variables in any phase?
2. Were the Experimental patients successful in achieving their goals for
 - a) between dialyses weight gains?
 - b) pre-dialysis serum potassium?
3. Did adherence to the fluid restrictions by the Experimental patients change over the study period? Did adherence to the diet by the Experimental patients change over the study period?
4. Did the patient's estimate of his well-being change over the study period?
5. Was well-being related to adherence to
 - a) the fluid restrictions?
 - b) the diet restrictions?
6. Was the patient's estimate of his well-being significantly different on those days when he was able to achieve his goals for between dialyses

weight gains and pre-dialysis serum potassium levels than on those days when he was not able to achieve his goals?

STATISTICAL ANALYSES

For each additional research question, the method of statistical analysis is given below. The 0.05 level of significance was used for all tests of the data.

1. The demographic variables of the group as a whole were compared with the weight gains and pre-dialysis serum potassium levels obtained in each phase using the t-test for the variables marital status and employment status; and Pearson Product Moment Coefficient of Correlation for age, length of time on dialysis and education.
2. Simple percentages were used to indicate the number of patients who were able to achieve their goals for between dialyses weight gains and pre-dialysis serum potassium levels during the Intervention Phase.
3. The mean values for weight gains and serum potassium levels obtained by the Experimental group patients during the Intervention Phase were correlated with the positional number of the dialysis at which they were obtained, using Pearson Product Moment Correlation Coefficient.
4. The mean Well-Being Ratings obtained by the Experimental group patients at each dialysis during the Intervention Phase were ranked from lowest to highest and correlated with the positional number of the dialysis at which they were obtained, using Spearman Rank Order Coefficient of Correlation.
5. Mean between dialyses weight gains and Well-Being Ratings obtained by the Experimental group patients at each dialysis during the Intervention Phase were ranked from lowest to highest, and correlated using Spearman Rank Order Correlation Coefficient. The data for pre-dialysis serum potassium levels were treated in the same manner.

6. The mean Well-Being Rating obtained by the Experimental group patients at those dialyses during the Intervention Phase when their goals for between dialyses weight gains were met was compared with the mean Well-Being Rating obtained at those dialyses when their goals were not met, using the t-test. This was repeated for the data pertaining to pre-dialysis serum potassium levels.

SUMMARY

This chapter provided a description of the methodology of the study. The research design is outlined, with a description of the setting of the study, the criteria for sample selection, and the tools used. The hypotheses and additional research questions are stated, and the methods used in the collection and analysis of the data are described.

CHAPTER IV

RESULTS

The results of the study include a description of the characteristics of the study participants, an analysis of the responses to the structured interview and a report of the results of the Balance Sheet and Goal Setting Procedures.. Each of these provides the background against which the hypotheses were tested. The results of the hypotheses testing follows, and the trends observed by each group in each phase of the study are reported. Finally, the findings relating to the additional research questions are presented.

THE SAMPLE

A total of seventeen patients met all the established criteria for inclusion in the study, and of these, only one refused to participate. The remaining sixteen patients were randomly assigned to either Experimental or Control conditions, with eight patients in each group. Data on the between dialyses weight gains and pre-dialysis serum potassium levels were available for all subjects for the six-month Pre-Intervention Phase, and the entire Intervention Phase. One patient in the Control group left for a holiday immediately after the Intervention Phase, and therefore no data are available for this patient in the Follow-Up Phase.

The demographic characteristics of each group are summarized in Table I.

TABLE I
DEMOGRAPHIC CHARACTERISTICS
EXPERIMENTAL AND CONTROL GROUPS

	EXPERIMENTAL	CONTROL
AGE	42.8	45.3
MARITAL STATUS		
married	3	5
widowed, divorced single or separated	5	3
SEX		
males	4	7
females	4	1
EDUCATION (years)	11.1	11
LENGTH OF TIME ON DIALYSIS (months)	32.6	67.6
LENGTH OF ILLNESS (years)	10.8	9.5
EMPLOYMENT		
part-time or full time	4	4
unemployed	4	4
MONTHS SINCE LAST EMPLOYMENT	39	42

The Experimental and Control groups were essentially equivalent on all variables except the number of males to females in each group, and the average length of time on dialysis. The Control group had significantly more males than females, and had a significantly greater average number of months on dialysis than did the Experimental group. The average length of time on dialysis differs so greatly between the two groups chiefly due to the fact that two patients in the Control group were "veterans" with 93 and 98 months on dialysis. In addition, the patient with the least experience on dialysis, six months, was assigned to the Experimental group in the randomization process. When these three patients were removed from the calculations, the means for each group were: Experimental - 37 months, Control - 44 months. Moreover, both groups had known about and had been under medical supervision for their conditions for a comparable length of time, which was 10.8 years for the Experimental group, and 9.5 years for the Control group.

RESPONSES TO THE INTERVIEW

1. What kinds of things are important to you? What are your plans for the future?

Seventy-five percent of the patients stated that work was important to them. This was the most common response, and was found in both those patients who had a job, and in those who did not. Half the patients felt that being active was important; and activity versus being considered as sick by others was highly valued. Survival itself was considered an important goal, as reflected in these statements: "I want to live as long as I can," "It's really important for me to live long enough to see my nephews grow up," and "I want to do as much as possible in the time I have left."

Transplantation was a future hope for more than sixty percent of

the patients. For these patients, other future plans seemed to rest heavily on receiving the transplant, especially plans for extensive travel. Patients who were not hopeful of receiving a transplant were more inclined to state that they hoped for increased health and energy to accomplish their goals such as going to school, working, and raising a family.

2. What things are necessary for you to do in order to reach your goals or plans?

Significantly, all patients readily stated that their health was of utmost importance to them if they hoped to achieve their goals.

3. Which people are most important to you?

Six out of the eight patients mentioned members of their immediate families as the most important people in their lives. Two patients stated that their friends were most important to them.

4. What are your diet and fluid restrictions?

Protein: The lack of specific knowledge in this area was evident. Six patients knew their protein limits in terms of ounces of meat per day, but had little understanding of high and low quality protein, or the protein content in foods other than meat. Two patients did not know their protein restriction at all.

Sodium: The knowledge was better in this area, although patients associated sodium almost exclusively with salt. For the most part, patients stated that they were supposed to avoid highly salted foods such as smoked meat, frankfurters, pickles and bacon, and that they should not add salt to their food at the table.

Potassium: All patients except one associated potassium with fruit. One patient was not aware that he should avoid excessive intake of fruit; in fact, he thought he should eat more fruit. Only one patient noted that

potassium was found in meat and vegetables as well as fruit.

Fluid: Half the patients stated that their fluids were restricted and were able to state their allowed amounts. The other half replied that they were allowed fluids "to satisfy thirst". However, all except one patient said that they restricted their fluids in order to keep their weight gains to a minimum.

