

TREATMENT MODALITY FOR END STAGE RENAL DISEASE
AND FEELINGS OF DEPENDENCE

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CHAPTER I

INTRODUCTION

Little more than two decades ago, the diagnosis of chronic renal disease meant death from progressive uremia. With the development of avenues for repeated vascular access for hemodialysis, improvements in hemodialysis techniques, and the refinement of renal transplantation, the life span of the individual with this diagnosis has greatly increased.

As the quantity of days of life increases for the individual with end stage renal disease (E.S.R.D.), questions arise as to the quality of that life. Quality is described by caregivers as being dependent on many factors from simple physical functioning to complex definitions which embrace every aspect of the individual's existence.

More pertinent than the caregivers' definitions of quality of life are the perceptions of the individuals experiencing chronic renal disease. Minimal descriptive research (Jackle 1974, Willis 1978) done in this area has found that the person involved relates quality of life to independence and purposefulness.

The two major modalities of treatment for E.S.R.D. in the United States are in-center limited care hemodialysis and renal transplantation. That feelings of independence or purposefulness are promoted by transplantation and thwarted by dialysis might be assumed by some, but whether this is true is unknown. Dependence on a machine is obvious when hemodialysis is selected as the modality of therapy; the dependency of transplantation is more subtle, with its constant threat of rejection and resultant need for daily medication and close medical follow-up.

Recognition by caregivers of differences of feelings of purposefulness related to treatment modality for E.S.R.D. could assist them in counseling the individual with the diagnosis of chronic renal failure. This study concentrated on determining if a difference in feelings of dependence related to modality of treatment for chronic renal failure actually exists.

Statement of Problem

The problem of this study was to determine if a difference in expressed feelings of dependence exists between patients with end stage renal disease (E.S.R.D.)

treated with renal transplantation and those treated with chronic hemodialysis.

Purposes

The purposes of the study were:

1. To describe the subjects by means of demographic data
2. To ascertain the level of dependency expressed by renal transplant recipients
3. To ascertain the level of dependency expressed by chronic hemodialysis patients
4. To compare the level of dependency expressed by renal transplant recipients with the level of dependency expressed by chronic hemodialysis patients

Theoretical Framework

Social learning theory (Rotter 1954) asserts that a reinforcement acts to strengthen the expectancy that a particular behavior or event will be followed by the reinforcement in the future. If the individual perceives the reinforcement as unrelated to his own behavior, the reinforcement is less likely to influence the individual's expectation that the same reinforcement will reoccur following similar behavior. Dependent on past experience with reinforcement, individuals will differ

in the degree to which they attribute reinforcement to their own actions (Rotter 1966).

Expectancies related to reinforcement will generalize from a specific situation to a series of situations perceived as related or similar. This generalized attitude regarding the relationship of one's own behavior to events or occurrences affects a variety of choices in many life situations.

The experience of control--the sense that one actively chooses, successfully wills, or achieves mastery over himself and the circumstances in which he finds himself--is obviously one of the most fundamental features of human experience (Coan, Fairchild, and Dobyns 1973, p. 53).

Rotter developed an Internal-External Locus of Control Scale to measure individual belief in control of reinforcement. Individuals with an internal locus of control tend to believe that events and rewards are dependent upon their own behavior; while individuals with an external locus of control believe that events and rewards are largely the result of luck, chance, fate, or dependence on others (Rotter 1966). "A belief in external control of reinforcements is related to general passivity" (Rotter 1966, p. 3).

Rotter's Internal-External Locus of Control Scale is an instrument which can be used to determine an

individual's beliefs related to dependency and powerlessness. Roy (1976) defined powerlessness as the "perception on the part of the individual of a lack of personal or internal control over events within a given situation" (p. 225). Seeman and Evans (1962) linked the powerlessness aspect of the concept of alienation to internal-external control. Roberts (1976) described the alienated man as one who "does not experience himself as the active bearer of his own powers . . . but as an impoverished 'thing' dependent on power outside of himself" (p. 116).

Some researchers (Johnson 1968, Roberts 1976) have stated that powerlessness as measured by locus of control represents a more or less permanent personality trait. Other studies (Smith 1970; Joe 1971; Gentry and Davis 1972; Kilpatrick, Miller, and Williams 1972) have demonstrated changes in measures of locus of control related to various treatment programs.

While several studies (Goldstein and Reznikoff 1971; Gentry and Davis 1972; Kilpatrick, Miller, and Williams 1972; Foster, Cohn, and McKegney 1973; Adler 1975, Goldstein 1976; Mock 1976) have measured locus of control in chronic dialysis patients, no studies using the Internal-External Scale (I-E Scale) with renal

transplant recipients have been reported. This study used the I-E Scale as a tool to determine if a difference in feelings of dependence exists related to treatment modality of E.S.R.D.

Background and Significance

Uremia is newly diagnosed in sixty to ninety persons per million Americans each year. Until the 1950s, development of renal failure resulted in a slow, agonizing death. In 1954 John Merrill in Boston performed the first renal transplant. With the development of immunosuppressive medications, human transplantation has advanced to the point that it no longer is considered experimental or even extraordinary (Friedman 1978). In 1977, over 2,500 renal transplants were performed in the United States (Gailiunas 1979).

Long-term maintenance hemodialysis became possible with the development, in 1960, of the external arteriovenous Teflon silastic shunt by Belding Scribner at the University of Washington in Seattle. The problems and complications associated with external shunts were largely alleviated with the introduction of the internal arteriovenous fistula by Brescia and his associates in 1966 (Friedman 1978).

With the development of these methods for prolongation of life for the individual with uremia, renal failure became a chronic disease, with inherent psychosocial problems. Drawing from a paper by Jonsen (1976), Friedman (1978) stated:

All chronic illness fosters dependence and interferes with the essence of human life-purposefulness. Chronic illness causes the patient to deflect from his set and spontaneous purposes and imposes upon him the foreign purposes of fighting debility and rearranging his life. The best treatment of any chronic illness is the one which minimizes dependence and fosters a restoration of normal, purposeful behavior (p. xii).

Increasing numbers of individuals must undergo treatment for chronic renal failure. If a particular treatment maximizes independence, this information should be shared with individuals having to choose between therapies. This study was undertaken to determine if a difference in feelings of dependence exists related to treatment modality for E.S.R.D.

The two major modalities for treatment of end stage renal disease are in-center limited care hemodialysis and renal transplantation. Both therapies can prevent death, but neither is actually a "cure". In either therapy, the patient is dependent on professional care to stay alive, and as this dependency becomes greater,

. . . the more tempting it becomes for staff members to broaden the scope of their ministrations to include practically all aspects of the patient's life. While some patients are able to endure and sometimes even to thrive under this kind of forced dependence, eventually the average patient's defenses crumble under what seems to him to be an assault on his integrity (Sullivan 1973, p. 216).

The whole treatment process of hemodialysis places the individual in a position of greatly increased dependency. Wright, Sand, and Livingston (1966) spoke of an "umbilical symbolism" associated with the dialysis blood lines attaching the patient (fetus) to the machine (placenta). DeNour and Czaczkes (1976) identified this dependence on machines which are controlled by others as one of the major sources of stress for the hemodialysis patient.

Abram (1970) noted that while other conditions result in dependence on machines (mechanical respirators, electrocardiograms), this dependency is limited in duration. For the renal failure patient on dialysis, this dependence is chronic and lifelong in nature.

This chronicity may contribute to the "infantilizing" behavior sometimes demonstrated by caregivers. This is best described by an "uncooperative" hemodialysis patient as reported by Abram (1974a):

Regarding the independency-dependency conflict, I fully accept the theory that the conflict revolves around the machine; however, consciously I have only been able to view the situation as an insufferable dependency on unit personnel. . . . For example, nurses have coercively attempted to discourage my positioning the dialysis machine so that I could monitor the alarm system and operate my alarm reset controls; I interpreted this absurd behavior as an effort to force me into greater dependency on the nurses . . . (pp. 58-59).

Many patients look to transplantation as a panacea certain to give improved health and greater independence. If the transplant is successful and is not rejected, the patient regains a degree of independence in that he is no longer tied to dialysis. But transplantation has its own "side effects":

Patients must stay on immunosuppressive drugs for life with reactions that include facial swelling, acne, loss of hair, and frightening out-of-body experiences. The drugs also make patients particularly susceptible to infection (Levine 1978, p. 8).

The dream of return to independence may also be shattered as "frequent trips to the Center for laboratory surveillance . . . become a way of life" (Beard 1971, p. 25).

Individuals choosing either of the most common treatment modalities for E.S.R.D. may develop feelings of dependency. Exploration of the possibility that one

therapy is more conducive to the development of dependency feelings than the other therapy was the purpose of this study.

Hypothesis

The null hypothesis for this study was that there is no significant difference in the level of dependency expressed by renal transplant recipients and the level of dependency expressed by chronic hemodialysis patients.

Definition of Terms

For the purposes of this study, the following definitions were utilized:

1. End stage renal disease (E.S.R.D.)--irreversible uremia requiring a therapeutic regimen to prevent death
2. Chronic hemodialysis--use of in-center limited care hemodialysis for treatment of the individual with E.S.R.D.
3. Renal transplantation--use of kidney transplantation for treatment of the individual with E.S.R.D.
4. Dependency--feelings of decreased personal control over events affecting oneself; powerlessness; the individual's score on Rotter's Internal-External

Locus of Control Scale (1966) indicating greater feelings of external control

Limitations

The following variables were limitations that could have affected the conclusions of the study:

1. The stimuli in the environment
2. The past experiences of the individual
3. The inherent personality of the individual
4. The limited population of E.S.R.D. patients

who were eligible to participate in the study

Delimitations

The delimitations of this study were:

1. Participants in the study were at least eighteen years of age
2. No participant had been hospitalized during the preceding thirty days
3. All participants had initiated therapy (started hemodialysis or had been transplanted) between January, 1977 and March, 1978
4. All participants were able to speak and understand English
5. All participants initiated their present treatment modality in one major city in the Southwest

6. All transplant participants were still followed by the local transplant service

Assumptions

The assumptions relevant to this study were:

1. Individuals experiencing chronic illness have potential for developing feelings of dependency
2. Lack of control, feelings of dependency, and resultant alientation interfere with the individual's achievement of a satisfactory quality of life

Summary

Chapter I has presented an introductory description of a study designed to determine the effect of treatment modality for E.S.R.D. on the patient's expression of dependence. The problem and purposes of the study were stated, and the theoretical framework, Rotter's social learning theory, was discussed. A brief review of the literature related to the study was presented. Relevant terms, limitations, delimitations, and assumptions were defined.

CHAPTER II

REVIEW OF LITERATURE

Uremia is newly diagnosed in sixty to ninety persons per million Americans each year (Friedman 1978). These persons are faced with a choice of life-prolonging treatment modalities: chronic dialysis or renal transplantation. Both therapies can extend the quantity of life, but both may affect the individual's quality of life.

The essence of quality of life is purposefulness (Jonsen 1976). Feelings of dependence interfere with achievement of purposefulness (Strauss 1975, Roberts 1976). In this chapter the literature is reviewed as it relates to dependence and E.S.R.D. The following framework was utilized: basic renal function, renal failure, end stage renal disease, treatment modalities, dialysis, renal transplantation, dependence in chronic illness, dependence and hemodialysis, dependence and renal transplantation, studies with locus of control, and nursing measures to decrease feelings of dependence.

Basic Renal Function

While the most obvious function of the kidneys is to make urine, a more specific definition would divide the function as follows: to regulate volume and composition of body fluids by adjustments in excretion and to regulate certain biological systems by nonexcretory functions (Papper 1971). These functions are fulfilled in a very complex manner in the normal kidney, which consists of about a million nephrons (Robinson 1972).

The basic function of the nephron is to clean the plasma of unwanted substances. These include the end products of metabolism, such as urea, creatinine, uric acid, sulfates, and phenols. The plasma content of nonmetabolic substances such as sodium, potassium, or chloride ions is also regulated by excretion or reabsorption by the nephron.

Excretion and reabsorption are accomplished after filtration of the plasma through the glomerular membrane into the tubules. As this filtrate flows through the tubules, a selective reabsorption process occurs so that needed substances are brought back into the peritubular capillaries and those not needed remain inside the tubule, eventually passing via the collection system into the urine. One-hundred sixty to 180 liters of plasma are

filtered daily by the glomeruli, and this volume is reduced to about one liter of urine (Guyton 1971).

While the loss of urination can in of itself have psychological significance (DeNour 1969), this function can be physiologically replaced. The nonexcretory functions of the kidney have been more difficult to replicate. The juxtaglomerular apparatus is the site of origin of the renin angiotensin mechanism that has a significant role in blood pressure regulation. These same cells may be the source of erythropoietin, a substance produced by the kidney which influences red blood cell formation in the bone marrow. Erythropoietin deficiency may be the major reason for the anemia seen in renal failure (Papper 1971). Additionally, Vitamin D is converted to its most active form by the kidney--when the kidney is diseased, disturbances in the metabolism of Vitamin D result, contributing to the calcium/phosphorus imbalances which lead to the bone disease seen in chronic renal failure (Epstein and Merrill 1977).

Normal kidney function involves a complex series of events which can only partially be artificially replaced. The physiological functions not replaced result in symptomatology seen in individuals with renal failure.

Renal Failure

Thirteen million Americans have renal and urological disease (Robinson 1979). The causes are varied and include congenital defects and diseases, infection, obstruction, immunological assault, trauma, and failure of other body systems, such as the cardiovascular. These causes may be reversible, as in acute renal failure secondary to contracted intravascular volume; or may be irreversible, as in chronic renal failure secondary to diabetic nephropathy (Friedman 1978). Friedman (1978) noted that distinguishing between acute and chronic renal failure is complicated by the fact that chronic renal failure may begin acutely, and acute renal failure may take months to resolve. This distinction between acute and chronic is not as critical as was once considered since a diagnosis of chronic renal failure is no longer equivalent to certain death from uremia.

Acute renal failure can be defined as the abrupt onset of oliguria (less than 400 ml. of urine in twenty-four hours) and progressive azotemia (Friedman 1978). The two most common causes are acute tubular necrosis following shock and damage by nephrotoxins. Most cases of acute renal failure follow trauma, surgery, or

complicated pregnancy (Kerr 1972). In the past, many persons died from acute renal failure within days because of hyperkalemia. With increased knowledge and technical capabilities, close observation and hemodialysis have greatly decreased this mortality rate.

Chronic renal failure often progresses so insidiously that over one-half of the patients who present with severely compromised renal function deny previous awareness of a "kidney problem" (Friedman 1978). These patients may come to the physician complaining of symptoms related to the effect of renal dysfunction on the other body systems, such as "tired" from the anemia, "headaches" from the hypertension, or "pain" from the bone disease. Progressive uremia may also result in gastrointestinal, cardiovascular, and central nervous system disorders (Papper 1971).

With currently available treatment modalities, these individuals are now faced with a choice: dialysis, transplantation, or death. What effect these modalities have on patient's feelings of dependence was the subject of this study.

End Stage Renal Disease

Whatever the original cause or time course, progressive destruction of functioning nephrons leads to the same ultimate end-point, which is now termed end stage renal disease (E.S.R.D.). This diagnosis encompasses those patients who before 1950 would surely have died from uremia.

Since Scribner developed a permanent Teflon extra-renal arteriovenous shunt in 1960, the prognosis of E.S.R.D. has been altered from an always fatal disease to one in which over 90 percent survive for at least a year with therapy (Friedman 1978). The choice for the person with chronic renal failure has been broadened to include dialysis or transplantation in addition to the remaining choice: death. Conservative management, involving close monitoring, medications to control symptomatology, and dietary and fluid restrictions, is used to prolong the need to choose the treatment modality, and as the treatment if the choices of dialysis or transplant are not taken.

The word dialysis is of Greek origin and means a "loosening from something else" (Gutch and Stoner 1971, p. 33). Used as a treatment for renal disease, dialysis removes the toxins or excesses which the failed

kidneys cannot excrete. Two types of dialysis are currently in use--peritoneal dialysis and hemodialysis.

The mechanism of peritoneal dialysis is described by Epstein and Merrill (1977):

Physiologic fluid (dialysate) is introduced into the peritoneal cavity via an indwelling plastic catheter placed by paracentesis. The dialysate is left in place for 20 minutes to one hour, during which time solute diffuses from the blood across the peritoneal membrane into the dialysate. The dialysate is then removed. This process is repeated for the desired number of times . . . (p. 1436).

The complications seen with chronic peritoneal dialysis are infection, pain, protein loss into the peritoneal cavity, and occasional bleeding (Epstein and Merrill 1977). Answers to each problem have made this a viable alternative therapy for some patients. Although this therapy is not yet commonly used for long-term maintenance, recent improvements in catheters, delivery system, and dialysate have increased its acceptability for chronic use (Scribner and Blagg 1972, Epstein and Merrill 1977, Oreopoulos 1978).

The basic principle of hemodialysis

. . . is to pass blood through very minute channels between thin cellophane membranes. On the other sides of the membranes is a dialyzing fluid into which unwanted substances in the blood pass by diffusion (Guyton 1971, pp. 319-320).

Repeated hemodialysis requires ready access to the circulation. In the early days of this therapy, glass cannulas were inserted into vessels for each treatment, and the distal artery was lost with the cannulas' removal at the completion of the dialysis. This greatly limited the number of times dialysis could be performed, as arterial sites had a finite exhaustion point. With the development of the Teflon shunt by Scribner and associates in 1960, repetitive hemodialysis as a treatment modality for chronic renal failure became a reality (Friedman 1978).

The major problems with the external shunt were infection, clotting, erosion of the skin, and accidental dislodgement (Gutch and Stoner 1971). In 1966 Brescia and associates developed a surgical method to create a subcutaneous arteriovenous fistula. This internal device alleviates the problems of the external shunt, but requires the unpleasant need for repeated venipuncture (Scribner and Blagg 1972).