It should be noted here that all patients in this particular unit receive similar instructions regarding their diet and fluid restrictions. There are two specially trained renal dietitians who provide each new patient with thorough instructions on the diet, his specific restrictions, and meal planning. Each patient receives a diet manual, complete with his own diet and fluid restrictions recorded, menus, and food exchange lists.

5. What difficulties, if any, have you had in the past with your restrictions?

Half the patients claimed never to have had problems as a result of non-adherence with their restrictions. Two patients recalled at least one episode of pulmonary edema and fluid overload, and three patients said that they had had problems with very high potassium on occasion. One patient said he had problems taking the phosphate-binding medication.

6. What part(s) of the restrictions do you find the most difficult?

Half the patients stated that they had the most difficulty with the fluid restrictions. Two patients found their potassium restriction the most difficult to adhere to, and two patients claimed no problems at all with the restrictions.

7. How much weight do you usually gain between dialyses?

Seven of the eight patients reported that their weight gains varied with the number of days between dialyses, especially if the three

day span was over the weekend. All patients stated that they usually gained more weight over the weekend. Weight gains varied from as little as half a kilogram in two days to as much as two kilograms over a weekend.

8. What is the safe range for potassium? What happens when the potassium level is very high?

Three patients knew what the safe range for potassium was; while three knew only that a potassium level of six or more was high and considered dangerous. All but one patient identified the danger of "heart attack" as the possible outcome of a very high potassium level.

9. What was your potassium level the last time you had it tested? Do you try to "aim" for a certain potassium level? If so, what?

Half the patients knew what their potassium level was the last time it was tested, and the other half of the patients said that either they had not been told the result, or else they could not remember.

Two patients said they try to "aim" for a specific pre-dialysis potassium level, and another two said that they try to keep their potassium level down by minimizing their intake of high-potassium foods. Half the patients said they make no real effort to control their potassium levels.

10. Do you try to "aim" for a certain weight gain in between dialyses?

If so, what?

Half the patients claimed they did not try to "aim" for a specific weight gain between dialyses, or to keep their weight gains below a certain maximum, although only one patient admitted to drinking all that he wanted to. The others said that they weighed themselves at home and tried to keep their weight gains down.

11. What is your dry weight?

All of the patients knew their dry weight, although one patient

disagreed with the doctor on the exact figure, claiming that it was too low.

12. Do you have your own kidneys? What is your estimated daily urine output?

The amount of urine output did not appear to influence a patient's difficulty with the fluid restrictions. Of the two patients with bilateral nephrectomies, one had difficulties with excessive weight gains, and the other did not. Of the two patients with less than 200 milliliters per day output, one claimed excessive weight gains, and the other said he had no problems with his weight. Neither of the two patients who said they continued to have almost normal urine outputs had difficulty with excessive weight gains between dialyses, however.

RESULTS OF THE BALANCE SHEET PROCEDURE

The responses to the Balance Sheet Procedure will be reported in terms of the anticipated consequences of adhering to the diet and fluid restrictions, and then the anticipated consequences of not adhering to the restrictions, within the gains and losses format already described. The anticipated consequences of adhering to the diet were:

GAINS TO SELF: All patients identified "better physical health" as a result of adherence to the diet and fluid restrictions. This was sometimes expressed as "a lack of symptoms" or problems, such as, "no shortness of breath", "not being so tired" and "no problems while on dialysis". Significantly, all patients were able to associate their long-term goals or the accomplishment of important goals in life with adherence to their diet and fluid restrictions as is shown in such statements as, "I would be better able to do my job", "I would have more energy to do things that are important to me".

GAINS TO SIGNIFICANT OTHERS: Seven patients identified the increased enjoyment of family members and friends as a positive result of adhering to the restrictions. This was expressed in such statements as, "my family enjoys being around me when I'm well", " I feel like doing things for my family when I'm feeling well, and I'm nicer to them". Five patients said that their families would worry less if they followed their diets. Four patients stated that friends and family would benefit as a result of what the patient could do for them if he felt well, such as helping around the house, participating in social activities, and providing for the family.

One patient, for whom his ability to work was very important, identified his boss as a significant other person who would benefit as a result of the patient's ability to adhere to the diet and fluid restrictions as he would be better able to do his job if he felt well.

APPROVAL FROM SIGNIFICANT OTHERS: All patients stated that family and friends approve of them when they adhere to their restrictions, and the patients felt positive feelings as a result of this approval. One patient said that his boss and co-workers admired his will-power and praised him for his ability to stick to his diet. Another patient identified the nurses in the unit as significant others who would approve of his ability to adhere to the restrictions.

SELF-APPROVAL: All patients described an increased feeling of self-esteem and pride in their ability to control their impulses when they adhered to their restrictions.

LOSSES TO SELF: All patients but one were able to admit the loss of pleasure and gratification of eating and drinking what they wanted and as much as they wanted. One patient said that the diet was "boring" and tasted "flat" and uninteresting. Three patients said that their

lives were restricted because of the diet. They could not participate in some social functions, or else did not enjoy themselves as much at these occasions when they followed their restrictions.

LOSSES TO SIGNIFICANT OTHERS: Half the patients acknowledged that the special diet created more work for the family member responsible for preparing the meals, and three patients added that the rest of the family also suffered as a result of the fact that some favourite dishes were no longer prepared because the patient could not eat them. Two patients felt that family members refrained from eating forbidden foods in front of the patient, and another patient noted that friends often were disappointed if she did not eat food they had prepared for her; and in this way her adherence to the diet resulted in a loss of pleasure for others.

DISAPPROVAL FROM SIGNIFICANT OTHERS: Only three patients felt that there was some disapproval from significant others if the patient did follow his diet, but this was usually related to a special occasion, or a night out with friends. One patient felt that his family members would disapprove of his adherence to the diet if it interfered with the meals that the rest of the family had to eat, and this might cause them to resent the patient.

SELF-DISAPPROVAL: Two patients said they would disapprove of carrying the restrictions too far; either in telling everyone about it, or talking at great length about what foods they could not have. As one patient said, "I don't want to make a career out of it!"

The anticipated consequences of not adhering to the restrictions were:

GAINS TO SELF: Only four patients were able to identify any gains to self that could occur when they did not follow their diet and fluid restrictions. All of these said that the taste and sensory satisfaction

of eating favourite foods was a significant gain when they did go off their diets. Three patients associated this with eating on a special occasion, or going out to a restaurant. These patients stated that it was virtually impossible to adhere to the restrictions when they were not at home.

GAINS TO SIGNIFICANT OTHERS: Two patients stated that meal preparation was much easier when they did not adhere to their restrictions, as a member of the family did not have to cook a special meal for the patient. Three patients pointed out that friends and family could better enjoy an occasional meal at a restaurant or a special dinner when they disregarded their restrictions and ate with the rest.

APPROVAL FROM SIGNIFICANT OTHERS: Five patients admitted a certain approval from significant others when they went off their diets for a special occasion. At times friends and family even encouraged this behavior, "It won't hurt, just this once".

SELF-APPROVAL: Only one patient stated that he felt proud of himself for not adhering to the diet and fluid restrictions as prescribed by his doctor. This patient stated that he was given a very strict diet, and by experimenting with increased food and fluid intake, he found that he could tolerate greater amounts than he was allowed in the diet, without untoward symptoms or an increase in his blood chemistries. He was therefore proud of having established his own pattern of non-adherence to his diet and fluid restrictions.

LOSSES TO SELF: Almost all patients identified loss of health and the experience of unpleasant symptoms, such as shortness of breath, feeling tired, lethargic, and an inability to do things, as a result of non-adherence to the restrictions. Three patients identified long-term physical difficulties that could result from non-adherence to the

restrictions, such as hypertension, which could lead to a stroke; visual and cardiac problems. Six patients identified the loss of important life goals as a possible result of dietary non-adherence if this behavior resulted in ill-health, such as the loss of time at work or permanent loss of their job, not being able to travel, and general decreased enjoyment in life as a result of ill-health.

LOSSES TO SIGNIFICANT OTHERS: Five patients said that their family would worry about the possible consequences for the patient if he did not follow the diet. This worry would be more intense if the patient experienced ill-health or uncomfortable symptoms, such as nausea and vomiting or shortness of breath. Half the patients mentioned that their family and friends would suffer the loss of the patient's company if ill-health prevented him from visiting or socializing with them in his usual manner. Two patients stated that their families would suffer if ill health prevented them from helping around the house or providing for their families.

One patient again mentioned the loss to his boss and co-workers which would occur if ill-health prevented him from doing his job, or if it forced him to retire altogether.

DISAPPROVAL FROM SIGNIFICANT OTHERS: Seven patients stated that their families and friends would disapprove of a continuous abuse of the diet and fluid restrictions. Patients felt that the disapproval would stem from a disappointment in the patient's lack of control over his eating and drinking habits, as well as worry over the negative consequences that this behavior might incur.

SELF-DISAPPROVAL: All patients stated that they would disapprove of their behavior if they were not able to adhere to their restrictions at all, particularly if they were ill as a result. They felt that this behavior

would make them angry at their lack of self-control, disappointed in themselves, and would lower their self-esteem.

GOAL SETTING

Patients demonstrated their ability to make their own decisions and to set realistic goals. None of the patients had great difficulty in establishing their goals. For each of the dependent variables, the goals established by the patients were as follows:

Potassium - The goals for pre-dialysis serum potassium ranged from a desired maximum of 5.0 milli-Equivalents per liter (mEq/L) to 6.0 mEq/L.

Fluid - The goals for weight gains between dialyses were stated in kilograms per day or else two goals were stated; one desired weight gain for a two day period, and another for a three day period. Goals for weight gains between dialyses ranged from a maximum gain in two days of 0.5 kilogram (Kg.) to a maximum gain in three days of 2.0 Kg.

Two patients revised their goals for weight gain between dialyses during the intervention, one after four dialyses and one after six dialyses. Both patients found that their goals were unrealistic and increased their desired maximum weight gain between dialyses. For both these patients, the new goal still represented a challenge; that is, the new goal was a figure lower than the amount they usually gained, and moreover, was a weight gain at which they felt comfortable.

The above reports are the presentation of the initial interaction in the intervention. The next section deals with the results of the testing of the hypotheses. This is followed by the analysis of the data in relation to the additional research questions.

HYPOTHESES TESTING

Hypothesis 1. stated that there will be no significant difference in adherence to fluid restrictions between hemodialysis patients exposed to a nursing intervention utilizing goal setting in a decision-making model and hemodialysis patients who were not exposed to the intervention as measured by between dialyses weight gains.

The mean between dialyses weight gains, in kilograms, obtained by each group during the intervention phase and the results of the t-test for these data are shown in Table II. Although the Experimental group tended to gain less than the Control group between dialyses, the difference is small and statistically insignificant.

On the basis of these data, the Null Hypothesis was accepted: there was no significant difference between the two groups in between dialyses weight gains during the Intervention Phase.

TABLE II

MEAN BETWEEN DIALYSES WEIGHT GAINS
INTERVENTION PHASE
EXPERIMENTAL AND CONTROL GROUPS

EXPERIMENTAL GROUP	CONTROL GROUP	t-TEST
1.01 Kg.	1.13 Kg.	t= 0.63 df= 14 not significant

Hypothesis 2. stated that there will be no significant difference in adherence to the diet restrictions between dialysis patients exposed to a nursing intervention utilizing goal setting in a decision-making model and hemodialysis patients who were not exposed to the intervention as measured by pre-dialysis serum potassium levels.

The mean pre-dialysis serum potassium level, in milli-Equivalents per liter, obtained by each group during the Intervention Phase, and the results of the t-test for these data are shown in Table III. The Experimental group obtained a significantly lower mean pre-dialysis serum potassium level during the Intervention Phase than the Control group. This difference is significant beyond the 0.025 level of significance in a one-tailed test. The Null Hypothesis was therefore rejected, and the Alternative hypothesis: that the pre-dialysis serum potassium levels will be significantly lower for hemodialysis patients exposed to a nursing intervention which utilized goal setting in a decision-making model than for hemodialysis patients not exposed to the intervention, was accepted.

TABLE III

MEAN PRE-DIALYSIS SERUM POTASSIUM LEVELS
INTERVENTION PHASE
EXPERIMENTAL AND CONTROL GROUPS

EXPERIMENTAL GROUP	CONTROL GROUP	t-TEST
4.84 mEq/L	5.37 mEq/L	t= 2.47 df= 14 p< 0.025

In order to examine the changes that occurred in between dialyses weight gains and pre-dialysis serum potassium levels in the two groups throughout the study, the data for each group were compared in all three phases. The mean values for between dialyses weight gains obtained by the Experimental and Control group patients in all three phases are shown in Table IV.

For between dialyses weight gains, there were no significant differences between the Experimental and Control groups in any phase. Thus the two groups were essentially the same in their average weight gains before the intervention, and did not substantially alter their patterns during or after the intervention. It is noted, however, that the Experimental group's average weight gain decreased slightly during the Intervention Phase and remained at that level in the Follow-Up Phase, while the Control group's average weight gain between dialyses dropped during the Intervention Phase and returned to the Pre-Intervention level in the Follow-Up Phase.