Over thirty thousand Americans now undergo maintenance hemodialysis (Friedman 1978). Advances in hemodialysis therapy include improved techniques and equipment, better efficiency of filtration methods, and greater patient convenience (Tilney et al. 1975).

Death in hemodialysis patients is usually the result of infection or vascular disease (Epstein and Merrill 1977). The complications of chronic hemodialysis include accelerated atherosclerosis, hypertension, anemia, osteoporosis, increased susceptibility to infection, gastrointestinal problems, and neurological disturbances (Tilney et al. 1975).

In the early 1950's, John Merrill's group in Boston performed the first successful kidney transplant using an identical twin as the donor. With the development of immunosuppressive drugs and methods of kidney preservation, renal transplantation has moved from the stage of tentative experiment to that of routine therapeutics (Hamburger et al. 1972). Several hundred kidneys are transplanted each year in this country (Sachs 1977).

Immunosuppression is the major cause of morbidity and mortality in the transplant population. The complications of long-term immunosuppression include obesity, malignancy, atherosclerosis, diabetes, cataracts, aseptic necrosis of major joints, bizarre infections, and psychological disturbances (Tilney et al. 1975). "The greatest risk to life that the transplant recipient faces is late slow deterioration of the homograft and

cardiovascular and other complications of the recurrent uremia" (Starzl et al. 1974, p. 613).

In the search for the "best" treatment modality for E.S.R.D., more than survival and complications must be considered. The renal patient

. . . whose life is extended (by dialysis or transplant) has an important investment in whether his prolonged life can be lived in a meaningful and significant way, and while he holds onto life with intensity, he considers the quality of that life to be equally as dear as life itself (Beard 1971, p. 24).

These same patients have related quality to purposefulness and independence (Jackle 1974, Willis 1978), agreeing with the most basic meaning of quality of life as the ability to formulate and implement purposes (Jonsen 1976). Whether a particular treatment modality for E.S.R.D. makes a significant difference in allowing an individual to enjoy this freedom from dependence is the question which remains.

Dependence in Chronic Illness

Intrinsic to a state of illness or injury is usually some degree of dependency or control by others. Although nursing academicians (Orem 1971, Kinlein 1977) advocated encouraging patient independence and self-care, and health workers ascribed high value to the ability

to make decisions for oneself (Berg, Hallauer, and Berk 1976), the actual practice of many caregivers becomes so entangled with the pursuit of technical excellence that the ultimate goal of restoring the individual to purposefulness is forgotten. A physician dying of leukemia expressed this in his initial reaction to hearing two nurses check the identification before hanging platelet packs

. . . one of the voices read "Expiration Date, March 17, 1971." How dare they, I thought! I had given them the right to decide when I could move my arm, when I should open or close my mouth. Now they even had assumed the right to set my expiration date, and with damn little notice in advance! (Levine 1972, p. 2)

Engel (1968) described a "giving-up, given-up complex" which may be seen to precede the onset of illness. A key element in this complex is a feeling of powerlessness on the part of the victim. Chronic illness results in a fear of incapacitation which seems worse than death for many. This fear of incapacitation is built on anxiety generated as one becomes dependent on others (Parets 1967).

Often a dependency role is established for the patient, with restrictions placed on both physical and mental activity, especially decision making (Luce and Dawson 1975). When the chronically-ill person is

hospitalized, he cedes responsibility for the management of his illness to hospital personnel. This may be devastating to his sense of personal worth if he feels no longer competent to handle his own affairs (Strauss 1975). With further loss of control and increased feelings of powerlessness, he may become alienated (Roberts 1976), believing that his own behavior cannot determine what happens to him (Seeman 1959). Levy and Clark (1976) stated that chronic illness fosters dependency as the patient increasingly relies upon a single physician, a small group of professional personnel, and the personal support group who help him at home. "Dependency may be increased by the nature of the treatment of the illness" (Levy and Clark 1976, p. 83).

Dependence and Hemodialysis

Shortly after chronic hemodialysis became feasible as treatment for E.S.R.D., Gombos et al. (1964) recognized the possibility that "an individual might not be able to tolerate the degree of dependency necessitated by the program" (p. 462). Early in the history of chronic dialysis authors began to report patients' expressions of the uncomfortable symbolism and fantasies related to the maintenance of their lives by a machine. Wright, Sand,

and Livingston (1966) referred to the "umbilical symbolism" of the machine--"The patient being repeatedly attached through his bloodstream and tubing to something outside him that maintains life" (p. 613). Viederman (1974) echoed this by correlating the dialysis treatment "to the earliest development stages, having to do with the mother-child interaction and with total helpless dependency" (p. 77).

Abram (1968) described a patient who saw the machine as a "monster" which had a "powerful, almost frightening hold on my life" (p. 1354). Kempf (1966) detailed the feelings of a hemodialysis patient who likened himself to a "sick puppet" (p. 1272) being jerked about by strings (the dialysis tubing). Some patients have spoken of themselves as mechanical men (Shea et al. 1965) or as Frankenstein monsters (Abram 1969), referring to the fact that a vital part of their existence is nonhuman (Abram 1970).

These fantasies are one way of handling the stress caused by hemodialysis. DeNour and Czaczkes (1976) identified three major sources of this stress:

- 1) the many restrictions forming part of the treatment, including the diet and fluid restriction;
- 2) the dependence and loss of mastery caused by the fact that life is machine dependent and

- the machines (i.e. life) are controlled by others;
- 3) increased aggression caused by the restrictions, the frustrations, and the loss of mastery (p. 324).

Abram, Moore, and Westervelt (1971) appealed to personnel to understand the psychological stress hemodialysis produces. "The assault on the patient's independence, self-esteem, body image and physical sense of well-being is significant to the point of intolerance" (p. 1202). They quoted a suicide rate in the hemodialysis population that is 100 to 400 percent greater than that of the general population. Chronic hemodialysis imposes "a prolonged stress, so severe that it forces the individual into passivity, dependence and denial of his reality, and in most cases ultimately into depression" (Shanan, DeNour, and Garty 1976, p. 25).

Abram, a prolific writer in this field, in a 1972 paper related this depression to the multiple losses faced by the dialysis patient: loss of freedom and independence, financial security, and sexual potency. Levy (1977) also spoke to the losses associated with E.S.R.D., losses over which they have no control and which result in "an overwhelming feeling of powerlessness" (p. 36).

Pritchard (1977) developed a factor he labeled "helpless dependence" from chronic dialysis patients' responses to a questionnaire designed to measure aspects of illness behavior. He maintained that this primary factor had an "obvious relevance to the dialysis situation with its dependence for the patient on machine, hospital staff, family, etc." (p. 46). Moore (1976) asked readers to consider this dependence based on the fact that no matter what else might be occurring in the patient's life, three times a week he must either go to a dialysis center or be hooked to a machine at home to be dialyzed to simply live.

Norton (1969) questioned his patients regarding their fears, asking them to rank ten possible concerns from those that might worry them the most to those that would worry them the least. Number one was "I will become a burden to others" and number two was "I will not be able to take care of my responsibilities" (p. 725).

Autonomy was the most frequently mentioned positive factor, after health, in a survey asking dialysis patients to describe the best and worst possible lives (Jackle 1974). Hemodialysis patients defined "quality of life" by relating it to purposefulness and independence (Willis 1978).

The dependency imposed by hemodialysis runs counter to the culturally desired value of independence (Cummings 1970). Hemodialysis units are frequently staffed by a highly motivated, self-demanding professional group of people who may place their own high expectations on others, including their patients (Levy 1973). Sullivan (1973) warned personnel about placing their own expectations of what a patient "should be" or "act like" on the hemodialysis patient. Such assignment of value may frustrate the patient in his effort to reach a compromise between the demands of his illness and the other aspects of his life. An example of the failure to recognize the predicament of the patient is the lack of references in the literature to home dialysis as "work". Sullivan (1973) reported a home patient who once said, "If keeping yourself alive ain't work, what is?" (p. 215)

Alexander (1976) related double bind theory to hemodialysis. Independent behavior on the part of the dialysis patient is both demanded and denied: "Whatever you do, it's wrong" (p. 1356).

This problem is frequently described in the literature as the "dependency-independency conflict". This conflict results from the need of the patient to

. . . come to terms with the reality of his abject dependency upon this procedure while maintaining sufficient independence in life outside the treatment to engage in the highest degree of work, family, and other activities within the limitations of his illness and its treatment (Levy 1976, p. 56).

Reichman and Levy (1972), in outlining stages of adaptation to dialysis, said that becoming productive again is a major conflict for most patients. The patients feel helpless and trapped between their desires to be passive and dependent and the staff's expectations that they be active and independent.

Abram (1968, 1974b), too, spoke about this conflict: accepting dependency upon the personnel, regimen, and dialyzer, but reassuming independent behavior, that is working, when not on dialysis. In a 1970 paper reviewing the psychological stresses of chronic hemodialysis, Abram proposed that, for patients, being "hooked" to the dialysis machine also meant being "addicted" to it, because of the patient's physiological dependence on the dialysis unit nurses and physicians. In this 1970 paper Abram also reported that the patient receives conflicting messages to "cooperate" (accept dependency) and to lead a "normal" life.