TABLE IV
BETWEEN DIALYSES WEIGHT GAINS
PRE-INTERVENTION, INTERVENTION, AND FOLLOW-UP PHASES
EXPERIMENTAL AND CONTROL GROUPS

PHASE	EXPERIMENTAL	CONTROL	t-TEST
PRE-INTERVENTION	1.12 Kg.	1.24 Kg.	t= 0.43 df= 14 not significant
INTERVENTION	1.01 Kg.	1.13 Kg.	t= 0.63 df= 14 not significant
FOLLOW-UP	1.01 Kg.	1.20 Kg.	t= 0.95 df= 13 not significant

The mean values for pre-dialysis serum potassium levels obtained by the Experimental and Control group patients in all three phases are shown in Table V. While there was no significant difference in pre-dialysis serum potassium levels between the Experimental and Control groups in the Pre-Intervention Phase, a difference significant at the 0.025 level was obtained for this variable in the Intervention Phase. The average pre-dialysis serum potassium level obtained by the Experimental group increased in the Follow-Up Phase, although not to the Pre-Intervention level, and no significant difference was found between the Experimental and Control groups on this variable in the Follow-Up Phase. The mean pre-dialysis serum potassium level obtained by the Control group remained relatively constant throughout all three phases.

TABLE V
PRE-DIALYSIS SERUM POTASSIUM
PRE-INTERVENTION, INTERVENTION, AND FOLLOW-UP PHASES
EXPERIMENTAL AND CONTROL GROUPS

PHASE	EXPERIMENTAL	CONTROL	t-TEST
PRE-INTERVENTION	5.13 mEq/L	5.41 mEq/L	t= 1.40 df= 14 not significant
INTERVENTION	4.84 mEq/L	5.37 mEq/L	t= 2.47 df= 14 p< 0.025
FOLLOW-UP	4.92 mEq/L	5.35 mEq/L	t= 1.45 df= 13 not significant

In order to determine whether there were significant changes within each group between phases, the data for between dialyses weight gains and pre-dialysis serum potassium levels for each group were compared from Pre-Intervention to Intervention Phases, from Intervention to Follow-Up Phases, and from Pre-Intervention to Follow-Up Phases. The results of this analysis for between dialyses weight gains is reported in Table VI, and for pre-dialysis serum potassium levels in Table VII.

Small changes in between dialyses weight gains are noted for both groups between phases, but statistical analysis shows these changes to be insignificant for all comparisons. The average weight gains between dialyses obtained by both the Experimental and Control group patients remained relatively unchanged throughout all phases of the study.

For pre-dialysis serum potassium levels, however, a significant difference is observed in the Experimental group from the Pre-Intervention Phase to the Intervention Phase, indicating that between these two phases, the Experimental group patients experienced a significant drop in their average pre-dialysis serum potassium level:

Although there was an insignificant increase in the pre-dialysis serum potassium level between the Intervention and Follow-Up Phases in the Experimental group, this increase negated the significant change observed between the first two phases, and there is no significant difference observed between the Pre-Intervention and Follow-Up Phases for this group.

The Control group experienced only slight changes in their average pre-dialysis serum potassium levels in each phase, and none of these changes is significant.

TABLE VI
BETWEEN DIALYSES WEIGHT GAINS
BETWEEN PHASES
EXPERIMENTAL AND CONTROL GROUPS

GROUP	PHASE 1	PHASE 2	t-TEST	PHASE 2	PHASE 3	t-TEST	PHASE 1	PHASE 3	t-TEST
EXPERIMENTAL	1.12 Kg.	1.01 Kg.	t=0.67 df=7* N/S	1.01 Kg.	1.01 Kg.	t=0.05 df=7 N/S	1.12 Kg.	1.01 Kg.	t=0.67 df=7 N/S
CONTROL	1.24 Kg.	1.13 Kg.	t=0.08 df=7 N/S	1.13 Kg.	1.20 Kg.	t=0.44 df=6 N/S	1.24 Kg.	1.20 Kg.	t=0.45 df=6 N/S

PHASE 1 Pre-Intervention Phase
PHASE 2 Intervention Phase
PHASE 3 Follow-Up Phase

*N/S = not significant

TABLE VII
PRE-DIALYSIS SERUM POTASSIUM
BETWEEN PHASES
EXPERIMENTAL AND CONTROL GROUPS

GROUP	PHASE 1	PHASE 2	t-TEST	PHASE 2	PHASE 3	t-TEST	PHASE 1	PHASE 3	t-TEST
EXPERIMENTAL	5.13 mEq/L	4.84 mEq/L	t=2.32 df=7 p<0.05	4.84 mEq/L	4.92 mEq/L	t=0.41 df=7 N/S *	5.13 mEq/L	4.92 mEq/L	t=1.13 df=7 N/S
CONTROL	5.47 mEq/L	5.37 mEq/L	t=0.74 df=7 N/S	5.37 mEq/L	5.35 mEq/L	t=0.10 df=6 N/S	5.47 mEq/L	5.35 mEq/L	t=0.57 df=6 N/S

PHASE 1 Pre-Intervention Phase
PHASE 2 Intervention Phase
PHASE 3 Follow-Up Phase

* N/S = not significant

In summary, the data support the acceptance of the first hypothesis, and rejection of the second hypothesis. The Alternative hypothesis to Hypothesis 2, that the pre-dialysis serum potassium levels will be significantly lower for hemodialysis patients exposed to a nursing intervention which utilized goal setting in a decision-making model than for hemodialysis patients not exposed to the intervention, was accepted.

Examination of the data for between dialyses weight gains and pre-dialysis serum potassium levels within each group between phases, and between groups in each phase, reveal that the Experimental and Control groups were essentially the same in these two variables prior to the intervention, and that no significant differences were found between the two groups in the Follow-Up Phase.

During the Intervention Phase, the Experimental group obtained a significantly lower average pre-dialysis serum potassium level than the Control group; but no significant difference was found for between dialyses weight gains. Pre-dialysis serum potassium levels showed a significant decrease from the Pre-Intervention to the Intervention Phases for the Experimental group, but during the Follow-Up Phase the average pre-dialysis serum potassium level increased, so that no significant difference was observed between the Pre-Intervention and Follow-Up Phases. All other between phase differences were found to be insignificant. The implications of these findings are discussed in Chapter V.

The next section reports the results of the analysis of the data in relation to the additional research questions.

DATA ANALYSIS--ADDITIONAL RESEARCH QUESTIONS

The data analysis will be presented in terms of each specific question posed:

1. Were the results obtained for between dialyses weight gains and pre-dialysis serum potassium levels significantly related to the demographic variables in any phase?

The demographic variables of the group as a whole were compared with the between dialyses weight gains and pre-dialysis serum potassium levels in each phase. As shown in Table VIII, there were no significant relationships between the dependent variables and age, length of time on dialysis and education, and no significant differences between married and unmarried or employed and unemployed patients in the dependent variables.

2. Were the Experimental patients successful in achieving their goals for a) between dialyses weight gains?

Patients appeared to have great difficulty in adhering to their goals for between dialyses weight gains, as is evidenced by the fact that only one patient was able to achieve his goal for between dialyses weight gain consistently throughout the Intervention Phase, and this patient claimed that his urine output was essentially normal.

- b) pre-dialysis serum potassium levels?

In contrast to the above, all patients except one were able to achieve 100 percent success in adhering to the goals they had established for pre-dialysis serum potassium. The one patient who was not able to achieve this had a long-standing problem with excessively high potassium levels. Her records show several pre-dialysis potassium levels of 6.5 to 7.0 mEq/L in the six month period preceding the Intervention Phase. She had set her goal at 6.0 mEq/L and was able to achieve this goal sixty-seven percent of the time.

TABLE VIII
RELATIONSHIPS BETWEEN
DEMOGRAPHIC AND DEPENDENT VARIABLES
EXPERIMENTAL AND CONTROL PATIENTS*

DEMOGRAPHIC CHARACTERISTIC	PRE-INTERVENTION PHASE		INTERVENTION PHASE		FOLLOW-UP PHASE	
	Weight gains	Potassium	Weight gains	Potassium	Weight gains	Potassium
Age (N=16)	r= -0.15	r= 0.37	r= -0.09	r= 0.44	r= -0.15	r= 0.45
Length of Dialysis (N=16)	r= -0.14	r= 0.38	r= -0.08	r= 0.45	r= -0.14	r= 0.45
Education (N=16)	r= -0.15	r= 0.32	r= -0.12	r= 0.26	r= -0.20	r= 0.35
Females (N=5) x	\bar{x} = 0.90 [†]	\bar{x} = 5.26 [§]	\bar{x} = 1.07	\bar{x} = 5.13	\bar{x} = 1.08	\bar{x} = 5.30
Males (N=11) y	\bar{y} = 1.23 t= 1.23	\bar{y} = 5.32 t= 0.32	\bar{y} = 1.09 t= 0.12	\bar{y} = 5.10 t= 0.10	\bar{y} = 1.12 t= 0.17	\bar{y} = 5.04 t= 0.79
Married (N=8) x	\bar{x} = 1.06	\bar{x} = 5.12	\bar{x} = 1.00	\bar{x} = 4.96	\bar{x} = 1.02	\bar{x} = 4.90
Unmarried (N=8) y	\bar{y} = 1.20 t= 0.53	\bar{y} = 5.48 t= 1.50	\bar{y} = 1.16 t= 0.82	\bar{y} = 5.25 t= 1.17	\bar{y} = 1.19 t= 0.87	\bar{y} = 5.37 t= 1.58
Employed (N=8) x	\bar{x} = 0.97	\bar{x} = 5.27	\bar{x} = 1.04	\bar{x} = 5.23	\bar{x} = 1.11	\bar{x} = 5.17
Unemployed (N=8) y	\bar{y} = 1.30 t= 1.26	\bar{y} = 5.32 t= 0.18	\bar{y} = 1.13 t= 0.48	\bar{y} = 4.99 t= 0.97	\bar{y} = 1.10 t= 0.05	\bar{y} = 5.10 t= 0.21

* For all calculations, the degrees of freedom (df) are 14. None of the Pearson Product Moment Correlation Coefficients (r) or the t-tests (t) are significant.

[†] Mean weight gain in kilograms

[§] Mean serum potassium in milli-Equivalents per Litre

3. Did adherence to the fluid restrictions by the Experimental patients change over the study period?

When the positional number of each dialysis in the Intervention Phase was correlated with the mean weight gain obtained by the Experimental patients at that dialysis, an insignificant relationship was found, ($r = -0.05$). This indicates that patients did not tend to gain either more or less weight between dialyses as the Intervention Phase progressed.

Did adherence to the diet by the Experimental patients change over the study period?

When the same procedure was applied to the data for pre-dialysis serum potassium levels versus the positional number of the dialysis at which the value was obtained, a non-significant relationship was found, ($r = -0.03$). This indicates that the Experimental patients did not tend to adhere either more or less to their diet restrictions as the Intervention Phase progressed.

4. Did the patient's estimate of his well-being change over the study period?

Well-being, as measured by the mean Well-Being Score, tended to increase as the Intervention progressed, but this relationship is not significant, ($r_s = 0.13$).

5. Was well-being related to adherence to a) the fluid restrictions?

The correlation for the Well-Being Score and the patient's between dialyses weight gains approaches significance, ($r_s = -0.48$), indicating that patients tended to feel better, as measured by their total Well-Being Score, as their weight gains decreased.

- b) the diet restrictions?

The correlation between the total Well-Being Score and the

and the pre-dialysis serum potassium levels is not significant, ($r_s = -0.14$). This indicates that the patient's estimate of his well-being was relatively unaffected by changes in his pre-dialysis serum potassium levels.

6. Was the patient's estimate of his well-being significantly different on those days when he was able to achieve his goals for between dialyses weight gains and pre-dialysis serum potassium levels than on those days when he was not able to achieve his goals?

Patients tended to feel better, as reflected in the total Well-Being Score, when they achieved their goal for weight gain between dialyses. Five patients showed a higher mean Well-Being Score for those dialyses at which they were at or below their weight gain goal than for those dialyses at which they were above this goal, although this was significant for only two patients. One patient showed a slight reverse trend, and one patient showed no difference. For the group taken as a whole, there was a significant difference between the Well-Being Score obtained at those dialyses when the goals for weight gain were met and those dialyses when they were not met, ($t = 3.21$, $df = 102$, $p < 0.005$).

This same tendency was also true for the only patient who did not consistently meet her goal for pre-dialysis serum potassium levels, although it was not significant, ($t = 1.81$, $df = 13$, not significant).

SUMMARY

In this chapter, the results of the study have been presented, with an analysis of the responses to the interview and the Balance Sheet and Goal Setting Procedures; the results of the hypotheses testing; and the findings in relation to the additional research questions.

CHAPTER V

SUMMARY, IMPLICATIONS FOR NURSING AND RECOMMENDATIONS

The results of an experimental study of the effects of a nursing intervention on hemodialysis patients' adherence to their diet and fluid restrictions are presented in this report. A sample consisting of sixteen hemodialysis patients from one renal unit was selected according to pre-established criteria, and then randomly assigned to either Experimental or Control conditions. The Experimental group was exposed to the independent variable, the nursing intervention, which consisted of an initial interview, the use of a Balance Sheet Procedure as an adjunct to decision-making, and the establishment of goals by the patient for pre-dialysis serum potassium levels and between dialyses weight gains. The Experimental patients completed a Well-Being Rating Scale at each dialysis during the five-week Intervention Phase. The dependent variables were between dialyses weight gains and pre-dialysis serum potassium levels.