Anger (1975) listed the variety of ways a patient may respond to the dependency-independency dilemma:

He may attempt to meet both requirements, that is, to follow his treatment program and continue to lead an active, productive life. The other alternative is that he may either become excessively dependent, and unable to relinquish the sick role if his past dependency needs have been unresolved, or he may totally rebel, refusing to follow his treatment program (p. 452).

The secondary gains available to the dialysis patient who assumes the sick role are detailed by DeNour and Czaczkes (1972), Reichman and Levy (1972), and Dansak (1972). "When 'sick' the patients can allow themselves some of the regression found in others who are organically ill; dependency is more acceptable . . ." (DeNour, Shaltiel, and Czaczkes 1968, p. 531).

Example of "hyperindependent" behavior may be described as instances of "acting out", such as abuse of the diet or refusing to record one's weight as described by DeNour and Czaczkes (1972). This behavior can become life threatening when it extends to refusal to report for dialysis.

Recommendations for dealing with this conflict involve allowing the patient to take more responsibility for his treatment. With in-center dialysis, a major difficulty arises in that some staff members feel greatly

threatened when patients "take charge" (Abram 1974a). While the preponderance of long-term dialysis does occur in in-center, limited care settings, two other settings, self-care in-center and home dialysis, do offer greater independence. Jenkins (1977) ascribed decreased patient mortality and improved rehabilitation to the independence fostered by self-dialysis. Two patients described self-dialysis as meeting their needs to be in control of their lives and to function independently (Berman 1973, Oberly 1977).

Dependence and Renal Transplantation

The type of existence provided by chronic hemodialysis can be so difficult and unacceptable that many patients look to transplantation with hope for an improved quality of life (Tilney et al. 1975). The patient on dialysis may view transplant as a panacea. If the kidney functions and is not rejected, the patient does escape from the need for dialysis (Abram and Buchanan 1978).

In comparing the choice of transplant or dialysis, Levine (1978) recognized the benefits of a "good" transplant: increased energy and vitality and improved general health. The results of lifelong

immunosuppressive drugs are also recognized: "facial swelling, acne, loss of hair, and frightening out-of-body experiences" in addition to the increased risk of infection (p. 8).

In providing psychotherapy for transplant recipients, Kempf (1967) found that soon after recovery from the operation the patients began to become aware of unexpected limitations on their activities. Many of these limits were related to the steroids and their side effects, including anxiety concerning the need to periodically increase the dose when signs of rejection appeared. This served to remind the patients of the "precarious balance of factors which determined their survival" (Kempf 1967, p. 627). Remarks of strangers and friends concerning the physical side effects of obesity and acne also keep the transplant recipient from easily forgetting his dependence on medications for maintenance of the graft (Abram 1972).

Dependency on a machine may be replaced by dependence upon a donor. With a living related donor, the recipient may have ambivalent feelings of hostility and dependency. "How can I be angry with my brother if he's been good enough to give me one of his kidneys?" (Abram and Buchanan 1978, p. 23)

If the kidney comes from a cadaver donor, the patient may "become concerned with the notion that his continued life depended upon the death of someone else" (Abram and Buchanan 1978, p. 23). Fox (1970) indicated the importance of shielding the identity of the cadaver donor from the recipient so that this sense of indebtedness does not result in the imposition of heavy social and psychic demands.

Beard (1969), in an article entitled "Fear of Death and Fear of Life," discussed the dilemma facing the E.S.R.D. patient. Patients experience thoughts and feelings

dominated by the fear of death alternating with the fear of living a life restricted and incomplete, dependent upon the life prolonging abilities of the dialysis apparatus or on the uncertain function of a transplanted kidney (Beard 1969, p. 376).

This "uncertain function" must be closely monitored, requiring constant communication with the medical team and frequent trips for laboratory examinations. The impact of this surveillance is apt to be great, as patients struggle to accept the uncertainties, the impossibility of planning ahead, and the necessity of living from day to day (Beard 1971). Kempf (1966) reported that even patients with a "good result" do not

plan their lives "more than one week ahead" as they know from experience that "without warning" they could be "back in a hospital bed and close to death" (p. 1272).

Eisendrath (1969), in evaluating the relationship of grief and fear to death in eleven transplant patients, found a significant level of hopelessness in eight patients. He likened this to the "giving-up given-up" complex described by Engel (1968), in that the patients had suffered significant losses and their autonomy and ability to get what they needed and wanted was impaired.

Even though the transplant recipient may do well for some time after transplantation, he could yet experience increasing chronic rejection or return of his original disease. Christopherson and Gonda (1973) discussed a patient who described his feelings:

I feel like I'm always walking around with a sword hanging over my head. It's tied up with a strong rope, but some day it's going to fall and that will be the end of me. At times I don't think of dying for days or weeks--not even when I take my pills or come in for clinic visits. But then it all comes back to me. My creatinine is higher than it was a year ago; my clearance is lower. I'd like to tell my wife what to do if I die, but she just can't take it (p. 1052).

These authors also cited one of the major coping tasks of the transplant recipient as being to reconcile himself to

the fact that there is really little he can do to ensure continued survival of the graft.

Beard (1971) followed five patients for a maximum of nine months to assess their quality of life before and after transplantation. He reported that renal transplantation was no more likely than hemodialysis to "guarantee an acceptable existence, at least not immediately" (p. 30). Shanan, DeNour, and Garty (1976) questioned if the decline in ego strength seen with the dependency of chronic dialysis can be reversed by treatment intervention, especially one as uncertain of success as renal transplantation.

This review of the literature related to dependence and renal failure has revealed many studies that indicate both transplantation and hemodialysis can increase patient's feelings of dependence on someone or something outside himself. Whether this dependence is greater with a particular modality is unknown. This study utilized a particular instrument, the Internal-External Locus of Control Scale, to evaluate the possibility of greater feelings of dependence related to either dialysis or renal transplantation.

Studies of Locus of Control

The view that one lives in an intelligible world may be a prerequisite to expectancies for control (Seeman 1959). The uncertainties inherent in both treatment modalities for E.S.R.D. may be conducive to the development of high expectancies for external control.

Although searching the literature failed to reveal studies of locus of control in transplant recipients, several researchers have used the I-E Scale in studies involving hemodialysis patients. Goldstein and Reznikoff (1971) examined the high suicide rate in chronic hemodialysis patients. High scores for externality of control were found in the hemodialysis group, leading the authors to suggest that in a chronically-ill patient, external locus of control may result in disaster when his cooperation is needed for his survival but he is unable to recognize the effects of his own behavior on his condition.

Goldstein (1976) found external locus of control to be significantly and positively correlated with denial in chronic dialysis patients. He attributed this to the need to lessen the anxiety felt when the patients realized that failure to follow severe restrictions could cause

their deaths. They adopted an external orientation to deny the importance of their own actions.

Kilpatrick, Miller, and Williams (1972) evaluated Goldstein's hypothesis that dialysis makes individuals more external in their locus of control. This hypothesis was not supported; the greater the length of dialysis, the more internal was the locus of control of the patients studied. One possible explanation offered was that failure to follow the treatment regimen was more prevalent in external patients and resulted in a decreased length of survival for external patients, leaving long-term dialysis samples who were preponderantly internal.

Gentry and Davis (1972) partially supported the hypothesis that external patients have a decreased length of survival when compared with internal patients in a study that assessed the effect of number of months in dialysis and number of treatments on patient's psychological adaptation. Reported anxiety and depression diminished as the number of dialysis treatments increased. However, locus of control did not correlate with these measures of dialysis exposure, as all subjects scored on the external side of the mean. Gentry and Davis felt

that more relationship might be found between severity of illness rather than length of time on dialysis.

Brown and others (1974) interviewed eleven home dialysis patients to assess their adjustment to this therapy. While admitting that their ultimate definition to a patient's adjustment was based on the researcher's subjective judgment, they found four areas which separated the well-adjusted patient from the poorly adjusted. These were:

- 1) the impact of change in physical and mental state;
- 2) sources of financial support;
- 3) the effectiveness of the patient's helper;
- 4) the prominence that dialysis plays in the patient's daily life (p. 168).

Using these criteria for evaluation, Brown and others (1974) found that well-adjusted home dialysis patients eventually developed a sense of independence from their machines. Less well-adjusted patients seemed to become "engulfed in the process of staying alive by dialysis" (p. 169).

Foster, Cohn, and McKegney (1973) reported an extensive "psychobiologic" study on twenty-one male chronic hemodialysis patients who completed the I-E Scale. They were unable to explain a significant correlation between external locus of control and hypochloremia and recommended a larger study and

sequential administration of the I-E Scale to determine if feelings of diminishing control might correlate with approaching metabolic encephalopathy.

Mock (1975, 1976) undertook a study to evaluate the claims in the literature that home dialysis allows the E.S.R.D. patient greater independence and control. She attempted to validate this claim using the Locus of Control Scale with home-trained patients and their wives and a control group of in-center patients and their wives. Home patients were significantly more internally oriented. She suggested that locus of control could be used as part of the selection process of patients to dialyze at home.