Two hypotheses were proposed and tested in this study:

1. There will be no significant difference in adherence to the fluid restrictions between hemodialysis patients exposed to a nursing intervention utilizing goal setting in a decision-making model and hemodialysis patients who were not exposed to the intervention as measured by between dialyses weight gains.

2. There will be no significant difference in adherence to the diet restrictions between hemodialysis patients exposed to a nursing intervention utilizing goal setting in a decision-making model and hemodialysis patients who were not exposed to the intervention as measured by pre-dialysis serum potassium levels.

The data partially supported the hypotheses. The first hypothesis was accepted in the Null form, and the second hypothesis was rejected. Accepted instead was the Alternative Hypothesis to Hypothesis 2: Pre-dialysis serum potassium levels will be significantly lower for hemodialysis patients exposed to the nursing intervention than for those hemodialysis patients not exposed to the intervention.

The data indicated that patients experienced the most difficulty with their fluid restrictions. The nursing intervention did not appear to have been effective in assisting patients to adhere to their fluid restrictions, but it did have a significant effect in assisting patients to adhere to their dietary restrictions. Weight gain between dialyses was an important factor in the patient's estimate of his well-being.

IMPLICATIONS FOR NURSING

The nursing intervention was shown to have a significant effect in lowering pre-dialysis serum potassium levels in the group of patients studied. The Experimental patients obtained significantly lower pre-dialysis serum potassium levels during the Intervention Phase than did the Control patients, and the pre-dialysis serum potassium levels obtained by the Experimental patients during the Intervention Phase were significantly lower than the levels they had obtained prior to the intervention. As extremely high blood levels of potassium are life threatening, this result offers strong support for the intervention.

Between dialyses weight gains were unaffected by the intervention however, showing only a small decrease in the mean weight gain obtained by the Experimental patients from the Pre-Intervention Phase to the Intervention Phase. In view of the fact that between dialyses weight gains appear to be closely associated with the patient's sense of well-being, this result is disappointing.

An important finding is the tendency for between dialyses weight gains and pre-dialysis serum potassium levels to return to Pre-Intervention baseline levels when continuous nursing surveillance was withdrawn in the Follow-Up Phase. This finding makes it difficult to judge the exact mechanism responsible for the noted decrease in pre-dialysis serum potassium levels, as it may represent an "attention-placebo" effect. The possibility exists, however, that the length of the Intervention Phase was insufficient for patients to develop their own inner controls for achieving their goals. Increasing the length of the intervention might encourage the development of this inner control.

Alternatively, this result may indicate that patients require continuous nursing support to assist them to achieve their goals. A periodic review, perhaps weekly or bi-monthly, between the nurse and the patient in relation to the patient's stated goals and his actual weight gains and potassium levels might provide the nursing guidance and attention that would sustain the patient's interest and effort to adhere to his diet and fluid restrictions. At the same time, this periodic review would allow the patient to alter his goals in view of his changing physical health and medical condition.

It seems clear that a long-term change in patient adherence to the diet and fluid restrictions cannot be effected in a "one-shot" intervention. Rather, some program of regular, sustained interaction

between the staff and patients in relation to the patient's decision-making regarding his goals is indicated.

Research indicates that continuity of care and patient satisfaction with his care are important factors in his compliance.¹ An interesting suggestion is the use of a primary nursing system, as has been advocated by several dialysis specialists,² where each nurse is responsible for two or three patients. This would provide each patient with "his nurse," who was thoroughly familiar with his condition, needs, and goals and could periodically review with him his progress.

Goal setting appears to be a valuable means of transforming decisions into actions. The patients in this study were able to make decisions regarding desired weight gains between dialyses and pre-dialysis serum potassium levels without difficulty. Many of these patients had actually set desirable limits for themselves, based upon previous experience of the effects of exceeding these limits. While some patients retained goals which were not substantially different than the patterns they had already established, others set their goals at a lower level because they did not feel comfortable with their previous weight gains and potassium levels.

The results indicate that patients experienced more difficulty with their fluid restrictions than with the potassium restrictions. The patients in this study were able to control their potassium levels, as

¹R.B. Haynes, "A Critical Review of the 'Determinants' of Patient Compliance With Therapeutic Regimens," in Compliance With Therapeutic Regimens, eds., D.L. Sackett and R.B. Haynes (Baltimore: The Johns Hopkins University Press, 1976), p.35.

²S. Conlon et al., "An Experiment in Primary Nursing," Journal of the American Association of Nephrology Nurses and Technicians, 3:133-8, 1976, see also, M.R. Leonard, "Health Issues and Primary Nursing in Nephrology Care," Nursing Clinics of North America, 10:413-20, September, 1975.

evidenced by the fact that all but one patient were able to achieve their goals for pre-dialysis serum potassium levels consistently throughout the Intervention Phase. In contrast, only one patient was able to achieve his goal for between dialyses weight gains all of the time.

The establishment of goals by the patient in relation to his diet and fluid restrictions may provide the necessary means of avoiding the situation where patients are dependent on the dialysis staff for decision-making. Patients ultimately make the decision to adhere or not to adhere to their diet and fluid restrictions, and the factors governing this behavior are more directly related to the patient's perception of what is desirable for him, than they are with a fear of the negative consequences of non-adherence as seen by the dialysis staff. A very possible result of the repeated use of threats and warnings by nurses, is that the patient begins to perceive the nurse as a negative and criticizing force, rather than as a resource person he can seek out to help him with his problems. The result is withdrawal by the patient, and the resignation by both the staff and the patient that nothing can be done to change the pattern.

Encouraging evidence in support of the nursing intervention is obtained from the results of the Well-Being Rating Scale which indicate that well-being tended to improve as the intervention progressed, although this was not statistically significant. Patients also rated their well-being higher on those days when they had met their goals for weight gains and potassium levels. A correlation was found, such that well-being was rated higher by the patient when his weight gains were low, suggesting that weight gains are an important determining factor in hemodialysis patients' sense of well-being. This relation did not hold for well-being and pre-dialysis serum potassium levels.

Perhaps this is because weight gain has more meaning for the patient. It is more observable and understandable, as the patient can measure his weight gains between dialyses at home, and he often can detect physical changes as a result of his weight gain such as facial or pedal edema. Potassium on the other hand, causes no physical symptoms unless it reaches very high levels in the blood.

For the group as a whole, well-being was surprisingly high, with an average Well-Being Score of 41.8 on a scale of 50. It should be emphasized however, that the Well-Being Rating Scale sought answers to specific aspects of well-being; that is, the patient's estimate of the positive and negative outcomes identified in the Balance Sheet Procedure.

The questions in the Interview Guide that dealt with knowledge of the diet and fluid restrictions indicated that patients had a poor understanding of their diets. As all these patients were seen regularly by renal dietitians and had been instructed in all aspects of their diets, this may indicate that patients are indeed using denial to avoid the threatening realization of their role in maintaining their lives, as suggested by Goldstein and Reznikoff.³

Regular and frequent repetition of information in a non-threatening and non-critical manner may be necessary to reinforce the learning of the restrictions. The primary nursing system offers a possible vehicle for the diagnosis of learning deficits and the creation of individualized teaching plans. These might, from time to time, involve referral to the renal dietitian. Nurses in this way could assist the

³A.M. Goldstein and M. Reznikoff, "Suicide in Chronic Hemodialysis Patients From an External Locus of Control Framework," American Journal of Psychiatry, 127:1204-1207, March, 1971.

effectiveness of the renal dietitian by identifying specific learning needs on which the dietitian could base her teaching. Presenting the often overworked dietitian with the information that the patient "does not understand his diet" does not help her to concentrate her teaching on those aspects of the restrictions which the patient does not understand.

RECOMMENDATIONS FOR FURTHER RESEARCH

The nursing intervention described in this study receives sufficient support to recommend its use in the clinical area, and in future research designs. This intervention, based on a decision-making model in conjunction with goal setting by patients in relation to their medical regimens, appears to offer an effective method for nurses to assist patients in adhering to their diet and fluid restrictions.

Investigators who plan to utilize the theoretical framework described in this study, are advised to consider the following suggestions: a) attempts should be made to increase the sample size of the study group, b) if possible, utilize patients from more than one clinical area in order to increase the reliability and generalizability of the findings, c) designs which involve the use of a randomly assigned control group are strongly encouraged on methodological grounds, and finally, d) increasing the length of the Intervention and also the Follow-Up Phases would provide the researcher with substantially more information on which to base his or her conclusions.

The inclusion of a pre and post intervention test of the patient's self-esteem could be an interesting and valuable addition to the design of future studies. In this way, the researcher could test the assumption that providing opportunities for patient control of decision-making enhances self-esteem. Another interesting research possibility would be to examine patient adherence to the diet and fluid restrictions in a

design which incorporates decision-making and goal setting within a primary nursing framework.

The investigator recommends that future studies incorporate into the design some means of evaluating the patient's well-being, self-esteem or some other measure of the occurrence of the positive outcomes for the individual resulting from his adherence to the diet and fluid restrictions. It seems important to relate improved patient compliance with his regimen with some means of evaluating the benefits from the patient's point of view. Perhaps a refined well-being questionnaire that more specifically evaluates those personally relevant patient outcomes would reflect more accurately the benefits to be achieved in strategies to improve compliance. Compliance for its own sake should not become the goal of nursing care.

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APPENDIXES

APPENDIX A

BALANCE SHEET PROCEDURE

Explanation to the patient: Studies have shown that people can benefit from looking carefully at all the possible results of any activity they are considering, both the good results and the bad ones. I would like you to consider all the possible effects for yourself and people important to you, that occur when you 'stick' to your diet and fluid restrictions and when you do not 'stick' to them. For each category mentioned, try to think of as many outcomes as possible. The negative or undesirable outcomes are just as important as the good results you expect. Remember, there are no right or wrong answers.

(The following two pages present the Balance Sheet Procedure in the form given to the patients. The first page included the positive and negative outcomes that the patient anticipated as a result of adhering to his diet and fluid restrictions, and the second page the positive and negative outcomes anticipated as a result of not adhering to the diet and fluid restrictions.)

Include here all the outcomes you can think of that would occur when you followed your diet and fluid restrictions:

GAINS TO SELF	LOSSES TO SELF
GAINS FOR IMPORTANT OTHERS	LOSSES FOR IMPORTANT OTHERS
APPROVAL FROM IMPORTANT OTHERS	DISAPPROVAL FROM IMPORTANT OTHERS
SELF-APPROVAL	SELF-DISAPPROVAL

Include here all the outcomes you can think of that would occur when you did not follow your diet and fluid restrictions:

GAINS TO SELF	LOSSES TO SELF
GAINS FOR IMPORTANT OTHERS	LOSSES FOR IMPORTANT OTHERS
APPROVAL FROM IMPORTANT OTHERS	DISAPPROVAL FROM IMPORTANT OTHERS
SELF-APPROVAL	SELF-DISAPPROVAL

APPENDIX B

GOAL SETTING CONTRACT

My weight gains between dialyses will not exceed: _____ Kg./day

My pre-dialysis serum potassium will not exceed: _____ mEq/L.

Date: _____

Signature: _____

APPENDIX C

WELL-BEING RATING SCALE

Explanation to the patient: The purpose of this scale is to give me an idea of how much or how often the outcomes you have listed on the Balance Sheet occurred in between each dialysis. If many of the good outcomes occurred, and few of the bad ones did, you probably felt better, and therefore your well-being was greater. The following questions refer to your evaluation of the past two or three days since your last dialysis. For each question, indicate your answer by circling the number that most closely estimates how you feel. Number one means "not very well" or "very seldom" progressing to number five which means "very well" or "all of the time". The value for each answer is given in brackets below the first set of numbers.

1. How well were you able to "stick" to your diet?

1	2	3	4	5
(1)	(2)	(3)	(4)	(5)

2. How well were you able to restrict your fluid intake?

1	2	3	4	5
(1)	(2)	(3)	(4)	(5)

3. How well did you feel physically?

1	2	3	4	5
(1)	(2)	(3)	(4)	(5)

4. How much or how often did the "gains to self" occur?

1	2	3	4	5
(1)	(2)	(3)	(4)	(5)

5. How much or how often did the "losses to self" occur?

1	2	3	4	5
(5)	(4)	(3)	(2)	(1)

6. How much or how often do you feel the "gains to important others" occurred?

1	2	3	4	5
(1)	(2)	(3)	(4)	(5)