Adler (1975) would disagree with this utilization of the I-E Scale as a screening device as she found the scale non-discriminatory between successfully adapted and unsuccessfully adapted dialysis patients. Both groups she evaluated scored at approximately the standardized population mean.

Johnson (1968) stated that powerlessness as measured by generalized expectancy for the control of events reflected a "life philosophy" and represented a "more or less permanent personality trait" (p. 41). However, several authors have reported that changes in

expectancy of control can be effected. Gottesfeld and Dozier (1966) reported changes in beliefs regarding control as persons gained experience in leadership positions. Gillis and Jessor (1970) found a change toward greater internality in psychiatric patients who were tested before and after a brief course of psychotherapy. Joe (1971), in his review of over one hundred studies of the locus of control construct, agreed that certain of these studies "suggest that an external expectancy of control can be changed to an internal frame of reference" (p. 634).

Smith (1970) questioned the effect of acute situation factors on changing locus of control. Thirty patients presenting for crisis intervention were given the scale initially and again after six weeks of treatment. The results were compared to a non-crisis control group. A significant change toward internality was seen in the crisis group. Smith suggested that this might be attributed to an increased feeling of powerfulness as more effective coping mechanisms were developed.

Demographic variables which may influence locus of control were outlined by Joe (1971) in his review of this construct. He listed race, sex, and socioeconomic status as sometimes influencing the score on the I-E

Scale, since he found that minority groups, women, and lower socioeconomic classes generally have higher external scores. Joe attributed this finding to the possible perception of limited opportunities by these groups and in the case of the women, to the cultural role of submissiveness formerly assigned to females. Age and marital status as additional demographic variables were considered by Boor (1974). He supported the hypothesis that internal orientation could be related to level of maturity and hence to age, and that married subjects would score more internally.

This review of studies with locus of control revealed that the I-E Scale has been used to evaluate hemodialysis patients, but not transplant recipients. Results of the studies with hemodialysis subjects demonstrated an association of external locus of control with feelings of dependence, denial, and with a decreased length of survival. Opinion differs as to whether locus of control within a given individual can be altered, but several studies have demonstrated changes in locus of control related to various treatment measures.

Nursing Measures to Decrease
Feelings of Dependence

As in most chronic disease settings, nursing personnel interact must closely with the E.S.R.D. patient (Cummings 1970). The literature details nursing behaviors and attitudes helpful in decreasing feelings of dependence in patients with E.S.R.D.

Jackle (1974) warned nurses to avoid becoming "too problem oriented, focusing on the patient's difficulties rather than identifying and building on his strengths" (p. 366). She encouraged nurses to help plan programs for the care of E.S.R.D. patients which "keep restrictions down to a safe minimum, . . . include the patient in the planning of his schedule, and . . . have flexible hours and service patterns" (p. 367). Jackle further expressed belief that the nurse should be aware, and cause the family to be aware, of the patient's need to exercise control over his life. "One of the most helpful things she (the nurse) can do is to point out alternatives so as to give the patient a range of options" (p. 367).

Cummings (1970) would agree that the nurse's role as information giver is an important one. He emphasized the need for repetition of information, particularly

optimistic data, as many E.S.R.D. patients seem to be "selectively more sensitive to somber news than to the positive side of the ledger" (p. 76).

DeNour and Czaczkes (1972) described patients who act out their intolerance of the dependency of E.S.R.D. with increased hostility and aggression. Finding ways to decrease the actual dependency alleviates the need for the "acting out".

One way of decreasing this dependency was suggested by Sullivan (1973). Health care workers should avoid giving excessive direction and should facilitate patients maintaining as much control as possible over their own affairs. This author, too, stressed the need for the patient to know the "practical options" (p. 217) available to him.

Hellickson, Macmillen, and Swanson (1976) emphasized the need for intervention early in renal failure to prevent excessive dependency. The patient should be expected to actively participate in his care; the family encouraged to allow the patient to reacquire independence; and the community urged to recultivate their trust in the patient's capabilities.

Blagg and others (1977) agreed that early emphasis of the expectation of patient participation in his

treatment is essential. Greater acceptance of and compliance with the treatment regime was found in the patients who were actively involved in the actual performance of their own dialysis.

The patient who actively participates in the planning of his care assumes some responsibility for the outcome of that care (Tryon and Leonard 1965). Tyron and Leonard (1965) stated that this active patient role requires more of those persons working with the patient, rather than less. The patient must be encouraged to ask questions, to express his feelings, and to participate in the planning of his care. These same actions are easily discouraged, with the result being the patient assumes that a passive dependent role is the proper one; he then becomes unable to take responsibility when necessary. A suggested way to avoid this assumption was a nursing practice based on "doing with" the patient rather than "to" or "for" him (p. 125).

Roy (1976) listed nursing interventions useful in dealing with powerlessness. These include helping the patient identify and use control measures and assisting the patient in setting realistic goals for himself. Roy also advocated modifying the hospital environment to decrease factors which contribute to feelings of

powerlessness. The nurse does this by personalizing her nursing care and involving the patient in planning and delivering nursing care.

The formation of patient groups as a way of encouraging patients to assume more independence was suggested by Buchanan (1975). Such groups allow the sharing of experiences, and may motivate some participants to be more assertive when they see "others with similar problems make attempts at solutions without harm befalling them" (p. 526). The author reported that group members often entered the group expecting to be spectators. Buchanan (1975) attributed this to the all too common experience with illness which is

. . . to have external forces, i.e., doctors, nurses, medicines and machines impinge their demands upon the patient. Although unrealistic this becomes the expected means to have their problems solved (p. 527).

Participation in the group encouraged alteration of attitude, development of a more active role in their treatment, and acceptance of responsibility for their treatment.

In a discussion of selection and motivation of patients for self-dialysis, the need to give the E.S.R.D. patient a true choice in treatment modality was stressed (Blagg et al. 1977). Caregivers should avoid representing

any one particular treatment, such as home dialysis, self-care dialysis, in-center dialysis, or transplantation, as the "best" or "only acceptable" treatment for renal failure.

To summarize, nursing actions to decrease feelings of dependence hinge primarily on involving the patient actively in his care, giving choice in as many areas as possible, including choice of treatment modality. Information gained through this study will add to the knowledge base of the nurse who assists the E.S.R.D. patient in making informed choices.

Summary

The literature related to hemodialysis and renal transplantation as modalities of treatment for E.S.R.D. has been reviewed with regard to effects on patient's feelings of dependence. The concept of locus of control as a measure of dependence has been presented, and studies using the Locus of Control Scale to evaluate hemodialysis patients were reviewed, as well as studies documenting change in locus of control secondary to therapeutic intervention. Demographic data which may influence locus of control were outlined. Nursing measures to decrease feelings of dependence were described.

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

The design of this study was explanatory research (Abdellah and Levine 1965) to evaluate the effect of different modalities of treatment for E.S.R.D. on patient's feelings of dependence. Demographic data were recorded and Rotter's Internal versus External Control Scale (1966) was administered. The entire population of transplant patients meeting the study definition were asked to participate; while a purposive sample (Treece and Treece 1977) was selected from the dialysis population.

Setting

Located in a large southwestern metropolitan area with a population greater than one million, the agencies that were utilized for the collection of the data comprise a tertiary care center for E.S.R.D.: that is patients with chronic renal failure are treated with conservative medical management, maintenance dialysis, and renal transplantation. The facilities that provide this care

include both a public clinic and several private clinics, all managed by the same nephrologists.

At the beginning of therapy, all patients receive a careful explanation of various options: maintenance in-center hemodialysis, self-care dialysis in the center, home dialysis, chronic peritoneal dialysis, and renal transplantation. All patients who have a living related donor and wish to be transplanted are assessed immediately. Those who choose to be candidates for cadaver transplantation are evaluated and placed on a waiting list for a suitable kidney.

Medical services for E.S.R.D. patients afford considerable continuity in that many of the staff physicians who supervise dialysis at the proprietary centers also rotate to the transplant service. A registered nurse functions as a transplant coordinator. She coordinates transplant evaluations of living related donors, maintains a current list of patients awaiting cadaver kidneys, and provides outpatient care from the transplant clinic.

Population and Samples

There were twenty-one transplant patients at the transplant center chosen for this study who met the study

delimitations. All were asked to participate as representatives of the universe of renal transplant recipients who met the study criteria. One transplant recipient declined the request to complete the instruments; one did not come to the transplant clinic during the data collection period; and one who completed the instruments left three items blank. Thus the sample for the transplant group consisted of eighteen subjects.

A purposive sample (Treece and Treece 1977) of a similar number of hemodialysis patients who met the delimitations was planned to represent the universe of persons on dialysis who met the study requirements. A careful review of records at the dialysis center revealed only twenty patients who met the age and length of treatment delimitations of the study. All of these patients were asked to participate; three were unable to do so, thus the dialysis group consisted of seventeen subjects.

The demographic data obtained were used to describe the subjects. An "ex post facto" (Abdellah and Levine 1965) approach was utilized in an attempt to control variables such as age, length of illness, race, and marital status.

Protection of Human Subjects

The human rights of the individuals agreeing to participate in the study were protected by the following measures:

1. Permission to conduct the study was secured from the Human Research Review Committee of Texas Woman's University (appendix A)

2. Permission to conduct the study was secured from the agencies in which the study took place (appendix B)

3. Oral and written explanations regarding all aspects of the study were provided each participant; any questions were fully answered (appendix C)

4. Permission was obtained in writing from each individual agreeing to participate in the study (appendix C)

5. The data obtained from each individual were handled with every consideration of confidentiality

6. A subject's decision not to participate in the study was respected and such decision did not affect his further treatment

7. If an individual initially chose to participate in the study and later decided to withdraw, this action was respected

8. Assistance was provided to any participant who had difficulty reading or understanding the data collecting instruments

Instruments

Two instruments were utilized in this study, a demographic data questionnaire (appendix D) and the Rotter Internal versus External Control Scale (appendix E). The demographic data questionnaire was completed on each individual in the study. To assist in selecting the dialysis population, information regarding variables which have sometimes been found to have an effect on locus of control was recorded. These included age (Boor 1974), sex (Boor 1974, Joe 1971), race (Joe 1971), marital status (Boor 1974), and socioeconomic group, as reflected by educational background and occupation (Joe 1971).

Rotter's Internal versus External Control Scale (I-E Scale) is composed of twenty-nine forced-choice items, twenty-three which compare an internal belief with an external belief and six fill items (Items 1, 8, 14, 19, 24, and 27) intended to make the purpose of the test

somewhat more ambiguous. The total score represents the number of items answered in the external direction. The range of scores is from 0, which represents the most internal score, to a score of 23, reflecting the most external score.

The mean score of a normal sample of 1,080 tested by Rotter was 8.29. Scores higher than this mean reflect a greater degree of external control while scores lower than 8.29 reflect greater internal control.

The items deal exclusively with the subjects' belief about the nature of the world. That is, they are concerned with the subjects' expectations about how reinforcement is controlled (Rotter 1966, p. 10).

Concerning validity and reliability of this scale, in a 1966 review, Rotter stated:

Item analysis and factor analysis show reasonably high internal consistency for an additive scale (coefficients .65-.79). Test-retest reliability is satisfactory (.49-.83), and the scale correlates satisfactorily with other methods of assessing the same variable such as questionnaire, Likert scale, interview assessments (.61), and ratings from a story-completion technique. Discriminant validity is indicated by the low relationships with such variables as intelligence, social desirability, and political liberalness (p. 25).

Construct validity is perhaps best assessed by comparing scores on the I-E Scale with attempts by the individual to control his environment in important life

situations. Seeman and Evans (1962) found that the I-E Scale appeared to measure a psychological equivalent to the sociological concept of alienation in the sense of powerlessness. Individuals in a tuberculosis hospital who scored as having greater feelings of internal control also knew more about their own condition, questioned the doctors and nurses more, and expressed less satisfaction at the amount of information about their condition they were getting from hospital personnel.

Rotter concluded his 1966 monogram reviewing Internal-External Control of Reinforcement by stating:

Most significant evidence of the construct validity of the I-E Scale comes from predicted differences in behavior for individuals above and below the median of the scale or from correlations with behavioral criteria. A series of studies provides strong support for the hypotheses that the individual who has a strong belief that he can control his own destiny is likely to (a) be more alert to those aspects of the environment which provide useful information for his future behavior; (b) take steps to improve his environmental condition; (c) place greater value on skill or achievement reinforcements and be generally more concerned with his ability, particularly his failures; and (d) be resistive to subtle attempts to influence him (p. 25).

Method of Data Collection

The data from the transplant patients were collected during outpatient visits as these visits occurred during the data collection period. A small

(7' x 9') unused examining room was used to provide privacy for those participating in the study during a clinic visit. This room contained a chair and a student's chair-desk. There was no telephone in the room.

The dialysis patients were selected from the population dialyzed at the larger proprietary center for limited care hemodialysis in the same metropolitan area. The data from these patients were collected during a dialysis treatment. The large dialysis area housed fifty individual hemodialysis units. The room was subdivided into three sections--one of eighteen chairs and two of sixteen chairs each. Each individual chair and dialysis unit was contained in approximately 42 square feet. Noises from the machines and alarm devices were constantly present.

An oral introduction and a written presentation (appendix C) regarding the study were made to each proposed subject. When the individual agreed to participate, the demographic data were collected by interview and utilization of medical records when necessary. The subject was then asked to read the instructions and complete the I-E Scale (appendix E). The researcher left the subject alone while the questionnaire was being completed unless assistance was requested.

Treatment of Data

The scores for the two groups on the I-E Scale were compared for significant differences by the use of the Mann-Whitney U test (Siegal 1956), with the acceptable level of significance being 0.05. The Mann-Whitney U test was chosen because it is one of the most powerful of the nonparametric tests and is usable with small, uneven sample sizes (Siegal 1956).

Summary

Individuals with chronic renal disease associate quality of life with purposefulness, autonomy, and maintenance of independence (Jackle 1974, Willis 1978). This study was designed to add to information and understanding concerning the effects of two different treatment modalities for E.S.R.D. on patients' feelings of dependence as measured by Rotter's I-E Scale (1966). The methodology of data collection and the planned treatment of data were described.

CHAPTER IV

ANALYSIS OF DATA

The analysis of the data collected includes a description of the sample emphasizing variables described in the literature as affecting locus of control. The findings of the study are presented, using the Mann-Whitney U as the test of statistical significance. All findings are then summarized.

Description of Sample

Eighteen renal transplant recipients and seventeen chronic hemodialysis patients were able to participate in the study. When these two convenience samples were analyzed regarding factors described in the literature as affecting locus of control, only two factors, race and educational level, were significantly different between the groups.

One of the characteristics of the group that was examined was age. These data are presented in table 1. Although there are more subjects in the older group in the hemodialysis subjects, the range and mean age are similar.

TABLE 1

COMPARISON OF THE AGE DISTRIBUTION
OF THE SAMPLE SUBJECTS

Age in Years	Group	
	Hemodialysis (N = 17)	Transplant (N = 18)
18 - 24	0	1
25 - 30	2	5
31 - 35	2	1
36 - 40	3	4
41 - 45	3	4
46 - 50	3	2
51 - 55	4	1
Mean Age (from raw scores)	42.17 years	39.05 years

A demographic characteristic reviewed was the distribution of sex. The distribution of sex of the sample subjects is presented in table 2. The distribution of sex in the sample groups was very similar. Both groups were preponderantly male.

Another demographic characteristic audited was racial background. The distribution of race in the two samples is presented in table 3. As these data illustrate, almost exactly opposite pluralities were

found in comparing the two samples. The hemodialysis sample contained a greater number of minority members.

TABLE 2
DISTRIBUTION OF SEX OF SAMPLE SUBJECTS

Sex	Group	
	Hemodialysis (N = 17)	Transplant (N = 18)
Male	12	14
Female	5	4

TABLE 3
DISTRIBUTION OF RACE OF SAMPLE SUBJECTS

Race	Group	
	Hemodialysis (N = 17)	Transplant (N = 18)
White	3	13
Black	12	2
Latin-American	2	3

Marital status was another variable assessed by the demographic data instrument. The results of this assessment are presented in table 4. The hemodialysis and transplant samples were again similar. Both samples contained greater numbers in the married category.

TABLE 4
MARITAL STATUS OF SAMPLE SUBJECTS

Marital Status	Group	
	Hemodialysis (N = 17)	Transplant (N = 18)
Married	12	11
Separated/Divorced	4	3
Single	1	4

Because of the difficulty of objectively assigning socioeconomic status in populations which may be underemployed secondary to chronic illness, educational level was used as a less biased criteria to assess probable social class. Data obtained in response to the query "Last grade of school completed" are presented in table 5. The transplant group had a somewhat higher level of education than the hemodialysis group. More of the transplant sample had completed some college, and the mean grade completed (from ungrouped data) by the transplant subjects was 13.27 years as compared to the hemodialysis subjects of 11.15 years.

Length of illness before dialysis was instituted was to have been used to select the hemodialysis sample to match the transplant sample regarding severity of

TABLE 5

DISTRIBUTION OF EDUCATIONAL LEVEL ATTAINED
BY SAMPLE SUBJECTS

Level of Education	Group	
	Hemodialysis (N = 17)	Transplant (N = 18)
8th grade or less	3	0
11th grade or less	6	1
High school graduate	5	6
Some college	2	9
College graduate or plus	1	2
Mean grade completed (from raw scores)	11.15 years	13.27 years

illness. Although this "matching" was impossible, the information obtained from both groups was reviewed and is presented in table 6. Length of illness before dialysis was instituted was found to be similar between the hemodialysis and transplant subjects. Most subjects in both groups had been ill one year or less before dialysis was instituted.

The number of problems each subject had experienced with his therapy was used as a measure of severity of illness. Loss of access was used as the problem in

TABLE 6

LENGTH OF ILLNESS BEFORE DIALYSIS
OF SAMPLE SUBJECTS

Length of Illness pre Dialysis	Group	
	Hemodialysis (N = 17)	Transplant (N = 18)
1 year or less	8	10
3 years or less	6	3
More than 3 years	2	5

the hemodialysis group while "treated rejection episodes" was the equivalent event in the transplant sample. The information obtained regarding problems with therapy is presented in table 7. The samples were convenience selected rather than matched. It would have been difficult to "match" more closely for this variable; the sample are almost exactly the same.