7. How much or how often do you feel the "losses to important others" occurred?
- | | | | | |
|-----|-----|-----|-----|-----|
| 1 | 2 | 3 | 4 | 5 |
| (5) | (4) | (3) | (2) | (1) |
8. How much or how often did you feel approval from important others?
- | | | | | |
|-----|-----|-----|-----|-----|
| 1 | 2 | 3 | 4 | 5 |
| (1) | (2) | (3) | (4) | (5) |
9. How much or how often did you feel disapproval from significant others?
- | | | | | |
|-----|-----|-----|-----|-----|
| 1 | 2 | 3 | 4 | 5 |
| (5) | (4) | (3) | (2) | (1) |
10. How much or how often did you feel satisfied or happy with yourself or your behavior?
- | | | | | |
|-----|-----|-----|-----|-----|
| 1 | 2 | 3 | 4 | 5 |
| (1) | (2) | (3) | (4) | (5) |
11. How much or how often did you disapprove of or were you disappointed with yourself or your behavior?
- | | | | | |
|-----|-----|-----|-----|-----|
| 1 | 2 | 3 | 4 | 5 |
| (5) | (4) | (3) | (2) | (1) |
12. All things considered, how would you rate the past two days?
- | | | | | |
|-----|-----|-----|-----|-----|
| 1 | 2 | 3 | 4 | 5 |
| (1) | (2) | (3) | (4) | (5) |

TOTAL: _____

APPENDIX D

CONSENT FORM

I, _____ hereby agree to participate as a subject in the study being carried out by Janice L. McCormick, R.N. The terms and purpose of this study have been fully explained to me as indicated below:

I will be interviewed by Miss McCormick at the beginning of the study and will be asked to fill out a form. Thereafter, at each dialysis I will be asked to complete a brief questionnaire for a period of five weeks. (This section was omitted in the consent forms given to the Control group patients).

I agree to allow one (1) milliliter of blood to be taken at the beginning of each dialysis for the purpose of serum potassium determination, for a period not to exceed eight (8) weeks. The results of this test will be shown to me. My pre and post dialysis weights will also be recorded.

I agree to allow Miss McCormick to examine my chart to record information on vital statistics. I understand that at no time will personal information that would identify me be recorded or used in the written report of this study, and I may choose to withdraw from the study at any time. Upon completion of the study, the results and conclusions will be made available to me.

Date _____ Signed _____

Attending physician _____ Witness _____

APPENDIX E

MEASUREMENT OF DEPENDENT VARIABLES

The techniques used to determine between dialyses weight gains and pre-dialysis serum potassium levels were as follows:

Between dialyses weight gains:- This was defined as the difference between the patient's pre-dialysis weight and his most recent post-dialysis weight. The practice in the renal unit in which this study took place was for patients to weigh themselves pre and post dialysis. All patients had been instructed in the proper procedure for obtaining accurate weight measurements. This procedure involved:

1. "zeroing" the scale before each use
2. moving a weighted bar along a scale until the marker was aligned in the central position.

Patients had been instructed to wear the same clothing for both the pre-dialysis and post-dialysis measurements. Weights were obtained in kilograms, to one decimal place.

At the beginning of the study, the investigator observed all patients complete this process to ensure that the correct procedure was understood and practiced; thereafter, the patients made the determinations unassisted, and reported the amount on their daily dialysis sheet.

Pre-dialysis serum potassium - One milliliter of blood was obtained from each patient immediately before dialysis and placed in a dry test tube to which no anticoagulant was added. The specimens were stored at room temperature until analyzed. This storage time did not exceed three hours. Whitby et al. report that potassium is released from the erythrocytes

when blood samples are refrigerated or left for long periods. The amount of potassium released from the cells is negligible until about four hours of storage.¹

All specimens were analyzed by the investigator using an automated flame photometer, which measured potassium and sodium simultaneously. Thorough instructions and demonstrations of the technique were obtained from the laboratory staff. This procedure was as follows:

1. centrifuging the whole blood
2. aspirating an aliquot (0.5 ml.) of serum
3. "zeroing" the flame photometer with lithium sulfate
4. setting the sodium and potassium readout with a standard solution of known sodium and potassium concentration
5. testing the results of the high sodium and potassium and low sodium and potassium standard solutions
6. running the patient samples.

¹L.G. Whitby, T.W. Percy-Robb and A.F. Smith, Lecture Notes on Clinical Chemistry, (London: Blackwell Scientific Publications, 1975), p.153.

APPENDIX G

INTERVIEW GUIDE

Explanation to patient: I am doing a study about the diet and fluid restrictions of dialysis patients and trying to look at a different way of how nurses can help patients keep their weight gains and potassium levels down. What I plan to do in this interview is to ask you some questions about your diet and fluid restrictions to find out any problems you may be having and then find out from you what weight gains and potassium levels you consider satisfactory for yourself and would like to aim for.

1. What kinds of things are important to you? What are your plans for the future?
2. What things are necessary for you to do in order to reach your goals or plans?
3. Which people are most important to you?
4. What are your diet and fluid restrictions?
5. What difficulties, if any, have you had in the past with your restrictions?
6. What part(s) of the restrictions do you find most difficult?
7. How much weight do you usually gain between dialyses?
8. What is the 'safe' range for potassium? What happens when the potassium level is very high?
9. What was your potassium level the last time you had it tested? Do you try to aim for a certain potassium level? If so, what?
10. Do you try to aim for a certain weight gain in between dialyses? If so, what?

11. What is your dry weight?
12. Do you have your own kidneys? What is your estimated daily urine output?

APPENDIX H

PROGRESS SHEET

Explanation to the Patient: Each patient in the Experimental group was given a Progress Sheet, which was a graph with a space provided to plot his weight gain, potassium level, and Well-Being Score for each dialysis during the Intervention Phase. The goals the patient had established for between dialyses weight gains and pre-dialysis serum potassium levels were marked on the graph in red ink so that the patient could easily see his progress toward his goals.

Patients were instructed in the use of the Progress Sheet, which involved placing an "x" on the graph to indicate his weight gain and potassium level at each dialysis. This procedure was completed before the patient answered the Well-Being Rating Scale. When the latter form had been completed, the patient placed his Well-Being Score in the space at the bottom of the Progress Sheet. Thus, the Progress Sheet served as a recording tool for the data, and as a visual indicator to the patient of his progress over the Intervention Phase.

A sample of the graph is included, with fictitious data and goals to demonstrate the function of this tool.

Pre-Dialysis Serum Potassium	8.0															
	7.5															
	7.0															
	6.5															
	6.0															
	5.5			x						x						
	5.0	*****	*****	*****	*****	*****	*****	*****	*****	*****	*****	*****	*****	*****	*****	
	4.5		x		x		x			x	x	x				
	4.0	x				x			x				x		x	
	3.5							x								
	3.0															
	2.5															
	2.0			x	*****		*****		*****		*****		*****		*****	
	1.5						x				x					
	Weight Gains Between Dialyses	1.0	*****	x	*****	x	*****		*****	x	*****	x	*****	x	*****	x
.5								x	x			x		x		
0																
Well-Being Score		39	41	34	40	45	43	47	44	32	36	38	41	43	47	45
Dialysis Number		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15

PROGRESS SHEET