Summary of Sample Description

The hemodialysis sample (N = 17) and the transplant sample (N = 18) were similar in the variables of age, sex, marital status, length of illness before dialysis was instituted, and problems with therapy. Differences were noted in the variables of race and

TABLE 7

PROBLEMS WITH THERAPY OF SAMPLE SUBJECTS

Number of Problems*	Group	
	Hemodialysis (N = 17)	Transplant (N = 18)
1 or less	11	11
2 or 3	4	5
More than 3	2	2

*Problem in hemodialysis--loss of access; in transplant--treated rejection episode.

educational level. The hemodialysis sample had more minority members and less education than the transplant sample.

Findings

The null hypothesis for this study was that there is no significant difference in the level of dependency expressed by renal transplant recipients and the level of dependency expressed by chronic hemodialysis patients. Rotter's Internal-External Locus of Control Scale (1966) was used as the measure of level of dependency with the sample groups.

The raw scores are presented in appendix F. The calculated mode, median, and mean are shown in table 8.

TABLE 8

MEASURES OF CENTRAL TENDENCY OF SAMPLE
SUBJECTS' SCORES ON I-E SCALE

	Group	
	Hemodialysis (N = 17)	Transplant (N = 18)
Mode	8.5	11
Median	8	8.5
Mean	8.29	8.38

The raw data and measures of central tendency reveal no striking differences, except for a mode of 11 in the transplant group, and 8.5 in the dialysis group. The normative mean of this twenty-three item scale is approximately 8.29 (Rotter 1966). The mean of the hemodialysis sample was exactly the same as this normative mean. The mean of the transplant sample was slightly higher at 8.38.

Utilization of the Mann-Whitney U failed to reveal a statistically significant difference between the two samples. For the level of significance of 0.05 to be met, the critical value had to be less than 93. For the transplant sample, U = 151 and for the hemodialysis sample U = 155. Thus, there was no statistically significant difference between the hemodialysis sample

and the transplant sample. The null hypothesis was therefore accepted.

Summary of Findings

This study was undertaken to determine if a difference in feelings of dependence, as measured by Rotter's I-E Scale (1966), related to modality of therapy exists in persons with E.S.R.D. No statistically significant difference was found in subjects selected from hemodialysis and transplant populations.

In selecting the subjects, a preponderance of older (55+) individuals was found in the hemodialysis group. This so greatly reduced the group who met the study delimitations that matching was impossible. However, the resultant groups were remarkably similar in most criteria that would have been "matched." Only in the variables of race and educational level were sizable differences found, with the hemodialysis sample containing more minority group members and being less educated.

An interesting similarity was found in reviewing the problems with therapy. Using "loss of access" as equivalent to "treated rejection episodes," there was a striking sameness of occurrence between the groups. The

majority in both groups had had one or less incident representing a medical crisis.

CHAPTER V

SUMMARY OF THE STUDY

This final chapter presents a summary of the study and a discussion of the findings, relating these findings to pertinent literature. The conclusions reached and the implications of the findings are discussed. Recommendations for further study are given.

Summary

Using Rotter's I-E Scale, this study compared feelings of dependence expressed by patients with E.S.R.D. treated with chronic hemodialysis with the feelings of dependence expressed by E.S.R.D. patients treated with renal transplantation. To accomplish this purpose, the level of dependence expressed by renal transplant recipients was ascertained, the level of dependence expressed by chronic hemodialysis patients was ascertained, and these levels were compared.

The theoretical framework which served as the basis for this study was social learning theory (Rotter 1954). Social learning theory asserts that a reinforcement acts to strengthen the expectancy that a particular behavior or event will be followed by the reinforcement

in the future. Rotter (1966) developed a scale to measure the belief of an individual regarding control of reinforcement. The individual who believes that reinforcement is contingent on his own behavior is said to have an internal locus of control, while the individual who believes that something or someone outside himself has control of reinforcement is said to have an external locus of control.

All individuals who received a renal transplant at one transplant center from January, 1977 through March, 1978 and met the other delimitations were asked to participate as representatives of the transplant population. The hemodialysis sample was selected from one large dialysis center. All persons who met the study delimitations were asked to participate. The final number for the transplant sample was eighteen; the hemodialysis sample was seventeen.

All participants supplied demographic data which the literature review had indicated might influence locus of control. The subjects then completed the I-E Scale. The data obtained were analyzed for significant differences, using the Mann-Whitney U to evaluate the scores on the I-E Scale.

The demographic variables of both groups were similar except for race and educational level. The hemodialysis sample had more minority group members and was less educated.

There was no statistically significant difference in the locus of control scores of the two groups. For the level of significance of 0.05 to be met, the critical value of \underline{U} had to be less than 93. The transplant sample had a $\underline{U} = 151$, and the hemodialysis sample had a $\underline{U} = 155$. Both the hemodialysis and the transplant sample means were near the normative mean for the I-E Scale. From this study, there appears to be no significant difference in the expression of dependence of individuals with E.S.R.D. treated with chronic hemodialysis and the expression of dependence of recipients of renal transplants.

Discussion of Findings

The initial identification of the hemodialysis group revealed a preponderance of patients fifty-five years of age or older. The researcher did not anticipate this, but conversations with nephrologists since have verified that the dialysis population has increased in age (Hull 1979). Boor (1974) found that older persons

scored more internally on locus of control. The age range of these two samples were similar, and the mean age of the hemodialysis subjects (42.17 years) was only slightly older than the mean age of the transplant subjects (39.05 years).

Marital status and sex were two variables reported to affect locus of control. Boor (1974) supported the hypothesis that married subjects would score more internally. The marital status of the two sample groups of this study was similar. Joe (1971) attributed higher external scoring in females to the submissive role formerly culturally assigned to women. Both samples of this study were predominantly male.

While the demographic data regarding length of illness before dialysis is similar in both groups, no data were collected regarding length of time on dialysis before transplantation. It is possible that some members of the transplant sample were on dialysis for several years before being transplanted. If length of illness is related to locus of control as suggested by several researchers (Gentry and Davis 1972; Kilpatrick, Miller, and Williams 1972; Goldstein 1976), this information would be important in interpreting the data.

The assumption by many that feelings of independence would be promoted by transplantation and thwarted by hemodialysis was not supported by this study. No difference was found in feelings of dependence expressed by patients undergoing either of these two treatment modalities. This lack of difference presents in the face of a hemodialysis sample which is less educated and primarily composed of minority racial groups, two reasons cited by the literature to favor externality (Joe 1971).

The small number of complications noted by most members of both samples might be related to a hypothesis by Kilpatrick, Miller, and Williams (1972). These researchers proposed that internal patients were more likely to follow treatment regimens, and thus had an increased survival when compared with external subjects.

That survivors tend to be internally oriented may be the key to understanding the findings of this study. All subjects had been undergoing their modality of therapy for at least twenty-four months. In addition, all had experienced varying lengths of illness before instituting their present treatment. Various researchers (Goldstein and Reznikoff 1971; Gentry and Davis 1972; Kilpatrick, Miller, and Williams 1972; Brown et al. 1974;

Goldstein 1976) have found internality to be positively related to survival.

To summarize, the two sample groups, although convenience selected, were remarkably similar in most demographic characteristics. All subjects could be termed "survivors." Individuals who feel that their behavior has an affect on what happens to them are more apt to survive a chronic illness, particularly one with multiple restrictions and requirements of patient cooperation, such as those entailed with E.S.R.D.

Conclusions and Implications

No significant difference in feelings of dependence as measured by Rotter's I-E Scale (1966) was found between patients on chronic hemodialysis and patients receiving a renal transplant after two years of their current treatment modality. A conclusion drawn from this finding is that all the subjects studied would be classified as "survivors," who tend to be more internally oriented, believing they have some control over what happens to them.

That neither therapy inherently "allows" a patient independence or "causes" his dependence can also be concluded from the finding of no significant difference

in feelings of dependence expressed by patients receiving either hemodialysis or renal transplantation as treatment for E.S.R.D. The implication of this conclusion is that, in counseling patients with E.S.R.D., emphasis needs to be placed on the importance of maintenance of independence and feelings of control, rather than on a particular modality of therapy.

Further implications of this study are referrent to the nursing care planning for the E.S.R.D. patient. This care planning must include measures to promote and encourage independent behavior. These measures become even more essential when one recalls that both quality of life and survival have been related in the literature to the patient's perception of independence.

Recommendations for Further Study

The results with the relatively small numbers sampled in this study would be better supported if the study were replicated with a larger sample size. Matching for variables indicated by the literature to affect locus of control could be done were a larger population available.

There is no information available related to what alterations, if any, hemodialysis or transplantation make

on locus of control. A longitudinal study, administering the I-E Scale sequentially during the course of E.S.R.D., might yield this information.

Patients undergoing other modalities of therapy for E.S.R.C., such as self-care dialysis, home dialysis, and chronic ambulatory peritoneal dialysis, need to be evaluated regarding feelings of dependence. These results could be compared with those of patients on in-center hemodialysis and transplant recipients.

Long-term survivors need to be evaluated for commonalities which could be utilized in counseling E.S.R.D. patients early in their course. The weight of survival should shift from the external: the machine, someone else's kidney to the internal: feelings of control by the individual enduring E.S.R.D.

APPENDIX A

TEXAS WOMAN'S UNIVERSITY

Human Research Committee

Name of Investigator: Glenda Payne Center: Dallas
Address: 2504 Aaron Circle Date: 3-19-79
Dallas, Texas 75233

Dear Ms. Payne:

Your study entitled Effect of Modality of Treatment of E.S.R.D. on Patient's Feelings of Dependence has been reviewed by a committee of the Human Research Review Committee and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health, Education and Welfare regulations require that written consents must be obtained from all human subjects in your studies. These forms must be kept on file by you.

Furthermore, should your project change, another review by the Committee is required, according to DHEW regulations.

Sincerely,

Estelle D. Kurtz

Chairman, Human Research
Review Committee

at Dallas.

APPENDIX B

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
DENTON, TEXAS

DALLAS CENTER
1810 Inwood Road
Dallas, Texas 75235

HOUSTON CENTER
1130 M.S. Anderson Blvd.
Houston, Texas 77025

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Parkland Memorial Hospital

GRANTS TO Glenda M. Payne

a student enrolled in a program of nursing leading to a Master's Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem:

The effect of modality of treatment of end stage renal disease on patient's feelings of dependence

The conditions mutually agreed upon are as follows:

1. The agency (may) (~~may not~~) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (~~may not~~) be identified in the final report.
3. The agency (~~wants~~) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (~~unwilling~~) to allow the completed report to be circulated through interlibrary loan.
5. Other: It was agreed to a copy of the findings

Date

4-17-79

Glenda M. Payne RN
Signature of Student

[Signature]
Signature of Agency Personnel

[Signature]
Signature of Faculty Advisor

*Fill out and sign three copies to be distributed as follows: Original - Student; first copy - agency; second copy - T.W.U. College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
DENTON, TEXAS

DALLAS CENTER
1810 Inwood Road
Dallas, Texas 75235

HOUSTON CENTER
1130 M.S. Anderson Blvd.
Houston, Texas 77025

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Dallas Kidney Disease Center

GRANTS TO Glenda M. Payne

a student enrolled in a program of nursing leading to a Master's Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem:

The effect of modality of treatment of end stage renal disease on patient's feelings of dependence

The conditions mutually agreed upon are as follows:

1. The agency (may) (~~may not~~) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (~~may not~~) be identified in the final report.
3. The agency (~~wants~~) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (~~unwilling~~) to allow the completed report to be circulated through interlibrary loan.
5. Other: _____

Date 4-17-79

Glenda M. Payne
Signature of Student

[Signature]
Signature of Agency Personnel

[Signature]
Signature of Faculty Advisor

*Fill out and sign three copies to be distributed as follows: Original - Student; first copy - agency; second copy - T.W.U. College of Nursing.

APPENDIX C

TEXAS WOMAN'S UNIVERSITY

Consent to Act as a Subject for Research and Investigation:

(The following information is to be read to or read by the subject)

1. I hereby authorize Glenda M. Payne to perform the following procedure(s) or investigation(s): to obtain descriptive information (ex.: age, sex, race, marital status, length of illness) about me, and to have me answer a short questionnaire to find out how certain events in our society affect different people.
2. The procedure of investigation listed in Paragraph 1 has been explained to me by Glenda M. Payne.
3. I understand that the procedures or investigations described in Paragraph 1 involves the following possible risks or discomforts: the loss of anonymity within my care-giving group. All possible steps will be taken to prevent this from occurring.
4. I understand that the procedures and investigations described in Paragraph 1 have the following potential benefits to myself and/or others: to increase caregivers knowledge and understanding of patients with renal disease, which may help them design more helpful programs of care.
5. An offer to answer all of my questions regarding the study has been made. If alternative procedures are more advantageous to me, they have been explained. I understand that I may terminate my participation in the study at any time.

Subject's signature

Date

APPENDIX D

DEMOGRAPHIC DATA SHEET

HD TP _____

Date: _____

Sex _____ Race _____

Age _____ Marital status _____

Education (last grade completed) _____

Occupation (of self or supporting person) _____

Cause of renal disease _____

Length of illness _____

Length of time on dialysis _____

Number of access revisions _____

Length of time with a functioning transplant _____

Number of treated rejection episodes _____

Date of last hospitalization _____

APPENDIX E

QUESTIONNAIRE

Instructions

This is a questionnaire to find out how certain events in our society affect different people. Each item consists of a pair of statements lettered "a" or "b." Please circle the letter of the one statement of each pair (and only one) which you more strongly believe to be the case as far as you are concerned. Be sure to select the one you actually believe to be more true rather than the one you think you should choose or the one you would like to be true. Since this is a measure of personal belief, obviously there are no right or wrong answers.

Please answer these items carefully but do not spend too much time on any one item. (Be sure to find an answer for every choice.) In some instances you may discover that you believe both statements or neither one. In such cases, be sure to select the one you more strongly believe to be the case as far as you are concerned. Also try to respond to each item independently when making your choice; do not be influenced by your previous choice.

Example

1. ☒ a. I often feel Christmas is too much hassle.
b. Christmas is the best time of year for me.

1. a. Children get into trouble because their parents punish them too much.
b. The trouble with most children nowadays is that their parents are too easy with them.
2. a. Many of the unhappy things in people's lives are partly due to bad luck.
b. People's misfortunes result from the mistakes they make.
3. a. One of the major reasons why we have wars is because people don't take enough interest in politics.
b. There will always be wars, no matter how hard people try to prevent them.
4. a. In the long run people get the respect they deserve in this world.
b. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.
5. a. The idea that teachers are unfair to students is nonsense.
b. Most students don't realize the extent to which their grades are influenced by accidental happenings.
6. a. Without the right breaks one cannot be an effective leader.
b. Capable people who fail to become leaders have not taken advantage of their opportunities.
7. a. No matter how hard you try some people just don't like you.
b. People who can't get others to like them don't understand how to get along with others.
8. a. Heredity plays the major role in determining one's personality.
b. It is one's experiences in life which determine what they're like.
9. a. I have often found that what is going to happen will happen.
b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

10. a. In the case of the well prepared student there is rarely if ever such a thing as an unfair test.
b. Many times exam questions tend to be so unrelated to course work that studying is really useless.
11. a. Becoming a success is a matter of hard work, luck has little or nothing to do with it.
b. Getting a good job depends mainly on being in the right place at the right time.
12. a. The average citizen can have an influence in government decisions.
b. This world is run by the few people in power, and there is not much the little guy can do about it.
13. a. When I make plans, I am almost certain that I can make them work.
b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.
14. a. There are certain people who are just no good.
b. There is some good in everybody.
15. a. In my case getting what I want has little or nothing to do with luck.
b. Many times we might just as well decide what to do by flipping a coin.
16. a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.
b. Getting people to do the right thing depends upon ability, luck has little or nothing to do with it.
17. a. As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.
b. By taking an active part in political and social affairs the people can control world events.
18. a. Most people don't realize the extent to which their lives are controlled by accidental happenings.
b. There really is no such thing as "luck."

19. a. One should always be willing to admit mistakes.
b. It is usually best to cover up one's mistakes.
20. a. It is hard to know whether or not a person really likes you.
b. How many friends you have depends upon how nice a person you are.
21. a. In the long run the bad things that happen to us are balanced by the good ones.
b. Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.
22. a. With enough effort we can wipe out political corruption.
b. It is difficult for people to have much control over the things politicians do in office.
23. a. Sometimes I can't understand how teachers arrive at the grades they give.
b. There is a direct connection between how hard I study and the grades I get.
24. a. A good leader expects people to decide for themselves what they should do.
b. A good leader makes it clear to everybody what their jobs are.
25. a. Many times I feel that I have little influence over the things that happen to me.
b. It is impossible for me to believe that chance or luck plays an important role in my life.
26. a. People are lonely because they don't try to be friendly.
b. There's not much use in trying too hard to please people, if they like you, they like you.
27. a. There is too much emphasis on athletics in high school.
b. Team sports are an excellent way to build character.
28. a. What happens to me is my own doing.
b. Sometimes I feel that I don't have enough control over the direction my life is taking.

- 29. a. Most of the time I can't understand why politicians behave the way they do.
- b. In the long run the people are responsible for bad government on a national as well as on a local level.

APPENDIX F

TABLE 9

RAW SCORES ON I-E SCALE OF SAMPLE SUBJECTS

Hemodialysis Group (N = 17)		Transplant Group (N = 18)	
I-E Scale:	1		1
	2		3
	5		4
	6		4
	6		5
	7		5
	8		6
	8		8
	8		8
	9		9
	9		10
	9		11
	10		11
	10		11
	14		12
	14		12
	15		13
			18

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